



Quality of Tuberculosis Services Assessment in Uganda

Report on Qualitative Findings

June 2020



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Cover

Conducting the QTSA survey outside a health facility in Uganda. Photo: Jeanne Chauffour

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ABBREVIATIONS

CHWV	community health worker and volunteer
FGD	focus group discussion
HC IV	health center level four
MLI	Makerere University Lung Institute
NTLP	National Tuberculosis and Leprosy Programme (Republic of Uganda)
PWTB	people (or person) with tuberculosis
QTSA	Quality of Tuberculosis Services Assessment
TB	tuberculosis
USAID	United States Agency for International Development
VHT	village health team
WHO	World Health Organization

EXECUTIVE SUMMARY

This report describes findings of a qualitative study on tuberculosis (TB)-related stigma among community members from two regions in Uganda. This research is part of a broader Quality of Tuberculosis Services Assessment (QTSA) conducted in Uganda in 2019 that also includes findings on TB-related stigma from the perspectives of healthcare workers and TB patients. The QTSA was conducted by MEASURE Evaluation, which is funded by the United States Agency for International Development (USAID), in collaboration with the Uganda National TB and Leprosy Programme (NTLP), and implemented by the Makerere Lung Institute—a local research organization at Makerere University’s College of Health Sciences that was contracted by MEASURE Evaluation. Details of the Uganda QTSA are presented in a separate report available at the following link: www.measureevaluation.org/resources/publications/tr-20-398/

Stigma is a recognized challenge affecting prevention, diagnosis, treatment, and care of infectious diseases, including TB. Studies show that social stigma associated with disease makes it more difficult for patients to get the treatment they need and to stop the chain of transmission (Datiko, Jerene, & Suarez, 2020; Craig, Daftary, Engel, O’Driscoll, & Ioannaki, 2017). Craig, et al. (2017) conclude that stigma is a social determinant of health that can affect health-seeking practices and illness management. Stigma associated with TB is shown to cause delays in care-seeking and TB diagnosis, and discontinuation of treatment (Cremers, et al., 2015; Macfarlane & Newell, 2012). Stigma is a complex social construct shaped by inadequate knowledge and information about modes of transmission, care, and prevention and is exacerbated by the inadequate availability of TB services and low-quality services, especially in rural areas. In Uganda, despite initiatives to implement effective TB prevention and treatment strategies, stigma still manifests as a significant barrier (Macfarlane & Newell, 2012).

Objective

This qualitative study explored community-level knowledge, attitudes, and perceptions of TB-related stigma to inform the NTLP to design interventions to improve TB prevention, diagnosis, and treatment in Uganda. The study had the following objectives: (1) assess the causes of TB-related stigma; (2) document the manifestations of stigma; (3) determine the perceived effects of stigma on treatment-seeking behavior; and (4) provide evidence-based recommendations to address stigma and discrimination toward people with TB (PWTB) at the community level.

Methods

Eight focus group discussions (FGDs) were conducted at randomly selected health facilities with adults (ages 18–50 years) who reported never having had TB treatment, who visited or accompanied someone else to the health facility outpatient department on the day of the assessment (for services unrelated to TB), and who were willing to participate in a FGD for the study. For this research, the responses of non-TB patients were used as a proxy to understand knowledge and stigma related to TB at the community level. Participants represented both sexes and urban and rural populations. The randomly selected health facilities were located in the Central and Northern regions of Uganda and also participated in the quantitative data collection for the QTSA.

The tool used to conduct the FGDs is a FGD guide available at the following link: <https://www.measureevaluation.org/resources/publications/tl-20-79/>

Results

FGD participants reported that they often witnessed PWTB being insulted, ridiculed, discriminated against, socially excluded, and isolated. Findings further demonstrated that stigma is a common phenomenon in both urban and rural settings, among all age groups, and regardless of sex. FGD participants revealed mixed knowledge and understanding of TB. The perceived danger of acquiring TB symptoms was usually the basis for stigma, and stigma toward individuals was expressed as a means of distancing oneself from risk.

TB was also closely linked with the acquisition of HIV and the perceived immoral behavior of individuals with HIV/AIDS. HIV/AIDS was perceived to be hereditary, incurable, and connected to different blood types and stereotypes about TB etiology. These perceived associations with TB fueled the stigma and discrimination the community directed toward PWTB. Participants shared that healthcare providers asking caretakers to separate TB patient from other family members at home contributed to discriminatory community attitudes toward PWTB.

Participants believed that the stigma experienced by PWTB resulted in low self-esteem. They also thought that some PWTB might avoid or delay visiting the facility for TB screening or treatment because they were fearful of knowing their TB status and experiencing stigmatizing behaviors from healthcare providers.

However, despite evidently overwhelming stigma, study participants still observed the moral obligation to care for PWTB, and the FGDs showed that particular forms of isolation of PWTB were not socially or culturally acceptable.

Recommendations to Address Stigma

This study adds to the understanding of the breadth and scope of stigma associated with TB in Uganda, the thought processes through which TB-related stigma arises, and how different forms of TB stigma are manifested. The study findings show that current efforts to reduce stigma are not yet optimal and that stigma presents a strong barrier to effective TB programming. Close examination of why communities react in a particular way—and why some community members stigmatize and others do not—is one way to address stigma and is an essential part of any strategy that seeks to tackle TB as a public health problem.

The findings indicate a clear need for increased **health education and community mobilization** around TB. Community-level resources such as village health teams (VHTs), community health workers or volunteers (CHWVs), village leaders, religious leaders, etc., should be leveraged to carry out both community-wide education and health communication campaigns as well as one-on-one mentoring to PWTB. The community-wide education and health campaigns, led by trusted members of the community, would help to positively change community perspectives and the individual mentoring could help PWTB to better understand and manage their illness, as well as equip them to cope with instances of stigma and discrimination.

Improved awareness and knowledge of TB among community members would address misconceptions and misunderstandings. Hence, implementing **TB outreach activities**, particularly in rural areas with limited access to TB care services, could help combat stigma. Strengthening the work of VHTs and CHWVs to increase the ability to access services outside of the formal medical system will reduce access barriers for PWTB while also minimizing the potential to experience stigma or discrimination that they feel may be associated with being seen at the health facility.

Finally, **additional qualitative research** inclusive of other perspectives on TB-related stigma, particularly from current and recovered TB patients, can provide clearer insights into the factors associated with TB-related stigma and guide the design of interventions to reduce TB-related stigma within communities across Uganda.

INTRODUCTION

Stigma is often described as a discrediting attitude that leads to rejection, exclusion, or discredit to one's social status and position (Goffman, 2009). Deacon, et al. (2005) define disease stigma as an understanding that identifies and links the presence of a biological disease agent or physical signs of a disease or condition with negatively defined behaviors of groups toward other individuals or groups in society. Craig, et al. (2017) observe that such factors as disease biology and epidemiology and social interactions converge to influence the manner and degree to which a disease is stigmatized. Stafford and Scott (1986) observe that the concept of stigma can be endlessly elastic and can be used to explain a wide range of problems.

Previous studies suggest that stigma can accompany a tuberculosis (TB) diagnosis, with damaging effects. Cremers and colleagues (2015) state that TB-related stigma represents negative attitudes and affects social status. Furthermore, in conjunction with biological, economic, and cultural barriers that hinder effective TB control, stigma remains one of the major social factors causing people with TB symptoms to delay seeking help (Craig, et al., 2017; Cremers, et al., 2015). Nebulous definitions of stigma, combined with its implications for disease and TB specifically call for clarification of what stigma means in relation to TB, how it arises or is constructed, and how it manifests, to allow the development of strategies to reduce its negative impact on society.

Although effective TB prevention, diagnosis, and treatment strategies are available, stigma can be a significant barrier to optimal implementation of the range of activities needed to address the TB epidemic, especially in resource-limited settings. Studies show that social stigma associated with the disease makes it difficult to get treatment and to stop the chain of transmission (Cremers, et al., 2015; Macfarlane & Newell, 2012). TB-related stigma has also been shown to cause delayed care seeking, diagnosis, nonadherence to treatment, and discontinuation of treatment. Stigma should therefore be a key target of any efforts aimed at addressing social barriers to TB prevention and treatment.

The past five years have seen vigorous efforts in the form of policies and programs aimed at curbing the devastating effects of TB. The 2014 resolution of the World Health Organization (WHO) (WHO, 2014) and the 2018 United Nations High-Level Meeting on Ending Tuberculosis (WHO, 2018) approved The End TB Strategy, which aims to reduce TB deaths by 95 percent and cut the incidence of new cases by 90 percent between 2015 and 2035, while also ensuring that no family is burdened with catastrophic expenses due to TB. However, the vision of The End TB Strategy will not be achieved unless stakeholders address the barriers to diagnosis and treatment, including community-level stigma and discrimination. Therefore, understanding TB-related stigma in the general population, especially families and community members (often non-TB patients) who patronize healthcare services, will guide program managers and policymakers to design policies and interventions that support prompt diagnosis and treatment adherence and minimize the negative effects of stigma.

Understanding the breadth and scope of TB stigma in Uganda, and why Ugandans react to TB the way that they do, is essential to any strategy that seeks to tackle TB as a public health problem and improve the quality of care provided to TB patients. To that end, a qualitative component to specifically explore TB-related stigma from the perspective of community members was added to the Uganda Quality of Tuberculosis Services Assessment (QTSA). This component complements the quantitative findings in the QTSA on TB-related stigma from the perspectives of healthcare workers and TB patients. Both quantitative and qualitative

components of the QTSA were conducted from September to December 2019 by MEASURE Evaluation, which is funded by the United States Agency for International Development (USAID), with Uganda’s National TB and Leprosy Programme (NTLP) and implemented by the Makerere Lung Institute (MLI)—a local research organization at Makerere University’s College of Health Sciences that was contracted by MEASURE Evaluation. The full Uganda QTSA report, including TB-related stigma findings from healthcare workers and TB patients, can be found at the following link: <https://www.measureevaluation.org/resources/publications/tr-20-398/>

This study explored local perceptions and experiences of TB-related stigma in Uganda through focus group discussions (FGDs) with community members from both rural and urban areas. Specifically, the study aimed to understand community-level knowledge of TB, its perceived causes, and the manifestation and consequences of TB-related stigma, and to identify strategies to address the negative effects of stigma on health-seeking behavior.

The way that stigma is defined by a particular community structures the understanding of how it operates in a specific setting and affects how best to address it. Here, the term “stigma” refers to what people do, say, or believe that creates a negative environment where people with TB, or with symptoms indicative of TB, are not able to respond rationally to access diagnosis, treatment, care, and to engage in other social interactions.

This report provides more detail on the qualitative findings from non-TB patients collected as part of the QTSA. It provides important insights on how TB stigma is understood in Ugandan sociocultural contexts, including how it arises in the community, why some people stigmatize and others do not, and how stigmatizing beliefs and actions at the community level can be addressed to promote TB prevention and care-seeking behaviors. The findings will help guide the development of interventions to address stigma as a barrier to high-quality care.

More information on QTSA, including reports on and tools used in the assessments in other countries, may be found at the following link: <https://www.measureevaluation.org/our-work/tuberculosis/quality-of-tb-services-assessments>

METHODS

The qualitative component of the study was conducted in two regions, selected from the 10 regions included in the QTSA. Eight FGDs with non-TB patients were conducted in four randomly selected health facilities: two hospitals representing urban settings (one in the Northern Region and one in the Central Region), and two health centers level four (HC IVs) representing rural settings (one in the Northern Region and one in the Central Region). Four FGDs were conducted with men and four with women, each with 10 to 12 participants, ages 18–50 years.

The tool used to conduct the discussions with community members is a FGD guide developed by MEASURE Evaluation and the MLI in collaboration with the NTLP. The guide includes questions and prompts relating to four major themes: (1) knowledge and local perception of TB, (2) dimensions of TB stigma, (3) perceived treatment seeking for TB, and (4) prevention and control of TB. The FGD guide is available at the following link: <https://www.measureevaluation.org/resources/publications/tl-20-79/>

FGD participants were individuals who reported never having had TB treatment, who visited or accompanied someone to the health facility outpatient department on the day of the assessment, and who were willing to participate in a FGD for the study. For this research, the responses of these non-TB patients were used as a proxy to understand knowledge and stigma related to TB at the community level. These FGD participants were also asked how they thought knowledge and stigma might affect TB control in Uganda.

Some questions were meant to elicit participants' perceptions of the stigma and discrimination that people with TB (PWTB) experience, so the responses were based both on observed stigma and discrimination toward PWTB and the participants' perceptions of what PWTB experience. Some participants may have had family members, friends, or neighbors who were infected with or affected by TB. The discussions lasted one to two hours and were conducted in two local languages (Luganda in the Central Region and Luo in the Northern Region). All responses were audio recorded. Discussions were transcribed into English for thematic analysis. Codes based on the study objectives and research questions were developed to capture thematic patterns, and the research team conducted deductive coding using the ATLAS.ti software. The outputs of the coding process were then reviewed for similarities and differences within and among groups, analyzed, and synthesized into key findings.

LIMITATIONS

This qualitative study had several limitations. The findings are not transferable given that they were based on eight FGDs that were conducted in locations in two regions of Uganda, limiting the range of perspectives and cultural norms. Because this research was part of a larger facility-based study, the sample was further limited by the fact that participants selected to take part in the FGDs were men and women who were accessing non-TB related services at the health facilities included in the study. Community members who regularly access services at the health facility could have different perspectives on the stigma associated with TB disease compared with community members who seldom use health facility services. Moreover, findings about stigma in this study were limited to the viewpoints of community members who were not PWTB. Although this population can provide very useful insights on perceptions of TB at the community level, our sample does not give a full picture of TB-related stigma experienced by PWTB.

RESULTS

This qualitative component of the QTSA explores community-level knowledge and perceptions of TB-related stigma and the implications of this stigma for prevention, diagnosis, treatment, and care in Uganda. The study had the following objectives: (1) assess the causes of TB-related stigma; (2) document the manifestations of stigma; (3) determine the perceived effects of stigma on treatment-seeking behavior; and (4) provide evidence-based recommendations to address stigma and discrimination toward PWTB at the community level.

Causes of TB-Related Stigma

Knowledge and Perceived Causes of TB

Participants demonstrated a mixed understanding of TB disease. Visible symptoms, such as weight loss, progressive physical deterioration, prolonged coughing, bloody sputum, and the chronic nature of the condition, all contributed to social perceptions of TB. TB was also understood as a disease that evolves from other diseases or conditions. It was thought to originate from various sources, including animals—e.g., by associating with cats and coming into contact with animal fur or hair—which were believed to cause a prolonged cough that often did not respond to treatment. Rather than perceiving the persistent cough as a symptom of TB, the common understanding among participants was that persistent cough *causes* TB.

FGD participants revealed a common perception that TB has different “strains” characterized by different types of coughs: a cough with mucus (*akakololo ak’olumuzi*), a prolonged, persistent cough (*akakololo akakalakiiro*), an incurable cough (*akakololo akatawona orakakongoliro*), and a kind of cough associated with corncocks because it was thought to sound like the persistent cough of a person with pieces of corncock stuck in the back of his or her throat (*okukotyonka*).

Participants also attributed TB infection to the varying strengths and weaknesses of individual physical bodies. Some bodies were perceived to “fear” disease more than others. Similarly, some blood types were perceived to be more resistant to TB than others. People with blood type O were perceived to be more resistant to TB than others.

It depends on the strengths of blood in different people. Some blood types are stronger than others. . . . We hear people with blood type O are more resistant to diseases. People’s blood also has different weights. . . . For example, the blood of younger people is heavier and stronger than that of the older people. [Male FGD, Central Region HC IV]

TB was also perceived to be hereditary.

What I know is that TB “walks” [passes on] through blood, as is the case with cancer. If someone says that he/she has cancer, people will start saying that the children of that person will also have cancer. This may be the same with TB; if the parents have the disease, the children also will get it. . . . Some people bear children when they are infected; therefore, TB can be transmitted from mother to child through blood. [Male FGD, Northern Region hospital]

Some participants, especially in Northern Uganda, mentioned the shortage of antiretrovirals as responsible for TB acquisition among people living with HIV.

A few years back, my sister was a TB patient, but she started with HIV and AIDS. She was taking ARVs [antiretrovirals] for a period of four to five years but missed out some of her refills because of lack of medicines here in [name of facility]. At one stage, her condition deteriorated, and when she tested she was found with TB and was started on the TB treatment, and kept taking the HIV medication too. [Male FGD, Northern Region HC IV]

TB was also believed to be caused by cold weather.

Especially when the weather is cold, their cough always increases, as if someone is there pumping it through their throat. That is why, especially at night, they wear heavy clothes, cover themselves in a blanket, or wear a jacket even when it is hot . . . meaning that TB patients always feel cold and during cold weather it becomes worse. [Male FGD, Northern Region hospital]

Certain economic activities were perceived to be causes of TB. *Boda-boda* (motorcycle taxis) were perceived as a risk factor because they expose the riders to “excessive” wind and dust that make their lungs congested, thereby “causing” TB.

Most of the TB patients I have seen were once boda-boda drivers. . . . They also swallow lots of things including insects [germs] that cause TB in the process of riding a boda-boda, which can cause TB. TB patients usually feel cold even when it's hot, and for that reason, they are always putting on jackets, which most boda-boda drivers do. [Male FGD, Central Region hospital]

Other forms of contamination believed to cause TB involved polluted water or food.

Drinking water from the roof of the house with colored or rusted iron sheets, or with a lot of dust, may cause endless coughing that may result in TB. Water from such iron sheets is contaminated, not clean, and not safe for human consumption. [Male FGD, Northern Region HC IV]

TB was perceived as a curse because PWTB have to follow specific instructions and are often restricted from doing certain things or moving to specific places.

Those patients are told not to eat particular foods by the health workers. They are told to stop drinking, smoking, eating certain foods of their preference, or not go to places of their choice, . . . stopped from doing things that make one happy. They are advised to eat other foods and drink certain things not of their preference. This means that the TB patients are cursed because what they are told to not do by the health worker are not things they would like to miss as individuals. [Male FGD, Central Region hospital]

TB was perceived as a disease of unfortunate, cursed people, or the poor in the community. The understanding was that when one was cursed or subjected to an ill omen, one was frequently attacked by persistent and repeated coughs that were believed to turn into TB. Being cursed was also associated with a

lack of appropriate information about the disease. Because TB manifested in the form of different unexplained symptoms, in some cases, it was also interpreted to be witchcraft:

You just start suffering unclear complications that cannot be explained, then you start losing energy and your life starts deteriorating, [there is] swelling of the different parts of the body, high fevers, difficulty in breathing, pain in the chest and other parts of the body, abnormal sound of the cough, general body weakness, sunken eyes. [You] start experiencing loss of weight and growing thinner each day that passes; one looks unhealthy, and the end point is death. . . . So, most people start to think that one is bewitched. [Male FGD, Central Region HC IV]

The general understanding among participants with such perspectives was that whatever disrupted the health of the PWTB was a result of spiritual haunting or failure to perform rituals. Moreover, the persistence of symptoms before getting appropriate treatment led to the belief that TB was incurable, especially among those who rarely visited health facilities.

Some people believe that it is witchcraft because of ignorance. Therefore, the government should deploy its specialists to carry out the diagnosis and sensitization. It should not wait for the patients to come to hospitals. [Male FGD, Central Region hospital]

Participants also said that it would be useful for the public to become aware of TB and take precautionary measures to curb its spread.

Perception of Risk

Across all groups, participants perceived stigma as a process or an act of avoiding, isolating, or discriminating against someone because of that person's actual or perceived risk of transmitting TB. The participants perceived themselves to be at risk of acquiring TB because of their interaction with other people in public places, including TB patients.

Minimal symptoms among some PWTB and inadequate knowledge about TB, in general, were the main challenges participants reported. This made it difficult to know who had TB and who did not, which caused uncertainty. The quote below highlights community members' fears and the recognition that they do not have sufficient or correct information about the disease.

We are not completely safe because we can get TB any time. We are not sensitized on how we can protect, prevent, and control ourselves from TB. We do not have information on how TB can be spread, the modes of its transmission, and how to control and prevent the transmission. So, it is still a very big challenge. Our community members are still at risk of getting that deadly disease. [Male FGD, Northern Region HC IV]

TB was perceived to be transmitted through contact with the sputum of an infected person, breathing in air contaminated with TB germs, contact with the saliva of a PWTB, and sharing drinks, utensils, clothes, linens, and other domestic items. These views were similar in both the Central and Northern regions.

In rural areas like here, TB easily spreads because rural people share drinks. For instance, when taking alcohol, men drink from the same glasses or gourd when having beer, those who smoke share cigarettes. . . . This is unlike the urban areas where each person can buy [his or her] own drink. [Male FGD, Central Region HC IV]

In Northern Uganda, where meals are communal, with food, water, and beer shared from the same container, PW/TB were discriminated against because the disease was perceived to move and spread through physical contacts.

Even in social gatherings, we share drinks, and if one has TB, one can easily transmit it because, at this point, no one knows if someone has TB. If the TB patient breathes out, the person nearby can also get infected with TB. It is important for people to know when they may or may not get infected by TB—at what stage of the disease may one transmit or not transmit it. [Male FGD, Northern Region HC IV]

When they eat, they avoid getting satisfied because when they start coughing, sometimes they vomit. When they cough, you see their body shaking, and the ribs enlarging and can actually count them. They also feel too much heat in their stomach and other parts of the body. All this can be passed on to you through sharing utensils or being in contact with the infected person, having “weak” lungs, or a “weak” blood type. [Male FGD, Northern Region HC IV]

TB was viewed as a danger and therefore a marker of biological and social differences. This stemmed particularly from perceptions about TB disease agents, modes of transmission, and local manifestations in terms of symptoms. In Northern Uganda, with its history of Ebola, participants likened the risk of getting infected with TB to that of the highly infectious Ebola.

I cannot work with a [PW/TB], because a TB-infected person is as dangerous as the Ebola patient. If a person with Ebola comes around now, I am sure most of us will run away immediately. Similarly, a TB patient will cause the same reaction. We are scared of a [PW/TB] in all ways. . . . When he/she laughs, talks or coughs, comes near you, or gets in contact with you in any way, he/she will infect you with TB. What people do is to make sure that they keep a distance away, even those who may be compelled to work with him/her. Even health workers are not comfortable [around] TB patients. They put masks to protect themselves. [Male FGD, Northern Region hospital]

The perceptions of these symptoms shaped the social processes of isolation whereby people distanced themselves from the perceived danger and risk presented by PW/TB. The perceived danger of acquiring these symptoms was the basis for stigma, and stigma toward individuals became a means of distancing oneself from risk. Similar perceptions were shared in the North and Central regions.

If am forced to work with TB patients then I will automatically discriminate [against] them, and I will keep as much distance as possible. If it's something to be done by two people, I would avoid it or do it alone. Because TB is an airborne disease which may lead to TB infection through close contact with a [PW/TB], it is very easy to breathe in TB-contaminated air, and consequently become infected with TB. [Male FGD, Central Region hospital]

Participants reported similar treatment of PW/TB even in the home environment.

A [PW/TB] is given his/her own room/space to stay alone. They will tell the patient to remain in the room. They instruct him/her not to come out because he/she may infect others in the family and community at large. In some cases, they build another house [for the PW/TB] behind the main house to keep him/her there, far from others, and materials like towels are burnt or thrown in latrines. [Male FGD, Northern Region HC IV]

Participants reported that community members found dealing with PWTB challenging and described difficulties arising from isolating, separating, and even discriminating against PWTB. They further discussed how healthcare providers contribute to stigma by asking caretakers to separate the TB patient from other family members.

We are told to separate everything . . . separate room, separate utensils, separate basins, clothes. . . . But there are things we cannot separate, . . . like the bathrooms, the latrines, . . . and we can still get it through these. [Female FGD, Central Region hospital]

The perception of risk and stigma was also reported to be caused by the behavior of the TB patients themselves.

If you are coughing, you do not have to cough among people, you are supposed to get a handkerchief or a piece of paper, and you cough when you have covered your mouth so that you do not spread it to the people around. Secondly, you are not supposed to cough in places where there are many people or public places. You are supposed to go somewhere [where] you are alone or find a private place so that you can cough from there and not spread the TB germs to others. But some TB patients behave as if they want to transmit their disease to others, . . . which makes it difficult to help them. I know one who used to mix his sputum in edible stuff like porridge and other foods and then shared with children. Sometimes, he would cough while among other people deliberately to spread TB. [Male FGD, Central Region hospital]

The participants' perceptions of the risk of contracting TB were largely related to the perceived modes of transmission of the disease. Participants associated negative attributes with TB disease because TB has negative effects that they wished to avoid.

Participants' knowledge about transmission revealed a mixed understanding of TB disease. The results showed that the participants knew the correct mode of transmission but that this understanding was mixed with incorrect information. However, the discussions revealed that there was a clear interest in the community learning more about the modes of transmission and how to prevent TB.

Manifestation of TB Stigma

TB stigma was found to take different forms and varied in breadth and scope. Some people were stigmatized; others were not, and different forms of TB stigma emerged in social contexts. Participants described various forms of stigma present in their own beliefs and actions and the words and actions of others toward PWTB or suspected PWTB. TB stigma was commonly characterized by a combination of observable physical characteristics and behaviors. Certain stigmatizing behaviors were described by the participants as reactions to antisocial tendencies of some PWTB, such as the propensity of PWTB to isolate themselves from the community. This was often a result of instructions from healthcare workers for PWTB to refrain from being in close quarters for extended periods with others but misunderstood by family and community members and leading to more widespread fear of the disease. Participants reported that as a result, people who did not have TB often avoided, isolated, or neglected an individual or group of PWTB through actions and words that did not accommodate or tolerate their condition.

According to the FGD participants, the experience of stigma varied depending on one's home environment, source of income and workplace, ability to access care, and sex. Moreover, different terms were used to describe

the varied experiences of stigma. Some social settings were associated with a more widespread manifestation of stigmatizing beliefs and actions than others, and stigmatization occurred in many different ways.

Terminology

FGD participants expressed stigma through the local names, labels, and phrases used in the community to describe TB. Most participants reported that it was not common for someone to simply start abusing PWTB or use demeaning terms in reference to TB as a condition. However, they also explained that there were situations where some people undermined PWTB by using certain labels or words. These terms, phrases, and sayings specific to Uganda were used to describe TB as a biological condition, PWTB themselves, and the activities and relationships with which PWTB are associated. In the Northern and Central regions, it was common for people to refer to PWTB by their condition.

TB was described with terms that portrayed it as a dangerous, widely spread, disease of immoral people. The terms and phrases used by community members were illustrated by the participants when asked to talk about the local understanding of TB as a disease. It was referred to as something that burns like fire (*aekibabu*), something complex and dangerously widespread (*nawokeera*), or as a “disease of these days” (*obuhwaddde bwe nakku zino*), a phrase commonly used to refer to HIV, which implies a perceived close association between TB and HIV. TB patients were described as dismantled engines (*kayingini kayiika*), implying that they were useless in life. PWTB were also referred to as a moving corpse or “walking dead” (*yaffa’ dda*). The understanding was that PWTB can easily die because the persistent cough destroys one’s lungs.

If you get TB, it means that your time to die has come, because your lungs can tear up any time because of the strong coughing all the time. . . . In fact, one is just a moving corpse.
[Male FGD, Northern Region HC IV]

Similar descriptions were used in the Central and Northern regions.

As they walk, you see no signs of life in them. . . . They look very worried and look as if they have given up on life. They do not have strength, they are very weak, very emotional, some of them do not greet or talk to anyone. When you talk to them, they are very rude. At home, they do not think of going to the garden like other people, or do other simple things at home, they do not try to be productive in any way. Their minds are very preoccupied by the illness, and loss of hope. They often fail to get sleep all day and night for days, coughing . . . coughing and spitting bloody sputum in a rotten form. It is these conditions that make them get a negative thinking of preferring to die or spreading the disease to others. [Male FGD, Northern Region HC IV]

Other terms related to physical appearance and the perceived experiences of PWTB. PWTB were referred to as cartoons (*kakokoolo*), and religious people associated the cartoon-like appearance of PWTB to “Satan”—someone who was perceived to be a “sinner.” PWTB were also described as being sickly (*lunnuma*) or as having stepped on burning charcoal (*yalinya ku hyanda*). The other related saying was *kamuyoola*, meaning that the TB bacteria “picked” him or her. *Kamuyoola* is actually the phrase commonly used to refer to people living with HIV or AIDS—TB patients were reportedly given the same label because they were perceived to also be HIV patients, thereby confirming the perceived connection between HIV and TB.

It is difficult to find a person suffering from TB alone. Those people are in most cases battling HIV/AIDS too. [Male FGD, Central Region hospital]

Other language used had the intent of undermining PWTB—the term *kateyamba* (one who is helpless) described PWTB as no longer able to do certain things. Questions such as, “Have you also managed to do such and such a thing or go to such and such a place?” insinuated that PWTB were not supposed or expected to have the ability to do certain things or go certain places. Expressions shunning responsibility were also common: “Am I the one who infected you with TB?”

Asked why stigmatizing phrases and terms were used to refer to PWTB, FGD participants reasoned that although the terms and phrases may be stigmatizing, in some instances, using them was an attempt to alert others about one’s dangerous condition without “hurting” the affected person by directly referring to their condition; the idea was simply to be “polite.”

We use such language or phrases to keep off the outsiders in our community. If you are not part of us, you will most likely not understand what we are communicating amongst ourselves. It is a way of informing other people to be aware of the danger or prevailing situation to avoid a problem. It is a “polite” or indirect way of avoiding direct stigma and scaring one off by referring to their condition directly. [Male FGD, Northern Region HC IV]

In the FGDs, the condition of the PWTB’s body, along with that person’s activities and social interactions, influenced the terms used.

Physical Appearance and Presentation Associated with TB Stigma

One commonly expressed idea was that PWTB were often not well-dressed, which was taken to indicate that the person was too ill or otherwise troubled (or *just not able*) to take care of him or herself.

Other signs and symptoms of TB are abnormal dressing during normal weather conditions. For example, men with TB usually dress in more than one shirt plus a jacket on top of that, [even] during very hot weather conditions. I think it is because they are feeling coldness all the time due to their health condition. [Male FGD, Central Region hospital]

The response from a male participant to the question, “What bodily/physical difficulties/challenges do individuals with TB usually experience?” illustrated the community perspective on the physical appearance of PWTB and the common association of appearance with TB stigma.

The problem with many of the TB patients is that they are not themselves. They look emaciated, weak, and miserable, and often wear oversized clothes. When you are not smart [well-dressed], people may attribute the shabbiness to having TB, but it may also mean you are not a good person yourself. People start questioning why you do not have people—friends or relatives—who can help you get appropriate clothing. If people see you as an isolated person, they say that you are a bad person because how can all people abandon you at once? [Due to] being isolated and not smart, some people are mistaken to be TB patients. But if you are smart and clean, who can think that you have TB? [Male FGD, Central Region hospital]

Some participants had the view that once one had TB, it was difficult to disguise one's appearance.

It is difficult for PWTB to change their physical appearance however smart they may try to be. Once a person looks at a [PWTB], one easily realizes that there is problem, and immediately the mood changes. If one held you in high esteem before knowing that you have TB, that esteem reduces the moment he/she learns about your illness, and this depends a lot on your appearance. [Male FGD, Northern Region hospital]

TB patients are very weak, and they do not have the strength to work. . . . Generally, they suffer bodily weakness and loss of strength to work. Even if they eat a good meal with a balanced diet, still they hardly gain weight, and still look thin. It is difficult to believe that they can be productive or imagine that they can ever do anything in the future. That is one of the challenges we have seen with TB patients. [Male FGD, Northern Region HC IV]

Moral Judgment

In some cases, TB was described as a punishment for “irresponsible” (risky) behaviors, like smoking, sharing drinks, “unnecessarily” interacting with—or failing to avoid—already infected people, or the “immoral” behavior of those who violate social norms. If the “victim” had ever done anything disagreeable to some people, it could be used to blame the PWTB and portray him or her as responsible for the condition. This was especially likely in cases where TB disease was perceived as avoidable; getting infected was linked to one's carelessness or recklessness. PWTB were, therefore, differently stigmatized depending on how they contracted the disease.

To me, being infected with TB means that the patient was once a cigarette smoker. Smoking cigarettes is like inviting TB into your life. Those people who smoke are the ones causing TB to themselves. [Male FGD, Central Region hospital]

TB was perceived to be a disease of young people who engaged in high-risk behaviors. The understanding was that such people got “self-inflicted” TB by ignoring certain vital information and not behaving “appropriately” according to social norms. Connected to this, PWTB were seen as potentially dangerous, and participants related that it was God's plan to make such people sick as a way of “punishing” or “taming” them to stop them from being socially dangerous.

When you suffer from a disease like TB, people start talking bad about you. Some say, “I wonder how and where they got that disease.” They are now a dangerous person. [Male FGD, Central Region HC IV]

In such cases, a TB diagnosis was described as “payback” for someone perceived as socially uncooperative or stubborn. It was seen as a deserved consequence, and PWTB were often neglected, isolated, abandoned, or stigmatized. These perceptions were shared by FGD participants in the Central and Northern regions.

In a few instances, however, PWTB were considered “innocent” because they were perceived to have either contracted TB from public places, like minibuses and hospitals, or from “legitimate” supportive social interactions, such as caring for a TB patient. Some FGD participants also recognized that PWTB may have gotten infected from a family member, rather than their disease being associated with an HIV-positive status.

The negative meanings and social responses associated with TB-related stigma also had a gender dimension. Although both men and women were subject to stigma, men were perceived to be more at risk of getting TB due to the association of TB with smoking and drinking. The perceived risk for women was associated with their exposure to smoke from firewood while cooking, which was thought to be less dangerous than cigarette smoke, and thus, less stigmatizing. However, FGD participants were more concerned for women than for men because of women's role as the primary caretaker for PWTB in the family.

Stigma and Livelihood

PWTB were described as not only suffering the physical effects of the disease, but also as being denied opportunities for employment, their children's schooling, and social interaction in general. Stigma in the form of discrimination in the workplace was also reported. According to FGD participants, most PWTB were isolated or unwilling to work together with their colleagues; and some lost their jobs because of their TB diagnosis. In terms of work, a TB diagnosis symbolized perceived weakness and an inability to perform at expected levels, leading to many PWTB being dismissed from their jobs, whereas others had difficulty finding employment. This was illustrated by a male participant in his response to the question, "Have TB patients you know experienced stigma or discrimination? If yes, in what way have they been stigmatized/discriminated against?"

Some employers are indifferent, just don't care about the conditions of the TB patients, and demand similar output like that of others. [Male FGD, Northern Region hospital]

Participants discussed how knowledge of a person's TB diagnosis by employers and coworkers often resulted in job loss because of either a poor attitude among employers and fellow employees or the physical inability to accomplish tasks properly. The threat of job loss or the inability to gain employment was described as putting immense pressure on PWTB to continue working, despite feeling unwell, to maintain an income.

Stigma at Home

In the home setting, participants reported different modes of isolation associated with having TB. The most common was the fear of contracting TB from sharing bedrooms, eating utensils, cups, glasses, clothes, linens, and other domestic objects. This was described as often leading to stigmatization due to misinformation and unclear instructions from health facilities.

Health workers advise us on how to handle the TB patient, including avoidance and preventing the infection in other people. A PWTB is segregated during mealtime. They eat food separately from other family members; they are made to avoid others, sit alone away from others. The patient does not share plates, cups, etc. with others. After eating, they wash their own utensils and keeps them separate as they are perceived to be infected with TB germs. The person who serves food to the TB patient is supposed to use gloves, which unfortunately are not available in rural areas . . . and reducing other forms of contact with the TB patient. [Female FGD, Central Region HC IV]

According to FGD participants, incorrect information provided by health workers to TB patients or a misunderstanding of information given by health workers to the TB patients often caused PWTB to avoid social interaction.

Some TB patients are very unhygienic, filthy, and look dirty and sometimes smelly, . . . therefore worth avoiding. The practice of TB patients spitting all the time makes some people feel bad about TB patients and therefore avoid them. For instance, when serving food, they are served food last. When it comes to domestic activities, TB patients often get left out using the excuse that they are weak, “dangerous.” [Male FGD, Central Region HC IV]

FGD participants reported that some people at home looked at the PWTB with disgust (*ekyenyinyala*). At home, some TB patients were called grumpy, whiny (*entondo*), touchy and picky, unappreciative and difficult to satisfy, and big-headed (*mputu*). Participants said that PWTB did not want to take their medication and were therefore not easy to care for or support. Other PWTB were reported to be “malicious” or “unkind” for various reasons, including the general misunderstanding by community members of the PWTB’s condition.

One of [the] problems they experience is that we the people without TB do not have trust in the TB patients and do not take what they tell us seriously. . . . When they say that they are strong enough to do something, or not feeling so bad . . . no one believes them, sometimes because of their appearance. At the same time, when they say that they are so weak or feeling bad, some [other] people say they are pretending [and] getting undeserved support, so the whole situation is confusing. [Male FGD, Northern Region HC IV]

It was also noted that the social position of PWTB in the household was important to the process of care. According to the FGD participants, the PWTB who were not closely related to the head of the household tended to suffer more than those who were closely related.

The challenge is when the instructions are to isolate the head of the household—most men do not like this and do not accept it because it compromises their power. [Female FGD, Central Region HC IV]

Various forms of stigma toward current and former PWTB, and caretakers, were reported to occur in the home. Participants reported situations where TB-related stigma spread to family members, friends, and coworkers of PWTB. Those who associated with PWTB were also subject to social stigma and negative reactions from others.

They do not want to marry from the family associated with TB disease. Usually, a family associated with TB disease is avoided, as no one wants to borrow things from them, pay a visit, or have a meal with them, as they are often linked with the curse of being infected with TB. [Female FGD, Central Region HC IV]

FGD participants discussed the experience of a female TB survivor:

After completing the TB treatment, she was engaged. But when her fiancé found out that she was a TB survivor, he stopped the relationship. She felt so bad, got depressed, and it was unbearable for her. Since then, it has not been possible to get proposals from other men who knew a bit of her history of previous TB disease. Now, she is engaged to someone outside this community, but she has not told him that she is a TB survivor. She is afraid of losing him, too, if she tells him. She fears to go through the same experience again. [Female FGD, Northern Region HC IV]

According to FGD participants, stigma was also linked to people living with HIV or those with sickle-cell disease, who were perceived to be PWTB because of their appearance and associated symptoms.

At the same time, participants pointed out that families still observed the moral obligation to care for PWTB. They did not completely isolate PWTB, owing to the fear of inflicting psychological pain on them, and often warned those who seemed to be isolating PWTB. Participants said that discrimination hurt and isolated PWTB. Ideally, the obligation to care for PWTB brought the family and community members together to create and expand opportunities to solve stigma-related challenges.

Some of us, after getting educated about TB from different television programs such as “BULAMU” stopped isolating TB patients in our communities and homes; instead, we support them to secure quality TB care from appropriate health facilities. We accompany them to the hospital for treatment. [Female FGD, Central Region HC IV]

In some settings, well-intentioned interactions to avoid transmission of TB were described as possibly being misconstrued and perceived as isolating or stigmatizing.

It is more difficult to stop children, in particular, from interacting with the TB patient, and in the process, stigma is much more manifested. We have some [PWTB] who think they are not loved, and neglected because of their sickness, and yet family members and relatives care for them but just try to follow the advice given by the health workers. [Male FGD, Northern Region HC IV]

Such responses, in which precautions advised for providing care required some level of distancing and separation, made it difficult to clearly identify stigma in the caregiving process.

Perception of Facemasks

Part of TB stigma originated from what people saw at health facilities. Participants reported perceived stigmatization of TB patients by healthcare providers, specifically related to their use of masks around TB patients. Use of a facemask at the health facility, or even at home, induced stigma. The understanding was that giving TB patients masks was an indication that they were infectious and, therefore, worth avoiding. FGD participants pointed out that PWTB were only helped when others did not know that they had TB. A facemask was a clear indicator of TB status, and the moment people saw it, they rejected the person wearing the mask.

Health workers who treat TB patients, they usually cover their nose and mouth because of fear of transmission just in case the TB patient coughs and the air in the room is contaminated. When PWTB go to the health facilities and they start coughing nonstop, the health provider goes away and comes back with a mask on, or can tell the TB patient to get out. If health providers can fear infection, how about us? [Male FGD, Central Region HC IV]

TB patients with masks were referred to as “cartoons” (*akakokoolo*), and the mask was perceived as worsening the condition of the TB patient. The local understanding was that the more the PWTB breathed out the “bad air,” the faster they were supposed to recover. With the mask on, the bad air circulated back into the body, increasing the disease. This understanding made it difficult for PWTB to use masks, as may have been recommended by the health providers.

Self-Stigma

Participants reported that PWTB sometimes stigmatized themselves.

When TB patients cough, others look away, leave the place, . . . which makes them feel bad. [PWTB] tend to feel bad; some lose hope. . . . Your people leave you. . . . A person can have many friends before, but after getting infected with TB, all his friends disappear and are nowhere to be seen. Even on buses, they isolate you. . . . You are usually alone. Even pastors fear to touch you, they pray for you from a distance. [Female FGD, Central Region HC IV]

A similar observation was made in the Northern Region.

Being infected with TB means getting into another type of life. When most people acquire TB, they tend to develop many thoughts and always worry about dying sooner than they had to. They are always fighting with themselves. . . . The worried patient starts losing weight and suffering other complications, and this makes his relationship with the rest of the family members difficult. [Male FGD, Northern Region hospital]

Participants attributed changes in PWTB's daily life to worries, uncertainties, and side effects associated with TB disease and its treatment, such as weakness, fatigue, or emotional disturbances (e.g., mood swings, irritability, being touchy), the lengthy period of treatment, and a lack of proper information about TB transmission, treatment, and prognosis among family members.

Most TB patients are very emotional because they are rejected in life and are not hopeful in any way. They may not be openly rejected, but one can easily tell that they are being rejected and can isolate themselves. . . . Some of them think that they will not live long because of the TB disease. . . . They think that they are not worth living or [that] their life is not useful. This involves accepting some of the stigmatizing judgements upon oneself, leading to self-stigma. As a result, they start to isolate themselves from people, they stay on their own, and sometimes, they stop thinking in a right way, which is dangerous." [Male FGD, Northern Region HC IV]

However, participants also reported PWTB sometimes isolated themselves from the rest of society as a way of avoiding infecting others, a behavior that was self-discriminatory even though their family and friends may not yet have been aware of their health condition. This preemptive measure was often employed and could lead to poor adherence to treatment plans and negative outcomes, especially when patients failed to take their anti-TB drugs regularly.

Those who go to health facilities get information and counseling from the health workers on how they can protect themselves and not spread TB to anyone, including family members. This means that the TB patient has to inform all family members and the community about their condition. This usually does not happen, as the patients just keep quiet and just isolate themselves as a way of avoiding spreading the disease. [Male FGD, Northern Region HC IV]

Perceived Barriers to TB Care-Seeking and Treatment

The problem of TB-related stigma in Uganda was identified by participants as a potential barrier to TB testing, treatment, access to care, and treatment adherence. Participants also perceived differences in access to care between rural and urban settings from their experience receiving other health services, and stated they believed that rural-based TB patients suffered more than urban-based TB patients because TB services were less accessible in rural areas. Participants pointed out that this was because most health facilities in rural areas did not provide TB services, and people did not know where to access TB services. TB testing was rarely mentioned in the FGDs, but some participants indicated that they knew that there was a TB testing “machine” somewhere, but not in the health facilities near them.

In Northern Uganda, it was pointed out that the Ministry of Health introduced village health teams (VHTs) and community health workers and volunteers (CHWVs) to connect the community with health facilities—hospitals, health centers level three (HC IIIs), and HC IVs. The CHWVs and VHTs circulated around communities to help sensitize and educate people on any kind of disease outbreak, including TB. The objective of these education and sensitization sessions was to encourage PWTB, or those with other diseases, to visit the health facility to seek treatment. However, facilities offering TB care services in rural areas were reported to be far from some communities (more than 20 kilometers for some localities), creating accessibility and affordability (transportation costs) obstacles for people living in poverty, who may need such services the most.

But there are so many people out there in the community who are dying because they live very far, and some simply do not want to come to the health facilities. They visit herbalist, traditional healers, elders, and friends who give them herbs presumed to cure TB, and when they realize that they are not getting cured, they get defeated [disappointed]. That's when they go to health facilities to seek appropriate treatment. . . . It is when one coughs persistently without stopping and sometimes spits or vomits blood. It is at this stage that most people are forced to visit the hospital, because if they do not, one can lose their life.
[Female FGD, Central Region hospital]

Especially among rural participants and those who rarely visited health facilities, the treatment of TB was rather mysterious, and TB was seen as a complex, rarely curable disease. This perceived difficulty in curing TB, and the lack of information on the nature of treatment, delayed or diverted treatment seeking for TB. Participants also inquired about TB vaccination for adults as a preventive measure. Although all children are vaccinated against TB at birth, the FGD participants pointed out that in rural areas, many mothers did not deliver at health facilities and their babies were therefore seldom immunized.

TB treatment and prevention is complicated and as a disease, it is very difficult to cure. In the olden days, one had to be given 60 injections. That kind of treatment alone could create some fear in the mind of an individual, and people would just hide and avoid treatment. [Male FGD, Northern Region HC IV]

One predominant view was that TB was associated with HIV. The common understanding was that all PWTB had HIV/AIDS. One of the most salient concerns about having TB was the fear that one would be labeled HIV-positive and, therefore, stigmatized.

If we are to go to the community right now, most people will refuse to test for TB disease because of [their] fear of the outcome [or of the] test results [that, if positive, would lead them to] most likely be labeled HIV-positive. People prefer to stay in ignorance because they think that if they are told their [TB] status, they will die earlier than if they did not know. This is a big problem that the health workers have to deal with. [Male FGD, Northern Region HC IV]

These stereotypes were present alongside additional challenges, including the limited provision of TB diagnosis tests and the availability of medicines.

At the facility here, some patients come from far and then service providers tell them that there are no testing kits, reagents, or even health workers themselves may not be available. For example, sometimes even children are not immunized [against TB (i.e., the BCG vaccine) because] vaccines are not available. If TB patients cannot get treatment, yet they come from far, they get frustrated and are not likely to come back to the health facility again. The health facilities should also consider allowing caretakers to pick medications for those patients who are very far. [Male FGD, Northern Region HC IV]

The perceived complexity of TB, combined with stockouts and the lack of accessible screening and testing services and medicines, were described as discouraging people from seeking care at health facilities. Participants noted that PWTB resorted instead to ineffective alternative treatments, such as substances given to them by traditional healers.

Traditionally among the Acholi [in Northern Uganda], it is believed that eating a liver of a desert fox can help cure a number of diseases, including TB. But the challenge today is that these kinds of animals are very rare because the traditional healers have killed most of them in search of the medicines. [Male FGD, Northern Region HC IV]

Others reported that PWTB often resort to religious interventions for care.

Some TB patients visit the born-again churches for spiritual healing. The pastors in these churches claim to heal all diseases including TB through prayer. But they also end up going to health facilities after failing to get results from the pastor's prayers, but sometimes this is rather late. [Female FGD, Central Region hospital]

In the few rural areas where TB services were provided, services were perceived as inappropriate.

He had TB but had not yet known. One day, he went to the hospital to get tested for TB and the health worker who did the test on him told him that the result of the test showed that he did not have TB, but the boy kept coughing and the condition became worse day-by-day. So, the option the young man had was to try traditional healers. I remember he visited the traditional healers several times and was given herbs, but instead the boy's condition just became worse. He developed complications in his back, lost his appetite, lost weight, and started feeling pain all over the body and could not even walk. We started to fear the young man, thinking that we can also be attacked by the witchcraft. All the goats at home were being killed because we were taking all of them to the traditional healers, until we said, "No, let us go back to hospital for another investigation," and this time we took the boy to Lacor Hospital. The boy was tested again and found out that he had TB, then he began treatment, and little-by-little he recovered; and as we speak now, this boy is fine and walking very well. [Male FGD, Northern Region HC IV]

There was also an element of fatalism—people who developed the attitude, “What do I have to lose?” Participants shared that patients they knew who had this attitude tended to give up on life and sometimes even stopped taking their medication. They found it difficult to change their lifestyle, a necessary measure to properly recover from TB.

They are people who are already waiting to die because it seems they have made up their minds. Such patients ignore the advice from the health workers and instead do the opposite—go by what they want. . . . They say, “If this kills me, then let it kill me.” . . . and the truth is, they end up dying. [Female FGD, Central Region HC IV]

Prejudice and stereotypes of masculinity were speculated as a key reason for reluctance by male PWTB to disclose their condition or come forward for screening and to access treatment. Participants reported that men with TB symptoms feared making their first visit to the health facility because they did not want to disclose their status if diagnosed with TB and be subject to the discrimination associated with TB.

When a married man gets TB, some [of their wives] decide to leave their husbands because the man can no longer provide the necessary support to take care of the home. The women reason also that they are taking away the children to save them from TB, leaving [their husband] to suffer on his own. They leave until the man cures from the TB or dies. This happens in our community and leaves the affected men mentally confused; and this is when they suffer most, because this is the time when they need the family support most. With no support from the immediate family, most men feel helpless and think that they are useless. [Male FGD, Northern Region HC IV]

Similar prejudices were encountered in the Central Region.

Especially for us, the men, whether it is TB or any other disease, we do not want to get tested or go to health facilities. Men think that they are very strong and will always be strong. They think that if they can still drink alcohol, then they are still strong. So, some people just refuse to go to health facilities even when they know that they may have TB. Most of us men just stay at home without going to the hospital until we are seriously sick, in a situation where one just has to be carried to the health facility, and from the health facility you may hear that so and so is dead. [Male FGD, Central Region HC IV]

The implication was that people tended to wait too long to visit the health facilities, delaying until serious symptoms appeared.

Limited Sources of TB Information

Almost all participants had received some information about TB through radio, television, newspapers, or informal discussions with relatives and friends. However, these sources were reported to be limited only to those who could afford to own and play their radio or television. Sources of information about TB included community radios (referred to as *ekizindaalo* in the Central Region’s rural areas) and the mobile megaphones used by local authorities and some nongovernmental organizations. However, these sources provided very limited information and did not allow participants to ask questions and obtain answers. Consequently, most FGD participants had very little information on the details of TB—its modes of transmission, how it is diagnosed, the availability of treatment, the care process, or preventive measures. Without appropriate

information, participants pointed out that it was a challenge to detect PWTB early enough to seek treatment while also balancing control and prevention measures in the home and the community.

There is a need for rural communities to be provided with enough and continuous information and knowledge about TB. This will raise their awareness about how TB disease spreads and how it can be controlled and/or prevented and facilitate testing people to know who has TB or not. Where possible, dissemination of factual information through the use of radio, television, posters, pamphlets, and drama should be widely disseminated.
[Male FGD, Northern Region HC IV]

Participants recommended holding multiple educational sessions in defined areas or targeted at specific populations as effective ways of increasing awareness and thereby reducing stigma. FGD participants suggested that, if trained, TB survivors would be effective health educators.

People who survived TB would be the best educators. They can act as role models because at one point they were patients for a long time but got cured from their condition. These health educators can talk to, counsel, and give advice to the community members to visit the health facility in case of any TB-related symptoms. Some of the people in the villages here do not listen to advice, particularly from us, the common people. But these CLFs [community linkage facilitators] are trained in communication and mobilization techniques; they can convince the local person to go to the hospital. The CLFs that went through the same condition are normally the best people to help talk to the PWTB and get treatment straightaway. [Male FGD, Northern Region HC IV]

FGD participants said that to increase awareness, education activities should emphasize the availability and reliability of services at health facilities along with health education. They suggested that a TB diagnosis should be considered an opportunity for healthcare providers to spread awareness about the disease, encourage patients and their family members to commit to TB care, and address stigma as the cause of discrimination, the reluctance to get tested, nonadherence, and other negative outcomes.

DISCUSSION

Although the study was unable to speak directly to TB patients and other key populations affected by TB, FGD participants were able to provide valuable insights that added to the understanding of stigma at the community level in Uganda. The FGD findings revealed that TB was perceived as a stigmatized health condition by community members who were receiving healthcare for illnesses other than TB. The study also demonstrated the community's uneven knowledge about TB disease.

This study supports previous research suggesting that societal norms and values that lead to stigmatization of TB can interrupt efforts to prevent, diagnose, and treat TB (Cremers, et al., 2015; Craig, et al., 2017; Datiko, et al., 2020). Like others, the Uganda study found that some forms of stigma are induced by physical appearance of PWTB and the way certain physical differences are interpreted by society. In the case of TB, discrimination usually occurs when TB is diagnosed, and sometimes long after it has been cured, an idea articulated by one FGD participant, who said, “Once a TB patient, always a TB patient.” The negative attitude toward TB patients or survivors after treatment continues because other community members continue to hold stigmatizing beliefs about a person who acquired TB even long after that person has been cured. A person formerly infected, therefore, has to learn new ways of dealing with stigma over time. Stigma is based on these prejudicial understandings, which people internalize in different forms. It is important to fight recurring stigma.

Some of the stigma-related TB perceptions that align with previous research include the assumption that TB patients are careless and responsible for their own infections and that TB is hereditary, linked to HIV and immoral behavior, and is associated with weather conditions or specific economic livelihoods. This finding is consistent with the assertion in the TB literature that such perceptions are often associated with patients' fear of disclosure, discrimination, social exclusion, or isolation (Cremers, et al., 2015; Craig, et al., 2017).

The importance of community-based health education and awareness strategies to address misconceptions and incorrect beliefs about TB is stressed in previous studies (Cremers, et al., 2015; Datiko, et al., 2020). Yet, such studies are limited, and few focus on interventions among community members. Sommerland and colleagues (2017) found only two of seven interventions aimed to reduce TB-related stigma in the community in their systematic review of evidence-based interventions to reduce TB-related stigma.

It is also clear from the FGDs that some discrimination has causes other than stigma; there is a need to understand and address all factors causing or exacerbating discrimination and stigma against PWTB. This is critical because each separate factor may require distinct remedies. Each barrier should be considered individually to develop appropriate and effective interventions that address them. For example, the findings from these FGDs suggest that it is important to distinguish between TB stigma (negative beliefs that people have about TB and PWTB) and discrimination (what people actually do to unfairly disadvantage PWTB). Moreover, there is a need to distinguish between discrimination based on stigma and ignorance, and differential treatment based on a rational assessment of risk, although determining how much differential treatment is influenced by the social constructions, interpretations, and meanings attached to TB disease is challenging.

Eliminating TB in Uganda therefore requires focusing on the main problems exacerbating TB in Uganda—barriers to care, discrimination against PWTB, and the additional burden of TB-related stigma in poor and

underserved settings. There should be greater focus on anti-stigma interventions using a more holistic and integrated approach (Datiko, et al., 2020)—combining educational programs, for example, with counseling, skills acquisition, and contact with PWTB; encouraging community involvement in anti-stigma programs; or coupling education and awareness programs with income-generating activities. Some sources suggest that anti-stigma interventions need to be based on programs for social advocacy, legal rights protection, and general poverty initiatives (Parker & Aggleton, 2003).

This qualitative study highlights a number of challenges for how care is provided, as differential care may be perceived by patients and other community members as justification for stigma. In the process of accommodating the special needs of PWTB, differential treatment should only be justified if it reduces the risk of infection and should not take away any rights to which PWTB are entitled. Differential treatment to protect oneself or others from getting infected and spreading the disease (e.g., physical distancing and having separate sleeping quarters), while also showing the PWTB respect and preserving their dignity, are behaviors that can be encouraged and are fully justified. Such prevention measures and, perhaps, exclusionary behaviors, should not be diminished in the interests of “inclusion” (Sayce, 2003).

The potentially deleterious actions undertaken by PWTB (e.g., refusing to get tested or take medication) cannot be entirely attributed to the stigma they experience; other factors may also influence their behavior. They can include the reactions and feelings of their family members and social circles, specific meanings associated with TB (for example, its close association with HIV), lack of access to facilities or lack of appropriate diagnosis supplies and treatment when patients do reach the facility, and the lack of confidentiality in healthcare settings.

These findings suggest the importance of individual- and community-level education to clarify the modes of transmission and build awareness about prevention and treatment. The findings also give critical insight into community-level beliefs about TB in the two regions that should be used to help design health messaging going forward. The findings likewise highlight community knowledge that is important to either reinforce or refute in future behavior change communication messages. Psychosocial support and counseling services should accompany TB patients during treatment and beyond to help TB survivors manage continued discrimination and other negative social responses to their condition.

A more comprehensive study to further explore the variability of TB stigma across different cultures, regions, historical periods, and socioeconomic contexts would provide valuable information for prevention and treatment interventions. Although the perspectives of healthcare workers and TB patients are captured in the quantitative components of the larger QTSA in Uganda, additional qualitative study is needed to assess the consequences of stigma for TB patients and healthcare workers. Findings could inform a more targeted strategy to remove the biopsychosocial barriers that shape TB stigma, and increase the availability and accessibility of TB services in Uganda and other underserved settings.

Despite the fears expressed by FGD participants, there is a clear sense of obligation in families and among community members to support and care for PWTB. Multiple participants discussed getting information about TB via radio and television programming, indicating that current health communication efforts are having at least some impact. Most encouraging is the evidence of a significant appetite for more information among the FGD participants, which includes many requests for information on prevention, how they can protect themselves, and how to safely support and care for PWTB, all of which demonstrate the potential for the success of future community-level TB education and stigma-reduction efforts.

RECOMMENDATIONS

During the FGDs, participants offered a range of insights into perceptions of stigma toward PWTB in their community. These insights informed the following key recommendations for improving strategies to address stigma toward PWTB in Uganda.

Health Education and Community Mobilization

Facilities can capitalize on the resources that are VHTs and train them to educate PWTB. VHTs could help PWTB understand and accept their condition, demonstrate hygiene practices to avoid spreading TB, equip PWTB with skills to cope with stigma they may experience, and provide them access to a patient community that can help them feel less isolated. Use of VHTs and CHWVs for health education in the home and in the community can lead to significant impact in reducing stigma and improving how PWTB manage discrimination they may encounter, especially if former TB patients are recruited as VHTs and CHWVs, because they understand the experience best.

Communication strategies should also be designed to educate the community about TB transmission, its curability, and the differences between TB and HIV. These communication campaigns should also showcase and encourage ways in which community members can contribute to combatting TB stigma.

TB Outreach

TB outreach services should be introduced, especially in rural areas where TB services are scarce. These outreach services can take the form of health camps, training for community health workers to provide extension services, or use of mobile (*boda-boda*) treatment systems. The objective of TB outreach services should be to increase the clear instruction, on the part of the outreach actor, and correct understanding, on the part of the PWTB, of the causes, modes of transmission, and treatment protocols for TB. These conversations would be valuable opportunities to dispel myths and by so doing, reduce self-stigma and increase the likelihood of PWTB seeking care and adhering to treatment. Interacting with TB patients outside of the formal medical setting may also contribute to reducing discomfort among PWTB and their family members, and perceived stigma associated with being seen at the health facility.

Additional Research

Given the limitations of this study, further qualitative research that includes additional perspectives on TB-related stigma, especially from current and recovered TB patients, would be valuable to further inform stigma reduction efforts being implemented throughout Uganda. Future studies could be designed with bigger sample sizes encompassing different regions, ethnic groups, communities, and subgroups of patients (e.g., PWTB or former TB patients). Given our limited findings in some areas, the exploration of topics such as gender differences in both experienced stigma and stigmatizing actions, as well as links between HIV- and TB-related stigma, could be of particular interest. Expanding the scope and depth of this research will provide a clearer explanation of the factors associated with TB-related stigma and guide the design of interventions to reduce stigma in the community.

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