

# Stigma in head and neck tuberculosis patients: Evaluation and analysis

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## Abstract

**Aim:** Stigma means wound, scar, degrading situation, labeling. In particular, patients with infectious diseases are exposed to stigma. The presence of stigma has a detrimental effect on the healing process, physical and mental problems of patients. For this reason, the study was performed to evaluate the stigma condition in head and neck tuberculosis cases.

**Materials and Methods:** The research was carried out as descriptive with tuberculosis patients in the otorhinolaryngology clinic of a university hospital. The sample of the study consisted of 32 head and neck tuberculosis patients who are active in the treatment period. The data of the study were collected using the Patient Questionnaire and the Tuberculosis Patients Stigma Scale. The data obtained were evaluated by Pearson correlation analysis and t-test.

**Results:** The average age of the patients was  $39.5 \pm 19.6$  years, 65.6% were female, 31.3% were high school graduates, cervical region tuberculosis ranked first with 81.3%, and 34.4% of the patients were in denial regarding the disease. While 87.5% of patients had Bacillus Calmette-Guérin vaccine scar; 3.1% Acid-resistant bacilli test was found to be positive. The scale score average of the patients was found to be  $99.8 \pm 8.8$ . It was determined that the mean score of female patients was high, but there was no statistically significant difference between the mean scores of female and male patients ( $p > 0.05$ ).

**Conclusion:** In our study specifically for Head and Neck tuberculosis patients; The scale mean scores of all patients were found to be high. This shows that patients have high stigma levels. For this reason, it is recommended to inform the patient and family that head and neck tuberculosis patients can fully recover if they use their medication regularly by providing them with the necessary training about tuberculosis from the moment of diagnosis.

**Keywords:** Head and neck tuberculosis; stigma; tuberculosis; tuberculosis lymphadenitis

## INTRODUCTION

Although tuberculosis (TB) is a treatable and preventable disease, it remains an important public health problem and is the seventh cause of death worldwide. According to the data of the World Health Organization (WHO) 2019 report, approximately 10.0 million TB cases were reported (1). TB brings about many physical, social, and economic problems, as well as mental/psychological problems (2,3). One of the most important problems that make it difficult for patients to adapt to treatment is that patients feel stigmatized (4). Long-term treatment, difficulties in drug use, socio-cultural level and self-esteem of the patient, stigma applied to the patient by both society and the patient himself/herself are the most important factors affecting the success of the treatment (5).

Stigma means "an unfair treatment of a person or a group because of prejudice about a particular quality they have" (6). Stigma is the feeling of "undesirable" or "diminished reputation" that reduces the status of the individual in the eyes of society. The stigmatized individual internalizes

the sense of worthlessness, develops attitudes such as avoiding interpersonal relationships, shame, disgust, and guilt (7). Stigma means wound, scar, sign, degrading situation, labeling as words (8).

Stigma is a social determinant of health (9), has been a major obstacle in accessing healthcare, access to management of the disease and full treatment, and (10) studies have shown various levels of isolation, including loss of employment in TB patients, reduced opportunity for education, exclusion from their families and society (11).

The exposure of TB patients to stigma; is one of the most important reasons that cause delay or avoidance of the patients' seeking treatment or poor compliance to treatment (12). For this reason, stigma is the biggest obstacle in the elimination of TB. Moreover, the social relationships of TB patients are negatively affected by their environment, community members, and healthcare professionals (13). Since stigma affects the physical and social consequences of TB negatively, this situation needs to be effectively reduced (2,14).

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In line with this information, while there are many studies on stigma in lung TB, no studies involving stigma have been found in head and neck TB patients. For this reason, our study was carried out descriptively to evaluate stigmatization specifically for head and neck TB patients.

## MATERIALS and METHODS

The research was carried out descriptively with head and neck TB patients in a university hospital in Gaziantep. The sample of the research; in 2019, 32 patients who were diagnosed with head and neck TB, were actively treated, were available between September and November 2019, had no communication problems or psychiatric diagnoses, and were willing to participate in the study.

Research data; collected through a questionnaire and the Tuberculosis Patients Stigma Scale (TPSS) from patients. Patient questionnaire was prepared by the researcher by examining the existing literature (5,15). In this form, there are 14 questions including socio-demographic characteristics and medical history. While receiving active treatment from all patients, the data were collected by the researcher by the face-to-face interview method. Before the study, the necessary approval was obtained from the Gaziantep University Faculty of Medicine Non-Interventional Clinical Research Ethics Committee. Informed consent was obtained from the patients before the study, paying attention to the principle of volunteering.

**Tuberculosis Patients Stigma Scale (TPSS):** In 2010, the reliability was validated by Sert. It is a four-point Likert-type scale consisting of 33 positive and negative expressions aimed at measuring the stigma level of patients with TB. The scale is graded as 4 if the patients agree with the statements about the stigma, 3 if they agree, 2 if they do not agree, 1 if they do not agree. As the score obtained from the scale increases, the stigma level of the patients also increases. The highest score obtained from the scale is 132 and the lowest score is 33. The scale consists of a total of 33 items and four sub-dimensions: stigma, self-perception, family-friend relationships, and internalized stigma. TPSS Cronbach's alpha coefficient is 0.91(15).

**Evaluation of the Data:** SPSS (Statistical Package for Social Sciences) program was used for the obtained data and statistical analysis. It was evaluated by chi-square, t-test, and pearson correlation analysis methods.  $P < 0.05$  was considered statistically significant.

## RESULTS

The average age of TB patients included in the study was  $39.5 \pm 19.6$  years, 65% of the patients were female and 53.1% were married. When asked regarding occupations, head and neck TB was most common in housewives (46.9%) (Table 1).

While 93.7% of the patients were new cases, 6.3% were recurrent cases and 34.4% had additional diseases. 3.1% of the patients had a family history of TB. The rate of those who can say that they are TB is 15.6%. Patients said, "How did you feel when you heard you were TB?" The question;

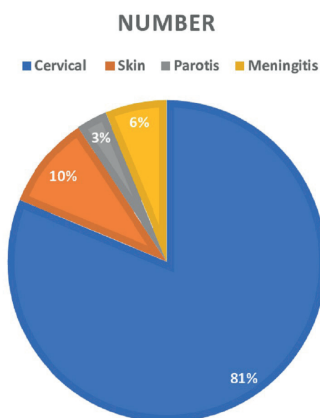
they responded as sadness in 56.3%, denial 34.3%, in 3.1% acquiescence, and 6.3% anger. The rate of non-acceptance/denial of the disease was 34.4% (Table 2).

**Table 1. Distribution of Socio-Demographic Specifications**

Specifications	Number	%
<b>Gender</b>		
Male	11	34.4
Female	21	65.6
<b>Education Status</b>		
Literate	9	28.1
Primary School	8	25.0
Highschool	10	31.3
Undergraduate	5	15.6
<b>Occupation</b>		
Civil-servant	1	3.1
Worker	2	6.3
Self-employed	6	18.8
Unemployed	3	9.4
Retired	1	3.1
Student	4	12.5
Housewife	15	46.9
<b>Marital Status</b>		
Married	17	53.1
Single	15	46.9
<b>Economic Status</b>		
Good	2	6.3
Middle	19	59.4
Bad	11	34.4
<b>Social Security</b>		
Exists	26	81.3
Does not Exist	6	18.8
<b>Total</b>	<b>32</b>	<b>100.0</b>

**Table 2. Findings Related to the Disease of Patients**

Specifications	Number	%
<b>Case Status</b>		
New	30	93.7
Recurrence	2	6.3
<b>Additional disease</b>		
Exists	93,7	34.4
Does not Exist	6,3	65.6
<b>TB Status in the Family</b>		
Exists	1	3.1
Does not Exist	31	96.9
<b>Being Able to Say the existence of TB</b>		
Yes	5	15.6
No	27	84.4
<b>What she felt when she first heard that she/he has TB</b>		
Sadness	18	56.2
Denial	11	34.4
Acquiescence	1	3.1
Anger	2	6.3
<b>Total</b>	<b>32</b>	<b>100.0</b>



**Figure 1.** Head-Neck TB Localizations

81.3% of patients have cervical, 9.4% skin, 3.1% parotid, and 6.3% TB meningitis (Figure 1).

Based on the acid-resistant bacillus (ARB) results of the patients, 3.1% ARB positive, and Bacillus Calmette-Guérin (BCG) vaccines have 87.5% BCG vaccine scar (Table 3).

Table 3. Patients' ARB and BCG Vaccine Scar Results		
<b>ARB Result</b>		
Negative	28	87.5
Positive	1	3.1
N/A	3	9.4
<b>BCG vaccine</b>		
Exists	28	87.5
Does not exist	4	12.5
<b>Total</b>	<b>32</b>	<b>100.0</b>

The mean scores of TPSS of the patients were found to be  $99.8 \pm 8.8$ . The mean score received by the patients from the "Felt Stigma" sub-dimension is  $41.40 \pm 3.32$ , the "Self-perception" sub-dimension is  $18.50 \pm 1.88$ , the "Family / Friend Relationship" sub-dimension is  $17.12 \pm 2.66$  and "Internalized Stigma" sub-dimension mean score was determined to be  $22.46 \pm 3.02$  (Table 4).

Table 4. Mean Scores and Sub-Dimensions of Patients Received from Stigma Scale	
<b>Specifications</b>	<b>Mean±SD</b>
<b>Total Stigma Scale Score</b>	<b>99.8±8.8</b>
Felt Stigma Sub-Dimension	41.4±3.3
Self-Perception Sub-Dimension	18.5±1.8
Family-Friend Relationship Sub Dimension	17.1±2.6
Internalized Stigma Sub-Dimension	22.7±2.5

In the scoring of the stigma scale, all of the patients scored above the average. Although the TPSS score mean of female patients is higher than that of male; There was no statistically significant difference between the mean scores of male and female patients ( $p > 0.05$ ). It was found that there was no significant relationship between the age of the patients and TPSS ( $p > 0.05$ ).

No significant difference was found between female and male genders, between married and single in terms of the total score and sub-dimensions of stigma scale ( $p > 0.05$ ). Besides, it was determined that the stigma scale scores were not distinctive by occupation.

There was no significant difference between the stigma scale according to age, economic status, and education level, and when evaluating between those with and without TB in the family ( $p > 0.05$ ).

## DISCUSSION

TB, which is an important public health problem, is one of the two most common infectious diseases in the world (1). TB patients are stigmatized and excluded by society due to the long duration of TB treatment and false beliefs about the contagiousness of head and neck TB (5). Stigma can be as dangerous as the disease itself (16) and causes the disease to be hidden (17,18). In the study of Mak et al., It was reported that the most stigmatized patients after HIV were TB patients (8). When the stigma status of TB patients was investigated in our country, it was reported that patients experienced stigmatization (19,20), a large part of them hid their diseases and were excluded by the society (21).

Studies showing that stigma, which has become an important problem, should be evaluated for its negative effects for TB patients and that TB patients are exposed to stigma when the literature is examined (22,23). It has been reported in many of these studies that TB patients are exposed to low levels of stigma (17,24,25). In a study by Jittimane et al., High levels of TB stigma were reported in 65% of HIV + TB patients (26). When the studies conducted using the TPSS are evaluated; In the study of Bayraktar and Khorshid, it was low (25), in the study of Yiğit Açıkel and Çınar Pakyüz, the average score of the patients with pulmonary TB was (5), and in Öztürk's study, the mean score from the overall stigma scale in patients with TB was  $69.6 \pm 12.6$ . (53.4%) were found to have high stigmatization levels (19).

When the literature is examined, stigma levels of lung TB patients were evaluated in the studies and no specific study evaluating stigma in head and neck TB patients were found. In our study where we investigated the level of stigma for the first time in head and neck TB patients, it was determined that the mean score of TPSS was high and the mean scale was  $99.8 \pm 8.8$  in all patients. The average score in our study was higher than the average scores in other studies. According to this; It can be said that stigma levels of head and neck TB patients are high, therefore patients feel highly stigmatized. This result can be attributed to the study being conducted in different geographical regions and the use of different scales in the study; It suggests that head and neck TB is not contagious except for larynx TB and this is not known to the public. For this reason, it is thought that patients and their relatives, even healthcare professionals should be educated on this issue, and society should be informed about this issue.

It is thought that studies should be done on this subject with larger samples.

Stigma can be affected by many factors such as age, gender, education, occupation, marital and economic status, and information about the disease (27). 10 million new TB patients appeared worldwide in 2018. Of these, approximately 5.7 million are men ( $\geq 15$  years), 3.2 million are women ( $\geq 15$  years) and 1.1 million are children (less than 15 years old). The total number of TB cases registered in TB war dispensaries in our country in 2018 is 11,786. 6,778 (57.5%) of the patients are male and 5,008 (42.5%) are female (28). In our study; It was determined that 65% of TB patients were female and 35% were male. This data differs compared to other studies.

Many studies support that women experience more stigmatization than men. It was determined that women were stigmatized more than men (29,30), fear of stigmatization was higher, and stigmatization had severe socioeconomic consequences for women (31). In the study conducted by Sert (2010), it was found that women's self-perception subscale scores were higher (15). In a study by Dhingra and Khan (29), it was observed that families were hesitant about explaining their daughter's illness to their surroundings and getting treatment because of the risk of not getting married. However, some studies have found that gender (6,24,32) and marital status (6,32) do not affect stigmatization. In our study, while the mean score of female patients was higher, no statistically significant difference was found between the mean scores of female and male patients. It is thought that it was statistically insignificant due to the numerical limitation of our patients.

The association of head-neck TB, especially TB lymphadenitis and lung TB, gives various rates in the literature. Lung findings were also detected in 14-20% of patients with cervical TB lymphadenitis (33). In this study, 3.1% of the patients were found to have an ARB result (+). While evaluating the patients, we think that necessary bacteriological examinations should be performed for lung TB.

In our study, we also researched categories such as age, education, occupation, marital status, and economic status. Considering whether the stigma states of TB patients vary according to these characteristics, no significant difference was found in terms of the total score and sub-dimensions of the stigma scale.

In the study conducted by Bayraktar and Khorshid (25), it was reported that 78% of individuals with TB told the environment that they had TB. In our study, 15.6% of the patients can tell their environment that they are TB patients, while 84.4% of them tried to hide their diseases. In the study of Duyan et al., It was found that patients' relations with their neighbors, social and colleagues decreased, their quality of life decreased, and they experienced tensions with their family members (34). In another study, stigma was detected in 16.3% of patients, exclusion by the society in 10%, and deterioration of

family relations in 5.6% (35). In a study conducted by Macq et al. on social stigmatization, individuals affected by TB-related stigmatization experienced job loss, family, or community exclusion (17). The results of our study and the results of other studies reveal that the majority of patients with TB experience serious social problems due to stigmatization.

## CONCLUSION

In this study conducted to evaluate stigmatization in head and neck TB patients; It was found that the mean scores of patients' TPSS were high. This shows that patients have high stigma levels. There is no relationship between marital status, occupation, and economic status of patients and stigma; In terms of gender, it was observed that stigma was higher although it was not statistically significant in female patients. Patients can fail to meet treatment obligations due to stigma, they experience difficulty in starting treatment, or continuing treatment due to lack of support. For this reason, It is recommended that the patient and his family be informed that he/she can fully recover if he/she uses his medication regularly by giving the necessary training about TB from the moment of diagnosis and that TB diseases except the larynx and extrapulmonary TB, are not contagious.

Although non-larynx head and neck TBs are not contagious, precise information should not be given on whether they are non-contagious without evaluating the results of Lung and ARB. The results of this study provided basic information for the studies to determine the adverse effects of stigmatization in head and neck TB patients and to adapt the treatment to diagnosed individuals and prevent social isolation. The limited number of cases has restricted our ability to discuss the data better. Studies with larger series are needed.

To conclude; prevention of stigma is as important as compliance with treatment in patients with TB. For this purpose; Patients, patient relatives, and the society should be informed about the disease and transmission routes, including the history of TB before. In order to minimize the stigmatization levels of patients, we recommend evaluating the factors affecting stigmatization by all healthcare professionals and raising awareness of the society in this regard.

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