

Introduction

According to the World Health Organization's latest estimates, the Philippines is among seven (7) countries with the highest number of people with TB. There is an estimated 581,000 Filipinos infected with TB. However, almost 50% of these people have not yet been diagnosed or notified.

Based on the 2016 National TB Prevalence Survey (NTPS), one to two (1-2) of every three (3) bacteriologically confirmed PTB cases were missed using symptoms alone. Also, two (2) out of three (3) bacteriologically confirmed XDR cases were smear negative. These point to a need to upgrade the kind of testing equipment that local health centers have, especially because these public health facilities are the most accessible to the communities.

Additionally, poor health-seeking behavior plays a factor in the gap between the number of TB cases and those that are notified. According to the NTPS, trivial nature of symptoms, the loss of income, travel, and side effects of drugs are among the primary reasons for not consulting a healthcare provider. This is further reflected by figures showing that about 41% of survey respondents (N=2,815) with screening symptoms did not take any action while 40% opted to self-medicate. Thirty-four percent of bacteriologically confirmed TB cases with screening symptoms did not take any action and 37% self-medicated.

If these trends continue, the Philippines will not be able to reach its targets to end TB by 2022. After the High-Level Meeting to End TB in 2018, the Philippines committed to diagnose and treat 2.44 Million Filipinos with TB by 2022. As of 2017, the TB diagnosis and treatment reached only 317,266. There is a very long way to go to reach the targets.

In 2016, the Philippine Congress enacted Republic Act 10767 or the Comprehensive TB Elimination Plan Act. This national policy provides a framework to enhance TB elimination by strengthening the healthcare sector, improving public-private partnership and making TB notification mandatory. But there are glaring gaps in this law: the very limited role of communities in the national TB response, and the lack of protection against TB-related stigma and discrimination.

Assessment of the national TB response from the perspectives of communities, human rights and gender is crucial at this point to help reach national targets on TB elimination.

Objectives of the Assessments

The goal of this study is to enhance the national TB elimination program by integrating the perspectives of affected communities, and the gender and human rights dimensions related to the TB epidemic, and utilizing these perspectives in identifying the vulnerable communities that are still unreached. Specifically, the study aims to:

- Generate data on the gender and human rights-related factors that affect access of vulnerable communities to TB programs and services;

- Generate data on the issues and challenges encountered by the TB program and service providers in implementing programs and delivering services to eliminate TB; and
- Generate program and policy recommendations to improve the access of vulnerable communities to TB programs and services.

Significance of the Study

The results of this study will contribute to a more holistic approach to the TB programming and policy in the country. The data it will generate will enhance the understanding of TB stakeholders, including the affected communities, on the intersection of gender and human rights in the context of TB so that they can evaluate how to improve the current approaches in program and policy on TB prevention, treatment and care. In turn, this will contribute to the eventual elimination of TB in the country.

Moreover, this research will contribute to knowledge and will respond to the current gaps in TB-related literature, especially its intersection with gender and human rights. It also amplifies the voices of communities affected by TB, which have so far been unheard. This would aid future researchers, policymakers, program implementers, and medical professionals by providing them with a baseline on tackling similar studies in the Philippine setting.

Scope and Limitations

Due to financial and time constraints, this situational analysis was only implemented within Metro Manila and gathered qualitative data through focus group discussions (FGD), key informant interviews (KII) and in-depth interviews. The data collected here is not envisaged to be generalized to a bigger population. It will however, provide an important baseline for further study on the gender, human rights and other related social factors that communities affected by TB experience, which might provide insight for program and policy development and enhancement.

Literature Review

Gender and Tuberculosis

Approaches in Studying the Gender Dimensions of Tuberculosis

Before the 1990s, TB research emphasized the biomedical aspect of the disease. The next decade saw the development in research of TB – one that considered the gender aspect. Gender and tuberculosis were studied qualitatively and quantitatively. Two of the earliest studies in gender and TB were case studies that compared the prevalence between men and women (Onyango, 1995), and a review on the epidemiological aspect of TB and its differences on sexes (Holmes, Hausler, & Nunn, 1998).

Gender and tuberculosis research further developed when International Organizations initiated the conduct of studies to explore the gender dimension of TB. Specifically, in 2002 the WHO wrote a report that synthesized the information available at that time. These pieces of information were collected to examine the gender dimension and overcome the barriers it produces in prevention, coverage, and treatment of TB.

Through this, the succeeding work on gender and tuberculosis focused on the welfare of the women population (Allotey & Gyapong, 2008). This development brought forth the understanding on the effects of gender social construction on the treatment and prevention of TB – and other diseases as well.

In a review conducted by van den Hof and her colleagues (2010), they showcased different approaches utilized by researchers in studying gender and tuberculosis. Four primary themes were identified in the collection of TB and gender research: (1) Health-care seeking, (2) Diagnosis and treatment initiation, (3) Treatment adherence, and (4) Treatment outcomes. For each theme, van den Hof and her colleagues extracted several information on the differences between men and women in relation to TB and healthcare practices.

Studies focused on the health-care seeking behavior were able to provide information on access to healthcare services, help-seeking patterns, and patient delay. Moreover, gender-related factors that influence their access to healthcare, help-seeking patterns, and patient delays were identified in the collection.

Accordingly, literature on diagnosis and initiation of TB treatment emphasized the access to TB diagnostics, health care system-related delays in TB diagnosis, results of diagnosis, initiation of treatment after diagnosis, and interaction between healthcare staff and their patients.

The topic on treatment adherence was the least explored theme among the four. Nevertheless, research on treatment adherence yielded findings on the patient's adherence to treatment of TB and latent TB infection. Additionally, qualitative studies to explain these were also identified. Due to the limited scholarship in this area, van den Hof and her group posited prospective studies that may assess interventions on adherence.

Finally, studies done on treatment outcomes explored the different outcomes when treating TB: (1) successful, (2) death, (3) default, (4) failure, (5) smear and culture conversion, and (6) adverse events. Other outcomes were also identified in this theme such as: (a) radiological, (b) pharmacokinetics/biochemical, (c) body mass index, (d) quality of life, (e) hospitalizations, and (f) relapse.

Findings in Research of Gender Dimensions of TB

Research on TB saw that males are more notified compared to women. This dubbed TB as the 'disease of men than of women.' It led to the development of the gender dimension in tuberculosis research, which emphasized the identification of barriers among women when seeking TB treatment. Biological, socio-cultural, and economic factors were the focus in discussing this scholarship.

HIV was the primary biological factor that posed challenges in treating TB (Allotey & Gyapong, 2008; PATH). HIV contributed to the development of TB among the infected individuals – new infection or reactivation of latent infection. Also, TB has been the primary cause of mortality among HIV patients.

In addition, the consideration of HIV has provided depth and complexity in TB research. Consolidating HIV in TB research paved way for deeper understanding of the social challenges that affected HIV patients who contracted TB – and vice versa (TB patients who contracted HIV). Moreover, inclusion of HIV in the study posited several gender-related areas of studies that may explain TB incidences such as biological functions, access to care, health seeking behavior, and stigmatization.

Biological functions and social construction of gender were found to be a reason in hindering TB prevention and treatment among males and females – especially in developing countries (van den Hof, Najlis, Bloss, & Straetemans, 2010; Onifade, et al., 2010; Horton, et al., 2016; Bhutia, 2016). Females encountered greater barriers in receiving appropriate medical attention due to their subordinate status, lack of independence, and deficient knowledge towards TB.

In developing countries, females are socially constructed to be subordinates (Onifade, et al., 2010; Horton, et al., 2016). They are expected to submit themselves to their male member within their family – husbands, brothers, fathers, and uncles. This view renders the female to be considered less valuable in their families and minimal importance are given to their welfare. Moreover, this perspective towards female attracts stigma and discrimination and thus contracting diseases makes them prone to become outcasts of their families.

The stigma and discrimination received by women discourages them to access healthcare services (Karim, Begum, Islam, & Chowdhury, 2003; Mitchell, 2014; Neyrolles & Quintana-Murci, 2009). Additionally, women become subject to violent abuses and become outcast of their families. For instance, TB-infected women in Kenya are evicted from their households and left to live by themselves in the streets wherein they are raped by roaming men in the neighborhood (KELIN, 2018; Onyango, 1995).

Additionally, females in developing countries lack independence, which can be attributed to their lack of economic resources and relegation as caretakers. Such situation hinders women from attending to their

own welfare, including their health. Along with the stigma and discrimination, lack of independence due to insufficient economic resources restricts their mobility to access healthcare services.

Accordingly, women in developing countries have low knowledge on TB due to low literacy and the failure of information to reach them. (van den Hof, Najlis, Bloss, & Straetemans, 2010). As a result, this lack of understanding of TB increases the stigma on the disease, which leads women to hide their condition and prevent them from seeking healthcare services.

Furthermore, in Western Pacific and Southeast Asia, it is important to note that women in developing countries do exert effort to ensure that their health concerns are addressed (World Health Organization, 2016; Carter, 2015; World Health Organization, 2002; Tomorrowmakers, 2018). However, they tend to seek help from less qualified private healthcare service provider in lower level healthcare facilities, which could potentially risk their lives by prolonging the infection which may already require complex medication or treatment by the time they are referred to more qualified healthcare professionals.

On the other hand, men have more capacity to access healthcare services because they are the primary income earner in their family (LSHTM, 2014). However, because of their role as breadwinners, they would also rather not go to health centers if it meant losing a day's wages. Moreover, prevailing concepts of masculinity lead to low regard for health among men, which prevent them from accessing health services and may leave their TB condition either undiagnosed or untreated.

In terms of diagnosis and initiation of treatment, it is apparent that men are diagnosed more often than women (van den Hof, Najlis, Bloss, & Straetemans, 2010). However, it is not clear whether this is directly related to women's difficulty in accessing healthcare services. In fact, more sensitive diagnostic approaches diminish the differences between the two genders.

The prominence of gender roles among developing countries is one of the sociocultural factors that causes problems to diagnosis and treatment of female patients (Yang, et al., 2014; Govender, 2017). Interaction with male doctors causes discomfort among female patients. Gender roles dictate that women's serve the men, not the other way around. This dilemma leads to late diagnoses and treatment among women.

Nevertheless, female patients are notably more adherent to treatment compared to males. Independence of men and the lack thereof among women were seen to be the reason for such compliance patterns (van den Hof, Najlis, Bloss, & Straetemans, 2010). Moreover, sociocultural factors dictate how they should adhere to their treatment. Men as primary income provider are forced to work while minimizing their costs. On the other hand, women as caretakers hasten their recovery to ensure that their children will not contract the disease.

As per the limited literature, it can be drawn that their adherence correlates with their treatment outcomes (van den Hof, Najlis, Bloss, & Straetemans, 2010; LSHTM, 2014). Women have better treatment outcomes—they get cured of TB while men either default treatment and die. Nevertheless, it is important to note that strong conclusions cannot be drawn due to thinness of the literature.

Legal Environment of Tuberculosis Treatment, Prevention, and Elimination: The Philippine Case

Initiatives to control Tuberculosis in the Philippines

In recent years, there have been several mechanisms established to control TB. These mechanisms can be traced back as far as 1910 wherein a private organization named, Philippine Islands Anti-Tuberculosis (now Philippine Tuberculosis Society, Inc. – or PTSI) pursued case finding and provided in-patient services. At that time, no exact regimen was provided for TB patients. They addressed the disease via hospitalization and bed rest (DOH and PhilCAT, 2004).

The 1930s and 1940s saw the development of TB control in the Philippines through the creation of the TB Commission. This paved the way for the establishment of Chest Clinics in selected areas in the Philippines. This provided an accelerated provision of in-patient services. Moreover, streptomycin was included as part of treatment for TB.

In 1950s to 1960s, TB Commission became the Division of Tuberculosis under the Secretary of Health. The new Division created the TB Center at DOH and collaborated with the TB Ward of San Lazaro Hospital. Chest x-rays, sputum and bronchial washing examinations, and case holding were being provided. Bacille Calmette-Guerin – or BCG – vaccination was introduced as preventive measure for TB – a program assisted by United Nations Children Fund (UNICEF).

In 1954, the Congress passed the Republic Act 1136 which became the basis for the creation of both the Division of Tuberculosis and the National Tuberculosis Center of the Philippines established in the DOH compound. It also mandated the provision of funds and support for the operationalization of the National TB Control Program. At this period, a triple therapy of isoniazid, streptomycin, and Para-amino salicylate was initiated. Additionally, the National TB program accelerated its coverage in rural health units which was established.

TB Control responsibilities in 1970s to 1980s were increased in the rural health units. The domiciliary care program was launched, and the Philippine College of Chest Physicians was formed as a non-government organization society of Philippine Medical Association that puts TB as one of its initial concerns.

The partnership between DOH and Philippine Tuberculosis Society resulted to the establishment of National Institute of Tuberculosis (NIT) with the help of WHO and UNICEF. The institute focused on human resources development wherein they undertook operational researches and trainings via primary health care approach. Moreover, Presidential Decree No. 996 providing for compulsory BCG vaccination was issued on September 16, 1976. This soon became a key part of the Expanded Program for Immunization.

The NIT conducted the first National TB Prevalence Survey – through the assistance of WHO and UNICEF – while the Lung Center of the Philippines was created as a tertiary hospital for pulmonary cases including TB. This period also saw the introduction of a new regimen called Short-Course Chemotherapy (SCC). Moreover, a fourth drug, was included – either streptomycin or ethambutol – for Intensive Phase of the treatment regimen for in-patients.

Upon the conclusion of the 1986 revolution, there were several changes in different sectors of the country – including the health sector. Ministry of Health was renamed to and reorganized as the Department of Health. The TB Control Services was established under the Office of Public Health Services and the Strengthened National TB Control Program was launched. Under it, the TB Control Services was given a Php 200M budget for drugs, and the SCC was adopted nationwide. In 1987, PTSI adopted the expanded community-oriented TB control program which created microscopy centers in the provinces.

From 1990s to early 2000s, support from international entities boosted the TB control programs in the Philippines. Moreover, the provision of health services devolved from the DOH to the local government units took place in accordance to the Local Government Code of 1991. Thus, allowing the local government to manage their TB program and deliver it to their constituents. It also created a division of labor wherein the local government served as the implementers while the DOH became dedicated in policy development, regulation, and provision of financial and technical support.

Moreover, in the mid 1990s, there was amplified national awareness campaign and mobilization of support for TB prevention and control. It was also during these years when the DOTS was first piloted in selected areas within the country – an initiative by the TB clinic of University of Sto. Tomas. The method was used primarily for outpatients. The second TB prevalence survey was conducted during this period.

Furthermore, DOH reformed the health sector agenda to improve the delivery of health services in the country. The reform included the funding for priority public health programs, promotion of the development of local health systems, fiscal autonomy to government hospitals, strengthening of capacities of health regulatory agencies, and the expansion of the National Health Insurance Program.

From 2000s to early 2010s, the initiatives to address the TB has further developed. Most notably, in 2012, the DOH – in partner with USAID and PBSP – implemented the IMPACT program (DOH, USAID & PBSP, 2014). The program aimed to provide a 5-year technical assistance to the selected project sites across the Philippines. The assistance involves the reinforcement of the city's or municipality's (1) health service delivery, (2) health financing, (3) health workforce, (4) health information systems, (5) access to medications, and (6) health leadership and governance.

IMPACT targeted 43 LGUs from National Capital Region, Luzon, Visayas, and Mindanao. The distribution of targeted project sites are as follows: 11 from NCR, 14 from Luzon, 5 from Visayas, and 13 from Mindanao. As per the reports disseminated by DOH in 2012-2016, there are similarities among the problems faced by these selected project sites.

For instance, problems on health service delivery consisted of inadequate capacity to perform laboratory tests due to scarce number of providers that focused on TB – including the provision of TB-DOTS. Moreover, the lack of materials and facilities, specifically for TB, showed that TB was not a priority.

In health financing, the problem was simply that the budget to address TB was not enough. Moreover, there was low PhilHealth coverage particularly for TB. PhilHealth benefits were usually not availed or utilized. As for access to medications, there were fewer stocks for medicines provided by healthcare service providers. Also, there were several laboratories that did not comply with the guidelines for the

implementation of the quality assurance system on direct sputum smear microscopy (DSSM) under Department of Health Administrative Order No. 2007-0019.

For governance, there was a lack of supervision of treatment partners, some of whom were not properly mobilized to participate in TB control activities. Policy guidance was intermittent and inconsistent across the different LGUs and implementation of existing policies was also problematic. In terms of human resource, trained Medical Technologist and DOTS providers and microscopists were also lacking.

Finally, the health information system was also greatly challenged due to lateness in reporting of accomplishments, misclassification of records, lack of computers and trained personnel, and the lack of capabilities to analyze and utilize strategic TB-related information.

Nevertheless, the project succeeded in achieving its objective. The program addressed the deficiencies of the project sites in dealing with TB. This led for the 43 project sites to have an improved and equipped health system that would allow them to address their respective TB concerns.

In 2016, the National Tuberculosis Program (NTP) released a Joint Program Review (JPR) which assessed the (1) TB epidemiology and the capacity of the national TB surveillance system to measure the level and trends of the TB burden and program performance; (2) progress on the performance targets defined in PhilPACT strategy; (3) accomplishments toward the recommendations of the 2013 JPR; (4) implementation gaps among the thematic areas; and (5) to provide and present recommendations to all stakeholders to support the next Plan of Action to Control TB (Department of Health, 2016).

The review showed a variety of unaddressed, addressed, and in progress goals. As per the review, constraints on human resource, funding for second-line drugs, and reimbursement package for drug-resistant cases remained unaddressed. In areas such as financial management capacities, improvement in drug supplies, operationalization of electronic data systems, supervision and quality assurance, delivery efficiency, and mobilization and communication, the report showed that the NTP was having progress but was still challenged to completely attain the desired goal.

Finally, the review showed that NTP was able to meet the goals set in the following aspects: Programmatic Management of Drug Resistant TB rollout in DOTS network, trust funds for TB reimbursements, guidance to ensure sharing of reimbursements to TB care providers, fast tracking of eligibility portals to DOTS facilities, development and dissemination of community- and patient-targeted materials, implementation of intensified case finding, and the recognition of TB as a notifiable disease thru the enactment of the RA 10767.

[The Republic Act 10767: Comprehensive Tuberculosis Elimination Plan Act](#)

In April 2016, the Philippines enacted the Republic Act 10767, also known as the Comprehensive Tuberculosis Elimination Plan Act. It focuses on eliminating TB in the Philippines by institutionalizing the creation of the Philippine Strategic Elimination Plan (PhilSTEP). The PhilSTEP is a comprehensive plan of action with a goal to decrease TB deaths by 50% and reduce TB incidence rates. In its development, it was

identified that there was still limited reach among key populations, such as people living with HIV and incarcerated populations.

In the PhilSTEP, performance targets included the crucial role of communities in referring TB notifications to the health facilities. At the same time, 90% of people living with both TB and HIV had to be treated by 2022. From 2015 data of the DOH, however, only 43% of people living with HIV who had TB have been treated. Broadly, there is no available baseline data that looks at the valuable contributions of people affected by TB and living with HIV, including TB survivors, to the national TB response.

RA 10767 aims to achieve its objective – elimination of TB – through consultation with public and private entities. As per the policy, the plan of action shall tackle the targets and strategies in addressing the disease – necessitating the identification of components such as prevention, diagnosis, treatment, care, and support.

Moreover, the policy aims to include the exploration of different technologies and their application to diagnose and treat the disease. Partnerships with other local and international entities and organizations shall also be considered to boost the education, advocacy, research, and funding of the TB elimination plan. Immediate mobilization of anti-TB services during and after natural and man-made disaster is also a key component considered in the policy.

Additionally, the policy includes the establishment of review and monitoring system that would track the progress of eliminating TB in the Philippines. The DOH heads the implementation of the policy while being assisted by educational institutions – Department of Education and Commission on Higher Education – and Philippine Information Agency for information dissemination, education programs, and media campaigns

Engagement of private institutions and communities should also be considered and shall be utilized to achieve the objectives of the act. The Implementing Rules and Regulations of the law also provides for education and information campaigns that would empower the key target populations – as well as the healthcare service providers – to equip them for productive involvement in pushing for the policy's success.

However, it is important to note that, there was no virtual participation of key population communities during the policy designing phase of RA 10767. According to the Samahan ng Lusog Baga (SLB), an organization of people affected by TB, they were not involved in the development of the TB Law. A reflection of this gap in community participation in the development of the law is the fact that there are no provisions that address structural barriers like stigma and discrimination among communities affected by TB. Also, there has never been a program to systematically address these social barriers.

Gaps of the Literature

The Need for a CRG Perspective in Tuberculosis Programming

In line with the adoption by the World Health Assembly of the global End TB strategy, the Philippines, as a significant contributor to the global disease burden of TB, needs to look more closely at the conditions that hinder the effectiveness of the National TB Program in finding the missing cases of TB in the country, as well as the success of the treatment and care coverage among those who have already been diagnosed and notified.

One of the biggest gaps in current TB programming in the Philippines is the CRG perspective. This is evident in the whole process leading up to the enactment of the TB Law. Transcripts of interpellation in Congress show that the law was constructed by policy makers and medical professionals, with virtually no meaningful participation of the affected communities, as attested to by SLB. To be fair, however, the TB Law provides for an enhanced system for TB detection and notification and strengthens the current medical intervention for TB.

Moreover, literature on gender and human rights in relation to TB yielded very limited results. Although there is gender disaggregation of TB epidemiological data between males and females, there has not been any baseline study to determine gender-related determinants in terms of accessing TB screening, treatment and care. So far, no study that investigates the effect of existing policies on TB on the communities affected by it has been found.

This may be attributed to the nature of the National TB Program that is medicalized and lacks community perspective. There are a few non-government organizations working on TB, but these are also professional organizations that help facilitate the delivery of medical interventions. There are a couple of patient groups, including SLB, but their role is limited to peer education and support for other patients undergoing treatment. They sit in the technical working group (TWG) for TB as well as in the Country Coordinating Mechanism (CCM) of the Global Fund to Fight AIDS, TB and Malaria but they also express that their engagement is limited because they lack the capacity for advocacy.

This current situation of TB in the Philippines calls for an assessment in the areas that have long been ignored in the program to eradicate TB in the country. With the availability of the CRG assessment tools from Stop TB Partnership and roll out of these tools in the Philippines by ACHIEVE, it is envisaged that a more comprehensive TB situationer could be provided to help enhance the strategies and services of the National TB Program.

Research Methodology

Research Design

This research employed qualitative research methodology. This approach involved the utilization of document checklist, KII, in-depth interviews and FGD. These methods were appropriate in producing qualitative information on the social, structural, and legal factors that hinder or promote access of communities to TB healthcare services.

The FGDs were conducted with members of communities that have been identified by the WHO as key populations of TB. Those who have contracted TB and have navigated the current TB program and service delivery structure were also be included. From among the participants of the FGDs, several participants were selected for in-depth interviews. This served to gain a deeper understanding of the experiences of these individuals in relation to the gender and human rights dimension of the study.

Additionally, KIIs were conducted among key stakeholders in the national TB program and service delivery. This set of interviews provided the researchers with knowledge on the implementation of the national TB program, as well as its issues and challenges from the perspective of those who have designed and implemented such programs and services.

Finally, the document checklist was used to examine and analyze secondary data sets, including epidemiological data, policy and program documents that available from the DOH, National Demographic and Health Survey (NDHS), Congress, Hospitals and health centers, and other relevant institutions.

Research Participants and Recruitment Process

As previously mentioned, the research participants are from communities that have been identified by the WHO as key populations for TB and those who have experienced having Category 1 and MDR TB. The following list shows the groups who were included in the FGDs and in-depth interviews:

- Filipino males in Metro Manila who have had Category 1 Tuberculosis and contracted MDR Tuberculosis within the past 5 years, aged 18 to 49 years old.
- Filipino females in Metro Manila who have had Category 1 Tuberculosis and contracted MDR Tuberculosis within the past 5 years, aged 18 to 49 years old.
- Filipino males in Metro Manila living with HIV and have contracted TB within the past 5 years, aged 18 to 49 years old.
- Filipino females in Metro Manila living with HIV and have contracted TB within the past 5 years, aged 18 to 49 years old.
- Filipino males in Metro Manila who use drugs, aged 18 to 49 years old.
- Filipino females in Metro Manila who use drugs, aged 18 to 49 years old.

For this situational analysis, Category 1 TB patients are those who contract pulmonary TB and were newly diagnosed (whether by bacteriological confirmation or clinical diagnosis) (Department of Health, 2014).

As such, our participants are those individuals who experienced both Category 1 TB and MDR TB. The reason for choosing those who have experienced Category 1 and MDR is to determine whether the disease progression in these cases are due to social or structural factors like gender and human rights or legal related issues.

The inclusion of persons living with HIV (PLHIV) was based on available literature which reflect that the incorporation of HIV in TB research paved way for the gender dimension to be included in TB studies. Therefore, hearing their sentiments are important in discovering the challenges they face in treating TB and sensitizing the current TB prevention and treatment program towards gender and HIV.

Lastly, people who use drugs (PWUD) who contracted TB were chosen to participate in this study because among the three groups, they are the only ones who are criminalized in the context of present laws. They may potentially face more social, structural, and legal barriers TB programs services.

For the exclusion criteria, the investigator did not consider potential participants that are not capable to provide an informed consent to participate in the research.

The following agencies and institutions have been identified as participants for the KIIs:

- DOH – National TB Control Program
- PhilHealth
- Samahang Lusog Baga (SLB)
- Philippine Business for Social Progress (PBSP)
- Philippine Coalition Against Tuberculosis (PhilCAT)
- United States Agency for International Development (USAID)
- World Health Organization (WHO)
- Quezon City Health Department
- Philippine Tuberculosis Society, Inc.
- National AIDS and STD Prevention Control Program (NASPCP)
- Congresswoman Helen Tan

ACHIEVE, Inc., with assistance from its partners, SLB and PhilCAT, lead the recruitment of the participants within Metro Manila. Participants were recruited from communities with help from community of TB and HIV groups. The participation for FGD, in-depth interviews, and KII was voluntary. Uninterested and declining individuals were not forced to join the research study. Participants for the FGD and in-depth interviews were asked to sign a consent form before the interviews.

The recruitment process was documented throughout the duration of the field work to provide a clear context with regards to the interviews and focus group discussions. Moreover, this served as a protection from biases that may pose risks when organizations and institutions recruit the participants.

Research Procedures

This research protocol was created in accordance with the advice of the NTP-TWG and has undergone Ethics Review screening by the Single Joint Review Ethics Board of DOH. Upon the approval of the Ethics Review Committee, ACHIEVE proceeded with data collection.

In the FGDs, 10 to 12 participants were recruited for each group of participants. Participation in the FGD and in-depth interviews was voluntary, and no forceful recruitment was done. Participating individuals were asked to sign consent forms. The FGD facilitators introduced themselves and explained to the participants the consent form and the purpose of the discussion. Only those who have signed the consent forms participated in the FGD.

The FGD facilitator guided the participants throughout the entire content of the consent form. This included a brief discussion of the purpose of the study and the respective rights of the participants during the discussion. Specifically, the facilitator reminded the participants that they have the right to not answer the questions that they do not want to answer and to discontinue participation at any point of the FGD without consequences. Moreover, the facilitator asked permission from the participants to use documentation paraphernalia during the FGD, including voice recorders, camera, pen, and paper. The facilitator also introduced the documenter for the discussion and explained clearly the need to document the FGD. The facilitator took note of the agreements made regarding the use of documentation tools and applied these accordingly.

During the FGD, the facilitator collected basic demographic information from the participants such as name, age, sex/gender, civil status, number of dependents, educational attainment, source of income, and address. These pieces of information are kept confidential and shall only be known by the researchers conducting the study. Questions that asked in the FGD included their experiences as TB patients, and their experiences in navigating the TB program and service delivery points. The FGD usually lasted for one to two hours.

Secondary data such as epidemiological information gathered through government agencies' online publication or during the KIIs. Incomplete, but necessary, information were requested directly from concerned government institutions. Epidemiological data on the Philippine TB situation that are published by credible non-government organizations were identified and collected. These were used to triangulate data collected from the field.

Data gathered from the KIIs, FGDs and in-depth interviews were transcribed and encoded in a computer through a basic word processor. Upon encoding, the data was analyzed through content analysis and recurring and relevant themes were identified in accordance to the gender assessment and legal environment assessment tools. Pseudonyms for names and locations were used to keep the participants' identity confidential. Findings of the research were written and organized to construct a research report.

The research findings were presented to all concerned stakeholders. Input from the stakeholders were gathered and considered in the finalizing the research report. Funding limitation does not allow for publication of the report in hard copies. However, the report will be disseminated online.

Analytical Tools

This research utilized two analytical tools to examine the social and structural barriers experienced by the vulnerable populations of TB. These are the (1) Gender Assessment Tool and (2) Legal Environment Assessment Tool. These tools were designed by The Global Fund to identify the challenges faced by vulnerable populations of TB in developing countries. Specifically, these tools are aimed at developing countries that are commonly hindered by underdeveloped policies, social, cultural, and gender-related factors.

Gender Assessment Tool

The Gender Assessment Tool aims to determine the gender-related factors that affects the patients' access to healthcare services (The Global Fund, 2013; The Global Fund, 2017; STOPTB, 2017). Specifically, it evaluates HIV and TB responses to develop them from being gender-blind to gender-sensitive, and eventually to become gender-transformative (Richardson, 2015). This tool utilizes UNAIDS' definition of gender – a socially constructed set of norms, roles, behaviors, activities, and attributes that a given society gives to a man and woman. Accordingly, there are instances wherein an individual feel differently from the sex they are assigned at birth. These instances allow for gender prejudices – such as stigma and discrimination – to exist.

In this framework, there are three types of interventions for HIV and TB. Firstly, the gender-blind (or gender negative) interventions are interventions that fail to acknowledge the different needs and realities of men, women, and transgender people. They insist in imposing the predetermined gender norms and inequalities as evident in their approach. This kind of interventions encourage gender-based stigma and discrimination. Therefore, they discourage individuals from seeking treatment causing them to aggravate their condition that may eventually lead to death.

The second type refers to gender-sensitive interventions. These interventions recognize the realities of men and women. These needs and realities are highly considered and incorporated in the program. These interventions ensure that men, women, and transgender individuals have equal access to treatment. These interventions significantly decrease the presence of stigma and discrimination that discourages individuals. Thus, it can cater to more people compared to gender-blind interventions.

Finally, the gender-transformative interventions seek to redefine the existing gender norms and inequalities. These aim to empower men, women, and transgender people, and encourage them to have better grasp of their life decisions. Therefore, it would allow them to access what they deem to be the best options for their welfare.

Legal Environment Assessment Tool

The Legal Environment Assessment Tool utilizes the human rights-based approach (The Global Fund, 2017; STOPTB, 2017). This approach entails the prioritization of human right principles in ensuring that the patients acquire appropriate healthcare services. This would include tackling the policy development

and amendment procedures. Moreover, this approach aims to thoroughly analyze other policies that could hinder or promote human right principles in the context of accessing TB programs and services.

The tool aims to build national capacity to facilitate a participatory process to develop a human rights framework for TB and align national policies with it. It plays an important role in identifying contextual issues that impact access to diagnosis, treatment, and care. It analyzes important legal and human right issues that affect people in accessing healthcare services.

The Legal Environment Assessment Tool works in tandem with Gender Assessment Tool because it identifies areas wherein human rights violation hamper the individual's access to healthcare services – gender-based or not. Moreover, both tools aim for the same goal wherein policies – or interventions – are aligned with human rights principles and eliminate inequalities.

Ethical Considerations

Belmont Report and National Ethical Guidelines for Health and Health-Related Research 2017

This study was conducted in full conformance with the Belmont Report (1979), National Ethical Guidelines for Health and Health-Related Research by the Philippine Research Ethics Board (2017), and within the laws and regulations of the Republic of the Philippines. The Belmont Report consolidates the ethical principles and guideline in conducting research that involves human subject. It is an internationally renowned guideline that serves as basis for most health-related research ethics guideline used across the globe.

The National Ethical Guidelines for Health and Health-Related Research – which also adopted components of the Belmont Report – is the nationally recognized and utilized guideline for health and health-related research. The guideline provides details on the inclusions of a research protocol: the need and significance of the study, research design, procedures and methods, and ethical considerations.

Informed Consent

The investigator acquired the consent of the community before commencing the fieldwork proper. To do so, the investigator prepared a communication letter that was sent to the community leader to inform them of the study that was going to be conducted and asked for their permission to execute the research. Moreover, the investigator utilized this to request assistance for the recruitment of the participants had the community leader granted the investigator to conduct the study.

The consent of the participants was obtained during the field work, before the commencement of FGDs, KIIs, and in-depth interviews. The facilitator explained thoroughly to the participants the details of the study. The facilitator guided the participants in understanding the contents of the consent form and utilized the Filipino language to better explain the research and the activity in details.

The participant's participation was voluntary, and acquisition of their consent was documented through signing of the informed consent form. The facilitator was primarily involved in obtaining their consent and was the one tasked in collecting the consent forms.

Moreover, the facilitator was tasked to examine the comfortability of each participant. The facilitator ensured that the participants are always aware of their rights and that they can discontinue at any point of the activity. The facilitator was also in charge in determining the wholehearted participation of each participant. This was essential in guaranteeing that all participants participated willingly and voluntarily.

FINDINGS

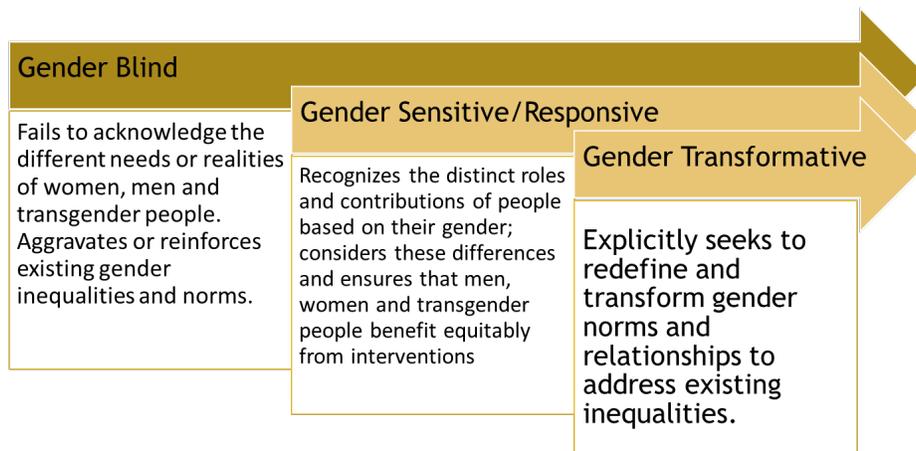
Legal Environment Assessment

Gender Assessment of the Philippine National Tuberculosis Response

According to the World Health Organization, there is an estimated

The Gender Assessment Tool¹ provides a framework for analyzing the level at which TB and HIV responses in countries have been able to take into consideration the differences among men, women and transgender people in how they are able to avail of or access related services; as well as how they are treated by the healthcare service providers based on their gender identities.

Figure #. Gender Analysis Framework



The framework progressively moves towards systems that are gender transformative, those that not only provide differentiated services in response to the specific needs of men, women and transgender people, but also seeks to change gender norms that are the underlying causes of inequalities.

For the gender assessment of the TB response in the Philippines, ACHIEVE also reviewed the bigger context of health and gender. It looked into existing legal frameworks that promote the rights and welfare of women, as well as health-related and gender-related laws, policies and programs. The assessment of these systems and structures were then analyzed in relation to the experiences of the communities who were involved in the study.

Legal Framework on Gender in the Philippines

There are no laws specifically framed for gender equality that aims to benefit all people of diverse gender identities, gender expressions or sexual orientation. In fact, there is a SOGIE (sexual orientation, gender identity and expression) Equality Bill that has languished in Congress for 19 years. It's been filed again under this new Congress but the future of it remain bleak for as long as the conservative block are in power in the House of Representatives and the Senate. However, since the Philippines has a devolved

¹ Gender Assessment Tool for National HIV and TB Responses: Towards Gender-transformative HIV and TB Responses. UNAIDS and Stop TB Partnership

form of government, local government units (LGUs) are able to promulgate their own local ordinances, as long as they do not violate existing national laws. The absence of a national law on SOGIE equality, however, does not prevent LGUs in having ordinances that apply within their respective jurisdictions. To date, there are 28 Cities, Provinces, Municipalities and Barangays that have local anti-discrimination ordinances that prohibit discrimination on the basis of age, health status, disability, sexual orientation, gender identity, ethnicity and religion.

These local government policies protect everyone, essentially, but especially those from the lesbian, gay, bisexual, transgender (LGBTQ) communities from discrimination in the workplace, in schools and other educational and training facilities, and in public places. There are provisions that protect transgender people from being banned from public restrooms that are designated for women.

These ordinances prohibit discrimination in the health care setting, specifically in terms of denying health care services. There are ordinances that also prohibit subjecting or forcing anyone, based on actual or perceived disability, health status, age, sexual orientation, gender identity, ethnicity or religion, to undergo any medical examination without their expressed consent.

These policies are considered milestones especially in a country that is predominantly Catholic and with a strong Evangelical Christian movement against LGBT rights. In themselves, these policies are quite progressive. But there is still room for improvement in terms of actually articulating the need to address specific health care needs of people with diverse gender identities and orientations. For instance, none of the anti-discrimination ordinances go as far as providing for medically safe hormone therapy and medical-related transition procedures for transgender people. There are still no clear guidelines for the management of HIV and Tuberculosis treatment among transgender people who are also taking hormones for their transition. As a result, doctors would advise transgender people to stop taking hormones when they initiate HIV treatment, without regard for the importance and the value of hormones to the transgender person living with HIV.

The newly enacted Philippine HIV and AIDS Policy Act of 2018² is the first national legislation that has included language on SOGIE in its Declaration of Policies, which reads:

“Policies and practices that discriminate on the basis of perceived or actual HIV status, sex, gender, sexual orientation, gender identity and expression, age, economic status, disability and ethnicity hamper the enjoyment of basic human rights and freedoms guaranteed in the Constitution and are deemed inimical to national interest.”

Additionally, the concepts of sexual orientation, gender identity and gender expression are also defined under this Law, which means that in principle there is a level of legal recognition that these concepts exist and that the implementation of the Philippine HIV and AIDS Policy Act, through the various policies, programs and services that it mandates, SOGIE-equality principles should be mainstreamed or integrated. Since the Implementing Rules and Regulations of this Law has just been signed by the Philippine National

² https://www.senate.gov.ph/republic_acts/ra%2011166.pdf

AIDS Council last July 12, 2019, there is a huge opportunity for a more gender transformative HIV response in the country.

Legal Framework on Women in the Philippines

The most comprehensive legislation on women is the Magna Carta for Women³ that was enacted in 2009. In its Declaration of Policy, the Act stipulates the following:

“Recognizing that economic, political and sociocultural realities affect women’s current condition, the State affirms the role of women in nation building and ensures the substantive equality of women and men. It shall promote empowerment of women and pursue equal opportunities for women and men and ensure equal access to resources and to development results and outcome. Further, the State realizes that equality of men and women entails the abolition of the unequal structures and practices that perpetuate discrimination and inequality. To realize this, the State shall endeavor to develop plans, policies, programs, measures, and mechanisms to address discrimination and inequality in the economic, political, social, and cultural life of women and men.”

The Act also condemns and prohibits discrimination against women, and in accordance with the country’s ratification of the Convention of the Elimination of All Forms of Discrimination Against Women, aims to institute means to eliminate such discrimination.

The Magna Carta covers all aspects of women’s development in various sectors and contexts. It has two (2) sections that specifically mention women’s access to health, Section 10 and Section 17. The details are below:

“Sec. 10. Women Affected by Disasters, Calamities and Other Crisis Situations. Women have the right to protection and security in times of disasters, calamities, and other crisis situations especially in all phases of relief, recovery, rehabilitation, and construction efforts. The State shall provide for immediate humanitarian assistance, allocation of resources, and early resettlement, if necessary. It shall also address the particular needs of women from a gender perspective to ensure their full protection from sexual exploitation and other sexual and gender-based violence committed against them. Responses to disaster situations shall include the provision of services, such as psychosocial support, livelihood support, education, psychological health, and comprehensive health services, including protection during pregnancy.

Section 17 is about Women’s Right to Health. It has two major components: 1) comprehensive health services, and 2) comprehensive health information and education. The section mandates the State to the provision of “comprehensive, culture-sensitive, and gender-responsive health services and programs covering all stages of a women’s life cycle and which addresses the major causes of women’s mortality

³ <https://pcw.gov.ph/law/republic-act-9710>

and morbidity, Provided, That in the provision for comprehensive health services due respect shall be accorded to women's religious convictions, the rights of spouses to found a family in accordance with their religious convictions, and the demands of responsible parenthood, and the right of women to protection from hazardous drugs, devices, interventions, and substances."

Specific health services that shall be ensured for women under this section are the following:

1. Maternal care to include pre- and post- natal services to address pregnancy and infant health and nutrition;
2. Promotion of breastfeeding;
3. Responsible, ethical, legal, safe, and effective methods of family planning;
4. Family and State collaboration in youth sexuality education and health services without prejudice to the primary right and duty of parents to educate their children;
5. Prevention and management of reproductive tract infections, including sexually transmitted diseases, HIV and AIDS;
6. Prevention and management of reproductive tract cancers like breast and cervical cancers, and other gynecological conditions and disorders;
7. Prevention of abortion and management of pregnancy-related complications;
8. In cases of violence against women and children, women and children victims and survivors shall be provided with comprehensive health services that include psychosocial, therapeutic, medical, and legal interventions and assistance towards healing, recovery and empowerment;
9. Prevention and management of infertility and sexual dysfunction pursuant to ethical norms and medical standards;
10. Care of the elderly women beyond their child-bearing years; and
11. Management, treatment, and intervention of mental health problems of women and girls.

The Magna Carta also encourages healthy lifestyles among women to prevent diseases. The second component on Health Information and Education requires the State to "provide women in all sectors with appropriate, timely, complete, and accurate information and education on all the above-stated aspects of women's health in government education and training programs, with due regard to the following:

1. The natural and primary right and duty of parents in the rearing of the youth and the development of moral character and the right of children to be brought up in an atmosphere of morality and rectitude for the enrichment and strengthening of character;
2. The formation of person's sexuality that affirms human dignity; and
3. Ethical, legal, safe, and effective family planning methods including fertility awareness.

Gender mainstreaming efforts in government is based on the Magna Carta, which also mandates the automatic allocation of a percentage of the budget of all government agencies and local government units to be earmarked for Gender and Development (GAD), also known as the GAD budget. This fund should be used for GAD related activities that advance the rights of women both within the respective government units, as well as the women these units or agencies serve.

The Gender Gap Report⁴

Over the years, the World Economic Forum (WEF) has rated countries on their efforts to bridge inequalities between men and women. Perhaps because the implementation of the Magna Carta of Women, the Philippines has been in the Top 10 for the past couple of years. In 2018, the Philippines ranked 8th in the Global Gender Gap Report of the WEF⁵, which has been translated by media as the country being among the most gender equal countries in the world.

The report measures the gender gap in four aspects: labor force, participation, political empowerment, and health and survival. Countries are also ranked under each of these aspects individually. The Philippines, despite being ranked 8th overall garnered only the 42nd place in health and survival, which is measured in terms of mortality rate. To some extent this score card may reflect the gender situation in countries, they are limited in that they only show the narrowing of disparities between men and women in the abovementioned categories. However, they do not necessarily show the substantive realities faced by either men or women. For instance, even though the Philippines may have ranked first in the level at which it was able to close the gap between the number of men and women in the labor force, it does not show the actual labor conditions that men and women face in this sector.

The Health Sector: Policies, Programs, Systems

The extent to which the health sector has mainstreamed gender should have benefitted women as it has elevated reproductive health and maternal and child health services in the country. However, the Responsible Parenthood and Reproductive Health Act has done little to prevent the rise of teenage pregnancies in the Philippines, which now has the highest rates in the region.

Moreover, in other diseases, gender mainstreaming remains to be at the level of sex-disaggregation of data, which also is binary: men and women. There is a dearth of studies on the situation of transgender people in general, much less in terms of their health-related needs, issues or concerns.

This is a reflection of the limited operationalization of the concept of gender, in general, and in the health care system in particular. First of all, “gender” has long since been equated with “women” and this may be a result of the fact that the Gender and Development framework of the Philippine Government emanates from the Philippine Commission on Women.

But even the understanding for women’s health, as reflected in the Magna Carta for Women, is largely in terms of sexual and reproductive health of women. In fact, the listing of the coverage for comprehensive health services for women is based on the elements of reproductive health. But reproductive health is just one aspect of women’s health. Thus, the health sector response for women’s health is also limited. Disease surveillance data and research related to health concerns of Filipinos are sex disaggregated but that’s where gender mainstreaming ends. And sex disaggregation is still binary and fails to reflect the experiences of transgender people.

⁴ <https://www.weforum.org/reports/the-global-gender-gap-report-2018>

⁵ http://www3.weforum.org/docs/WEF_GGGR_2018.

Even in the HIV response, which directly affects people of diverse gender identities and expressions, has continued to lump transgender women within MSM (men who have sex with men) data. The clamor from the transgender community to be separated from the MSM has resulted in simply modifying the category from MSM to M/TGSM (men and transgender women who have sex with men). But the numbers are still lumped together, which limits the understanding and utilization of surveillance data for responsive programming and service delivery.

In 2018, the Department of Health (DOH) published the results of the first health system responsiveness survey⁶ in the Philippines on its website. Health system responsiveness is defined as “the ability of the health system to meet the population’s legitimate expectations regarding their interaction with the health system, apart from their expectations for improvement of health or wealth.”⁷

Although the available report is brief and by no means comprehensive in scope nor description, there are a few notable findings that need to be addressed to improve the performance of the health sector. These are the following:

1. 65% of health care providers seldom, once or never treat them with respect;
2. The biggest hindrance to getting the health care they need were social class (81%) and capacity to pay (75%);
3. 8% of the respondents said sex was a hindrance to getting the health care they need;
4. 31% of males and 21% of females said physical examinations and treatment were seldom, once or never done in a way that respected their privacy.

Note the 8% of the respondents who pointed to sex as a barrier to getting the healthcare they need. A deeper investigation might be required to unpack what this means exactly. Unfortunately, the nature of the study did not allow for this. Nevertheless, it is indicative of an area of inquiry that is not often explored in studies related to access to health care systems.

The Comprehensive Tuberculosis Plan Act of 2016

Republic Act 10767 or the Comprehensive Tuberculosis Plan Act was enacted in 2016. The law mandates the development of a comprehensive plan to eliminate TB as a national health emergency. The law also directs the establishment of coordinating mechanisms from the national to local levels, as well as requisites for the effective implementation of the comprehensive plan of action.⁸

However, as the main policy framework for the TB elimination in the country, it fails to recognize the different experiences and realities of women, men and transgender people in accessing health care services in general, and TB-related services, in particular. Gender is absent in its Declaration of Policies, which customarily reflects the main principles upon which laws are anchored.

⁶ https://www.doh.gov.ph/sites/default/files/health_magazine/WHRB4.5%20Performance%20Accountability.pdf

⁷ <https://www.who.int/responsiveness/hcover/en/>

⁸ <https://www.officialgazette.gov.ph/2016/04/26/republic-act-no-10767/>

Consequently, there are no provision in the law that touches on strengthening gender-based determinants that facilitate community access to services. There are also no provisions that aim to reduce or eliminate gender-based barriers to the TB programs and services.

The Philippine Strategic Elimination Plan Phase 1 (PHILSTEP1)⁹

The development of the PHILSTEP1 was the outcome of Republic Act 10767, whose timeframe was from 2017 to 2022. But aside from this, other developments motivated the creation of this new strategic plan: a new administration has just come to power after the 2016 elections, ushering in the new President's new health agenda; the World Health Organization (WHO) has also just come up with the End TB Strategy that currently guides the global TB response; and the 2016 National TB Prevalence Survey showed that TB remained to be a national health issue.

The long-term goal of the National TB Elimination Program is to “Reduce TB burden by decreasing TB mortality rate to 95% and TB incidence by 90% by 2035.” PHILSTEP1, which is the first phase of the country's blueprint to end TB in the country specified three (3) medium-term goals:

1. Reduce TB burden by decreasing TB deaths by 50% and TB incidence rate by 25%;
2. Reduce catastrophic costs incurred by TB-affected households to zero;
3. At least 90% of patients are satisfied with the services of the DOTS facilities.

The strategic plan is anchored on the following principles:

1. Government stewardship and accountability, with monitoring and evaluation;
2. Engagement of the private sector, civil society organizations and communities;
3. Protection and promotion of human rights, ethics and equity; and,
4. Adaptation of the strategies and targets at the local levels.

Given these principles, there is bound to be some level of gender integration into the framework. So, unlike the Comprehensive Tuberculosis Plan Act, the PHILSTEP1 included gender in its language. For instance, under the Performance Target, “90% of DOTS facilities are adopting integrated patient-centered approach,” the key activities are:

1. Develop models for TB services with focus on gender, human rights and patient-centeredness;
2. Support DOTS facilities to provide TB services that are patient-centered, gender sensitive and human rights-promoting.

Similarly, under the Performance target, “80% of provinces/Highly Urbanized Cities are with functional DOTS network providing expanded and integrated TB care and prevention services,” one of the key targets are to “Integrate TB with other programs such as Maternal, Newborn, Child Health and Nutrition

⁹ http://www.ntp.doh.gov.ph/downloads/ntp_data/ntp_vmg_and_org_and_tb_burden.pdf

(MNCHN), Non-Communicable Diseases (NCD), other infectious disease programs, drug rehabilitation, and nutrition.

These are the only times that “gender” is mentioned in the strategic plan and the integration of TB in MNCHN is the only instance that there is mention of a gender-related health concern being integrated with TB. As mentioned above, the health sector’s view on gender has been limited to women and women’s reproductive health concern.

In reality, however, integrating TB in MNCHN has not yet reached the practice on the ground. At the very least, service delivery is inconsistent among pregnant women who have TB. During an focus group the participants shared that they’ve heard of the following:

“There was also an experience where a pregnant woman was diagnosed with TB because she was given an x-ray, with protective cover for her abdomen.”

But among the participants, two women experienced different protocols when they were diagnosed with TB in the context of their pregnancy. One participant suspected that she was pregnant four (4) months into her TB treatment. She informed her doctor and the latter told her,

“Ganito na lang, reresetahan na lang kita ng vitamins pare din dun sa baby mo. Basta ituloy-tuloy mol ang yang gamot. Bumalik ka na lang sa akin pag natapos ka na kasi magsi-six months ka na.” *(This is what we’ll do. I will prescribe some vitamins for you and your baby. But you just keep taking your medicines [for TB] and just come back to me when you’re done because you’re almost to your sixth month [of treatment].) – Irene, Female respondent*

Another participant, however, had a different experience. She said she was pregnant when she started to feel sick.

“Wala na akong ganang kumain. Inuubo ng one month pero hindi siya [TB] na-detect. Sabi nila bawal yung gamot sa ubo. Mga five months, nagpa-check up ako sa private. And sabi lang sa akin pneumonia siya. Pwedeng alisin ng gamot. Pero ang sabi nila sa akin, yung baby pwedeng alisin ng five (5) months, CS. Siyempre hindi ako pumayag. Ang hirap na pag umuubo ako, naihi ako. Pumutok yung panubigan ko. Akala ko ubo lang siya, yung baby ko na pala. Yung baby ko premature. Dun nila nalaman na positive ako sa Tuberculosis.” *(I had no appetite. I was coughing for a month but it [TB] was not detected. They told me I can’t take cough medicine. Five months later, I went to a private clinic. They told me it was pneumonia and that it could be treated with medicines. They also said I should go through Caesarian Section to remove my baby. Of course, I refused. But the coughing was so bad. Then my water broke. I thought it was just a hard fit of coughing but it turned out it was my baby. My baby was premature and it was only then that they were able to diagnose me positive for Tuberculosis.) – Mae, Female respondent*

After being diagnosed with TB, the participant was confined in a hospital for six months until she was treated, while her baby was incubated until term. It would be six months later before she would get to see and hold her baby.

Integrating gender into the PHILSTEP1 remains limited and short-sighted because it simply relegated gender integration at the level of key activities related to service delivery. And even then, it has yet to be proven effective given the experiences shared by the participants.

The TB strategy treats gender as specific activities that are separate from the others and responds only to a particular strategy, rather than an over-arching principle that permeates into all the various levels of the plan. Although the set of principles anchoring the plan includes the “protection and promotion of human rights, ethics and equity,” it may not be enough to assume that the entire plan is also cognizant of the gender dynamics experienced by the community. As a result, the targets and indicators are not gendered. If there are no gender-related indicator, it would be difficult to measure the plan’s success on this matter.

For example, one of the impacts is “Responsive delivery of TB services.” The impact target statement reads, “At least 90% of patients are satisfied with the services of DOTS facilities. The gender perspective would require gender-related indicators to illustrate satisfaction with the services of DOTS facilities. But because the target is gender-blind, chances are the indicators would be gender-blind, as well.

Thus, a clear articulation of gender in the statement of principles may have helped in ensuring that every aspect of the Plan is imbued with gender responsive or even gender transformative perspectives, strategies and activities.

Experiences on the Ground

“Even sa proposal development, for example, diba hinihingan ka ng human rights angle, gender angle? Pagdating sa TB, hindi siya lumulutang. Para lang masabi na may human rights na aspect yung programa, sabihin lang sa patient-centered care. So yun yung pinaka-expression niya ng human rights... In terms of gender, wala naman specific na approach or strategy. Whether you’re female or you’re male, yung TB services is the same for all.”

(Even in proposal development, we get asked to provide the human rights angle and the gender angle. But in TB, these do not surface. So in order to say that there is a human rights angle, we just indicate ‘patient-centered care’. So that’s how human rights is expressed. In terms of gender, there’s really no specific approach or strategy. Whether you’re female or male, the TB services are the same for all.) – Key Informant, Philippine Business for Social Progress

Again, the preceding comment is reflective of the lack of gender perspective in the national strategy to eliminate TB, which is the primary basis of the project proposals submitted to the donors like the

Global Fund to Fight AIDS, Tuberculosis and Malaria. It is, therefore, not surprising that the communities who interact with the national TB response also experience gender-related issues.

At the individual level, the research participants from the communities shared that men are less likely to go for a check-up when they are feeling unwell. Some of the feedback from the participants include:

“Ang lalake kasi, kalabaw yan.” (Men are [strong like] carabaos.) – Eric, Male respondent

“Eh tayong mga lalake, malakas tayo. Mas malakas ang resistensiya.” (Us, men, we are strong. We have stronger resistance.) – James, Male respondent

“Yang mga lalake, ma-pride. Ayaw tanggapin na may sakit sila.” (Men refuse to accept it when they get sick.) – Rosa, Female respondent

These responses from the community are consistent with common stereotypes that men are expected to be strong, which shapes their regard for their own physical well-being. It is also stereotypical for men to perceive women as weaker and need to be taken care of. Respondents observed that women were more likely to seek medical attention and they gave the following reasons:

“Kasi mas inaalagaan natin ang mga asawa natin.” (Because we have to take better care of our wives.) – Jess, Male respondent

“Mas pinapauna natin ang mga babae.” (We have to prioritize them [women]). – Ben, Male respondent

Interestingly enough, the women participants were also in the habit of delaying medical consultation until their condition have gotten worse or a family member forced them to see a doctor. One participant shared,

“Hindi ko kayang bilhin ang bawat tableta. Maliit pa yung mga anak ko tapos magkakasakit pa ako. Paano na yung gatas ng anak ko? (I cannot afford to buy the medicines. I have a small child and if I am sick, how will I be able to manage my child’s milk?) – Cristy, Female respondent

Women’s priorities, especially if they belong to the poorer communities, are always a challenge. They would usually put their needs last to that of their family, especially their children. Another participant who did go to the doctor was told that she needed to be confined in the hospital. But she begged the doctor to find another way.

“Eh, tinanong ko yung doctor kung pwedeng, kung merong gamot na pwede kasi malliit pa ho ang mga anak ko, elementary. Walang mag-aalaga kung iko-confine

ako.” *(I had to ask the doctor if it was possible, if there were medicines that I could take instead, because my children were still young. They were still in elementary school. No one would take care of them if I was admitted in the hospital.)* – Marie, Female respondent

Stigma and discrimination also hit both men and women who are diagnosed with TB, which could also affect their relationships with their loved ones.

“Tingin ko po sa sarili ko walang silbi.” *(I saw myself as useless.)* – Karen, Female respondent

“Yung mahirap din yung side effects kasi minsan nag-aaway kami ng asawa ko. Konting galaw niya, nade-depress ako.” *(The side effects are also difficult to deal with and sometimes they lead to fights with my husband.)* – Mae, Female respondent

“Kapag sinasabi nila, ‘Wala ka na namang silbi,’ sinasabi ko ihanda niyo na yung kabaong.” *(When they (family members) tell me, ‘You’re useless,’ I tell them, ‘Just start preparing my coffin.)* – Mae, Female respondent

Men also experience similar problems with their loved ones. One participant felt so ashamed when he was diagnosed with TB and he felt that this was the reason his relationship broke down.

“Madami pong nawala sa akin. Meron po kasi akong asawa. Hindi ka, I kasal pero may anak kami. Yung sakit na ito ang sinisisi ko. Siguro kung hindi ako nagkasakit, ok pa kami nung babae.” *(I lost so much. I had a partner. We were not married but we had a child together. I blame this disease [TB]. Perhaps, if I had not gotten sick, we would still be together.)* – Ramon, Male respondent

Unfortunately, stigma reduction for TB is not a priority in either the Law or the strategic plan. Awareness-raising on TB is limited. When people with TB experience discrimination, they have no recourse for redress because neither the law nor the strategic plan respond to TB-related discrimination. As a result, stigma persists and people continue to be ashamed and fearful of being diagnosed with TB.

Recommendations

There is a glaring gap in the legal framework, in the strategic plan and in practice in terms of the gender responsiveness of the TB response. Gender transformative approaches are not even on the horizon yet. But with clear entry points in the national strategic plan, the response could be enhanced considerably.

There was an attempt to amend the TB Law in the previous Congress. The process was interrupted by the national elections that took place this year so it means that if there is still interest in pursuing it, the amendment process would start from the beginning again. It is critical that CSOs and communities be engaged in the legislative process to ensure that the concerns of the communities affected by TB are reflected in the amended law. When the legal framework is enhanced, there is also a greater push to revise existing strategies. Various levels of recommendations would need to be in place for this to happen:

Community-building is crucial. Although there are patient groups that were organized by the treatment centers and hospitals, these groups were activated only to provide peer support during treatment and to encourage community uptake for testing. They have no experience in advocacy. But the **community organizations have to be capacitated to engage at the level of legislative advocacy.**

The existing strategic plan for TB need to be reviewed and revised. **Gender-related indicators have to be developed** in relation to the strategies and activities that already integrate the gender perspective. Additionally, there might be room to also **operationalize gender and human rights in all the other aspects of the strategic plan** that are currently blind.

The Gender and Develop Program of the Philippine Government, which includes gender trainings for government personnel, need to be required for all TB practitioners. There seems to be a difficulty in connecting gender with a health issue like TB. This could also benefit from more knowledge products on the connection of gender and Tuberculosis.

Expand research on gender and TB. This assessment is very limited. But it could open avenues for expanding the scope of the study, as well as deepen the investigation into the gender issues faced by people affected by TB.

TOWARDS A PEOPLE-CENTERED APPROACH TO TB RESPONSE: COMMUNITY PERSPECTIVES IN ACCESSING TB PREVENTION, CARE, AND SUPPORT IN THE PHILIPPINES

INTRODUCTION

The 2018 Political Declaration on TB recognizes that the only way to curb the tuberculosis (TB) epidemic is to implement a people-centered approach to prevention, treatment, care, and post-care support¹⁰. This holistic approach to addressing TB as recognized by the Declaration presents a new paradigm in framing the TB response towards a more inclusive, responsive, and centered around the needs of the people. More importantly, this paradigm shift highlights the importance of regarding those affected by and living with TB from recipients of healthcare to regarding them as equal partners in the TB response, and that their participation in the response is crucial.

The World Health Organization (WHO) defines people-centered approach to healthcare to consciously include the perspectives of individuals, families, and communities and see them as participants in shaping the health care system¹¹. This also calls on a gender-responsive response and human rights-based approach to TB care, which highlights the need to be more inclusive and affirming towards human diversity and experiences; and the recognition, fulfilment, and respect to human rights. This concept on people participation finds its roots from the Denver Principles developed in 1983, which calls on the participation of people living with HIV to be involved at every level of decision-making, and to be included with equal credibility as other participants¹². Framed within the Principles are the demands that people living with HIV must not be seen as solely patients seeking care for their illness but rather a person as a whole, which begs that other related needs that contribute towards alleviating their condition will need to be addressed. Over the years, the role of communities, particularly those living with HIV, became crucial in the progress towards addressing the HIV epidemic. This does not only apply to service delivery, as the role of communities expanded to also include advocacy, social mobilization, and community-led research¹³. UNAIDS Strategic Investment Framework, established in 2011, clearly identified community-led responses as “critical enablers” and that these engagements and responses must be funded three-folds¹⁴.

While community organizing and engagement in the TB response have only begun quite recently, TB-affected communities and TB survivors have also developed a document similar to the Denver Principles, which is the Declaration of the Rights of People Affected by Tuberculosis. This 25-article document asserts the various rights of people with and affected by tuberculosis as asserted in international and regional human rights law mandates and State obligations. In particular, Article 21 of the Declaration details a person with tuberculosis’ right to participate meaningfully “in all process and mechanisms for development, implementation, monitoring, and evaluation of laws, policies, regulations,

¹⁰ 2018 Political Declaration on TB, 2018, <https://www.un.org/pga/72/wp-content/uploads/sites/51/2018/09/Co-facilitators-Revised-text-Political-Declaration-on-the-Fight-against-Tuberculosis.pdf>

¹¹ <https://www.who.int/servicedeliverysafety/areas/people-centred-care/ipchs-what/en/>

¹² http://data.unaids.org/pub/externaldocument/2007/gipa1983denverprinciples_en.pdf

¹³ https://www.unaids.org/sites/default/files/media_asset/UNAIDS_JC2725_CommunitiesDeliver_en.pdf

¹⁴ Ibid.

guidelines, budgets, and programs related to tuberculosis, health care for tuberculosis, and medical research for tuberculosis at all levels of governance.”¹⁵ Consequently, TB-affected communities require support from the State and other stakeholders to ensure meaningful and effective participation.

Historically, countries, guided by the World Health Organization, follow a particular concept, called “patient-centered approach”, as a way to ensure that preferences, needs, and values are respected and responsive in providing care¹⁶. Under this approach, service providers should recognize people with TB’s rights, and fulfil their responsibilities by giving due considerations to clients’ values and needs. This means that strategies must consider the person’s right and welfare in the provision of treatment and care for people with TB as patients and direct beneficiaries of TB care. It needs to be kept in mind, however, that the context of patient-centered care, as opposed to people-centered care, is restricted only within the healthcare facility. While patients are regarded as the “heart of service delivery”, the focus of this approach remains disease-focused, since the goal of addressing these barriers and ensuring that the patient follow and complete their treatment regimen. Patient-centered approach is also contextualized within clinical encounters; thus while patients’ needs and preferences are heard, broader issues around the dynamics between doctors and patients, and an understanding of shared responsibility remains unclear. In the end, patient-centered approach leaves the responsibility to remain to the healthcare provider and to decide whether these values and preferences should be considered as part of establishing the person’s treatment adherence.

Eventually, the development towards a person-centered approach from patient-centered approach has shifted the orientation to broaden the definition of care towards the overall health of an individual in the absence of a disease of infirmity¹⁷. This also considers that the overall state of health or a well-being of a person must also take into consideration other determinants of health, to include physical, mental, and social well-being of an individual. This also broadens the dimensions in assessing the needs of a particular individual seeking health care by looking at issues beyond health care, and thus breaking the biomedical approach¹⁸. Mezzich and colleagues perfectly describe this approach as a healthcare “of the person, for the person, by the person, with the person; well-grounded in science and in collaboration and in partnership with the individual and the families”¹⁹.

People-centered approach further expands the person-centered concept by understanding that regardless of whether a disease is present or not, individuals interact with their environment and the people around them that determine their overall health-seeking behavior. This contextualizes individuals with the values and cultures that shape their decision-making in their lives and determines how and when to access health care services. At the same time, using the term “people” as opposed to “person” signifies that these definitions are shaped collectively, in a shared manner, and that health

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<http://www.stoptb.org/assets/documents/communities/FINAL%20Declaration%20on%20the%20Right%20of%20People%20Affected%20by%20TB%2013.05.2019.pdf>

¹⁶ <https://apps.who.int/iris/bitstream/handle/10665/272467/WHO-CDS-TB-2018.13-eng.pdf?ua=1>

¹⁷ <https://www.who.int/about/who-we-are/frequently-asked-questions>

¹⁸ <https://pdfs.semanticscholar.org/4e62/3bafd4033718b1f39e2a49aaa6d652c92dff.pdf>

¹⁹ Ibid.

promotion, disease prevention, and treatment patterns and adherence activities are impacted by how people and communities respond as a collective. Thus, it is imperative that in the design of a health system, people and communities remain integral. However, to be able to fully participate in the decision-making, individuals, families, and communities require that they receive adequate education and support as part of empowering the communities. This is not to say that communities do not have the capacity in the first place; rather these kinds of support are needed to ensure that communities develop towards their full potential, and that structures and systems are in place to facilitate capacity-building.

As the Political Declaration suggests, people-centered approach is framed around developing integrated, gender-responsive, human rights-based health approach that covers not only service delivery but also in the development and evaluation of better diagnostics, drugs, treatment regimens, as well as in addressing social and economic factors that not only perpetuates the disease but also impede the delivery of TB services on the ground.

FRAMEWORK ON INTEGRATED PEOPLE-CENTERED HEALTH SERVICES

In 2016, the 69th World Health Assembly proposed a framework on integrated, people-centered health services²⁰. This framework includes five interdependent strategies that aims to build an inclusive and effective health system that provides particular services to the populations it serves. These five strategies have corresponding policy interventions that do not only focus on issues around ethics and knowledge sharing, but also put priority in supporting communities towards better and more efficiently engage in the decision-making and programmatic planning within the health sector by introducing policy interventions and systematic changes in existing healthcare systems. Hence, the success of this implementation will then result in reorienting the health system to focus less on the disease and more towards its people and their needs.

Table. Framework on integrated people-centered health services²¹

Strategy	Strategic approach
1. Empowering and engaging people and communities	1.1 Empowering and engaging individuals and families 1.2 Empowering and engaging communities 1.3 Empowering and engaging informal carers 1.4 Reaching the underserved and marginalized
2. Strengthening governance and accountability	2.1 Bolstering participatory governance 2.2 Enhancing mutual accountability
3. Reorienting the model of care	3.1 Defining service priorities based on life course needs 3.2 Revaluing promotion, prevention, and public health 3.3 Building strong primary care-based systems

²⁰ http://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_39-en.pdf?ua=1&ua=1

²¹ Ibid.

	<p>3.4 Shifting towards more outpatient and ambulatory care</p> <p>3.5 Innovating and incorporating new technologies</p>
4. Coordinating services within and across sectors	<p>4.1 Coordinating care for individuals</p> <p>4.2 Coordinating health programmes and providers</p> <p>4.3 Coordinating across sectors</p>
5. Creating enabling environment	<p>5.1 Strengthening leadership and management for change</p> <p>5.2 Strengthening information systems and knowledge</p> <p>5.3 Striving the health workforce</p> <p>5.4 Reorienting the health workforce</p> <p>5.5 Aligning regulatory frameworks</p> <p>5.6 Improving funding and reforming payment systems</p>

The analysis for this section of this document will be based on the framework on integrated people-centered health services as mentioned above. However, it should be cleared that due to the dearth of information gathered, the assessment was only limited to the state of standardizing healthcare in the Philippines in responding to the needs of, and in involving those most-affected by the TB epidemic.

PEOPLE-CENTERED APPROACH AND THE PHILIPPINE HEALTH AGENDA 2016-2022

The Department of Health (DOH)’s Philippine Health Agenda 2016-2022 provides strategic direction of the country’s health priorities under the Duterte administration. This Health Agenda aspires to achieve three goals: the first is Financial Protection, which ensures that anyone, most especially the marginalized and the vulnerable, can access health care services; the second is Better Health Outcomes, that seeks to ensure that Filipinos attain best possible health outcomes with no disparity; and the third, Responsiveness, where Filipinos feel respected, valued, and empowered in all of their interaction with the health system²². These three aspirations of the Philippine Health Agenda revolve around the incumbent Health Secretary Francisco Duque’s priority towards Universal Health Care Agenda, which he sees as his unfinished agenda²³. The Health Sector Agenda commits to three guarantees: (1) health coverage across all life stages to tackle what the Health Agenda coined as the “triple burden of disease”, namely, communicable, non-communicable, and disease due to rapid urbanization; (2) establishment of a fully functional service delivery networks compliant with existing clinical practice guidelines that are able to provide health care services online and offline whenever the client needs; and (3) universal health insurance, which is meant to address financial freedom by expanding benefits and contracting networks of providers through service delivery networks to close the gap in health coverage. These three intersecting guarantees are geared towards ensuring Filipinos that the Philippine health system is prepared to provide any form of health care service to anyone at any given point in time regardless of

²² https://www.doh.gov.ph/sites/default/files/basic-page/Philippine%20Health%20Agenda_Dec1_1.pdf

²³ <https://www.doh.gov.ph/press-release/DUQUE-DOH-TO-HIT-THE-GROUND-RUNNING-ON-UNFINISHED-UHC-AGENDA>

location. The Universal Health Care Law, passed recently, extends these guarantees further, and allows additional hinge for the Philippine Health Agenda by providing a clear executive and legal framework to support its implementation.

People-centered approach is alluded to in the Philippine Health Agenda. The third goal, Responsiveness, takes into consideration views and interactions of Filipinos with the health system; and that they are respected, valued, and empowered to participate in the health response. At the same time, a Strategy under the Philippine Health Agenda was proposed to establish participation and redress mechanisms in order to involve, and instructs health agencies and establishments to collaborate with civil society organizations and other stakeholders on budget development, monitoring, and evaluation.

EMPOWERING AND ENGAGING PEOPLE AND COMMUNITIES IN THE TB RESPONSE THROUGH PARTICIPATORY GOVERNANCE

For the TB response, the National TB Law provides the legal framework with regards to the participation of TB-affected communities. As such, this includes acceleration of the strengthening of the National Coordinating Committee (NCC) and Regional Coordinating Committees (RCCs) and ensuring that there is a representative from TB key affected populations in these committees²⁴. The law’s Implementing Rules and Regulations (IRR) also instructs the Secretary of Health to collaborate with local organizations “in various activities and in providing technical and funding support for research, demonstration projects, model centers, and education and training”²⁵. While not mentioned specifically, this provision can also be used to include civil society organizations and TB-affected communities in the provision of technical and funding support for various TB-related activities. On World TB Day, Health Secretary Duque also emphasized the strengthening of the NCC, and at the same time committed to ensure that there is a multi-sectoral approach to “win the fight against TB”²⁶. This pronouncement of a multi-sectoral approach must include civil society organizations and TB-affected communities.

Corresponding the National TB Law, the Philippine Strategic TB Elimination Plan (PhilSTEP) also provides a national framework for action on the country’s response to the TB epidemic. With a vision towards TB-free Philippines by 2022, PhilSTEP establishes, in its core principles, the need to engage private sector, civil society organizations, and communities to ensure that TB services are responsive to the needs of the clients, particularly in ensuring that at least 90% of patients are satisfied with the services of DOTS facilities²⁷. The ACHIEVE Strategy of PhilSTEP affirms this core principle, and cites clear set of activities around engaging with TB support groups and communities in accessing quality TB services as stated in ACHIEVE Strategy 1.

Table. Relevant ACHIEVE Strategies related to Community Engagement to End TB

Performance targets	Key Activities
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²⁴ <https://www.philcat.org/images/irr.pdf>

²⁵ [bid.](#)

²⁶ <https://www.doh.gov.ph/press-release/World-TB-Day-2019>

²⁷ https://www.philcat.org/PDFFiles/PhilSTEP1_PhilCAT_2017.pdf

15% of total TB notifications came from community referrals	Mobilize NGOs and CSOs to organize communities
50% reduction of non-action takers among the presumptive TB	Implement Integrated Marketing Communications
Patient's agenda incorporated into NTP plan and policies	Support the organization and activities of patient groups Promote patient's rights and active participation in program management
90% of TB patients are with documented HIV status	Provide services beyond Category A and B areas
90% of DOTS are adapting integrated patient-centered approach	Develop models for TB services with focus on gender, human rights, and patient centeredness Support DOTS facilities to provide TB services that are patient-centered, gender sensitive, and human rights promoting

While support to people with TB is institutionalized in PhilSTEP, the support that people with TB and those affected by communities receive are lacking. For example, Samahang Lusog Baga (Association of Healthy Lungs) receives minimal support due to a pre-conceived notion of how communities should be engaged in the TB response:

Di ba ganon yung Samahang Lusog Baga; ang mga activities nila is magbigay ng gamot...dapat more of counseling lang, sila na yung group discussion. Siguro yung role ng MDR-TB...not anymore to look for patients doon pa sa community masyado na yung maano...kasi nandon naman yung barangay health worker, nandun naman yung task forces, so more of hanggang family sila. Kasi nga kung ang palagi nilang sinasabi, they have to work, they have to earn, so ano lang.. dapat din kasi yung mga support group they tell us, ano ba talagang isusupport sa inyo? – Key Informant

[Isn't it how Samahang Lusog Baga is; their activities is to provide the drugs...they should do more on counseling and group discussion instead. Perhaps the role of MDR-TB...not anymore to look for patients in the community...because the village health worker is there, the task forces are there, so they should focus more on the family. It's because if they keep on saying that they have to work, they have to earn, so...the support groups should tell us, what kind of support are you really looking for? – Key Informant]

There also seems to have a perception that communities particularly TB survivors, while having experienced the disease, lack the capacity to contribute fully in the TB response. This contradicts the demands made under the Denver Principles and the Declaration of the Rights of People with

Tuberculosis, which have underlined participation as a right^{28 29}. Data also shows that, albeit limited to community service delivery, community referral in 57 reporting countries increases by an average of 27%, which contributes to treatment success rate of 87% in the countries that reported engaging with communities in referral and treatment support.

While TB survivor-led organizations in the Philippines, such as *Samahang Lusog Baga* (SLB), have represented the TB community in spaces such as the Technical Working Group of the National TB Program and the Country Coordinating Mechanism (CCM), such representation is insufficient. Such TB survivor-led organizations need their capacity be built beyond service delivery and treatment support.

Gusto rin naming masama, yung sa monitoring and yung sa mga monitoring (activity), kasi doon sa monitoring dun namin makikita, dun namin pwede kami pumasok dun. Tsaka support para maitrain si SLB kung paano imomonitor at mag-engage. – Eden Mariano, President, Samahan ng Lusog Baga

[We want to join the monitoring, and in the monitoring (activity) that is where we see that we can really engage. And support to train SLB how to monitor and engage. – Eden Mariano, President, Samahan ng Lusog Baga]

Moreover, it is unclear how these legal and policy frameworks are measuring these engagements of civil society and TB-affected community, and the contribution of these engagements into PhilSTEP performance targets. With the PhilSTEP plan to undergo midterm review by late 2019, it is important that while these activities were indicated as strategies, community engagement indicators in the TB response – from service delivery to decision-making participation - will need to be developed.

REORIENTING MODELS OF CARE: BUILDING THE POWER OF THE COMMUNITY TOWARDS SELF-DETERMINATION

The Philippine National TB Program’s treatment management protocol is designed around Directly Observed Treatment (DOT). This method, as defined, is developed “to ensure treatment compliance by providing constant and motivational supervision to TB patients”³⁰. DOT is said to work by having a “responsible person”, referred to as treatment partner, to watch the TB patient take the medicine every day until completion. The language “responsible” to pertain to the treatment partner rather than the person with TB is problematic. First, this clearly perpetuates mistrust towards the person with TB, and that those undergoing treatment must be dependent towards their health provider and treatment partner. Second, calling the treatment partner as “responsible” connote that people with TB are irresponsible and should not be trusted with their treatment regimen.

²⁸ <https://www.thebody.com/article/denver-principles>

²⁹

<http://www.stoptb.org/assets/documents/communities/FINAL%20Declaration%20on%20the%20Right%20of%20People%20Affected%20by%20TB%2013.05.2019.pdf>

³⁰ https://www.philhealth.gov.ph/partners/providers/pdf/NTCP_MoP2014.pdf

Kapag nagpunta ka ngayon sa barangay dun ka pa lang nila bibigyan ng gamot. Kasi yung iba kasi, daw po ah, ang sabi-sabi lang, yung iba kasi na kahit binigyan na sila ng gamot (para iuwi), yung iba hindi naman daw po iniinom. – Female who use drugs FGD

Hindi, araw-araw ka pupunta dito,” which is requirements. Gusto nila talaga makita na iniinom mo ng harap-harapan. – People living with HIV FGD

[Whenever you go to a barangay, that’s the only time they will provide you with medicine. Others said that they were not allowed (to take their medicine home), others don’t really drink them – Female who use drugs FGD].

[“No, you have to come here,” which is requirements. They really want to see that you are drinking the medicine in front of them. – People living with HIV FGD]

The requirement for people with TB to frequent health centers on a daily basis, unless otherwise agreed mutually between the health service provider and the client, falls contradictory to the concept of patient-centered, directly-observed treatment (DOT) that aims to foster adherence to TB drugs. While DOT has already been considered an optional approach for clients with TB since 2019 (conditional recommendation, moderate certainty in evidence), the 2016 Clinical Practice Guidelines for TB Diagnosis, Treatment, Prevention, and Control of Tuberculosis continues to implement DOT as a treatment supervision procedure^{31 32}.

How should anti-TB medications be administered?

Patient-centered, directly observed therapy (DOT) should be offered to all patients who will undergo treatment for TB in health facilities with accredited DOTS programs. In patient-centered DOT, a patient is given the opportunity to choose where they want to be treated, and who will supervise them, either a healthcare worker, community health worker or family member, depending on clinical, social, cultural circumstances.

Outcomes are better with patient-centered DOT in terms of completion of treatment, smear conversion and default rates compared to daily health facility-based treatment and is less expense in a programmatic setting. *(Strong recommendation, high-quality evidence)*

Despite this procedure in administering TB treatment, clinical decision still remains solely on the onus of the health service provider and not in collaboration with the client. This keeps the client from making important informed decisions that can help them in their treatment, and be able to verbalize issues that

³¹ <https://apps.who.int/iris/bitstream/handle/10665/255052/9789241550000-eng.pdf>

³² <http://philchest.org/v3/wp-content/uploads/2013/05/CPG-E-copy.pdf>

could potentially disrupt the treatment process. Arnel, a former person who use drugs and was detained during *Oplan Tokhang*, when asked if he was to wear a mask after he was diagnosed:

Facilitator (F): Bakit daw hindi pinasuot nang [mask]?

Arnel (A): Ewan ko lang, walang sinabi.

F: May mga pinagbawal ba sa inyo na gawin?

A: Hindi, naka-separate lang yung ano namin, yung pagkain namin.

[Facilitator (F): Why did they tell you not to wear {a mask}?

Arnel (A): I don't know. Nobody told me.

F: Is there anything that they restrict you in doing?

A: No. Ours is already separated, our food is already separate.]

Such unidirectional approach in DOT results to low self-management to care among people with TB, reliance to health service provider, and client uninformed of the decisions being made by the health service provider and of the treatment regimen being provided in their behalf. Asked if he believes that his TB infection would relapse due to incomplete treatment, Arnel said:

Ewan ko lang. Hindi ko alam. Hindi pa ako nagpa-check e. Dapat nagpa-xray ako o kaya magpa-sputum daw ako...

[I don't know. I don't really know. I haven't enrolled myself for a check-up. I was intending to do an x-ray or undergo a sputum test...]

It must be noted that Arnel's experience with DOT took place at the detention center, where people diagnosed with TB are forcibly isolated and taken to a treatment wing or a center. While no data is currently available in the Philippines to determine the prevalence of TB in detention centers, globally, people in detention facilities are 23 times higher to be at risk of TB than the general population³³. While efforts have been put in place to screen and protect detainees from TB through regular screening, overcrowding and lack of health service providers to attend to the needs of detainees remain as major challenges in keeping people from TB in these settings³⁴. Issues around confidentiality and privacy of people diagnosed with TB also continue to be a challenge. Interviews among people who use drugs who were detained during the height of *Oplan Tokhang* by the Duterte administration share insights of how TB is handled inside detention centers:

Sabi nga po dun sa mga babae na sa amin mo na lang malalaman yung resulta, pero yung totoo, kapag inakyat na yung tao, marami nang nakakaalam. – male who use drugs FGD

[Some of the women were told that only they will know their results, but the truth is, when they bring you upstairs, people will know what your results are. – male who use drugs FGD]

³³ http://www.stoptb.org/assets/documents/resources/publications/acsm/kp_prisoners_spreads.pdf

³⁴ <https://www.icrc.org/en/document/philippines-fighting-tb-detention-places-0>

Nonetheless, some people with TB who are undergoing treatment find their way to circumvent DOT. This is either faking doctor's signatures, or self-administering medications to avoid going to the health center for DOT. This shows that while DOT is expected to be patient-centered, the onus remains among health service provider, and that the experiences and challenges that people with TB expect to face during the treatment process are neglected or unaddressed.

Parang sabi ko ang hassle naman kasi pag Sabado, Linggo, walang center. Pupunta ka pa sa ospital sa emergency room para magpa-inject tapos magpapapirma. Ang ginawa ko, sabi ko, IM (intramuscular) lang naman 'to, ako na lang gagawa. Everyday, nag-iinject ako left and right sa braso ko. Ako na lang din ang pumipirma, pumipirma sa ano. – Male living with with HIV FGD

[I told myself that it's a hassle if Saturday, Sunday, the center is closed. I have to go to the emergency room of the hospital to be injected and then for signature. What I did, I told myself, since this is only IM (intramuscular), I will do it myself. Every day, I inject at my left and my right arm. I'm also the one who signs my {health card}. - Male living with HIV FGD]

Person-centered DOTS, even if it is recommended based on the 2016 Clinical Practical Guidelines, are not followed according to national standards. Based on interviews conducted, some health service providers at the health centers still prefer people with TB undergoing treatment to visit the DOTS clinic every day and observe their patients taking their medicine in front of them.

Yung noon kasi sa barangay [health center] pag pumunta ka bibigyan ka na kaagad ng gamot mo for one month na kaagad. Ngayon kasi parang mas abala na po, pag pumunta ka ngayon sa barangay dun ka pa lang nila bibigyan ng gamot. Kasi yung iba daw po, ang sabi-sabi lang, yung iba kasi na kahit binigyan na sila ng gamot, yung iba hindi naman daw po iniinom. – Female who used drugs FGD

[Before, when you go to the village {health center} when you go there, they will immediately give you medicine for one month. Now, it's inconvenient, since when you go to the village, that's the only time when they will provide you with the drugs. Others, according to rumors, even if you give others their medicine, do not drink their medicine. – Female who used drugs FGD]

This kind of approach to instill adherence to clients with TB does not only contradict with the principles of a people-centered DOT; this also signifies the level of distrust of service delivery providers towards their clients. While it is expected from physicians that they should competently provide medical care with full professional skill in accordance with the current standards of care, this principle of competence should not be misconstrued that patients do not play a role in the decisions that they make for themselves and their health conditions³⁵. The 2016 Clinical Practical Guidelines advised, based on evidence, that healthcare workers should develop a good relationship with the patient in order to discuss issues about TB treatment, as this yields increased adherence compared to those who only provide treatment without establishing an encouraging relationship with people with TB³⁶.

³⁵ <https://www.philippinemedicalassociation.org/wp-content/uploads/2017/10/FINAL-PMA-CODEOFETHICS2008.pdf>

³⁶ <http://philchest.org/v3/wp-content/uploads/2013/05/CPG-E-copy.pdf>

We can also infer from the quotes presented above how rumors and beliefs towards the 'patient' contributes to the broader conception of the patient as an inferior, especially around treatment adherence. Howard and Hammond argues that these "rumors of inferiority" or stereotypes pervade the consciousness of people, including those who are targeted by these remarks, which eventually lead to low sense of self-efficacy and demotivation³⁷. Within the TB response, rumors that surround clients' behaviors or beliefs around how they adhere to their medicines perpetuate distrust and justifies the need for clients to visit DOTS clinics every day for their medicines.

This practice of DOT wherein clients are required to be present in front of the health service providers does not only clog many DOTS facilities and health centers; this also contributes to an already overburdened health service delivery. With a doctor-population ratio of 1:33,000, requiring people with TB to visit the clinics and watch them take their medicines for the next few months is an added burden³⁸. Further, while service providers are able to meet with their clients, the level of attention and quality of care do not commensurate to the time that is being given. In one interview with a male MDR-TB survivor:

Ang problema kasi sa health center, yung doktor ng isa, doktor ng lahat. Di ba. Yung doktor na tumitingin sa akin, doktor din nung mga, sa mga general medicine. Siya din yung ano; ang tendency nun tumatagal [ka doon] sa center, kumbaga imbes na one-on-one kami, imbes na medyo masinsinan pag-uusap namin, namamadali.

[The problem at the health center is, the doctor for TB is the doctor for everybody. The doctor that attends to me is the doctor for general medicine. The doctor is also the...; the tendency is that you stay longer at the center, instead of being able to have the doctor one-on-one, instead of being able to talk to the doctor more intently, I am being rushed.]

Reorienting models of care to build the capacity of people with TB to decide for the kind of treatment approach that respects their choices and their rights also requires health providers and facilities to observe ethical considerations in the management of the disease. This is particularly true on issues surrounding isolation. Experience in the Philippines show that forced isolation is still being required by health service providers among people with TB as a priority intervention, even at home. It was apparent in the interviews, however, that such approach does not work among people with TB. One female who used drugs, when she was instructed by her doctor to separate her things from the rest of her family at home, said that she could not do so because she knows that two weeks after treatment would not make her any more contagious.

Hindi ko siya ginawa eh (laughs) kasi feeling ko sa sarili ko bakit ko, parang, parang feeling ko ay nailalayo ko yung anak ko sa inyo eh nagagamot naman na ako.

³⁷ <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.544.4560&rep=rep1&type=pdf>

³⁸ <https://today.mims.com/doctor-shortage-in-the-philippines--an-analysis>

[I did not do it {laughs} because I feel like, why would I keep myself from my child when I am already undergoing treatment.]

While TB is considered contagious if remain untreated, isolating a person with TB once enrolled under treatment can take in various forms. The 2017 Ethical Guidance for the Implementation of the End TB Strategy published by the World Health Organization (WHO) provides a set of ethical standards to manage TB that follows principles of human rights, ethics, and equity³⁹. The Guidance recommends not isolating the person if not contagious; however, should the person remain contagious, certain less restrictive isolation measures can be made (e.g. wearing masks) and physical isolation should be considered final resort⁴⁰. Service providers also need to consider the person's preferences and decision to isolate oneself, and that the service providers' responsibility is to provide all the information needed to the person undergoing treatment and guide them in making those decisions. This ensures that the person's well-being is minimally affected by interventions that are perceived to delimit the person's movement and daily activities. One woman living with HIV who participated in the FGD, after being provided with sufficient information about ways to isolate herself during her initial treatment, decided to isolate herself because she cares for her family and wanted to protect them from TB.

Participant (P): Natakot [ako] sa pamilya ko [kaya] ako na lang ang nagkusang nagpahiwalay sa mga pinggan.

Facilitator (F): Yan ba ay choice mo? Sinabi sa iyo na ganyan ba yung dapat gawin?

P: Choice ko rin, kasi nga naaano din ako sa family ko, naaawa din ako syempre maaanuhan din sila, magkakaroon din sila.

[Participant {P}: I was afraid for my family {that's why} I voluntarily isolated my plates.

Facilitator {F}: Was that your choice? Were you told to do it?

P: It was my choice, because I was, for my family, sad for my family but they will understand because I don't want them to be infected.]

While it can be seen from the quote above that the participant was given the choice to the kind of isolation approach that she needs to take, this decision is contingent to the kind of information that is provided to the client. In this case, however, the belief that TB can be transmitted through sharing of utensils is an indication of the level of misconception surrounding the infection and the disease. Thus, it is important that these pieces of information should be accurate and based on evidence; otherwise, such misconceptions and stigmatization would continue to proliferate.

CREATING ENABLING ENVIRONMENT: ADDRESSING MISCONCEPTIONS AND STIGMA

Globally, there is a scant research done on TB stigma and its effects on uptake and management of TB treatment and other pathways⁴¹ ⁴². In the Philippines, the approach towards addressing TB-related stigma has been less of a priority and is perceived as an afterthought. For instance, TB-related stigma is

³⁹ <https://apps.who.int/iris/bitstream/handle/10665/254820/9789241512114-eng.pdf?sequence=1>

⁴⁰ Ibid.

⁴¹ <https://www.sciencedirect.com/science/article/pii/S120197121631195X>

⁴² <https://bmcmecine.biomedcentral.com/articles/10.1186/s12916-019-1250-8>

perceived as a reason for people's non-disclosure of their TB status, rather than a determinant that aggravates people's health-seeking behaviors. In the Philippines, the discussion on stigma has not been tackled as part of the 2016 National TB Prevalence Survey but was rather regarded as part of recall bias⁴³. However, data from the FGDs show that the experience of stigma that communities experience is crucial in understanding the challenges in diagnosis and treatment adherence in the country.

Misconceptions around TB continue to perpetuate among villages and other geographically-defined communities in the country. Despite the government's intensified approach to increase TB awareness, the level of misconception that has been ingrained since childhood aggravates how TB is being regarded at the community-level⁴⁴.

Kapag ako kunwari umuubo ako ng matagal – isang linggo, “o ayan ano magpa-ano, magpa-checkup ka na, yung ano na, magpa-check up ka na baka may TB ka na. Yung high school pa lang, diba? Yung mga jokes dati sa high school, diba? Yung tahol ka ng tahol... - male living with HIV FGD

[When, for instance, I cough for too long – one week, “hey, you should head for check up, maybe you have TB. Back in high school, right? The jokes back in high school, right? Things like cough that sounds like barking. – male living with HIV FGD]

Misconceptions such as these contribute to the triviality of the symptoms and to the disease itself. To some, TB has become so common that because of its high prevalence and belief that it is hereditary, symptoms of TB would not warrant a visit to the doctor or a DOTS clinic. Moreover, 4 in every 10 Filipinos with symptoms of TB (i.e. coughing of at least two weeks) would not take any action at all or would resort to self-medication⁴⁵.

These misconceptions that shape stigma around TB does not only impact the way people regard TB; this also shape the kind of inaccurate information given to people with TB coming from the health service providers, which are believed to be true. In one example shared among female CAT1 MDR survivor FGD:

Meron kasi akong nakausap na doktor, sabi niya, kung wala raw side effects yung mga gamot na yan, ibig sabihin hindi daw sila effective.

[I was able to talk to one doctor, he said, if the medicines do not have side effects, it's not effective.]

The tolerance towards the side effects, no matter how aggravating, then becomes part of the experience of and consciousness of treating TB, making TB treatment scary to undertake, or could possibly drive people not to seek diagnosis or treatment. This could also affect people with TB's treatment intake and eventually stop their medications. As a result, some people with TB would choose to discontinue their treatment. In 2016 alone, at least 16% or almost 2 in every 10 stop their

⁴³ https://www.philcat.org/PDFFiles/2.NTPSPHilCAT_17Aug2017_Dr.%20Lansang.pdf

⁴⁴ <https://www.pna.gov.ph/articles/1045890>

⁴⁵ https://www.philcat.org/PDFFiles/2.NTPSPHilCAT_17Aug2017_Dr.%20Lansang.pdf

medications at some point during their treatment; the primary reason of which is the side effects of the drugs⁴⁶.

RECOMMENDATIONS

It is clear in the framework of the integrated people-centered healthcare services that to be able to ensure that our health response to TB is inclusive of communities, their issues, and their priorities, it is imperative that certain elements on community empowerment and engagement, inclusive governance, responsiveness of the models of care, and enabling environments are in place. These set of recommendations reflect these elements based on the findings of this research, and have been laid out targeting particular actors in the TB response.

For the government and relevant actors (this includes the Department of Health National TB Programme, the Philippine Country Coordinating Mechanism, and the Technical Working Group on TB):

1. **Clarify** activities to implement PhilSTEP Strategy 1 in terms of mobilizing NGOs and civil society, particularly TB-affected and TB survivor-led groups
2. **Develop** clear performance targets that measure TB-affected and TB survivor community's engagement in the TB response
3. **Develop** clear financial targets that aim to support the social mobilization and service delivery activities of NGOs and TB-affected communities that work and contribute towards the national TB prevention and treatment targets
4. **Create** a financing mechanism that supports TB support groups to participate in the TB program beyond volunteer support. This includes outreach, referral, and community-based screening.
5. **Provide** at least one seat to TB-affected community representation in the National Coordinating Committee (NCC) and Provincial Coordinating Committees (PCCs).
6. **Develop** mechanisms and programs, in collaboration with members of NCC and PCC, to reduce catastrophic costs of people with TB undergoing treatment are covered
7. Under the NCC, **review** its current national campaign on TB by ensuring that TB-affected communities and civil society are involved in the process, and **develop** a comprehensive education and information strategy that will incorporate TB knowledge and issues in various sectors and institutions – from media to education systems.
8. **Encourage** people with TB to participate in the monitoring, evaluation, and accountability of the national TB response, to allow the improvement towards a more holistic TB response.

For technical partners and funding agencies, including WHO, Stop TB Partnership, and USAID:

1. **Allocate** funding support to NGOs and civil society organizations working on TB, with specific funding allocation dedicated to social mobilization, service delivery, research, and advocacy
2. **Support** the Philippine government in developing clearer performance and output targets on community engagement
3. **Support** the Philippine government in developing mechanisms, programs, and strategies necessary to ensure that catastrophic costs are reduced, and that information and education about TB prevention and treatment, as well as in combating stigma, are addressed

⁴⁶ https://www.philcat.org/PDFFiles/2.NTPSPPhilCAT_17Aug2017_Dr.%20Lansang.pdf

- 4. Support** operational researches, assessments, and other research-related interventions conducted by various partners that will provide further evidence in improving the TB response that are community-inclusive, rights-based, and gender-responsive. This includes researches that unpack and provide additional data about various key populations and communities most affected by TB