

## **Depressive status of leprosy patients in Bangladesh: association with self-perception of stigma**

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*Summary* Stigmatization by the general population and their negative attitudes towards leprosy negatively impacts on patients' mental health, and so too does patients' perception of that stigma. The objective of this present study is to assess the depressive status of leprosy patients, the patient perception of that stigma, and its association with their depressive status in Dhaka, Bangladesh. Subjects were 140 patients, and a selected comparison group of 135 local people without any chronic diseases. To evaluate depressive status, the Center for Epidemiologic Studies Depression scale (CES-D) Bengali version was applied. The patient group's depressive status was significantly more severe than that of the comparison group. Depressive status of those who answered affirmatively was significantly more severe than that of those who answered negatively for three responses to questions: 1) 'I have been physically attacked by people', 2) 'I feel people regard me as strange' and 3) 'I have been refused the purchase of something by a shopkeeper'. The results showed that the depressive status in leprosy patients was greater than that of the general public. Further, actual experiences of discrimination based on stigma associated with the depressive status of leprosy patients. Mental health care for patients, regulation of discriminatory action and education that would decrease social stigma among the general population, especially people who might often have contact with patients, seem necessary to improve the mental health of Bangladeshi leprosy patients.

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## Introduction

Leprosy has long been stigmatized because of the visible deformities resulting from the progressive and permanent physical disabilities associated with the disease. These may trigger physical and psychological isolation.<sup>1-4</sup> The government of Bangladesh, recognizing the importance of this aspect, is now trying to include raising awareness of the disease and educating patients and the community into a leprosy control programme.<sup>5</sup>

Previous studies in Bangladesh<sup>6</sup> and other countries<sup>7-9</sup> have revealed that people harboured a stronger stigma against leprosy than other stigmatized diseases such as epilepsy, tuberculosis and various dermatological disorders. Members of the general public have also shown aggressive discriminative attitudes towards leprosy patients.<sup>2,6-11</sup> A study in Botswana illustrated that even healthcare personnel had negative attitudes against leprosy patients due to their lack of knowledge.<sup>12</sup> Stigma has also negatively influenced patients' health-seeking behaviour.<sup>2,13-15</sup>

The mental health of leprosy patients has been shown to show a higher prevalence of psychiatric problems, diagnosed by the DSM-III-R (Diagnostic and Statistical Manual of Mental Disorders, 3rd edition, revised) criteria<sup>16</sup> than the general population or patients of other diseases.<sup>17,18</sup> A study in India indicated a high prevalence of anxiety and depression among institutionalized patients.<sup>19</sup> Psychiatric morbidity in displaced leprosy patients was much higher than in non-displaced patients.<sup>20</sup> However, while public stigma and the negative attitude toward leprosy could be anticipated to have a negative impact on patients' mental health, past research has paid little attention to this issue. Due to the impact of stigma and discrimination, a high percentage of patients feel desperate and have verbalized suicidal ideas, with some actual suicide attempts.<sup>21</sup>

However, there has been no research on mental health status of leprosy patients in Bangladesh, and so patient perception of stigma and its association with their mental health are unclear. Such associations are critical for an understanding of leprosy patients' well-being. Thus, this study investigated 1) the depressive status of leprosy patients compared to the general public, and 2) patients' perception of stigma and its associations with their depressive symptoms.

## Materials and methods

### SUBJECTS

Subjects were 111 outpatients and 29 inpatients from the Government Leprosy Institute and Hospital Compound who agreed to participate in this study. As a comparison group, taking the situation of the patients' living area into account, we randomly selected two urban areas in the Lalbag District, one a rural area in Keraniganj District and other a slum area in Tejgaon District, utilizing the latest Bangladesh census (1991).<sup>22</sup> Beginning from the official branch in each area, interviewers visited houses clockwise one by one until they got about 30 respondents from every area. After confirming whether respondents had leprosy or any chronic diseases, 135 local people without diseases were selected and their consent obtained. Response rate was 89%.

## MEASUREMENTS

Three male and one female health workers, unrelated to the patients and the hospital, conducted household interviews using a structured questionnaire after 1 week of training. The female interviewer was principally in charge of interviewing female respondents.

The structured questionnaire contained questions relating to: 1) socio-economic and demographic characteristics, 2) self-perception toward stigma, and 3) CES-D (The Center for Epidemiologic Studies Depression scale)<sup>23</sup> to assess depressive status. We also obtained disability grades and impairments from medical records based on the classification by the WHO Expert Committee on Leprosy.<sup>24</sup>

CES-D is one of the best-known survey instruments for identifying symptoms of depression.<sup>23</sup> It contains 20 items (0–3 response set) covering the major components of depression: depressed mood, feeling of guilt and worthlessness, feeling of helplessness and hopelessness, psychomotor retardation, appetite loss and sleep disorder. Higher scores meaning a more severe depressive status. The validity and reliability of the CES-D English version has been well established.<sup>12</sup> Experienced leprologists, a mental health specialist and a health researcher of the research team translated the English version into Bengali and back translation was made into English in the present study. Cronbach's  $\alpha$  of the CES-D Bengali version was 0.92, which indicated sufficient internal validity. In this study, we did not use the cut-off point (16 points) of the English version, but compared total scores because determination of a cut-off point for the Bengali version needed further discussion.

For data analysis, Mann–Whitney and Kruskal–Wallis tests were used because data were not normally distributed. The Chi-square test was employed for categorical data. All differences were considered significant at  $P < 0.05$ , using two-tailed tests. The statistical software package SPSS (version 10.0J) was used to analyse data.

## Results

There were 115 male and 25 female patients, even though the comparison group comprised almost equal numbers of male and female (66 males versus 69 females), resulting in a significant difference in gender between the two groups ( $P < 0.001$ ) (Table 1). With marital ( $P = 0.023$ ) and working status ( $P = 0.01$ ), there were also significant differences between the two groups (Table 1). Fifteen (10.7%) patients and one (0.7%) member of the control group had other leprosy patients in their families, which was significantly different ( $P < 0.001$ ) (Table 1). Literacy rate, mean age, school educational background completed and household cash income were found to have no significant differences (Table 1).

The median of the CES-D total score of the patients group was 28.0 (interquartile range; 16.0–37.0), while that of the comparison group was 12.0 (interquartile range; 7.0–22.0) ( $P < 0.001$ ) (Table 2). Each median score of the 20 items of the patient group was significantly higher than that of the comparison group ( $P < 0.05$ ) (Table 2). Because of the difference in sex ratio between the two groups, we undertook a stratified analysis by gender. Among males, the total median score in the patient group was 28.0 (interquartile range; 15.0–36.0), while that of the comparison group was 12.0 (interquartile range; 6.75–20.25) ( $P < 0.001$ ) (data not shown in the tables). For females, the total median score of the patients group was 32.0 (19.5–40.5)

**Table 1.** Socio-economic and demographic data in leprosy patients and controls

	Patients ( <i>n</i> = 140)	Controls ( <i>n</i> = 135)	<i>P</i> -value
<i>Sex</i>			<0.001**
Male	115	66	
Female	25	69	
<i>Age (years)</i>			0.480*
Mean	36.4	35.3	
SD	15.0	11.0	
Range	15–80	18–70	
<i>Household monthly income (Tk)<sup>a</sup></i>			0.260*
Median	4000	4750	
25th–75th percentile	3000–8000	2500–10,000	
<i>Religion (%)</i>			0.106**
Muslim	134 (95.7)	133 (98.5)	
Hindu	6 (4.3)	1 (0.7)	
Others	0	1 (0.7)	
<i>Completed education (%)</i>			0.118**
None	44 (31.4)	37 (27.4)	
Informal education	9 (6.4)	15 (11.4)	
<5 years of school	28 (20.0)	18 (13.3)	
Primary School	38 (27.1)	28 (20.7)	
Secondary School	6 (4.3)	10 (7.4)	
High School	8 (5.7)	15 (11.1)	
More advanced	7 (5.0)	12 (8.9)	
<i>Literacy (%)</i>			0.794**
Can both read and write	81 (57.9)	76 (56.3)	
<i>Marital status (%)</i>			0.023**
Married	95 (67.9)	114 (84.4)	
Separated	2 (1.4)	4 (3.0)	
Divorced/annulled	1 (0.7)	1 (0.7)	
Widowed	4 (2.9)	2 (1.5)	
Unmarried	36 (25.7)	14 (10.4)	
Other	2 (1.4)	0	
<i>Working status<sup>b</sup> (%)</i>			0.010**
Working	71 (52.6)	54 (40.6)	
Non-working	38 (28.1)	10 (7.5)	
Housewife	16 (11.9)	63 (47.4)	
Student	10 (7.4)	6 (4.5)	
<i>Family history of leprosy (%)</i>			<0.001**
Leprosy patients in the family	15 (10.7)	1 (0.7)	

\* Mann–Whitney *U*-value.

\*\* Chi-square test.

<sup>a</sup> US \$1 was equivalent to 50 Tk.<sup>b</sup> Numbers of the analysis for working status were 133 in the control and 135 in the patient group.

while that of the comparison group was 12.0 (interquartile range; 8.0–24.0) ( $P < 0.001$ ) (data not shown in the tables). In addition, the total score between males and females in the comparison group was not significantly different ( $P = 0.376$ ); this was also the case in the patients group ( $P = 0.181$ ) (data not shown in the tables).

As shown in Table 3, there were significant differences between each of the three grades

**Table 2.** Depressive status of patients and controls

	Patients (n = 140) (median)	Controls (n = 135) (median)	P-value (Mann–Whitney)
1 I was bothered by things that usually don't bother me.	2.0	1.0	0.001**
2 I did not feel like eating; my appetite was poor.	0.0	0.0	0.001**
3 I felt that I could not shake off the blues even with the help from my family or friends.	1.0	1.0	<0.001**
4 I felt that I was just as good as other people.	2.0	1.0	<0.001**
5 I had trouble keeping my mind on what I was doing.	2.0	0.0	<0.001**
6 I felt depressed.	2.0	1.0	<0.001**
7 I felt that everything I did was an effort.	1.0	0.0	<0.001**
8 I felt hopeful about the future.	2.0	1.0	0.015*
9 I thought my life had been failure.	1.0	0.0	<0.001**
10 I felt fearful.	1.0	0.0	<0.001**
11 My sleep was restless.	1.0	0.0	0.008**
12 I was happy.	2.0	1.0	<0.001**
13 I talked less than usual.	1.0	0.0	<0.001**
14 I felt lonely.	1.0	0.0	<0.001**
15 People were unfriendly.	0.0	0.0	0.031*
16 I enjoyed life.	2.0	2.0	0.032*
17 I had crying spells.	1.0	0.0	<0.001**
18 I felt sad.	2.0	1.0	<0.001**
19 I felt that people disliked me.	0.0	0.0	<0.001**
20 I could not get 'going.'	2.0	0.0	<0.001**
Total score	28.0	12.0	<0.001**
Interquartile range (25th to 75th percentile)	16.0–37.0	7.0–22.0	

\*  $P < 0.05$ .

\*\*  $P < 0.01$ .

of group ( $P = 0.005$ ). As the grade advanced, the total CES-D score also showed a tendency to increase. However, in grade II patients, total scores were not significantly different between outpatients (32.0 interquartile range; 20.5–38.0) and inpatients (32.0 interquartile range; 24.0–40.5) ( $P = 0.613$ ) (Table 3).

Table 4 shows the association between the total CES-D score and the self-perception of stigma in the patient group. The negative self-perception group was defined as being those patients who had affirmative answers, except for one 'It seems that people sympathize with me', which was worded positively. The positive self-perception group was defined as those who had negative answers except for the above-mentioned response. Medians of the total CES-D scores on each item of the negative self-perception group were higher than those of the positive self-perception group. The difference was significant in three questions: 'I have been physically attacked by people', 'I feel people regard me as strange' and 'I have been refused the purchase of something by a shopkeeper' ( $P < 0.05$ ). Patients who had experience of dismissal from a job showed a tendency to have higher CES-D scores. There was no significant difference in CES-D scores between patients who felt isolation and those who did not. Of the 140 patients, 123 (87.9%) had felt isolation from their family, 95 (67.9%) from relatives or friends and 96 (68.5%) from society. One hundred and eleven (85.0%) patients had an experience of being hurt by their family's negative attitude against leprosy.

**Table 3.** Correlation between depressive status and leprosy grade

	Grade 0 (n = 55) (median)	Grade I (n = 27) (median)	Grade II (n = 58) (median)	P-value (Kruskal-- Wallis)	Grade II		P-value (Mann-Whitney)
					Outpatients (n = 29) (median)	Inpatients (n = 29) (median)	
1 I was bothered by things that usually don't bother me.	2.0	2.0	2.0	0.295	1.0	2.0	0.675
2 I did not feel like eating; my appetite was poor.	0.0	1.0	0.0	0.716	0.0	0.0	0.506
3 I felt that I could not shake off the blues even with the help from my family or friends.	1.0	1.0	1.5	0.03*	2.0	1.0	0.994
4 I felt that I was just as good as other people.	2.0	2.0	2.0	0.242	2.0	3.0	0.161
5 I had trouble keeping my mind on what I was doing.	1.0	1.0	2.0	0.087	2.0	2.0	0.420
6 I felt depressed.	1.0	2.0	2.0	0.028	2.0	2.0	0.557
7 I felt that everything I did was an effort.	1.0	1.0	2.0	0.047*	1.5	2.0	0.893
8 I felt hopeful about the future.	1.0	1.0	2.0	0.083	2.0	2.0	0.649
9 I thought my life had been a failure.	0.0	0.0	2.0	0.001**	1.0	2.0	0.073
10 I felt fearful.	0.0	1.0	1.0	0.091	1.0	1.0	0.637
11 My sleep was restless.	0.0	1.0	1.0	0.025*	1.0	1.0	0.834
12 I was happy.	2.0	2.0	3.0	0.133	3.0	3.0	0.891
13 I talked less than usual.	1.0	0.0	1.0	0.552	1.0	1.0	0.859
14 I felt lonely.	1.0	1.0	1.0	0.454	1.0	1.0	0.388
15 People were unfriendly.	2.0	0.0	0.0	0.246	0.0	0.0	0.544
16 I enjoyed life.	1.0	2.0	2.0	0.601	2.0	3.0	0.055
17 I had crying spells.	1.0	1.0	1.0	0.018	1.0	1.0	0.025*
18 I felt sad.	1.0	2.0	2.0	<0.001**	2.0	2.0	0.713
19 I felt that people disliked me.	0.0	0.0	0.0	0.279	0.0	0.0	0.534
20 I could not get 'going.'	1.0	1.0	2.5	<0.001**	2.0	3.0	0.356
Total score	20.0	24.0	32.0	0.005**	32.0	32.0	0.613
Interquartile range (25th to 75th percentile)	10.0–32.0	16.0–39.0	23.5–39.25		20.5–38.0	24.0–40.5	

\*  $P < 0.05$ .\*\*  $P < 0.01$ .

**Table 4.** Depressive status and self-perception

	Yes (median)	Interquartile	(n)	No (median)	Interquartile	(n)	P-value
I have been physically attacked by people.	38.5	23.75–40.25	14	27.5	15.0–36.0	126	0.024*
I have been fired my job because of leprosy.	32.5	25.0–39.0	16	26.5	15.0–37.0	124	0.050
I feel people regard me strange.	36.0	21.75–41.0	30	28.0	14.75–34.0	54	0.015*
I have been refused the purchase of something by a shopkeeper.	34.0	24.5–40.75	20	26.0	15.0–36.0	119	0.035*
It seems that people never sympathize with me.	31.0	22.0–38.0	57	28.0	17.0–35.0	27	0.305
I have been hurt by family's negative attitude toward leprosy.	28.0	17.0–38.0	119	19.0	9.0–34.5	21	0.069
I have felt isolated from the society because of leprosy.	28.0	17.0–37.0	96	25.0	11.5–37.75	44	0.587
I have felt isolated from relatives or friends because of leprosy.	28.0	17.0–37.0	95	27.0	12.0–38.0	45	0.668
I have felt isolated from my family because of leprosy.	28.0	16.0–37.0	123	23.0	13.0–37.0	17	0.738

\*  $P < 0.05$ .

## Discussion

This is the first study to investigate depressive status in leprosy patients in Bangladesh. The totals and the each score of 20 items of CES-D in the leprosy patient group were significantly higher than those of the comparison group. The result indicated that the depressive status in leprosy patients was more severe than that of the general public. This finding is consistent with studies in India, which illustrated a higher prevalence of mental disorders among leprosy patients than in other conditions or in the general population.<sup>18</sup> The general population also showed high CES-D scores comparing with other countries, which might be a reflection of the poverty in Bangladesh or of cultural differences. In this regard, further research is needed. Even considering this, we can assume that leprosy patients in Bangladesh are at higher risk of depression than the general population because the differences between patients and comparisons were obvious.

We also found a tendency for exacerbation of depressive status with disability grade, as was shown in the earlier study in India,<sup>17</sup> which indicated that patients with deformities had more psychiatric disorders. This implies that deformity impacts significantly on the mental health of leprosy patients. Although we could only identify significant differences between grade 0 and II, scores increased accordingly and with a larger sample size we might have been able to show significant trends. However, hospital admission is unlikely to affect depressive status. It can be assumed that grade II patients would have been severe enough not to be affected by admission. Intensive and improved treatment also might give patients a feeling of relief. In addition, the non-compulsory nature of admission and improved knowledge on leprosy could give a better image of admission. A future study should investigate this point.

Patients' actual experiences of being discriminated against, for example being physically attacked by people and refusal of shopping amenities, were associated with higher CES-D scores. This suggests that the patients' feelings that they sustain some social handicap or disadvantage due to the disease aggravate their depressive status. There is a possibility of improving the mental health of leprosy patients by educating people in the community to decrease socially discriminative acts against them.

Before the advent of effective chemotherapy, leprosy patients were isolated physically and psychologically from society.<sup>3</sup> Today, patients tend to live in the community while undergoing treatment. In this study, their socio-economic condition was not different with the comparison group. Nonetheless, the majority still felt isolation, although their depressive status was not associated with this feeling. This implies that though society might appear to have come to accept leprosy patients, it is only superficially and patients still suffer from feelings of isolation. This study would have underestimated the real state of mental problems among leprosy patients because it included only patients who had access to a hospital in an urban area. Patients with no access to medical care may have had greater mental problems. The gender ratio between the patient and the comparison group in our study did not distort the results because stratified analysis indicated the same results.

Leprosy patients in Bangladesh had more severe depressive status than the general population, and the majority felt isolated. The provision of appropriate mental care and a programme to decrease discriminative actions against leprosy patients are essential to improve their mental health status. Mental health care is also important for leprosy patients, and psychotherapy as a brief therapy and cognitive behavioural therapy might be helpful, as has been shown in other chronic disease like rheumatic disease and osteoarthritis.<sup>25-27</sup> These



effective interventions must be employed with careful consideration for their cultural backgrounds. In addition, reducing stigma by enlightening the general public, especially shopkeepers and workplace managers who are frequently in contact with leprosy patients, could be an effective way of intervention.

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