

Magnitude and Consequences of TB-Related Stigma Experienced by People with Tuberculosis in Tanzania

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Abstract: Background: TB-related stigma is a barrier to ending TB. Because of stigma, patients with TB can be delayed in seeking treatment, receiving a diagnosis, initiating and completing treatment, and consequently increasing the transmission of the disease within a community. Information regarding the magnitude and consequences of TB-related stigma in Tanzania are generally missing in our setting. The study aimed to generate such information to inform the planning and implementation of TB-related stigma reduction strategies. Methods: Between September 2021 and February 2022, a cross-sectional survey was conducted to collect data on TB-related stigma among people with or who had TB (PWTB) in five regions of Tanzania. The survey utilized adapted structured questionnaires developed by the Stop TB Partnership. Data collection was carried out through face-to-face interviews. Data were analyzed using SPSS version 26, and the results were presented in tables. Results: The study recruited a total of 418 PWTB, with 276 (66%) being male and 86 (18.4%) having TB-HIV co-infection. Among the participants, 86 PWTB (20.6%) reported experiencing stigma due to their TB status. The most common settings where PWTB encountered stigma were within their families (50%), communities (36%), and workplaces (10%). Delays in seeking care (16.7%), obtaining an accurate diagnosis (15%), and initiating treatment (27%) were identified as the most common consequences associated with TB-related stigma. Participants' region, age, education level, and type of TB were factors significantly associated with experiencing TB-related stigma. Conclusion: This study revealed a moderate level of TB-related stigma experienced by TB patients, primarily originating from family members, neighbors, and co-workers. Furthermore, the findings emphasized the impact of TB-related stigma on the delay in seeking medical care for TB diagnosis and treatment. Therefore, this study highlights the need for the prompt inclusion of TB stigma reduction strategies in the TB prevention and control program in Tanzania.

Keywords: Tuberculosis, Stigma, Magnitude, Consequences, Tanzania

1. Introduction

Tuberculosis (TB) is an airborne infectious disease that poses significant morbidity and mortality worldwide, particularly in resource-limited countries like Tanzania [1]. TB, on the other hand, contributes to poverty, discrimination, and stigma [2, 3]. TB-related stigma is increasingly recognized as a barrier to efforts to control TB. It hinders care seeking [4, 5], early diagnosis [6], and timely initiating and completing treatment [7, 8]. To end TB, barriers to accessing TB health services must be removed. This goal aligns with the resolution made by the UN General Assembly high-level meeting on tuberculosis in 2018, where the UN adopted a political declaration aimed at accelerating progress towards the End TB targets, including the elimination of stigma and all forms of discrimination associated with the disease [9]. Understanding the nature of TB-related stigma and measuring its magnitude and consequences are critical steps towards mounting a proper response to the problem.

Typically, stigma is a complex process that is influenced by institutional and community norms and interpersonal factors and begins when the characteristics or traits of an individual or group are perceived to be undesirable or disvalued by others. As a result, stigmatized individuals adopt self-regarding attitudes that include shame, disgust, and guilt, resulting in behaviors that include hiding the stigmatized trait, withdrawing from interpersonal relationships, or increasing risky behaviors [10–12]. In the context of TB disease, experienced TB-related stigma refers to the range of stigmatizing behaviors, messages, and effects experienced by a person with TB in different settings, such as at home, in the community, in a health care facility, or at work [13]. It has been documented that because of TB, people with TB are isolated, avoided, shunned away, neglected, gossiped about, and verbally abused [14, 15]. Such stigmatizing behaviours and actions could negatively impact their decision to seek care, start, and maintain treatment, as well as disclosing their TB status, consequently impacting the quality of care, and depriving people with TB of their rights, security, support system, and means of income from their family members, neighbors, workmates, and care providers [16–18].

Tanzania is among the countries with the highest TB burden, with an estimated TB incidence of 208 per 100,000 people [Programmatic Data of NTLP 2023], which is far above the rate recommended by the Center of Disease Control (CDC) to attain national TB control of 1.4 cases per 100,000 [19]. Information regarding TB-related stigma is generally missing in Tanzania. However, previous studies have shown that TB-related stigma is prevalent, operates differently for men and women, and is driven by fear of infection, a general lack of health knowledge, and cultural

beliefs about TB [20, 21]. This study adds to the body of knowledge about the magnitude and consequences of TB-related stigma among people with TB to inform TB stigma reduction strategies and ultimately TB control in our setting.

2. Material and Methods

2.1. Design, Study Area and Settings

This article is part of the larger study to assess TB-related stigma and gender-based violence in Tanzania, where a cross-sectional design was applied to collect data in five regions of Tanzania between September 2021 and February 2022. Kilimanjaro, Mwanza, Njombe, Pwani, and Unguja Kaskazinia were the regions involved. Moreover, the study recruited participants who attended 20 health facilities in both rural and urban settings.

2.2. Participants, Inclusion and Exclusion Criteria

The participants in this study were PWTB who were at least 18 years of age or older and fulfilled the following criteria: (i) newly diagnosed TB patients, (ii) TB patients who were undergoing treatment, and (iii) TB patients who had completed their treatment within the past two months. By including a broader range of participants, we aimed to obtain a comprehensive understanding of the TB-related stigma experienced throughout different stages of the treatment process. Participants who were too sick to participate or declined to provide consent were excluded from the study.

2.3. Sampling Strategy and Sample Size

Both random and convenient sampling methods were used to obtain study areas and participants. Kilimanjaro, Mwanza, Njombe, and Pwani were regions that were randomly selected to represent the northern, western, southern highland, and east coast geographical zones on the Tanzanian mainland, respectively. Likewise, Unguja Kaskazini was selected to represent five regions of Tanzania-Zanzibar. In each region, two lists of the top 10 health facilities with higher TB notifications for urban and rural settings were created using 2020 TB notification data from the National TB and Leprosy Programme (NTLP). Thereafter, four health facilities were randomly selected (2 from each list), making a total of 20 health facilities across all the regions. The areas where selected health facilities were located formed the primary study sites. List of selected health facilities is provided in Table 1. TB patients from the study areas who received or were receiving care at the selected health facilities and met the inclusion criteria were identified, contacted, and invited to participate in the study. A total of 418 participants were recruited across the study sites.

Table 1. Selected health facilities by region and settings.

Region	Health facilities	
	Urban	Rural
Kilimanjaro	Mawenzi Hospital	Huruma Hospital
	St Joseph Hospital	Kibosho Hospital
Mwanza	Sekou Toure Hospital	Misungwi Hospital
	Nyamagana Hospital	Sengerema Hospital
Njombe	Njombe Hospital (Kibena)	Wanging'ombe Hospital
	St. Joseph Hospital (Ikulu)	Makete Hospital
Pwani	Tumbi Hospital	Kibiti Health Center
	Mkoani Health Center	Mkuranga District Hospital
Unguja Kaskazini	Kivunge Health Centre	Kidoti PHCU
	Mahonda Health Centre	Kitope PHCU

2.4. Data Collection Procedures

The data were collected by researchers who had received training. The head of TB clinics and the DOT nurses from the health facilities involved in this study made prior arrangements to identify, contact, and invite potential participants. The recruitment of participants was based on specific inclusion and exclusion criteria. On the day of data collection, the leader of the research team explained the objectives of the study, addressed any raised concerns, and responded to questions. Subsequently, the participants were invited to take part in the study. Prior to recruitment, written informed consent was obtained from each participant. To suit the Tanzanian context, a questionnaire developed by the Stop TB Partnership [22] was adapted and translated into Swahili. This questionnaire captured demographic information and other details pertaining to TB-related stigma. Data were collected using face-to-face interviews.

2.5. Data Management and Statistical Analysis

The data were collected and stored using tablets with an Android-supported data collection system (Open Data Kit). SPSS v. 26 (IBM® Corp., Armonk, NY, USA) was used to analyze descriptive data, with results summarized in frequency tables. Pearson's Chi-square test was used to determine factors associated with experiencing TB-related stigma. A significant association was considered at $p < 0.05$.

2.6. Ethical Consideration

The National Health Research Ethics Committee (NatHREC) and the Zanzibar Health Research Ethics Committee (ZAHREC) approved the study. Additional approval was obtained from the respective regional, district, and health facility authorities. The interview was conducted in a private setting, and participants consented before participating. Participant's information are presented

anonymously.

3. Results

3.1. Demographic Characteristics of the Participants

Table 2 summarizes the demographic and disease characteristics of the participants. The study recruited 418 participants. The majority of the participants were from Kilimanjaro Region 117 (28%), followed by Pwani 109 (26%), Njombe 89 (21%), Mwanza 67 (16%), and Unguja Kaskazini 36 (8.6%), respectively. Males had a greater representation than their female counterparts by 276 (66%). The majority of the participants, 252 (60.3%), were in the age group of 30 to <60, while other age groups had almost equal proportions. Over half of the participants, 243 (58%), were married, and about two-thirds, 252 (60.3%), had a primary level of education. Most of the participants were farmers and self-employed, which accounted for 35% and 42%, respectively. A quarter of the participants, 102 (24.4%), had a monthly income of at least TZS 138,000 (\geq \$57), and about a third, 125 (29.9%), had monthly incomes ranging from TZS 69,000 to 138,000 (\$28–57). Moreover, the larger proportion of the participants, 191 (45.7%), had monthly incomes of less than TZS 69,000 (\leq \$28). Participants self-identified as rural dwellers, people living with HIV (PLHIV), and urban slum dwellers by 23%, 18.4%, and 17%, respectively. One hundred seventy-six (37.7%) participants, however, did not self-identify with any of the key populations. At the time of data collection, the majority of the participants, 297 (71%), were still on treatment; 116 (27.8%) had completed their treatment; and 5 (1.2%) had recently been diagnosed and had not started treatment. Among the participants recruited, 187 (44.7%) had pulmonary TB, 31 (7.4%) had extra-pulmonary TB, 5 (1.2%) had multidrug-resistant TB, and nearly half 195 (46.7%) were not aware of the type of TB they had.

Table 2. Demographic and disease characteristics of the participants.

Demographic Characteristic	Category	Participants
N = 418		n (%)
Region	Kilimanjaro	117 (27.99)
	Mwanza	67 (16.03)
	Njombe	89 (21.29)

Demographic Characteristic	Category	Participants
N = 418		n (%)
Gender	Pwani	109 (26.08)
	Unguja Kaskazini	36 (8.61)
	Male	276 (66.03)
	Female	142 (33.97)
Age group	>30	86 (20.6)
	30-<60	252 (60.3)
	≥60	80 (19.1)
	Single	89 (21.3)
Marital Status	Married	243 (58.1)
	Divorced/ Separated	54 (12.9)
	Widow/widower	32 (7.7)
	No formal education	61 (14.6)
Level of Education	Primary education	252 (60.3)
	Secondary education	82 (19.6)
	College/ University education	23 (5.5)
	Not employed	61 (14.59)
Occupation	Farmer	146 (34.93)
	Student	11 (2.63)
	Self-employed/business	175 (41.87)
	Formal-employed	25 (5.98)
Monthly income	<TZS 69,000.00	191 (45.69)
	TZS 69,000 -138,000	125 (29.9)
	>TZS 138,000	102 (24.4)
	Person living with HIV	86 (18.42)
Self-identification of PWTB in key population*	Healthcare worker	8 (1.71)
	Urban slum dweller	80 (17.13)
	Rural slum dweller	107 (22.91)
	Person who uses drugs	2 (0.43)
Type of TB	Person with disability	3 (0.64)
	Former prisoner	5 (1.07)
	None identified	176 (37.69)
	Pulmonary TB	187 (44.74%)
Stage of TB treatment	Multidrug resistant TB	5 (1.2%)
	Extra pulmonary TB	31 (7.42%)
	Unknown	195 (46.65%)
	Completed TB treatment within six months	116 (27.75%)
Type of TB	Currently on TB treatment	297 (71.05%)
	Newly TB diagnosed not yet in treatment	5 (1.2%)

* Participants had multiple self-identities, n is greater than 418, and percentage (%) is more than 100%.

3.2. Experiences and Consequences of TB-Related Stigma Among PWTB

Eighty-six (20.57%) of the recruited participants reported being stigmatized because of their TB status. Participants were stigmatized most frequently in their families, communities, and workplaces, as recorded in 49.5%, 35.8%,

and 10%, respectively. Thirty-eight out of 86 participants (44.2%) reported not being inhibited from accessing TB care because of stigma. However, delays in seeking care (16.7%), getting an accurate diagnosis (15%), beginning treatment (27%), and adhering to treatment (10%) were the most frequently reported consequences associated with TB-related stigma experienced by the other participants (Table 3).

Table 3. Experiences and consequences of TB-related stigma among PWTB.

Question	Response	
	Yes n (%)	No n (%)
Have you ever felt you were stigmatized because of your TB status (N = 418)	86 (20.57)	332 (79.43)
In which setting(s) do you experience stigma? (n* = 109)	Setting	Frequency
	Hospitals/clinics	3 (2.75)
	Community/neighbors	39 (35.78)
	Home/Family	54 (49.54)
	Workplace	11 (10.09)
	School/college	1 (0.92)
	Church/mosque	1 (0.92)

Question	Response	
	Yes n (%)	No n (%)
Did the experienced stigma in the identified setting(s) above inhibit you from the following? (n* = 78)	Consequence	Frequency
	Recognizing symptoms	11 (14.10)
	Seeking timely care	13 (16.67)
	Going to a health facility	8 (10.26)
	Getting an accurate diagnosis	12 (15.38)
	Beginning treatment	21 (26.92)
	Adhering to treatment	8 (10.26)
	Completing treatment	2 (2.56)
	Getting post-treatment follow-up services	3 (3.85)
	None (n* = 86)	38 (44.19)

n* number of frequency response in the specific question

3.3. Factors Associated with TB-Related Stigma Experienced by PWTB

Participants' region, age, education level, and type of TB were factors significantly associated with experiencing TB-

related stigma. There was, however, no significant statistical association between gender, marital status, occupation, monthly income, or stage of TB treatment (Table 4).

Table 4. Factors associated with TB-related stigma experienced by PWTB.

Factor N=86	Category	Experienced TB-related Stigma n (%)	P- value
Region	Kilimanjaro	15 (12.8)	0.0112
	Mwanza	23 (34.3)	
	Njombe	21 (23.6)	
	Pwani	21 (19.3)	
	Unguja kaskazini	6 (16.7)	
Gender	Male	56 (20.3)	0.8411
	Female	30 (21.1)	
	>30	17 (19.8)	
Age	30-<60	62 (72.1)	0.009
	≥60	7 (7.1)	
	No formal education	5 (5.8)	
Education level	Primary education	53 (61.6)	0.043
	Secondary education	22 (25.6)	
	College/ University education	6 (7)	
	Single	21 (24.4)	
Marital Status	Married/ Cohabit	45 (52.3)	0.1634
	Divorced/ Separated	16 (18.6)	
	Widow/widower	4 (4.7)	
	Famers	10 (16.4)	
Occupation	Student	28 (19.2)	0.7153
	Employed (self/formal	3 (27.3)	
	Self-employee	38 (21.7)	
	Formal-employed	7 (28)	
Monthly income	< TZS 69,000	33 (17.3)	0.0878
	TZS 69,000-138,000	34 (27.2)	
	> TZS138,000	19 (18.6)	
Treatment stages	Completed TB treatment	29 (25)	0.2195
	Currently on TB treatment	57 (19.2)	
	Newly TB diagnosed	-	
Type of TB	Pulmonary TB	51 (27.3)	0.0184
	Multidrug resistant TB	-	
	Extra-pulmonary TB	5 (16.1)	
	Don't know	30 (15.4)	

4. Discussion

The present study assessed the magnitude and consequences of TB-related stigma experienced by TB patients in Tanzania. The study found one in five TB patients (20.6%) experienced TB-related stigma along the

TB journey [i.e., starting from recognizing symptoms till they reach the phase of post-treatment follow-up services]. To our knowledge, there is generally a scarcity of comparable studies in our region that quantitatively assess the level of stigma experienced by TB patients. TB stigma index studies in Ghana (West Africa), Ukraine (Eastern Europe), and India (Asia) reported levels of experienced

TB-related stigma among TB patients of 22%, 39%, and 26%, respectively [23–25]. In addition, experienced TB-related stigma is, however, commonly described in qualitative studies [14, 26, 27]. To win the TB war, we would have to fight stigma more aggressively to reduce it to zero or a minimum.

In line with previous research [7, 28–30], TB-related stigma has a detrimental impact on access to TB services, adherence to treatment, and ultimately the control of the disease. For instance, a study conducted in Zambia identified challenges faced by TB patients in accessing TB services and adhering to treatment due to stigma [31]. In the present study, a significant number of TB patients experienced delays in seeking care, receiving a diagnosis, and initiating treatment due to stigma. Conversely, it is widely recognized that delayed diagnosis and treatment interruption significantly impede TB control efforts. Typically, TB patients who interrupt their treatment face increased risks such as prolonged hospitalization, heightened disease severity, higher mortality rates, acquisition of drug resistance, and continued transmission of mycobacterium strains within the community [32–36].

Research has demonstrated that individuals who experience stigmatization are more likely to develop resilience and effectively cope with stigma if they have supportive, stable, and reciprocal relationships with their families and peers [37, 38]. In addition, family members and friends play a crucial role as treatment supporters, as they are responsible for providing social support and ensuring that the TB patient adheres to the prescribed medication consistently and on schedule, roles that are vital for successful TB cure and control [39, 40]. In this study, TB patients experienced TB-related stigma in various settings, including their families, communities, and workplaces. This observation suggests that family members, neighbors, and coworkers were the primary sources of stigmatization (perpetrators). Noteworthy stigmatization from close relatives and peers often manifests as shaming, blaming, maintaining socio-physical distance, imposing participatory restrictions, and engaging in gossip [14, 41, 42]. These experiences make TB patients less inclined to disclose their TB status and result in weaker social support networks. Consequently, hiding TB status places TB patients at a higher risk of negative clinical outcomes and increases the risk of community transmission of TB. Our findings emphasize the need for broader community involvement in combating TB-related stigma. This can be achieved through community sensitization and educational campaigns that specifically target actions, beliefs, myths, and stereotypes that contribute to the stigmatization of TB patients in specific settings and within the community as a whole.

Our study was not without limitations. First, participants were conveniently recruited, thus limiting generalization. In addition, due to the sensitive nature of the topic of stigma, there was a possibility of socio-desirability bias in reporting self-experiences of TB-related stigma. However, a larger sample size, wider national geographical representation, and

the involvement of various groups of vulnerable TB patients validate the current study and provide insight to inform TB stigma reduction interventions in our settings.

5. Conclusion

This study showed a relatively moderate level of experienced TB-related stigma among TB patients (20.6%), with family members, neighbors, and co-workers acting as the main perpetrators. Moreover, as a result of experiencing TB-related stigma, TB patients delay seeking medical care, getting a diagnosis, and initiating and complying with treatment, suggesting that TB-related stigma constrains efforts to end TB. Therefore, it's high time to incorporate strategies for TB stigma reduction into the national TB prevention and control programme. Future studies should strive to identify and test appropriate TB stigma reduction strategies in our settings.

Consent for Publication

All authors read the manuscript and approved it for publication.

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Authors Contributions

E. P. K., W. D. M., N. G. M., and L. E. M designed the study, collected data, analysed and wrote the manuscript, R. M. K., E. H. M., H. O. K., G. P. M., P. M. M., O. G. L., O. L. K., and M. J. E collected data, analysed and helped to draft the manuscript.

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Conflicts of Interest

The authors declare that, they have no conflict of interest.

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