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Perceived Stigma and Psychological Distress among Tuberculosis Patients: Insights into Psychosocial Challenges at a Healthcare Center

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Abstract

Background: Stigma associated with tuberculosis (TB) negatively impacts patients' self-esteem and quality of life. This study aimed to evaluate perceived stigma and psychological distress among TB patients and identify associated sociodemographic and clinical factors.

Methodology: A cross-sectional survey was conducted with 155 patients at the Tuberculosis Health Care Center in Rawalpindi. Perceived stigma was assessed using the Tuberculosis Stigma Data Collection Instrument, while psychological distress was evaluated with the Oslo-3 Social Support Scale, PHQ-9, and GAD-7. Data analysis was performed using SPSS Version 23.

Results: The mean age of participants was 45 years (SD ± 17.4), with 67.1% males and 32.9% females. Perceived stigma was reported by 59.4% of patients, and 52.9% experienced poor social support. Mild to moderate depression was observed in 44.5%, and 52.9% reported moderate to moderately severe anxiety. Perceived stigma was significantly associated with education ($p = 0.01$), disease duration ($p < 0.0001$), and severity ($p < 0.0001$). Poor social support correlated with education, income, disease severity, and duration. Depression was linked to marital status, education, disease duration, and severity, while anxiety was associated with treatment phase and illness duration.

Conclusion: Perceived stigma and psychological distress, including depression, anxiety, and poor social support, are prevalent in TB patients. Counseling sessions and public awareness campaigns are essential to mitigate these issues.

Keywords: Tuberculosis; stigma; social support; depression; anxiety

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Introduction

TB is not only a physical illness but also a socially stigmatized condition, often leading to discrimination and isolation. This stigma can cause significant psychological distress, which may deter patients from seeking timely treatment, adhering to therapy, or fully engaging with healthcare services. Understanding these psychosocial dimensions is essential for developing holistic TB care strategies that not only treat the disease but also support the mental and emotional well-being of patients (1). Despite advancement in treatment, the social and psychological dimensions of Tuberculosis remain a big challenge for the Policy makers. Patients often encounter isolation and even rejection by the community exuberating the distress and diminishing quality of life. Analyzing the interaction between psychological distress and Perceived Stigma is vital for developing intervention to address these mental issues (2). Stigma is a social determinant resulting from the subjective feeling of being devalued and victimized and is responsible for delayed health seeking behavior (3) It is a societal problem related to the power supremacy and discrepancy. Perceived stigma is a belief of discrimination due to which people are reluctant to share their experiences and have a strong feeling of unworthiness. (4).

TB-related stigma is a hard challenge for TB prevention and control and should be seen as a social problem that needs to be addressed (5). Anticipated/perceived prejudice against those with TB, experience of discrimination and feeling shamed are among the most commonly reported TB related stigma (6). Poor anti-tuberculosis treatment adherence can also be attributed to the stigma (7). A community-based survey conducted across 30

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districts of India found that 73% of the Tuberculosis patients felt Stigmatized. It was reported in the study that delay in health seeking might aggravate this issue leading to a larger pool of infectious TB cases, increasing the risk of transmission within household and broader community (8). In a tertiary care clinic of Malaysia one third of the stigmatized patients were suffering from depression with majority being categorized as severe while the medical institutions in China also experienced that depression and anxiety were directly related to Stigma (9,10). Private and public sector hospitals of Lahore reported that the poor social support was the most important predictor for stigma among tuberculosis patient. (11) Similarly, a cross sectional study carried out in Peshawar to investigate the causes of depression and anxiety in Multiple Drug Resistant Tuberculosis patients also identified stigma as the main determinant of disease. (12)

Around 10.6 million people worldwide suffer from TB annually (13). Ranking 5th Pakistan is one of the 30 high burden TB countries (14). There is lack of disease-specific knowledge which is an important determinant of person's response to the disease (15). Prevailing misconceptions about TB lead to social discrimination, aversion and stigmatization. Stigma generates a sense of disvalue resulting in withdrawal from interpersonal relationships, self-isolation, psychological stress and depression (16). In certain situations, differences in race, class, religion, and gender are used as a tool for further marginalization of the already stigmatized individuals, hence multiplying the effects of stigma (17). Therefore, addressing stigma is a crucial factor in prevention, transmission and control of tuberculosis. Evidence suggests that improved awareness regarding TB leads to better treatment outcomes and a better control over the spread of TB (18). The current study highlights the critical impact of stigma and psychological distress on tuberculosis patients in Pakistan. Understanding these factors is essential for improving treatment adherence, reducing transmission, and enhancing patient well-being, ultimately contributing to more effective TB control and better public health outcomes The purpose of this study was to estimate TB related Stigma and Psychological Distress in patients suffering from Tuberculosis and to identify the related socio-demographic and clinical factors for providing updated data to the health planners for necessary action.

Methodology

It was a cross-sectional survey conducted on the Tuberculosis patients attending the TB Health Care Center located in Rawalpindi from September 2022 to May 2023. Respondents were selected through convenient sampling technique. Sample size was 155 calculated through Sample Size Population Proportion Formula with 95% CI and 3% prevalence rate. All male and female patients above 15 years attending the clinic during the survey period were part of the survey while critically ill patients were excluded from the study. Consent was taken from IRB of National University of Medical Sciences and from the administration of TB Health Care Center. Informed consent was also taken from the patients individually before start of the survey.

Data were collected through a self-administered tool adapted from Tuberculosis Stigma Data Collection Instrument hosted by UNOPS (19). Data were collected through Health care providers of the Tuberculosis center ensuring optimum response rate. Questionnaire was translated in Urdu for easy interpretation by the researcher. Data included Socio-demographic profile with additional information regarding duration and severity of disease, treatment phase, history of substance abuse and comorbidities. Perceived Tuberculosis Related Stigma was measured with five-point Likert scale. Psychological Distress was assessed by Oslo 3 for Social Support (20) and PHQ 9 and GAD 7 for Depression and Anxiety (21) respectively.

Data were analyzed through SPSS Version 23. Frequencies and percentages were calculated for Categorical variables. The overall mean score was calculated for Perceived Tuberculosis Related Stigma and Psychological Distress by adding scores of individual questions and dividing by the sum of number of questions. Respondents scoring more than the mean value were considered to be suffering from Perceived Stigma ad Psychological Distress. Inferential analysis was done, using the $\chi 2$-test to check the association of categorical data where required. p value less than 0.05 was considered statistically significant.

Results

Data were collected from 155 patients, with a mean age of 45 years (SD ± 17.4, range 15–95 years). Among the participants, 104 (67.1%) were males, and 93 (61.9%) were married. Nearly half (66, 48.6%) reported a monthly family income between 26,000 and 50,000 PKR.

Regarding clinical history, 84 (54%) had a disease duration of less than six months, and 93 (60%) were in the continuous phase of therapy. Additionally, 70 (45.2%) rated their illness as moderate in severity. Of the total respondents, 58 (37.4%) were cigarette smokers, and 68 (43.9%) reported a history of co-morbidities (Table 1).

Frequency of Perceived Stigma and Psychological Distress:

Out of total, more than half participants 92(59.4%) were the sufferer of perceived stigma due to Tuberculosis (Figure:1). With respect to Psychological Distress 83(53.6%) respondents were the victims of poor Social Support and 69(44.5%) were experiencing mild/ moderate depression. Furthermore, almost half of the patients 82(52.9%) were having moderate/ moderately severe anxiety attacks in recent 2 weeks duration. (Table: 2)

Table 1: Sociodemographic Profile and Clinical Presentation (n = 155)

Items		Freq.	(%)
Gender	Male	104	67.1
	Female	51	32.9
Marital Status	Married	93	60.0
	Unmarried	36	23.2
	Widow/ Divorced	26	16.8
Education	Illiterate	17	11.0
	Primary	18	11.6
	Matric	59	38.1
	Graduate Post/Graduate	61	39. 3
Family Income / month (PKR)	25,000 or less	44	28.4
	26,000 – 50,000	66	42.6
	51,000 – 100,000	41	26.5
	More than 100,000	4	2.5
Duration of Illness	Less than 6 Months	84	54.3
	Between 6 months – 1 year	47	30.3
	More than 1 year	24	15.4
Phase of Treatment	Intensive	62	40.0
	Continuous	93	60.0
Severity	Mild	35	22.6
	Moderate	70	45.2
	Severe	50	32.2
History of Substance Abuse	Cigarette	58	37.4
	Huqa	21	13.5
	None	76	49.1
Comorbidities	Diabetes	33	21.3
	Hypertension /Heart Diseases	30	19.4
	HIV/AIDS	2	1.3
	Cancers	3	1.9
	None	87	56.1

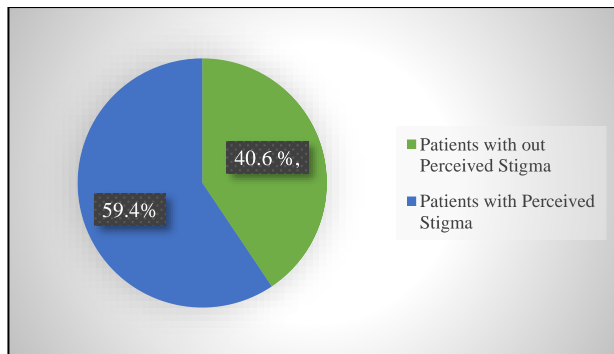

Figure 1: Perceived Stigma:

Table 2: Frequency of Psychological Distress (n=155)

Items	Grades	Freq.	(%)
Social Support	Poor	83	53.6
	Moderate	45	29.0
	Strong	27	17.4
Depression	Minimal	29	18.8
	Mild /Moderate	69	44.5
	Moderately Severe/ Sever	57	36.7
Anxiety	Mild	36	23.2
	Moderate/ Moderately Severe	82	52.9
	Severe	37	23.9

Regarding association of Perceived Stigma with sociodemographic factors and clinical presentation, a close correlation was observed with educational standards (p value= 0.01), with duration of disease (p value= 0.0001) & Severity of disease (p value= 0.0001) (Table: 3).

With respect to psychological distress, it was analyzed that poor social support was closely related with educational standards (p value=0.001) family income (p value = 0.03). Additionally, a strong correlation was also observed with severity (p value=0.001) and duration (p value = 0.001) of disease. It was analyzed that prevalence of depression was more in unmarried, widow and divorced patients as compared to married ones (p value=0.004) and in respondents with low educational standards (p value=0.003). Furthermore, patients with more than 6 months disease duration (p value=0.0001) and with more severe form of disease (p value=0.0001) had complaints of depressive attack. Regarding Anxiety a significant association was present with duration (p value=0.0001) and phase of treatment (p value=0.004). Furthermore, it was also analyzed that patients with perceived stigma are more prone to develop depression and anxiety and they are also the sufferer of poor social support (Table: 4).

Table3: Association of Perceived Stigma with Sociodemographic factors and Clinical Presentation

Items		Perceived Stigma			p value
		Yes	No	Total	
Gender	Male	60	44	104	0.54
	Female	32	19	51	
Educational Level	Illiterate/ Primary	28	7	35	0.01
	Matric	32	27	59	
	Graduate/Post Graduate	32	29	61	
Family Income	25,000 or less	29	15	44	0.49
	26,000 – 50,000	36	30	68	
	More than 50,000	25	18	43	
Duration of Illness	Less than 6 months	37	47	84	0.000
	More than 6 months	55	16	71	
Self-Rated Severity of Illness	Mild	11	24	35	0.000
	Moderate	40	30	70	
	Severe	41	9	50	
Phase of Treatment	Intensive	32	29	61	0.28
	Continuous	60	34	94	

Table 4: Association of Perceived Stigma with Psychological Distress

Items		Perceived Stigma			p Value
		Yes	No	Total	
Social Support	Poor	70	13	63	0.0001
	Good	22	50	92	
Depression	Present	49	11	60	0.0001
	Absent	14	81	95	
Anxiety	Present	77	25	102	0.0001
	Absent	15	38	53	

Discussion

Tuberculosis is not solely classified as disease, it is labelled as sickness because in addition to bear the pain of ill health, patients of tuberculosis have to face the mental trauma and social dysfunction as a consequence of highly discriminating behavior of the people around them. It is evident from the current study that stigma and psychological distress are prevalent in more than half of the patients experiencing tuberculosis. The study conducted in China revealed that 42% patients were suffering from pain of stigma (22). Stigma was also correlated with anxiety and social support as patients were facing apprehension and segregations from the family members. Furthermore, the result of Chinese study showed that prevalence of stigma was more in females however no such association was reported in the current study may be due to smaller number of female participants. In another study conducted in rural areas of China revealed the 62.5 % patients were having perceived stigma and here again a close association was observed with the psychological distress (23). Additionally, a close relationship (p value 0.0001) was also found with the severity of diseases. Here the results are comparable with our study where strong correlation was found between stigma and psychological distress while stigma was more among patients with duration of diseases more than one year. A mixed methods study conducted in Cambodia also revealed that prevalence of perceived stigma was present in 51% tuberculosis patients (24). Another mixed method study conducted on 208 Tuberculosis patients of Kenya revealed presence of both perceived and experienced stigma (25). The results of an Indian study showed that stigma was prevalent in 50.57% patients (24). Here a close correlation was observed with education (p value 0.0001) and socioeconomic class (p value 0.001) however association with gender (p value 0.07), age (p value 0.26) and marital status (p value 0.45) was not much significant. Another study conducted in Karnataka District of India revealed that out of 208 patient's stigma was present in 51.2% patients (27). Here again education was a strong correlating factor with no association with gender, income, occupation and marital status. The results of both Indian studies are comparable with the results of present study with more than half patients suffering from Stigma with a close relationship with educational standards probably because of similar sociocultural dimensions.

The results of our study regarding prevalence of Depression and anxiety associated with Tuberculosis are also comparable with regional study conducted in Pakistan which showed prevalence of depression in 50.2% patients of Tuberculosis (28). Another study conducted in Karachi revealed existence of 56% patients suffering from moderate to severe depression while 65% showing moderate to severe degree of anxiety (29).

A nationwide survey conducted in Ethiopia with 844 patients had mean stigma score of 21.3, again education level above secondary school having lower stigma (30). A cross sectional survey conducted on 417 patients of Ethiopia revealed perceived stigma in 42.4% patients whereas using the binary logistic regression analysis a close association was observed with phase of treatment and poor social support (31). The results of our study are comparable with both studies with a frequency of 59.4% and positive association with education, and social support however no association was observed with phase of treatment in our study. A institutional based survey (32) showed 57% prevalence with a correlation with poor social support (AOR 2.41) presence of Depression (AOR 8.1) and duration of illness(2.48) again matching with the result of current study.

Conclusion

Perceived stigma is commonly prevailing in tuberculosis patient while psychological distress like depression, anxiety and poor social support intensifies the problem. Furthermore, sociodemographic factors compound with prolonged duration and severity of diseasing are making the situation worse. To address these issues, it is important to implement policies which prevent TB patients from being marginalized and ensure that they don't become a burden on the society. Developing and promoting strategies to increase public awareness is crucial for fostering a more compassionate and supportive approach toward both the disease and those who suffer from it. These efforts will not only improve the quality of life for those affected but also create a more inclusive and understanding community

Limitations:

Due to shortage of resources the study was conducted in only one Health Care Center. Due to non-probability sampling technique the reliability and validity may be compromised.

Ethical Approval:

This study was approved by IRB & Ethical Committee of National University of Medical Sciences, Rawalpindi.
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Authors' Contribution:

TNJ: Title, objective, questionnaire development, analysis
RZ: Data collection, analysis
HS: Data entry, result writing
RA: Discussion writing, literature search.
UH: Data analysis
NT: Introduction writing, literature search

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