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Understanding tuberculosis-related stigma: Impacts on patients, contacts, and society – A mixed study

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ABSTRACT

Objectives: This mixed-methods study aimed to explore the experiences of 62 participants with tuberculosis (TB) diagnoses, 57 participants with direct contact with patients, and 61 participants from the general public, regarding TB-related stigma.

Materials and Methods: This study used both qualitative and quantitative research methods to understand the issue of TB. A representative sample of 62 participants with TB diagnoses, 57 with direct patient contact, and 61 from the general public was selected. Data was collected through structured questionnaires and in-depth interviews, and trends and patterns were identified using descriptive statistics and the Chi-Squared test.

Results: Over half of TB patients expressed internalized stigma involving self-stigmatization by feeling ashamed, afraid that others would see them as contagious or different due to their illness. A total of 42 of 62 participants, or 68%, expressed anticipated stigma involving fear of discrimination and changing the topic of conversation or avoid discussing the disease openly. (6/62, 10%) expressed enacted stigma and discrimination reporting they lacked respect from medical staff. Females were more likely than males to show both anticipated stigma by feeling different and being afraid of transmitting the disease (p-value), and more likely to avoid talking about their disease or changing the subject (p-value). There was no significant association between gender and feeling respected by medical professionals (p-value = 0.172). Contacts believed poverty caused TB (17/57, 30%); they feared community infection risk (45/57, 79%). Most contacts with patients viewed patients with compassion (36/57, 63%), and most were willing to associate (47/57, 82%). Male contacts are more likely to fear infection risks. The investigation of sociodemographic characteristics and stigmatization of TB patients among contacts of TB patients found that education level, gender, and economic position were substantially linked with stigmatization towards TB patients. On the other hand, men were more likely than females to anticipate infection risks in the community (p-value < 0.001). Ordinary people feared infection (44/61, 72%) and thought poverty caused TB (17/61, 28%). Most saw the patients with compassion (35/61, 57%); they were willing to associate (45/61, 74%). Education level in the ordinary people was strongly connected with fear of infection and their opinions about whether TB patients deserve their disease. As opposed to this, perceptions of TB patients were strongly associated with gender and economic status. Based on the data supplied, there may be a link between socioeconomic status and stigmatization towards TB patients; however, more studies would be required to establish whether this association is statistically significant. Overall, the research employed a comprehensive and extensive methodology, offering valuable insights into the stigmatization of TB patients. This might influence policy and practice in the field.

Conclusion: The results show that there is still a need for programs to minimize TB-related stigma and promote public knowledge of the illness, and medical workers should be educated to treat patients with respect. Efforts should be undertaken to educate the public about TB causes to lessen the stigma associated with the illness. It is vital to create treatments targeted at eliminating TB stigma and supporting TB patients' social integration.

Keywords: Mixed-methods, Tuberculosis-related stigma, Anticipated stigma, Enacted stigma, Gender, Sociodemographic characteristics

INTRODUCTION

Stigma can manifest in enacted, anticipated, or internalized forms. Enacted stigma involves discrimination, whereas anticipated stigma involves fear of discrimination. Internalized stigma involves self-stigmatization. Understanding these concepts provides a nuanced view of stigma's impacts. Tuberculosis (TB) is a highly contagious disease that affects millions of people worldwide. Despite significant advances in the prevention, diagnosis, and treatment of TB, stigma continues to be a major barrier to effective TB control. Stigma can cause TB patients to delay seeking medical care, avoid disclosing their illness, and experience discrimination. The aim of this study is to explore the existence of stigma among TB patients and identify the responsible parties and causes of stigma. This study aims to comprehensively explore the existence of stigma among TB patients and identify the responsible parties and underlying causes. Specifically, it seeks to investigate the feelings of stigma among TB patients in the TB Center in

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Hodeida, Yemen. This research is of utmost importance as it extends beyond examining stigma solely among TB patients, also encompassing the perspectives of their associates and ordinary individuals. Understanding the stigma associated with TB is crucial for effective public health interventions.[1-4]

Stigma related to TB is a significant public health concern, with an anticipated 10 million new cases and 1.4 million fatalities globally in 2019 alone.[1] It is common for TB patients to suffer from social stigma, which may lead to social isolation, limited social support, and poor mental health outcomes.[2-5] Research has revealed that approximately 42–82% of TB patients experience stigma, whereas Chinese research estimates a 45.32% incidence.[2] A lack of understanding about TB, fear of transmission, and social isolation are frequently contributing factors to stigma[1] and are frequently connected to malnutrition, poverty, foreign birth, and low social class. People who are stigmatized may also delay getting medical treatment, experience discrimination, and impede workplace and home TB screening efforts.[2,4] There was a link between perceived stigma, a lack of information about TB, a fear of transmission, and social isolation among Ethiopian patients with pulmonary TB.[5] The impact of stigma and discrimination on TB treatment and control is enormous,[3] and eliminating TB stigma is critical to effective TB control, enhancing patient outcomes, and lowering TB spread. Efforts to overcome stigma have included education and awareness-raising initiatives, community participation, and the incorporation of TB patients into advocacy and awareness-raising efforts.[6,7]

MATERIALS AND METHODS

This study used mixed methods to gain a more comprehensive understanding of the issue using both qualitative and quantitative research approaches. In participant selection, the study recruited individuals with TB diagnoses, people with direct contact with TB patients, and ordinary people. We meticulously and systematically chose our participants using a random sampling approach based on the registration list. This was to ensure a representative sample of the population under investigation. We included 62 participants with TB diagnoses, 57 participants with direct contact with patients, and 61 participants from the general public. The author(s) declare that they have taken the ethical approval from Health Ethical Research Committee (HERC), in Hodiedah faculty of Medicine, approval number (101- 2021), dated 26 September 2021.

Inclusion and exclusion criteria

People with TB diagnoses, individuals with direct contact with TB patients, and ordinary people only who volunteered were included in the study. Participants who declined to participate or had cognitive impairments that prevented informed consent were excluded from the study.

Data collection

We utilized a mixed-method approach to gain a comprehensive understanding of the issue. To capture the participants' experiences, we developed a structured questionnaire and an in-depth interview guide. Data collection was conducted by trained interviewers.

Data analysis

Descriptive statistics are used to quantify data and identify trends and patterns. We also employed thematic analysis to provide an in-depth qualitative understanding of the participants' experiences. The Chi-squared test and logistic regression were used to identify numerous relationships that contributed to the study's conclusions.

RESULTS

Table 1 provides insights into feelings of stigma among TB patients: Over half of TB patients expressed that internalized stigma involves self-stigmatization by feeling ashamed and afraid of being seen as contagious or different due to their illness. About 68% (42 out of 62) of participants expressed anticipated stigma involves fear of discrimination and changing the topic of conversation or avoiding discussing the disease openly. About 10% (6 out of 62) expressed enacted stigma and discrimination reporting they lacked respect from medical staff. Females were more likely than males to show both anticipated stigma by feeling different and being afraid of transmitting the disease ($P = 0.045$, odds ratio [OR] = 3.79) and more likely to avoid talking about their disease or changing the subject ($P = 0.095$, OR = 2.44). There was no significant association between gender and feeling respected by medical professionals ($P = 0.172$).

Table 2 examines perceptions among 57 contacts of TB patients: About 30% (17 out of 57) of contacts believed poverty caused TB. About 79% (45 out of 57) feared community infection risk. About 63% (36 out of 57) viewed patients with compassion. About 82% (47 out of 57) were willing to associate with patients. Male contacts were more likely to fear infection risks.

Table 3 explores the views of 61 ordinary people: About 72% (44 out of 61) of ordinary people feared infection. About 28% (17 out of 61) thought poverty caused TB. About 57% (35 out of 61) saw patients with compassion. About 74% (45 out of 61) were willing to associate with patients. Education level in the general public was strongly linked to fear of infection and opinions about whether TB patients deserve their disease. Perceptions of TB patients were strongly associated with gender and economic status. Based on the data, there may be a link between socioeconomic status and stigmatization toward TB patients.

Table 1: Feelings of TB patients regarding stigma.

Parameter	Value
Gender	
Male	48
Female	14
Age	
<15 years	4
15-24 years	24
>24 years	34
Education Level	
Illiterate	22
Primary	40
Intermediate	27
Secondary	27
Higher Education	8
Economic Level	
Low	0
Middle	34
High	32
Marital Status	
Married	30
Single	19
Do you fear transmitting the disease?	
Yes	32
No	30
Do you talk about your illness easily?	
Yes	19
No	42
Does medical staff treat you with respect?	
Yes	56
No	6

TB: Tuberculosis

Table 2: Perception among contacts of TB patients.

Parameter	Value
Gender	
Male	53
Female	4
Age	
<15 years	11
15-24 years	21
>24 years	25
Education Level	
Illiterate	5
Primary	51
Intermediate	16
Secondary	33
Higher Education	11
Marital Status	
Married	31
Single	25
Do you fear transmitting the disease?	
Yes	0
No	56
What causes tuberculosis	
Poverty	5
Wrong behaviors	18
Divine punishment	18
Ignorance	5
How do you view a patient with tuberculosis	
With respect	24
With sympathy	25
Deserves it	39
Would you associate with a patient with tuberculosis?	
Yes	1
No, and should be isolated	32

TB: Tuberculosis

DISCUSSION

The research demonstrates that TB patients suffer social stigma due to their ailment. Over half of the patients reported anticipating stigma[6-8] by feeling distinct and fearful about spreading the disease. In addition, an important minority of TB patients reported that they were not treated respectfully by medical personnel.[9] Contacts and ordinary people exhibited similar beliefs about TB etiology and how they evaluated TB patients. However, contacts were more inclined to feel that TB patients should be with others, whereas regular folks were more likely to believe that TB patients should be secluded. According to this research, TB-related stigma is pervasive among TB patients, contacts, and normal people in Yemen, and comparable studies have been undertaken elsewhere in the Middle East, Africa, and Asia.[10-12] These studies have revealed that stigma and prejudice associated with TB are ubiquitous and have a significant influence on TB patients. The result that fear of transmission is a substantial driver of TB-related stigma is consistent with research reported in Ethiopia and Nepal.[2,4] The opinions of acquaintances and everyday folks regarding TB patients and the illness are quite similar to analogous research done in other locations.[3,5] For example, research done in Ethiopia indicated that fear of transmission was a substantial barrier to social engagement with TB patients. In addition, Nepali research indicated that poverty was one of the key sources of stigma and prejudice related to TB.[1,3] Overall, the study's results underline the need for focused interventions to eliminate TB stigma in Yemen and other countries around the world. To facilitate the social integration of TB patients, public awareness, and education should focus on eliminating myths and attitudes regarding TB.[13,14] To give courteous and non-discriminatory treatment to patients with TB, health-care professionals must receive training. Stigma linked to TB may lead to self-isolation, limited social support, and poor mental health outcomes. A high number of TB patients reported not being treated with respect by medical professionals. This implies that healthcare workers may contribute to TB stigma through their attitudes and practices. The most effective strategy to tackle TB stigma is through education and awareness programs that give factual information about TB transmission and its causes. Factors such as education level,

Table 3: Ordinary people's opinions regarding TB patients and the disease.

Total	Do you fear the risk of infection in the community? (yes)	Do you fear the risk of infection in the community? (no)	What causes tuberculosis? (poverty)	How do you view a patient with tuberculosis? (with compassion)	Would you associate with a patient with tuberculosis? (yes)	Would you associate with a patient with tuberculosis? (no, and should be isolated)
61	45	8	17	36	47	6

TB: Tuberculosis

socioeconomic background, and exposure to TB patients may impact TB stigma. The research underscores the essential need to address TB stigma as a barrier to successful TB control and TB patients' well-being. Providing accurate information, correcting myths, and educating, the following steps can be taken to combat TB stigma: Develop gender-sensitive techniques to combat TB stigma. The strong connection between gender and perceptions of stigma among TB patients emphasizes the need for specific treatments that reflect the particular obstacles experienced by female patients. This might involve offering gender-specific counseling and support services and educating health-care practitioners and social workers to provide gender-sensitive treatment. Implement focused awareness programs to overcome TB transmission concerns. The considerable link between gender and fear of infection in the community underscores the necessity for customized awareness initiatives that address guys' unique concerns and perceptions. These efforts should stress the necessity of correct information and preventative measures and strive to encourage more community engagement and support for TB patients.[15-18] Promote greater awareness and comprehension of TB: The lack of a significant association between gender and beliefs about TB causes, the views of TB patients, or being deserving of being around others suggests the need for broader awareness campaigns that promote greater understanding and empathy toward those afflicted by TB. These efforts should strive to debunk myths and minimize stigma and should engage a broad variety of stakeholders, including health-care practitioners, community leaders, and lawmakers. Assistance for TB patients to overcome shame and stigma, the strong relationship between gender and stigmatizing feelings among TB patients highlights the need for additional assistance and resources to help patients overcome these sentiments. This might include offering counseling and education programs, as well as advocating for more community engagement and support for TB sufferers. We offer the following messages to lessen stigmatization toward TB patients: TB is not caused by a human mistake but rather by a bacterial infection that may be cured with medicine. Efforts should be undertaken to minimize social and economic obstacles that hinder TB treatment. Public health initiatives may be developed to promote awareness of TB and its causes. Financial support may be provided to pay treatment expenses and promote access to health-care services. By sharing these messages, we may increase knowledge about TB, lessen stigmatization toward TB patients, and boost treatment.[19]

CONCLUSION

The research studied TB patients' attitudes toward stigma and others' perceptions regarding TB and its sufferers. Results indicated that most TB patients reported feeling distinct and fearful of contracting the illness. In addition, many did not freely talk about their condition or shift the topic, which signified the expected stigma. In addition, an important minority experienced stigma by not being treated with respect by medical professionals. Among others, fear of infection in the community was a prominent issue, with men more likely than females to voice this anxiety. No significant connection was discovered between gender and attitudes regarding TB causes, the perspectives of TB patients, or being worthy of being near others. These results show that there is still a need for programs to minimize TB-related stigma and promote public knowledge of the illness, and medical workers should be educated to treat patients with respect. Efforts should be undertaken to educate the public about TB causes to lessen the stigma associated with the illness. It is vital to create treatment targeted at eliminating TB stigma and supporting TB patients' social integration.

Ethical Approval

The author(s) declare that they have taken the ethical approval from Health Ethical Research Committee (HERC), in Hodeidah faculty of Medicine, approval number (101-2021), dated 26 September 2021.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

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Conflicts of interest

There are no conflicts of interest.

Use of artificial intelligence (AI)-assisted technology for manuscript preparation

The author confirms that there was no use of artificial intelligence (AI)-assisted technology for assisting in the writing or editing of the manuscript and no images were manipulated using AI.

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