

Level, Experiences and Manifestations of Community TB-Related Stigma in Tanzania

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Abstract: *Background:* Tuberculosis (TB) is an infectious disease of public importance worldwide including Tanzania. There is increasing recognition that TB-related stigma is a barrier to TB control and prevention. However, there is a paucity of information about community TB-related stigma in our settings. This study was objected to assess the level, experiences, and manifestations of community TB-related stigma. *Methods:* Between September 2021 and February 2022, a cross-sectional study was conducted to collect quantitative and qualitative information about community TB-related stigma in five regions of Tanzania. Face-to-face interviews were used to collect data among community members using a modified questionnaire to assess community TB stigma created by the Stop TB Partnership. Descriptive statistics and thematic analysis were used to summarize and present findings of this study. *Results:* One hundred seventy-one (171) community members were recruited. The overall level of community TB-related stigma was 71.5%. The TB stigma was mainly characterized by supporting behaviours and attitudes that limit contact with TB patients. Sixty-three percent (63%) of the community members experienced community members being stigmatized because of their TB status. The common manifestations of community TB-related stigma were isolation, mistreatment, being denied supports, and refusing to share housing, eating and drinking utensils. *Conclusion:* This study showed a relatively high level of community TB-related stigma in Tanzania, suggesting the need to include TB stigma reduction interventions in national TB control and prevention response strategies.

Keywords: Tuberculosis, Stigma, Community, Manifestations, Tanzania

1. Introduction

Tuberculosis (TB) is an important public health problem, responsible for significant morbidities and mortalities worldwide including in Tanzania, and an important factor for poverty and poor social and psychological well-being [1–3]. There is an increasingly recognition that TB stigma as a social determinant of health, undermine TB control efforts because it negatively impacts health seeking behavior, engagement in care and adherence to treatment [4–6]. In 2018, the UN General Assembly high-level meeting on tuberculosis endorsed a political declaration to accelerate progress towards End TB targets in 2022, this includes eliminating stigma and all types of discrimination related to TB [7]. Understanding the magnitude and how TB-related stigma unfold in community setting is an integral aspect to reducing its impact on health.

Stigma is the collectively held contempt, and generally inferior and helpless status that society bestows on those who exhibit a particular trait or fall under a specific group or category [8, 9]. Community stigma, in the context of TB disease, refers to a collection of stigmatizing actions, prejudices (i.e., a negative evaluation of people with TB), stereotypes (i.e., beliefs about characteristics associated with people with TB), and discriminatory attitudes (i.e., a belief that people with TB should not be allowed to participate fully in society), which makes TB patients fearful and expect societal devaluation and judgment [10, 11]. Stigmatizing actions includes a range of behaviors, such as exclusion or rejection from social events, avoiding people, and verbal abuse or gossip. When stigmatized people adopt harmful societal beliefs, they frequently experience feelings of guilt, shame, and disgust. As a result, they often engage in avoidance behavior, withdraw from social interactions, and isolate themselves. These behaviors could eventually delay diagnosis, treatment initiation, and treatment completion [12–14]. In addition, it may result in psychological stress, depression, fear, and further deterioration of health [12, 15]. More often, TB-related stigma is driven by fear of TB transmission, inadequate knowledge about TB transmission, myth, cultural believes and misconception about TB disease.

Tanzania is one of the 30 countries with greatest TB burden in the world, with an estimated incidence rate of 253 TB patients per 100 000 people. In 2021, according to the National TB and Leprosy Programme (NTLP) report, treatment success rates for TB were reported to be 96%, exceeding both national and WHO targets, however, about 35% of the TB cases remain undiagnosed [16]. The issue of unreported cases of TB or delayed diagnoses is influenced by many factors, including stigma. Previous studies on the stigma associated with tuberculosis among TB patients in Tanzania have indicated that this stigma is not uncommon, differs for men and women, and is mostly associated to HIV/AIDS, and has a detrimental

impact on how people seek medical care and how well they adhere to treatment [17, 18]. Unfortunately, there is typically a lack of data addressing the extent, manifestations, and scope of TB-related stigma in the community. Hence, as part of efforts to create data to support TB stigma reduction measures and eventually TB control in our settings, this study was conducted to establish baseline data on the highlighted gaps.

2. Methods

2.1. Design, Study Area and Settings

This article is part of a larger study aimed at assessing TB-related stigma and gender-based violence in Tanzania. The study used a cross-sectional design to collect both quantitative and qualitative data from 10 selected communities (wards) in both rural and urban settings across five regions of Tanzania. The regions that were involved are Kilimanjaro, Mwanza, Njombe, Pwani, and Unguja Kaskazini.

2.2. Participants, Inclusion and Exclusion Criteria

This study recruited representatives of community members in the study areas. Before being recruited, participants had to meet the following criteria: they had to have resided in a particular community for at least six months, and they had to fall into one of the following categories: community leader, religious leader, community healthcare worker, teacher, or influential community member. Exclusion criteria included refusal to participate in the study and lack of consent.

2.3. Sampling Strategy and Sample Size

Random and purposive sampling methods were used to select study areas and participants. Tanzania has 31 regions: twenty-six (26) regions on Tanzania's mainland and five regions on Zanzibar. In this study, 26 regions of Tanzania's mainland were divided into four zones (east coast, northern, western central, and southern highlands). Likewise, five regions of Zanzibar formed one zone. Simple random sampling was used to choose one region from each zone, which had at least five regions. Selected regions were Pwani, Kilimanjaro, Mwanza, and Njombe from Tanzania's mainland, and Unguja Kaskazini from Zanzibar. By using 2020 TB notification data from NTLP, a list of the top 10 health facilities with higher TB notification rates in urban and rural settings was made for each chosen region. After the creation of lists of healthcare facilities, two facilities were randomly selected (i.e., two healthcare facilities from a rural and urban setting, respectively). As a result, four healthcare facilities were selected for each region, and a total of 20 facilities across all five regions. The areas where the healthcare facilities were located (catchment areas) became the primary study sites. From those health facilities

catchment areas, one ward was purposively selected, making a total of ten wards in all five regions. The selected wards are the ones with the largest number of TB patients reported to their respective healthcare facilities. Conversely, at least 8 representatives of community members from each ward were invited to take part in this study. Finally, the study recruited 171 community members across all study sites.

2.4. Data Collection Procedures

Data collection was carried out by a research team that had received training about the objectives, procedures, and research ethics associated with this study. The regional/district TB and leprosy coordinator (RTLTC and DTLC) and community leaders, particularly the ward and village executive officers, made prior plans to identify and invite possible participants from the community based on the inclusion criteria. On the day of data collection, the research team leader presented the aim of the study, responded to inquiries, and clarified any difficulties brought up in relation to the study before inviting them for participation. Each participant gave their consent before deciding to take part in the study. Face-to-face interview was used to collect data about the stigma associated with TB in the community using a semi-structured questionnaire created by the STOP TB Partnership [9]. The questionnaire was modified to fit context of Tanzania and translated into Swahili. The survey tool included demographic data as well as the Van Rie *et al.* scale to measure TB-related stigma in the community [20]. The survey tool also asked open-ended questions to examine the manifestations, experience, and consequences of TB-related stigma observed in the community. Data were collected and stored using an android-supported data collection system (Open Data Kit-ODK) that were installed on tablets.

2.5. Data Management and Statistical Analysis

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 participant characteristics 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 community were contacted for additional approval. The interview was conducted in an area that ensures privacy, and consent for participation was obtained before the interview.

3. Results

3.1. Social-Demographic Characteristics of the Participants

A total of 171 community members were recruited, with almost similar distribution per region. The majority of the participants 106 (62%) were adults aged between 36-60 years, followed by those who aged 18-35 years and 60 and above years by 33 (19.3%), and 32 (18.7%), respectively. Compared to female, male had slightly higher representation 91 (53.2%). Majority of the of the participants 137 (80%) were married. Half of the participants attended primary education 86 (50.3%), about a quarter of them attended secondary school 41 (24%), and few of them attended university education 9 (5.3%). The primary occupation of 34.5% of the participants were farming and self-employment, respectively. More than half of the participants, 92 (53.81%), made more than TZS 138, 000.00 (\$60.10) per month (Table 1).

Table 1. Socio-demographic characteristics of the participants.

Demographic characteristics	Category	Participants n (%)
N = 171		
Region	Kilimanjaro	34 (19.88)
	Mwanza	33 (19.3)
	Njombe	29 (16.96)
	Pwani	39 (22.81)
	Unguja Kaskazini	36 (21.05)
Age group	18-35	33 (19.3)
	36- 60	106 (61.99)
	>60	32 (18.71)
Gender	Male	91 (53.22)
	Female	80 (46.78)
Marital Status	Single	19 (11.11)
	Married	137 (80.12)
	Cohabit	1 (.58)
	Separated	3 (1.75)
	Widow/Widower	11 (6.43)
Level of education	No formal education	1 (.58)
	Primary education	86 (50.29)
	Secondary education	41 (23.98)
	College education	34 (19.88)
	University education	9 (5.29)
Occupation	Not employed	9 (5.26)
	Farmer	59 (34.5)
	Self-employed	59 (34.5)
	Formal employed	44 (25.73)
Monthly income	< TZS 69,000.00	38 (22.22)
	TZS 69,000 -138,000	41 (23.98)
	>TZS138,000	92 (53.81)

3.2. Level of Community TB-Related Stigma Among Community Members

A set of ten statements that describe the attitudes and feelings that members of the community have about people with TB were used to measure community TB-related stigma. The mean score with standard deviation (SD) was 26.5 ± 4.52 , while the overall level of TB-related stigma in the community was 71.52%. In general, TB stigma was high in the surveyed communities, and people were inclined to limit their contact with TB patients in order to avoid infection. A majority of community representatives, 156 (91.23%),

concurred that they felt uncomfortable around TB patients. One hundred forty (81.87%) of the respondents were inclined to think that some TB patients were disgusting. Most of the participants, 151 (88.3%), supported the statement that they were afraid of those with TB. Most of the respondents were inclined to keep their distance, refusing to eat and drink with, talk with, touch, or let their children play with TB patients. The majority of respondents were likely to have a long-term negative attitude toward people with TB, with 81.29% agreeing that if a person has TB, some community members will treat him or her differently for the rest of their lives (Table 2).

Table 2. Dimensions of anticipated TB related stigma in the community: (N= 171).

Statement	Agree	No opinion	Disagree
Some people might not want to eat or drink with friends who have TB	143 (83.63)	1 (.58)	27 (15.79)
Some people feel uncomfortable being near those who have TB	156 (91.23)	2 (1.17)	13 (7.6)
If a person has TB, some community members will behave differently towards that person for the rest of their life	139 (81.29)	1 (.58)	31 (18.13)
Some people do not want those with TB playing with their children	149 (87.13)	2 (1.17)	20 (11.7)
Some people keep their distance from people with TB	150 (87.72)	2 (1.17)	19 (11.11)
Some people think that people with TB are disgusting	140 (81.87)	1 (.58)	30 (17.54)
Some people do not want to talk to others with TB	120 (70.18)	3 (1.75)	48 (28.07)
Some people are afraid of those with TB	151 (88.3)	1 (.58)	19 (11.11)
Some people try not to touch others with TB	135 (78.95)	6 (3.51)	30 (17.54)
Some people may not want to eat or drink with relatives who have TB	115 (67.25)	6 (3.51)	50 (29.24)

3.3. Experiences of Community TB-Related Stigma

Two-thirds 108 (63.16%) of the surveyed participants affirmed they had witnessed or overheard a member of the community being stigmatized due to their TB status. The most frequent settings where they observed TB patients stigmatized were the hospital and the workplace, as indicated by 63 (42.86%) and 56 (38.1%), respectively. Though in small proportions, TB patients were also observed to

experience stigma in churches, schools, and neighbourhoods. The observed stigma in the setting(s) above was linked to a number of outcomes, such as delaying prompt care seeking 30 (20.13%), delaying treatment initiation 25 (16.8%), and delaying going to Direct Observing Treatment (DOT) facilities 28 (20.8%). Additional effects included poor treatment adherence 19 (12.8%), preventing getting accurate diagnosis 14 (9.4%) and preventing completing treatment 10 (6.7%) (Table 3).

Table 3. Experiences and consequences of community TB-related stigma.

Question	Frequency (percent)	
Have you seen or heard a member in your community who had TB being stigmatized because of his or her TB status? N = 171	Yes n (%)	No n (%)
	108 (63.16)	63 (36.84)
In which setting (s) were they stigmatized? n* = 147	Yes n (%)	
Hospitals/clinics	63 (42.86)	
Community/neighbors	14 (9.52)	
Workplace	56 (38.1)	
School/college	8 (5.44)	
Church/mosque	6 (4.08)	
Did the stigma observed in the aforementioned setting (s) inhibited a community member with TB on the following? n* = 149	Yes n (%)	
Recognizing symptoms	15 (10.07)	
Seeking timely care	30 (20.13)	
Going to a DOT facility	28 (18.79)	
Getting an accurate diagnosis	14 (9.4)	
Beginning treatment	25 (16.78)	
Adhering to treatment	19 (12.75)	
Completing treatment	10 (6.71)	
Getting post-treatment follow-up services	8 (5.37)	

n* represents the number of response frequencies in the specific question

3.4. Manifestations of Community TB-Related Stigma

Being neglected and denied help, refusing to share housing, eating and drinking utensils, and losing one's job are just a few ways that TB stigma manifested. The fear of TB transmission is what motivates these stigmatizing behaviours, which were mostly perpetuated by close family members and their neighbours as described below;

Neglecting and denying support

Close family members, even parents frequently stop being supportive of TB patients for fear of contracting TB. Likewise, TB patients sometimes experience neglect and denial of basic needs like food, as illustrated by the quotes below:

"I witnessed my neighbours who was infected with TB starving for a long time because some of his relatives were afraid to send him food due to fear of contracting TB. Only his son was sending him food, when the son was not around, he was not given food by any other relatives" (Male, 38 years, Community representative).

"My brother contracted TB away from home. When our father was told that his son is suffering from TB, he completely refused to return home... so his sister transported him to her home and took care of him for nine months. After recovering he returned to his parents but four months later, he contracted TB again and his father expelled him from home. The patient returned to his sister where he was treated and so far, he is doing quite well". (Female, 46 years, Community representative).

Isolation and refusal to share accommodations and eating utensils

TB patients become vulnerable to mistreatment and are avoided and isolated in a variety of ways, including by refusing to share accommodations and eating utensils because they are thought to be contagious, as portrayed below;

"I witnessed my grandmother being stigmatized with my fellow family members where her room and utensils were separated from others. (Male, 52 years, Community representative).

"I witnessed my grandmother being stigmatized with my fellow family members where her room and utensils were separated from others. The family members also avoided the mat that was used by the grandmother for fearing to be infected with TB". (Male, 43 years, Community representative).

"... When my younger sister had TB, she was hated by her family members, they set her a room, she was also given her own food utensils, and they did not want to approach her for fear that she would infect them. Some members of the community also began to isolate her, and as she approached them, they were running away from her for fear that she might infect them with TB" (Woman, 39 years, community representative).

"When I was in my grocery, I witnessed my client being stigmatized by other customers, they did not want to sit next to him and even the glass he was using to drink beer other customers did not want to use it afterward. Also,

they wanted me to throw away the glass used by that man because they thought they might become infected with TB" (Female, 37 years, Community representative).

Loss of job

TB patients are likely to lose their jobs during the course of their treatment. People avoid doing business with them as witnessed below;

"The man was running a restaurant business, when customers found out he was taking TB drugs, they stopped eating from his restaurant, as a result, this led to the closure of the business" (Male, 48 years, Community representative).

4. Discussion

TB-related stigma is the significant barrier to TB control and thus deserves equal attention. The current study assessed the level, experiences, and manifestations of community TB-related stigma in Tanzania.

In this study, an estimated level of community TB-related stigma was as high as 72%. This finding is comparable to those from other studies conducted in various regions, including India (73%) [21], Ukraine (70%) [22], Ghana (60%) [23], and Cambodia (51%) [24]. Nevertheless, they are lower than those from Lagos, Nigeria, both in the rural and urban communities, by 93% and 95.7%, respectively [25]. The variations in the magnitude of TB stigma in the community could be explained by differences in sample sizes, participant characteristics, and type of tool that were used to assess stigma. In this study, we utilized the Stop TB Partnership's developed and recommended tool to assess TB stigma, which includes a validated Van Rie scale to assess TB stigma in the community [19, 20]. In addition, the majority of respondents ($\geq 80\%$) agreed with stigmatizing statements encouraging decreasing interaction with TB patients, including refusing from talking, eating, or drinking with them and forbidding their kids from playing with them. However, similar resentments toward TB patients have been reported in a systematic review objected to assess TB stigma and its effects [26].

Among all the respondents, 108 (63%) had experienced seeing or hearing a community member stigmatized because of their TB status. As a result of TB-related stigma, TB patients were prevented to seek medical attention promptly (20%), Visit DOT facilities (18.8%), receive an accurate diagnosis (9.4%), start treatment (16.8%), and adhere to treatment (12.8%). These consequences mirror previous study findings that have been published elsewhere [27–30]. In addition, experienced TB-related stigma was mostly perpetuated by close relatives and neighbors. Family members typically help TB patients' treatment, therefore their participation in stigmatizing TB patients calls attention to the level of motivation and quality of supports that they might be able to offer throughout the course of TB treatment. The roles of treatment supporters in TB treatments have been shown to be much more crucial. These roles include making sure the patient takes the TB medications regularly, on schedule, for the entirety of the treatment, listening to and

encouraging the patient, providing support for feeding (when there is no food or a means to eat), and covering travel expenses to the TB clinic when necessary [31, 32].

Mistreatment, denied supports, refusing to share housing, eating and drinking utensils, isolation, and losing one's employment were the main revealed manifestations of TB-related stigma in this study. Similar findings, including verbal abuse, loss of marriage or marital prospects, and forced absence from school, were also documented in the community study to explore TB-related stigma and consequences among Indian female TB patients in Kolkata [12]. As reported elsewhere [33–35], manifestations of TB-related stigma stem from the concept of exaggerated contagiousness and the fear of contracting TB.

This study was not without limitations. Selection bias may have impacted our findings due to the convenience sampling of community representatives, thus limiting generalization. Also, there was a chance of socio-desirability bias because the study assessed stigmatizing attitudes and behaviours toward TB patients. However, this study presents an important piece of evidence about the magnitude and pattern of how TB-related stigma unfolds in Tanzanian communities to inform TB stigma reduction interventions.

5. Conclusion

This study showed a relatively high level of community TB-related stigma in the community, which was defined by behaviors and attitudes to avoid contact with TB patients and was primarily motivated by fear of contracting TB. This suggests the necessity for the national TB response to include stigma-reduction interventions. These interventions should be contextualized and developed through community engagement. Future research should continue to measure the levels and dimensions of TB-related stigma among key TB populations through behavioral surveillance using standardized tools.

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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