A New Instrument to Measure Leprosy Internalised Stigma: the Leprosy Internalised Stigma Scale (LISS)

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Summary
Purpose: Leprosy is a stigmatised disease and the assessment of stigma is particularly important. There is a need for comprehensive, valid and reliable instrument to assess internalised stigma.
Objective: To develop a scale to measure internalised stigma for people affected by leprosy.
Methods: A cross sectional scale development study was carried out in a tertiary leprosy referral centre, Purulia, West Bengal, India using standard methods. A 27-item scale was developed to measure the internalised stigma. The scale was administered with a consecutive sample of 416 people affected by leprosy aged above 18 years and 54 completed the scale twice within an interval of 3–4 weeks. Developing the scales involved face and content validity, internal consistency, factor analyses, construct validity and test–retest reliability. Construct validity of the scale was determined by using Participation Scale and World Health Organization Quality Of Life (WHOQOL-Bref) scale.
Results: Exploratory factor analysis revealed a four-factor solution accounting for 81% of the total variance. The four underlying sub-scale dimensions were self

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acceptance, self isolation, social withdrawal and disclosure. Cronbach's alpha was 0·96, and test intra-class correlation coefficient was 0·77. The total score of the LISS scale had a significant moderate positive correlation with the *P* Scale ($r = 0.51$, $p = 0.00$) and a weak negative correlation with WHOQOL total score ($r = -0.36$, $p = 0.00$).

Conclusion: The LISS scale is acceptable, valid and reliable for measuring the Internalised stigma of the persons affected by leprosy. It is a promising tool which can be easily incorporated into leprosy programmes.

Keywords: Leprosy, Internalised stigma, Stigma, Disability, Scale development

Introduction

Stigma 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.[1] Health-related stigma describes a social concept that has an enormous impact on the lives of many people that suffer from a certain health condition.[2]

Stigma is a common phenomenon worldwide and leprosy is often associated with high levels of stigma. It is a disease that is associated with fear, ostracism and discrimination in many parts of the world.[3] Research has shown that leprosy stigma has a negative impact on social participation, work, socioeconomic status and mental health.[4,5] Several components of stigma can be distinguished. Stigma can be categorised from the perspective of the non-affected person into perceived and enacted stigma, and from the perspective of the affected person into internalised, perceived, and experienced stigma.[2,6] These different aspects are all interrelated and may have an impact on the self-efficacy of the affected person, his or her participation in the community, personal well-being, and self-esteem.[6]

Internalised stigma or self-stigma is the outcome of a subjective process embedded within a socio-cultural context which may be characterised by negative feelings about oneself, maladaptive behaviour, identity transformation or stereotype-endorsement regarding oneself resulting from an individual's experiences, perceptions or anticipations of a negative social reaction on the basis of their health or other condition.[7,8] It has been associated with a number of negative outcomes, including increased depression, avoidant coping, decreased hope and self-esteem, worsening psychiatric symptoms and poor adherence with the treatment facility. The person internalises the stigma, feels loss of control and accepts denigration. This leads to a self-perception of shame, guilt and fear, which paves the way to protective action, usually the individual avoiding others and living in isolation, making their situation worse.

Leprosy is a stigmatised disease and the assessment of stigma is particularly important. Various instruments have been developed or modified to assess leprosy-related stigma. The International Federation of Anti-Leprosy Associations,[9] recommended the Internalised Stigma of Mental Illness (ISMI) scale,[10] Child Attitude Towards Illness Scale (CATIS),[11] Berger HIV Stigma Scale,[12] and Tuberculosis stigma scale,[13] for measuring the internalised stigma of people affected by leprosy. Renson *et al.* measured the internalised stigma among people affected with leprosy by using the ISMI scale,[6] Govindharaj *et al.* measured the internalised stigma among children and adolescents affected with leprosy by using the CATIS scale,[14] and the Berger scale was adopted by Dadun *et al.*[15] However, these scales were not

originally developed for leprosy. With the intention to develop an additional instrument with specific subscales to measure the internalised stigma, this research was initiated to develop a new instrument to measure internalised stigma for people affected by leprosy. Hence, this study aimed to develop a scale that quantitatively measures internalised stigma among people affected by leprosy.

Methods

STUDY DESIGN

A cross-sectional instrument validation study was conducted among people affected by leprosy to develop a tool to measure internalised stigma.

STUDY SETTINGS

The validation study took place in the Purulia Leprosy Mission Home and Hospital which is located in district of Purulia in the state of West Bengal in Eastern India from April, 2017 to June, 2017. Purulia district is endemic for leprosy.[16] Every year more than 500 people were diagnosed as new active cases of leprosy in the study institute, and 1938 new cases were diagnosed from 2013 to 2015.[17]

PARTICIPANT ELIGIBILITY

All adult people affected with leprosy who were 18 years and above, diagnosed with leprosy at least one year before the time of interview, who were willing to participate and gave a written informed consent, were included. Those who were living in a leprosy colony or had difficulties in communication were excluded.

SAMPLE SIZE

To achieve adequate power for the various statistical calculations to determine the measurement equivalence, it was estimated that a sample of at least 189 people affected by leprosy was needed in the main quantitative part of the study. Terwee *et al.* (2007), recommended a minimum sample size as corresponds to seven times the number of items.[18] To achieve an adequate sample size for the reliability calculation, at least 50 repeated measurements are necessary.[18]

THE SCALE DEVELOPMENT PROCESS

Items

Items were collected through field observation, interviews with experts and from the literature.[10,12] Following item collection, duplicate items were eliminated, and the remaining items were converted into questions.

Translation

Since the items were prepared in English, the questions were translated into the Bengali language for interviewing the study subjects. Following the World Health Organization guidelines for scale translation,[19] the instruments were translated into Bengali by three experts in leprosy treatment and rehabilitation who were fluent in both English and Bengali. Additionally, they were asked to suggest any modifications which may be required in the context of culture. The Bengali translated versions were then back translated into English by an independent person who was not involved in the study and checked for comparability with the original English questionnaire.

Validity

To assess face and content validity, the scale was simultaneously given to a three-member expert panel, experienced in leprosy treatment and rehabilitation (apart from the authors). The expert panel reviewed the LISS scale and judged the instrument to be meaningful and relevant to the cultural context. The panel noted that a few questions were repetitive and suggested some items could be removed. Further, to determine content validity, we purposively recruited 15 respondents to test the instrument. An informal discussion was held with them about their perceptions of the relevance and adequacy of the concepts and language used in the scale as they related to the concept of internalized stigma. They indicated that similar questions were being asked in slightly different ways. Based on their suggestions the investigators redrafted the tool and after several reviews and revisions, the validity of the scale was established.

Construct validity

The Bengali version of the Participation scale (*P* Scale),[20] and World health Organization quality of life (WHOQOL-BREF) scale,[21,22] were used to establish the construct validity of the newly developed scale. The *P* scale and WHOQOL-Bref were used to measure the social participation restriction and quality of life of people affected by leprosy respectively. The researcher hypothesised that internalised stigma of people affected by leprosy would be positively correlated with the *P* scale and inversely correlated with WHOQOL-Bref.

Reliability

Test-retest reliability was performed using the interclass correlation coefficient. The coefficients were estimated, considering results above 0·70 as acceptable.[18]

Scale

The final instrument was named the Leprosy Internalised Stigma Scale (LISS), which is comprised of 27 items to measure internalised stigma in the following four broad domains: self-acceptance (7 items), self-isolation (9 items), social withdrawal (5 items) and disclosure (6 items). The scores follow a 4-point Likert scale, with the items each scoring from 0 to 3 (0 - 'Never', 1 - 'Rarely/Once', 2 - 'Sometimes' and 3 - 'Always/Often'); the total thus ranges from 0 to 81.

PROCEDURE

One author was assigned to recruit participants, describe the study to the respondents, obtain informed consent and perform the interviews, with the assistance of trained field investigators. The scales are administrated by the interviewer. Each respondent's demographic information and clinical information was extracted from the hospital database, followed by administration of the LISS, P scale and WHOQOL. The interviews were conducted in the vernacular language, Bengali. The interview was conducted in strict privacy after building a rapport with the respondents and precautions were taken to avoid emotional distress of participants. In case of any emotional distress, the interview was terminated.

The field investigators administered the scales with 15 respondents affected by leprosy for testing the new scale. A discussion with the field investigators followed, and they checked the items for consistency, understanding and terminology. After that, the pilot study was carried out and the instruments tested. Finally, the quantitative validation was conducted.

ETHICAL CONSIDERATIONS

Approval of this study was obtained from the Doctoral Research Committee members, Department of Sociology, Bharathidasan University and The Research Committee of Leprosy Mission Trust India, New Delhi. Participation was voluntary and information was collected anonymously after obtaining written consent from each respondent by assuring confidentiality throughout the data collection period.

DATA ANALYSIS

The data were entered into a Microsoft Excel database and analysed using SPSS. Descriptive statistics were used to describe the demographic and disability profile of the respondents. Reliability analysis and factor analysis was performed for 27 items of the scale. Pearson correlation analysis was performed for construct validity. Independent 't' test and analysis of variance (ANOVA) test was performed for significance among variables on the LISS scale.

Results

A total of 416 respondents participated in this study. Of these respondents, 38% were females, the age ranged from 18–70 with a mean age of 40·4 ± 14·2. Two hundred-sixteen respondents were illiterate (52%), and half of them were farmers (24%), and labourers (29%). The majority of the respondents had a family income below Rs.5000 per month. Nearly one third of the respondents (39%) had Grade 2 disability (Table 1).

The mean total score of the LISS scale was 26·81 (95% CI 24·56–29·06) and range 0–81. The distribution of total scores is normal with Kurtosis −0·51 and Skewness 0·71. The mean scores of the total LISS scale and the sub-scales is shown in Table 2.

The sub-scale scores for the domain 'social withdrawal' are relatively low compared to the other domains. The mean scores of all the 27 items on the scale and the corrected item-total correlation are shown in Table 3.

Table 1. Demographic details of the respondents ($n = 416$)

Status	Frequency	Percent
Gender		
Male	260	62·50
Female	156	37·50
Age		
18–30 years	122	29·33
31–45 years	147	35·34
46–60 years	112	26·92
Above 60 years	35	8·41
Education		
Primary	40	9·62
Secondary	115	27·64
Higher Secondary	45	10·82
Illiterate	216	51·92
Occupation		
House wife	138	33·17
Labor	55	13·22
Skilled Labor	66	15·87
Farmer	100	24·04
Government, Private and Business	32	7·69
Student	25	6·01
Family Income		
Below Rs.5000	303	72·84
Above Rs.5000	113	27·16
Disability Grade		
Grade '0'	182	43·75
Grade '1'	71	17·07
Grade '2'	163	39·18

INTERNAL CONSISTENCY

Cronbach's alpha was computed for internal consistency to test the reliability of the LISS scale. The alpha for the 27 items was 0·96, which indicates that the items from a scale that has good internal consistency. The sub-scale analysis yielded similar levels of alphas; sub-scale 1 'Self-acceptance' 0·94; sub-scale 2 'Self-isolation' 0·95; sub-scale 3 'Social withdrawal' 0·97 and sub-scale 4 'Disclosure' 0·98.

FACTOR ANALYSIS

Both the Kaiser-Meyer-Olkin (KMO) value (0·94) and the statistical significance of the Bartlett's test of sphericity ($\chi^2 = 15220.57$; $p = 0.00$(df-351,) suggested that the data were

Table 2. Mean scores of the LISS scale and sub scales ($n = 416$)

	Mean	Median	Min	Max	95% CI
Full Scale	26·81	21	0	81	24·56–29·06
Domains					
Self Acceptance (7 items, score 0–21)	7·92	7	0	21	7·23–8·60
Self Isolation (9 items, score 0–27)	6·86	2	0	27	6·03–7·69
Social Withdrawal (5 items, score 0–15)	3·44	0	0	15	2·91–3·98
Disclosure (6 items, score 0–18)	8·59	9	0	18	7·82–9·37

Table 3. Descriptive statistics of the items of the LISS (range per item 0–3) and corrected item-total correlation ($n = 416$)

Items	Mean	Std. Deviation	Corrected Item-Total Correlation
Self Acceptance			
1 I feel the disease has spoiled my life.	1·44	1·23	·624
2 I feel that it is my fault that I got this disease.	1·21	1·18	·631
3 I feel embarrassed or ashamed.	1·03	1·19	·745
4 I feel guilty.	1·07	1·19	·721
5 I feel I got punishment.	1·11	1·19	·660
6 I feel life is unfair to me.	0·95	1·17	·681
7 Living with leprosy has made me a tough survivor.	1·09	1·21	·758
Self Isolation			
8 I feel lonely	0·80	1·16	·735
9 I feel out of place in the world.	0·65	1·07	·758
10 I feel inferior	0·69	1·07	·751
11 I think less of myself.	0·67	1·06	·762
12 Negative stereotypes about leprosy keep me isolated from the normal world.	0·87	1·13	·775
13 I feel, leprosy affected people should not marry.	0·85	1·20	·524
14 I need others to make most decisions for me.	0·86	1·18	·774
15 I isolate myself from other to avoid rejection	0·68	1·07	·756
16 I feel worthless.	0·79	1·18	·655
Social Withdrawal			
17 I am scared of others reaction in the social events (Marriage, festival etc)	0·73	1·20	·692
18 I avoid visiting people.	0·66	1·15	·736
19 I stay away from social situations to avoid embarrassment to my family	0·65	1·15	·754
20 I feeling uncomfortable, when people around me	0·69	1·17	·704
21 I decided not to attend social gathering.	0·72	1·20	·692
Disclosure			
22 I avoid telling people about my condition	1·47	1·42	·615
23 I feel, telling someone about my condition is risky.	1·45	1·42	·585
24 I regret having told to someone about my condition	1·42	1·41	·589
25 I told people close to me not to reveal to any one	1·41	1·41	·611
26 I feel not to reveal to friends/family about my condition	1·43	1·42	·626
27 I worry that people may judge me when they know about my condition.	1·42	1·42	·646

Table 4. Factor analysis of the LISS (4 factor) (*n* = 416)

Item	Self Acceptance	Self Isolation	Social withdrawal	Disclosure
1 I feel the disease has spoiled my life.	·741			
2 I feel that it is my fault that I got this disease.	·824			
3 I feel embarrassed or ashamed.	·661	·408		
4 I feel guilty.	·821			
5 I feel I got punishment.	·831			
6 I feel life is unfair to me.	·581	·551		
7 Living with leprosy has made me a tough survivor.	·552	·522		
8 I feel lonely		·712		
9 I feel out of place in the world.		·862		
10 I feel inferior		·864		
11 I think less of myself.		·859		
12 Negative stereotypes about leprosy keep me isolated from the normal world.		·721		
13 I feel, leprosy affected people should not marry.		·659		
14 I need others to make most decisions for me.		·698		
15 I isolate myself from other to avoid rejection		·861		
16 I feel worthless.		·525	·450	
17 I am scared of others reaction in the social events (Marriage, festival etc)			·852	
18 I avoid visiting people.			·888	
19 I stay away from social situations to avoid embarrassment to my family			·861	
20 I feeling uncomfortable, when people around me			·866	
21 I decided not to attend social gathering.			·883	
22 I avoid telling people about my condition				·896
23 I feel, telling someone about my condition is risky.				·919
24 I regret having told to someone about my condition				·918
25 I told people close to me not to reveal to any one				·944
26 I feel not to reveal to friends/family about my condition				·933
27 I worry that people may judge me when they know about my condition.				·903
% of Variance	17·439	24·912	18·507	20·560
Eigenvalues	4·708	6·726	4·997	5·551

Table 5. Correlation and floor and ceiling of the domains of the LISS ($n = 416$)

	Self Acceptance	Self Isolation	Social Withdrawal	Disclosure
Correlation of the domain				
Self Acceptance	1			
Self Isolation	0·759**	1		
Social Withdrawal	0·563**	0·603**	1	
Disclosure	0·346**	0·366**	0·413**	1
Floor and ceiling effects				
Floor	25·7	40·9	67·1	41·6
Ceiling	10·1	5·1	13·2	34·1

Note: ** p value < 0.001.

appropriate for exploratory factor analysis. Principal axis factor analysis with varimax rotation was conducted to assess the underlying structures for the 27 items of the LISS scale and the results shown in Table 4.

For factor extraction, eigenvalues are fixed as greater than 4 and the number of factors are not requested. After rotation, the results accounted for 81% of the variance as follows: Self-acceptance, 18·51%; Self-isolation, 24·91%; Social withdrawal, 20·56% and Disclosure, 17·44%. Table 4 shows the items and factor loading for the rotated factors, with loadings less than 0·40 omitted to improve clarity. All the 27 items were fitted in the assigned sub-scales as expected. There are four items (Items; 3, 6, 7 and 16) loaded in two factors. However, items are high loaded on original of the sub-scales.

Between the sub-scales, a moderate positive correlation was found, except the disclosure score with self-acceptance and self-isolation, which had a weak positive correlation (Table 5).

FLOOR AND CEILING EFFECTS

The results found no floor and ceiling effects for the LISS scale. Fifty-three (12·7%) respondents scored the lowest possible score (0) and 10 respondents (2·4%) had highest score of 81. Floor effects were found in all the four sub-scales and ceiling effects were found in one sub-scale (Table 5).

CONSTRUCT VALIDITY

The total score of the LISS scale had a moderate positive correlation with the P Scale ($r = 0.51$, $p = 0.00$) and a weak negative correlation with WHOQOL total score ($r = -0.36$, $p = 0.00$).

TEST-RETEST RELIABILITY

Test–retest reliability of the final scales was evaluated on 54 of the 416 respondents to whom the LISS scales were administered twice within four weeks. The interclass correlation coefficient (ICC) of the LISS scale was 0·77 (95% CI ·63–·86) and the mean difference between interviewers was 2·85 ± 13.01.

Table 6. Mean total score and 95% CI by demographic category and full scale ($n = 416$)

Status	N	Mean	95% CI	*p* value
Gender				
Male	260	22·12	19·55–24·70	0·00
Female	156	34·63	30·69–38·56	
Age				
18–30 years	122	25·22	21·27–29·17	
31–45 years	147	30·84	26·84–34·85	0·06
46–60 years	112	24·93	20·43–29·43	
Above 60 years	35	21·46	15·17–27·75	
Education				
Illiterate	216	31·36	27·95–34·77	0·00
Primary	40	25·03	18·90–31·15	
Secondary	115	21·76	18·03–25·49	
Higher Secondary & above	45	19·49	13·64–25·34	
Occupation				
House wife	138	33·97	29·85–38·09	0·00
Labor	55	31·13	24·61–37·65	
Skilled Labor	66	19·27	14·56–23·98	
Farmer	100	21·76	17·48–26·04	
Government, Private and Business	32	22·25	13·87–30·63	
Student	25	23·76	14·96–32·56	
Family Income				
Below Rs.5000	303	28·33	25·59–31·08	0·03
Above Rs.5000	113	22·73	18·95–26·52	

INTERPRETABILITY

The LISS total mean scores and corresponding confidence intervals of demographical variables are shown in Table 6.

The results shows that the females (34·63) had a significant higher mean score than males (22·12, $p = 0·00$). The variables of education, occupation and family income had a significant mean score difference among the groups.

The LISS mean scores and corresponding confidence intervals of disability grade are shown in Table 7.

The mean total LISS score for persons with Grade 2 disability (35·37) was significantly higher than for Grade 0 (19·95 $p = 0·00$) and Grade 1 (24·77, $p = 0·00$). The difference between the mean total scores for people with Grade 0 and Grade 1 disability was not significant ($p = 0·27$). The mean score was higher for persons with grade 2 than grade 0 and grade 1 in all the four domains, although the difference was significant only in three domains: self-acceptance, self-isolation and social withdrawal.

Discussion

Assessment of the level of stigma is important to assess the effect of interventions in leprosy programmes. The scale development process can be carried out in three basic steps; Item generation, theoretical analysis and psychometric analysis.[23] In order, this study followed the scientific scale development procedure and developed and tested a new scale to measure the internalised stigma among people affected by leprosy using the Bengali language.

Table 7. Mean total score and 95% CI by Disability grade with full scale and domains ($n = 416$)

Status	N	Mean	95% CI	*P* value
Disability Grade				
Grade 0	182	19·95	17·14−22·75	0·00
Grade 1	71	24·77	19·41−30·13	
Grade 2	163	35·37	31·47−39·27	
Domain sub-scale				
Self Acceptance				
Grade 0	182	5·76	4·84−6·67	0·00
Grade 1	71	7·15	5·50−8·81	
Grade 2	163	10·66	9·54−11·77	
Self Isolation				
Grade 0	182	4·48	3·44−5·52	0·00
Grade 1	71	6·51	4·40−8·62	
Grade 2	163	9·67	8·24−11·10	
Social Withdrawal				
Grade 0	182	1·82	1·20−2·44	0·00
Grade 1	71	3·00	1·73−4·27	
Grade 2	163	5·45	4·47−6·44	
Disclosure				
Grade 0	182	7·89	6·70−9·08	0·13
Grade 1	71	8·11	6·13−10·10	
Grade 2	163	9·59	8·38−10·79	

Always there will be challenges when developing a new scale or translation. Also, this study had challenges when translating to the Bengali language. The meaning of words was discussed with experts during translation and testing the scale. Further, the discussion was held with field investigators who were native speakers, understanding the meaning of the words and testing them with the respondents. After the testing, discussion was held with the respondents, the scale was finalised and the quantitative interview was conducted.

The scale was developed in a statement format, so that it can be used by both interviewer administration and self-administration. In addition, items on the scale were prepared in a manner that was easy for the respondents to answer, and at the same time easy for the interviewer to ask. In this study, the final format of the scale has 27 items and the items are grouped in four domains; self-acceptance (7 items), self-isolation (9 items), social withdrawal (5 items) and disclosure concerns (6 items). The minimum total score is 0 and maximum total score is 81. There is no missing value on the items, implying that the items are understood well by respondents.

The internal consistency of the LISS scale was good and the Cronbach alpha was 0·96. The Stigma Assessment and Reduction of Impact (SARI) stigma scale, based on the Berger HIV stigma scale, developed by Dadun *et al.* (2017), assessed stigma among people affected by leprosy in Indonesia, with a Cronbach alpha of 0·88.[15] Renson *et al.* (2010), measured the stigma among people affected by leprosy in India by using the Internalised Stigma of Mental Illness scale (ISMI), with a Cronbach alpha of 0·96.[6]

The construct validity of the LISS was supported by the moderately positive correlation with the P-scale and weak negative correlation with the WHOQOL-BREF. The SARI stigma scale also found similar results.[15] Further research should be conducted to investigate the relationship between internalised stigma and quality of life. The ICC of the LISS scale was good (0·77).

This study found no floor or ceiling effects in the overall LISS using the criteria of Terwee.[18] All the four sub-scales have floor effects and ceiling effects were found in one sub-scale. Floor effects are due a lack of sensitivity at the lower end of the scale. This is not necessarily a problem in a stigma tool, since mild levels of stigma would not be acted upon anyway.[15] The high proportion of floor effects in the sub-scales of social withdrawal, self-isolation and disclosure, might be due to respondents' positive attitude towards illness. However, a 34% ceiling was observed for disease disclosure concerns. If the people have a positive attitude towards their illness, internalised stigma will not occur and their psychosocial wellbeing and quality of life will improve.

The factor analysis showed that four items loaded in two factors; however, the highest value resulted in the expected factor. Three items ('I feel embarrassed or ashamed', 'I feel life is unfair to me' and 'Living with leprosy has made me a tough survivor') were loaded into self-acceptance and self-isolation. The item ('I feel worthless') was loaded into self-isolation and social withdrawal. There can be an overlap in factor loading because these items are all measuring internalised stigma. All items of the scale fit well into their respective sub-scales, with factor loadings ranging from 0·53–0·94.

Visible deformity (Grade 2 disability) gave a significantly higher mean score in all the domains than for respondents with no visible deformity (Grades 0 and 1), except in sub-scales of disease disclosure. Concerning disease disclosure, fear of stigma and discrimination may affect respondents who have no visible deformity as much as those with visible deformity.

This study has strengths and limitations. The study only validated the LISS scale in Bengali, India. Cross-cultural validation is needed to ensure that a scale will produce valid data on what it intends to measure, especially in India because of the multilingual country. Reliability and validity were high and factor analysis resulted in a 27 item scale that possessed good psychometric properties. Test-retest reliability, another important measure of overall reliability, indicated stability over time. The LISS demonstrated high internal consistency, suggesting that items within the scale could be similar and the scale could be shortened without impacting its psychometric properties.

The LISS scale measures internalised stigma using four sub scales; self-acceptance, self-isolation, social withdrawal and disclosure. We believe the LISS Scale is suitable for use as a generic instrument to measure internalised stigma in leprosy, in addition to other available tools.[6,14,15] Moreover, it can be used for other stigmatised conditions and neglected tropical diseases.

Conclusion

The LISS scale is a reliable and valid measure of internalised stigma in people affected by leprosy. Validated and culturally relevant measures are essential to appropriately assess internalised stigma to address the psychosocial consequences of leprosy and provide early interventions. It is a promising tool which can be easily incorporated into leprosy programmes to identify individuals in need of psychological support to improve their psychosocial wellbeing and quality of life.

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Author contributions

Mr. Pitchaimani Govindharaj, was involved in study conceptualization and design, preparing the questionnaires, analysis and interpretation of data and preparation of the manuscript.

Dr. Sampathkumar Srinivasan, was involved in study design, assisting for finalizing the questionnaires and comments on the manuscript.

Dr. Joydeepa Darlong, was involved in monitoring the study, getting approval from The Leprosy Mission Trust, India, New Delhi and comments on the manuscript.

Mr. Babananda Mahato, was involved in translation of questionnaires and assisting participant's requirement.

Mr. Premendra Acharya, was involved in translation of questionnaires and assisting participant's requirement.

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