

Prevalence, Characteristics and Socio-Demographic Correlates of Self-Stigma among Leprosy Affected Persons - A Case Study

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This study has determined the prevalence of self-stigma, its characteristics in terms of alienation, stereotype endorsement, perceived discrimination and social withdrawal and stigma resistance among leprosy-affected persons and its relationship and extent of this relationship with various socio-demographic features. This has been done by carrying out a cross-sectional survey of 120 active people affected by leprosy during 2020-21. An internationally validated and standardised instrument (ISMI) was used to measure self-stigma. Statistical techniques such as independent t-test, Pearson's and point biserial correlation and regression analysis were used for data analysis. The study found significant correlations between ISMI self-stigma scores and socio-demographic variables with moderate to minor deviation across the four components of the ISMI scale. The high to low correlation of various components of the ISMI scale found is discrimination experience, followed by stigma resistance, stereotype endorsement and alienation. Overall, the highest self-stigma was found in disabled people affected by leprosy, followed by those whose age was less than 40 years, followed by unemployed and male people affected by leprosy. It was concluded that alienation was maximum among people affected by leprosy who were either disabled, aged less than 40 years or were males. Discrimination experience was reported mainly by unemployed, disabled, males and younger people affected by leprosy. The findings indicate that proper methodology and components of Cognitive Behavioural Therapy may help reduce self-stigma among leprosy-affected persons.

Keywords : Leprosy Affected Persons, Perceived Stigma, Enacted Stigma, Self-Stigma, Internalized Stigma, ISMI Scale, Stigma Correlates.

Introduction

Preconceived notions and perceptions about leprosy disease lead to prejudice, social exclusion and discrimination resulting in mental suffering of leprosy-affected persons (LAPs), including stigmas related to death and mutilation. The stigma associated with chronic health conditions

such as leprosy is a global phenomenon. It severely impacts the quality of life of affected persons and their families and harms the effectiveness of prevention and intervention measures (van Brakel 2006). The adversely affected areas include access to health and social welfare services, employment opportunities, marriage,

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friendship, self-esteem, and educational opportunities causing great emotional stress, depression and anxiety (Pescosolido & Martin 2015). Stigma in many health conditions has been well researched. Weiss defined stigma as 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). It has also been defined as discredited and undesirable attribute (Brown et al 2003) reducing an individual's status in society and social processes wherein, out of fear, people want to maintain social control by contrasting those who are 'normal' with those who are 'different' (Parker & Aggleton 2003).

Initially, two types of stigmas i.e. enacted stigma and felt stigma, were differentiated by Erving Goffman (1963). He described 'enacted stigma' as an experience of discrimination and felt stigma as the fear of being discriminated against. Goffman also qualified stigmatised people as those whose stigma is visible to others (the discredited) and those who can conceal their stigma (the discreditable). Whether experienced or not, the detrimental effects of stigma apply to both. His framework defines stigma as "an attribute that is deeply discrediting". Another framework developed by Jones et al. identifies six dimensions of stigma, which are concealability – conceal condition or not, course – is reversible overtime or not, disruptiveness – indicates the extent of the mark considered deviant by society, aesthetics – reflects what is attractive or pleasing to one's perceptions (the extent to which a mark elicits an instinctive and affective reaction of disgust, origin – how the condition came into being, and peril – indicates feelings of danger or threat that the mark induces in others. Link & Phelan (2001) opined that stigma is exhibited when labelling, stereotyping, separation, status

loss, and discrimination co-occur. This study identified fundamental challenges to the concept of stigma that demands a reassessment of the conceptualisation of stigma, such as by describing it concerning its relationship with different interrelated concepts. Stigma experienced by LAPs may be subtle such as being questioned, labelled or gossiped about, then called enacted, discrimination or experienced stigma (Brohan et al 2010, Weiss 2008). Another kind of stigma is perceived or anticipated, or felt stigma (Struenkel & Wong 2009) wherein a leprosy-affected person may fear discrimination for some reason, such as awareness of the negative attitude in society about LAPs. In another type of stigma called internalised or self-stigma, a leprosy patient starts believing in some pre-heard belief among people about himself (Cavelti et al 2012). This may lead to the loss of self-esteem and dignity with the consequent development of fear, shame, hopelessness and guilt.

The stigma associated with leprosy and its adverse effects on an individual has been widely reported (Cross & Choudhary 2005, Stevelink et al 2011, Sermrittirong & van Brakel 2014). However, despite several studies on measuring stigma and proposals for intervention, some studies (Hamlington et al 2015) argue that more research needs to be focused on the stigma and conditions leading to stigmatisation which in some cases gets so intense that even close associates of LAPs, including their family members, turn away from the affected individuals (Brouwers et al 2011).

The objectives of this study are i) measurement of self-stigma among leprosy-affected persons of Jammu and Kashmir in terms of alienation, stereotype endorsement, perceived discrimination, social withdrawal and stigma resistance; and ii) finding the relationship and the extent of this relationship between measured self-stigma and socio-demographic features.

It has been hypothesized that the factors responsible for high self-stigma in leprosy-affected people of Jammu and Kashmir are stereotype endorsement, discrimination experience and alienation, controlled by socio-demographic features. This study attempts to test this hypothesis by surveying Leprosy Affected Persons (LAPs) residing in different districts of Jammu & Kashmir.

Materials and Methods

This study was conducted as part of the first author's doctoral research (LB) in 2020-21 after receiving approval from the University of Kashmir, GMC Srinagar's Institutional Ethics Committee. This study relied on survey data from 120 LAPs of various districts of Jammu and Kashmir between 2020 and 2021. The study area was Srinagar and Jammu leprosarium; data were collected from 120 leprosy-affected persons (LAPs) from the J&K State who lived in leper colonies (65 out of 71 in Srinagar and 45 out of 52 in Jammu), as well as 10 LAPs who did not live in leper colonies but visited state hospitals during the study period. A socio-demographic data questionnaire was employed with a study instrument based on the ISMI scale that was produced using the instrument's adaption technique. Various inclusion and exclusion criteria were adopted in selecting LAPs for the study, and 23 were excluded from the study. The inclusion criteria were as follows: 1) physical fitness of the patient to understand and answer the questions; 2) leprosy-affected persons aged between 15 and 65; 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) were lack of reliable informer or refusal of the patient or relatives.

Measures

To get a comprehensive and accurate measure of different types of stigma associated with leprosy, different kinds of instruments containing questions about the disease and how it affects the LAPs' dignity and feelings, how LAPs fear other people, the experience of reaction from people, perception regarding other people towards themselves, and how they are treated in the community have been used. In addition, the socio-demographic data of subjects were recorded using a self-report questionnaire, which included information about age, gender, education, occupation, and marital status. This study used internationally validated and standardised instruments (ISMI) to measure anticipated stigma among people affected by leprosy (Zimet et al 1988).

Internalized Stigma of Mental Illness (ISMI) (to measure self-stigma):

It is a structured questionnaire helpful in measuring self-stigma in multiple health conditions, including leprosy, with applicability in mental health, disability and other generic situations. It can be self-rated, or interviewer's based. The International Federation of Anti-Leprosy Associations recommended the ISMI scale for measuring stigma (Ritsher et al 2003). The ISMI has sound psychometric properties across various languages, cultures, conditions, and situations. It has over 50 language versions, including one in Urdu and one in Hindi, which have been tested for internal consistency and reliability (Boyd et al 2014) and, as such, have been used in multiple leprosy studies (Tanabe et al 2016, Susanti et al 2017, Ibikunle & Nwokeji 2017, Singh et al 2016). It is a lengthy questionnaire compared to the Explanatory Model Interview Catalogue (EMIC). It comprises 28 questions, grouped into five components: Alienation, Stereotype endorsement, perceived discrimination and social withdrawal and stigma

resistance. The ISMI contains 28 questions with four answer options (strongly disagree-1, disagree-2, agree-3, and strongly agree-4) divided into five components (alienation, stereotype endorsement, perceived discrimination, social withdrawal, and stigma resistance). The higher the scores, the higher the level of self-stigma. The total ISMI Scale score ranges from 29 to 116.

Table 1 : Detailed items of the ISMI self-stigma scale.

A) Alienation
1. I feel out of place in the world because I have leprosy.
2. Having leprosy has spoiled my life.
3. People without leprosy could not possibly understand me.
4. I am embarrassed or ashamed that I have leprosy.
5. I am disappointed in myself for having leprosy.
6. I feel inferior to others who don't have leprosy.
B) Stereotype Endorsement
7. Stereotypes about leprosy-affected people apply to me.
8. People can tell that I have leprosy by the way I look.
9. Because I have leprosy, I need others to make most decisions for me.
10. People with leprosy cannot live a good, rewarding life.
11. Leprosy affected people should not marry.
12. I can't contribute anything to society because I have leprosy.
C) Discrimination Experience and Social Withdrawal
13. People discriminate against me because I have leprosy.
14. Others think that I can't achieve much in life because I have leprosy.
15. People ignore me or take me less seriously just because I have leprosy.
16. People often patronise me or treat me like a child, just because I have leprosy.
17. Nobody would be interested in getting close to me because I have leprosy.
18. I don't talk about myself much because I don't want to burden others with my leprosy.
19. I don't socialise as much as I used to because my leprosy might make me look 'weird'.
20. Negative stereotypes about leprosy keep me isolated from the normal world.
21. I stay away from social situations in order to protect my family or friends from embarrassment.
22. Being around people who don't have leprosy makes me feel out of place or inadequate.
23. I avoid getting close to people who don't have leprosy to avoid rejection.
D) Stigma resistance (Reverse Subtract from 5)
24. I feel comfortable being seen in public with a person obviously affected by leprosy.
25. In general, I am able to live life the way I want to.
26. I can have a good, fulfilling life, despite my leprosy.
27. People with leprosy make important contributions to society.
28. Living with leprosy has made me a tough survivor.

Table 2 : Consolidated responses of people affected by leprosy to questions of the ISMI Scale.

Component and Question	Responses (120 respondents, 28 questions, n is the total number of responses for questions in each component)															
	Strongly disagree				Disagree				Agree				Strongly agree			
	n	%	N	%	N	%	N	%	N	%	n	%				
Alienation	76	10.56%	152	21.11%	262	36.39%	230	31.94%								
Q1	13	10.83%	33	27.50%	41	34.17%	33	27.50%								
Q2	13	10.83%	24	20.00%	47	39.17%	36	30.00%								
Q3	9	7.50%	29	24.17%	44	36.67%	38	31.67%								
Q4	13	10.83%	20	16.67%	43	35.83%	44	36.67%								
Q5	13	10.83%	22	18.33%	46	38.33%	39	32.50%								
Q6	15	12.50%	24	20.00%	41	34.17%	40	33.33%								
Stereotype Endorsement	89	12.36%	143	19.86%	232	32.22%	256	35.56%								
Q7	21	17.50%	27	22.50%	38	31.67%	34	28.33%								
Q8	16	13.33%	23	19.17%	43	35.83%	38	31.67%								
Q9	13	10.83%	19	15.83%	33	27.50%	55	45.83%								
Q10	9	7.50%	25	20.83%	44	36.67%	42	35.00%								
Q11	16	13.33%	29	24.17%	33	27.50%	42	35.00%								
Q12	14	11.67%	20	16.67%	41	34.17%	45	37.50%								
Discrimination Experience	211	15.98%	255	19.32%	365	27.65%	489	37.05%								
Q13	25	20.83%	24	20.00%	31	25.83%	40	33.33%								
Q14	21	17.50%	22	18.33%	34	28.33%	43	35.83%								
Q15	24	20.00%	18	15.00%	33	27.50%	45	37.50%								

Continued....

Table 2 : Continued....

Q16	30	25.00%	16	13.33%	28	23.33%	46	38.33%
Q17	12	10.00%	26	21.67%	33	27.50%	49	40.83%
Q18	15	12.50%	26	21.67%	31	25.83%	48	40.00%
Q19	16	13.33%	25	20.83%	30	25.00%	49	40.83%
Q20	17	14.17%	25	20.83%	37	30.83%	41	34.17%
Q21	15	12.50%	27	22.50%	31	25.83%	47	39.17%
Q22	19	15.83%	21	17.50%	36	30.00%	44	36.67%
Q23	17	14.17%	25	20.83%	41	34.17%	37	30.83%
Stigma Resistance	219	30.42%	162	22.50%	104	14.44%	115	15.97%
Q24	43	35.83%	31	25.83%	21	17.50%	25	20.83%
Q25	44	36.67%	28	23.33%	24	20.00%	24	20.00%
Q26	51	42.50%	31	25.83%	18	15.00%	20	16.67%
Q27	45	37.50%	36	30.00%	12	10.00%	27	22.50%
Q28	36	30.00%	36	30.00%	29	24.17%	19	15.83%
Total	595	17.71%	712	21.19%	963	28.66%	1090	32.44%

Table 3 : Comparison of the self-stigma level of LAPs with different socio-demographic variables.

Demographic Feature	n (%)	ISMI Score															
		Alienation			Stereotype Endorsement			Discrimination Experience			Stigma Resistance			ISMI Total Score			
		Mean	SD	T/F	P	Mean	SD	T/F	P	Mean	SD	T/F	P	Mean	SD	T/F	P
Gender	120			8.206**	0.000	19.380	2.024	8.907**	0.000	6.482**	0.000	3.823**	0.000	87.800	11.573	7.258**	0.000
<i>Male</i>	71 (59.17)	19.085	2.483			34.169	5.073			15.169	3.749			87.800	11.573		
<i>Female</i>	49 (41.93)	15.000	2.944			27.490	6.175			12.470	3.879			69.650	15.823		
Age (years)	120			3.086**	0.003	18.704	3.279	2.163*	0.036	2.786**	0.008	2.168*	0.032	87.410	13.998	2.852**	0.006
<40	27 (22.50)	19.000	2.935			34.185	5.609			15.519	3.118			87.410	13.998		
≥40	93 (77.50)	16.957	3.329			17.108	3.687			30.645	6.465			78.350	16.196		
Region	120			0.054	0.957	17.283	3.425	-0.549	0.584	-0.751	0.454	-0.544	0.587	79.580	15.542	-0.548	0.585
<i>Kashmir</i>	60 (50)	17.433	3.217			31.000	6.470			13.866	3.920			79.580	15.542		
<i>Jammu</i>	60 (50)	17.400	3.494			17.650	3.878			31.883	6.420			81.200	16.780		
Marital Status	120			7.153**	0.000	18.244	3.043	14.133**	0.000	7.662**	0.000	7.497**	0.000	83.810	13.862	10.187**	0.000
<i>Married</i>	90 (75)	18.056	2.850			32.656	5.879			14.856	3.552			83.810	13.862		
<i>Unmarried</i>	24 (20)	16.208	3.956			16.125	3.530			12.375	4.362			73.830	16.675		
<i>Widowed</i>	3 (2.50)	13.000	4.000			15.000	4.359			11.333	4.619			65.330	21.221		
<i>Separated/Divorced</i>	3 (2.50)	12.333	2.082			17.467	3.648			19.000	1.732			45.330	6.807		
Employment Status				18.688**	0.000	17.656	3.615	20.585**	0.000	22.626**	0.000	13.824**	0.000	78.660	16.599	22.957**	0.000
<i>Part-Time</i>	32 (26.67)	17.812	3.277			30.500	6.839			12.688	5.070			78.660	16.599		
<i>Homemaker</i>	27 (22.50)	14.000	2.841			13.667	2.948			11.296	3.582			64.000	14.005		
<i>Disabled</i>	36 (30)	19.200	1.527			18.778	3.006			15.778	2.565			87.440	11.891		
<i>Unemployed</i>	25 (20.83)	17.417	3.345			19.440	1.895			35.160	2.656			90.160	5.864		

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

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

Table 4 : Pearson correlation analysis /point-biserial correlation of anticipated stigma-related factors.

Demographic Feature	n (%)	Alienation						Stereotype Endorsement						Discrimination Experience						ISMI Total Score	
		r	p	r	p	r	p	r	p	r	p	r	p	r	p	r	p	r	p		
Male	71 (59.17)	.603**	0.000	.634**	0.000	.512**	0.000	.332**	0.000	.556**	0.000	.332**	0.000	.512**	0.000	.332**	0.000	.556**	0.000		
Female	49 (41.93)	-.603**	0.000	-.634**	0.000	-.512**	0.000	-.332**	0.000	-.556**	0.000	-.332**	0.000	-.512**	0.000	-.332**	0.000	-.556**	0.000		
Age <40	27 (22.50)	.256**	0.005	.183*	0.045	.231*	0.011	.196*	0.032	.235**	0.010	.196*	0.032	.231*	0.011	.196*	0.032	.235**	0.010		
Age ≥40	93 (77.50)	-.256**	0.005	-.183*	0.045	-.231*	0.011	-.196*	0.032	-.235**	0.010	-.196*	0.032	-.231*	0.011	-.196*	0.032	-.235**	0.010		
Kashmir	60 (50)	0.005	0.957	-0.050	0.584	-0.069	0.454	-0.050	0.587	-0.050	0.585	-0.050	0.587	-0.069	0.454	-0.050	0.587	-0.050	0.585		
Jammu	60 (50)	-0.005	0.957	0.050	0.584	0.069	0.454	0.050	0.587	0.050	0.585	0.050	0.587	0.069	0.454	0.050	0.587	0.050	0.585		
Married	90 (75)	.332**	0.000	.371**	0.000	.328**	0.000	.342**	0.000	.369**	0.000	.342**	0.000	.328**	0.000	.342**	0.000	.369**	0.000		
Unmarried	24 (20)	-.181*	0.047	-.185*	0.043	-.181*	0.048	-.212*	0.020	-.204*	0.025	-.212*	0.020	-.181*	0.048	-.212*	0.020	-.204*	0.025		
Widowed	3 (2.50) †	-.212*	0.020	-0.109	0.237	-0.136	0.139	-0.109	0.234	-0.150	0.102	-0.109	0.234	-0.136	0.139	-0.109	0.234	-0.150	0.102		
Separated/Divorced	3 (2.50) †	-.244**	0.007	-.447**	0.000	-.311**	0.001	-.296**	0.001	-.350**	0.000	-.296**	0.001	-.311**	0.001	-.296**	0.001	-.350**	0.000		
Part-Time	32 (26.67)	0.072	0.437	0.031	0.733	-0.089	0.336	-.208*	0.023	-0.065	0.479	-.208*	0.023	-0.089	0.336	-.208*	0.023	-0.065	0.479		
Homemaker	27 (22.50)	-.553**	0.000	-.564**	0.000	-.539**	0.000	-.373**	0.000	-.550**	0.000	-.373**	0.000	-.539**	0.000	-.373**	0.000	-.550**	0.000		
Disabled	36 (30)	.191*	0.037	.236**	0.009	.313**	0.001	.280**	0.002	.288**	0.001	.280**	0.002	.313**	0.001	.280**	0.002	.288**	0.001		
Unemployed	25 (20.83)	.275**	0.002	.279**	0.002	.298**	0.001	.294**	0.001	.312**	0.001	.294**	0.001	.298**	0.001	.294**	0.001	.312**	0.001		

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

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

†Given very few participants, they have been omitted from the discussion.

Internal consistency coefficients range from 0.84 alphas to 0.96 alphas, and test-retest reliability coefficients range from 0.61 to 0.9. Although various researchers have used different cut-offs, the originator of the scale used a cut-off of 2.5 for total and subscales of the ISMI Scale to categorize the presence or absence of stigma. The details of the ISMI scale are given in Table 1.

Statistical Analysis

Besides basic statistical techniques, the data was analysed using the SPSS software package. The distribution was examined with the 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. The analysis of the anticipated-stigma score of the recorded ISMI Scale was made with respect to various socio-demographic parameters using pairwise comparisons through t-tests and one-way ANOVA. In addition, Pearson's correlation analysis and point biserial correlation have examined the correlation between stigma scores obtained from the ISMI scale and socio-demographic parameters. Further, a regression analysis was made to find the extent of each correlated factor that predicates the level of stigma.

Results

As can be observed from Table 2, in the aggregate, the highest percentage of responses for ISMI

questions were recorded as 'strongly agree' (32.44%), followed by 'agree' (28.66%), 'disagree' (21.19%) and 'strongly disagree' (17.71%). In the Alienation component of the ISMI scale, the highest recorded responses were 'agree' (36.39%), followed by 'strongly agree' (31.94%), 'disagree' (21.11%) and 'strongly disagree' (10.56%). In the stereotype endorsement component, 35.56% responded with 'strongly agree', which was followed by 'agree' (32.22%), 'disagree' (19.86%) and 'strongly disagree' (12.36%). The discrimination experience component followed a similar pattern with 37.05%, 27.65%, 19.32% and 15.98% respondents responding with 'strongly agree', 'agree', 'disagree' and 'strongly disagree', respectively. Finally, the stigma resistance component showed the highest responses (30.42%) as 'strongly disagree', followed by 'disagree' 22.50%, 'strongly agree' 15.97%, and 'agree' 14.44%.

The socio-demographic profile of respondent LAPs and correlation with self stigma levels is reflected in Table 3. The total anticipated stigma scores across all components of the scale (Table 3) showed significant differences with respect to *gender* ($t=7.258$, $p<0.000$), *age* ($t=2.852$, $p<0.006$), *marital status* ($F=10.187$, $p<0.000$) and *employment status* ($F=22.957$, $p<0.000$). Across all four components and the total, the region did not show any significant impact on the level of the stigma. Employment status showed the highest T/F values across all four scale components. This was followed by marital status for components

Table 5 : Pearson correlation analysis of various components of the ISMI scale.

ISMI Component	<i>r</i>	<i>p</i>
<i>Alienation</i>	.842**	0.000
<i>Stereotype Endorsement</i>	.908**	0.000
<i>Discrimination Experience</i>	.979**	0.000
<i>Stigma Resistance</i>	.922**	0.000

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

Table 6 : Multivariate regression analysis of anticipated stigma-related factors (Total ISMI Scale).

Demographic Feature	Regression coefficients	95% confidence interval for regression coefficients	t	p
Male	0.268	5.075, 12.425	4.719	0.000
Female	0 [§]			
Age <40	0.451	14.263, 20.450	11.118	0.000
Age ≥40	0 [§]			
Jammu	0.308	7.156, 12.633	7.159	0.000
Kashmir	0 [§]			
Unmarried	-0.367	-17.890, -11.580	-9.256	0.000
Widowed	-0.100	-18.288, -2.233	-2.533	0.013
Separated/Divorced	-0.296	-38.885, -22.078	-7.188	0.000
Married	0 [§]			
Homemaker	-0.201	-12.590, -2.884	-3.159	0.002
Disabled	0.484	13.360, 20.574	9.321	0.000
Unemployed	0.415	12.451, 20.336	8.240	0.000
Part-Time	0 [§]			

[§]IMSI: $R^2=0.843$ (adjust $R^2 = 0.831$); $F(9,110) = 65.811$, at $p < 0.000$.

[§]This parameter is redundant and is set to zero.

other than alienation, wherein gender remained the next contributor to the stigma.

A significant negative correlation was observed (Table 4) for the following variables: gender (female: $r = -.556$, $p < .000$); employment status (homemaker: $r = -.550$, $p < .000$), age (≥ 40 : $r = -.235$, $p < .010$) and marital status (unmarried: $r = -.204$, $p < .025$). Anticipated stigma scores that showed a significant positive correlation included the following: marital status (married: $r = .369$, $p < .000$), employment status (unemployed: $r = .312$, $p < .001$) and employment status (disabled: $r = .288$, $p < .001$). Similar positive and negative correlations were observed across all individual components of the ISMI scale.

All components showed a considerably high correlation to the final stigma score—the highest being discrimination experience, followed by stigma resistance, stereotype endorsement and

alienation (Table 5).

The regression analysis (Tables 6 and 7) demonstrates that in the total stigma score, the following variables were significant contributors: employment status (disabled: $b = .484$), age (<40: $b = .436$), employment status (unemployed: $b = .415$) and gender (male: $b = .268$). These variables are significant contributors to the ISMI scale's components. Out of these four variables, in the stigma resistance component, employment status (disabled: $b = .553$, and unemployed: $b = .511$), while in the discrimination experience component, employment status (disabled: $b = .524$) and age (<40: $b = .448$) are the two highest contributors to stigma. In the alienation and stereotype endorsement components, age (<40: $b = .436$), age (<40: $b = .366$) and gender (male: $b = .341$) (male: $b = .344$), respectively, are the two highest contributors to anticipated stigma.

Table 7 : Multivariate regression analysis of anticipated stigma-related factors (individual components of ISMI Scale).

Demographic Feature	¹Alienation			²Stereotype Endorsement			³Discrimination Experience			⁴Stigma Resistance						
	Regression coefficients	95% confidence interval for regression coefficients	T	p	Regression coefficients	95% confidence interval for regression coefficients	T	p	Regression coefficients	95% confidence interval for regression coefficients	t	p				
Male	0.341	1.279, 3.339	4.441	0.000	0.344	1.691, 3.388	5.934	0.000	0.234	1.384, 4.720	3.626	0.000	0.104	0.571, 2.271	1.185	0.239
Female	0 [§]															
Age <40	0.436	2.611, 4.346	2.611	0.000	0.366	2.473, 3.901	8.847	0.000	0.448	5.470, 8.278	9.702	0.000	0.399	2.620, 5.013	6.322	0.000
Age ≥ 40	0 [§]															
Jammu	0.173	.382, 1.918	2.968	0.004	0.256	1.230, 2.495	5.840	0.000	0.337	3.081, 5.567	6.893	0.000	0.320	1.499, 3.617	4.786	0.000
Kashmir	0 [§]															
Unmarried	-0.342	-3.733, -1.964	-6.381	0.000	-0.330	-3.722, -2.266	-8.150	0.000	-0.337	-6.826, -3.962	-7.466	0.000	-0.350	-4.719, -2.279	-5.683	0.000
Widowed	-0.139	-5.218, -.716	-2.612	0.010	-0.044	-2.885, .821	-1.104	0.272	-0.091	-7.380, -.093	-2.032	0.045	-0.099	-5.629, .579	-1.612	0.110
Separated/Divorced	-0.187	-6.337, -1.625	-3.348	0.001	-0.393	-11.084, -7.205	-9.344	0.000	-0.261	-14.513, -6.885	-5.559	0.000	-0.260	-9.907, -3.408	-4.060	0.000
Married	0 [§]															
Homemaker	-0.251	-3.365, -.643	-2.919	0.004	-0.250	-3.294, -1.054	-3.847	0.000	-0.189	-5.095, -.690	-2.603	0.011	-0.070	-2.542, 1.211	-0.703	0.484
Disabled	0.291	1.101, 3.124	4.140	0.000	0.340	1.867, 3.532	6.425	0.000	0.524	5.692, 8.966	8.871	0.000	0.553	3.431, 6.221	6.856	0.000
Unemployed	0.240	.863, 3.074	3.530	0.001	0.275	1.548, 3.368	5.353	0.000	0.440	5.151, 8.730	7.686	0.000	0.511	3.502, 6.552	6.534	0.000
Part-Time	0 [§]															

[†]Alienation component: R2=0.714 (adjust R2 = 0.690); F (9,110) =30.482, at p<0.000

[‡]Stereotype endorsement component: R2=0.837 (adjust R2 = 0.824); F (9,110) =62.775, at p<0.000.

[#]Discrimination experience component: R2=0.797 (adjust R2 = 0.784); F (9,110) =48.080, at p<0.000.

[§]Stigma resistance component: R2=0.622 (adjust R2 = 0.591); F (9,110) =20.112, at p<0.000.

^{||}This parameter is redundant and is set to zero.

Discussion

Self-stigma has been described by Livingston & Boyd (2010) as a 'subjective process, embedded within a sociocultural context which may be characterised by negative feelings (about self), maladaptive behaviour, identity transformation or stereotype endorsement, resulting from an individual's experiences, perceptions, or anticipation of negative social reaction based on their health condition'. Like various other studies (Rensen et al 2011, Stevelink et al 2012, Nicholls et al 2005), this study has also found self-stigma prevalent among studied LAPs restricting their participation and quality of life with varying impacts correlated to their socio-demographic features.

Self-stigma in people affected by leprosy is prevalent and correlates significantly with socio-demographic variables. Alienation was highly reported by people affected by leprosy who were either disabled, aged less than 40 years or were males. E.g. over 70% of responses to the questions: '*I am embarrassed or ashamed that I have leprosy*' and '*I am disappointed in myself for having leprosy*' were either 'agree' or 'strongly agree'. This is owing to their disability, hampering them from working or moving freely. Discrimination experience was reported mainly by unemployed, disabled, males and younger people affected by leprosy. E.g. over 65% of responses to questions: '*Nobody would be interested in getting close to me because I have leprosy*'; '*I don't talk about myself much because I don't want to burden others with my leprosy*' and '*I don't socialise as much as I used to because my leprosy might make me look weird*' were either 'agree' or 'strongly agree'. All components showed a considerably high correlation to the final self-stigma score—the highest being discrimination experience, followed by stigma resistance, stereotype endorsement and alienation. This study finds that stereotype endorsement was recorded highly by people

affected by leprosy who were unemployed, males, and less than 40 years of age.

The study found that irrespective of the component of the ISMI scale, males showed higher self-stigma than females; this is such because, in the studies settings, male family members are primary earners and caretakers of their families than female members; People affected by the leprosy of age lesser than 40 years have more self-stigma than those of age more than or equal to 40 years which indicate that younger LAPs find more difficulties despite their strong desires to work, be empowered, marry and progressive than elderly LAPs. The latter, with time, have come to believe that their condition will not change and therefore are less stigmatised. Many studies (Lee & Dugan 2015, Kitchen et al 2013, Corcoran et al 2013) focused on the self-stigma report that older adults feel related to the belief that depression is a normal part of the ageing process. Across marital status, married LAPs possess higher self-stigma than those who are not married, and this is due to their increased responsibility towards their families than unmarried people affected by leprosy. Further, the unemployed and disabled people affected by leprosy possessed greater self-stigma than those who worked to some extent, such as homemakers and part-time workers. Katoch et al (2017), in their cross-sectional study across India, also found that self-stigma was present in disabled LAPs, and some LAPs did not even tell their family about their disease. Utami et al (2017) found that the impact of self-stigma for people affected by leprosy is low self-esteem, fear, alienation, loss of employment due to discrimination, depression, and increased recurrence. Somar et al (2020) and Alonso et al (2008) have reported that anxiety disorder among LAPs is closely associated with self-stigma and unemployment.

The study found significant positive and negative correlations between ISMI self-stigma scores and

socio-demographic variables with moderate to minor deviation across the four components of the ISMI scale. The high to the low correlation of various components of the ISMI scale found is discrimination experience, followed by stigma resistance, stereotype endorsement and Alienation. Overall, the highest self-stigma was found in disabled people affected by leprosy, followed by those whose age was less than 40 years, followed by unemployed and male people affected by leprosy.

Gender: Except stigma resistance component, gender showed the highest correlation to other socio-demographic variables with the ISMI self-stigma score, with the male population showing more stigma than females.

Age: It also showed a significant correlation across all four components of the ISMI self-stigma score, with people affected by leprosy of age less than 40 years showing higher self-stigma than those having higher ages.

Marital Status: Married people affected by leprosy showed higher self-stigma than unmarried people affected by leprosy across all four components. Due to fewer samples (only 3 in each), windowed and separated are eliminated from discussions.

Employment Status: Unemployed people affected by leprosy, followed by disabled people affected by leprosy, showed the highest self-stigma than others in each component except for discrimination experience, wherein disabled people affected by leprosy showed the highest self-stigma followed by unemployed, suggesting higher discrimination experienced by disabled people affected by leprosy than unemployed people affected by leprosy.

Given the significant relationship between shame and avoiding treatment (Sirey et al 2001, Fung et al 2007), self-stigma can decrease treatment participation. Latalova et al (2014), in their study, found self-stigma to be a barrier to older adults

seeking treatment for depression. A study by Tsutsumi et al (2004) on the depression status of LAPs in Bangladesh found a relationship between the stigma felt by people affected by leprosy with depression in LAPs. Bharath et al (2001), in their study, have found that various factors, including self-stigma, correlate with the occurrence of psychiatric morbidity in LAPs. As discussed and presented in this study, self-stigma predominantly involves negative beliefs and misinterpretations and consequently causes problems for people affected by leprosy. Educating, training and counselling LAPs with proper methodology could help them overcome such negative beliefs and interpretations. Corrigan & Calabrese (2005) found that a structured approach, namely Cognitive Behavioural Therapy (CBT), comprises multiple components, including education, management strategies for stress and symptoms, and timely awareness about symptoms and situations, helping overcome feared stimuli and overcoming consequences of self-stigma. CBT also includes cognitive challenges¹ to change negative beliefs (Krishnamoorthy 2003). Hall & Tarrier (2003) have reported improvement in self-esteem and social functioning using CBT to treat schizophrenic LAPs. A similar study by Chan et al (2005) has demonstrated improvements in HIV-infected LAPs. Given the high prevalence and correlates of self-stigma on studies population, the present study can be useful in selecting the proper methodology and components of CBT to reduce self-stigma among LAPs effectively.

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