

# Level and Manifestations of TB-Related Stigma Among People with Tuberculosis in Tanzania

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**Abstract:** *Background:* TB-related stigma is a recognized barrier to efforts to End TB. It affects early diagnosis and timely initiation of treatment and can potentially interrupt treatment. Understanding the dimension of TB-related stigma and its manifestations is critical to planning appropriate TB stigma reduction responses. However, this information is largely unknown in Tanzania. This study assessed the level and manifestations of self-TB-related stigma among people with TB. *Methods:* A cross-sectional survey was deployed to collect quantitative and qualitative data among people with TB in five regions of Tanzania between September 2021 and February 2022. Face-to-face interviews were used to obtain data from the participants using a modified questionnaire developed by the Stop TB Partnership to assess TB-related stigma among TB patients. Descriptive and thematic analysis were used to summarize and present findings. *Results:* Four hundred eighteen (418) participants were recruited, of whom 276 (66%) were males. The overall level of self-TB-related stigma was 40%, predominated by agreement of behaviours and attitudes limiting disclosure of TB status. TB-related stigma commonly manifested as social isolation, fear of contracting TB, verbal abuse, gossip, and an unwillingness to share eating utensils. *Conclusion:* This study showed a relatively moderate level of self-TB-related stigma among TB patients, characterized by fear of disclosure of TB status. Moreover, TB patients are inclined to be socially isolated, gossiped, and maltreated. These findings suggest the need to include TB stigma reduction responses in national TB prevention and control efforts.

**Keywords:** Tuberculosis, Stigma, Level, Manifestations, Tanzania

## 1. Introduction

Tuberculosis (TB) is an infectious disease presenting a major public health threat worldwide; it causes significant morbidity and mortality, and contributes to poverty and poor quality of life among TB patients [1]. Ending TB demands addressing barriers that undermine the access to TB health services. TB-related stigma has been recognized as one of the social determinants of health hinders efforts to control TB [2–4] since, It can affects early health seeking behaviour, delays diagnosis, hinders disclosure of TB status, and interrupt treatment [5, 6]. In 2018, the UN General Assembly high-level meeting on tuberculosis endorsed a political declaration to accelerate progress towards End TB targets, which include eliminating stigma and all types of discrimination related to TB [7]. In this regard, understanding and averting all forms of stigma and discrimination are vital to promoting access to and equitable use of TB health services and, ultimately, TB control.

Stigma is a complex process; it is shaped by institutional and community norms, interpersonal factors, and attitudes. It begins when a particular trait or characteristic of an individual or a group is identified as undesirable or disvalued; as a result, the stigmatized individual adopts a set of self-regarding attitudes that include shame, disgust, and guilt, which produce a set of behaviors that include hiding the stigmatized trait, withdrawing from interpersonal relations, or increasing risky behaviors [8–10]. In the context of TB disease, TB-related stigma can manifest as self-stigma, anticipated stigma, or experienced stigma. Self-stigma captures the idea that TB patients endorse negative stereotypes about TB and therefore behave or think according to false portrayals and negative messages. Anticipated stigma, or perceived stigma, refers to the worry that one will be devalued after a TB diagnosis and is often the result of observing others being stigmatized. Conversely, experienced stigma reflects the range of stigmatizing behaviors, messages, and effects experienced by the person with TB in different settings, such as at home, in the community, in a health care facility, or at work [11].

Tanzania is among the countries with the highest TB burden, with an estimated TB incidence of 208 per 100,000 people, a decline of 32% compared to the 2015 TB incidence rate of 306 per 100,000 people [12]. In 2022, programmatic data on the TB case notification showed that about 36% of people with TB are missed by the healthcare system annually, suggesting existing barriers to accessing TB health services, including TB-related stigma as documented in other previous studies in Tanzania [13–15]. However, the dimension and manifestations of TB-related stigma among people with TB in Tanzania largely remain undocumented. Therefore, the goal of this study was to fill up those gaps in knowledge and collect up-to-date data on self-TB-related stigma among people with TB in order to inform TB control practices, strategies and policies.

## 2. Material and Methods

### 2.1. Design, Study Area and Settings

This article is part of a larger study to assess TB-related stigma and gender-based violence in Tanzania. The methods of this study have been described in other related articles [16–17]. Briefly, between September 2021 and February 2022, a facility-based cross-sectional design was used to collect both quantitative and qualitative data among TB patients in 20 health facilities in both rural and urban settings in five regions of Tanzania, as shown in “Table 1”.

### 2.2. Participants, Inclusion and Exclusion Criteria

The participants were people with TB (PWTB) who were 18 years of age or older and who, during the time of data collection, belonged to one of the following categories of TB patients: newly diagnosed TB patients, TB patients receiving treatment, or TB patients who had finished their treatment for TB within the previous two months. These categories of TB patients were considered to capture a wider experience of TB-related stigma that faced TB patients before diagnosis, during treatment, and after completing treatment. Participants who were too sick to participate or who refused to give their consent were excluded.

### 2.3. Sampling Strategy and Sample Size

Both random and purposive sampling methods were used to choose study areas and the participants. Tanzania is divided into 31 administrative regions, with 26 on the country’s mainland and 5 on Zanzibar Island. In this study, 26 regions of Tanzania’s mainland were divided into four zones; east coast, northern, western central, and southern highlands. Likewise, 5 regions of Zanzibar formed one zone. In order to obtain country-wide geographical representation, simple random sampling was used to choose one region from each zone, which had at least five regions. Pwani, Kilimanjaro, Mwanza, and Njombe on the Tanzania’s mainland, as well as Unguja Kaskazini in Zanzibar were the regions that were chosen. To ensure representation from both urban and rural locations in each region, a list of the top 10 health facilities with higher TB notification rates in urban and rural settings was created using 2020 TB notification data from the National TB and Leprosy Programme (NTLP). Then, two health facilities were randomly chosen from each list (i. e., urban and rural health facilities), respectively, making a total of 4 health facilities per region and 20 health facilities across all five regions. TB patients who received care at the selected health facilities and met the inclusion criteria were identified, contacted, and invited to take part in the study. A total of 418 participants were recruited across the study areas.

*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 (Ikolu)	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

A team of qualified researchers collected the data. Prior to data collection and fieldwork, the research team was trained on the study's objectives, methods, and research ethics. The regional and district TB and leprosy coordinators (RTLTC and DTLC) and health facility leaders, notably those in charge of TB clinics or DOT nurses, made advance arrangements to identify, contact, and invite potential participants based on the inclusion criteria. Before interviewing participants on the day of data collection, the research team leader explained the study's objectives, addressed any questions, and provided clarification on any matter raised by participants regarding the study. Each participant provided written consent before deciding to take part in the study. The study adapted a semi-structured questionnaire developed by the STOP TB Partnership for assessing TB-related stigma among TB patients [18], which was modified and translated in Swahili to increase comprehension and suit the Tanzanian context. Data were collected through face-to-face interviews. The questionnaire contained demographic information, a scale to assess self-TB-related stigma, and open-ended questions to understand how TB-related stigma manifested.

## 2.5. Data Management and Statistical Analysis

Data were collected and stored using tablets that were installed by an Android-supported data collection system (Open Data Kit). SPSS v. 26 (IBM® Corp., Armonk, NY, USA) was used to analyze quantitative data. The analysis was dominated by descriptive statistics, which included calculating the frequency and percentages of study variables and summarizing them in tables and figures. Data to assess the level of TB-related stigma were collected at 5 levels on the agreement-likert scale (strongly disagree, disagree, no opinion, agree, and strongly agree). The mean, standard error, and level of TB-related stigma were computed using five levels of agreement; however, the level of agreement for each statement was presented in three levels of agreement (agree, no opinion, and disagree) to make interpretation easier by combining strongly disagree and disagree to disagree and agree and strongly agree to agree. For qualitative data, analysis was performed after transcribing the interview

verbatim and translating the transcripts to the English language in MS Word. Transcripts were read thoroughly to get familiar with the contents; subsequently, coding was done manually to establish emerging codes with the subsequent formation of topics and themes. The narratives and distinctive ones that best describe the selected topics were presented alongside the generated topics/themes.

## 2.6. Ethical Consideration

The study was approved by the National Health Research Ethics Committee (NatHREC) and the Zanzibar Health Research Ethical Committee (ZAHREC) with reference certificate numbers NIMR/HQ/R.8a/Vol. IX/3668 and ZAHREC/03/OCT/2021/25, respectively. Conversely, authorities in each region, district, and health facilities were contacted for additional approval. The interview was conducted in an area that ensures privacy, and consent for participation was obtained before the interview. All data are presented anonymously.

# 3. Results

## 3.1. Socio-Demographic Characteristics of the Participants

Socio-demographic characteristics of the participants are shown in "Table 2". A total of 418 participants were recruited. 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. Most of the participants were males, represented more than two-thirds 276 (66%). Nearly half of the participants 202 (48.3%) were between the ages of 36–60; 45 (34.7%) were between the ages 18–35 years; and 71 (17%) were 60 years and older. The majority of participants (58.13%) were married, however, 21.3%, 13.2%, and 7.4% of the participants were single, divorced/separated, or widows/widowers, respectively. Two hundred fifty two (60.3%) of the participants had completed their primary education; 82 (19.62%) had completed their secondary education; 61 (14.6%) had no formal training; and 23 (5.5%) had college or university education. One hundred seventy five (42%) of the participants were self-employed, followed by

farmers 146 (35%), formal-employed 25 (6%), students 11 (2.6%), and 61 (14.6%) of the participants could not identify any particular occupation. A quarter of the participants 102 (24.4%) had monthly income of at least TZS 138,000 ( $\geq$  \$57), and a third 125 (29.9%) had monthly incomes ranging from TZS 69,000 to 138,000 (\$ 28-57). Moreover, the majority of participants 191 (45.7%) had monthly incomes of less than TZS 69, 000 ( $\leq$  \$28). Participants self-identified in seven key

populations, including rural slum dwellers 107 (22.91%), people living with HIV 86 (18.42%), and urban slum dwellers 80 (17.13%). The other key population included healthcare workers 8 (1.7%), former prisoners 5 (1%), people who use drugs 2 (0.4%), and people with disabilities 3 (0.6%). However, 176 (37.7 %) of the participants did not belong to any of the key vulnerable populations.

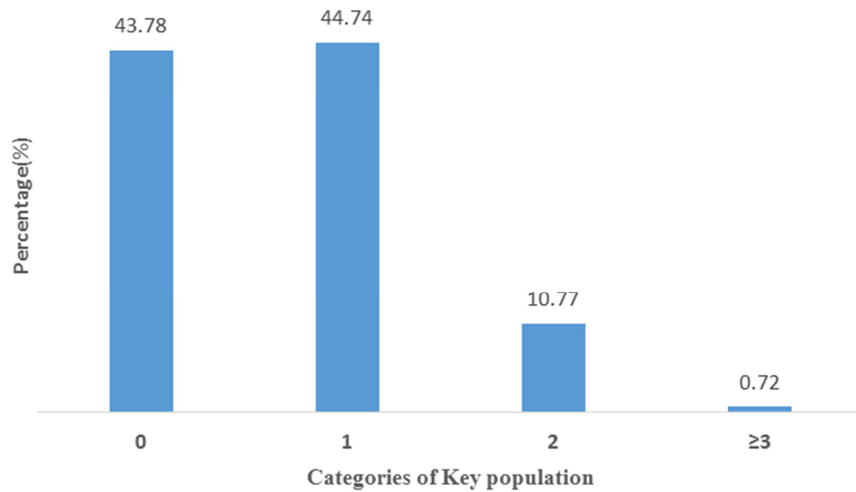
*Table 2. Socio-demographic characteristics of the participants.*

Demographic Characteristic	Category	Participants
N = 418		n (%)
Region	Kilimanjaro	117 (27.99)
	Mwanza	67 (16.03)
	Njombe	89 (21.29)
	Pwani	109 (26.08)
	Unguja Kaskazini	36 (8.61)
Gender	Male	276 (66.03)
	Female	142 (33.97)
Age group	18-35	145 (34.69)
	36- 60	202 (48.32)
	>60	71 (16.99)
Marital Status	Single	89 (21.29)
	Married	243 (58.13)
	Divorced/separated	55 (13.16)
	Widow/Widower	31 (7.42)
Level of Education	No formal education	61 (14.59)
	Primary education	252 (60.29)
	Secondary education	82 (19.62)
	College /university education	23 (5.50)
	University education	3 (.72)
Occupation	Not employed	61 (14.59)
	Farmer	146 (34.93)
	Student	11 (2.63)
	Self-employed	175 (41.87)
	Formal-employed	25 (5.98)
	<TZS 69,000.00	191 (45.69)
Monthly income	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)
	Person with disability	3 (0.64)
	Former prisoner	5 (1.07)
	None identified	176 (37.69)

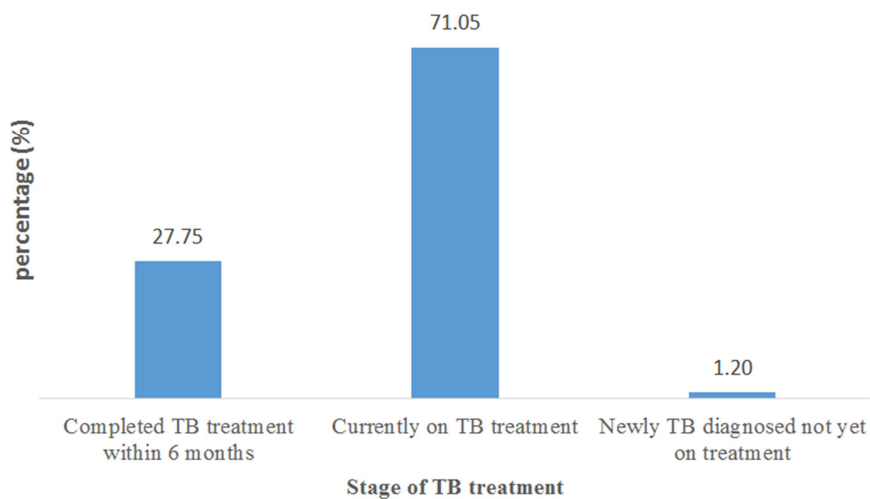
\* Some of the participants had multiple self-identities, total n is not equal to 418, and percentage (%) is more than 100%.

Participants who identified themselves to belong in one of the key populations, 187 (44.7%) identified themselves in only one group, 45 (10.8%) identified themselves in two categories, and 3 (0.7%) identified themselves in at least three categories “Figure 1”. At the time of data collection, the majority of the participants 297 (71%) were still on treatment,

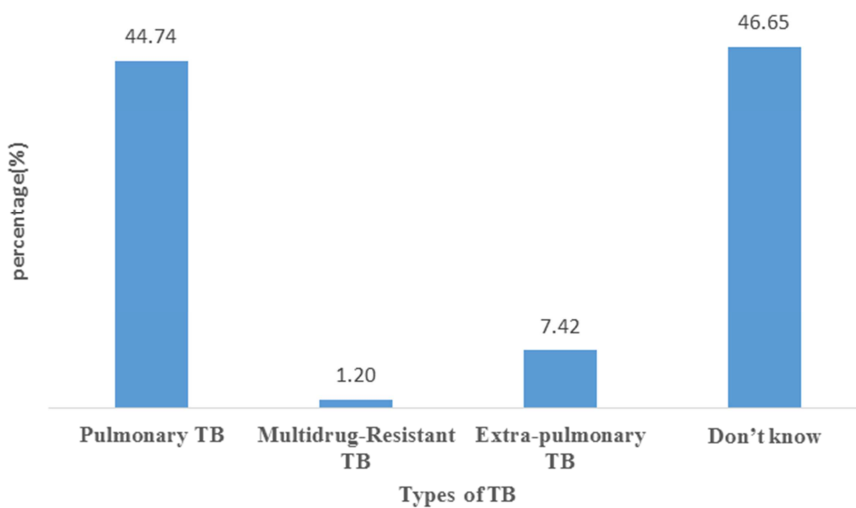
116 (27.8%) had completed their treatment, and 5 (1.2%) had recently been diagnosed and had not started treatment “Figure 2”. Among the participants who were recruited, 187 (44.7%) had pulmonary TB, 31 (7.4%) had extra-pulmonary TB, 5 (1.2%) had multidrug-resistant TB, and 195 (46.7%) were not aware of the type of TB they had “Figure 3”.



**Figure 1.** Distribution of the participant's self-identification in Key population ( $n = 418$ ).



**Figure 2.** Distribution of stages of TB treatment of the participants ( $n = 418$ ).



**Figure 3.** Distribution of the participant's type of TB ( $n = 418$ ).

### 3.2. Level of TB-Related Stigma Among PWTB

Self-stigma in PWTB was measured using a set of 12 statements scale describing the attitude towards social isolation,

feelings of guilt, and fear of TB status disclosure and so on. The mean  $\pm$  standard error, and overall level of self-TB-related stigma score were  $19.84 \pm 5.56$ , and 39.85%, respectively. Based on statements on the self-TB stigma scale, over one-third

of the respondents 136 (32.54%) identified with the feelings of loneliness because of having TB. More than half of the participants 240 (57.42%) limited social contact to prevent spread of TB by supporting the statement on keeping a distance from others to avoid spreading TB germs. About one-fifth of the respondents 125 (21.9%) reported to lose friends when they share their TB status. About a quarter of the respondents (25%) felt guilt for burdening their family for caring for them and for their careless behaviors such as smoking and alcohol drinking, which led them to contract TB, respectively. Nearly half of the respondents 196 (46.9%) identified with the feeling of being hurt to see how others react after finding out that they have TB. About quarter of the respondents 104 (24.9%) supported the TB

and HIV associated stigma by agreeing on the statement said that they were afraid to tell others that they have TB because they may think that they also have HIV/AIDS. More than one-third 151 (36.1%) agreed to the statement that they were worried to have HIV/AIDS. Fear of disclosure of the TB status to their family, and to those who are outside their family were supported by 38 (9.1%), and 135 (32.3%) respondents, respectively. More than half of the respondents 235 (56.2%) reported that they choose carefully whom to tell about their TB status. Twenty respondents (4.8%) supported the statement that they were afraid of going to TB clinics because other people might see them "Figure 4".

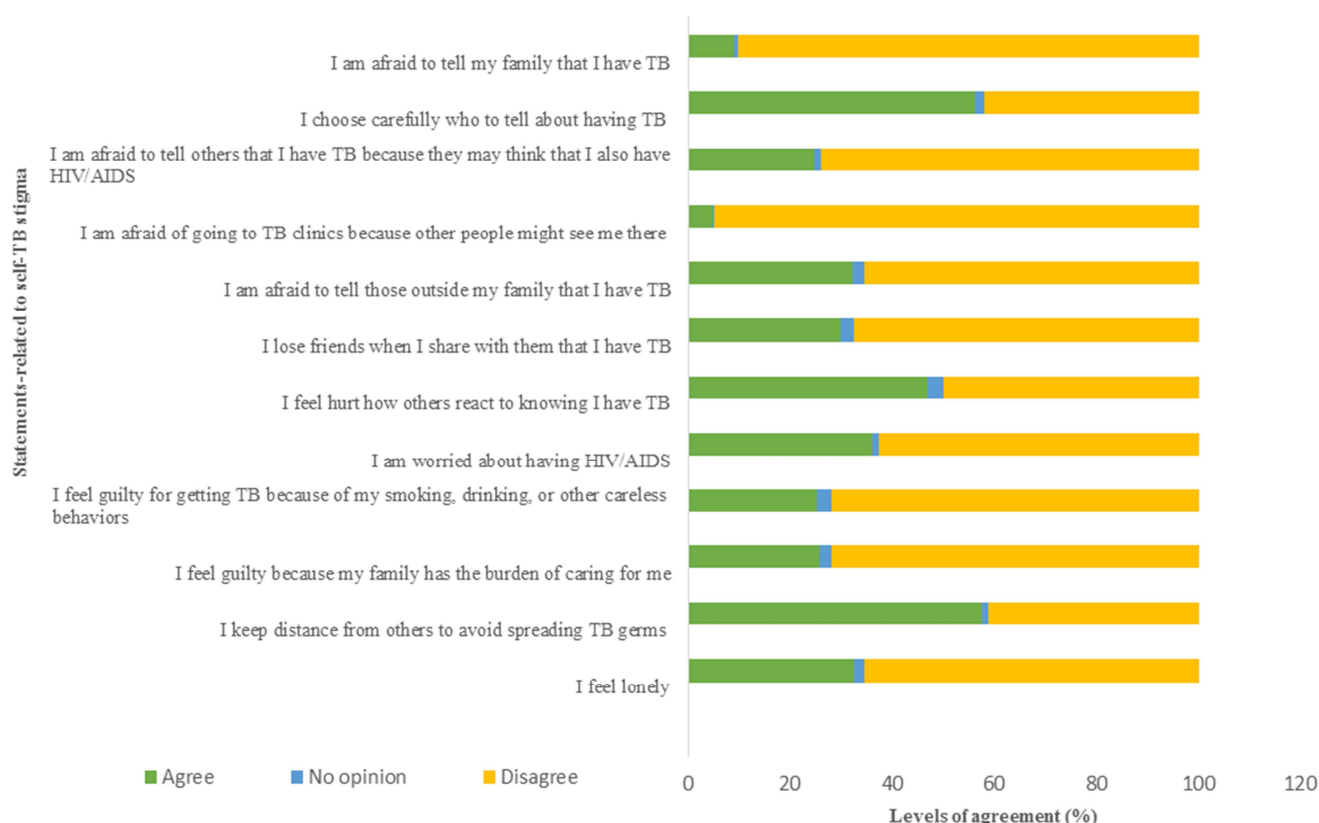


Figure 4. Level of agreement to statements-related to self-TB stigma among PWTB (n = 418).

### 3.3. Manifestations of TB-Related Stigma Among PWTB

During the survey, PWTB were asked to describe their experiences regarding TB-related stigma and how it was manifested. The common manifestations of TB-related stigma are described below:

#### *Social isolation and fear of being infected*

TB patients are isolated by people around them. Family members, relatives, and friends were the main perpetrators of stigmatizing behaviors as they tend to withdraw from interacting with TB patients mainly due to fear of contracting TB as exposed in the quote below

*"After being diagnosed with TB I noticed people were isolating me... my friends and relatives refused to come and see me because they feared I could infect them with TB,*

*some relatives said, I was about to die because I had TB"* (Male, 52 years, PWTB).

#### *Verbal abuse*

TB patients are abused verbally. People around them rebuked, mocked and blamed them for contracting TB as revealed in the quotes below:

*"The first time I was diagnosed with tuberculosis, my aunt scolded me for being sick with Tuberculosis, more often she used abusive language ...and sometimes blamed me for my smoking behaviors ".* (Male, 22 years PWTB)

*"Since I was diagnosed with TB I have been through a lot, I remember being scolded by my boss at work. They told me to stop working for two months, some said I should wear a mask all the time at work. Sometimes my co-workers run away from me every time I entered the office. ...at home my brothers*

*complaining that I had become a burden to them because of my TB status". (Male, 41 years, PWTB)*

#### *Unwillingness to share eating utensils*

TB patients are avoided and maltreated in public eating places as expressed in this quote.

*"... I used to eat at the restaurant in the place where I work and noticed that I was served by the same utensils. One of them was a broken cup for tea which was given to me all the time I visited that restaurant and the day I asked them why I was always given the same broken cup, the response was; that was the cup they set aside for me after realizing that I was suffering from TB". (Male, 25 years, PWTB)*

#### *Gossiping*

TB patients are talked negatively in community. They often be labeled with other stigmatizing diseases such as HIV/AIDS as portrayed in the quote below;

*"My neighbors used to gossip about me, that I had no TB, but rather I had HIV/AIDS. They said don't you see how he is wasted, always people in the streets, when they see someone lost weight, they will just conclude you are HIV/AIDS patient because the community members do not know that, not everyone who has TB also has HIV/AIDS, they know if you have one, then you probably have both" (Male 46 years, PWTB).*

## 4. Discussion

TB-related stigma constrains efforts to End TB. This study is the first of its kind to assess the dimension of self-TB-related stigma and its manifestations among TB patients in Tanzania. We found a moderately high level of self-TB-related stigma at 40%. Our finding is similar to other studies from Wolaita Sodo, Ethiopia (42.4%) [19], rural China (45.3%) [20], Ukraine (47%) [21], and lower than those in Northeast China (50.4%) [22], India (51.2%) [23], pastoralist communities in Kenya (73.6%) [24], and urban Zambia (82%) [25]. The variations in the magnitude of TB-related stigma may be attributed to differences in the characteristics of the study population, settings (Urban versus rural), tools used to assess TB stigma, and study designs.

Moreover, the observed self-TB-related stigma was dominated by feelings of guilt, shame, loneliness, and fear of disclosing TB status. Non-disclosure of TB status, in particular, represents a challenge in TB control as it risks others contracting TB, particularly contact persons such as household members and healthcare workers [26, 27]. Likewise, non-disclosure of TB status restricts access to social and emotional supports during illness, which may cause TB patients delays in diagnosis, initiation of treatment, and adherence to TB drug [28, 29]. Furthermore, the worry that other individuals would learn they have HIV/AIDS added to the fear of disclosing their TB status. The association of TB and HIV related stigma has been observed in other studies [30-32], underlining the greater need of considering the complex role of stigma in the delivery of TB/HIV healthcare in our settings.

Social isolation, fear of contracting TB, verbal abuse, gossip, and unwillingness to share eating utensils are the most

common manifestations of TB-related stigma observed in the current study. Our findings is consistent with results reported among Indian female TB Patients in Kolkata, where the main manifestations of TB stigma were social isolation and avoidance due to fear of contagion, gossip and verbal abuse, failed marriage prospects, and neglect from family [33]. Like wisely, the study conducted in Sekondi-Takoradi Metropolitan District in Ghana reported that due to fear of TB infection, TB patients were shunned, avoided, and advocated being segregated at home and in hospitals [34]. Furthermore, a study in three Asian countries (Bangladesh, Nepal, and Pakistan) showed that TB-related stigma has more destructive gender roles for women, to the point that it gives legitimacy to the rejection of marriage to a woman with TB [35].

Notably, in the present study we observed that most of the stigmatized behaviors were largely perpetuated by close family members, relatives, and friends of TB patients. Given that family members and friends are the primary treatment supporters, a role that is crucial for TB treatment and ultimately TB control efforts as they ensure various supports, including monitoring and supervision of drug in-take, encouraging and empowering patients to take the drugs as expected, providing feeding supports, and supporting TB patients to attend clinics [36, 37], this observation poses a threat to the level of motivation and support that can be offered to TB patients by their family members, underscore the need of involvement of treatment supporters in TB stigma reduction strategies.

This study was not without limitations. Selection bias may have limited our findings due to the convenience sampling of recruited participants, thus limiting generalization. However, the involvement of a broad group of participants in terms of gender, TB types, vulnerable populations, and geographical distribution, as well as the application of mixed methods in data collection, underscore the strengths of the current study to inform practices and TB stigma reduction interventions in Tanzania.

## 5. Conclusion

The present study showed, people with TB had a relatively moderate level (40%) of self-TB-related stigma, which is primarily characterized by behaviors and attitudes that are intended to keep their TB status confidential. Additionally, social isolation, verbal abuse, gossip, and a refusal to share eating utensils with TB patients were some of the most common manifestations of TB-related stigma, largely due to fear of contracting TB. In order to prevent and control TB, stigma-reduction interventions must be included in the national strategy. Future studies should focus to identify and test appropriate interventions for reducing stigma related to tuberculosis (TB) in our settings.

## Consent for Publication

All authors read the manuscript and approved it for publication.

## Conflict of Interest

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

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## Authors Contributions

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

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