

The Prevalence of Depression, Anxiety and Stress among People Affected by Leprosy in Muzaffarpur district, Bihar, India

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It is important to identify psychological distress and its associated factors for holistic care of persons affected by leprosy. This study aimed to determine the negative emotional states depression, anxiety, and stress experienced by people affected by leprosy, and the factors contributing to this distress. A cross-sectional study was conducted in Muzaffarpur district, Bihar, India. The Depression, Anxiety and Stress Scale (DASS-21) was used to assess negative emotional states over the past seven days, and socio-demographic as well as clinical variables were collected using a semi-structured questionnaire. The prevalence of depression, anxiety, and stress among participants was 58%, 59%, and 40%, respectively. Factors such as living in leprosy colonies and presence of disability were associated with higher odds of experiencing these emotional states. Conversely, individuals who underwent reconstructive surgery had lower odds of developing such emotions. The study highlights the need for integrating mental health support and psychosocial interventions alongside timely surgical/medical care for persons affected by leprosy. Addressing these risk factors can substantially improve their overall well-being and quality of life.

Key Words: Leprosy, Depression, Anxiety, Stress, Negative Emotions

Introduction

Despite the common perception that leprosy is a disease of the past (Fava et al 2020), globally, a few years ago the annual incidence of leprosy approximated 220,000 - mostly seen in less developed or developing settings (Rahevar et al 2021). Nerve damage is the key problem in leprosy and long-term consequences are visible limb deformities, burns and amputations (Sarawad & Mendagudli 2019). Research into the

burden of leprosy has been criticized for its lack of consideration of the impact on mental health and social participation of those affected and the family members (Somar et al 2020).

Leprosy can leave individuals with extensive physical damage, disability, and associated psychosocial issues. These can include stigmatisation, anxiety disorders, depression, stress, fear, shame, and reduced quality of life (Van'T Noordende et al 2021). A global

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review of psychosocial impact of leprosy found that feelings of guilt and shame due to the physical changes caused by leprosy, as well as fear, hopelessness, and low self-esteem were prominent in this population (Achdiat et al 2021). Many individuals felt that they were still unwell long after the leprosy was cured, as they continue to experience the stigma. People with leprosy felt 'extremely burdened', avoided engaging in social activities and often decided to isolate themselves. They faced extensive social barriers that, in combination with the impact on mental health, can lead to unemployment, financial concerns, and lack of social relationships (Bainson & Van den Borne 1998, Litt et al 2012). Previous studies often focused on one negative emotion at a time and overlooked the combination of negative emotions and its impact. Therefore, the objective of this research was to assess the prevalence of negative emotional states among people affected by leprosy and factors associated with it.

Materials and Methods

Study design

This was a cross-sectional study design conducted in the Muzaffarpur district, Bihar, India. The study area covered 15 blocks of the district. The study was approved by The Leprosy Mission Trust India Ethics Committee (Ref. No. C-066/TLMTI EC/23), dated 08/02/2023. Written informed consent was obtained from all participants prior to data collection. Ethical approval included provisions for referral of participants with significant psychological distress to the District Mental Health Programme (DMHP).

Sampling

All those registered for treatment for leprosy at the Community Health Centres of the public health system and the leprosy mission hospital of Muzaffarpur during the period 2014 to 2023, who were aged 18 years and above were screened for

inclusion. Staff appointed in the project traced these patients for inclusion. Those who were not traceable in the given address and those less than 18 years of age at the time of registration for MDT or at the time of recruitment were excluded from the study. As this was a community-based study involving tracing of persons affected by leprosy registered in the district over a period of 2014 to 2023, all eligible and traceable individuals who consented to participate were included in the study. Therefore, a formal sample size calculation was not performed, as the objective was to include the maximum feasible number of participants from this defined cohort.

Data collection

Data was collected using a pre-designed questionnaire for socio-demographic, clinical and social safeguard information. The Hindi version of the DASS-21 psychometric tool was administered to assess the negative emotional states. The DASS-21 is designed to screen for depression, anxiety, and stress. (Lovibond & Lovibond 1995, Kumar et al 2019). This scale has been evaluated in both clinical and non-clinical populations, demonstrating its validity and reliability in the Indian population (Gloster et al 2008, Musa et al 2011, Osman et al 2012, Gomez et al 2014). Questions were read out by the investigators to the respondents and their responses were recorded. The scale consists of twenty-one questions with three sub-scales with 7 items each for depression (D), anxiety (A) and stress (S). This tool has been translated in many languages and several studies have been conducted in medical and non-medical settings and have reported good consistency and reliability (Pezirkianidis et al 2018, Sariçam 2018, Thapa et al 2022, Zanon et al 2021). All data were collected through Kobo Toolbox platform using mobile phones. All research staff involved in the data collection were oriented appropriately to

administer the tools before the recruitment of first patient.

Analysis plan

Each question in the scale was rated on four-point Likert scale, scores ranging from 0 (does not apply to me) to 3 (applied to me most of the time.) The three subscales were summarized by summing the questions pertaining these subscales. The maximum score for each sub-scale was 21; higher the score represents the higher psychological distress. As per the guidelines of the DASS-21, the total score of each subscale was multiplied by two before analysis. The scores of each sub-scale was interpreted as follows: Depression (0-9 = normal, 10-13 = mild, 14-20 = moderate, 21-27 = severe and 28 and above as extremely severe), Anxiety (0-7 = normal, 8-9 = mild, 10-14 = moderate, 15-19 = severe and 20 and above as extremely severe) and Stress (0-14 = normal, 15-18 = mild, 19-25 = moderate, 26-33 = severe and 34+ = extremely severe).

Descriptive analysis were conducted for the demographic and clinical characteristics of the study participants. The percentage of study participants with depression, anxiety and stress were reported as per DASS guideline. A logistic regression analysis was performed to examine the association between presence of any negative emotional state and various clinical and demographic factors. For unevenly distributed variables, median value was used to categorise the variable to be included in the logistic regression. We combined grade I and grade II disability as one category to study its association with negative emotions. All factors associated with negative emotions in the univariate analysis were included in the stepwise multivariate logistic regression analysis.

Results

A total of 911 persons affected by leprosy in

the district of Muzaffarpur were listed from the government and TLMTI database; out of which 847 persons affected by leprosy met the inclusion criteria of 18-70 years age set for the study. 201 persons affected by leprosy were traceable who consented to participate and were included in the analysis.

The demographic and clinical details of the participants are presented in Table 1. Majority of the participants 84% (169) were from rural and semi-urban communities while remaining were from leprosy colonies (settlements of person affected by leprosy and their families). Out of the 201 respondents, 32% (65) were female and 53% (136) were equal or less than 45 years of age. Socio-economically, the majority of participants 64% (128) were below the poverty line. About 52% (104) of the participants were engaged in some form of employment, which includes 30% (61) engaged in daily waged labour. Approximately half of the participants (51%) had never been to school. Fifty percent of study participants were receiving a monthly pension (social security aid provided by the government).

Seventy-six percentage (153) of the participants have completed their full course of multi-drug therapy (MDT), while the remaining 24% comprised of 13% on MDT and 11% who had discontinued at the data collection. Disabilities of either grade I or grade II as per the WHO gradation, were present in 73% (147) participants; of them 23% (47) had ulcer. Majority, 60% (120) of the participants with disabilities, have had disabilities for more than 5 years. Forty percentage (80) of the participants underwent one or more corrective surgery (tendon transfer) to correct their deformities.

Prevalence of negative emotion states

The prevalence of negative emotional states in terms of depression 8% (15) and anxiety 8% (16)

Table 1 : Socio-demographic and clinical characteristics of study participants (N=201).

Socio-demographic and clinical characteristics		N (%)
Gender	Male	136 (68%)
	Female	65 (32%)
Age Group (in years)	18 – 30	43 (21%)
	31– 45	64 (32%)
	46-60	74 (37%)
	60 and above	20 (10%)
Economic Condition	Above Poverty Line	73(36%)
	Below Poverty Line	128(64%)
Education	Illiterate	102 (51%)
	Literate	99(49%)
Employment	Employed	104 (52%)
	Not employed	97 (48%)
Habitation	Colony	32 (16%)
	Communities (rural/semi-urban)	169 (84%)
Marital Status	Married	163(81%)
	Unmarried/Divorced/Widowed/Separated	38 (19%)
Pension	Not receiving	98 (49%)
	Receiving	103 (51%)
Disability grade	0	54 (27%)
	I	16 (8%)
	II	131 (65%)
Duration of Disability (in years)	1 to 4	81 (40%)
	5 and more	120 (60%)
MDT Status	Completed	153 (76%)
	Ongoing/ Discontinued	48 (24%)
Had deformity correction	Had deformity correction	80 (40%)
	Not performed/ NA	121 (60%)
Ulcer	Present	47 (23%)
	Absent	154 (77%)

were found to be equally distributed amongst the study participants, whereas only 1% (3) of the participants had shown the standalone symptoms of stress. Fifteen percentage (29) of participants had presented the symptoms of any two negative

emotions simultaneously. Meanwhile 37% (75) of the participants experienced all 3 symptoms of depression, anxiety and stress simultaneously. Overall, 69% of study participants exhibited presence of one or more negative emotional

Table 2 : Prevalence and severity of symptoms of negative emotion (N=201).

Degree	Depression	Anxiety	Stress
None	84 (42%)	82 (41%)	120 (60%)
Mild	23 (11%)	24 (12%)	14 (7%)
Moderate	28 (14%)	33 (16%)	25 (12%)
Severe	22 (11%)	13 (6%)	27 (13%)
Extremely severe	44 (22%)	49 (24%)	15 (8%)

Table 3 : Multivariate (stepwise) logistic regression analysis of factors associated with the presence of any negative emotions (N=201).

Factors	Category	Any negative emotions	Unadjusted OR (95% CIs)	Adjusted OR* (95% CIs)
Gender	Male	44/65 (67.7%)	1	-
	Female	94/136 (69.1%)	1.06 (0.5 – 2.0)	-
Age	18-45	70/107 (65.4%)	1	-
	46 and above	68/94 (72.3%)	1.4 (0.8 – 2.5)	-
Education	Some education	82/111 (73.9%)	1	-
	Illiterate	56/90 (62.2%)	0.6 (0.3 – 1.1)	-
Habitation	Rural/urban	110/169 (65.1%)	1	1
	Colony	28/32 (87.5%)	3.8 (1.4 – 13.1)	2.8 (1.0 – 9.9)
Income	APL	92/128 (71.9%)	1	-
	BPL	46/73 (63.0%)	0.7 (0.4 – 1.2)	-
Employment	Employed	73/104 (70.2%)	1	-
	Unemployed	65/97 (67.0%)	0.9 (0.5 – 1.6)	-
WHO Disability grade	0	27/53 (50.9%)	1	1
	1 & 2	111/148 (75.0%)	2.9 (1.5 – 5.6)	2.4 (1.2 – 4.8)
Presence of ulcer	Without ulcer	101/154 (65.6%)	1	-
	With ulcer	37/47 (78.7%)	1.9 (0.9 – 4.4)	-
Had deformity correction	Yes	63/80 (78.7%)	1	-
	No	73/121 (62.0%)	0.4 (0.2 – 0.8)	-

*Adjusted for gender, age, habitation, WHO disability grade and reconstructive surgery done

state. (Fig. 1)

The prevalence and severity of various negative emotional states amongst the study participants are presented in the Table 2. Among the

participants, 58% (95% CIs 51%-65%), presented with symptoms of depression in any degree (mild, moderate, severe and extremely severe) either standalone or along with anxiety and /

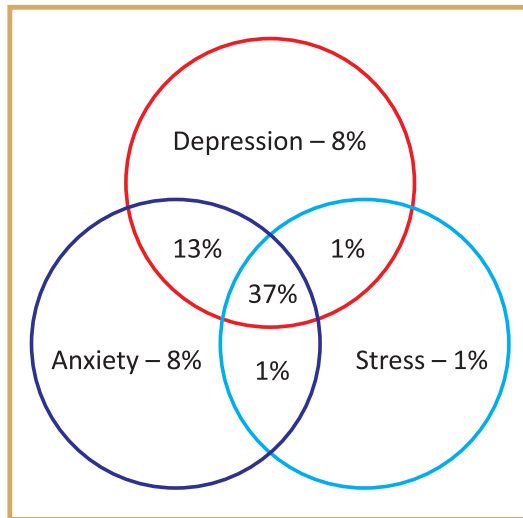


Fig 1 : Prevalence of negative emotions (N=201).

or stress. Of all with depression, 22% (44) of the participants presented with extremely severe degree of depression. About 59% (95% CIs 52%-66%), of the participants experienced symptoms of anxiety in any degree either standalone or in combination with depression and / or stress. Participants with symptoms of stress in any form either alone or with depression or anxiety were 40% (95% CIs 33%-47%). About 69% (138), reported at least one of the negative emotions.

The Table 3 shows the factors that are associated with the negative emotions. In the univariate analysis, place of living (habitation), the presence of disability, and those with disability were found to be associated with the presence of negative emotions. Odds of experiencing any negative emotions were 3.8 (95% CIs: 1.4 – 13.1) times higher among those living in a leprosy colony than those in the general community. Those with disability were 2.9 (95% CIs: 1.5 – 5.6) times likely to experience negative emotions than those with no disability. Those who underwent deformity corrections were 60% (OR 0.4 [95%

CIs 0.2-0.8]) less likely to experience negative emotions as compared to others. In the stepwise multivariate analysis, after adjusting for age and gender, the presence of disability and those living in the leprosy colony were independent factors associated with the presence of negative emotions.

Discussion

Prevalence

This study shows a high prevalence of negative emotional states among people affected by leprosy: depression (58%), anxiety (59%), and stress (40%). Overall, 69% of participants reported one or more negative emotions, as assessed using the DASS-21 scale. These findings are consistent with studies from India, where psychiatric morbidity was reported in 76% of displaced leprosy patients assessed using the General Health Questionnaire (GHQ) (Verma and Gautam 1994). Similarly, a study from a tertiary care leprosy hospital in Kolkata reported that 53.5% of patients had moderate to severe depression as screened with PHQ-9 (Roberts et al 2022). In Ethiopia, 71% of outpatients attending a leprosy hospital reported poor mental health (Damte et al 2013). Comparable prevalence rates have also been observed in Mozambique and Brazil, with 69% and 70.4% of respondents experiencing psychological distress, respectively, assessed using the Self-Reporting Questionnaire-20 (SRQ-20) (Finotti et al 2020, van Wijk et al 2024). The prevalence of negative emotional states (69%) in our study is notably higher than that reported in earlier studies from India and Nepal, where rates typically ranged from 20% to 44%. For example, one study in India reported the prevalence of depression and anxiety as 33% and 19%, assessed with the Patient Health Questionnaire-9 (PHQ-9) and the Generalized Anxiety Disorder-7 scale (GAD-7) (Govindasamy et al 2021). Another Indian study

compared psychiatric morbidity (measured with GHQ-12) between people affected by leprosy and healthy individuals, finding significantly higher rates in the former group (44.4% vs. 7.5%) (Bhatia et al 2006). In Nepal, community-based assessments estimated mental distress in 30–40% of individuals affected by leprosy (van Dorst et al 2020).

Variations across studies may be explained by differences in assessment tools (PHQ, GAD, GHQ, SRQ, DASS), recall periods, sampling settings (clinic-based versus community-based), and psychosocial environments. The higher prevalence observed in our study likely reflects contextual factors such as stigma, disability, social exclusion, and limited access to mental health support. Moreover, the use of DASS-21, which captures stress in addition to depression and anxiety, may contribute to higher prevalence estimates compared with instruments like PHQ-9 and GAD-7, which focus exclusively on depression and anxiety.

Determinants of negative emotions

Our study found that people affected by leprosy residing in leprosy colonies were at higher risk of experiencing negative emotions which is consistent with a study from India (Singh 2012). However, another study reported contradictory results, suggesting that individuals living in leprosy colonies had lower risk of mental illness compared to those living in urban slums (Verma & Gautam 1994). Such discrepancies may reflect contextual differences in study settings. Our participants resided in peri-urban and rural areas, rather than urban slums, where leprosy colonies are typically found. The higher risk of negative emotions in colony dwellers may be linked to isolation from the mainstream community, limited occupational opportunities (often restricted to begging), reinforcement of a leprosy-associated identity, fear regarding children's futures, lack of

reintegration opportunities with broader society, and limited professional and social support to cope with mental distress. Among disease-related variables, loss of sensation in the hands and feet, as well as visible deformities, were strongly associated with negative emotions. An Indian study similarly reported that disability, regardless of duration, was a significant predictor of depression and anxiety (Govindasamy et al 2021). Other studies have also established that visible impairments increase vulnerability to mental illness. For example, psychiatric morbidity was observed in 90% of individuals with visible impairments, compared with 47% among those without deformities (Verma & Gautam 1994). Such findings highlight how physical disability contributes to reduced mobility, impaired self-care, loss of work capacity, and diminished self-esteem, often resulting in internalized stigma. Visible deformities also exacerbate negative social attitudes and stigma. It is commonly observed in the study context that people diagnosed with leprosy, even after completing treatment and regardless of visible deformity or disability, continue to experience internalized and social stigma throughout their lives.

Our study also suggested that corrective surgery for deformities may act as a protective factor against negative emotions, though this association was not significant in multivariate analysis. Nevertheless, existing evidence shows that surgical correction can significantly reduce psychological distress: one study reported a 24% reduction in anxiety and a 32% reduction in depression following surgical correction of visible impairments (Ramanathan et al 1991). Thus, while disability contributes to negative emotions, corrective surgery can help mitigate these effects by addressing the secondary consequences of deformities.

Limitations of the Study

This study is not without limitations. First, many participants in this study were from colonies where people with multiple leprosy-related deformities reside, which may have contributed to a higher prevalence of mental health problems. Another limitation is that the study did not include a comparison group from the general population, making it difficult to assess how different the findings are from the wider community. Finally, the sample size was limited to persons affected by leprosy who could be traced and consented to participate, which may have implications on estimated prevalence and generalizability.

Conclusion

In conclusion, the study indicates a high prevalence of negative emotions among people affected by leprosy which needs to be addressed. The presence of disability and living in the leprosy colonies are independent risk factors of negative emotional states.

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