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### Adaptation of scales assessing perceived and internalized stigma, self-esteem and social participation of leprosy affected persons in colloquial Bengali language

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#### Abstract

The study aimed to translate original English versions of Explanatory Model Interview Catalogue for leprosy-affected persons, Internalized Stigma of Mental Illness scale adapted for leprosy-affected persons, Rosenberg Self Esteem Scale and the Participation Scale into colloquial Bengali and standardize these tools. Initially original English versions of all four tools were translated in colloquial Bengali language. The draft Bengali translations were submitted to three experts for evaluation. The experts independently rated the translations. Their suggestions were also recorded. Following their suggestions, drafts of the translated tools were partly modified. Inter-rater correlations (Spearman's Rho) between ratings of pairs of experts were computed. Chi-square test was conducted after categorizing the ratings; Likelihood Ratios were calculated. The translated versions of the four scales were administered through interviews on a random sample of 109 leprosy patients. Scoring was done. Split-half reliability coefficients were computed followed by calculation of coefficients of construct validity. Inter-rater correlations present mixed but informative results. Reliability coefficients were high and significant. Adequate construct validity were evident through correlations between scores on Bengali translations of :- a) Internalized Stigma of Mental Illness scale and Rosenberg Self Esteem Scale; b) Internalized Stigma of Mental Illness scale and Participation Scale; c) Rosenberg Self Esteem Scale and Participation Scale. Tentative norms were constructed.

**Keywords:** Adaptation of scales in colloquial Bengali, Leprosy-affected persons; Perceived and internalized stigma; self-esteem; social participation

#### 1. Introduction

Use of standardized tool is of great significance while researching any sensitive psychosocial issue. Leprosy is a disease where the patients suffer immense stigma and social ostracism. Although a lot of standardized scales have been developed to study psychosocial problems of leprosy in different languages across the globe yet there is paucity of standardized scales in Bengali to assess social stigma, self-esteem and social participation of leprosy patients. An effort was made<sup>[10]</sup> to adapt the original English versions of the Internalized Stigma of Mental Illness scale adapted for leprosy-affected persons, Explanatory Model Interview Catalogue for leprosy-affected and non-affected persons and the Participation Scale in Bengali language. But perusal of the scales reveals that those are worded in formal Bengali. Generally leprosy patients who come for treatment in government hospitals and non-government organizations (NGOs) belong to lower socio-economic strata of society and are not conversant with formal Bengali language. This might hamper accessing of insightful data. Hence an unmet need to translate the scales into simple and colloquial Bengali language was felt so that leprosy patients (with Bengali as the mother tongue) face no difficulty in understanding and responding to the scales. But merely translating the scales is not enough. These have to be standardized on samples of leprosy patients of West Bengal. In other words, reliability and validity have to be measured; appropriate norms have to be constructed. The present study aims to translate original English versions of Explanatory Model Interview Catalogue for leprosy-affected persons, Internalized Stigma of Mental Illness scale adapted for leprosy-affected persons, Rosenberg Self Esteem Scale and the Participation Scale into colloquial Bengali and standardize these tools.

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Standardization of data-gathering tool is required in any kind of research to ensure that the tool is: a) uniformly administered as well as scored; b) objective in nature; and c) amenable to interpretation. A standardized tool should have three characteristic features: reliability, validity and norms. Advantages of standardization are that the test can be shown to have adequate reliability (uniformity in techniques of administration and scoring across testing-sessions) and validity (objective assessment of a characteristic which the tool is designed to assess); as well as results which emanate can be interpreted and compared intra-individually and inter-individually with the help of frame of reference or norms [2, 5]. It is mandatory to report the inter-rater correlations of draft version of a scale during initial stage of standardization process. Inter-rater correlation refers to determination (through associations) of extent of similarity among the ratings of translations of individual items of the tool by different experts. Translations of items on which the experts differ considerably in their ratings are rephrased. Disagreement among experts on ratings of many translated items leads to low inter-rater correlation coefficient. Besides, those items which are thought to be poorly translated by the raters are again translated in order to improve validity of the tool. The goal is to improve the translations such that the translated items capture the true spirit of the original items and there is no ambiguity. These exercises raise the agreement among experts regarding the quality and appropriateness of the translated items which is reflected in high inter-rater correlation coefficient. After that the tasks of computing reliability and validity coefficients; as well as construction of norms begin. Reliability refers to the consistency of measurement—that is, how consistent test scores or other evaluation results are from one measurement to the other [2, 7]. Simply put, reliability of a tool indicates the extent to which the results of the tool remain similar across different testing-sessions (separated by reasonably long time intervals) with the same test-taker(s). Reliability is generally measured by calculating the correlation between two sets of data elicited from the same set of test-takers by administering the same tool in two testing-sessions. A type of reliability known as split-half reliability is especially advantageous in assessing internal consistency of a scale. It is the measure of the internal consistency of a tool i.e. to what extent the items consistently measure the characteristic being assessed. It is obtained by correlating responses of a group of test-takers on one half of the tool with responses of the same group on the other half. In this technique, the tool (in its entirety) is administered only once on the group of test-takers. The items of the tool are split up into two halves before scoring. The splitting up of the two halves is done either by considering the first 50% of the items as the first half and the rest 50% of the items as the second half. Otherwise, the items with even serial numbers are considered as one half and those with odd serial numbers are regarded as another half. These halves (either first and second halves; or halves comprising even-numbered and odd-numbered items) of the tool are scored separately for each test-taker. Two sets of scores (one from each half of the tool) for a given group of test-takers are correlated. High and positive correlation coefficient indicates adequate split-half reliability of the tool. Validity is defined as the extent to which a tool measures what it purports to measure. Computation of a type of validity viz. construct validity is important in test standardization. Construct validity refers to the degree to which the items of the tool separately and together test the array or category of behaviours or characteristics subsumed by the psychological process or the personality trait being

assessed [2, 12]. Convergent and discriminant validity are considered subtypes of construct validity. Convergent validity is defined as the extent to which measures of constructs that theoretically ought to be related to each other are evidently related to each other. A tool supposedly measuring a psychological construct is shown to have adequate convergent validity if scores on that tool are found to be highly and positively associated with those on another tool which has been found to assess the same construct. Discriminant validity is defined as the extent to which measures of constructs that theoretically ought to be unrelated to each other are manifestly unrelated to each other. A tool supposedly measuring a psychological construct is shown to have adequate discriminant validity if scores on that tool are found to be negligibly associated with those on another tool which has been found to assess a markedly different construct [2, 12]. Norms refer to information regarding the performance of a particular reference-group on a particular measure assessed by a particular tool with which a person's performance on that tool can be compared. Scores on a psychological tool are interpreted by referring to norms that represent the performance on that tool by a large sample of individuals [2, 4].

## 2. Methodology

### 2.1. Hypotheses

- i. For the Bengali translation of Explanatory Model Interview Catalogue there is relation between ratings of (a) raters I and II; (b) raters I and III; (c) raters II and III.
- ii. For the Bengali translation of Internalized Stigma of Mental Illness scale there is relation between ratings of (a) raters I and II; (b) raters I and III; (c) raters II and III.
- iii. For the Bengali translation of Rosenberg Self Esteem Scale there is relation between ratings of (a) raters I and II; (b) raters I and III; (c) raters II and III.
- iv. For the Bengali translation of Participation Scale there is relation between ratings of (a) raters I and II; (b) raters I and III; (c) raters II and III.
- v. Scores on two halves of Bengali translation of Explanatory Model Interview Catalogue are related.
- vi. Scores on two halves of Bengali translation of Internalized Stigma of Mental Illness scale are related.
- vii. Scores on two halves of Bengali translation of Rosenberg Self Esteem Scale are related.
- viii. Scores on two halves of Bengali translation of Participation Scale are related.
- ix. Scores on Bengali translations of Explanatory Model Interview Catalogue and Internalized Stigma of Mental Illness scale are positively related.
- x. Scores on Bengali translations of Explanatory Model Interview Catalogue and Rosenberg Self Esteem Scale are negatively related.
- xi. Scores on Bengali translations of Explanatory Model Interview Catalogue and Participation Scale are positively related.
- xii. Scores on Bengali translations of Internalized Stigma of Mental Illness scale and Rosenberg Self Esteem Scale are negatively related.
- xiii. Scores on Bengali translations of Internalized Stigma of Mental Illness scale and Participation Scale are positively related.
- xiv. Scores on Bengali translations of Rosenberg Self Esteem Scale and Participation Scale are negatively related.

## 2.2. Operational Definitions of Variables

1. **Leprosy Affected Persons:** Persons suffering from chronic infectious disease caused by the bacillus *Mycobacterium leprae* which occurs mainly in tropical and subtropical regions. It is characterized by formation of painful inflamed nodules beneath the skin and disfigurement as well as wasting of affected parts<sup>[3]</sup>.
2. **Perceived Stigma:** Also known as anticipated or felt stigma it is the perception, expectation or fear of discrimination experienced by an individual and her / his awareness of negative attitudes or practices in society directed against her / him<sup>[14, 15]</sup>.
3. **Internalized Stigma:** Also known as self-stigma it is the outcome of a subjective process embedded within a socio-cultural context which may be characterized by negative feelings about oneself, maladaptive behaviour, identity transformation or stereotype-endorsement regarding self resulting from an individual's experiences, perceptions or anticipations of negative social reaction on the basis of their health or other condition<sup>[1, 8]</sup>.
4. **Self Esteem:** Also known as self-regard it is the evaluative aspect of self-perception which might be thought of as the degree to which one likes herself/himself. An individual who generally considers herself/himself favourably; has a general feeling of approval of what she/he perceives in herself/himself; and thus likes herself/himself would be said to have a high level of self esteem<sup>[9, 11]</sup>.
5. **Social Participation:** It is a person's involvement in activities providing interactions with others in society or community<sup>[6, 13]</sup>.

## 2.3 Tools

1. Explanatory Model Interview Catalogue or EMIC Stigma Scale for use with leprosy-affected persons (Weiss, 1997) to be adapted in simple Bengali Language: The tool assesses socially ascribed stigma perceived by leprosy-affected individuals. The original English version of the tool consists of 15 questions each having four answer-options viz. yes, possibly, uncertain and no. The scores to be awarded are 3, 2, 1 and 0 respectively. Higher score indicates more perceived stigma. Internal consistency of the scale was reportedly .88<sup>[10, 15]</sup>.
2. Internalized Stigma of Mental Illness or ISMI for use with leprosy-affected persons (Boyd Ritsher *et al.*, 2003)<sup>[1]</sup> to be adapted in simple Bengali Language: Original English version of the tool has 28 statements related with self-stigmatization of leprosy-affected persons. Each statement is followed by four response-options – strongly disagree, disagree, agree and strongly agree. The scores to be awarded for endorsement of each response-option are 1, 2, 3 and 4. Higher score indicates more internalized stigma. ISMI scale has internal consistency of .90 for a sample of 127 individuals. The scale has positive correlation with measures of depressive symptoms demonstrating adequate construct validity<sup>[1]</sup>.
3. Rosenberg Self Esteem Scale (1965) to be adapted in simple Bengali Language: Original English version of the scale comprises 10 items with responses to be indicated on a four-point scale. The scale is a self-report measure of global self esteem of adolescents and adults. Response-options are strongly agree, agree, disagree and strongly disagree. The positively-worded items are reverse-scored i.e. strongly agree - 3, agree - 2, disagree - 1 and strongly disagree - 0. Negatively-worded items are scored in the

fashion: strongly agree - 0, agree - 1, disagree - 2 and strongly disagree - 3. Scores for all the items are summed. Scores range between 0 and 30. Higher score indicates elevated self-esteem. Internal consistency of the original scale ranges from .77 to .88. Construct validity with measure of anxiety is -.64<sup>[11]</sup>.

4. Participation Scale for use with leprosy-affected persons (Van Brakel *et al.*, 2006)<sup>[13]</sup> to be adapted in simple Bengali Language: It consists of 18 questions related to extent of social participation of leprosy-affected individuals aged at least 15 years. Each question is followed by four main response-options – not specified, yes, sometimes, no and irrelevant; four more response-options gauge the degree of problem faced – no problem, small, medium and large. The test-taker has to indicate her / his answer to each question. Scores range from 0 to 90. Higher score indicates more participation-restriction. Cronbach's alpha of .92 computed for a multi-cultural sample (N=497) showed very high reliability. The original scale has been validated for use with persons with leprosy; spinal injuries; polio etc.<sup>[13]</sup>.

## 2.4 Sample

A random sample of 109 leprosy-affected persons (30 women; 79 men aged between 18 and 70 years) who were native-speakers of Bengali language and undergoing treatment in Leprosy Mission and School of Tropical Medicine, Kolkata was selected from the population. There were many more men than women in the sample because leprosy-affected women generally avoid diagnosis and treatment due to greater fear of social ostracism than men. Most participants belonged to lower socio-economic status families as assessed by an appropriate scale.

## 3. Procedure

Initially original English versions of all four tools (sub-section 2.3) were translated in simple colloquial Bengali language. Then the draft Bengali translations were submitted to three experts – two Professors of Education and one Professor specializing in Applied Psychology for evaluation of the fidelity to the original, quality and appropriateness of the translations. These experts were well-versed in psychological test-construction and English as well as Bengali languages. The experts independently rated the translations of the instructions to the test-takers, items of the tools and the response-options on five-point scales. Their suggestions were also recorded. Then based on their suggestions, some modifications were made in the drafts of the translated tools. Inter-rater correlations (Spearman's Rho) between ratings of pairs of experts were computed. Chi-square test was conducted after categorizing the ratings; Likelihood Ratios were found out. Next the translated versions of the four scales were administered through interviews on a random sample of 109 leprosy patients undergoing treatment in Leprosy Mission and School of Tropical Medicine, Kolkata from May 2016 to November 2016. Scoring was done by consulting the manuals of the scales. Split-half reliability coefficients were computed followed by calculation of coefficients of construct validity (both convergent and discriminant). Finally, tentative norms were constructed.

4. Results and Discussion

**Table 1:** Inter-Rater Correlations of Scales Adapted in Simple Bengali Language

Scales	Statistics	Rater I x II	Rater I x III	Rater II x III
Explanatory Model Interview Catalogue	Spearman Correlation	-0.15 (SE 0.02)	-.24 (SE 0.1)	-.24 (SE 0.1)
	Chi-Square (Likelihood Ratio)	.36 (.62)	.84 (1.35)	.84 (1.35)
Internalized Stigma of Mental Illness scale	Spearman Correlation	0.10 (SE 0.19)	0.41* (SE 0.21)	-.16 (SE 0.08)
	Chi-Square (Likelihood Ratio)	1.62 (1.95)	28** (8.63)	.67 (1.02)
Rosenberg Self Esteem Scale	Spearman Correlation	-.37 (SE 0.34)	.43 (SE 0.25)	-.19 (SE 0.18)
	Chi-Square (Likelihood Ratio)	10.57 (7.21)	4.44 (3.73)	2.59 (2.68)
Participation Scale	Spearman Correlation	1** (SE 0.15)	1** (SE 0.15)	1** (SE 0.15)
	Chi-Square (Likelihood Ratio)	1 (1)	1 (1)	1 (1)

SE: Standard Error; \* $p < .05$ ; \*\* $p < .01$

Spearman rho and chi square values (Table 1) reveal that for the Bengali translation of Explanatory Model Interview Catalogue there seems to be non-significant relation between ratings of raters I and II; raters I and III; raters II and III. So hypotheses 1(a), 1(b) and 1(c) are rejected. In respect of the Bengali translation of Internalized Stigma of Mental Illness scale there is significant relation between ratings of raters I and III; hypothesis 2(b) is tenable. However, raters I and II; and II and III evidently did not share strong association in their ratings of the translated tool; hypotheses 2(a) and 2(c) are not supported. In case of the Bengali translation of Rosenberg Self Esteem Scale there appears to be feeble relation between ratings of raters I and II; raters I and III; raters II and III; hypotheses 3(a), 3(b) and 3(c) are rejected. The Bengali translation of Participation Scale presents a curious instance as far as the values of Spearman's rho are concerned - there is perfect correlation between ratings of raters I and II; raters I

and III; raters II and III as the ratings are identical; hypotheses 4(a), 4(b) and 4(c) are retained. However, significant relations are not borne out by the chi square values plausibly because of the categorization of data involved. Standard error (SE) values are all modest indicating precision of estimate. Likelihood ratios of 1 reported for Participation Scale suggest that the results do not reflect the probability of existence of relation between the evaluations of translation done by pairs of experts. Likelihood ratios exceeding 1 found out for relation between ratings by experts I and III; and II and III in case of Explanatory Model Interview Catalogue in translation; as well as association between ratings by pairs of experts for translations of Internalized Stigma of Mental Illness scale and Rosenberg Self Esteem Scale reveal increased probability that the ratings are similar. The remainder of Likelihood ratios fell short of 1 and pointed towards decreased probability of congruence between pairs of ratings.

**Table 2:** Reliability of Scales Adapted in Simple Bengali Language

Sl. No	Scales	Split-Half Reliability Coefficients
1.	Explanatory Model Interview Catalogue	0.82**
2.	Internalized Stigma of Mental Illness scale	0.85**
3.	Rosenberg Self Esteem Scale	0.84**
4.	Participation Scale	0.92**

\*\* $p < .01$

Results (Table 2) indicate high and significant internal consistency of Explanatory Model Interview Catalogue, Internalized Stigma of Mental Illness scale, Rosenberg Self Esteem Scale and Participation Scale which were adapted in simple Bengali language by the present authors. Thus hypotheses 5<sup>th</sup> to 8<sup>th</sup> are upheld. It has been demonstrated that

scores on two halves of Bengali translations of each of the tools: - Explanatory Model Interview Catalogue; Internalized Stigma of Mental Illness scale; Rosenberg Self Esteem Scale; and Participation Scale are related. Present findings are attested by those of prior researches [1, 10, 11, 13, 15].

**Table 3:** Validity of Scales Adapted in Simple Bengali Language: Inter-Correlations (N=54)

Sl. No.	Scales	I	II	III	IV
I	Explanatory Model Interview Catalogue	----	.25	.03	-.08
II	Internalized Stigma of Mental Illness scale	.25	----	-.42**	.44**
III	Rosenberg Self Esteem Scale	.03	-.42**	----	-.42**
IV	Participation Scale	-.08	.44**	-.42**	----

\*\* $p < .01$

Table 3 reveals that: - scores on Bengali translations of Explanatory Model Interview Catalogue and Internalized Stigma of Mental Illness scale are positively related but the

relation is non-significant. So the 9<sup>th</sup> hypothesis is not supported. Scores on Bengali translations of Explanatory Model Interview Catalogue and Rosenberg Self Esteem Scale

are negligibly related. Thus the 10<sup>th</sup> hypothesis is not tenable. Similarly, scores on Bengali translations of Explanatory Model Interview Catalogue and Participation Scale evidently share inconsequential association; the 11<sup>th</sup> hypothesis is not retained. Scores on Bengali translations of Internalized Stigma of Mental Illness scale and Rosenberg Self Esteem Scale are negatively and strongly related. The 12<sup>th</sup> hypothesis is supported. It indicates that leprosy-affected individuals with higher self-stigma tend to be lower in self-esteem while those with elevated self-esteem are likely to self-stigmatize less – this is consonant with outcomes of previous research [1, 11]. Scores on Bengali translations of Internalized Stigma of Mental Illness scale and Participation Scale have been found to be positively and intimately associated; the 13<sup>th</sup> hypothesis is

upheld. It shows that leprosy-affected persons with higher tendency of self-stigmatization perceive or volitionally impose more social participation-restrictions and vice versa which resonate with findings of earlier investigations [1, 13]. Scores on Bengali translations of Rosenberg Self Esteem Scale and Participation Scale are negatively related; the 14<sup>th</sup> hypothesis is tenable. It points out that leprosy-affected individuals with higher self-esteem generally perceive less social participation-restrictions while those with lower self-esteem perceive these restrictions more. This outcome echoes those of prior studies [11, 13]. Findings, particularly in respect of statistically significant correlation coefficients, suggest adequate construct validity of the adaptation of the said tools in simple Bengali language.

**Table 4:** Tentative Norms (N=109)

Scales	Mean	SD	Q1	Q2	Q3
Explanatory Model Interview Catalogue	18.17	10.36	9	19	26
Internalised Stigma of Mental Illness scale	76.85	14.22	65	77	89
Rosenberg Self Esteem Scale	13.05	4.88	10	14	17
Participation Scale	19.50	21.41	0	15	32.5

The norms (Table 4) are tentative because the sample is limited in size. The work of standardization of these translated tools is in progress. In future a much larger sample would yield more dependable norms.

## 5. Conclusion

Results demonstrate high and significant internal consistency of Explanatory Model Interview Catalogue, Internalized Stigma of Mental Illness scale, Rosenberg Self Esteem Scale and Participation Scale which were adapted in simple Bengali language by present investigators. Adequate construct validity are manifest through correlations between scores on Bengali translations of :- a) Internalized Stigma of Mental Illness scale and Rosenberg Self Esteem Scale; b) Internalized Stigma of Mental Illness scale and Participation Scale; c) Rosenberg Self Esteem Scale and Participation Scale. Tentative norms could be constructed.

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