



STIGMA INDEX STUDY

Assessing the Stigma of Tuberculosis in Ghana:
Consequences to Accessing and Provision of Services

2020
REPORT GHANA



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Declaration

This report describes the TB Stigma Study and provides information about procedures for conducting the study. Every care was taken in its drafting, but corrections or amendments may be necessary. This study adhered to the principles of Good Clinical Practice (GCP) and was conducted in compliance with the protocol, the Ghana Data Protection Act 2012 and other Ghana Health Service Ethics Review Committee (ERC) requirements as appropriate.

ABBREVIATIONS

AIDS	Acquired Immuno-Deficiency Syndrome
AvgPS	Average Percentage Score
AR	Ashanti Region
BER	Bono East Region
CDC	Centre for Disease Control and Prevention
COVID-19	Novel Coronavirus 2019
DOTS	Directly Observed Treatment Short-course
ER	Eastern Region
FGD	Focus Group Discussion
FM	Family Member
GAR	Greater Accra Region
HCW	Healthcare Worker
HIV	Human Immune Virus
IDI	In-depth Interview
KNUST	Kwame Nkrumah University of Science and Technology
NR	Northern Region
NTP	National Tuberculosis Control Program
OR	Oti Region
PLHIV	Person Living With HIV
PWTB	People diagnosed With TB

PWHTB	People Who Have Had Tuberculosis
REDCap	Research Electronic Data Capture
SARS COV-2	Severe Acute Respiratory Syndrome Coronavirus-2
STI	Sexually Transmitted Infection
STP	Stop Tuberculosis Partnership
TB	Tuberculosis
UER	Upper East Region
UNOPS	United Nations Office for Project Services
WHO	World Health Organization

DEFINITION OF KEY TERMS

Stigma: Described as a process of devaluation, whereby a person is discredited, seen as a disgrace, or perceived to have less value or worth in the eyes of others. Stigma is often associated with discrimination.

Discrimination: It involves treating someone in a different, unjust, unfair or prejudicial manner, often on the basis of his/her belonging or perceived belonging to a particular group. Discrimination is often viewed as the end result of the process of stigmatization.

Index: Refers to a collection of information (data) organized in a way which allows us to reach overall conclusions about particular issues and to measure differences in stigma and or how a situation has changed overtime among different populations.

Key Populations: Populations that are most at risk of acquiring or transmitting TB and stigmatized regardless of the legal and policy environment.

Internalized or self-stigma: Captures the idea that individuals may come to endorse negative stereotypes, and therefore behave or think according to false portrayals and negative messages.

Perceived stigma: Refers to the worry that one will be devalued after a TB diagnosis. For the person with a TB diagnosis, this is the fear (often the result of observing others being stigmatized) that the stigma against the person will be so bad that will affect access to TB services.

Secondary stigma: Refers to the idea that caregivers, friends or family members may expect negative attitudes or rejection because of their association with a person diagnosed of TB or who has had TB.

Structural stigma: Describes the laws, policies, media and institutional architecture that may be stigmatizing or alternatively protective against stigma. This includes societal level conditions, cultural norms and institutional practices that constrain the opportunities, resources and wellbeing of stigmatized populations.

Transgender: People whose gender identity and expression does not conform to the norms and expectations traditionally associated with their sex at birth.

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Executive Summary

Background

Tuberculosis (TB) is one of the serious airborne infectious diseases caused by *Mycobacterium tuberculosis* which usually makes approximately 10 million people ill every year. Given these devastating effects, the Stop TB Partnership proposed the 90-90-90 benchmark which aims at reaching 90% People with TB (PWTB) and putting them on treatment; reaching 90% of key populations; and achieving 90% treatment success by the end of 2020. However, PWTB or people who have had TB (PWHTB) fear to disclose their status because of the fear of stigma and discrimination which as a result causes loss of economic opportunities and loss of community respect. The fear of contracting TB by healthcare workers is also becoming a means of stigmatizing PWTB, making it harder to mitigate the spread of the disease. TB stigma discourages patients from seeking healthcare services hence causing the surge in the recrudescence and communicability of the disease. In review of the achievement of the 90-90-90 benchmark in Ghana, approximately 69% of PWTB were identified and put on treatment, treatment coverage was 34% and 84% treatment success rate were attained in 2019. Although stigmatization has been mentioned as one of the major barriers of attaining the benchmarks, the extent of TB related stigma as a cross-cutting barrier to accessing quality, affordable and timely TB care and support services in Ghana is not well understood. Furthermore, there are no clearly defined laws and policies for TB related stigma issues in the country.

The study aimed to assess the extent to which TB stigma affects access and provision of healthcare services and to support the development of recommendations to address TB stigma so that quality TB services are available, accessible and acceptable to all.

Methods

A mixed-methods approach, with a cross-sectional study design, was employed to recruit PWTB and PWHTB, family members or caregivers of PWTB and PWHTB, community leaders and health care workers from eight (8) out of sixteen (16) administrative regions of Ghana. A total of 4,261 (comprising 1,025 PWTB, 975 family members of PWTB/PWHTB, 1,966 community members and 295 healthcare workers) were interviewed. PWTB or PWHTB and family members were

selected for FGDs whilst community leaders, health care workers and policymakers were recruited for in-depth interviews. A total of 102 qualitative interviews (32 FGDs and 70 IDIs) were conducted. The quantitative data were collected using an electronic system (REDCap) and analyzed with Stata version 16 statistical software. The qualitative interviews were transcribed and imported into Nvivo software for thematic analysis

Key Findings

People diagnosed With TB or People Who Have Had TB

The prevalence of HIV among PWTB was 8.8%, with 19.8% of them being rural poor and miners being 7.6%. Across the dimensions of self-stigma assessed, majority of the respondents (79.0%) agreed to the statement “*I keep a distance from others to avoid spreading TB germs*” followed by the statement “*I choose carefully who I tell about having TB*” (70.0%). A little over seven percent had their TB treatment inhibited due to self-stigma. Nearly one-fifth (22%) of PWTB/PWHTB reported ever being stigmatized because of their TB status. Stigma among the males (13.3%) was higher compared to both females (8.7%) and transgender (0.3%). Sixty-five percent of those that experienced stigma, reported experiencing it in their communities, which inhibited them from seeking and accessing TB services. Stigma experienced in the community, mostly inhibited PWTB/PWHTB who identified as transgender from recognizing symptoms (29%), followed by the female (14%) and males (12%).

Family members or caregivers of People diagnosed With TB or People Who Have Had TB

More than seventy percent (71.0%) of family members/caregivers with PWTB/PWHTB agreed to the statement that “*I’ve noticed changes in my family member since the TB diagnosis.*” Ten percent of family members/caregivers of PWTB/PWHTB reported being stigmatized. High proportion of females (6.3%) experienced stigma compared with males (3.3%) Stigma experienced, mostly occurred in the community, which inhibited them mostly from supporting their family member with TB in terms of recognizing symptoms (8.0%) and seeking care (6.0%). Gossip (8.1%), avoidance from other community members (6.3%) and verbal/physical abuse (5.3%) were reported as the most common TB-related stigma experienced by family members of PWTB/PWHTB. The

results revealed that stigma experienced by the female family members was higher (6.3%) than the male family members (3.3%).

Community leaders

Majority of the community leaders agreed to the statement “*Some people might not want to eat or drink with friends who have TB.*” (82.0%) and “*Some people feel uncomfortable being near those who have TB*” (75.0%). Nearly half (48.6%) of the community leaders reported knowing at least one PWTB/PWHTB. More than one-quarter (27.1%) of them reported to know persons being stigmatized due to TB, indicating gossip (24.6%), verbal/physical abuse (13.9%) and avoidance and isolation PWTB at health facilities (11.9%) as the most common type of stigma experienced by PWTB/PWHTB. TB stigma was mostly experienced in the community. This inhibited PWTB/PWHTB from recognizing symptoms (24.0%), seeking care (18.0%) and getting diagnosis (16.0%).

Health Care Workers

Across the dimensions of self-stigma assessed, majority of the HCWs (88.0%) agreed with the statement “*Some health care workers feel pity for TB patients.*” Most also agreed to the statements “*Some health care workers think it would be best for TB patients to be isolated during the intensive phase of treatment*” (80%) and “*Some health care workers are nervous about treating TB patient*” (71.0 %). One-third (32.9%) of HCWs felt stigmatized because of their work involved interacting with PWTB/PWHTB. Compared with the males (13.6%) higher proportion of the females (19.3%) experienced stigma. Majority of the HCWs reported ever experienced stigma at the hospitals/clinics (29.0%). This was usually exhibited in the form gossip (23.7%) and avoidance from colleague HCWs (18.3%). More than a quarter (30.2%) of the HCWs reported seeing or hearing a fellow HCW who had been stigmatized because their work involves treating TB patients. stigma experienced was prominent among the female HCWs (30.0%) compared with the male HCWs (27.0%).

Policy makers

With regards to structural stigma (existing laws/policies, the enforcement of those laws/policies and the corresponding media coverage), the policymakers confirmed the existence of laws that protect the rights of PWTB at the national level (AvgS=4). However, these laws are enforced at

the sub-national level (AvgS=3) and its enforcement is supported only in the sub-national media coverage (AvgS=3). Response from the policymakers also suggest the existence of the policy that protect PWTB at the sub-national level (AvgS=3), enforcement of these policies at the national level (AvgS=4) and media coverage of these policies at the sub-national level (AvgS=3).

Stigma Radar

The stigma radar revealed a remarkable self-stigma among the PWTB/PWHTB (46%), secondary stigma among the family members of PWTB/PWHTB (47%), perceived stigma among the community leaders (60%) and perceived stigma among the health care workers (57%). However, perceived stigma did not inhibit seeking and accessing TB services.

Conclusion

Stigma remains a critical issue in the control of TB in Ghana, impeding access to and provision of TB services. PWTB, family members/caregivers and HCWs all reported being stigmatized and knowing others who also experienced stigma. Community leaders also reported knowing PWTB/PWHTB who experienced stigma, which mostly took the form of gossip and avoidance and isolation of PWTB/PWHTB in the community. Stigma was prominently exhibited in the community across all categories of the TB journey, mostly inhibiting recognition of symptoms and negatively affecting care seeking among PWTB/PWHTB. Stigma also inhibited families from providing support to family members with TB or had TB. The results also suggest the existence, enforcement and media coverage of laws and policies that protect PWTB/PWHTB at both the subnational and national level.

Recommendations

Key interventions required to reducing stigma and improving access to health care include a) reducing self-stigma by empowering individuals to believe they can alleviate their health condition and circumvent further negative consequences that inhibit them from seeking and accessing health care, b) organizing stigma reduction programs in the communities by raising awareness regarding the negative health consequences of stigmatizing PWTB and its effect on health care seeking and provision, and c) enacting and enforcing specific laws and policies that address and protect the fundamental human rights of individuals affected by stigma in the society.

1.0 Introduction and Rationale

Tuberculosis (TB) remains one of the oldest debilitating infectious diseases but disproportionately affect the world's poor in which approximately 10 million cases are estimated every year globally [1,2]. Nearly 2.5 millions of people who contracted TB and 665,000 of them who died from the disease in 2017 lived in the sub-Saharan African (SSA) region [3]. In Ghana, over 44,000 new cases of TB are estimated yearly and TB mortality rate is reported at 50 per 100,000 population [4,5]. According to the Stop TB Partnership (STP), and as articulated in the Global Plan to End TB 2016-2020, medical interventions alone will not be enough to end tuberculosis and thus, stresses the importance of universal health coverage and social determinants [6]. This approach should strive for equity; address the structural, social, socioeconomic, human rights and gender drivers of the disease; and ensure the meaningful engagement of empowered TB survivors and affected communities [6,7]. Howbeit, over the years, research on drug discovery and vaccines accounted for about 60% of all TB funded research with operational research being a limited target [8,9].

According to the Stop TB Partnership, reaching 90% of PWTB and putting them on treatment, reaching 90% of key populations and achieving 90% treatment success by the end of 2020 is a step in the right direction of ending TB. This was supported by modelling studies that showed that achievements of these benchmarks (90-90-90 benchmark) will enable to end TB worldwide by 2030 [13]. Moreover, the End TB strategy 2020 proposes there should be a 20% reduction in TB incidence, 35% reduction in mortality and zero costs burden for families by 2020 [10]. However, the 1.6-2.0% reduction in TB incidence and 11% reduction in TB mortality from 2015 to 2018 indicate that we are trailing far behind the benchmarks and nearly impossible to meet this target [10]. TB related stigma and discrimination is one of the commonly identified human rights-related barriers hindering the fight against the TB epidemic [11]. Furthermore, TB stigma has serious socioeconomic consequences and leads to distortion of health conditions making it difficult to treat, eventually increasing the infectivity and communicability of the disease [12,13]. Thus, understanding the dimensions and levels of TB related stigma will help countries to address the health disparities experienced by TB patients, inform interventions and policies to end TB stigma and implement a Community, Rights and Gender (CRG) approach to TB. From a blast of published works on TB, stigma and discrimination have been identified to play a major role in limiting access

to TB services and also at the forefront of low TB case detection and poor treatment compliance, and the poor quality of life of TB patients [14-16].

Stigma is described as a process of devaluation, whereby a person is discredited, seen as a disgrace or perceived to have less value or worth in the eyes of others whilst discrimination involves treating someone in a different, unjust, unfair or prejudicial manner often on the basis of the individuals belonging or perceived belonging to a group [16,17]. In the case of TB, stigma can lead to unwillingness of individuals to disclose their status which arises from fear of loss of economic opportunities, loss of community respect, fear of transmission, shame, blame and judgement and questions of “how did you or did she/he get it” and even death [18,19]. According to results from the 2014 Ghana Demographic and Health Survey (GDHS), approximately 33% of women and 25% would want to keep TB in their families and communities as a secret due to the fear of stigmatization [18].

Hitherto, TB patients were demonized and isolated mainly due to the fear of infectivity and outdated societal beliefs and practices about TB but the advent of inexpensive and effective chemotherapy drastically reduced the stigma and discrimination associated with the disease [20]. However, the association of TB with human immunodeficiency virus/acquired immune-deficiency syndrome (HIV/AIDS), perceived causes and spread of TB, public health practice and discourse and healthcare workers fear of TB is rekindling and increasing TB stigma in recent times [18,21,22]. Particularly labelling of all TB patients as persons living with HIV/AIDS has led to self-stigmatization by TB patients [18,23], and current reports shows that health professionals are becoming the conduit of exposing TB patients to stigmatization in society [22,24,25]. Reports from studies conducted in Ghana and other countries in the sub-Saharan African region shows that TB stigma is a major harbinger limiting access to TB healthcare, increasing of TB diagnostic delay or low case detection rate and poor treatment noncompliance [17-19]. In Ghana, approximately 69% of PWTB were identified and put on treatment, treatment coverage was 34% and 84% treatment success rate were attained in 2019 as a measure of the 90-90-90 benchmark. These gaps could be attributed to stigmatization (28). Nonetheless, TB related stigma in Ghana has been under addressed given that almost all studies employed qualitative approaches to measuring TB stigma rather than quantitative surveys or mixed-methods [27,22]. Hence, the true burden of TB related stigma as a cross-cutting barrier to accessing quality, affordable and timely TB care and support

services in Ghana is not well understood. Moreover, there are no clearly defined policies for TB related stigma issues in the country which as a result limits the systematic consideration and inclusion in the provision of health care for TB patients in the country.

The recent COVID-19 pandemic shows how stigma can worsen infection transmission and case detection in Ghana. However, the timely interventions of Governmental and political support and various stakeholders such as the media has helped to address the challenges of COVID-19 and alleviate the stigma associated with the disease. Interestingly, COVID-19 and TB share similar mode of transmission through aerosols, air droplets and close contact, and major symptom such as coughing, fever and difficulty in breathing. Hence in this era of COVID-19, TB patients are highly at risk of stigma and discrimination which must be given urgent attention. Given the severe implications that TB related stigma poses at individual, community and national level, it was needful to investigate the true representation in terms of prevalence and extent of TB stigma in Ghana, and identify measures which can be adopted to mitigate TB related stigma. In response to the specific objectives of this study, findings from the study is expected to enhance positive attitudes towards TB disclosure and encourage health-seeking behavior which will consequently lead to the increase of case detection as people were confident to access health care. Moreover, it will increase compliance to treatment of TB in the country. Additionally, understanding TB related stigma will serve as basis for advocacy of laws and policies and the enforcement of existing laws or policies against TB related stigma and the corresponding media coverage of TB related stigma. It will also strengthen TB health services across the country. TB is a highly infectious disease like the novel Coronavirus (COVID-19) and openness towards status disclosure is an important public health concern.

1.1 General Objectives

The study aimed to assess the extent to which and how TB stigma acts as a barrier to both accessing and providing services, and to support the development of recommendations to address TB stigma so that quality TB services are available, accessible and acceptable to all, with special considerations given to the needs of key, vulnerable and underserved populations.

1.1.1 Specific Objectives

1. To assess the levels and dimensions of TB stigma and gender differences among people diagnosed with TB in Ghana.
2. To assess the level and dimensions of secondary TB stigma observed by family members/primary caregivers of people diagnosed with TB in Ghana.
3. To assess the level of perceived TB stigma against people diagnosed with TB in communities and stigma observed by the community in Ghana.
4. To assess the level and dimensions of perceived TB stigma against people diagnosed with TB in health care settings and stigma against health care workers in Ghana.
5. To explore the extent to which structural stigma (any existing laws/policies, the enforcement of those laws/policies and the corresponding media coverage) could harm or protect people diagnosed with TB and their gender differences in Ghana.

2.0 METHODOLOGY

2.1 Study Area

The study was conducted in eight (8) administrative regions of Ghana. These regions include Northern, Upper East, Bono East, Oti, Ashanti, Eastern, Greater Accra and Western region.

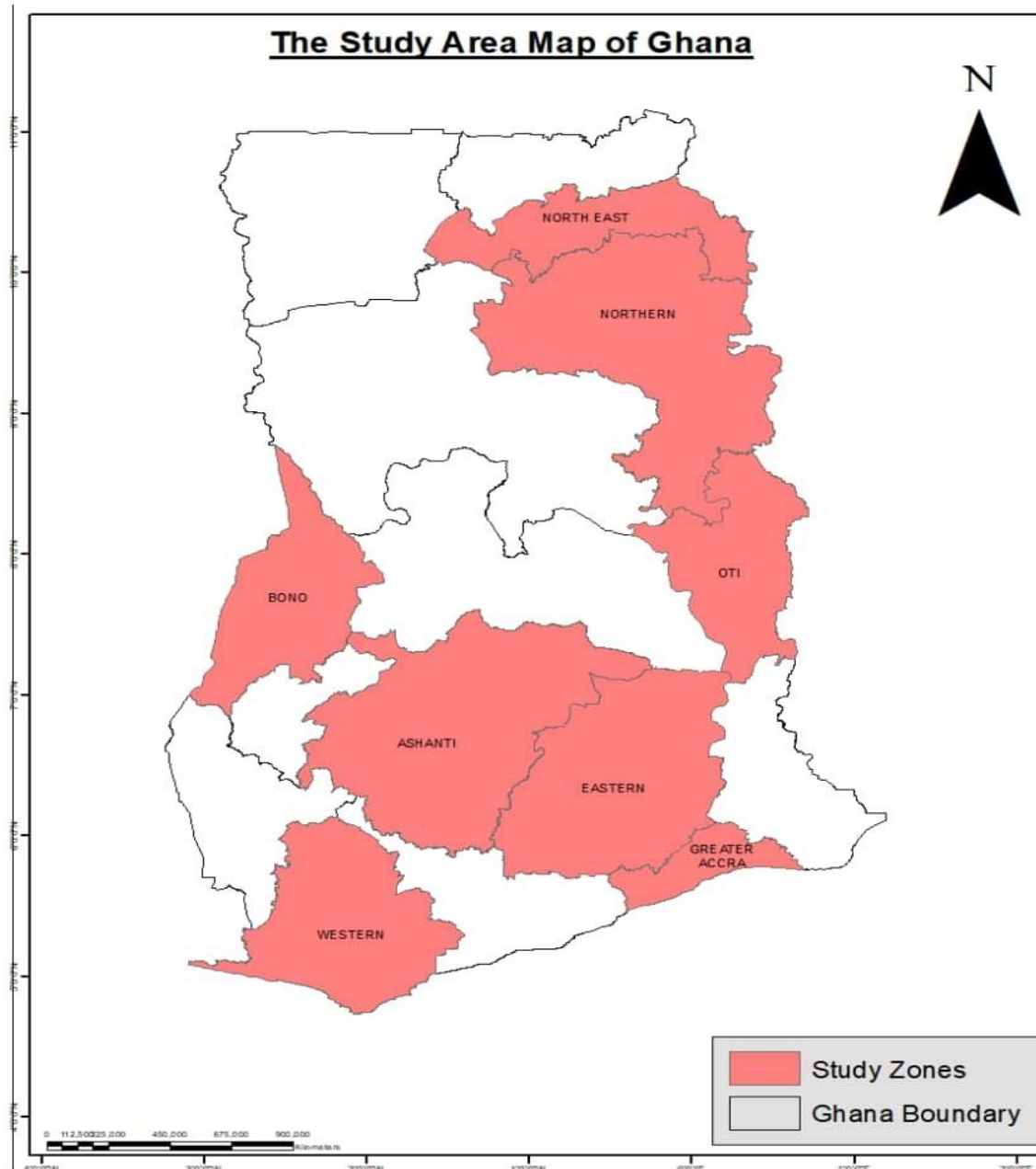


Figure 1: Map of Ghana showing the study regions

2.2 Study Design

The study employed a cross-sectional design with a mixed methods approach (using qualitative and quantitative data collection methods) among the selected eight regions of Ghana. The survey utilized diverse information collection methods including structured questionnaires, Focus Group Discussion (FGD) and In-depth Interviews (IDIs).

2.3 Sampling

2.3.1 Sample Size Estimation

Considerable geographic variability exists in the perceived prevalence of TB stigma, with 27% to 80% of at-risk individuals reporting stigmatization of TB in their communities [28–30]. The study estimated a sample size with an assumed prevalence of 50% of TB stigma (an average of previous studies) among our population with 95% Confidence level which corresponds to 1.96 standard values, a significant level of 5% and precision error of 3.5%.

$$n = \frac{Z^2 p(1-p)}{d^2}$$

Where n = estimated sample size

Z = standard normal variate at 95% confidence interval which correspond to 1.96

p = proportion of the TB patient who experience stigma (our estimate of stigma is 50%)

d = precision error

$$n = \frac{(1.96)^2(0.50)(1-0.50)}{(0.035)^2}$$

$$n = \frac{(3.8416)(0.50)(0.50)}{0.001}$$

$$n = \frac{0.9604}{0.001}$$

$$n = 960.4$$

A total of 961 PWTB/PWHTB was estimated. In other to understand the TB related stigma among family members/caregivers and community members, a ratio of 1:1:2 was applied. This was a modified formulation, adopted from a previous national survey conducted in Ethiopia (14). This

meant that for each TB case or TB recovered case identified, efforts were made to recruit 1 family member and 2 members in his/her neighborhood. Hence, the total estimated sample size was **3,844** (961 PWTB/PWHTB, 961 members of their family and 1922 persons living in the same neighborhood).

2.3.2 Sample Size Estimation for Health Care Workers

Eight (8) regions were sampled for the study, with two from each belt of Ghana (Northern belt, Middle belt, Southern belt and the Coastal belt). Table 1 shows the 2019 national data on the number of bacteriologically confirmed cases of TB selected from the study regions. Based on the distribution of health facilities in the study regions, a total of thirty (30) health care workers (doctors, nurses and physicians offering TB care services to TB persons at the health facilities) was estimated per each region, giving a total of 240 health care workers [32]. Health workers were selected from DOTS centres in each region.

Table 1: Allocation of sample size using proportional allocation of sample (PAS)

Region	Number of PWTB/PWHTB in 2019	Estimated Sample Size
Northern Belt		
Region 1 (Northern region)	220	32
Region 2 (Upper East region)	420	60
Middle Belt		
Region 3 (Bono East region)	346	50
Region 4 (Oti region)	210	30
Southern Belt		
Region 5 (Ashanti region)	1,557	224
Region 6 (Eastern region)	1,089	157
Coastal Belt		
Region 6 (Greater Accra region)	1,661	239
Region 8 (Western region)	1,176	169
TOTAL	6,679	961

2.4 Training of Research Team

Data collectors and field supervisors were recruited based on advertisement and with assistance from the study coordinator. The data collection team (data collectors and field supervisors) were trained to assist in collecting both qualitative and quantitative data. A 3-day training workshop was held for the research team made of the TB stigma experts, the study coordinator, the data manager,

the statistician, six (6) field supervisors, and twenty (20) field data collectors. A stigma assessment tool, developed by Stop TB Partnership (STP) [32,33] was adopted and used as reference material for the training and preparation for the survey. Each member of the data collection team was trained to collect primary data from an average of ten (10) PWHTB or PWTB and apply the recruitment ratio (1:1:2) for twenty-one (21) days. The training focused on areas including ethics in research (Good Clinical Practice), informed consent process, review of questionnaires, simulation (pairing of interviewers for practical's), and training on qualitative research methods with the aim of reducing interviewer biases.

Supervisors were trained to conduct random spot-checks (at least 3 per data collector) on key stigma questions during data collection in order to assess the extent of interviewer bias and addressed them accordingly. The data collection tools were pilot tested on the second and third day of the interviewers training. The questionnaires were revised based on the feedback/responses from the pilot test during the training.

2.5 Sampling Techniques

Probability sampling (systematic sampling) and purposive sampling techniques were employed in the study. The techniques used to select the regions and the districts (TB treatment facilities) are described below:

2.5.1 Sampling at National Level

In order to ensure geographical balance, the 16 administrative regions were divided into four zones; Northern belt, Middle belt, Southern belt and Coastal belt. Two regions were selected from each zone in a manner that the region with the highest TB prevalence within each belt was selected using purposive sampling and the remaining one selected by a simple random sampling approach.

2.5.2 Sampling of DOTS Centres

DOT centres (facilities offering TB care) were selected from each of the study regions. The selection included all facilities that had at least ten (10) TB cases per a clinic session for the year (2019) preceding the study.

DOT facilities were selected using proportional allocation sample (PAS). This selection procedure takes into account the number of cases and the likelihood of selecting a DOT facility in the study regions. *Table 2* shows the number DOT centres sampled from each study region.

Table 2: DOT Centres sampled from the study regions

Region	Number of DOT centers	DOTs selected
Ashanti region	65	13
Greater Accra	113	19
Eastern region	180	13
Upper East	68	5
Northern	19	5
Western	91	9
Bono East	23	6
Oti	17	4

2.6 Study Population

2.6.1 Inclusion Criteria

- Adults 18 years and above
- PWTB or PWHTB
- Is mentally sound and capable of providing consent to participate
- Family members or caregivers who have offered or offering support to PWHTB and PWTB
- Neighbors/community members residing in the neighborhood of PWTB and PWHTB.
- Health care workers at DOT centers who have been working for not less than 3 months.
- Policymakers who have adequate experience and involvement in stigma related issues.
- Has provided informed consent to participate in the study

2.6.2 Exclusion Criteria

- Persons below 18 years
- Persons who are mentally unstable or have psychiatric challenges and for that reason cannot understand the study procedures and provide consent.
- Health care workers working at the DOT center less than 3 months
- Policy makers who have no experience and involvement in stigma related issues.

2.7 Recruitments

2.7.1 Recruitment Strategies

PWTB were recruited during their clinic days (DOT center) after inviting them to participate in the study and seeking their consent to be enrolled into the study. In addition, the study was advertised on the TB community platform (TB voice network), inviting PWTB/PWHTB to participate in the study. Interested and available persons were asked to contact the study coordinator whose contact details was made available on the platform. Data collectors contacted these participants and interviewed them either at home or a place of convenience after obtaining their consent. PWTB/PWHTB who were interviewed were required to invite a family member or caregiver who meet the inclusion criteria to the facility or be followed up in the community as preferred by the respondent. Data collectors assessed the community of recruited PWTB/PWHTB and identified community leaders (chiefs, council of elders and opinion leaders, etc.) who met the inclusion criteria for an interview. In summary, a ratio of 1:1:2 (1 family member and 2 community leaders associated with each case was considered) was applied. Further, healthcare practitioners or workers who offered TB care services to TB persons at the health facilities and met the inclusion criteria were identified by data collectors for recruitment. A meeting was arranged with policymakers who met the inclusion criteria by the qualitative interview experts.

2.7.2 Recruitment of People diagnosed with TB or Have Had TB

PWTB who met the eligibility criteria and accessing care at a DOT center were invited to participate in the study. Informed consent was obtained and an interview was scheduled. In addition, PWTB/PWHTB were recruited from the TB community (TB voice network) following the advertisement of the study calling for invitations on this platform. A sampling frame obtained from the invitations and those accessing the DOT centres was subjected to simple random sampling (lottery) to recruit the required sample from the catchment area (geographically defined Ghana Health Service designated areas) of the study facilities (Appendix 13, Appendix 14, Appendix 15, Appendix 16, Appendix 17, Appendix 18, Appendix 19 and Appendix 20).

2.7.3 Recruitment of Family Members/Caregivers Living with PWTB or PWHTB

PWTB/PWHTB were asked to identify a family member/caregiver who supports or had supported them in their TB management. Such persons were interviewed after providing informed consent. In a situation whereby, the family member does not reside with the PWTB and/or PWHTB, a

follow up log was completed for that person and the interview were conducted later at the convenience of the family member/caregiver.

2.7.4 Recruitment of Healthcare Practitioners

Healthcare practitioners (including persons who play a role in TB management) at the sampled DOT centres were invited to participate in the study and their consent was sought to complete study instrument for healthcare practitioners. To be eligible for selection for interview as a healthcare practitioner, the person must have worked at the treatment centre or involved in TB treatment for at least three (3) months.

2.7.5 Recruitment of Community Leaders

Community leaders residing in the neighborhood of persons diagnosed with TB or have had TB were identified, invited to participate in the study, consented and interviewed.

2.7.6 Recruiting Qualitative Subjects

Participants considered for the qualitative interviews included PWTB/ PWHTB, family members who have in way offered or offering support for PWHTB or PWTB, community leaders residing with PWTB and/or PWHTB, health care workers and policymakers including TB program staff (national and subnational), representatives from judiciary and legal communities and legislators. The policy makers were tasked to deliberate on the extent to which the country's existing laws and policies harm or protect people with TB.

Data collectors were tasked to complete a qualitative interview follow-up log (Appendix 13) for PWTB/PWHTB, family member or caregivers, community leaders and health care workers during the quantitative interview based on the selection criteria outlined below:

- Study participants who eagerly provided more information than solicited during the interview
- Participants who showed the tendency of taking advantage of the opportunity presented by the study to express or pour out what has been “bottled” in them.
- Participants who appeared to show more interest during the interview and show no sign of being in a hurry to end the interview.
- Participants who shared an interesting experience during the quantitative interview, that could be further explored via a qualitative interview

- Participants with one of the above criteria who were willing to participate in the qualitative interview.

However, policymakers were recruited mainly using a number of inclusion criteria including being familiar with the laws and policies regarding stigma. Using the qualitative follow-up log for each study population, the team purposively selected PWTB or PWHTB and family member or caregiver for separate FGDs at a venue of convenience. Community leaders, health care workers and policymakers were also selected by purposive sampling for the IDIs. Below is a table describing the qualitative interviews that were conducted.

Table 3: Details of interviews conducted

Type of Interview	Category of Respondents	Number of Interviews	Total
IDI	Community leaders	4 per region	32
	Health care workers	4 per region	32
	TB program staff	2	2
	Representatives from judiciary and legal communities	2	2
	Legislators.	2	2
FGD	PWTB or PWHTB	2 per region	16
	Family member or Caregiver	2 per region	16
Total			102

2.8 DATA MANAGEMENT AND STATISTICAL ANALYSIS

2.8.1 Data Collection

The study adopted the concurrent mixed methods approach (that is collecting both quantitative and qualitative data).

2.8.1.1 Quantitative Data Collection

Quantitative data were collected using the electronic version of the questionnaire (Research Electronic Data Capture). Semi-structured questionnaires were employed to collect data from the study target population: PWTB/PWHTB, family members/caregivers, community leaders and HCWs.

2.8.1.2 Qualitative Data Collection

Qualitative data were collected using the Focus Group Discussion (FGD) approach and in-depth interviews (IDIs). At least two (2) FGDs were conducted for PWTB/PWHTB and 2 FGDs for family members or caregivers from each selected region. Each FGD session constituted 8-15 randomly selected participants, taking into consideration gender and age. Four (4) IDIs were conducted for 4 purposively selected community leaders and 4 health care workers from each region. Two IDIs were conducted for each of the various policymakers. Therefore, a total of about 102 (32 FGDs and 70 IDIs) qualitative interviews were conducted. Participants were informed of the rules and regulations guiding the interview after consent was sought. Audio recorders were used to collect the qualitative data and transcribed immediately after the discussions. The tapes were listened carefully, and checked for accuracy of the transcripts.

2.8.2 Instruments for Data Collection

Due to the multiple nature of languages spoken in Ghana (67 local languages and 29 dialects in Ghana) [34], translation and back translation was not feasible. Although efforts were made to recruit persons who were multi-lingual (For each of the regions we recruited individuals who speak English and or the primary language(s) that are spoken at the region/town). Quantitative data were collected using the REDCap. REDCap is a secure web application for building and managing online surveys and databases. REDCap had a mobile application that was installed on the tablets of each data collector. This allowed for offline data capture (i.e., data collection is possible even without internet access). The data were uploaded as soon as the tablet was connected to the internet. The semi-structured data collection tool had four (4) major sections: Stigma Scale, Experienced Stigma/ Discrimination, Observed Stigma/ Discrimination and demographics. The assessment questionnaire applied to only four (4) target group including PWTB/PWHTB, family members / primary caregivers of people diagnosed with TB, Community leaders living in the same community as PWTB/PWHTB and health care workers.

There were separate qualitative questions for PWTB/PWHTB, family members/primary caregivers of people diagnosed with TB, Community leaders living in the same community as PWTB/PWHTB, health care workers and policymakers.

2.8.3 DATA ANALYSIS

2.8.3.1 Quantitative Data Analysis

Data cleaning, validation and analysis was done using a combination of MS Excel and Stata version 16. Data were analyzed using Stata version 16 statistical software (StataCorp. 4905 Lakeway Drive Station, Texas 77845, USA). Descriptive statistics were performed for all variables and expressed as means and standard deviation for continuous variables. Categorical variables were expressed as proportions and presented using tables and charts. The analyses were aligned with the specific objectives as described below:

1. Levels and dimensions of TB stigma and gender differences among people diagnosed with TB.

Descriptive assessment of the various levels was analyzed and presented in charts. A table showing gender differences was done. In addition, based on the results, the levels and dimensions of TB stigma were categorized into two. This was used as the outcome variable and was related with all the background characteristics and other explanatory variables in order to assess possible association using the Chi-square/Fisher's exact test of association.

2. Level and dimensions of secondary TB stigma, stigma directly experienced, and stigma observed by family members/primary caregivers of people diagnosed with TB.

The first level of this analysis was considered a descriptive assessment of the results which were presented in a chart and tables. The dimensions of secondary TB and stigma experienced by family members were categorized and test of association was done using chi-square and regression analysis models.

3. Level of perceived TB stigma against people diagnosed with TB in communities and stigma observed by the community.

The data were analyzed to show two groups (having perceived stigma and not having perceived stigma). This group were compared with the explanatory variables.

4. To assess the level and dimensions of perceived TB stigma against people diagnosed with TB in health care settings and stigma against health care workers.

This data was described in line with the categories of health workers interviewed. Other characteristics of the respondents such as years worked was summarized and presented as means and standard deviation. Proportions were estimated and presented in tables.

5. The extent to which structural stigma could harm or protect people diagnosed with TB.

Self-stigma across the various category of respondents interviewed was assessed using a 5-point Likert scale, developed by Stop TB Partnership. The 5-point Likert scale was categorized as strongly disagree, disagree, no opinion, agree and strongly agree. Strongly disagree was coded as 0, disagree as 1, no opinion as 2, agree as 3 and strongly agree as 4. A composite of strongly agreed and agreed options was estimated for all perceived stigma for all the four target population.

The analysis was done to document existing laws that are in force to combat TB stigma and their means of enforcement. The analysis was done using the matrix method in Stata.

For each of the seven TB-related rights considered in this study, the policy makers scored the existence and enforcement of laws and policies, and media coverage of the enforcement of laws and policies according to a 5-point scoring system in a Law and Policy Matrices (below):

Table 4: Law/policy scoring matrix

Existence of Laws/Policies		Enforcement of Laws/Policies		Media Coverage of Enforcement of Laws/Policies	
Score	Description	Score	Description	Score	Description
0	Laws/policies that <u>harm</u> people with TB exist at <u>national level</u>	0	Laws/policies that <u>harm</u> people with TB are enforced at <u>national level</u>	0	Enforcement of laws/policies that <u>harm</u> people with TB is supported in <u>national media coverage</u>
1	Laws/policies that <u>harm</u> people with TB exist only at <u>subnational level</u>	1	Laws /policies that <u>harm</u> people with TB are enforced only at <u>subnational level</u>	1	Enforcement of laws/policies that <u>harm</u> people with TB is supported only in <u>subnational media coverage</u>
2	No laws/policies relevant to people with TB exist	2	No laws/policies relevant to people with TB	2	No media coverage

3	Laws/policies that <u>protect</u> people with TB exist only at <u>subnational level</u>	3	Laws/policies that <u>protect</u> people with TB are enforced only at <u>subnational level</u>	3	Enforcement of laws/policies that <u>protect</u> people with TB is supported only in <u>subnational media coverage</u>
4	Laws/policies that <u>protect</u> people with TB exist at <u>national level</u>	4	Laws/policies that <u>protect</u> people with TB are enforced at <u>national level</u>	4	Enforcement of laws/policies that <u>protect</u> people with TB is supported in <u>national media coverage</u>

A total score was computed for each category of policy maker, from which a composite score (average score) was obtained. This was done separately for all the seven (7) rights considered in this study. An average overall score was computed to denote the extent to which the laws and policies were considered in the context of TB stigma.

The scoring below was used for determining whether existence, enforcement and media coverage of the laws and/or policy harm or protect PWTB and PWHTB.

An average score (AvgS):

- **0** = Laws/policies that harm people with TB exist/enforced/has media coverage at national level
- **1** = Laws/policies that harm people with TB exist/enforced/has media only at subnational level
- **2** = No laws/policies relevant to people with TB exist/enforced/have media coverage
- **3** = Laws/policies that protect people with TB exist/enforced/has media only at subnational level
- **4** = Laws/policies that protect people with TB exist/enforced/has media at national level

2.8.3.2 Qualitative Data Analysis

The Qualitative interviews were transcribed verbatim from the audio-recordings. The data collected were cleaned. Although members of the TB community led the study, the stigma Consultant supported by other qualitative experts transcribed the recording into texts, and imported into Nvivo software for thematic analysis.

2.9 Quality Assurance

The research assistants (data collectors) were required to double check the entries done after each interview. Supervisors were tasked to go through the data collected to check for completeness, correctness and inconsistencies after each day before being uploaded to the REDCap server. Also, the data from the field were subjected to data auditing in the database. The data manager reviewed the various fields of the dataset for consistency and accuracy. Inaccurate and inconsistent data were queried and directed to the officer responsible for that recruitment.

2.10 Project Management

The Ghana-West Africa Program to Combat AIDS and STI (WAPCAS) together with the Scientific Advisory Committee (SAC) had oversight responsibility over the entire activities of the study including disbursement and accountability of funds. The NTP contributed to the development and review of the study protocol, and had an oversight on the implementation of the study. They also provided material resources and facilitated data collection by liaising with the regional and district health administrations of the study regions to grant health facility access to the data collection team. The Principal Investigator (PI) and the Co-Principal Investigators (Co-PIs) assisted with the development and review of study protocol, and acquisition of ethical clearance. In addition, the PI and Co-PIs reviewed the TB report. The study coordinator (from the TB community) steered the day to day running of the study including bringing together the members in the TB community, making travel arrangements and other related coordination tasks. The Research Consultant (TB stigma expert) had an oversight responsibility on the research study including the acquisition of supplies for the study, training of data collectors, ensure that data acquisition was done in accordance with the approved protocol, and also performed other research related activities in the study. The TB community members were engaged in the data collection and its supervision. The supervisors were tasked to ensure data collection is done in accordance with the study protocol and also address field related issues that were within their capabilities.

2.11 Ethical Considerations

The approval for the conduct of the study was sought from the Ghana Health Service Ethics Review Committee (GHS-ERC) and the Committee of Human Research Publications and Ethics at the Kwame Nkrumah University of Science and Technology (KNUST-CHRPE – Ref: CHRPL,

/AP /218/20). Ethical approval was requested from these institutions and permission was sought from the selected facilities at the selected regions or districts from the GHS. Furthermore, permission was sought from chiefs, district heads and other community leaders during community entry for data collection.

2.12 Risks Anticipated and COVID-19 Issues

The risk of identifying respondents by a study independent individual was anticipated. Therefore, the data collection team were trained to uphold high ethical standards including obtaining participants consent, respect participants responses, respect participants privacy, and the data collected contained no identifiable information, hence participants were not linked to the data. Moreover, the data were kept in a secured server under lock and made accessible only to the study team. If any other referral needs arose from the interviews, these were supported by the team and accommodated accordingly.

The risk of being exposed to the COVID-19 virus (SARS COV-2) was anticipated. This risk was mitigated through strict adherence to safety precautions/guidelines given by the Ghana Health Service, World Health Organization and the Centre for Disease Control and prevention. The measures taken in this study are outlined below:

2.12.1 Guidelines for Protecting Research Team Members and Respondents from COVID-19

These guidelines were to ensure that the safety precautions given by the WHO, CDC and Ghana Health Service [31,32] to prevent the spread of COVID-19 are strictly adhered to. For the purpose of the TB Stigma Index Study, the precautions were subdivided into two; observing COVID-19 preventive guidelines during project meeting and observing COVID-19 guidelines during interviews and Focus Group Discussions.

2.12.2 Observing Covid-19 Preventive Guidelines during Project Meetings

There were no large gatherings for the study team throughout the period of the study. The main project meeting held were stakeholders' meetings and training of the data collectors. The stakeholder meeting was done in groups with the number ranging from 10 to 40. Also, a total of twenty (20) interviewers and five (5) facilitators were present at the training. The COVID-19 safety guidelines were observed as follows:

- Training of data collectors was done in a larger conference room
- The research team ensured adequate physical distancing (persons were required to sit at 6 feet apart from each other).
- Hand hygiene facility (alcohol-based hand sanitizer, portable water with soap and tissues) was provided at the entrance of the meeting conference room
- All meeting attendees were offered nose masks and were required to use it throughout the period
- All meeting attendees were taken through a step-by-step procedure on correct use of face masks and hand sanitizers. The training aimed at equipping the attendees with the skills to be able to adopt the preventive practices and also educate prospective respondents (interviewees). The main source document for training on the correct use of mask was based on the Ministerial Directive on wearing masks in public places to prevent transmission of COVID-19 (which was authored by the Director General of Ghana Health Service, Reference number: GHS/DGS/1.5)
- Transportation allowances given to attendees was done through digital transfer using mobile money as a way of minimizing contacts.

2.12.3 Observing COVID-19 Guidelines during Interviews

The interview was both one-on-one and in some few instances, group discussion. The interviewer (research team member) took the opportunity to educate the respondents on the appropriate use of alcohol-based sanitizer and nose mask by ensuring that the following procedures were met.

- At the interview site, the interviewer and the respondents were required to be seated at 6 feet distance apart.
- The interviewer dispensed alcohol-based hand sanitizer to the respondents.
- The interviewer then gave each of the respondents a nose mask to put on before the interview
- The interviewer ensured that the respondents cover all surfaces of their hands and rub them together until they feel dry.
- After the interview, the interviewer dispensed alcohol-based sanitizer again on the hands of the respondents.

- The interviewer took the opportunity to educate the respondents on the need to continuously observe the safety protocols against COVID-19
- Respondents were given one 200 ml each of alcohol-based hand sanitizer for personal use

3.0 RESEARCH FINDINGS

3.1 People diagnosed with TB or Have Had TB (PWTB/PWHTB)

3.1.2 Regional enrollment

A total of 1,025 PWTB/PWHTB were recruited across eight selected regions of Ghana. Majority of the participants were recruited from the Greater Accra region (25.5%), followed by Ashanti region (22.6%), Western region (18.5%) and Eastern region (16.3%), with the least recruited from the Northern region. (Figure 2: Percentage distribution of PWTB/PWHTB).

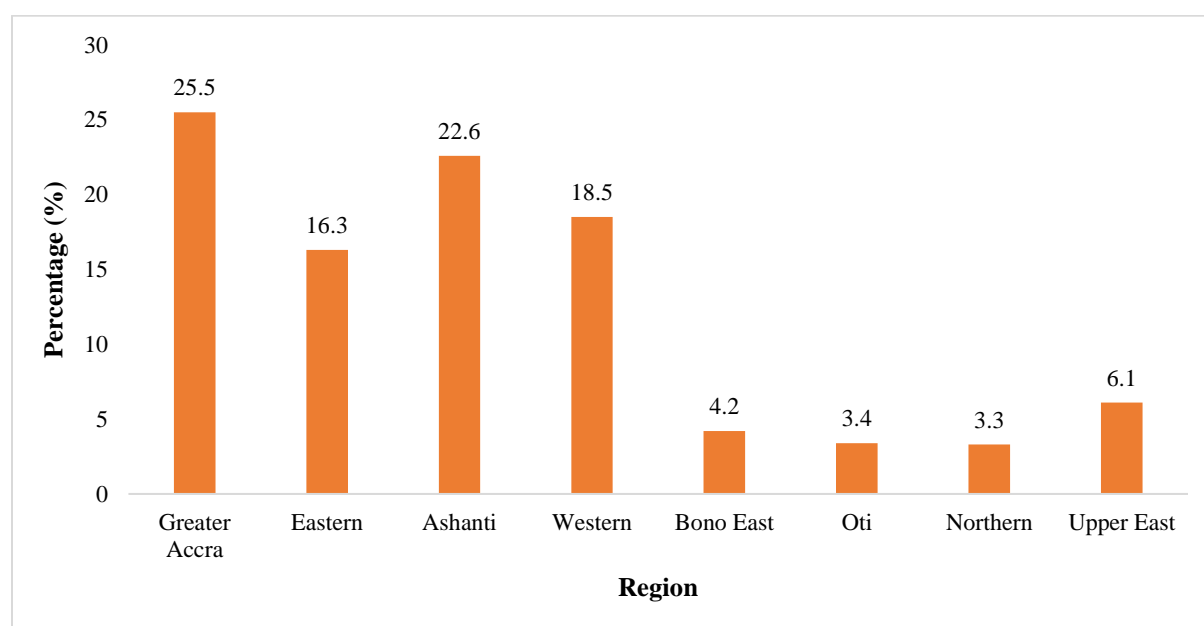


Figure 2: Percentage distribution of PWTB/PWHTB recruited from each region in Ghana

3.1.3 Socio-demographic characteristics of PWTB/PWHTB

The median age of the respondents was 40 years with inter quartile range of 30-51 years. More than half of the respondents reported being classified as male at birth (67.1%). Less than one percent (0.6%) described themselves other than Less than half (43.5%) of the respondents were married, or had a basic education (primary/JHS/middle school) (47.4%) and more than three-quarters are employed (Table 5: Socio-demographic characteristics of PWTB/PWHTB).

Table 5: Socio-demographic characteristics of PWTB/PWHTB

Background information	Frequency (n=1,025)	Percentage (%)
Age (years)	Median (IQR) = 40 (30-51)	
Sex classified at birth		
Female	337	32.9
Male	688	67.1
Current gender identity		
Female	334	32.6
Male	684	66.7
Transgender	7	0.7
Highest education status		
No formal education	169	16.5
Primary	129	12.6
JHS/Middle school	357	34.8
Secondary/Vocational school	298	29.1
Tertiary education	72	7.02
Marital status		
Single	346	33.8
Cohabiting	70	6.8
Married	446	43.5
Widowed	54	5.3
Divorced	109	10.6
Occupational status		
Unemployed	211	20.6
Trading	224	21.9
Farming/fishing	152	14.8
Private/public sector	98	9.6
Artisan*	209	20.4
Student	64	6.2
Other	67	6.5

*Artisan (painter, driver, mason, mechanic, beautician, etc.)

Tuberculosis occurs in all age groups but despite recruiting PWTB/PWHTB from the ages of 18 years and above, it was revealed in this that the burden of TB was higher among individuals aged 30-51 years. The burden of TB was higher among the male population, with a male to female ratio of approximately 2:1.

The qualitative synthesis of the recurring themes showed that men were more vulnerable to and defiant in seeking early care for TB. Men were found to have poor health seeking behaviour for TB care though they represent the gender category with the disproportionate burden of TB infection.

For us here in the north I think the men appear to be more vulnerable to TB and defiantly as a result of the risk factors. The risk factors here are so high such as smoking, alcoholism and most of them, the job that they do expose them often compared to the women. –Awudu, 43 years, Bolgantaga (FGD participant)

3.1.4 Stigma experienced by PWTB/PWHTB

Twenty-two percent (22.0 %) of PWTB/PWHTB reported ever being stigmatized due to their TB status (Figure 3). Stigma was prominent in males (13.0%) compared to the females (8.7%) and transgender (0.3%) (Appendix 1). This is considerably significant and may have several implications on accessing healthcare and the quality of life of PWTB/PWHTB. Therefore, if the war against TB would be won then the fight against TB stigma has to be intensified to reduce stigma to minimum or zero.

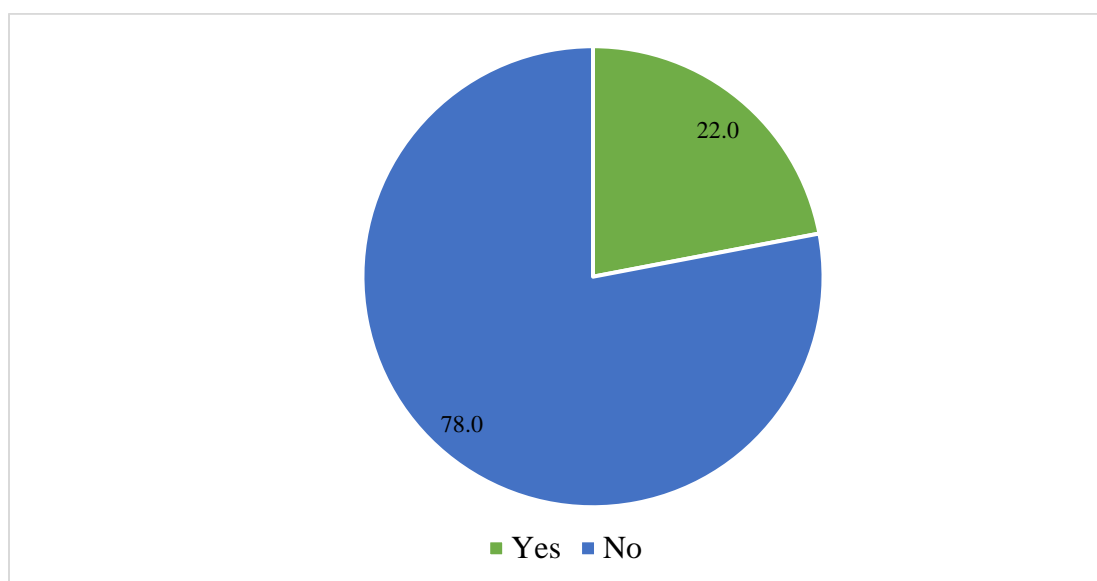


Figure 3: Stigma experienced by People diagnosed With TB or Have TB in Ghana

3.1.5 Self-identity of PWTB/PWHTB

Approximately, 9.0% of the study participants indicated that they were HIV positive. Almost 20.0% of respondents reported being rural poor, 11.8% being urban slum dwellers and 1.5% were persons living with disability. More than 50.0% reported being on TB treatment at the time of the

study but 0.3% had never been on TB treatment. Majority (60.9%) of the respondents had pulmonary TB and more than a third (31.7%) did not know the type of TB they had (Table 6).

Table 6: Self-identity of PWTB/PWHTB

Do you self-identify as any of the following? *	Female n (%)	Male n (%)	Transgender n (%)	Total n (%)
Person living with HIV	45(4.4)	44(4.3)	1(0.1)	90(8.8)
Miner	3(0.3)	73(7.1)	2(0.2)	78(7.6)
Health care worker	7(0.7)	6(0.6)	0(0)	13(1.3)
Refugee	1(0.1)	6(0.6)	0(0)	7(0.7)
Urban slum dweller	30(2.9)	91(8.9)	0(0)	121(11.8)
Rural poor	59(5.8)	141(13.8)	3(0.3)	203(19.8)
Person who uses drugs	2(0.2)	28(2.7)	0(0)	30(2.9)
Person who has a disability	2(0.2)	12(1.2)	1(0.1)	15(1.5)
Indigenous person	32(3.1)	89(8.7)	0(0)	121(11.8)
Former prisoner	2(0.2)	15(1.5)	0(0)	17(1.7)
None	175(17.1)	314(30.6)	1(0.1)	490(47.8)
TB Status				
Never had TB treatment	1(0.1)	2(0.2)	0(0)	3(0.3)
Completed TB treatment over one year ago	28(2.7)	52(5.1)	1(0.1)	81(7.9)
Completed TB treatment within the last year	88(8.6)	187(18.2)	2(0.2)	277(27.0)
Currently on TB treatment	217(21.2)	443(43.2)	4(0.4)	664(64.8)
Type of TB				
Pulmonary TB	202(19.7)	416(40.6)	6(0.6)	624(60.9)
Multidrug-Resistant TB	7(0.7)	16(1.6)	0(0)	23(2.2)
Extensively Drug-Resistant TB	0(0)	4(0.4)	0(0)	4(0.4)
Extra-pulmonary TB	12(1.2)	37(3.6)	0(0)	49(4.8)
Do not know	113(11)	211(20.6)	1(0.1)	325(31.7)

*Multiple response

The fact that TB stigma is higher among some key populations heightens the possibility of self-stigma and transmission of the disease to others, hindering both access and provision of services. This could also lead to defaulter rate among PWTB who are on medication. This justifies the need for TB stigma reduction programs that are tailored to the needs of these key populations. Even though this study identified very few of the respondents who had never had TB treatment, this is a crucial indicator of recrudescence and communicability of the disease since they may be having active infection. It is anticipated that the fear of stigma may have deterred them from seeking care hence the need for effective programs centered on the fight against stigma.

3.1.5.1 Association between self-identity of people with or have had TB and ever felt being stigmatized due to TB status

Table 7: Association between self-identity of people with or had TB and ever felt being stigmatized due to TB status shows percentage distribution of stigma experienced among key PWTB/PWHTB. More than forty percent (42.2%) of PWTB/PWHTB with HIV comorbidity reported being stigmatized. Although, it is known from many literatures that PLHIV/PWTB or PWHTB are often stigmatized but the rate recorded by this study may suggest it is becoming a menace in Ghana. It can also be argued that the perception that PWTB/PWHTB are usually infected with HIV could be a major barrier to accessing health care services. Being a person living with HIV ($p=0.000$), miner ($p=0.046$), rural poor ($p=0.018$) was associated with stigma experienced due to their TB status. This suggests the significance of considering key populations in TB programs, aimed at minimizing TB stigma and addressing stigma among PWTB/PWHTB.

Table 7: Association between self-identity of people with or had TB and ever felt being stigmatized due to TB status

Do you self-identify as any of the following? (n=1,025)	Have you ever felt you were stigmatized because of your TB status?		P-value
	No n (%)	Yes n (%)	
Person living with HIV			0.0001
No	745 (79.68)	190 (20.32)	
Yes	52 (57.78)	38 (42.22)	
Miner			0.0460
No	729 (76.98)	218 (23.02)	
Yes	68 (87.18)	10 (12.82)	
Health care worker			1.0000
No	787 (77.77)	225 (22.23)	
Yes	10 (76.92)	3 (23.08)	
Refugee			0.1880
No	793 (77.9)	225 (22.1)	
Yes	4 (57.14)	3 (42.86)	
Urban slum dweller			0.4851
No	706 (78.1)	198 (21.9)	
Yes	91 (75.21)	30 (24.79)	
Rural poor			0.0182
No	652 (79.32)	170 (20.68)	
Yes	145 (71.43)	58 (28.57)	
Person who use drugs			1.000

No	773 (77.69)	222 (22.31)	
Yes	24 (80.00)	6 (20.00)	
Person who has a disability			0.0530
No	789 (78.12)	221 (21.88)	
Yes	8 (53.33)	7 (46.67)	
Indigenous person			0.1043
No	710 (78.54)	194 (21.46)	
Yes	87 (71.9)	34 (28.1)	
Former prisoner			0.0750
No	787 (78.08)	221 (21.92)	
Yes	10 (58.82)	7 (41.18)	

3.1.6 Stigma Dimensions for PWTB/PWHTB

3.1.6.1 Self-Stigma among PWTB/PWHTB

Figure 4 reports self-stigma among the PWTB/PWHTB. Across the 5-point self-stigma scale, there was a general disagreement on statements that described the idea that individuals may come to endorse the negative stereotype about TB. Majority (79.0%) agreed with the assertion that they keep distance from others to avoid spreading the TB germs, 70.0% reported they choose carefully who they tell about their TB status. Also, 50.4% reported they feel hurt how others react to knowing they have TB.

Appendix 2 reports on of self-stigma among PWTB/PWHTB by gender. Across the various self-stigma assessed, all persons (n=7, 100%) who identified as transgender reported that they keep a distance from others to avoid spreading TB germs compared to the males (n=540, 79%) and females (n=264, 79%). Also, majority of transgender (n=6, 86%), males (n=472, 69%) and females (n=240, 72%) agreed to the assertion that they choose carefully who they tell about having TB.

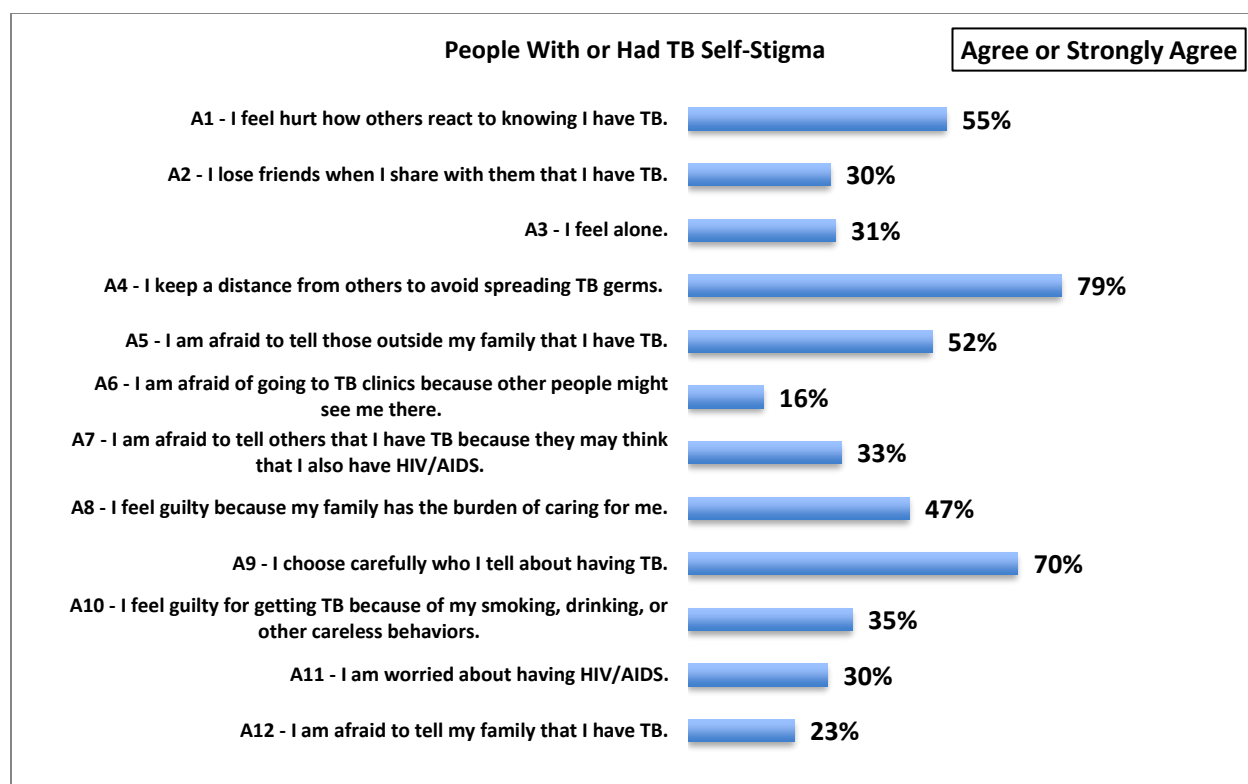


Figure 4: Percentage distribution of reported self-stigma among People diagnosed With TB or People Who Have Had TB -in Ghana. Proportions computed using a Likert scale by combining ‘agree’ and ‘strongly agree’

Overall, the data shows that self-stigma among the respondents was high and public trust was a major issue due to the fear of stigma. Consequently, this excessive self-stigma can negatively affect the psychosocial and economic wellbeing as well as quality of life of PWTB/PWHTB. Further, the absence of public trust has the tendency to discourage TB testing and/or seeking for treatment. In the FGD with PWTB/PWHTB, self-stigma was reiterated as a recurrent theme among discussants.

..... please in the case of myself when people are not even looking at me, I bow in shame and hurry to go home – Mary, 32 years, Axim (FGD participant)

TB related stigma has been a challenge for PWTB for long and though it may be reducing, it continues to be a problem for PWTB/PWHTB. Narrating how the condition of stigma existed over the past decade, one FGD discussant who has been treated of TB infection shared:

Oh... I have heard it before and myself I have gotten it before ...oh it was God who helped me that time in 2007. That time health insurance was working and so I went to the hospital and I did different labs. I did a different lab and when they check I was told I am okay. But subsequently, when I coughed and blood was coming, someone told me I should go and check for TB and I went to Mamobi Polyclinic. The first day they gave me small tube and they said I should go home and at dawn when I take first phlegm, I should bring it and when I did the first and second day, they told me it was TB. When it was confirmed, I became sick as if I have gotten aids and felt I was a bad person. – Akwesi, 40 years, Koforidua (FGD participant)

3.1.7 Summary of stigma dimension for PWTB/PWHTB

Most of the PWTB/PWHTB (69.0%) admitted that the self-stigma assessment scale described how they felt about TB. Approximately, 7% of these respondents indicated that these feelings inhibited them from seeking and accessing TB services (Table 8: Summary of stigma dimension for PWTB/PWHTB). Imperatively, this could be considered significant and a public health concern. Overall, self-stigma was high among the respondents which could have serious implications on the quality of life of PWTB/PWHTB.

Table 8: Summary of stigma dimension for PWTB/PWHTB

Summaries of feelings about TB (n=1,025)	No n (%)	Yes n (%)
Do any of the perception statements also describe how you feel about TB yourself?	318(31.0)	707(69.0)
Have any of these feelings you have about TB inhibited you from seeking and accessing TB services?	949(89.3)	76(7.4)

Contrary to the quantitative findings, an FGD revealed that not all PWTB/PWHTB had experienced stigma. However, this was subjective to disclosing his/her TB status to another person which suggests that disclosure influences stigma. This

since I got the sickness all friends come around and it made no one to point fingers at me before. Besides it was not anyone who knows that I have the sickness and if it is not my friend who will say it, nobody will know that I am sick. So, I have not seen that thing that

someone has pointed fingers at me that I have TB, I have not met some before- Kofie, 48 years, Prestea (FGD participant)

Same observations were made from the submissions of Kwadwo

initially when I had the sickness, I came to the clinic to take drugs but the nurse told me that it is a scary disease and I can't come closer to my family and things but when I went my friends were able to come to me and we talk alright. I think because I have not told them about the sickness that is why when I go out nobody points fingers at me that this gentleman has this sickness. My friends come to me and we talk all the time and my wife too has not discriminated against me before. Even my mum is not aware of my sickness. – Kwadwo, 32 years, Prestea (FGD participant)

3.1.8 Settings stigma occurred that inhibited access to TB services

Of the 1025 PWTB/PWHTB, 5.0% experienced stigma in hospitals or clinics, 14.4% from neighbors living in their communities, 8.8% at home and 4.3% at workplaces (Table 9: Settings PWTB/PWHTB experienced stigma). Comparably, stigma was very high in the community followed by the home and as a result inhibited the respondents from seeking and accessing TB services. Interventional programs designed to mitigate TB stigma should give utmost considerations to these settings.

Settings of TB stigma (n=1025)	Yes n (%)	No n (%)
Have you experienced stigma in hospitals or clinics that inhibited you from continuing to seek and access TB services?	51(5.0)	974(95.0)
Have you experienced stigma from your neighbors in your community where you live that inhibited you from seeking and accessing TB services	148(14.4)	877(85.6)
Have you experienced stigma at home that inhibited you from seeking and accessing TB services?	90(8.8)	935(91.2)

Have you experienced stigma at work that inhibited you from seeking and accessing TB services?	44(4.3)	981(95.7)
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Table 9: Settings PWTB/PWHTB experienced stigma

Buttressing the quantitative findings, Eduka, a focus group discussant shared:

I didn't believe the sickness was real when I was in school, till the time I got the sickness. I went through a lot of pains, even in the house my own brother doesn't want me to hold and read his book. Everything in the house when I am doing hay! And even when I am in the room nobody wants to come and it made me worried thinking that I am also going to die because when it happened like that all my loved ones forsake me. And the thing was painful and it was when I came to Axim that I got hope that I can survive. So, I will give thanks to brother Emma for supporting me throughout my treatment. - Eduka, 23 years, Kumasi (FGD participant)

Stigma originating from the household formed a more disturbing externalizing source of TB related stigma for people with TB.

Before I got diagnosed, I haven't seen anyone with the sickness before hence I was very worried. I stay in secondi but I took a transfer to live in Axim because I was told I will be on medication for 6 months. So, I took a transfer and came to Axim but the house I was living in they don't even want me to pick a bucket, when I pick a bucket before someone else, he or she will wait till another person comes for it. When I fetch water inside the bucket, no one comes closer to the water hence I decided to buy my own bucket, my plates, my cup and I don't use anybody's thing in the house. When I go out to visit the lavatory, I hear people saying "It is when they are about to die that they come home"— Sara, 43 years, Ashaiman (FGD participant)

3.1.9 Stigma experienced by PWTB/PWHTB on their TB journey under different settings

Error! Reference source not found. Figure 5 shows responses of PWTB/PWHTB who experienced stigma on their journey under different settings. Buttressing the findings in Figure 5, stigma was pronounced in the community, followed by the home/family and the hospitals/clinic. In the community, stigma inhibited a significant number of PWTB/PWHTB from recognizing symptoms (13.0%) and an equal proportion of them (9%) from seeking care, beginning treatment and getting treatment adherence support. A number of PWTB/PWHTB were inhibited from recognizing symptoms (8.0%), seeking care (7.0%), and an equal proportion of them from getting an accurate diagnosis, beginning treatment, and completing treatment due to the stigma experienced in the home/family. Further, stigma experienced at the hospitals/clinics inhibited a

number of PWTB/PWHTB from seeking care (6.0%), getting an accurate diagnosis (6.0%), recognizing symptoms (5.0%) and getting treatment adherence support (5.0%). PWTB/PWHTB who identified as transgender were the most stigmatized group in these settings followed by those who identify as females and males (**Error! Reference source not found.**). These findings suggest that the community, family/home and hospitals/clinics are the most critical settings of projecting TB stigma and therefore, community- and hospital-based interventions should be developed to reduce stigma in these settings.

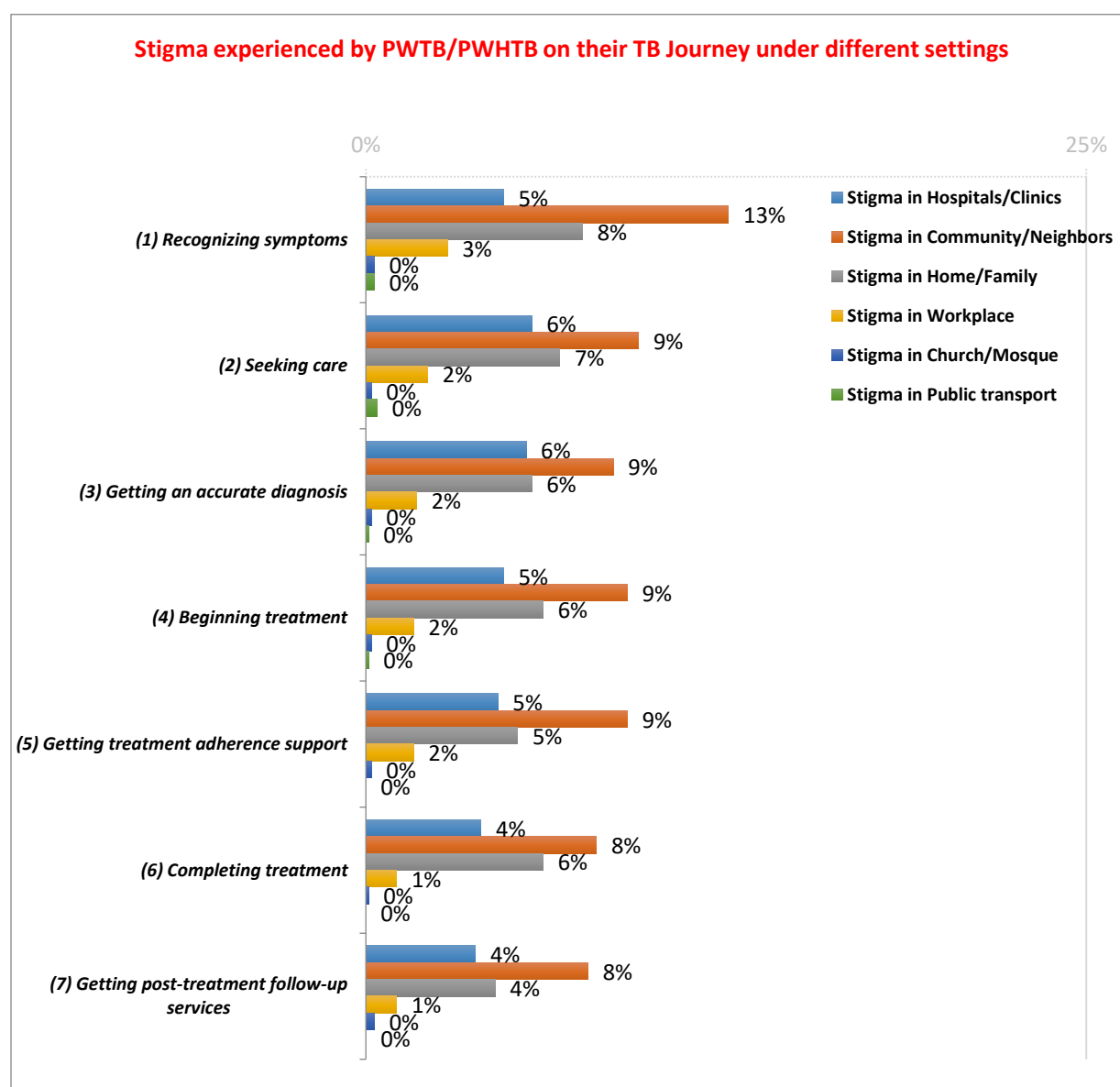


Figure 5: Percentage distribution of stigma experienced by PWTB/PWHTB during their TB journey under different settings in Ghana.

Though community level stigma was mentioned in the quantitative response, it emerged from the qualitative responses that, among PWTB/PWHTB enrolled in the Focus Group discussions, self-isolation and in-door stay limited their experience of community level stigma. Some persons rather mentioned hospital level stigma as a disturbing factor

Okay the government has to talk to the nurse and the doctors a lot about the sick people who come here. Like for some people like us we have lost hope and so we feel like coming to the hospital to take our drugs and the hospital encourages us to that we will get well. So, when we come from home to the hospital and the hospital to is not accommodating us and doing those things, it makes the person to lose hope because you came from the house with sorrow and the hospital you are coming for drugs you have also met sorrow. It is like from frying pan to fire and when it happens like that it is very disturbing. That is why the government has to intervene so that the nurses would have patience for us. Research about the doctors and nurses behaviour should be done- Mary, 32 years, Axim (FGD participant)

3.1.10 Specific TB related stigma experienced by PWTB/PWHTB

Table 10, shows the specific TB related stigma experienced by PWTB/PWHTB. The predominant stigma experienced was being gossiped about (18.3 %), followed by avoidance and isolation of PWTB (12.9%), and verbal/physical abuse (11.2%). Generally, gossip critically affects healthcare as well as directly affecting the wellbeing of people, therefore, it is anticipated that this form of stigma can be an albatross in the fight against the eradication of TB in Ghana. Moreover, avoidance and isolation and verbal/physical abuse are very key forms of stigma that has to be targeted by TB social interventional programs. Some of these findings such as loss of marriage and avoidance were also highlighted in the qualitative findings.

Table 10: Specific TB related stigma experienced by PWTB/PWHTB

Effect of TB stigma	Frequency (n=1025)	Percentage (%)
Gossip	188	18.3
Avoidance and isolation of TB patients	132	12.9
Verbal/physical abuse	115	11.2
Neglect/abandonment	58	5.7

Discrimination from medical staff	42	4.1
Long wait time at health facility	24	2.3
Denial of care	15	1.5
Loss of marriage	13	1.3
Provision of sub-standard care	7	0.7
Referring TB patients for HIV testing without counselling	19	1.9
Other	5	0.5

Corroborating loss of marriage as TB specific related stigma, one FGD participant explained how the diagnosis of TB led to denial of marriage of one PWTB:

there is one person I know. He wanted to marry but the family of the woman didn't accept him and he died through sorrow..... Abass, 42 years, Western region

(FGD participant)

PWTB/PWHTB were not only stigmatized by others by such persons avoiding them [PWTB/PWHTB] but also, some PWTB self-stigmatized themselves through self-initiated avoidance of significant others and immediate working colleagues to prevent discrimination and stigmatization from them. Amoakowaa, a nurse explains her experience:

There was a time that I coughed and that cough kept long. I went home and took a lot of anti-cough. I was shy to go to the hospital or go to the disease control officer to treat me because they may say me too, I have gotten TB. When it happened like that it was difficult for me, later the cough was severe and I went to see the disease control officer and he said if that is the case I should go and do a lab test but I refused because I don't think I have gotten TB and he said if that is the case I should take the drugs for him to see if I take the drugs like 3 days and maybe it will stop. I didn't want my colleagues to know because if they know that I have gotten TB, they won't come closer to me and things because of the stigma so it made me to hide it a little. Even I hide the drugs or taking the drugs from my husband until one day he saw it and asked me. But I told him, it was an immune booster. So, through that by the grace of God when I took it for 3 days the cough went off and when I became bold to do the test which was negative. Nursing Officer, 29, Prestea, (FGD participant)

3.1.11 Observed Stigma for PWTB/PWHTB

3.1.12 Know other PWTB/PWHTB being stigmatized

About ten percent (9.9%) had knowledge of people with or who have had TB being stigmatized because of their TB status (Table 11). This implies that observed stigma was considerably significant for PWTB/PWHTB and it is imperative to routinely measure this stigma as measure of fighting TB stigma.

Table 11: Know other PWTB/PWHTB being stigmatized

Do you know of other people with or who have had TB being stigmatized because of their TB status?	Frequency (n=1,025)	Percentage (%)
No	924	90.1
Yes	101	9.9

3.1.13 Know other PWTB/PWHTB being stigmatized during their TB journey under different settings

Like the respondents of this study, the most critical setting projecting TB stigma among other PWTB/PWHTB the respondents knew were mainly the community, home/family and the hospitals/clinics. Furthermore, the other PWTB/PWHTB who the respondents knew are more stigmatized in the community and this mostly inhibited them from recognizing symptoms (5.0%), seeking care (4.0%), getting an accurate diagnosis (3.0%), beginning treatment (3.0%) and getting treatment adherence support (3.0%) (Figure 6). The respondents knew other PWTB/PWHTB who were stigmatized in the home/family and hospitals/clinic which as a result inhibited them from recognizing symptoms (3.0% and 1.0% respectively), seeking care (3.0% and 1.0% respectively) and getting accurate (3.0% and 1.0% respectively) in these settings (Figure 6: Know other PWTB/PWHTB being stigmatized during their TB journey under different settings6). Although these findings were similar to the observations among the main respondents (PWTB/PWHTB), the proportions recorded were lower than that of the main respondents which could be attributed to recall difficulty. Nonetheless, it can be concluded that the community, home/family and hospitals

/clinics are very important to the aim of reducing or eliminating TB stigma in Ghana.

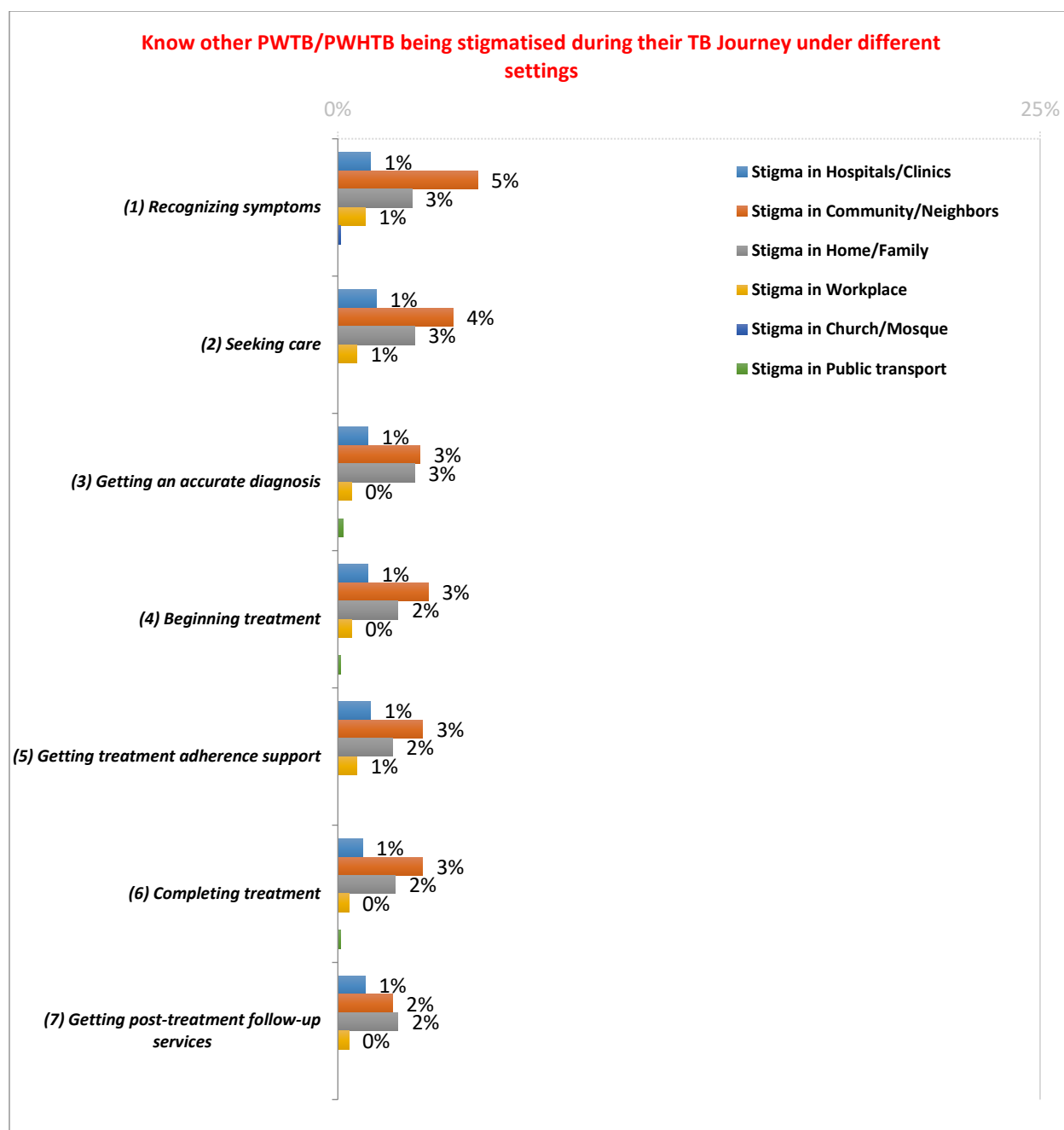


Figure 6: Know other PWTB/PWHTB being stigmatized during their TB journey under different settings in Ghana

A case of TB related stigma which led to the collapse of the business of one PWTB was mentioned. Accordingly, this level of stigma occurred to the PWTB at the time the symptoms began to surface. Describing how it occurred, **Margaret, 58yrs, Kumasi (FGD participant)**:

Oh, okay some time ago it has been long like 15 years ago, that time I was a teacher not a mistress and a woman who was a chop bar operator around the school, she was called Aunty Alice. She sells banku and others, people said she has gotten this sickness and through that even though the woman was not coming to where she sells the food, through rumors her business collapsed and couldn't come back to its feet. And so, with stigma it is there the woman passed away painfully and her business collapsed no one was able to continue her business

3.1.14 Specific TB related stigma experienced by other PWTB/PWHTB

Based on the account given by PWTB/PWHTB with knowledge of other people with or who have TB and experienced stigma, gossip (8.1%) and avoidance and isolation (6.3%) were the predominant stigma experienced (Table 12: Specific TB related stigma experienced by other people with or who have had TB). These were similar to the findings among the main respondents (PWTB/PWHTB) and therefore, it is anticipated that whatever the implications experienced by the main respondent of this study may be same among other PWTB/PWHTB whom the respondents knew.

Table 12: Specific TB related stigma experienced by other people with or who have had TB

TB related stigma (n=1025)	Frequency (n)	Percentage (%)
Gossip	83	8.1
Avoidance and isolation of TB patients	65	6.3
Verbal/physical abuse	37	3.6
Neglect/abandonment	22	2.1
Discrimination from medical staff	9	0.9
Denial of care	6	0.6
Long wait time at health facility	5	0.5
Loss of marriage	5	0.5
Referring TB patients for HIV testing without counselling	5	0.5
Provision of sub-standard care	2	0.2
Other	2	0.2

3.1.15 Treatment adherence

Less than five percent (4.3%) of the respondents reported ever missing their TB treatment within the last 6 months after TB diagnosis. The most common reason for the missed dose(s) was fear of side effects (1.2%), financial difficulties in accessing care (0.9%), and unavailability of TB drugs at hand (0.9%) (Table 13). The data shows that compliance to treatment was encouraging within the last 12 months even though a few missed their treatment. This is an indication that the National TB Program is on course and committed to the global aim of fighting TB in Ghana, hence needs more financial aid to roll out more interventional programs such active case finding using screening algorithms and diagnostic tools and as well Advocacy, Communication and Social Mobilization (ACSM) for stigma reduction and treatment adherence.

Table 13: Missing treatment and reasons for non-adherence

Factor (n=1,025)	Frequency (n)	Percentage (%)
Ever missed treatment in the last 6 months after TB diagnosis		
No	931	90.8
Yes, within the last 12 months	44	4.3
Yes, not in the last 12 months	14	1.4
I don't know/can't remember	36	3.5
Reason for drug adherence default*		
I was afraid that the TB drugs would cause some side effects	12	1.2
I did not have money to access care (transport charges, etc.)	9	0.9
No drug available at hand	9	0.9
I was worried/afraid that someone would find out my TB status	7	0.7
Felt better	6	0.6
Forgot	6	0.6
DOT Centre was far	5	0.5
I did not have means	5	0.5
I was not ready to deal with my TB disease	5	0.5
Non-availability of TB drugs in DOT centres	3	0.3
Other reason	2	0.2
I was worried the healthcare workers would treat me badly or disclose my TB status without my consent	1	0.1
I was denied TB treatment due to my gender identity	0	0.0

***Multiple response**

However, treatment non-adherence did not emerge as a dominant theme for PWTB. This is consistent with the 9 out of 10 persons who did not miss their TB medication. The increased levels of medication adherence for people diagnosed with TB had been observed by both health persons and community leaders who knew PWTB. In almost all the interviews from both health professionals directly engaged in TB care and community leaders with experience of persons who had been cured of TB, treatment adherence was considered high among people diagnosed with TB. A health professional share;

In terms of their adherence most of them take their treatment very well just that one or two of them that maybe once a while they forget to take their drugs or sometimes, they have travelled. Some miss one or two days of taking the drugs if not that it's cool and most of them adhere to the drugs very well.err to some extent I will say yeah because we had one case that traveled outside of Accra but even upon that we still followed up on her and she went to a different hospital and for some time now we have not had any defaulted cases
Amoakowaa (nurse), 34 years, Prestea (FGD participant)

Continued adherence to the TB medication was considered to have done the magic in restoring the severed relationships of people diagnosed TB with their families. In the summarized opinion of an FGD participant in Savelugu:

consistently because of the medicine they gave me, I was able to follow it consistently that made me out and I am now okay and have even married a different woman- **Awaley, 54 years, Svelugu, (FGD participant)**

At the national level, improved medication adherence was reported by national officers who expressed limited funds as constraints to sustaining the community directed approach to delivering TB medication. This was considered as one program approaches to ensuring medication compliance, cost reduction on persons seeking TB care and ensure reduction in facility level TB related stigma.

.... most often it treated in the community if it hasn't been that the supervisory role of making sure that the people come and they take the medication right in the hospital for you to see that they are taking then it will have been even be difficult for you to know who has

TB. For where I use to work such clients use to come very early and by the time others start coming, they would have come and gone so you wouldn't even know that they have come to take their medication. Now I think it has improved the way they go about things and if it further improved such that such medication will be given at home in the community. Such that the person will not need the supervision you want to do. It will be done at home. You go home the person takes the medication in your presence, swallows it and its safe. But maybe because of the luck of staffs that is why they will all have to come to the hospital/at a particular point. But that still is not the best. – Senior Program Officer (43yrs), Ghana Health Service, Accra

3.1.16 Gender issues

3.1.17 Perception of gender equality in human resource management (HRM)

Table 14: Perception of gender equality with regards to job acquisition reports gender equality issues with regards to job acquisition among PWTB/PWHTB. These responses, however, do not reflect the perception people have against PWTB/PWHTB. Self-stigma among could influence the way PWTB/PWHTB seek job. Over 25% of the PWTB/PWHTB believed that men and women were treated equally with regards to job acquisition, with the highest being in recruitment and selection (34%). The data shows the respondents perceived equal treatment with respect to human resource management among men and women in the general population.

Table 14: Perception of gender equality with regards to job acquisition among PWTB/PWHTB

Factor	Men & Women treated equally	Men treated less favorably	Women treated less favorably	Not applicable
	n (%)	n (%)	n (%)	n (%)
Recruitment & Selection	348(34)	65(6.3)	60(5.9)	552(53.9)
Remuneration (Wages)	335(32.7)	48(4.7)	49(4.8)	593(57.9)
Appraisal	298(29.1)	52(5.1)	64(6.2)	611(59.6)

Training and Development	296(28.9)	44(4.3)	72(7)	613(59.8)
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3.1.18 Experience and perception of gender inequality in community

The experience of loss of a job due to being a female was reported in 5.3% of the female respondents. More than one-fourth (23.2%) perceived that there were fewer opportunities for females in their community compared to men. Majority of the respondents reported equal treatment (75.3%) and involvement (75.2%) of males and females in the community (Table 15).

Table 15: Experience and perception of gender inequality in community

Factor	Experience/feeling	
	No n (%)	Yes n (%)
Lost job opportunity to a man (n=337) *	319(94.7)	18(5.3)
Fewer position than men (n=337) *	259(76.9)	78(23.2)
Harassed/bullied due to gender (n=1025)	962(93.9)	63(6.2)
Lower position due to gender (n=1025)	927(90.4)	98(9.6)
Equal access to resources(n=1025)	290(28.3)	735(71.7)
Inclusive culture (n=1025)	396(38.6)	629(61.4)
Discouraged (n=1025)	925(90.2)	100(9.8)
Treated equally (n=1025)	253(24.7)	772(75.3)
Equal involvement (n=1025)	254(24.8)	771(75.2)

***Females at birth only**

3.1.19 Treatment among men and women

Generally, more than half (71.7%) of the respondents reported to have equal access to resources and 75.3% reported men and women are treated equally in their community (Table 16: Treatment among men and women).

Table 16: Treatment among men and women

Treatment among men and women (n=1,025)	No n (%)	Yes n (%)
Harassed/bullied due to gender	962 (93.9)	63 (6.2)
Lower position due to gender	927 (90.4)	98 (9.6)
Equal access to resources	290 (28.3)	735 (71.7)
Inclusive culture	396 (38.6)	629 (61.4)
Discouraged	925 (90.2)	100 (9.8)

Treated equally	253 (24.7)	772 (75.3)
Equal involvement	254 (24.8)	771 (75.2)

Although the qualitative arm confirmed some findings in the quantitative arm, it appears women access more opportunities in terms of treatment. This was described in a similar context in the Upper East region:

Well, there are not but it looks as if the females access health facility more often as compared to their male counterparts. So probably where they have a challenge in terms of TB maybe the women might be picked up earlier than the men. The men might wait for a longer time when it is late before they appear at the hospital. That is the only difference that I see. Apart from that equal opportunities exist for everybody but the women take advantage of the opportunity of that access more as compare to the men. The men will try to solve it on their own take the local medicines and other things before it is very late that is when they will come to the hospital – Ayipala, 32years, Bolgantaga (FGD participant)

3.1.20 Decision making

Over sixty percent (67%) of respondents reported not being involved in community decision making and mobilization. This may be attributed to the cultural norms in most communities in Ghana. The inability to partake in decision-making was, however, largely attributed to low economic status (36.8 %), and gender (22.6 %) (Table 17).

Table 17: Community involvement in decision-making and perceived reasons for not being involved in community decision making

Involved in decision making	Frequency (n=1,025)	Percentage (%)
No	690	67.3
Yes	335	32.7
Reasons for not involved in decision		
Gender	232	22.6
Low economic status	377	36.8
TB status	163	15.9
General poor health	117	11.4

According to Table 16 and Table 17, men and women were equally treated in the community, however, women are offered fewer positions than men at the community. Therefore, more opportunities need to be created for females in order to reach the goal of gender transformation in the community. Comparably, the findings (Table 17) show that discrimination against PWTB/PWHTB was high but low economic status was the major perceived reasons for not being involved in community decision making. Although their TB status might not be a major perceived reason for not being involved in community decision making, a proportion of approximately 16% can be considered problematic and duly must be addressed.

3.1.21 Association between gender identity of PWTB/PWHTB and ever felt being stigmatized due to TB status

Assessing whether gender identity has influence on stigmatization of people diagnosed with TB or have had TB, the study revealed a significant association between gender identity ($p=0.007$) and stigmatization (Table 18; Association between gender identity of PWTB/PWHTB and ever felt being stigmatized due to TB status). The data shows that men were more stigmatized than women and this may explain why men hesitate to seek and access TB care services.

Table 18; Association between gender identity of PWTB/PWHTB and ever felt being stigmatized due to TB status

Do you self-identify as any of the following? (n=1,025)	Have you ever felt you were stigmatized because of your TB status?		P-value
	No n (%)	Yes n (%)	
Gender identity			0.007
Female/woman	247 (30.99)	90 (39.47)	
Male/man	550 (69.00)	137 (60.09)	
Prefer not to say	-	1 (0.44)	

However, this was contrary to themes developed from the qualitative interviews. While difference in gender was established for other domains of TB care and health seeking behaviour, the key informant interviews from the diverse group did not indicate difference in the levels of stigma on the basis of gender. This was identified in statements as below:

*So that when they suspect that someone might be having TB and they know where to send the person and what service they are supposed to get instead of relying on other traditional means of solving that problem. I don't have any record of gender playing a role in stigma and discrimination. Maybe the community where they are coming from and their desire is what may play a role but not in terms of gender. **Health officer, 40 years, Accra***

A regional health officer (31 years) in charge of Monitoring and Evaluation explained further areas of gender difference and non-difference

Yes, I mean the TB data indicates that TB is more among men. We report more TB cases among men as compared to women. Yes, that is what I have said. So that is where our reported data suggest that TB is more prevalent in men as compared to women. In terms of the risk factors that makes men more susceptible to TB Yes, for now I can't talk about any study that has been conducted but we can assume based on certain life style. Life style that is prevalent among men than women. Men engage in mining activities which is a risk factor, I mean developing lung related diseases and TB is one of those. The second one alcoholism and the rest that predisposes the men to, so these are the two factors that we can presume may be some of the reasons why we record more cases in men than in women.For stigma, No, I don't think the effect are different in respect to any particular gender. I think whatever stigma or whatever issue cut across it is not related to either men or women. I think stigma for TB cut across and it is not that I doubt it but we have not conducted any study to prove it. Yes, as we know from previous demographic and health survey behaviour of Ghanaians, females access healthcare more readily or early as compared to the males. Usually, the males will wait until the situation is worse before they will seek health care. So, females access healthcare on time and early and more often than males.

An IDI participant added;

*As I said I think majority of those in the northern region here who are TB positive apparently men thought the number is too small. I don't think it plays any important role in nation building and other things. The numbers who are positive are so small and I think they are quite ineligible. So, if they should have any negative impact at all it is not noticed. I have not noticed anything at all so I don't think that one should be a problem. **Community leader, 63 years, Upper East region***

3.2 Family members/Caregivers of PWTB/PWHTB

3.2.1 Socio-demographic characteristics of family members/caregivers

Nine hundred and seventy-five family members of PWTB/PWHTB were interviewed. The age ranged from 18 to 86 years with a median of 38 years (IQR: 30-50). Females (58.4%) dominated among this group. Most of the respondents had attained JHS/middle (30.5%) education, with 57.9%, married, 39% traders and 32.0% siblings of PWTB/PWHTB (Table 19: Socio-demographic characteristics of family members of PWTB/PWHTB).

Table 19: Socio-demographic characteristics of family members of PWTB/PWHTB

Background information	Frequency (n=975)	Percentage (%)
Age (years)	Mean (IQR) = 38 (30-50)	
Gender		
Female	569	58.4
Male	406	41.6
Highest education status		
No formal education	162	16.6
Primary	99	10.1
JHS/Middle school	297	30.5
Secondary/Vocational school	256	26.3
Tertiary education	161	16.5
Marital status		
Single	276	28.3
Cohabiting	29	3.0
Married	564	57.9
Widowed	58	5.9
Divorced	48	4.9
Occupational status		
Unemployed	123	12.6
Trading	380	39.0
Farming/fishing	119	12.2

Private/public sector	138	14.2
Artisan	111	11.4
Student	47	4.8
Other	57	5.8
Relationship to PWTB/PWHTB		
Parent	242	24.8
Grandparent	10	1.0
Child	163	16.7
Grandchild	14	1.4
Sibling	312	32.0
Other relative	234	24.0

3.2.2 Stigma experienced by family members/caregivers of PWTB/PWHTB

Of the 975 family members of PWTB/PWHTB, ten percent (10%) of them reported experiencing stigma (Figure 7). Across gender disaggregation, female family members of PWTB/PWHTB (6.3%) experienced the most form of the stigma as compared to their male (3.3%) counterparts (Appendix 8). This was nearly half of the proportion of the self-reported stigma by PWTB/PWHTB which implies that stigma also extends to family members/caregivers offering support to TB patients. Therefore, social interventional programs to battle TB stigma should also prioritize family members/caregivers in order to encourage and motivate them to continue supporting their family members with TB.

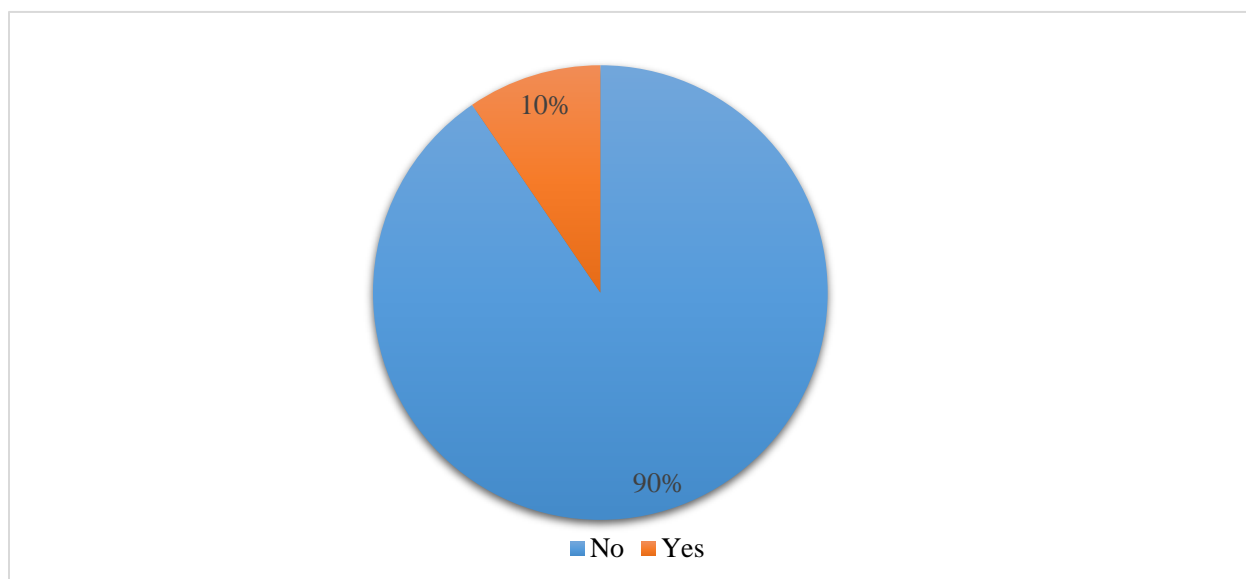


Figure 7: Stigma experienced by family members of people diagnosed with TB or have had TB in Ghana

3.2.3 Stigma Dimensions for family members of PWTB/PWHTB

3.2.4 Secondary Stigma among family members/caregivers

Secondary stigma may influence PWTB's decisions to disclose their TB status and risk behaviors such as seeking and accessing medical treatment. Secondary stigma was measured among family members/caregivers of PWTB/PWHTB. Using a 5-point Likert scale. There were varying response of perceptions on how family members expected negative attitudes or rejection because of their association with people diagnosed with TB (Figure 8). More than half of them disagreed to the statement that *"I feel ashamed because my family member has TB"* and *"I'm afraid that someone will see me at the health care clinic where my relative is being treated."* On the other hand, 58.0% reported that their family members hide their TB diagnosis from the community. Nearly half of the respondents strongly agreed to the statement that *"I am worried about becoming infected."* The results indicate that some family members of PWTB are worried that their association with their family member who has TB may negatively affect how the community members relate with them. This could affect not only the psychological wellbeing of the family member who has TB but also the social support they provide as caregivers to their affected family member.

Perceptions of secondary stigma was assessed by gender to establish whether a difference contributes to the experience. Nearly three quarters (74.0%) of the males agreed to the statement “*I’ve noticed changes in my family member since the TB diagnosis*” as compared to 69% of their female counterparts. On the other hand, an equal proportion (15.0% each) of the males and females agreed to the statement “*I’m afraid that someone will see me at the health care clinic where my relative is being treated*” (Appendix 10). This may imply that the role of gender does not necessarily translate into negative perceptions of secondary stigma. However, Stigma reduction interventions that encourage family members of PWTB could be developed to address this stigma gap in order to improve access to TB services. Overall, family members/caregivers did their best to conceal the status of PWTB and offered utmost support to their family members diagnosed with TB.

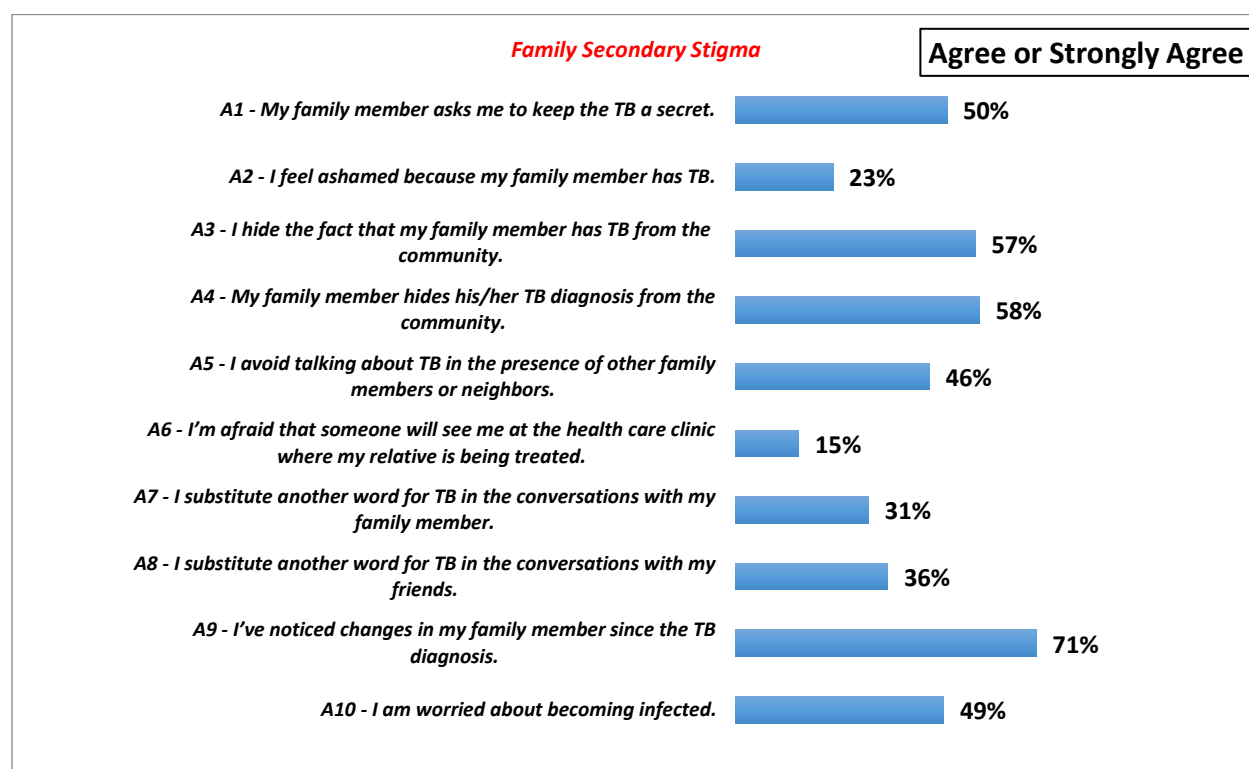


Figure 8: Percentage distribution of perceptions of secondary stigma among family members of PWTB in Ghana. Proportions computed using a Likert scale by combining ‘agree’ and ‘strongly agree’

The qualitative data reiterates the existence of secondary stigma among family members/caregivers of PWTB/PWHTB. Family members encouraged their relatives diagnosed of

TB to keep it a secret until treatment was over. The reasons were largely influenced by the need to protect their family member with TB and not to be protected from stigma themselves as family member.

Beatrice (17 years, Takoradi, FGD participant) whose brother is a PWTB submits;

oh, I told him plain that those things are not good but right now if he tells someone he will scare the person and so he should be careful and shouldn't talk about it. My brother also had it and he was at Takoradi hospital and for him he was taking alcohol and thingsno nobody did that and we were living together we eat and everything with different cups and plates but we didn't do something that will scare him or out of the family so we managed but we were very careful so he took the tablet 99 days every morning up till the time he finished.....what I want to add to make things fine is that Ghanaians like talking and such things they just talk about you, destroying you. In the end, you don't have company or any relationship with human being so I feel that the secret will help us, you see

Elizabeth (43 years, Koforidua, FGD participant) explains further why keeping the illness of their family member secret is important

well from my aspect my brother didn't complain that people were stigmatizing him.... oh, for me I didn't stigmatized him for getting the TB so far but my little opinion is that [I was shy to tell the community people that this was what has happened]. I was saying that it is a sickness that people see that it doesn't have medication and so definitely when you get nobody wants you to be closer to him to spread to him so I think basically that is the only thing that made people became shy to tell their friends because they have TB...oh no if my friend is very close to me I can tell him but not like I am going round telling everyone or something –

An FGD participant explains further that though the community members may have an idea of their family member being diagnosed of TB, keeping it secret was needed to achieve treatment goal for their family.

*I am called John. My friend got some and when he did it was normal though people saw a little but we covered it and we were walking with him and I was the one who was with him. Even if he will eat it is me and I said since you are put on medication you have to eat and he took the drugs and everything...oh our place it was known, oh we didn't cover it but our place was bungalow so nobody...yeah and we the friends only knew...oh when he was put on medication and came home, apart from our yard that he sometimes talk to people- **John, 36 years, Sunyani.***

3.2.5 Stigma experienced by family members when they supported their family member diagnosed with TB on their TB journey under different settings

Figure 9 shows experience of stigma by family members when they supported their family members on their TB journey under different settings. Less than 10.0% experienced stigma in the community, which ultimately inhibited them from supporting their family member with TB or had TB to recognize symptoms (8.0%), seeking care (6.0%), beginning treatment (5.0%) and getting treatment adherence support (5.0%). Moreover, the caregivers experienced stigma from the families/relatives which as a result inhibited them from supporting their family member with TB or had TB to recognize symptoms (3.0%), seeking care and getting an accurate diagnosis (2.0% each) through to completing treatment. However, stigma was mostly experienced by family members of people with TB or had TB mostly in the community which inhibited them from recognizing symptoms.

Across the gender disaggregation, the results suggest that stigma experienced by the female family members was higher (6.3%) than the male family members (3.3%). Stigma experienced by the females occurred mostly in the community, and this inhibited them from supporting their family members with or had TB from recognizing symptoms (7.7%) and seeking care (9.8%) compared with the males. (Appendix 9). These observations add to the evidence that the community, home and hospitals are major sources of TB stigma, and hence, would require a tailor-made stigma reduction intervention in order to improve access to TB services and care.

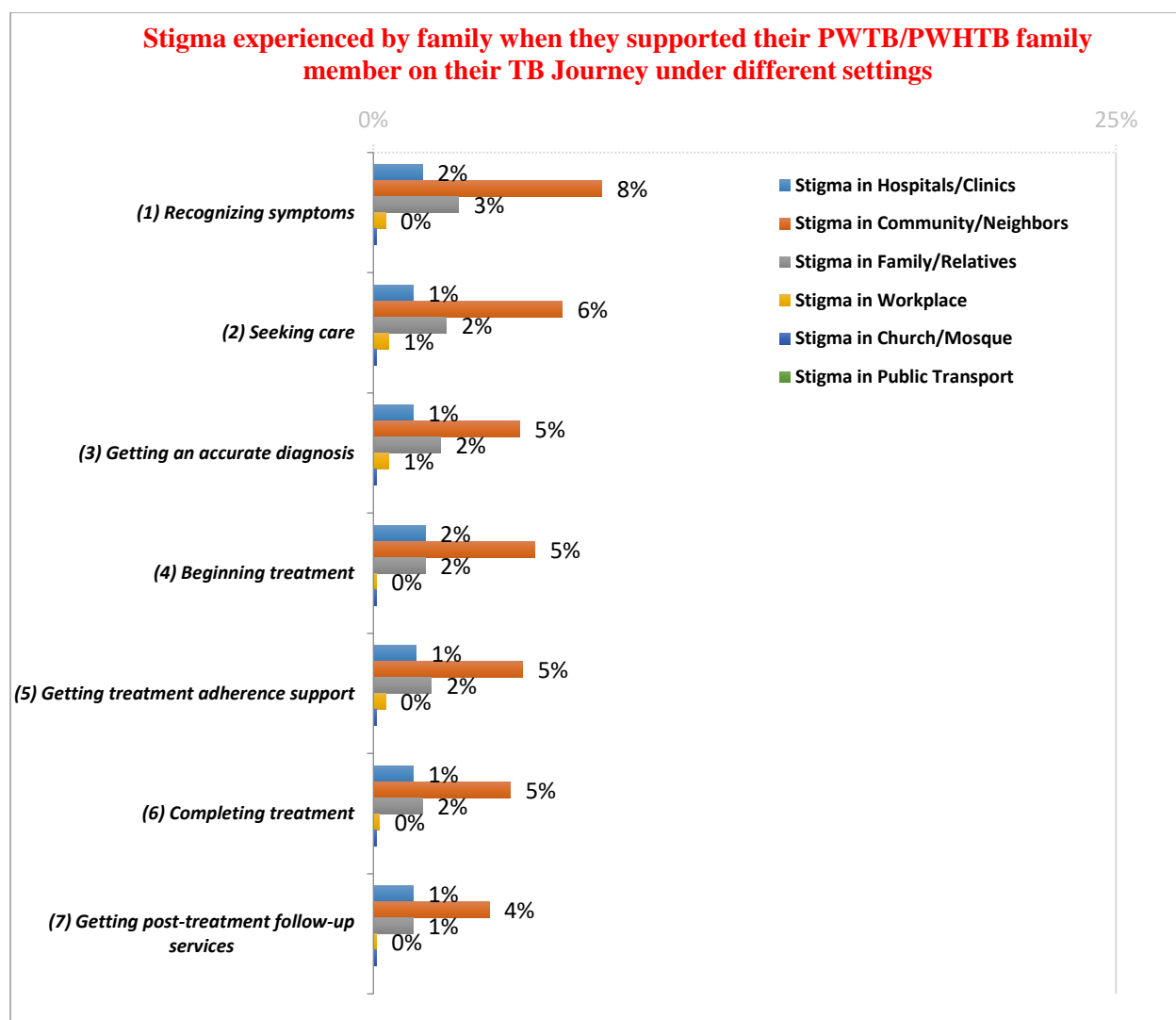


Figure 9: Percentage distribution of stigma experienced by family members when they supported their PWTB/PWHTB family members on their TB journey under different settings in Ghana

3.2.6 Observed Stigma for family members/Caregivers

3.2.7 Know other family members being stigmatized

More than ten percent (13.4%) reported knowing other families/caregivers who had been stigmatized due to supporting a family member infected with TB or who have had TB (Table 20).

Table 20: Know other family members being stigmatized when supporting their family members with TB

Have you seen or heard of other families being stigmatized because of their family member's TB status?	Frequency (n=975)	Percentage (%)
No	844	86.6
Yes	131	13.4

3.2.8 Specific TB related stigma experienced by family members of PWTB/PWHTB

Based on the account given by family members of PWTB/PWHTB with knowledge of other family members who also provide support to other PWTB/PWHTB, gossip (8.1 %) predominated specific stigma experienced by these families, followed by avoidance from other community members (6.3%) and verbal/physical abuse (5.3%) (Table 21). This may imply that whatever stigma PWTB/PWHTB experience, their family members/caregivers experience same stigma

Table 21: Specific TB related stigma

Can you tell me more about the TB-related stigma you have experienced (n=975)	Frequency (n)	Percentage (%)
Gossip	79	8.1
Avoidance from other community members	61	6.3
Verbal/physical abuse	52	5.3
Neglect/abandonment	29	3.0
Loss of marriage	4	0.4

3.2.9 Know other family members being stigmatized when supporting their family members with TB during their TB journey under different settings

Majority of the stigma experienced by other families when supporting their family members with TB occurred in the community. The stigma experienced by the families mostly inhibited them from providing health seeking support (9.0%) and getting accurate diagnosis and beginning treatment (each 7.0%) for their family members with or who had TB (Figure 10). Further, it was apparent that stigma was more pronounced in the community, by family/relatives and

hospitals/clinics similarly as reported by the main respondents (PWTB/PWHTB and their caregivers).

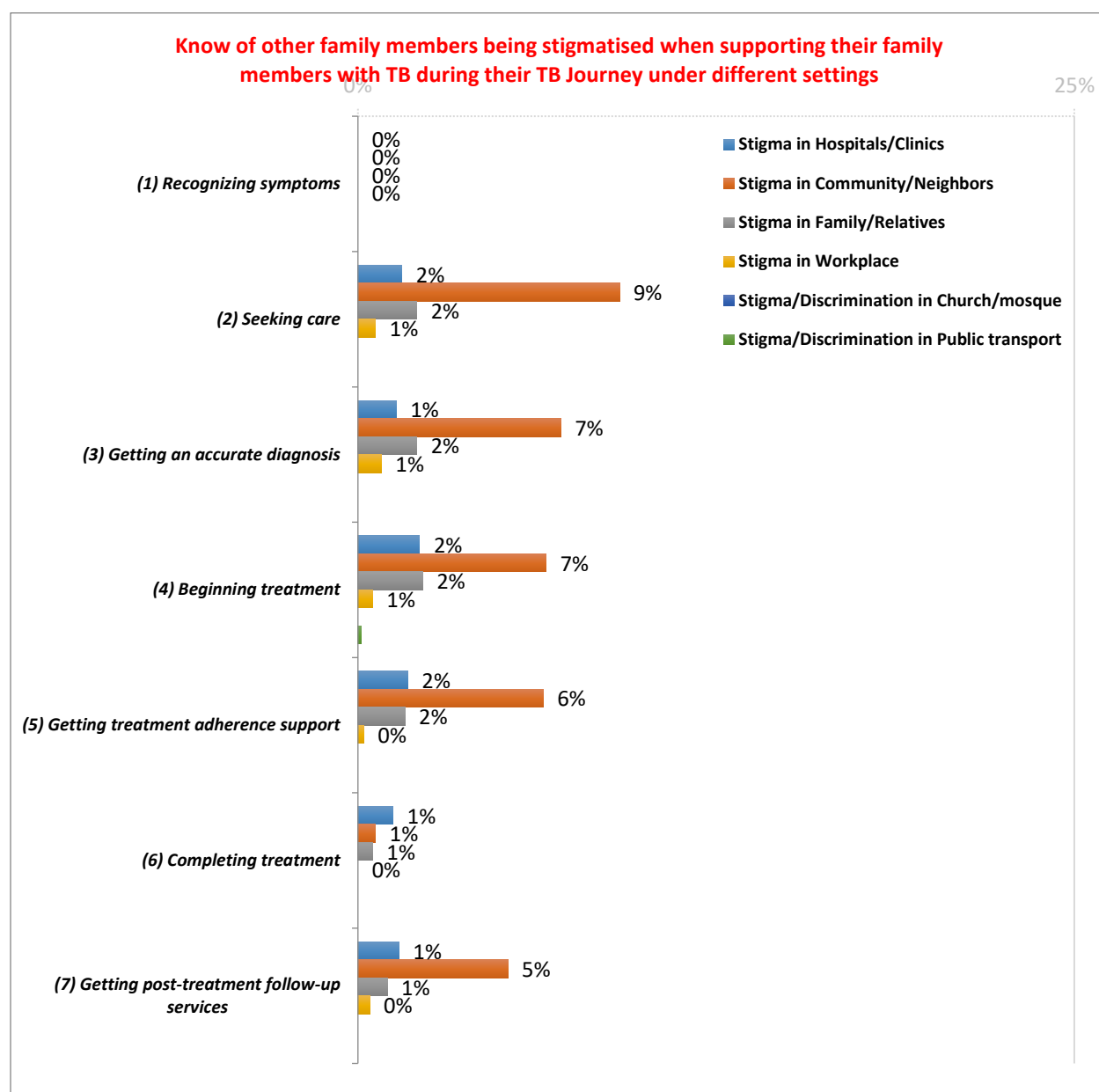


Figure 10: Percentage distribution of awareness by PWTB/PWHTB family members who knows other PWTB/PWHTB family members being stigmatized when supporting their family members with TB during their TB journey under different settings in Ghana

Even though, the qualitative interview did not mention other families but specifically individuals got stigmatized and some died as a result. Some family members/caregivers expressed initial worry

when their family hid the diagnosis from them but became generally more accommodating towards PWTB. When the personal driver of one lady was diagnosed positive, she explains

*oh, right now my children's driver that drives them to school got some but right now there is medication and things and so it was not a shyness disease anymore. When he showed the symptoms, he went to the hospital, got treated and didn't die. Even though time is passing but still the stigma is there and so he didn't say it and later when I got to hear, to be honest I didn't allow him to drive my kids again until he got well. So, when he got well, he continued. He is a taxi driver, he continues to drive my kids – **Head teacher, 59 years, Kumasi (FGD participant).***

Similar accommodating views had been expressed by other persons who lived close with people who had been diagnosed with TB.

*Yeah, the one that I have seen with my eyes are many and by the grace of God a lot of them have been able to survive, and the one who will see it earlier and go to the hospital. My own friend, today you will feel like he was not the one who was doing that coughing, he has survived so by the grace of God err the healthcare workers also made us to understand that right now there are drugs that can treat the sickness to make it go so by the grace of God those that we have seen like half of them have survived. **Assembly Member and family member of PWTB, 42 years, Prestea (FGD participant).***

3.2.10 Specific details of stigmatization experienced by other families due to their family member's TB status

Gossip (12.0%), verbal/physical abuse (6.5%) and avoidance & isolation of PWTB at health facilities (6.2%) were most reported (Table 22). These findings confirm that the specific stigma experienced by PWTB/PWHTB also extends to the family members/caregivers offering support.

Table 22: Specific details of stigmatization experienced by other families due to their family member's TB status

Details of stigma ^a (n=975)	Frequency (n)	Percentage (%)
Gossip about PWTB	117	12.0
Verbal/physical abuse (both PWTB and PWHTB)	63	6.5
Avoidance and isolation of PWTB at health facilities	60	6.2
Neglect/abandonment (both PWTB and persons living with PWHTB)	34	3.5
Loss of marriage (both PWTB and PWHTB)	13	1.3
Discrimination of PWTB from medical staff	11	1.1
Long wait time at health facility	11	1.1
Referring TB patients for HIV testing without counselling	9	0.9
Denial of care	8	0.8
Provision of sub-standard care	4	0.4
Other	3	0.3

^a*Multiple responses*

3.3 Community leaders in the neighborhood of PWTB/PWHTB

3.3.1 Socio-demographic characteristics of community leaders

One thousand, nine hundred and sixty-six community leaders were interviewed. The age ranged from 18 years to 95 years, with a mean of 45.8 years (SD: 12.3). Males (77.7%) dominated among this group, with 0.1% being transgender. Most of the respondents had tertiary education (30.5%), and were married (74.3%). More than 90% were employed (Table 23).

Table 23: Socio-demographic characteristics of community leaders

Background information	Frequency (n=1,966)	Percentage (%)
Age (years)	Mean (SD) = 45.8 (12.3)	
Gender		
Female	430	21.9
Male	1528	77.7
Transgender	2	0.1
Prefer not to say	6	0.3
Highest education status		
No formal education	187	9.5
Primary	111	5.6
JHS/Middle school	540	27.5
Secondary/Vocational school	529	26.9
Tertiary education	599	30.5
Marital status		
Single	324	16.5
Cohabiting	40	2.0
Married	1460	74.3
Widowed	77	3.9
Divorced	65	3.3
Occupational status		
Unemployed	118	6.0
Trading	389	19.8
Farming/fishing	275	14.0

Private/public sector	609	31.0
Artisan	389	19.8
Student	30	1.5
Religious leader	89	4.5
Retired worker/pensioner	21	1.1
Other	46	2.3

3.3.2 Stigma Dimensions for community leaders

3.3.3 Stigma towards PWTB/PWHTB

Figure 11: Percentage distribution of perceived stigma dimensions observed by community leaders in Ghana. Proportions computed using a Likert scale by combining ‘agree’ and ‘strongly agree’ shows the level of perceived TB stigma observed by the community leaders. Across the 5-point Likert scale, there was a general agreement on the extent of perceived stigma in the community. Majority agreed to statement “Some people might not want to eat or drink with friends who have TB” (82.0 %) and “Some people feel uncomfortable being near those who have TB” (75.0%). Also, a little over half (56.0 %) disagreed to the statement “Some people prefer not to have those with TB living in their community”. Overall, it is evident perceived stigma is highly prominent in the community and buttresses the findings reported among PWTB/PWHTB as well as family members/caregivers offering support. This could be attributed to low level of TB education and the absence of more support groups such as the TB voice network at the community level.

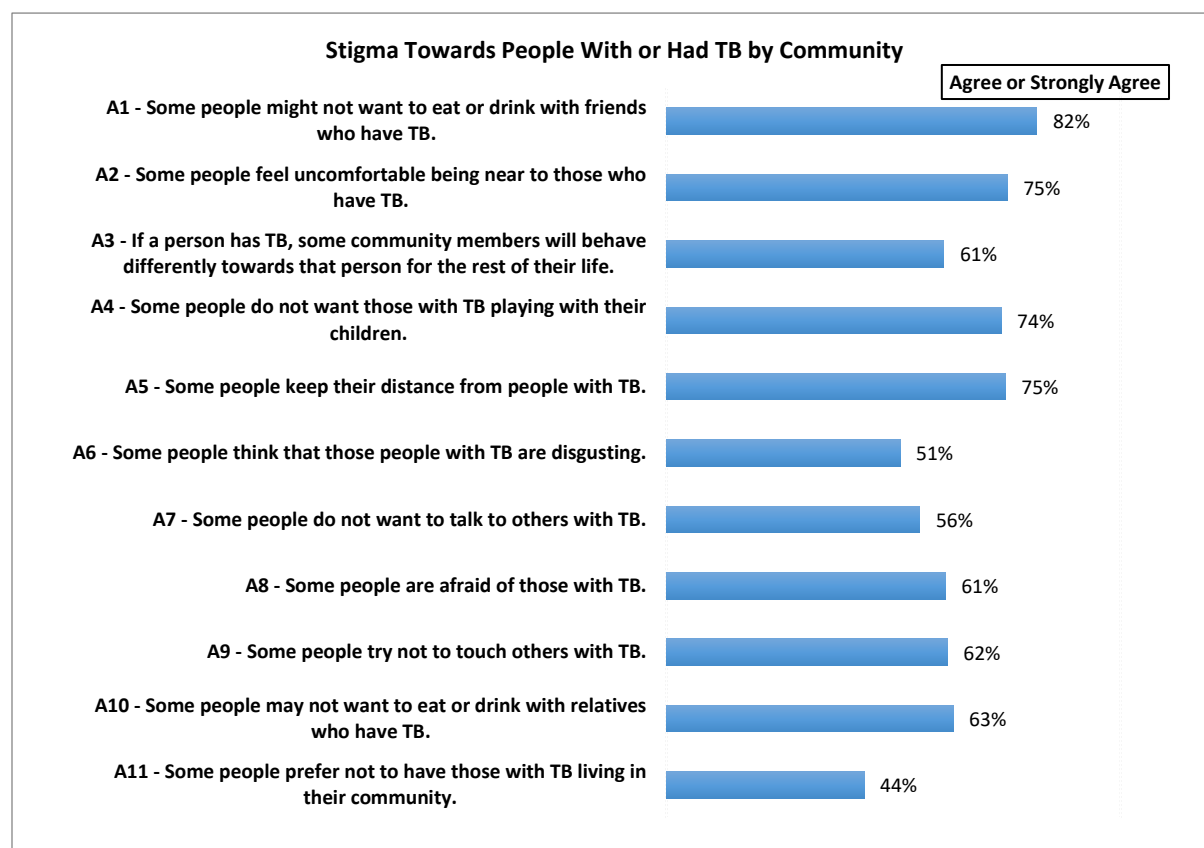


Figure 11: Percentage distribution of perceived stigma dimensions observed by community leaders in Ghana. Proportions computed using a Likert scale by combining ‘agree’ and ‘strongly agree’

3.3.4 Observed Stigma for community leaders

3.3.5 Know PWTB/PWHTB in the community being stigmatized

Nearly half (48.6%) of the respondents reported knowing at least one person with or have had TB. More than one-quarter (27.1%) of the respondents reported to have known of persons being stigmatized due to TB (Table 24).

Table 24: Know PWTB/PWHTB in the community being stigmatized

How many people with or who have had TB in your community do you know personally?	Frequency (n=1,966)	Percentage (%)
None	611	31.1
One only	537	27.3
Two or more	419	21.3
Do not know	399	20.3
Have you seen or heard of a member in your community who has TB being stigmatized because of his or her TB status? (n=1,966)		
No	1,433	72.9
Yes	533	27.1

Even though these figures look significant, TB program managers and community leaders during the qualitative interviews expressed minimal cases of known community level stigmatization. It is believed that PWTB/PWHTB keep to themselves their TB status without disclosing and among many reasons to avoid being stigmatized. This was considered a self-preservation strategy, as recounted by a TB program staff;

For now, as I said we have not received any information concerning any person who was diagnosed of TB and the community rejecting the person outright. Once you are able to

communicate with the community and you are able to talk to them. What we do sometimes is we get the people, treatment supporter we call them. Someone who is very close let me say a confidant to the client and matters explained to and the fact that the person needs support, the fact that it is curable and the person needs support whiles taking the medication. So, once we tell them and they are working for the client and the community and again being supported by the health care worker who are taking care of the patients. This time we don't have much of a problem in terms of the community rejecting or not accepting somebody who have been diagnosed of TB. We don't have that challenge.

Monitoring and Evaluation Officer (43 years), Ghana Health Service, Upper East region

In the expression of the medico-legal officer of the Ghana Health Service, such a practice amounts to self-preservation-a practice equally used by non- TB diagnosed persons to also preserve themselves from becoming infected. While non-TB positive persons adopted self-preservation to avoid contracting TB, PWTB/PWHTB used the same approach to avoid being stigmatized and discriminated against.

Persons who are known to be living with TB are very often marginalized by society basically because of the contagious nature of the disease and the lack of essential education on how to live with people who have contracted the disease. Very often, citizens tend to adopt "self- preservation" stance to minimize the risk of contracting the disease. I personally interacted with a person who had TB but I did not know this at the time of my interaction with him. I had to draw back after that interaction when I discovered he had TB to minimize my risk of contracting it. - Medico-legal Officer (39 years), Community leader, Accra

3.3.6 Specific TB related stigma observed by community leaders

Just like the observations among PWTB/PWHTB, gossip about PWTB/PWHTB (24.6%) predominated the specific stigma observed by community leaders, followed by verbal/physical abuse (13.9%) and avoidance and isolation of PWTB at health facilities (1.7%) (Table 25). Moreover, about 10.0% reported neglect/abandonment (8.9 %) of PWTB/PWHTB. This could be attributed to the communicability of the disease.

Table 25: Specific TB related stigma observed by community leaders

Details of stigma ^a (n=1966)	Frequency (n)	Percentage (%)
Avoidance and isolation of PWTB/PWHTB at health facilities	234	11.9
Gossip about PWTB/PWHTB	483	24.6
Verbal/physical abuse (both PWTB and PWHTB)	273	13.9
Discrimination of PWTB from medical staff	54	2.7
Denial of care	27	2.7
Provision of sub-standard care	22	1.1
Long wait time at health facility	25	1.3
Neglect/abandonment (both PWTB and PWHTB)	174	8.9
Loss of marriage (both PWTB and PWHTB)	58	3.0
Referring TB patients for HIV testing without counselling	40	2.0
Other	1	0.1

^a Multiple response

At the community level, secrecy, self-isolation and distancing from community participation characterized some persons who were diagnosed with or found to be TB positive. While the community members may not necessarily extend stigmatizing behaviors towards such persons, structural elements within the social structure made it such that TB positive persons themselves had to self-isolate. Corroborating this, *Opanin (elder) Owusu, a 73-year-old community leader from the Ashanti region shared that*

I have seen some before. There were 2 people that I saw they have some and how it happened to them, people didn't want to go closer to them and when it happened like that, they were also hiding themselves. And so, it was worrying ... oh, they hide themselves up till death came for them because people were not going to them and they

were also not going close to people. Yeah people really have those beliefs because if it was not the case, they (TB positive persons) wouldn't have isolated themselves from the people when they got the sickness. But they think it is a curse or a sin they have committed which has brought this upon them

In the Greater Accra region, a community leader shared

*I am 45 years old now. I am a unit committee member and the chairman. Oh, I have heard it before and myself I have gotten it before. I was coughing and someone said I should go to Mamobi clinic to go and do TB test and when it was done, I tested positive. There is a boy in this house, our neighbor but he is like a drug addict and so when I saw the signs, I told the family that it is TB and they should go and do a test. The time I got it if you see me you will think I am a bad person like I have gotten AIDs but I am not a bad person and so when I saw the signs, I told them to go and check for TB and when they checked they said it was TB. And he too his family didn't help him so it is not every time that he goes to the hospital to take the drugs so he is dead.... oh, the first time nobody knew it was TB but later they got to know it is TB. Others were coming to visit and others were not coming they were scared, yeah, they were scared but a lot of them came to visit me. There is someone too from the north, and later I heard he has died. Someone has told me before that when he comes to the mosque, they don't want to come closer to him- **Ayuba (Unit Committee member), 37years, Accra***

There are however instances where knowledge of TB was generally low limiting the ability of community members to further stigmatize PWTB since the disease itself was not known. In such instances, unless one came closer to a person diagnosed with TB, it remained unlikely to be known by opinion leaders. There was the absence of a community level TB related stigma until an infected person lived or came close to a community gathering. An opinion leader in Northern Ghana puts it this way:

No, I haven't seen or heard (any stigma on TB). No, I haven't...no I don't know any program like that in this community. I think we can do some education and create awareness of tuberculosis how to manage it; create some educational programs or set

aside days to invite all stakeholders to be invited about tuberculosis and do some screening so that people will know whether they have tuberculosis or they have other diseases- Awintuma (Community leader), 52years, Tamale

Another community leader added that

We have never had any education in relation to this case or this problem. This is just the first time- Rahamani (Community leader), 62 years, Savelugu

In Tamale, Awal a community leader with little to no knowledge on TB expressed his views and community level perspective

no I haven't seen or heard anyone who has TB....o no I haven't seen anyone go through stigma....no I don't know any program like that in this communityI think we can do some education and create awareness of tuberculosis how to manage; create some educational programs or set aside days to invite all stakeholders to be invited about tuberculosis and do some screening so that people will know whether they have tuberculosis or they have other diseasesno I have not seen anything any screening of Tb in this community, Awal (community leader), 47 years, Tamale

Some persons diagnosed with TB had severed family and marital relationships because their partners could not stay with them during treatment. In some instances, not only does externalized stigma cause emotional harm but it continues to manifest in discrimination and result in abuse of fundamental human right abuse of people diagnosed with TB. Razak, a community leader in northern region shares the experience his brother and one other in their community went through when they got diagnosed with TB.

yeah, its true I have a very closed brother who the woman left him just because of that incident. He is very well okay because of the medicine they gave him he was able to follow it consistently that made him out, he is now okay and took a different woman...yeah, he is married to a different woman today.... somebody too that I know they sacked him from that

premises because he got TB yeah – Mohammed (Community leader), 66 years Northern region

Affirming the community related levels of stigma, a health personnel and community leader submitted

*...yeah recently I had one client who has lost the shelter because of TB and doesn't have a place...yes according to him he is perching with a friend and when he was diagnosed with TB the person sacked him from the house. He was actually diagnosed somewhere else and he came back to our facility as a transferred client to manage in our facility so when he came and I asked him and he said he was staying with a friend and the friend sacked him from the house. He didn't want to come out clear with me, I asked him where he stays and he said he is staying close here which I am yet to do enquiries to see if he is still roaming around or he has gotten a place to stay ...yes as far as I am concern, he is the only one I know- **Community leader who doubles as TB Coordinator, Accra***

3.3.7 Know PWTB/PWHTB in the community being stigmatized during their TB journey under different settings

Majority of the stigma experienced by PWTB/PWHTB during their TB journey occurred in the community. TB stigma experienced in the community mostly inhibited PWTB/PWHTB from recognizing symptoms (24.0 %), seeking care (18.0 %) and getting treatment adherence support (17.0%) (Figure 12). These findings further buttress the observations among PWTB/PWHTB and their caregivers. It is now very much informative that the community is a major determinant of TB stigma and therefore, adequate measures have to be implemented at the community level to curtail the stigma expressed.

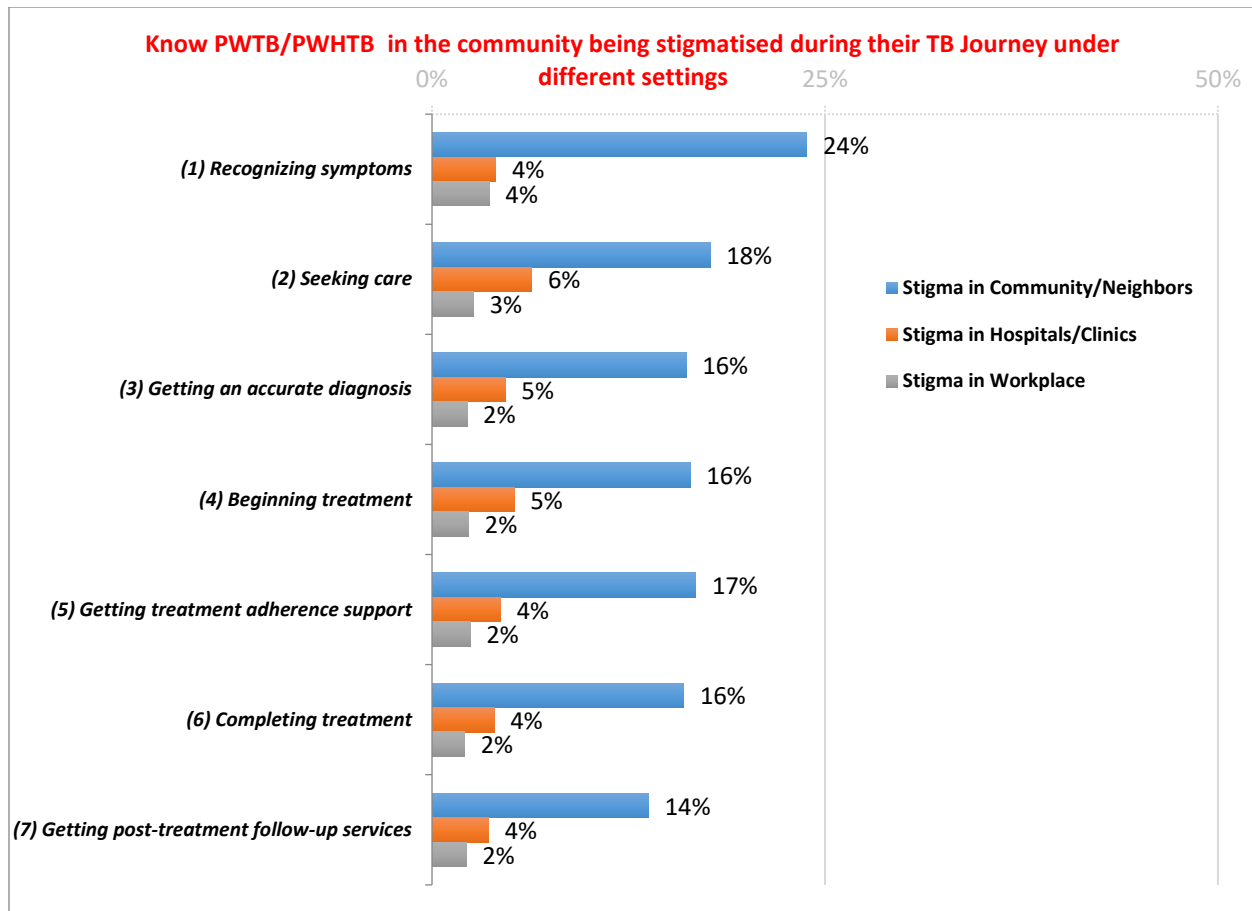


Figure 12: Percentage distribution of awareness of community leaders knowing PWTB/PWHTB in the community being stigmatized during their TB journey under different settings in Ghana

3.4 Health care workers who provide TB services

3.4.1 Socio-demographic characteristics of health care workers

The study recruited 295 health care workers (HCWs). The mean age of the HCWs was 33.3 years (SD: 8.5). More than half of the HCWs were female (58.0%). Almost all the HCWs had attained a tertiary level of education (98.3%). A little over half were married and more than one-third were single (45.1%). The predominant category of HCW interviewed was Nurses (74.2%) (Table 26: Socio-demographic characteristics of health care workers Table 26).

Table 26: Socio-demographic characteristics of health care workers

Background information	Frequency (n=295)	Percentage (%)
Age (years)	Mean (SD) = 33.2 (8.5)	
Sex		
Female	171	58.0
Male	124	42.0
Highest education status		
JHS/Middle school	1	0.3
Secondary/Vocational school	4	1.4
Tertiary education	290	98.3
Marital status		
Single	133	45.1
Cohabiting	7	2.4
Married	148	50.2
Widowed	5	1.7
Divorced	2	0.7
Occupational status		
Doctor	13	4.4
Nurse	219	74.2
Disease control officer	20	6.8
Lab tech/scientist	8	2.7
Health information officer	5	1.7

Pharmacist	2	0.7
Public health officer	8	2.7
TB task shifting officer	7	2.4
Other	13	4.4

3.4.2 Stigma Dimensions for Health Care Workers

3.4.3 Stigma towards people with or have had TB by health care workers

Figure 13 reports on stigma towards PWTB/PWHTB as perceived by health care workers that provide TB services. Across the 5-point Likert stigma dimension scale, majority of the HCWs (88.0%) agreed with the statement, *“some health care workers feel pity for TB patients.”* Most of them also agreed to the statements, *“some health care workers think it would be best for TB patients to be isolated during the intensive phase of treatment”* (80%) and *“some health care workers are nervous about treating TB patient”* (71.0%). In addition, most of the HCWs disagreed with the statement *some health care workers feel angry towards TB patients*” (65.0%) and *“some health care workers don't like helping TB patients”* (57.0 %).

Perceptions of stigma towards PWTB/PWHTB did not vary significantly by gender of HCW. Nearly the same proportions of the males (79.0%) and females (81.0%) agreed to the statement that *“some health care workers think it would be best for TB patients to be isolated during the intensive phase of treatment.* This implies that HCW, irrespective of their gender share similar views of perceptions of stigma towards PWTB/PWHTB they provide health care to. (Appendix 5).

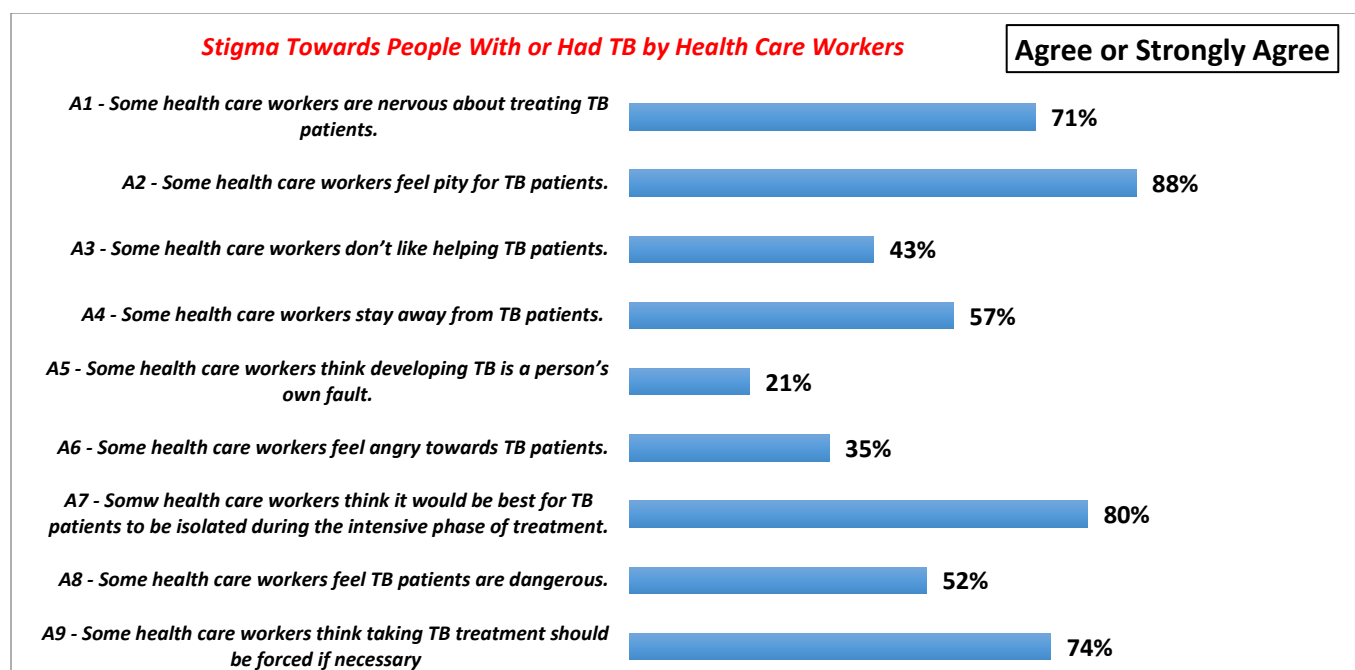


Figure 13: Percentage distribution of perceived stigma observed by health care workers towards people with TB or have had TB in Ghana. Proportions computed using a Likert scale by combining 'agree' and 'strongly agree'

3.4.4 Stigma experienced by health care workers

One-third of the HCWs (32.9%) had experienced stigma themselves (Table 27). Of those that experienced stigma, 19.3% were females and 13.6% males. Among the females, 33.3% experienced stigma and 32.3% experienced stigma among the males. (Appendix 5). More than a quarter (29.0%) experienced it at the hospitals/clinics and 9.0% at where they lived (Figure 14). Stigma was expressed mostly in the form of gossip (23.7%), avoidance from colleague HCW (18.3%) and verbal/physical abuse (13.2%) (Table 28: Details of personal stigma experiences by health care workers).

Across gender disaggregation, stigma experienced was prominent among the female HCWs (30.0%) compared with the male HCWs (27.0%) at the clinic/hospital setting (Appendix 7). Overall, the stigma observed among HCWs could be attributed to low level of knowledge about the psychosocial implications of stigma among the HCWs. This could have consequences on the adequate provision and support to PWTB, and willingness of other HCWs to accept providing services at the DOT units of health facilities.

Table 27: Stigma experienced by Health Care Workers

Have you ever felt you were stigmatized because your work involves interacting with people with or who have had TB?	Frequency (n=295)	Percentage (%)
No	198	67.1
Yes	97	32.9

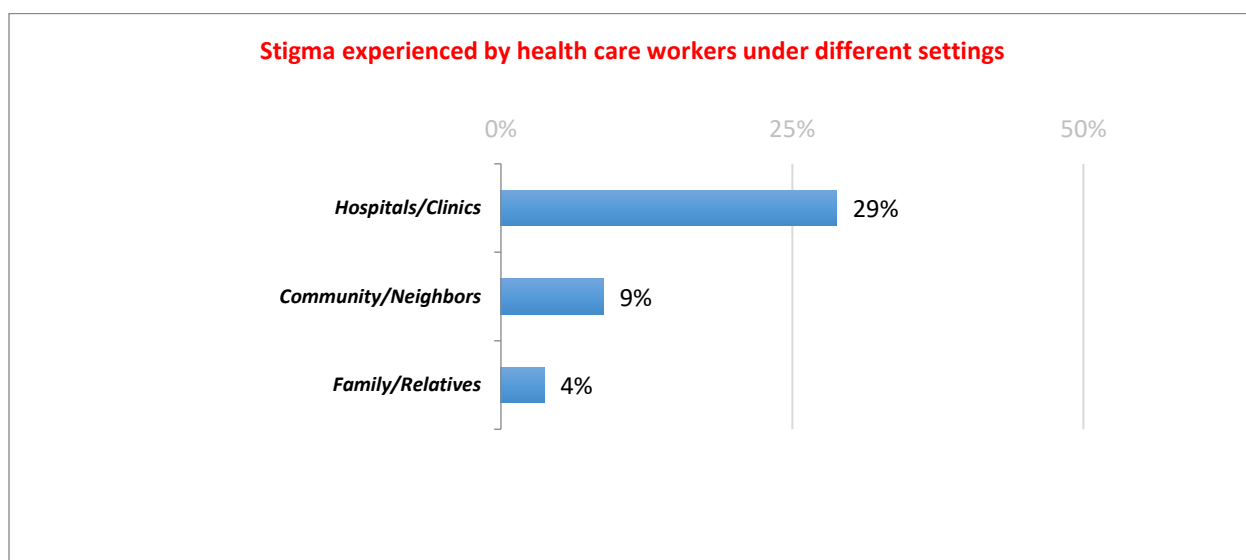


Figure 14: Stigma experienced by health care workers under different settings in Ghana

Table 28: Details of personal stigma experiences by health care workers

Details of personal experience (n=295)	Frequency (n)	Percentage (%)
Gossip	70	23.7
Avoidance from colleague HCW	54	18.3
Verbal/physical abuse	39	13.2
Neglect/abandonment	13	4.4
Loss of marriage	0	0.0
Other	8	2.7

^a *Multiple response*

The qualitative evidence points to mixed reports on reduced levels of TB related stigma from the perspective of health care workers. Healthcare workers had mixed experiences and perspectives

levels of stigma both at the facility level and family level. The notion of TB as a disease without cure among many continue to serve as a benchmark around which some persons stigmatize both PWTB and healthcare professionals attending PWTB. Staff working in other units of the hospitals and clinics covertly stigmatized against fellow health professionals working in the TB clinics. This was worsened by their own family members who demonstrated social distancing tendencies. In the Western region of Ghana, a health personnel working in the TB clinic of a health facility explained:

okay I think the stigma has gone down especially we that takes care of those who have the sickness. Initially because it was scary and there was no medication for it, it was the same sickness we were seeing and so when they hear that you are taking care of these people, they think the same as first that there was no medication. And so, they are scared and when you go home and they hear that you take care of TB patients. I remember I once got home and I was talking to my mum and I said oh those who have TB I am the one who take care of them, she said eii then don't go closer to them take care of yourself but when you get time to explain to them well and they get the understanding and everything becomes fine. So, it takes a lot unless you go back and explain to them before they get to understand to be able to do what they have to do with you. Adoma (Nurse), 29 years, Prestea

However, a medico-legal officer and head of the Ghana Health Service medico-legal unit viewed that the culturally underlying factors that influence TB related stigma in the past appeared to have reduced in recent times.

it used to be that many years ago that when someone has TB, they call it "Nsama wa" or whatever and even if someone is going to marry and the person's relations ever had TB it was one of the reasons that use prevent someone from marring in such a family thus someone form the family had TB. So, TB has been with us for a very long time and it used to be culturally unacceptable to marry form a family that it known that somebody das TB. People thought it was hereditary or something. - A medico-legal officer, Ghana Health Service, Accra

In respect of co-worker level of stigmatization, some nurses explained

.....at all cost there is little but it is minimal because constant education that we give them it has made a lot to have knowledge about TB sickness and a lot are willing to help in the TB treatment but as a society and there are people who are still holds some perceptions about those of us working at the TB center-Adoma (Nurse), 29 years Prestea

Some health professionals admitted that their co-workers do not however stigmatize against them and PWTB but showed reservations about working in the TB clinic. This is succinctly captured by a TB coordinator in Accra:

....no just that some nurses don't want to be at the unit but they don't actually stigmatize at work- TB coordinator (General hospital), Accra

Health facility level stigmatization is not only directed towards nurses working in the TB unit by other health professionals or co-workers but also directed towards other TB diagnosed persons seeking care. This appears to occur in health facilities where a single place has been designated for treatment of all infectious diseases.

yeah once a while they are being stigmatized at the wards even though some of the nurses actually understand them, they treat them as any other patients. Some few people do that- TB coordinator (General hospital), Accra

3.4.5 Know other health care workers being stigmatized

Thirty percent (30.2%) of the HCWs reported seeing or hearing of other HCW who had been stigmatized because their work involves treating TB patient (Table 29). More than a quarter (27.0%) of the HCWs reported that their colleague workers experienced the stigma at the hospital/clinics where they work (Figure 15), and it was mostly expressed in the form of gossip (21.7%) and avoidance from other HCWs (19.0%) (Table 30: Details of experience of fellow healthcare workers Table 30).

Majority of the male health workers (31.0%) reported to have seen/heard of fellow HCWs being stigmatized compared with one-fourth of the female health workers (Appendix 6).

Obviously, the dimensions of self-stigma and observed stigma appears the same across the four categories of respondents interviewed for this study. It could be anticipated that HCWs are

somehow distressed by the stigma they experience due to their association with PWTB/PWHTB and this could affect their motivation of supporting their patients.

Table 29: Know other health care workers being stigmatized

Have you seen or heard of your fellow health care workers being stigmatized because their work involves interacting with people with or who have had TB?	Frequency (n=295)	Percentage (%)
No	206	69.8
Yes	89	30.2

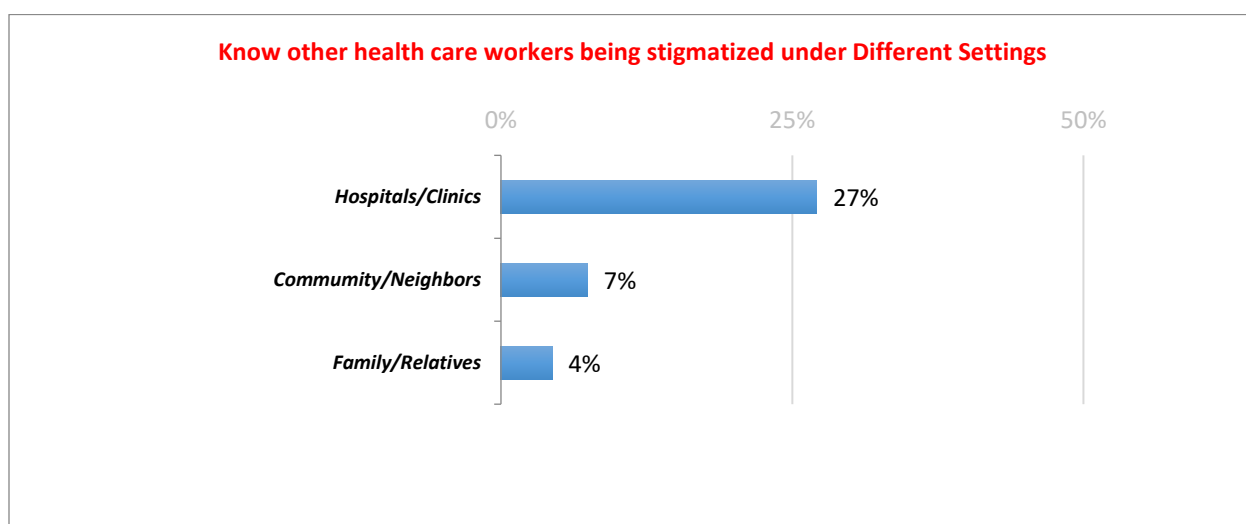


Figure 15: Percentage distribution of awareness of health care workers knowing other health care worker who experienced stigma under different settings in Ghana

Table 30: Details of experience of fellow healthcare workers

Details of experience of fellow healthcare workers ^a	Frequency (n)	Percentage (%)
Gossip	64	21.7
Avoidance from colleague Health	56	19.0
Verbal/physical abuse	39	13.2
Neglect/abandonment	13	4.4
Loss of marriage	1	0.3

Other	1	0.3
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^a Multiple response

3.4.6 Suggestion to address TB-related stigma

Majority of the HCWs suggested community education (95.3%), and indicated creating awareness on TB (84.4%) and organizing of TB related programs (76.3%) (Table 31).

Table 31: Suggestion to address TB-related stigma

What do you think health care workers can do to help address TB-related stigma? ^a (n=295)	Frequency (n)	Percentage (%)
Community education	281	95.3
Organization of TB related programs	225	76.3
Creating awareness of TB	249	84.4
Support for TB patients	186	63.1
Community advocacy groups	178	60.3
Other	26	8.8

The call for increase community TB education was elaborated during an in-depth interview. Increased education offers the prospects of changing both internalized stigma and community level externalized stigma towards persons affected by TB. This is reflected in responses such as;

everything will be on education, when we educate them and they understand like the COVID. So, we should educate them they will understand. There are some people even family members they think that when they come closer to you, they will get the sickness and so he won't come close to you, even cup he won't share and when you are coming then he will be running and it will leave the person with worries and so I think the education will help -A community nurse, 34 years, Ashanti

Rethinking the advantages and disadvantages of specializing or Integrating TB care centres/units within health facilities.

There is the need to reconsider the arguments and clinical importance of whether to separate /isolate the treatment centres/units in each health facility or whether to integrate it. A fair balance and case by case assessment is recommended for each setting in order to help reduce health professional co-worker stigma and labeling of persons diagnosed of TB

who move towards particular parts of the hospital building to seek for treatment to avoid hand pointing tagging or labeling- Medico-legal officer, Ghana Health Service, Accra

3.5 Structural stigma (any existing laws/policies, the enforcement of those laws/policies and the corresponding media coverage)

3.5.1 Law and Policy Environment Scoring Matrices

Table 32 and Table 33, below show details of the scoring matrix of national key stakeholders (NTP managers, legal community and the media personnel) on the existence, enforcement and media coverage of laws and policies that protect or harm human rights of PWTB in Ghana. These seven (7) rights include the Right to Freedom from Discrimination, Rights to Access Information, Rights to Access Services, Rights to Access Services, Rights to Privacy, Rights to Informed Consent, Rights to Freedom from Arbitrary Arrest/Detention and involuntary Isolation, and Rights to Safe Workplace). Seven (7) and six (6) stakeholders contributed to the scoring of law matrix and policy matrix, respectively.

3.5.1.1 The Law Matrix

Overall, the stakeholders reported the existence of laws that protect the rights of PWTB at the national level (AvgS=4). (Table 32) However, these laws are enforced at the sub-national level (AvgS=3). The enforcement of these laws that protect PWTB is supported only in the sub-national media coverage (AvgS=3). Laws on all the seven (7) rights existed at the national level. However, only rights to privacy and rights to safe workplace were enforcement at the national level. There was media coverage of four laws at the national level; right to freedom from discrimination, rights to access services, rights to access to services and rights to privacy.

Reports from the four (4) National TB program officers suggest that the existence and enforcement of the laws protect the rights of PWTB at the national level (AvgS=4). Enforcement of the laws that protected the PWTB was supported at the sub-national (AvgS=3) and its media coverage at the sub-national level (AvgS=3).

Reports from the two (2) legal personnel also suggests the existence of the laws that protect the rights of PWTB at the national level (AvgS=4). However, the enforcement and media coverage of these laws were supported only in the sub-national level (AvgS =3).

Reports from the media personnel suggests the existence of laws that protect the rights of PWTB at the national level (AvgS=4). The enforcement and media coverage of the laws was reported not to exist (AvgS=2).

Table 32: Scoring of the law matrix

Law Matrix	Existence of Laws	Enforcement of Laws	Media Coverage of Law enforcement	Total	Average score (AvgS)
	Score	Score	Score		
National TB Program Managers (n=4)					
Right to Freedom from Discrimination	4	3	4	11	4
Rights to Access Information	4	3	3	10	3
Rights to Access Services	4	3	4	11	4
Rights to Privacy	4	4	3	11	4
Rights to Informed Consent	4	3	3	10	3
Rights to Freedom from Arbitrary Arrest/Detention and involuntary Isolation	4	3	3	10	3
Rights to Safe Workplace	4	4	3	11	4
Total	4	3	3	10	3
Legal community (n=2)					
Right to freedom from discrimination	4	3	3	10	3
Rights to Access Information	4	3	3	11	3
Rights to Access to Services	4	3	4	11	4
Rights to Privacy	4	3	4	10	4
Rights to Informed Consent	4	3	3	10	3
Rights to Freedom from Arbitrary Arrest/Detention and involuntary Isolation	4	3	3	10	3
Rights to Safe Workplace	4	3	3	10	3
Total	4	3	3	10	3
Media (n=1)					
Right to freedom from discrimination	4	2	2	8	3
Rights to Access Information	4	2	2	8	3
Rights to Access Services	4	2	2	8	3
Rights to Privacy	2	2	2	8	3
Rights to Informed Consent	4	2	2	8	3
Rights to Freedom from Arbitrary Arrest/Detention and involuntary Isolation	4	2	2	8	3
Rights to Safe Workplace	4	2	2	8	3
Total	4	2	2	8	3
Overall Average Score	4	3	3	10	3

0 = Laws that harm people with TB exist/enforced/has media coverage at national level; 1 = Laws that harm people with TB exist/enforced/has media only at subnational level; 2 = No laws relevant to people with TB exist/enforced/have media coverage; 3 = Laws that protect people with TB exist/enforced/has media only at subnational level; 4 = Laws that protect people with TB exist/enforced/has media at national level

3.5.1.2 The Policy Matrix

Overall, the stakeholders reported the existence of policies that protect the rights of PWTB at the sub-national level (AvgS=3). (Table 33) These policies are enforced at the national level (AvgS=4). However, the enforcement of these policies that protect PWTB is supported only in the sub-national media coverage (AvgS=3). The existence of the policies on all the seven (7) rights differed by the stakeholder score; with an AvgS of 4, 3 and 2.

Table 33 shows the scoring matrix of the national key stakeholders (NTP managers, legal community and media) on the existence, enforcement and media coverage of the policies that protect or harm the right of PWTB.

Overall, reports from the policymakers suggest the existence of the policy that protect PWTB at the sub-national level (AvgS=3), enforcement of these policies at the national level (AvgS=4) and media coverage of these policies at the sub-national level (AvgS=3).

According to the four (4) national TB program officers, policies that protect the rights of PWTB exist at the sub-national level (AvgS=3). These policies are also enforced at the sub-national level (AvgS=3), with the enforcement of these policies supported in the sub-national media coverage (AvgS=3).

Reports from the legal practitioner suggests that policies that protect PWTB exist at the national level (AvgS=4), and are enforced at the national level (AvgS=4). However, the media coverage of enforcement of the policies are supported at the sub-national level in the country (AvgS=3).

On the contrary, the media personnel indicated the non-existence of the policies that protect the rights of the PWTB in the country (AvgS=2). However, these policies if existed are enforced at the national level (AvgS=4) and have media coverage support at the sub-national level (AvgS=3).

Table 33: Scoring of the policy matrix

Policy Matrix	Existence of Policies	Enforcement of Policies	Media Coverage of Policy enforcement	Total	Average score (AvgS)
Score	Score	Score	Score		
National TB Program Managers (n=4)					
Right to freedom from discrimination	3	3	3	9	3
Rights to Access Information	3	3	3	9	3
Rights to Access Services	3	3	3	9	3
Rights to Privacy	3	3	3	9	3
Rights to Informed Consent	3	3	3	9	3
Rights to Freedom from Arbitrary Arrest/Detention and involuntary Isolation	3	3	3	9	3
Rights to Safe Workplace	3	3	3	9	3
Total	3	3	3	9	3
Legal community (n=1)					
Right to freedom from discrimination	4	4	3	11	4
Rights to Access Information	4	4	4	12	4
Rights to Access Services	4	4	4	12	4
Rights to Privacy	4	4	4	12	4

Rights to Informed Consent	4	4	3	11	4
Rights to Freedom from Arbitrary Arrest/Detention and involuntary Isolation	4	4	3	11	4
Rights to Safe Workplace	4	4	3	11	4
Total	4	4	3	11	4
Media (n=1)					
Right to freedom from discrimination	2	4	3	9	3
Rights to Access Information	3	4	2	9	3
Rights to Access Services	3	4	2	9	3
Rights to Privacy	3	2	2	7	2
Rights to Informed Consent	2	4	2	8	3
Rights to Freedom from Arbitrary Arrest/Detention and involuntary Isolation	2	4	2	8	3
Rights to Safe Workplace	2	4	2	8	3
Total	2	4	2	8	3
Overall Average Score	3	4	3	10	3

0 = Policies that harm people with TB exist/enforced/has media coverage at national level; **1** = Policies that harm people with TB exist/enforced/has media only at subnational level; **2** = No policies relevant to people with TB exist/enforced/have media coverage; **3** = Policies that protect

people with TB exist/enforced/has media only at subnational level; 4 = Policies that protect people with TB exist/enforced/has media at national level

Generally, the human right dimensions of TB care and treatment is not lost on the nurses who work with the TB clinic. They have fair and adequate knowledge of the human right dimensions to TB care. In offering explanation, a **TB coordinator from Greater Accra** region detailed:

*err... every person has the right to health to access health so just as TB people once they are sick, they have access to health and is their right to come and is their right to accept the TB patient for treatment. The rights to access the nurse to them, if they don't want you to attend to you then you have the right choose....err they have the right to live the right to freedom because if you have TB doesn't mean society will neglect you or reject you, they also have the right just as any other person has so they have the right to live just that we advise them to as much as possible do things that will not spread the disease but rather reduce the spread. Because the way they are suffering it won't be right for others to suffer like that so we advise them to cover their mouth when they cough, when they are sleeping in the room with their relatives, it doesn't mean if you are having TB you don't have the right to a good shelter wherever you are coming from you can still sleep in the same room just that you have to open the window to allow for adequate ventilation so that it will reduce the risk of you spreading the disease to others. But we have right just as other person. **TB coordinator, 47 years, Accra***

Low levels of reportage on TB related issues and stigma related stories

In the IDI, it emerged that, there was little concern and story reportage on TB related issues. TB and its stigma related concerns took to the media limelight on rare occasions or international commemorative days partly because it is argued as a deeply secretive topic combined with the fact that many media practitioners and journalist have limited knowledge on the topic. Cementing this theme, a national TV correspondent with 15 years of media practice summarized this observation

Stigma is one issue that affects almost most ailments and TB is no exception. I know that persons who have had TB and cured are stigmatized because the general knowledge about the disease is not known and for that matter those cured are shunned and stigmatized. I only get to hear and read about TB on the day set aside to mark the day. Aside that there is low coverage of issues about TB in the media. It is very difficult for patients to open up to do a story on it. Even when they are given maximum assurance their identities would be protected their trust for the media is lost so it is always difficult to get them to share their stories to be open up- Health reporting is not an area most journalists are interested in. I think such persons should be identified and trained on TB and related stigma to be able to understand the subject and do more stories on TB. But I think generally the talk on TB is very low. A regional TV correspondent with 15-year media practice.

Policy direction and coordination gaps- need for health system and structural re-alignment

At the policy coordination level, the theme of specialized care without focus on integrated care surfaced dominantly. Calls on the need to re-structure the delivery of TB care and service in the hospitals was echoed in the discussions. The continued adoption of compartmentalization or units for isolated parts of the hospitals / health care centres to be offering TB care in health facility was questioned.

I handle a lot of medico-legal issues in court but I have not come across TB discrimination matter in court. Our system itself the way it is structured sometimes unintentionally put some people in that position. For instance, if you designated a place specifically for TB no body needs to know or to ask who is there because it is written boldly, TB ward, fevers unit for HIV patients. Immediately you are walking in whether you are a health staff or

whatever any bystander may think that you are a patient. So, the system itself unintentionally the way it is structured we have to make effort to find a way in order not to segregate such people by their disease or any form of disability. For instance, if I go to the OPD and it is announced that people who have such and such disease must be going to such and such a place. Immediately that is done and I move towards that place everyone around will know what is wrong with me. If it is something that is discriminated and others are not comfortable with, they may show their attitude- **Medico-legal expert, Ghana Health Service, head office, Accra**

The application of anti-discrimination laws

Legal actions against persons discriminating against TB diagnosed persons by the relevant state institutions appear non-existent. Response from the discussion shows that there have been no known cases of discrimination and stigmatization against persons diagnosed with TB that have come to the attention of lawyers. While buttressing this view, all the FGD participants indicated that once persons abused or discriminated against internalized the stigma and abuse and fail to report, very little could be done legally to seek remedy.

We haven't done any law against any particular disease or something. Discrimination itself is outlawed in the constitution. Discrimination, so you cannot discriminate against anyone because of disease, because of race, because of whatever unless that is a crime which I don't want to know. You see, legal come up to be address where there is the need. Now there is no need, there hasn't be the need because discrimination is banned in the constitution so no matter the form of discrimination, they all fall under it. If you discriminate because of my color, because of my gender or because of my disease I can still go to court and have a remedy but because I has not been done obviously against someone to be so absurd to go to court, we don't have such precedents to talk about or if there have been, they settled it anyway- **Legal practitioner, 51 years, Accra**

This did not suggest that legal services are not available if such cases of stigmatization, abuse and right violations occur. Once legal assistance is sought, it would be provided. While explaining the details, a focal person advanced.

if they are discriminated against and they seek assistance they will be offered. For instance, if the TB program itself is motivated to seek assistance, legal opinion on such matters it will be given. Also, to assist them educate their clients on how they should go about such matters. But lawyers don't go about asking clients or asking people to help. You know if the program sees the need that we are being overwhelmed we think we need legal assistance to educate or clients on such and such matters then we will do that. For the time being we haven't come to ask for our assistance. ...We are talking about a program which is funded and we are not talking about going to seek legal service form a corporate law firm. We have a legal unit in the service which will be offered free. So, it is not like you are coming to my law firm for me to tell you that it is expensive. Even in legal firms we have something we call pro bono cases that you have to do every year for free. It is not every case that we do we charge. Legal practitioner, 51 years, Accra

The existence of opportunities and avenue within which one could seek redress in upholding their human right entitlements were succinctly explained

TB patients as I said when they feel discriminated against, if someone has TB and the person was dismissed that person can seek legal assistance because you cannot. TB is a treatable disease. If someone has active TB all that you can say as medical personnel or an employer is the person goes through treatment and then the person comes back to work. You cannot terminate the persons appointment just because the person has TB. Then all those with hypertension and diabetes then all those have to be terminated because they are all forms of disease. But because the active TB is infectious that is why they are supposed to be isolated and not come into contact with others who may be prone to the infection. And it is treatable so if someone is dismissed because he is a TB Patient That is pure discrimination. That person will have a legal remedy. Going for employment and they say because you have TB you cannot be employed that person will have a legal remedy because

it is a treatable disease. It is treated and the person goes back to work. - Legal practitioner, 51 years, Accra

Right to freedom from discrimination

The right to freedom from discrimination appears to be the most dominant human right challenge that is faced by PWTB. The discussions showed that the abuse came from different sources. However, there was little mentioned occurrence of the abuse on a wider scale as the ability to know its occurrence was measured by how close one came to a victim and was told. The design of national contact tracing protocols takes into account these laws on confidentiality, respect for privacy and disclosure. **A national officer of the Ghana TB Control Program** sheds more light on it

Oh, I think human right every so far as every individual have their right. Every TB patient is also entitled to their own right and it should not be less because they have TB disease. I mean so we do generally we have not come across human right being abused in terms of TB.Ok one if a patient is diagnosed every patient is supposed to Identify a treatment supporter before treatment is commenced. In instances the person does not want any person at all to know any relative or any person at all to know. It means that they will not be able to choose a treatment supporter then the patient is allowed to take the medication without any second person. So far as they assure the health workers that they will comply with treatment. it is important and mandatory that once a patient is diagnosed a contact investigation is conducted in the patient's home to ensure that there is no person that has been infected or has the disease in the household. If the patient does not want to be linked with such an activity so that the household will get to know that that particular patient is suffering from something that is contagious that is TB then the contact tracing will be done in such a way that the patient will not be mentioned at all or will not be linked with the activity. In that case the activity will be conducted in general terms so that it is not linked to that patient that is undergoing treatment in that household. This are instanced to ensure that the patient is not stigmatized.

The phenomenon of persons overtly being discriminated against because they are TB positive does not have an externalized support.

I have not come across neither have I heard of any complaints of that sort at the national level. And even from my visit to all regions and facilities managing cases that has not been an issue. There have been students there are workers that are diagnosed and that have not been an issue. Patients are advice to take leave stay away from work for a duration so that they can convert from positive to negative but I have not heard instances where the school or work place respectively removing this person because they have TB no. NTP official, Accra

In some cases, the right to nondiscrimination is threatened and this pose challenges to treatment care. Family setting where love and care are expected to be nurtured becomes the place where such discrimination occurs.

So far err you have some family members still having this superstitious believes that it is a curse or something and it is only in those circumstances that the patient is discriminated against by family. Usually, the family are also educated through the home visits as to what the disease is and the fact that it can be cured. With a lot of advocacy that have gone on and education that have gone on a lot of people are aware of how TB is, it is transmitted and the fact that it can be cured and all that. So, I am not aware of such discrimination at the community level except as I said in some selected families that knowledge is still poor yeah... NTP, National Officer, Accra

3.6 Stigma Radar

The stigma radar conveys information on the extent of stigma in five different settings as shown in Figure 16. These TB indicators are core in the Global Fund Modular Framework. The stigma radar revealed a remarkable self-stigma among the PWTB/PWHTB (46%), secondary stigma among the family members of PWTB/PWHTB (47%), perceived stigma among the community leaders (60%) and perceived stigma among the health care workers (57%). However, this perceived stigma did not translate into inhibition of seeking and accessing TB services.

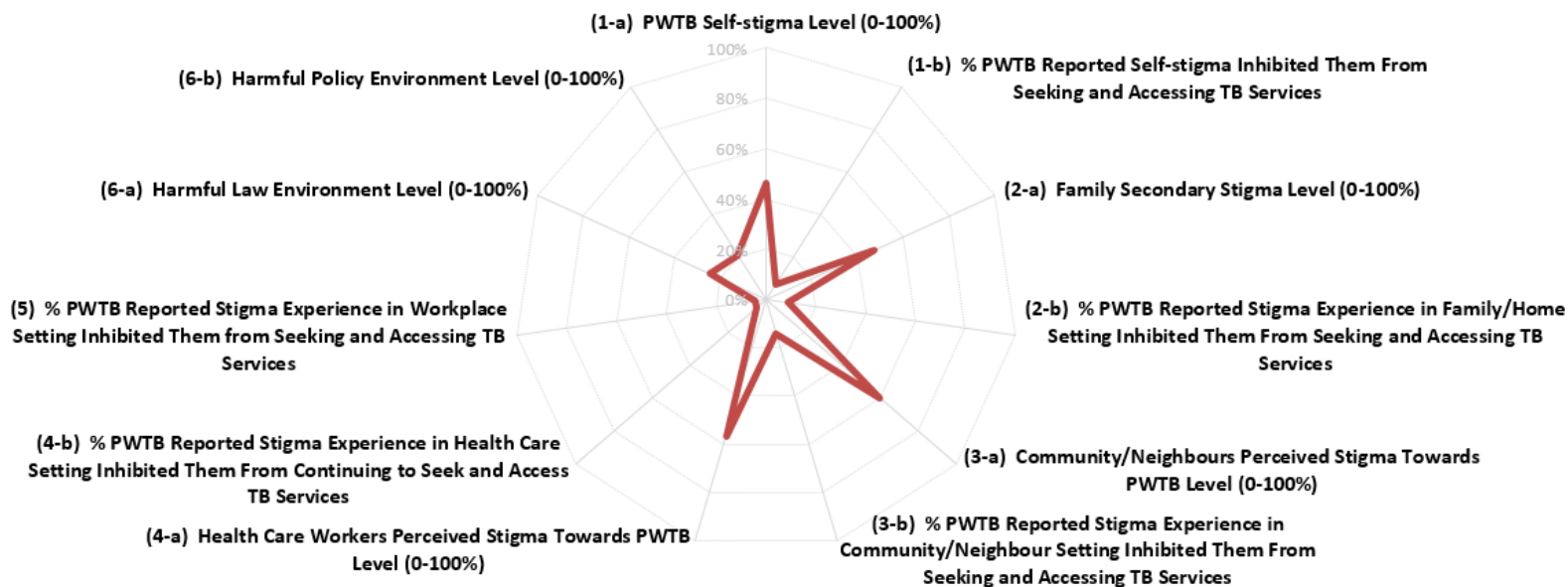


Figure 16: Stigma Radar

3.7 PSYCHOSOCIAL SUPPORT

Emotional support to enhance medication adherence

Diverse forms of psychosocial support were elicited in the interview with diverse stakeholders. Principally, community members considered a sense of belonging, welcoming and brotherliness as being adequate for ensuring care for PWTB. In their opinion,

The education and the shyness in people and there are some people even family members they think that when they come closer to you, they will get the sickness and so he won't come close to you, even cup he won't share and when you are coming then he will be running and it will leave the person with worries and so I think the education will help. if all of us we come closer to them and they feel encouraged, they won't even feel that the sickness is there. Even though they will take drugs and things but when we come close to them it will make them happy. – **Community leader, 72 years, Kumasi**

Non-availability of social protection intervention and package for people diagnosed with TB

While community opinion leaders rarely considered direct material support to persons diagnosed with TB probably due to their inability to provide, the Social Workers posited there was no package available in their operational packages for persons diagnosed with TB though the Department of Social Welfare acknowledges and considers curbing of TB infection as a social protection measure that ought to have a program arrangement for such persons.

No, we don't have package for people with TB ...no but we have packages for people who have health issues and then are not able to pay we have a station at various hospital so...yeah so there is no package ...no we don't have any data (on support to people affected by TB). Mostly we provide a lot of services to people especially the aged. We look at the LEAP disbursement which the department undertakes, issues of language become a problem and even the means to convey our staff to the various communities for the disbursement is really a problem. Sometimes too we work with the national health insurance to help LEAP beneficiaries to be on the insurance scheme-
Social Welfare Officer, 44 years, Tamale

The same narrative on the non-availability of funds to address the social protection concerns of people diagnosed with TB were corroborated by other Department of Social Welfare officers. However, other Social Welfare Officers did not think that providing for the psychosocial needs of people diagnosed with TB fell under the mandate of the department. When asked whether the department had any mandate related to people diagnosed with TB. The following response consistent with the views of many officers was given

please no...actually I am not aware of any support... my understanding I think social protection in relation to TB is just the measures in place either curb TB or to manage at least to manage TB. Actually, there this thing that I am aware of, I am not aware of any program. Please currently we don't have any data for that. Most at times you see these vulnerable persons you will meet them but financial support the financial support mostly is not available so most at time we are not able to support the vulnerable as expected- Social Worker, 49 years, Savelugu

At the hospital, although TB patients are entitled to nutritional support to person seeking treatment, it was highlighted by previously treated persons on the contrary. While treatment for TB was free, some reported incidental cost had to be paid by some participants while seeking treatment at various health facilities. Narratives on whether they had had any food or supplementary support are captured by a participant;

No nobody gave me anything but I have heard that they will give but nobody gave me. It was free because when we went to the polyclinic, I was weak and they asked me that which hospital is closer to me and I said King David hospital and now it is Kotobabi hospitaland they gave me information to go to the hospital and so the first day they gave me someone's drugs and after 3 days my drugs came. And the first day the doctor who was there made me to pay a small money for the first day (for the lab) – Ela, 29 years, Accra

Lack of access to social protection is associated with increased levels of stigma

Increasing lack of access to social support and social protection forms of any kind was identified to increase the levels of stigma among PWTB. When persons diagnosed with TB were unable to access basic necessities in life particularly within the context of being diagnose with TB, they either self-isolate, self-stigmatized or default in medication. Sharing

experiences from the northern region of Ghana, this theme cuts across and describes the context of many TB diagnosed persons.

We are aware of the social or stigma, the high level of stigma that clients who are diagnosed with TB goes through and apparently, we know that majority of our people who are diagnosed with TB come from a very poor background and once the person have been diagnosed of having TB the person might loss or might not be able to work effectively as it expected to feed him or herself or the family and so the purpose of psychosocial support is to offer them that support and counseling to enable them to go through the period that they are taking the medication. We are aware in most of our dialects or our languages and other things you know TB the local names connote something which is related to death. The Akan will mention “Nsaman wa” if you are coughing you are already ghost and it passes through all the languages so to the ordinary person in the community one you are diagnosed as having TB you are closer to death and this has had an effect on the client who have been diagnosed. **Regional TB focal person, 44 years, Northern region**

The ‘enablers’ package as the National TB programs flagship psychosocial support intervention

Though in theory, the regional and national TB principal officers suggest there are social protection packages, it emerges in the study that this not comprehensive enough. In advancing this, an enabler’s package is mentioned as the psychosocial package provided to support people diagnosed with TB and undergoing treatment. Data to support the scale of the intervention was however lacking at the regional level. The quote below attest to this.

Well, the program, occasionally what we call the enablers package where a client who have been diagnosed of TB receive some fortified food blend and other medications to boost their immunity and all those things that are offered to the clients. if we talk about clients who are taking medication for the multi-drug resistant TB definitely will also receive some sort of stipends because once they are on treatment, they will not be able to work as effectively as they were to be able to fend for themselves so to be able to encourage them to sit and take their medication the program also offers some sort of enablers in terms of financial stipends on monthly basis throughout the period they

are taking the medication they can use that to support themselves. And we are also aware that once they are sick and moving up and down to take care of themselves there might be other cost involved in terms of laboratory investigations, they can also use part of that stipends to alleviate that cost so that they don't end up losing on both sides. At least if they are sick and taking the medication their financial needs are taking care of. But when it comes to the enablers, fund and fortified food blend and other things that one it is based on availability. Those ones are provided from the national level so where it is available, we offer them but when it is not, we encourage them to use the local resources around them while they are on medication. **Regional Coordinator, national TB program, Northern region.**

Challenges around enabler package inclusion criteria

Despite acknowledging the difficulties around eligibility criteria for inclusion to benefit from the 'enablers package' being a multi-drug resistant TB client was a sure bet inclusion criterion in addition to other loosely defined criteria such as being vulnerability. Shortage of blended food supplements were setbacks in the efficient delivery of the intervention. **A sub national TB Control program** (Upper East region) officer sums it up;

I can say for sure that all those who are on the multi-drug resistant TB are all benefiting for now all of them. Even in the northern region I have seen about 7 of those. What happens is that you know they start with the medication and they complete and other people join so maybe I have to find the number who are active cases at the moment. You know the medication is taken for 9 – 11 months depending on how they respond. And then when the person completes and thus the last test is negative the person is considered cured and the then person is redrawn from our list. So currently we have about 7 people on treatment and all of the are benefiting, that is the MDR cases they are benefiting from this enabler.As at now we have run out of the fortified food blend so we are not able to offer it to the clients and many other things.

The challenges around the inclusion criteria for who qualifies or not has been articulated

Oh well, I think It needs to be consistent definably I mentioned most of the people who are diagnosed as TB are people who belongs to the poor in the. Society and most of

them eventually have to struggle to get their daily living and if the person is sick the person is not able to fend for himself and other things so they don't mostly take it lightly. so, most of the time you need to get closer to them and encourage them and counsel them, support them as the cases may be in terms of their moving up and down. And I think this is one of the reasons why the enablers, the food blend and other packages was introduced. But definably for the uncomplicated TB cases they are not given any support but those who are having the multi-drug resistant are those who are getting the support. **NTP Northern regional correspondent**

Narratives from the national TB control program however suggest that, the enabler's package was an intervention that was accessible by only a few TB diagnosed persons. Though the regional level implementers were unable to provide data to support how many beneficiaries the program had reached out to, national officers similarly requested for time to provide such handy data. The response from national principal officers of the NTP has confirms the targeted nature of the intervention.

okay, so the main one, let me say one is the enablers package what that does is that it would be.... so, these enablers package is not for is not for all patient but it is for specific patient, children and patients detected with multi drug resistance strains of TB. So, they are providing with support financially to help them in sustenance. So that in a form of support for feeding, probably transportation to and from the facility when they need to go for review or medicine refill- **Monitoring and Evaluation Technical officer Monitoring and Evaluation (M&E) for NTP, Accra**

The impact of the provision of the psychosocial packages have been articulated below

the confidence that the patient gets after they have receive the support and gone through the treatment and they are restored back, the confident they get in the health system I mean is reassuring and then, they are able to... and number two, I mean they are able to now get to know that certain diseases are not due to certain myth they had before like TB being a curse or HIV being a curse but now, they know that o is a disease condition that anybody can get and then it can be treated and with that support, they can be cured. **-NTP, Monitoring and Evaluation Head, Accra**

In northern Ghana, the provision of psychosocial intervention/ package saved and entire family. Recounting such positive experiences, the regional TB focal persons explain;

Oh, I think it is okay I can recount there are cases otherwise they wouldn't have taking the medication. There are some of them they made them follow up several times but once they knew of the fact that when they take the medication, they will get some sort of support, socials support while they are taking the medication and other things in fact, they develop interest all of a sudden. I can recount a case in Walewale where we have to travel there, we need to travel to the place more than 5 times. At a point in time the man brought out a cutlass that whoever steps in his house he is going to slash the person but along the line we were able to talk with the person and with the support of this psychosocial intervention later the man himself comes and ask for the medication and taking it because he knows that whenever he comes at least he will get something to support himself. So, it works, it works perfectly well

3.8 Stakeholder Validation Meeting

As part of this study, a two-day multi-stakeholder validation meeting was held from 21st -22nd December 2020 in Kumasi. In attendance of this meeting were experts in planning and public health, members of the National Tuberculosis Program (NTP), District TB coordinators, Monitoring and Evaluation Officers from Ghana Health Service (GHS) and TB champions or members of TB Voice Network. This meeting was to provide support ensuring the reliability and authenticity of the study findings and to look to the future the implementation and role of the action plan in reducing TB stigma in Ghana.

Day 1 (21st December, 2020)

Agenda:

- Discuss and score the law and policy environment matrices and formulate recommendations.
- Review findings according to the four open-ended questions; (a) experience of stigma, (b) observations of stigma, (c) suggestions for changes in TB services, and (d) further comments- for each of the four study objectives (PWTB/PWHTB, family member/caregiver, community leaders and HCWs)

Morning session

- Dr. Aliyu Mohammed, the study consultant, chaired the meeting. The morning session of the meeting on the first day includes a presentation of the study such as the Background, Methods, Key findings and Discussion and Recommendations by the study consultant. Further, the study consultant explained the scoring of the law and policy environment matrices to the stakeholders.
- The stakeholders were put into a group of four with each group composing of at least a stakeholder with a diverse background. Stakeholders discussed the scoring frame, agreed and provided recommendations for the Action Plan.

Afternoon session

- The groupings were maintained and each group was assigned all the other four specific objectives.
- Each group discussed the study findings in relation to the agenda for the afternoon session and reported their suggestions and recommendations in a booklet. Each group was afforded the opportunity to make a presentation of their report.
- The study consultant summarized the key issues and recommendations as agreed upon by the stakeholders.

Day 2 (22nd December, 2020)

Morning session

The study consultant presented the action plan developed and the summary of the key issues and recommendations on day 1. The presentation was done simultaneously with stakeholder discussions.

Afternoon session

- The four groups were maintained and tasked to discuss the following in relation to the objectives of the action plan:
 - I. What aspects of stigma and its manifestations need to be addressed most urgently/ prioritized to maximize impact?
 - II. What interventions are needed?
 - III. How do these priority interventions align with the National Strategic Plan?
 - IV. Where and when should the interventions be implemented?
 - V. Which organization should be the focal point to monitor the implementation of the Action Plan?
- Each group was given space to present on their report.
- The study consultant summarized the key issues and recommendations as agreed upon by the stakeholders.

Overall, the key issues and recommendations agreed on by the stakeholders were incorporated action plan.

Key issues raised on day 1 and day 2

1. Members of NTP had issues with the usage of “Persons living with TB (PLWTB)” and their explanations was that using the word “living” implies TB is chronic. i.e. the person lives with it throughout his/her lifetime without being cured. Unlike HIV which has no cure and for that matter the word “living” may appropriately describe them, individuals infected with TB unless a multi-resistant type are usually cured after 6 months of DOTs, they asserted. Therefore, it was inappropriate to use “Persons living with TB” as it has an implication to worsen the stigma associated with the disease.
2. The construct “TB community” was seen as ambiguous by all stakeholders and sought for clarity on the components making up the “TB community as used in the report and the action plan. The study consultant explained the “TB community” as persons who have recovered from TB. However, the stakeholders felt it was important to involve all persons who have been affected by TB in advocating for the right of persons with TB disease.
3. Stakeholders indicated that results on gender were standalone and adds no meaningful information to the scope of the work.
4. The action plan outlined that effective adherence counselling should be done for TB patients before initiating treatment. However, the stakeholders were of the view that pre-treatment counseling is not enough to get desired results hence the need for continuous counselling to improve treatment adherence.
5. Stakeholders especially NTP prompted that the right to informed consent is not entrenched in the NTP treatment guidelines as initially indicated in the action plan. they further recommend thus should be incorporated in the treatment guidelines.
6. In the action plan, it was proposed that there should be changes in infrastructure of health facilities to curb discrimination in our health facilities. However, the stakeholders deemed it unrealistic because it will be difficult to change the entire hospital infrastructure to suit

the needs of TB patients. Hence, rather suggested that structural changes in personnel and health facility activities such that TB care will not be restricted to only few staffs.

Recommendations by Stakeholders

1. Members of the NTP suggested that the construct “Persons living with TB” should be replaced with “Persons with TB (PWTB)”. With PWTB, it may imply that the person was diagnosed of TB and after 6 months of successful DOTs would be cured.
2. Stakeholders recommended the establishment of several TB community at district and national level, and should be adequately funded by the Ministry of Health, Ghana, to enable them reach out to all persons with TB or Persons who have had TB (PWTB or PWHTB). Implementation of this would create a sense of belonging among PWTB or PWHTB thereby minimizing stigma and enhancing access to TB services.
3. It was suggested that there should be disaggregation of the gender results and how gender influences stigma with effects on accessing TB services should be measured.
4. There should be intense public awareness about the consequences of TB related stigma through the local/national media outlets, and disseminate study findings to institutions in order to encourage utilization of study findings.
5. NTP policy guidelines for the control of TB in Ghana are must be enforced in all health facilities since there is less involvement of managers from facility and district levels.
6. Laws and policies that protect health care workers who are stigmatized due to the service they provide to PWTB should be enacted because such laws and policies would discourage stigma among health professional.
7. Engage media institutions in the discourse of TB related services and discuss findings of the study in order to improve their knowledge about TB stigma and rights of TB patients. Also establish a media arm that will be responsible for promoting TB related activities in the media cycle.
8. Organize training workshop for healthcare providers on the right, privacy and laws that promotes patient’s confidentiality and protection from stigma and discrimination.
9. Civil Society Organizations and other institutions must have a role to play to ensure TB stigma reduction interventions are implemented and scaled up. These interventions should also be geared towards protecting the fundamental rights of PWTB.
10. Free registration and renewal of National Health Insurance Scheme (NHIS) for persons diagnosed with TB could help mitigate the challenge of poverty among PWTB which was

found by this study as a barrier to accessing health care. The NHIS should cover all essential services when diagnosed with TB.

11. There should be laws/policies that prevent TB patients from losing their jobs in order to protect the livelihood of person diagnosed or being treated for TB or persons who have had TB.
12. Further studies should be conducted to identify key community, gender and behavioral drivers of TB stigma.
13. Commemoration of World TB day should be decentralized; regional, districts, sub-district, community and health facility level.
14. The Advocacy, Communication and Social Mobilization (ACSM) Unit must be established in the National Tuberculosis Control Program (NTP).
15. The ACSM should be empowered and resourced to undertake publicity and media coverage of all TB related activities.
16. There should be continuous availability of counselling services for persons with TB disease. The counselling should be held in the first language of these people or there should be an interpreting service whenever necessary.
17. Patients consent seeking process should be incorporated into the NTP and compels health care workers to give informed consent in diagnosing or treating patients.
18. Health facilities should be restructured in their management in their TB case.

Recommendations incorporated in Final Report

1. The construct “Persons infected with TB” was deliberated by all stakeholders presented at the meeting of which a consensus was reached and incorporated in the final report where necessary.
2. Gender of PWTB/PWHTB was disaggregated and a table showing the association between gender and stigma was inserted in the final report.
3. There should be intense public awareness about the consequences of TB related stigma through the local/national media outlets, and disseminate study findings to institutions in order to encourage utilization of study findings.

4. Establish a TB stigma reduction forum with TB networks which encourages and support PWTB to seek knowledge about their rights and other psychosocial support. This will help identify PWTB and provide immediate support when necessary.
5. NTP policy guidelines for the control of TB in Ghana are must be enforced in all health facilities since there is less involvement of managers from facility and district levels.
6. Laws and policies that protect health care workers who are stigmatized due to the service they provide to PWTB should be enacted because such laws and policies would discourage stigma among health professional.
7. Engage media institutions in the discourse of TB related services and discuss findings of the study in order to improve their knowledge about TB stigma and rights of TB patients. Also establish a media arm that will be responsible for promoting TB related activities in the media cycle.
8. Organize training workshop for healthcare providers on the right, privacy and laws that promotes patient's confidentiality and protection from stigma and discrimination.
9. Civil Society Organizations and other institutions must have a role to play to ensure TB stigma reduction interventions are implemented and scaled up. These interventions should also be geared towards protecting the fundamental rights of PWTB.
10. Free registration and renewal of National Health Insurance Scheme (NHIS) for persons diagnosed with TB could help mitigate the challenge of poverty among PWTB which was found by this study as a barrier to accessing health care. The NHIS should cover all essential services when diagnosed with TB.
11. There should be laws/policies that prevent TB patients from losing their jobs in order to project the livelihood of person diagnosed or being treated for TB or persons who have had TB.
12. Further studies should be conducted to identify key community, gender and behavioral drivers of TB stigma.

Recommendations incorporated in Action Plan

1. Stakeholders advocated for groups that should include all persons with TB and/or affected by TB to share their experiences, identify common struggles and collectively change harmful practices. For example, persons diagnosed with TB or cured of TB should be

encouraged to join TB Voice Network. These groups should be adequately funded by the Ministry of Health, Ghana, to enable them reach out to all persons with TB or Persons who have had TB (PWTB or PWHTB). Implementation of this would create a sense of belonging among PWTB or PWHTB thereby minimizing stigma and enhancing access to TB services.

2. Commemoration of World TB day should be decentralized; regional, districts, sub-district, community and health facility level. The Ministry of Health and Ghana Health Service should decentralize the commemoration of World TB day. It should be held at all levels including the community and health facility level to leave no one behind in the celebration and awareness creation.
3. The Advocacy, Communication and Social Mobilization (ACSM) Unit must be established in the National Tuberculosis Control Program (NTP). The Ministry of Health and Ghana Health Service must consider establishing Advocacy, Communication and Social Mobilization (ACSM) Unit under the National Tuberculosis Control Program (NTP).
4. The ACSM should be empowered and resourced to undertake publicity and media coverage of all TB related activities. This Unit (ACSM) must be empowered and resourced by the Ministry of Health/GHS to actively undertake publicity and media coverage.
5. There should be continuous availability of counselling services for persons with TB disease. The counselling should be held in the first language of these people or there should be an interpreting services whenever necessary. Counselling services should be readily available for TB patients to access it whenever needed. These should be placed within the cultural settings of the people. Counselling should be done in the local dialect of the people; interpreter should be used whenever necessary.
6. Patients consent seeking process should be incorporated into the NTP and compels health care workers to give informed consent in diagnosing or treating patients. The NTP guideline for TB management should be revised to ensure mandatory addition of informed consent prior to any diagnostic procedure or treatment for TB disease.
7. Health facilities should be restructured in their management in their TB case. Health facilities should be provided with the necessary logistics and equipment to ensure quality and safe caring of TB patients. Caring for TB patients must not be left in the hands of few

people or staffs. Health professionals should be rotated from time to time based on the facility schedule.

4.0 CONCLUSION

This is the first study in Ghana and sub-Saharan Africa that quantitatively measures the extent of TB stigma. TB related stigma was considerably high in both internal and external components that were measured to determine stigma levels and this evidence was further buttressed with qualitative themes. For instance, stigma experienced by PWTB/PWHTB and family members/caregivers offering support was 22% and 10% respectively. These could have significant implications on seeking and accessing TB care services if not given utmost consideration. Self-stigma was common among PWTB/PWHTB and key populations including persons living with HIV, miner and rural poor. PWTB/PWHTB most stigmatized in the community/neighborhood. Stigma experienced in the community/neighborhood where they reside mostly inhibited them from recognizing symptoms, followed by seeking care and treatment. Gossip, avoidance and isolation of PWTB and verbal/physical abuse were the specific TB related stigma experienced by PWTB/PWHTB.

PWTB/PWHTB cited financial difficulties in accessing care and unavailability of TB drugs at hand as main reasons for defaulting treatment. Generally, men and women were perceived to receive equal treatment with regards to job acquisition and access to resources. However, women were largely not involved in community decision making and mobilization and this may be due to cultural norms in most societies in Ghana. Interestingly, a higher proportion of men with TB or have had TB were more stigmatized than women.

Negative attitudes or rejections of family members/caregivers because of their association with PWTB/PWHTB was not prominent and non-disclosure could account for this observation since family members/caregivers mostly concealed the TB status their family members who have TB or have had TB. Secondary stigma was often reported in the community, to some extent the family/home and clinics/hospitals, and this often inhibited them from supporting their family member to recognize symptoms, seeking care, beginning treatment and getting treatment adherence. This was also reported as stigma experienced by other family members/ caregivers offering support to PWTB/PWHTB. Gossip, avoidance from other community members/isolation at health facilities and verbal/physical abuse must critically be looked at because they were

common specific TB related stigma reported among the respondents and other family members/caregivers offering support to PWTB/PWHTB.

At the community level perceived stigma was high. and Most of the community leaders knew at least a person diagnosed with TB or have had TB who have been stigmatized in the community they reside. Gossip about PWTB/PWHTB, verbal/physical abuse and avoidance isolation of PWTB at health facilities and neglect/abandonment were common specific stigma reported by community leaders. Moreover, stigma experienced at community level mostly inhibited PWTB/PWHTB from recognizing symptoms, seeking care and getting diagnosis

Contrary to the reports of other studies, the findings of this study suggest that HCW show compassion and utmost care to TB patients, although some reported fear or being nervous about treating them. HCWs who were stigmatized, indicated that it mostly occurred at the hospitals/clinics and where they lived. Specific stigma prominently experienced by HCWs were gossip and avoidance from colleague HCWs.

The National TB program managers, the legal community, policymakers and the media affirmed the existence, enforcement and media coverage of laws that protects the rights of PWTB/PWHTB at both the subnational and national level.

The stigma radar revealed that self-stigma, secondary stigma and perceived stigma by the community leaders and HCWs were prominent among the study population. However, perceived stigma did not translate into inhibition of seeking and accessing of TB services.

5.0 RECOMMENDATIONS

National TB Control Program, GHS

- a. Implement self-stigma reduction programs that seek to motivate and empower people diagnosed with TB to believe they can alleviate their health condition and circumvent further negative consequences that inhibit them from seeking and accessing health care.
- b. Increase public awareness about the consequences of TB related stigma and its negative effect on health seeking behaviour among PWTB through the local/national media outlets, and disseminate study findings to institutions in order to encourage utilization of study findings.
- c. Ensure that facility managers persons diagnosed with TB are given more priority and patients receive adequate counselling on stigma reduction processes during treatment. This is expected to reduce self-stigma and improve health seeking behaviors among PWTB.
- d. Develop and enforce policies that protect health care workers who are stigmatized due to the service they provide to PWTB. A disciplinary committee at the DOT facilities could be tasked to ensure existing policies are enforced, and routinely monitor and encourage reporting of medical ethics violations. The committee as part of its mandate could also organize medical ethics training for health care workers and programs to discourage discrimination among health professionals at the work place.
- e. Broadcast and discuss the fundamental rights of PWTB and their family members through local and national media outlets, as well as organize community durbars in order to mitigate the violation of basic human rights of PWTB that inhibit their access to health care.
- f. Engage media institutions in the discourse of TB related services and discuss findings of the study in order to improve public awareness of the laws/policies and their enforcement at both the national and sub-national level that seek to also protect the rights of people diagnosed with TB. Also establish a media arm that will be responsible for promoting TB related activities in the media cycle.
- g. Ensure the strict enforcement of existing TB treatment policy that authorize the need for health care workers to respect the right to informed consent before diagnosing or treating a patient.

- h. Ensure facility managers organize training workshop for healthcare providers on the right and laws that promotes patient's confidentiality and respect for privacy during and after treatment.
- i. Establish partnership with Civil Society Organizations and other institutions to ensure implementation of TB stigma reduction interventions are implemented and scaled up. These interventions should also be geared towards protecting the fundamental rights of PWTB. These interventions could include raising public awareness of right-to-health entitlement of PWTB in communities and training health care workers that provide service to the patients.
- j. Establish a TB stigma reduction forum in collaboration with TB networks (TB communities) in the country which encourages and provide psychosocial support to PWTB irrespective of their gender.
- k. Conduct regular operational research on TB stigmatization in order to monitor the trend of stigma and the enforcement of rights of PWTB.
- l. Conduct further studies to identify key community, gender and behavioral drivers of TB stigma.
- m. Advocate for the establishment of a TB network grant for PWTB to support TB stigma reduction research and interventions.

Ministry of Health (MoH)

- a. Revise policy guidelines to accommodate laws which mandates prescribers/clinicians to ensure that TB care and management are regarded as priority condition at all health facilities.
- b. Ensure that the existing laws and policies on TB stigma and discrimination for persons with TB, their families and health care workers are enforced to protect the rights of key populations.
- c. Ensure that existing laws and policies are enforced to identify and encourage patients with TB who refuse to seek treatment, especially MDR-TB patients.
- d. Establish free registration and renewal of National Health Insurance Scheme (NHIS) for persons diagnosed with TB in order to encourage access to health care. The NHIS should cover all essential services when diagnosed as having TB.

- e. Ensure laws/policies that allows TB patients to take mandatory leave during the intensive treatment face are enforced.
- f. Ensure laws/policies that prevent TB patients from losing their jobs in order to protect the livelihood of person diagnosed or being treated for TB.

TB Community

- a. Establish a forum where members of the TB community are able to channel their stigma concerns that inhibit them from accessing care during their TB journey.
- b. Ensure that voices of members whose rights are violated during the TB journey are channeled through the appropriate government authorities to take action.
- c. Establish a community monitoring system that monitors indicators that are relevant to the community in order to improve services such as quality and type of TB services.
- d. Establish a Community Treatment Observation (CTO) structure that routinely collect qualitative and quantitative data on the quality of services, in order to ensure that members of the TB community receive appropriate care at the DOT centres.

Civil Society Organizations (CSOs)

- a. Beside the TB Voice Network, other CSOs established to serve the TB community could be encouraged to revise their vision and mandate to accommodate stigma reduction related interventions across the country.
- b. Advocate for continued improvement on TB service delivery and programs designed to reduce or eliminate TB stigma and discrimination among key populations (especially PLHIV, miners and rural poor)
- c. Could support health facilities or DOT centers to reduce stigma to the minimum among HCWs through effective engagements such as workshops.
- d. Could support the discourse on the rights of PWTB and public awareness of laws and policies that protect TB patients, and also ensure to elucidate any repealing policies or laws that antagonize or criminalize PWTB/PWHTB.

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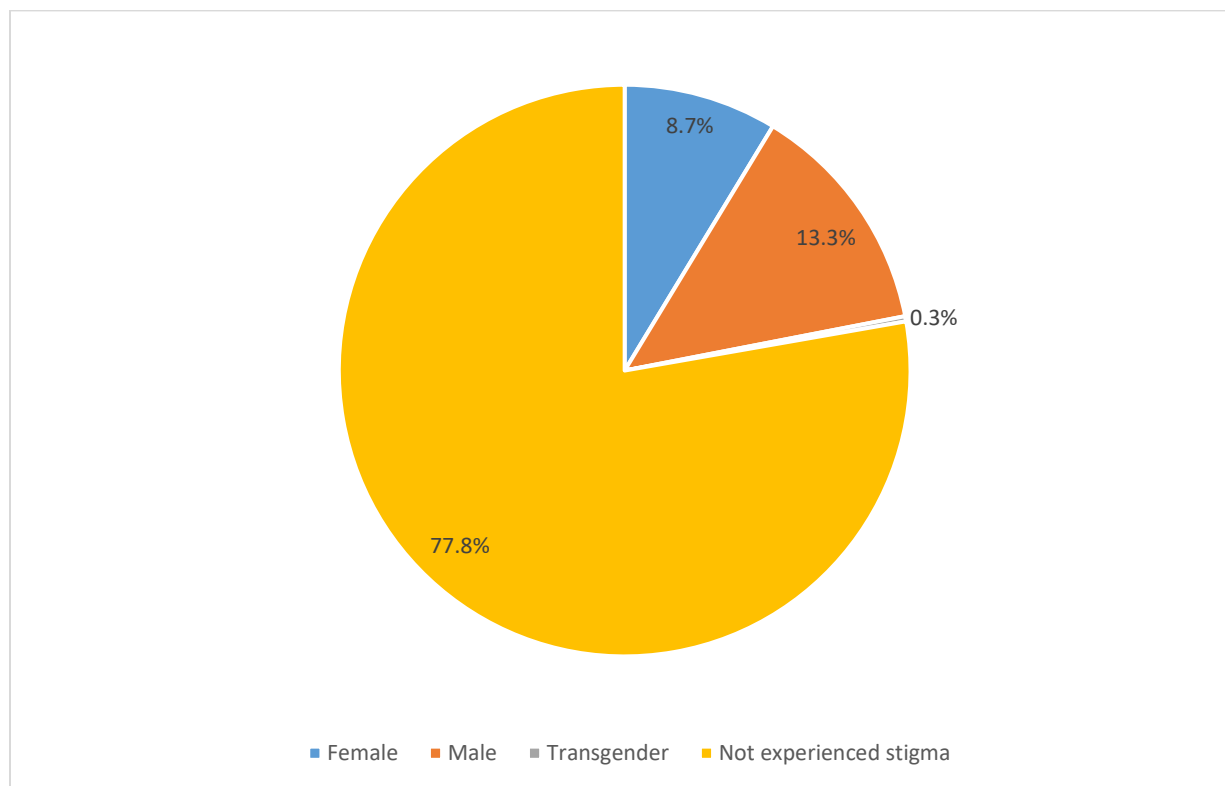
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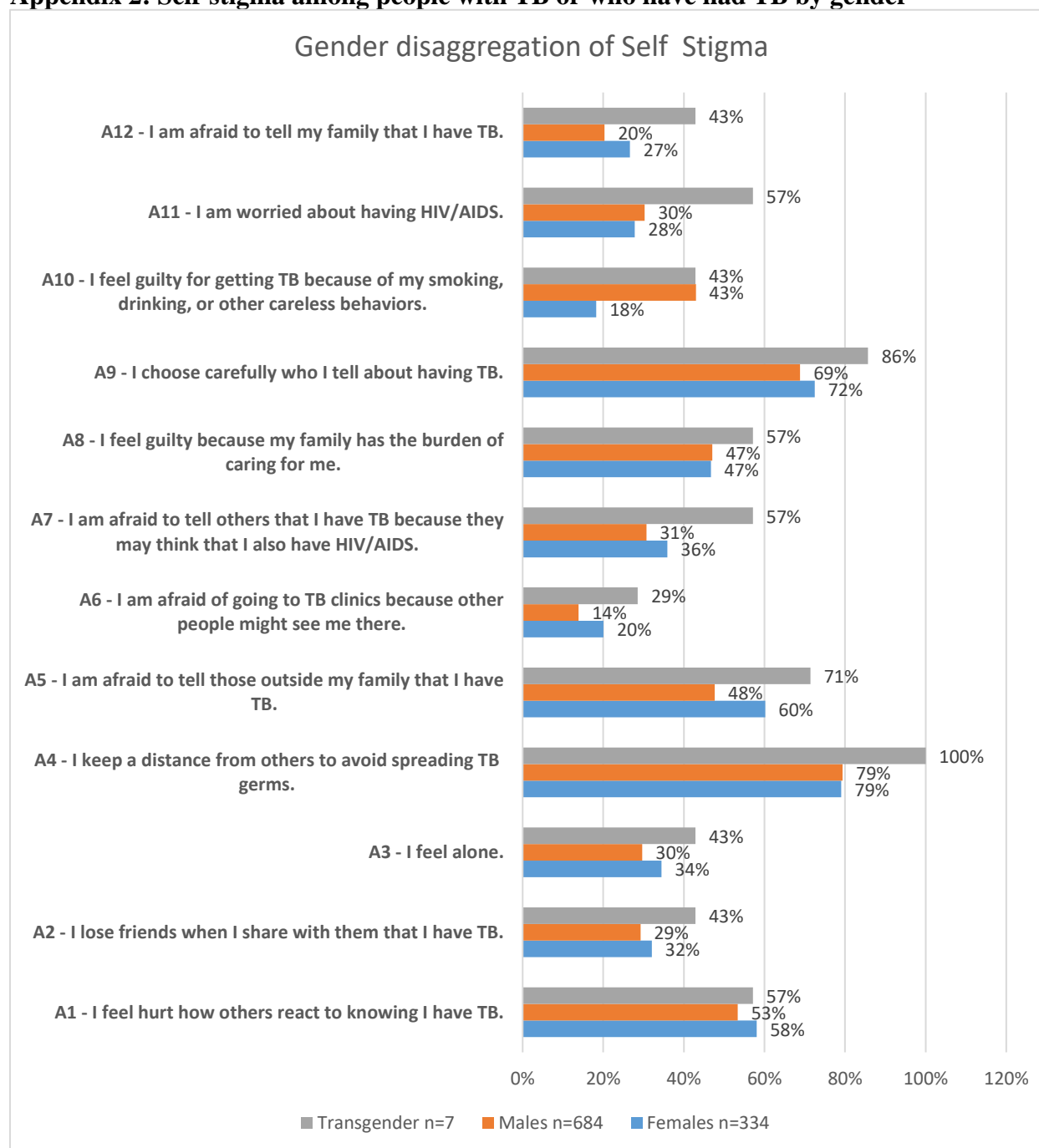
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APPENDICES

Appendix 1: Stigma experienced by PWTB/PWHTB by gender

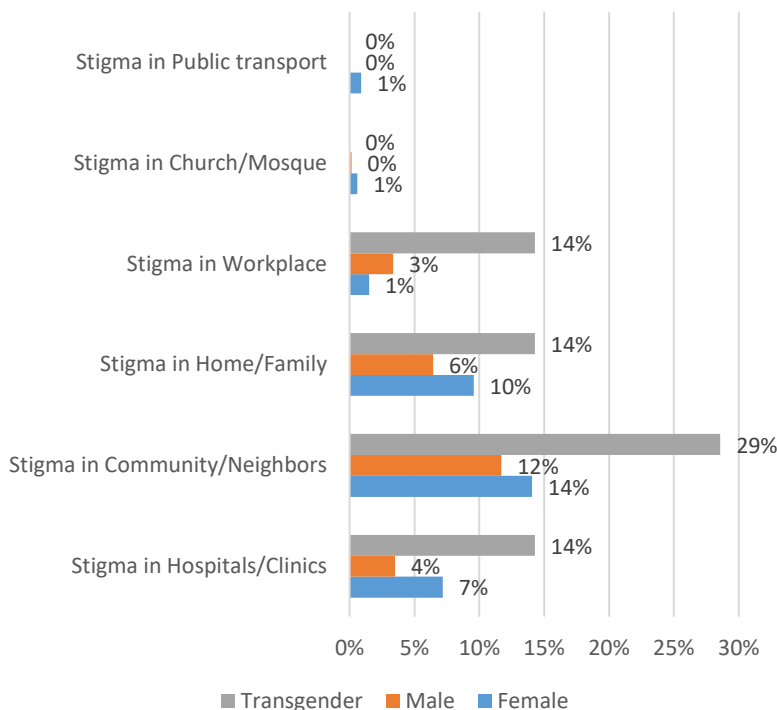


Appendix 2: Self-stigma among people with TB or who have had TB by gender

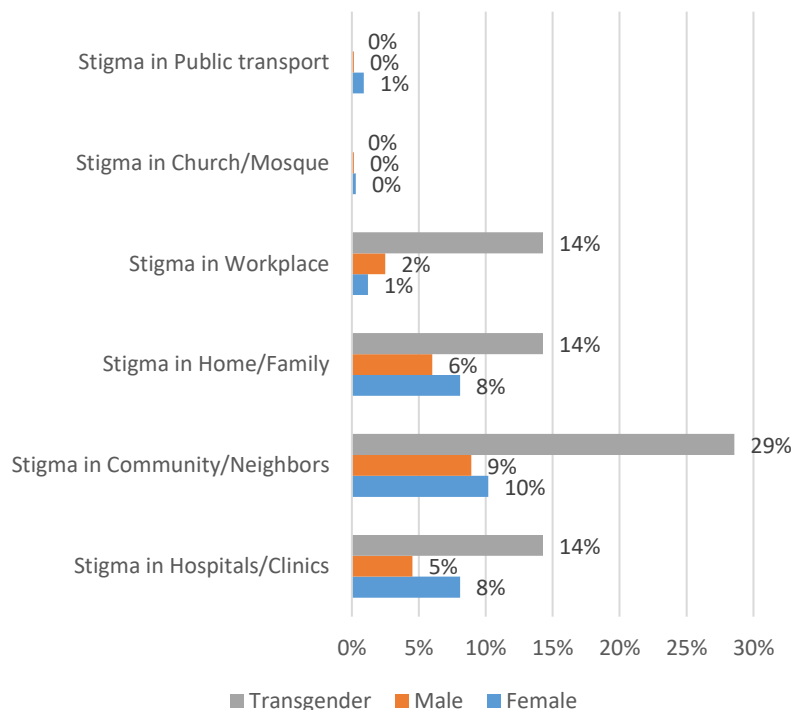


Appendix 3: Stigma experienced by PWTB/PWHTB on their TB journey under different settings by gender

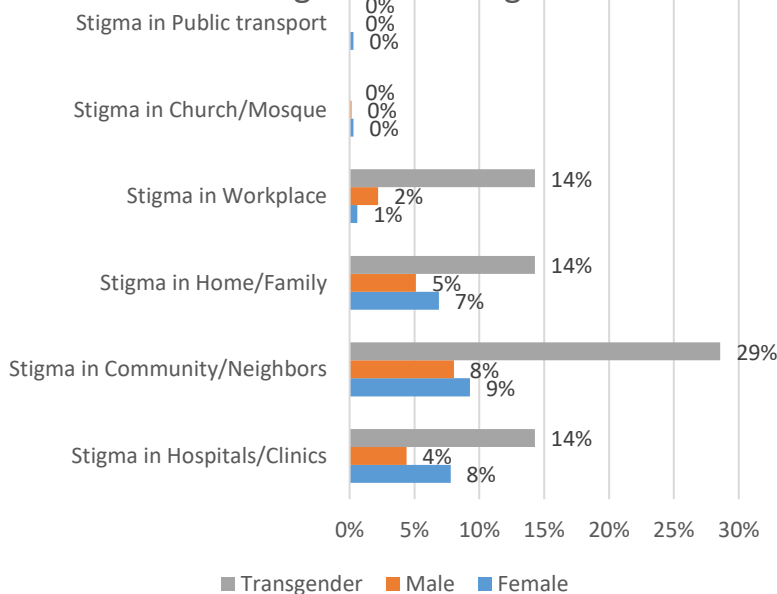
Recognizing symptoms



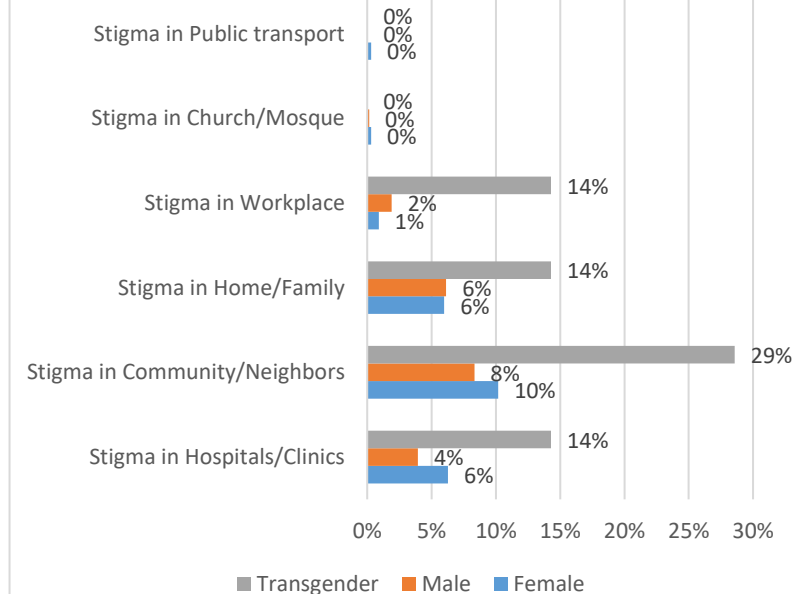
Seeking care



Getting accurate diagnosis

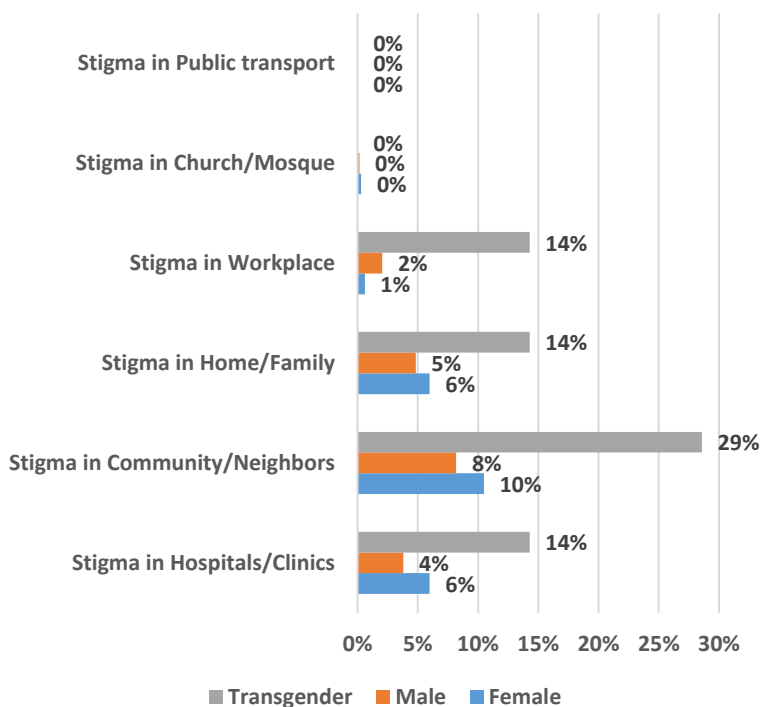


Beginning treatment

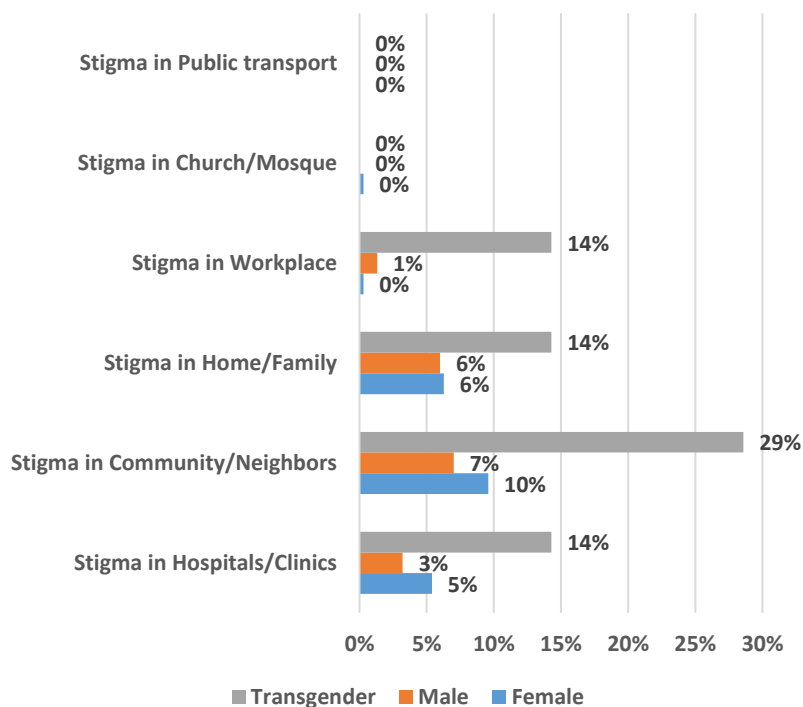


Appendix 4: Stigma experienced by PWTB/PWHTB on their TB journey under different settings by gender

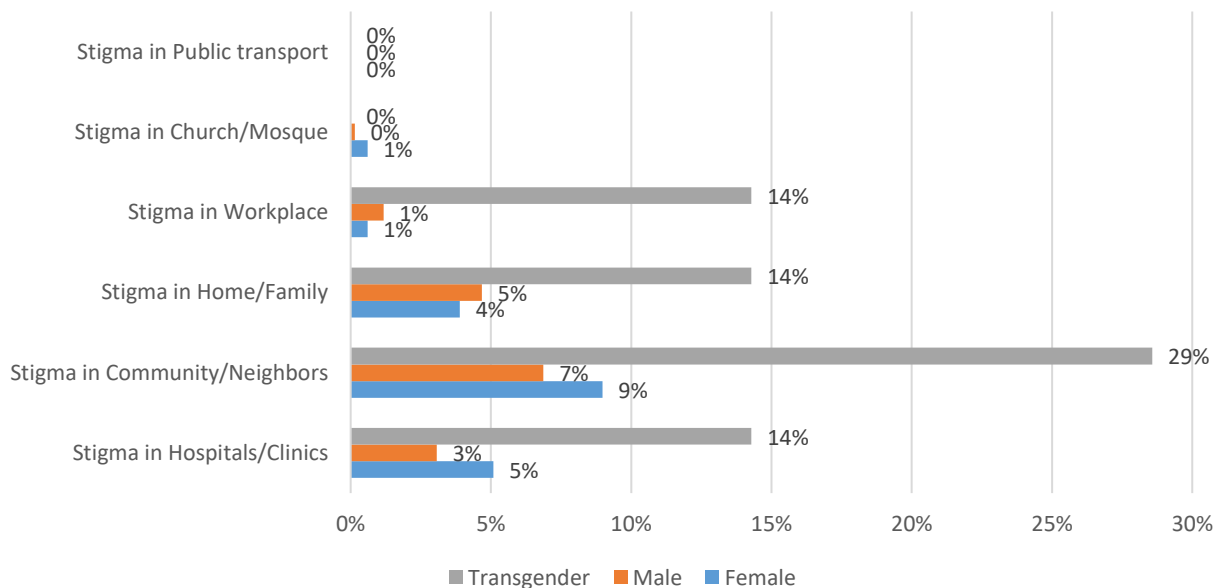
Getting treatment adherence support



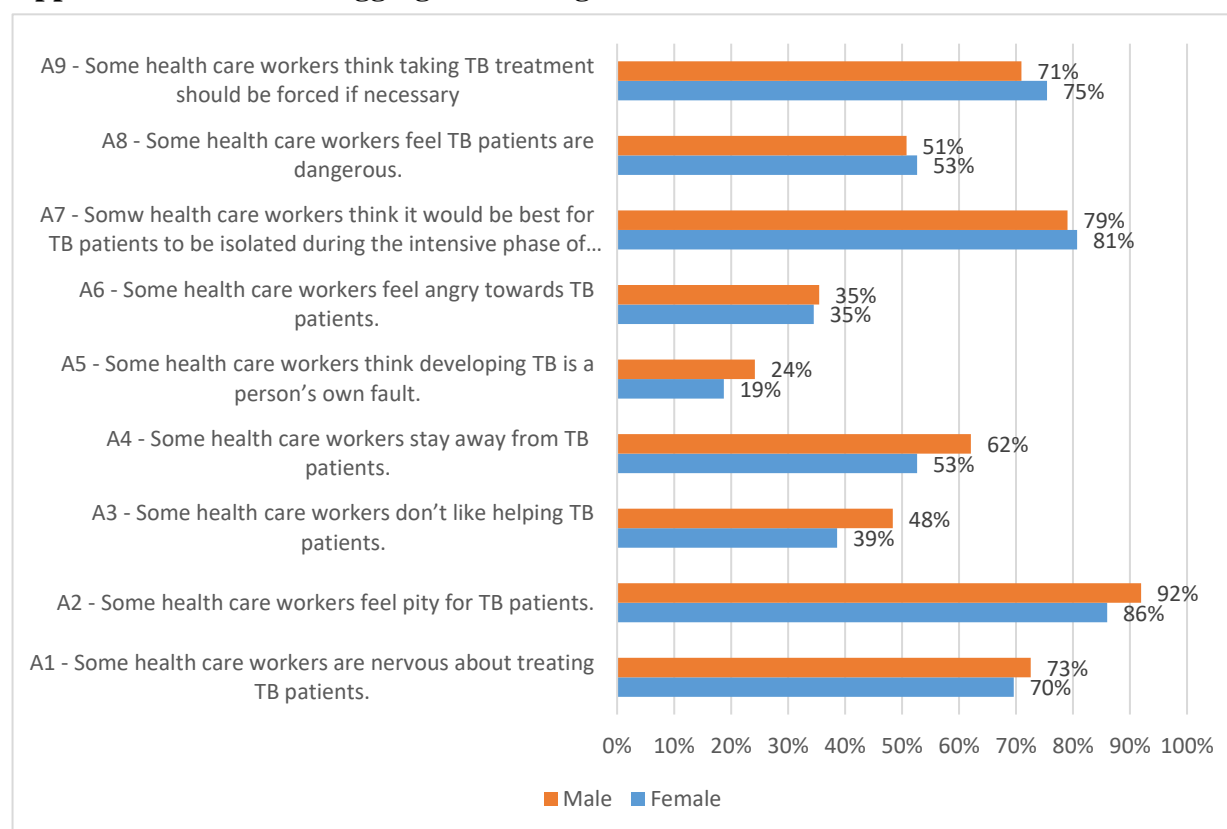
Completing treatment



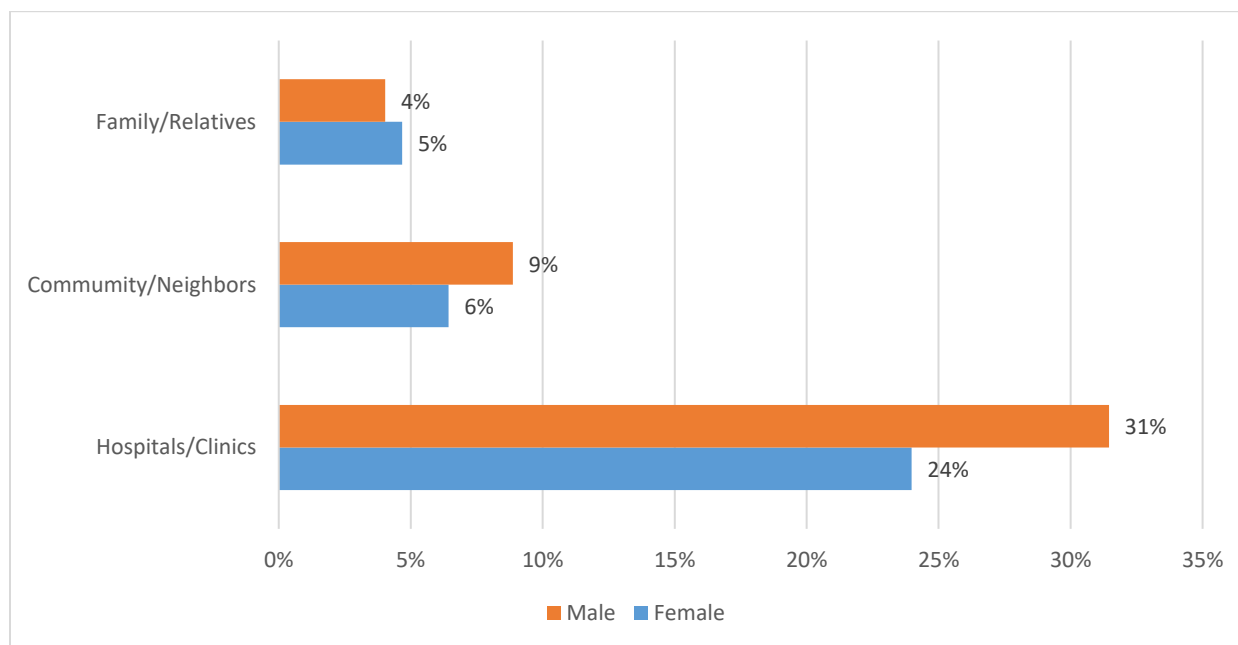
Getting post-treatment follow-up services

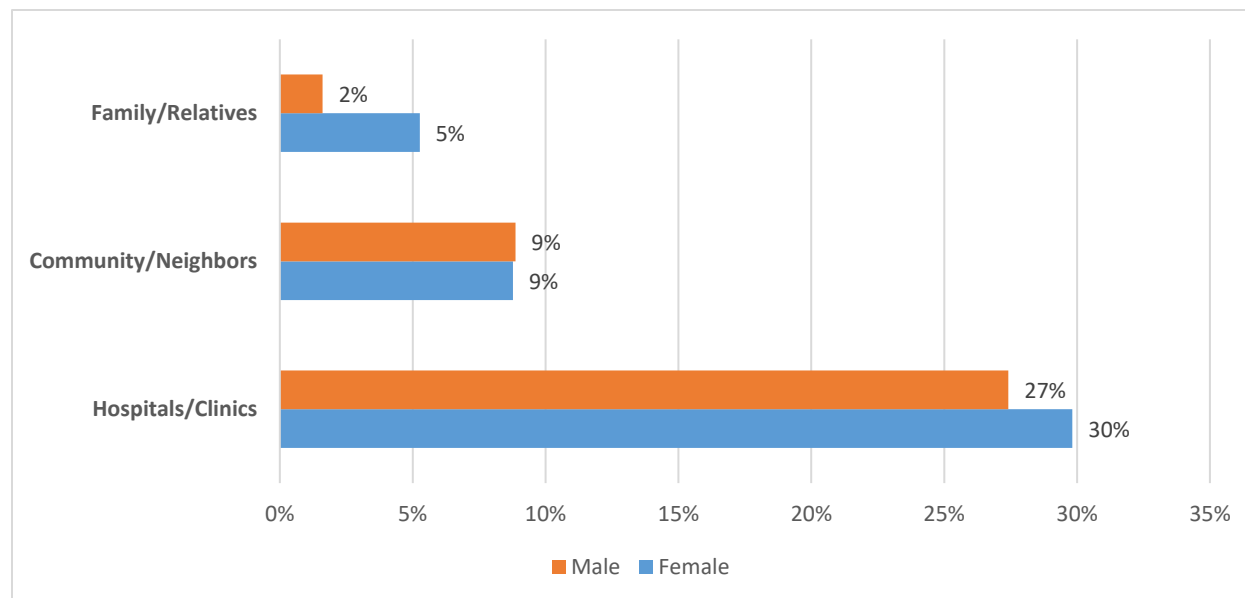
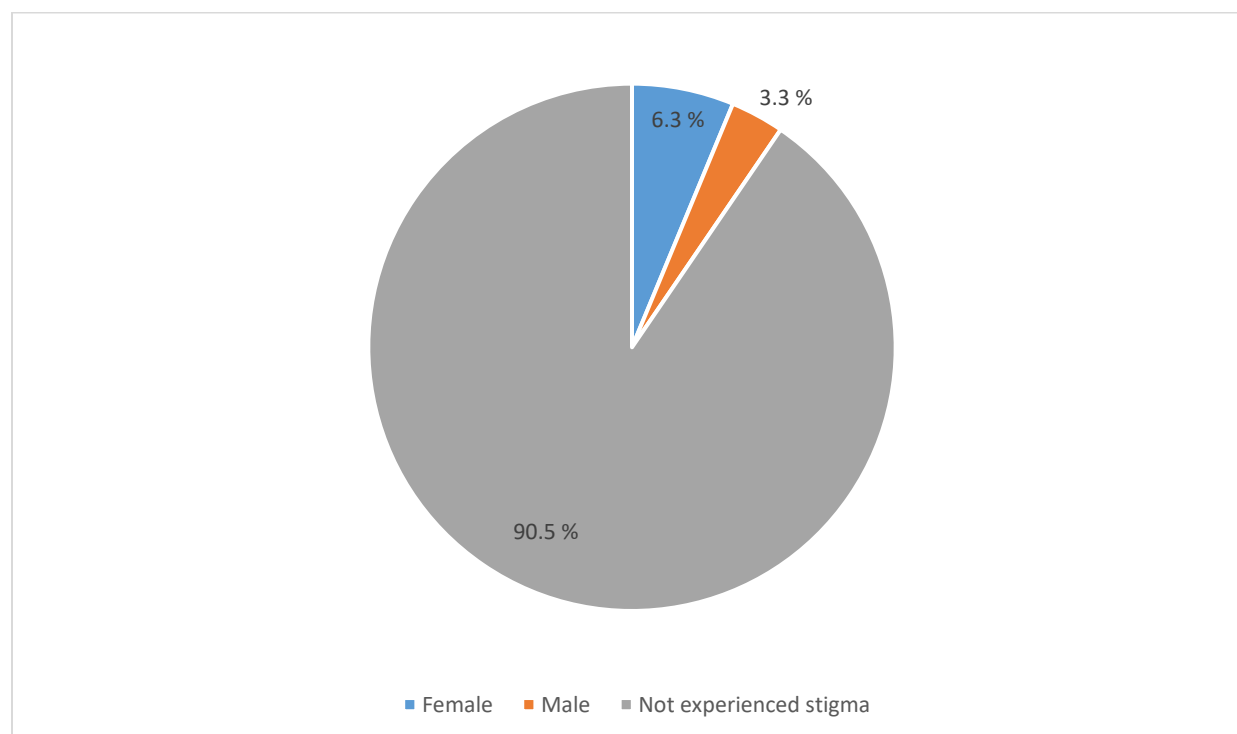


Appendix 5: Gender disaggregation of stigma towards HCWs

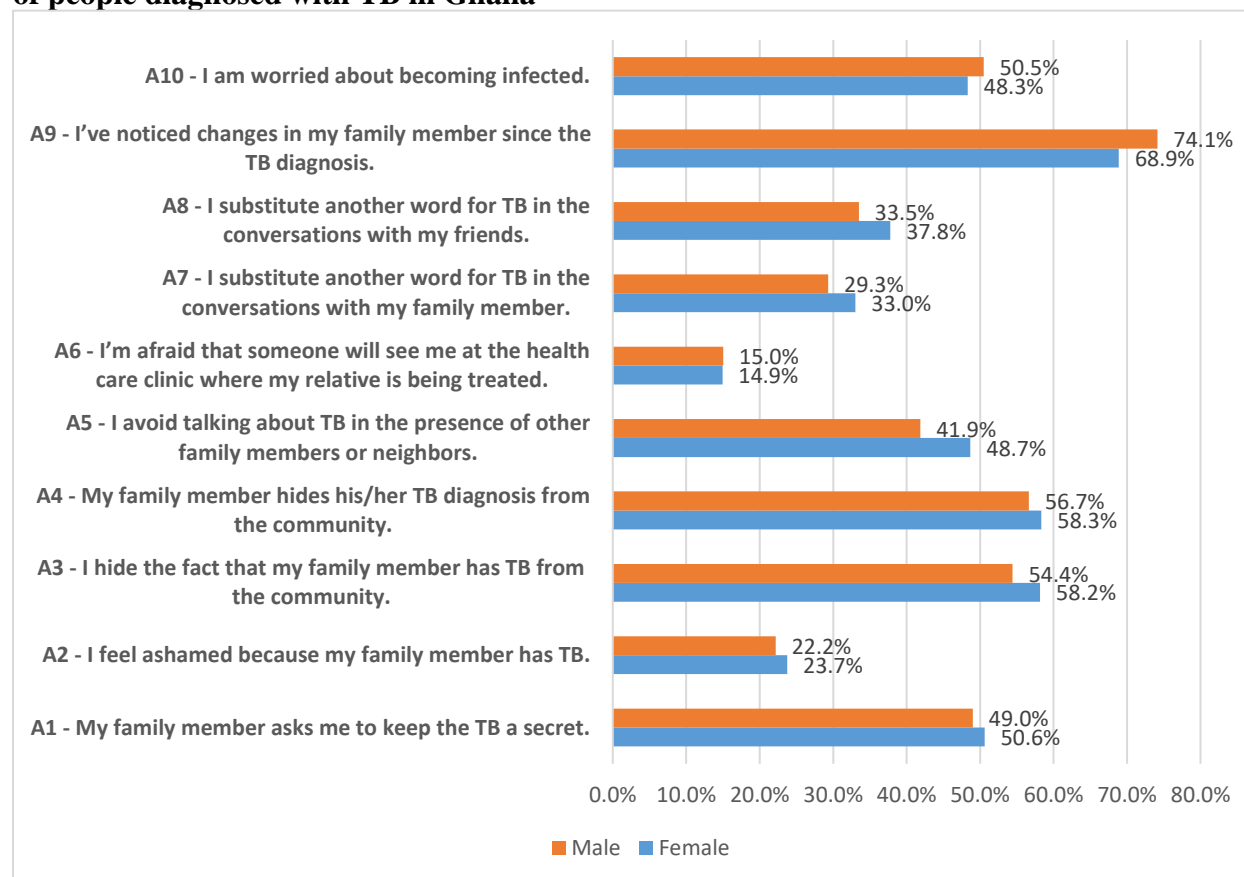


Appendix 6: Gender disaggregation of other health care workers being stigmatized



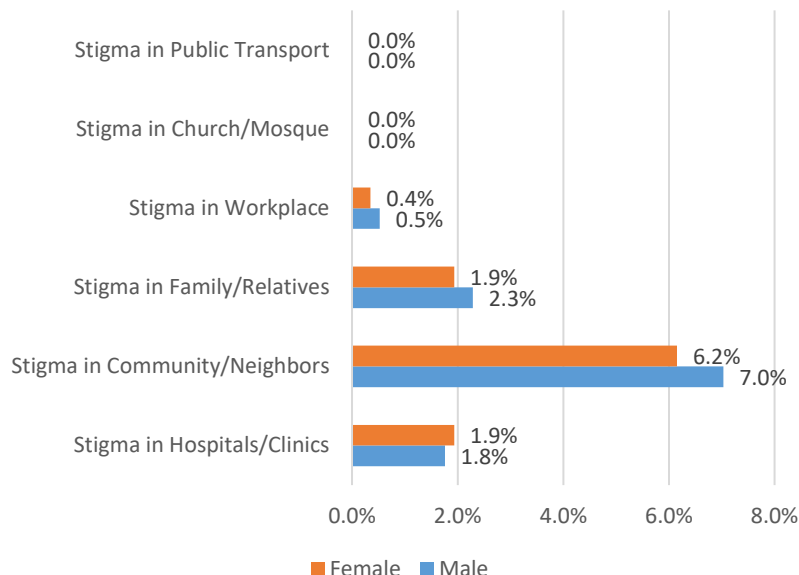
Appendix 7: Stigma experienced by health care workers under different settings by gender**Appendix 8: Stigma experienced by family members of PWTB/PWHTB by gender**

Appendix 9: Gender disaggregation of secondary stigma reported among family members of people diagnosed with TB in Ghana

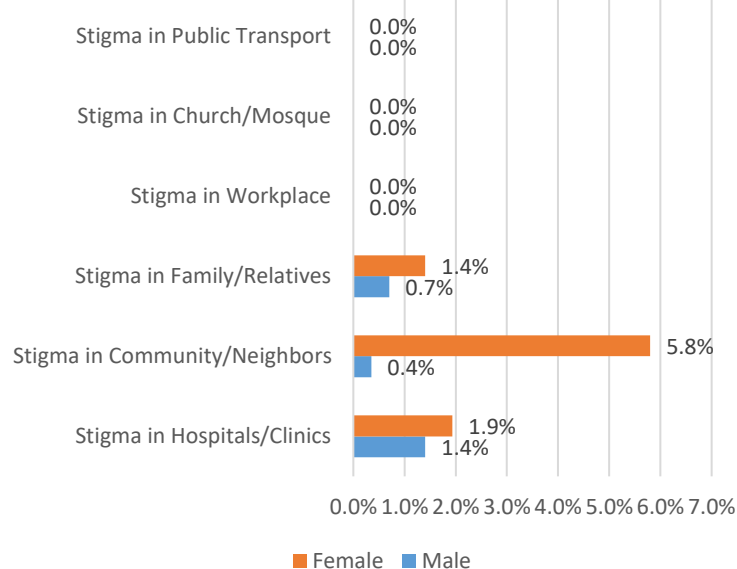


Appendix 10: Gender disaggregation of Stigma experienced by PWTB/PWHTB on their TB journey under different setting in Ghana

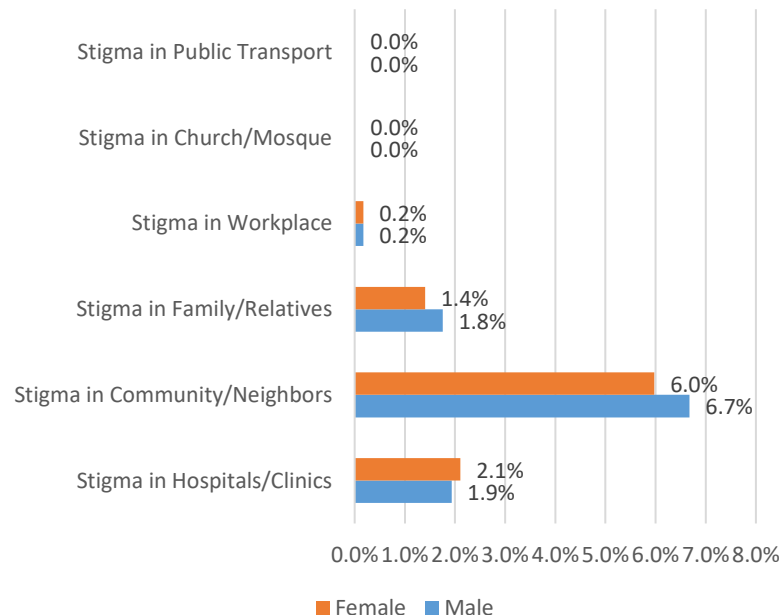
Getting an accurate diagnosis



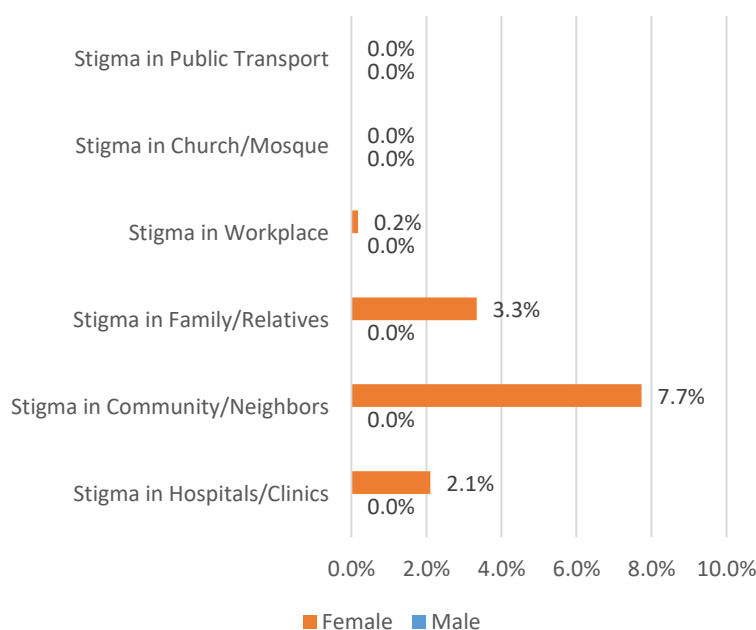
Completing treatment



Getting treatment adherence support

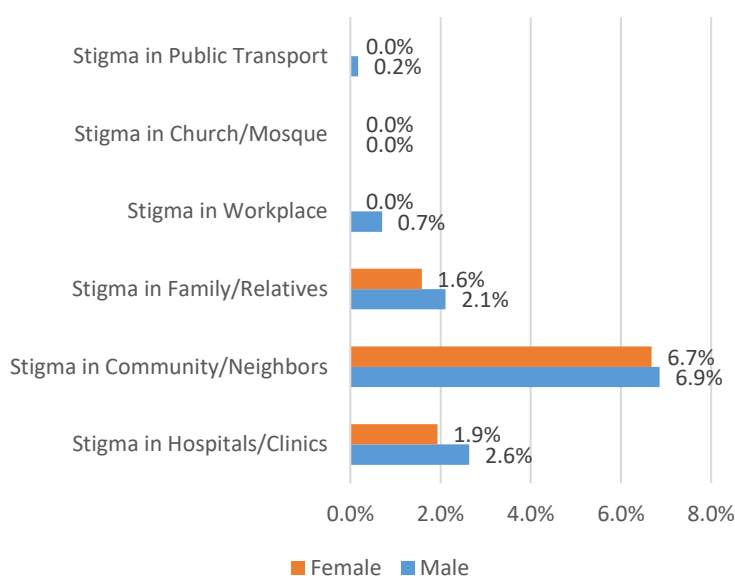


Recognizing symptoms

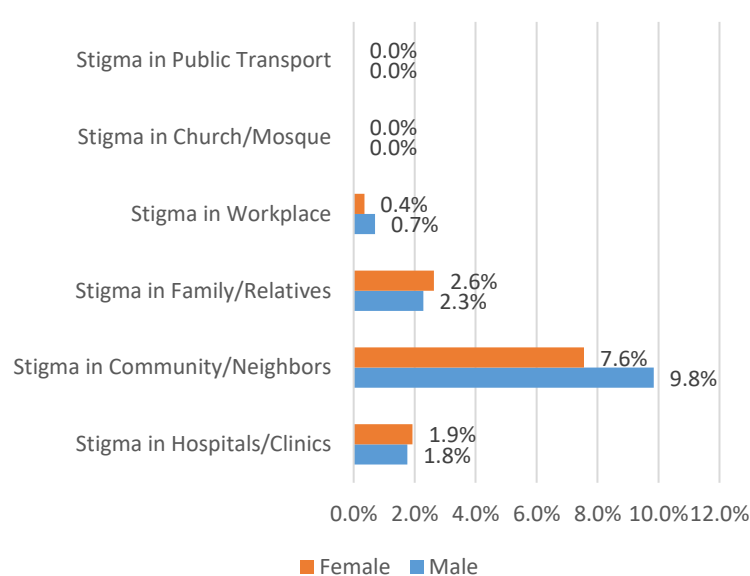


Appendix 11: Gender disaggregation of Stigma experienced by PWTB/PWHTB on their TB journey under different setting

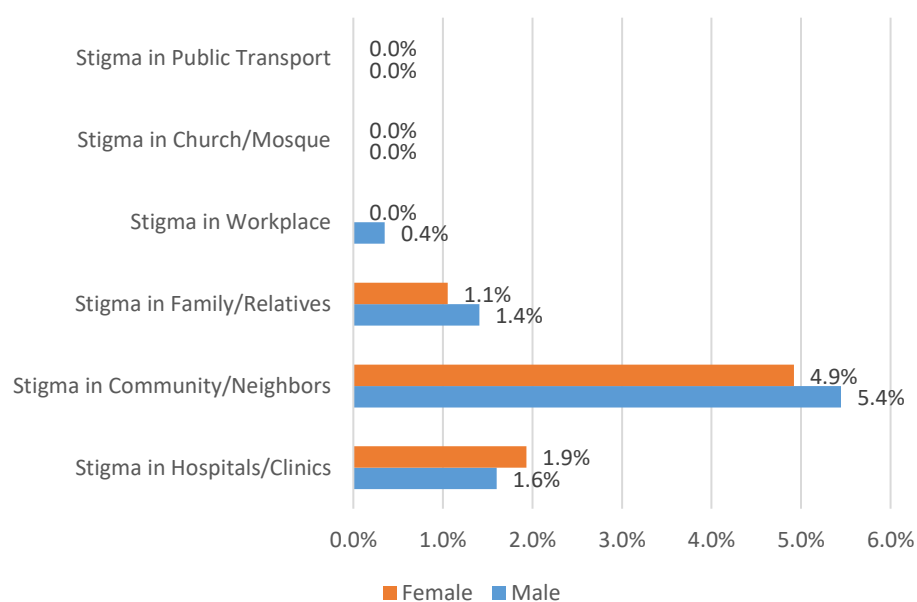
Beginning treatment



Seeking care



Getting post-treatment follow-up services



Appendix 12: Participant's Follow-Up Log for Qualitative Studies

No.	Study ID	Name of participant	Site of recruitment	Contacts	Available for follow-up or qualitative study			Preferred place for Interview
					<input type="checkbox"/> Y (Yes) <input type="checkbox"/> N (No)	If YES, indicate date and time of interview	Indicate mode of interview <input type="checkbox"/> Face-to-face (preferred) <input type="checkbox"/> Virtual	
					<input type="checkbox"/> Y <input type="checkbox"/> N		<input type="checkbox"/> Face-to-face <input type="checkbox"/> Virtual	
					<input type="checkbox"/> Y <input type="checkbox"/> N		<input type="checkbox"/> Face-to-face <input type="checkbox"/> Virtual	
					<input type="checkbox"/> Y <input type="checkbox"/> N		<input type="checkbox"/> Face-to-face <input type="checkbox"/> Virtual	
					<input type="checkbox"/> Y <input type="checkbox"/> N		<input type="checkbox"/> Face-to-face <input type="checkbox"/> Virtual	
					<input type="checkbox"/> Y <input type="checkbox"/> N		<input type="checkbox"/> Face-to-face <input type="checkbox"/> Virtual	
					<input type="checkbox"/> Y <input type="checkbox"/> N		<input type="checkbox"/> Face-to-face <input type="checkbox"/> Virtual	
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					<input type="checkbox"/> Y <input type="checkbox"/> N		<input type="checkbox"/> Face-to-face <input type="checkbox"/> Virtual	
					<input type="checkbox"/> Y <input type="checkbox"/> N		<input type="checkbox"/> Face-to-face <input type="checkbox"/> Virtual	

					<input type="checkbox"/> Y <input type="checkbox"/> N		<input type="checkbox"/> Face-to-face <input type="checkbox"/> Virtual	
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Appendix 13: Health Facilities for PWTB/PWHTB, Family Members or Caregivers and Health workers Recruitment and Data Collection in Northern Region

Region	District	Sub-district	Sampled facility	No. PWTB/PWHTB from each facility	No. Family members or caregivers	No. of Community leaders	No. Health workers from each facility
Northern	Nanumba North	Bimbilla	Bimbilla District Hospital	5	5	10	3-4
	Tamale	Tamale Central	Tamale Teaching Hospital	13	13	26	3-4
	Saboba	Saboba	Assemblies of God Hospital	4	4	8	3-4
	Savelugu	Savelugu	Savelugu District Hospital	4	4	8	3-4
	Yendi	Yendi East	Yendi District Hospital	8	8	16	3-4
Total				34	34	68	15-20

Appendix 14: Health Facilities for PWTB/PWHTB, Family Members or Caregivers and Health workers Recruitment and Data Collection in Upper East Region

Region	District	Sub-district	Sampled facility	No. of PWTB/PWHTB from each facility	No. of Family members	No. of Community leaders	No. Health workers from each facility
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or caregivers							
Upper East	Bawku Municipal	South Natinga	Bawku Presby Hospital	13	13	26	3-4
	Bolgatanga Municipal	Zaare	Bolgatanga Regional Hospital	33	33	66	3-4
	Builsa North	Sandema West	Sandema Hospital	5	5	10	3-4
	Kasena-Nankana	Navrongo Central	War Memorial Hospital	6	6	12	3-4
	Bawku West	Zebilla South	Zebilla Hospital	5	5	10	3-4
Total				62	62	124	15-20

Appendix 15: HEALTH FACILITIES FOR PLWTB OR PWHTB, FAMILY MEMBERS OR CAREGIVERS AND HEALTHWORKERS RECRUITMENT AND DATA COLLECTION IN BONO REGION

Region	District	Sub-district	Sampled facility	No. of PWTB/PWHTB from each facility	No. of Family members or caregivers	No. of Community leaders	No. Health workers from each facility
Bono East	Atebubu-Amanten	Atebubu	Atebubu Hospital	4	4	8	3-4
	Kintampo North	Kintampo	Kintampo Municipal Hospital	5	5	10	3-4
	Nkoranza South	Nkoranza	St Theresa Hospital-Nkoranza	6	6	12	3-4
	Pru	Yeji	Mathias Hospital Yeji	8	8	16	3-4

	Sene West	Kwame Danso	Sene District Hospital	9	9	18	3-4
	Techiman Municipal	Techiman North	Techiman Holy Family Hospital	19	19	38	3-4
Total				51	51	102	18-24

Appendix 16: HEALTH FACILITIES FOR PLWTB OR PWHTB, FAMILY MEMBERS OR CAREGIVERS AND HEALTHWORKERS RECRUITMENT AND DATA COLLECTION IN OTI REGION

Region	District	Sub-district	Sampled facility	No. of PWTB/PWHTB from each facility	No. Family members or caregivers	No. of Community leaders	No. Health workers from each facility
Oti	Biakoye	Worawora Apesokubi	Worawora Hospital	8	8	16	3-4
	Kadjebe	Kadjebe-asato	Kadjebe Health Centre	4	4	8	3-4
	Nkwanta North	Kpassa	Kpassa Health Centre	10	10	20	3-4
	Nkwanta South	Nkwanta (volta)	Nkwanta Municipal Hospital	10	10	20	3-4
Total				32	32	64	12-16

Appendix 17: HEALTH FACILITIES FOR PWTB OR PWHTB, FAMILY MEMBERS OR CAREGIVERS AND HEALTHWORKERS RECRUITMENT AND DATA COLLECTION IN ASHANTI REGION

Region	District	Sub-district	Sampled facility	No. of PWTB/PWHTB from each facility	No. Family members or caregivers	No. of Community leaders	No. Health workers from each facility
	Adansi South	New Edubiase	New Edubiase Government Hospital	18	18	36	3-4

Ashanti	Afigya Kwabre South	Afrancho	Afrancho Polyclinic	10	10	20	3-4
	Amansie Central	Jacobu	St. Peter's Catholic Hospital	12	12	24	3-4
	Asante Akim North	Agogo (ashanti)	Agogo (Asante Akim North) Presby Hospital	22	22	44	3-4
	Asokwa	Kumasi South	Kumasi South Hospital	35	35	70	3-4
	Kumasi	Subin North	Komfo Anokye Teaching Hospital	22	22	44	3-4
	Asante Akim Central	Konongo	Konongo - Odumasi Government Hospital	15	15	30	3-4
	Amansie South	Agroyesum	St. Martin's Catholic Hospital	14	14	28	3-4
	Bekwai	Bekwai	Bekwai Municipal Hospital	11	11	22	3-4
	Obuasi	Gauso	Obuasi Government Hospital	24	24	48	3-4
	Bosomtwe	Pramso	St. Michael's Catholic Hospital, Pramso	12	12	24	3-4
	Ejisu	Ejisu	Ejisu Government Hospital	10	10	20	3-4
	Old Tafo	Tafo Nhyiaeso	Tafo Government Hospital	23	23	46	3-4
Total				228	228	456	39-52

Appendix 18: HEALTH FACILITIES FOR PLWTB OR PWHTB, FAMILY MEMBERS OR CAREGIVERS AND HEALTHWORKERS RECRUITMENT AND DATA COLLECTION IN EASTERN REGION

Region	District	Sub-district	Sampled facility	No. of PWTB/PWHTB from each facility	No. of Family members or caregivers	No. of Community leaders	No. of Health workers from each facility
Eastern	Akwapim North	Mampong	Tetteh Quarshie Memorial Hospital	11	11	22	3-4
	Asuogyaman	Akosombo	Akosombo VRA Hospital	8	8	16	3-4
	Birim Central	Jamaica	Oda Hospital	11	11	22	3-4
	Birim North	Tweapease (eastern)	Tweapease Health Centre	10	10	20	3-4
	Denkyembour	Akwatia	St Dominic Hospital	29	29	58	3-4
	East Akim - Abuakwa South	Kibi	Kibi Government Hospital	14	14	28	3-4
	Fanteakwa North	Begoro	Begoro Hospital	12	12	24	3-4
	Kwahu West	Nkawkaw Central	Holy Family (Kwahu West) District Hospital	16	16	32	3-4
	Lower-Manya Krobo	Agormanya	St Martin's (lower Manya) Hospital	8	8	16	3-4
	New Juaben South	Koforidua 2	Eastern Regional Hospital	8	8	16	3-4
	Suhum	Ayekotse	Suhum District Hospital	12	12	24	3-4
	West Akim	Blue Diamond	Asamankese Government Hospital	12	12	24	3-4
	Yilo-Krobo	Somanya East	Somanya Polyclinic	9	9	18	3-4
Total				160	160	320	39-52

Appendix 19: HEALTH FACILITIES FOR PWTB OR PWHTB, FAMILY MEMBERS OR CAREGIVERS AND HEALTHWORKERS RECRUITMENT AND DATA COLLECTION IN GREATER ACCRA REGION

Region	District	Sub-district	Sampled facility	No. PWTB/PWHTB from each facility	No. Family members or caregivers	No. of Community leaders	No. Health workers from each facility
Greater Accra	Accra Metro	Okai Koi South Sub Metro	Kaneshie Polyclinic	18	18	36	3-4
		Ablekuma Sub Metro	Korle-bu Teaching Hospital	30	30	60	3-4
		Ablekuma Sub Metro	Mamprobi Polyclinic	25	25	50	3-4
		Ashiedu Keteke Sub Metro	PML Hospital	5	5	10	3-4
		Ashiedu Keteke Sub Metro	Ussher Polyclinic	10	10	20	3-4
	Ashaiman	Tsinai-agber	Ashaiman Polyclinic	13	13	26	3-4
	Ayawaso East	Kanda	37 Military Hospital	8	8	16	3-4
	Ayawaso North	Maamobi West	Maamobi General Hospital	11	11	22	3-4
	Ga West	Amasaman Sub District	Ga West Municipal Hospital	9	9	18	3-4
	Korle-Klottey	North Ridge	Iran Clinic	12	12	24	3-4

	Suhum	North Ridge	Ridge Regional Hospital	16	16	32	3-4
	La-Dade-Kotopon	Tenashie	La General Hospital	11	11	22	3-4
	La-Nkwantanang-Madina	Nkwantanang Sub Municipality	Madina Polyclinic (Kekele)	9	9	18	3-4
	Ledzokuku	Teshie North Sub-district	LEKMA Hospital	12	12	24	3-4
	Okai Koi North	Achimota	Achimota Hospital	18	18	36	3-4
	Shai-Osudoku	Dodowa Sub District	Shai Osudoku Hospital	10	10	20	3-4
	Tema	Manhean	Manhean Polyclinic	10	10	20	3-4
		Tema South	Tema General Hospital	10	10	20	3-4
	Weija-Gbawe	Weija Sub-Municipal	Weija-Gbawe Municipal Hospital	7	7	14	3-4
Total				244	244	488	57-76

Appendix 20: HEALTH FACILITIES FOR PWTB OR PWHTB, FAMILY MEMBERS OR CAREGIVERS AND HEALTHWORKERS RECRUITMENT AND DATA COLLECTION IN WESTERN REGION

Region	District	Sub-district	Sampled facility	No. of PWTB/PWHTB from each facility	No. of Family members or caregivers	No. of Community leaders	No. Health workers from each facility
	Ahanta West	Dixcove	Nana Hima Dekyi Hospital	13	13	26	3-4
	Nzema East	Axim-nsein	Axim Government Hospital	25	25	50	3-4

Western	Prestea-Huni Valley	Prestea	Prestea Government Hospital	35	35	70	3-4
	Sekondi-Takoradi	Effia Nkwanta	Effia Nkwanta Regional Hospital	33	33	66	3-4
	Tarkwa-Nsuaem	Tarkwa	Tarkwa Municipal Hospital	17	17	34	3-4
	Wassa Amenfi East	Bawdie	Bawdie CHPS	10	10	20	3-4
	Wassa Amenfi West	Asankrangwa	Father Thomas Alan Rooney Memorial Hospital	15	15	30	3-4
	Jomoro	Half Assini	Half Assini Government Hospital	12	12	24	3-4
	Wassa East	Ateiku	Ateiku Health Centre	10	10	20	3-4
Total				170	170	340	27-36