# Gender, Socio Cultural and Human Rights related Barriers in reaching Tuberculosis Prevention, Diagnosis and Treatment Services in Sri Lanka

**National Program for Tuberculosis Control and Chest Diseases,**

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## Message from Director

## National Program for Tuberculosis Control and Chest Diseases

Assessment of Gender, socio cultural and human rights related barriers in reaching Tuberculosis prevention, diagnosis and treatment services and preparation of a country action plan to address the identified issues has been a research priority in practice of evidence based TB care implementation strategies. Therefore, National Program for Tuberculosis Control and Chest Diseases (NPTCCD) prepared the country report for Sri Lanka , addressing the timely need in identifying and addressing Gender, socio cultural and human rights barriers in optimal TB care.

The development of the action plan for Gender, socio cultural and human rights barriers in TB care was a tedious process with the contribution of many individuals and organizations. I am thankful to the editor, research team from the central unit and participating district chest clinics, Government and Non-Government organizations and community members who had contributed in numerous ways in developing the country action plan. Last but not the least, I wish to acknowledge, all the study participants including patients with TB and their parents/guardians for taking part in the study, without their enthusiasm and willingness our research would never have been possible.

I hope successful implementation of the action plan for Gender, socio-ccultural and human rights barriers in TB care will aid in achieving End-TB targets in Sri Lanka.

Dr Hemantha Herath
Director - National Program for Tuberculosis Control and Chest Diseases

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## List of Abbreviations

| | |
|---|---|
| CBO | Community based organizations |
| CWO | Child Welfare Officers |
| DTCO | District Tuberculosis Control Officer |
| DO | Development Officers |
| IDI | In Depth Interviews |
| GP | General Practitioner |
| HCW | Health Care Worker |
| MDR-TB | Multi- Drug Resistant Tuberculosis |
| NGO | Non-Governmental organization |
| NPTCCD | National Program for Tuberculosis Control and Chest Diseases |
| OPD | Out Patient Department |
| PHI | Public Health Inspector |
| WHO | World Health Organization |

**Executive Summary**

Gender, socio cultural factors and human rights dimensions play paramount importance in all aspects of human social life. Tuberculosis (TB) is a disease of poverty and inequity. Gender, socio-cultural factors and human rights impact of TB is closely intertwined but yet a controversial phenomenon. Hence diagnosis, treatment and follow up of TB in the community can be affected by gender, socio cultural factors and human rights implications at large scale.

The present study was undertaken to understand gender, human rights and socio cultural barriers in reaching TB Prevention, Diagnosis and Treatment Services in Sri Lanka. There were three main categories included in the study population; Community Group, Patient Group and Health Care worker (HCWs) group. Sub group of Paediatric TB Patients was analysed separately. Inclusion of these diverse groups allowed analysis of different stakeholders for development of a country action plan for Sri Lanka in the future.

Eleven Focused Group Discussions (FDG) were conducted among Community and Patient Groups, five per each group in five selected districts in Sri Lanka; Jaffna, Nuwara Eliya, Amapra, Kalmunai and Colombo. One FDG was conducted in a subgroup of Paediatric TB from Lady Ridgeway Hospital in Colombo. Thirty In-Depth Interviews (IDI) were conducted in the HCW group which consist of representations from both curative and preventive health care staff; hospital staff (OPD Medical officers and Nursing officers in the medical ward) and staff from district chest clinics (District TB control officers and PHII).FGD Guide and IDI Guide were used as data collection tools.

Gender related barriers in TB care provision consist of factors such as issues in access to health care facilities, poverty, smoking, alcohol consumption, substance abuse, health seeking behavior patterns and treatment adherence.

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It is noteworthy that current study reported elicits smoking, alcohol and substance abuse as barriers in TB treatment and follow up. Delay in diagnosis of TB among men due to smoking and related complications such as smokers cough and COPD was predicted by the HCWs group in present study. Furthermore, it was the opinion of the study group that alcoholism was related to non adherence and ultimate treatment failure among TB patients. Alcohol intake is predominantly seen among males; however, there are reports on female alcohol consumption from the estate sector. Factors such as cold weather, less educational level, low social expectations in the community lead to increased alcohol consumption in the community.

Women are burdened with domestic work, looking after children and elderly in all of the districts where the present study was conducted. In addition, most of the women in urban areas and estate sector contribute to workforce at large. Access to health care is limited due to economic factors such as poverty, leading to inability to afford bus fare and other expenses in attending chest clinics which are faced by both genders, however predominantly among women. These factors along with poverty and female employment act as barriers for women to reach out for free health care facilities in the country.

In addition, poor accessibility to health care facilities was reported in rural, remote areas and the estate sector, due to its geographical location. The consensus of the study group was that women find it more difficult to access healthcare facilities in these locations due to physical excretion and the need for a companion due to safety issues. Inability of elderly patients and bed ridden patients to reach health care facilities is seen more among women.

Treatment adherence and completion is relatively higher among females. Once presented and diagnosed in the health facility, women tend to adhere to advice given by health care providers and continue medication, hence, the default rate is low among females in the community.

Stigma and discrimination are the biggest alienating human rights barriers for TB patients in Sri Lanka. Though, the current situation is more favorable than before due to extensive media campaigns by the National TB programme, discrimination lies within all levels of social systems irrespective of geographical location and population. However, stigma and discrimination among HCWs, towards TB patients was minimally reported in the study sample.

TB patients, mainly women face difficulties in marriage due to their TB status. Disgust towards the partner infected with TB which leads to break off in love affairs, matrimonial disharmony and concurrent breakage in marriage are seen in all sectors.

Structural gaps in health care services are invariably seen in the community. First level of contact in the health care service among the majority of TB patients is identified as private practitioners due to perceived delay in treatment provision within the government sector. Substantial amount of delay is evident in the health care from the time of first contact up to being diagnosed as TB. Inadequate knowledge on current status of TB and newer treatment modalities among health care professionals may be the causative factors for this delay in the study population.

Larger family size of TB patients is a notable factor in the present study; hence targeted interventions according to different communities should be set in consideration of the district situation.

In the present study, ethnicity and religion was not reported as barriers in TB diagnosis and treatment services in Sri Lanka. However, at times occupation can act as a socioeconomic barrier in TB care and prevention.

Presence of TB among children leads to psychological and social manifestations for the whole family. Potential reason for the child to catch TB predominantly points out at the main care giver, who is the mother of the child in most of the instances. Pediatric TB leads to disharmony in the household, economic crisis and psychological issues for both the child and parents.

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# Chapter 1: Introduction and Literature Review

## 1.1 Introduction

Tuberculosis (TB) is a communicable disease of major global public health interest. Globally an estimated number of 10.0 million (range 8.9- 11.0 million) people were diagnosed with TB in 2019. South East Asia has almost 44% of the global TB burden with estimated 4,370,000 cases in 2019 (WHO, 2020). Sri Lanka reported 8856 (NPTCCD, 2018) and 8434 (NPTCCD, 2019) new patients with TB in 2018 and 2019 respectively with an incidence rate of 64 per 100,000 populations. However, it falls far beyond the World Health Organization (WHO) estimated incidence of 13500 patients.

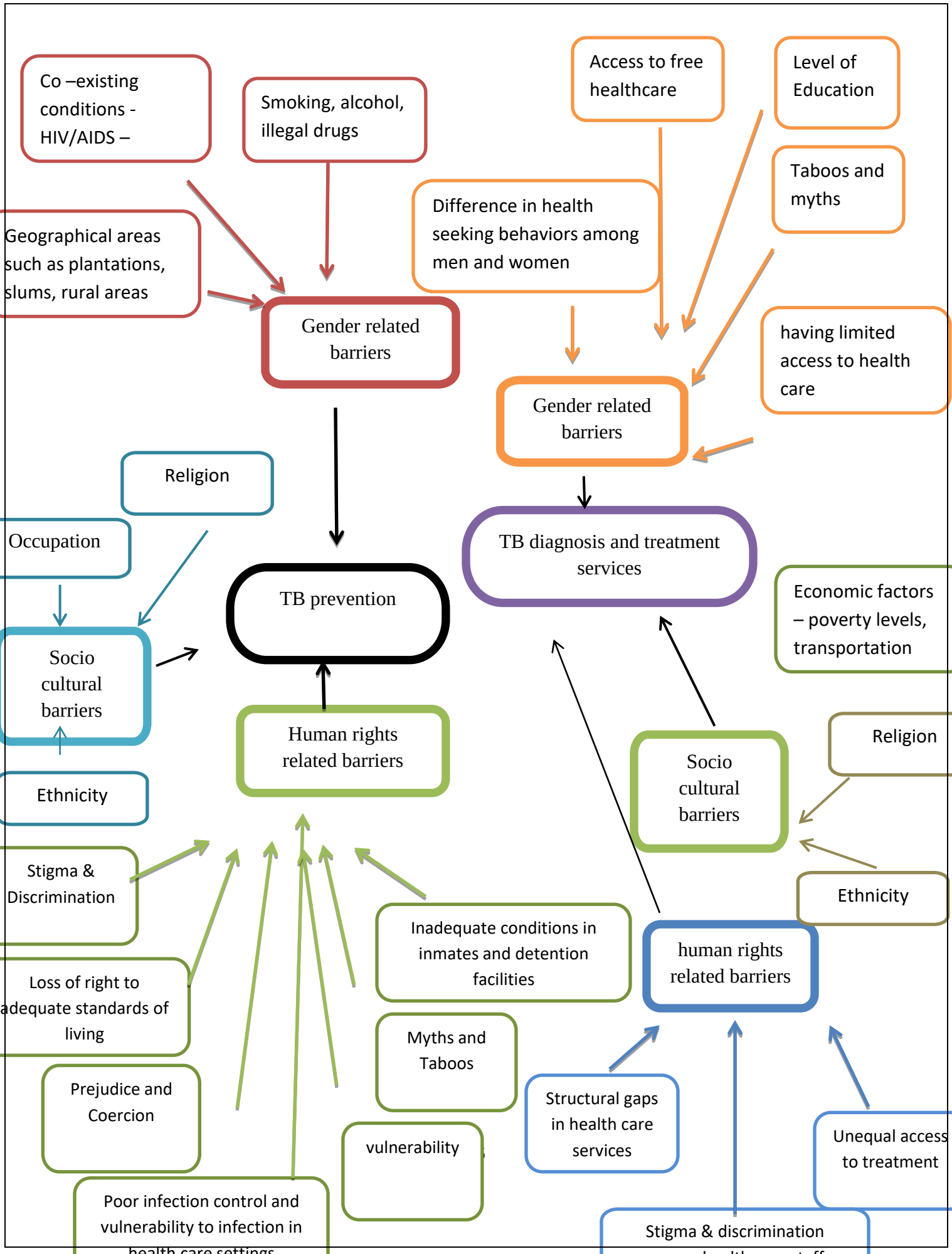
Currently, Sri Lanka is moving towards the End TB Strategy to end the global TB epidemic by 2025. It targets a 95% reduction in TB mortality, a 90% decline in TB incidence (to below 10/100,000 population) and zero catastrophic costs for TB-affected households. The National Program for Tuberculosis Control and Chest Diseases (NPTCCD) plays the central role in TB control in Sri Lanka and has been evolved through a long pathway using policy innovations based on programmatic experiences and research evidence. Many researchers have extensively worked on epidemiological, preventive and curative aspects of TB since the first piece of TB research work in Sri Lanka which could be traced back to the year of 1946 (Ranawaka, 1946), an era even before the independence. However, the gender, socio cultural behavioral and human cultural barriers for TB control is seldom studied in the Sri Lankan context. TB itself, being a centralized disease of low socioeconomic population, assessing the impact of such sensitive and specific barriers in Sri Lanka has become a timely need.

Gender, socio cultural factors and human rights dimensions play paramount importance in all aspects of human social life. TB is a disease of poverty and inequity. Being an illness of poverty and marginalization, gender, socio-cultural factors and human rights impact of TB is closely intertwined but yet a controversial phenomenon. Hence, diagnosis, treatment and follow up of

TB in the community can be affected by gender, socio cultural factors and human rights implications at large scale in Sri Lanka (Senanayake et al., 2018).

Furthermore, development of a national action plan to address gender, socio-economic and human rights related barriers in TB prevention, diagnosis and follow up in Sri Lanka is a vital part in uplifting the community, HCWs and people living with TB. Community at large needs to be socially mobilized and empowered to act on gender and human rights violations towards people who are suffering from TB and their families (Krieger & Gruskin, 2001) Stigmatization which is associated with TB needs to be addressed in order to uplift case detection rate in the country.

***Figure 1.1 Conceptual Framework for gender, socio-cultural and human rights related barriers in reaching tuberculosis prevention, diagnosis and treatment services***


Co –existing conditions - HIV/AIDS –
Smoking, alcohol, illegal drugs
Access to free healthcare
Level of Education
Taboos and myths
Difference in health seeking behaviors among men and women
Geographical areas such as plantations, slums, rural areas
Gender related barriers
having limited access to health care
Gender related barriers
Religion
Occupation
TB diagnosis and treatment services
TB prevention
Economic factors – poverty levels, transportation
Socio cultural barriers
Human rights related barriers
Socio cultural barriers
Religion
Ethnicity
Stigma & Discrimination
Ethnicity
Inadequate conditions in inmates and detention facilities
human rights related barriers
Loss of right to adequate standards of living
Myths and Taboos
Prejudice and Coercion
Structural gaps in health care services
Unequal access to treatment
vulnerability
Poor infection control and vulnerability to infection in health care settings
Stigma & discrimination among health care staff

## 1.2 Literature Review

TB is a global public health phenomenon and remains as one of the top 10 causes of death worldwide and the leading cause of death from a single infectious agent (ranking above HIV/AIDS since 2019) (WHO,2020).

### 1.2.1 Gender Dimensions of TB

Gender is referred as "The socially constructed characteristics of women and men-such as norms, roles and relationships and between groups of women and men"(WHO, 2002).Gender norms and roles affect people's susceptibility to different health conditions, treatment seeking behavior, disease acceptance, treatment and follow up. Gender dimensions of health is an area that has long been neglected (The Global Fund, 2020).

Gender is increasingly recognized as a critical dimension for understanding and responding to TB. Gender influences health seeking behavior of men and women suffering from TB in aspects of perception and acceptance of the disease, diagnosis, treatment and follow up. TB affects both sexes in all age groups but the highest burden (age group more than 15 years) are among men, who accounted for 56% of all global TB cases in 2019,while adult women accounted for 32% and children 12%(WHO, 2020). Furthermore, Borgdorff et al.,(2000) and Ben Jmaa et al.,(2020) reported higher incidence of TB among males compared to females and male sex as a significant predictor for negative treatment outcome (Ben Jmaa et al., 2020). In addition, current notable literature highlights the fact that notions of masculinity can negatively impact health- seeking behavior of men, which may be manifested as late or missing TB diagnoses and lower rates of TB treatment access and completion (Chikovore et al., 2017). Moreover, men are more likely to engage in certain behaviors which enhance the susceptibility of TB which includes smoking, alcohol consumption, and drug use.

Male predominance in reported new TB cases reflects gender patterns in societies and cultures, such as those relating to high-risk occupations and poor health-seeking behaviors (Senanayake et al., 2018). A deeper analysis of gender issues in TB care reveals complex dynamics in risk and access to services. For instance, TB among pregnant women living with HIV increases the risk

of maternal and infant mortality by almost 400% (WHO, 2018). Key and vulnerable populations for TB, which include groups such as prisoners, migrants, refugees and indigenous populations often face social marginalization that is compounded by gender. Similarly, several occupations predispose gender based susceptibility of TB. For example, mining, blasting and Armed forces often associated with crowded living conditions, can make men more at increased risk of TB; while a similar risk factor is faced by those working in the garment industry or living in peri-mining communities and crowded factory dormitories where the majority of occupants are women (The Global Fund, 2019).

Furthermore, women and girl child face greater barriers to healthcare information and services due to cultural gender norms such as economic dependence, patriarchal structure and their greater share and burden of domestic roles and responsibilities (Karim et al., 2007).Infrequently, women's health is given lesser importance in the domestic environment. In certain settings women are less likely to undergo diagnostic services, treatment facilities such as DOT provision due to cultural norms and perceptions of femininity in their culture. Begum et al., (2001) reported in Islamic culture gender dynamics of TB care providers play a significant role in women's access to TB diagnostic and treatment care provision. Furthermore, research from the SAARC region reports higher likelihood of lack of awareness, knowledge on disease burden and available treatment for TB among females in Nepal (Kumar et al., 2013).

Therefore, Gender equity and women empowerment can greatly enhance TB case diagnosis, management and follow up among women and girl children in the community (Needham et al., 2001). Gender equity is relevant across all aspects of responses to TB. Gender related barriers in TB prevention can determine the participation of women in community mobilization and access to available TB services. In relevance to TB detection and diagnosis, Gender can affect the decision of who is willing to give a sputum sample or who can have an x-ray (Krishnan et al., 2014). Within treatment, they can affect who is most likely to complete drug regimens or who experiences the best efficacy of multi-drug resistant treatment. Overall, gender is a critical factor in identifying the estimated global 4 million and 4000 Sri Lankan 'missing' people living with

TB who go undiagnosed, untreated or unreported every year. Key and vulnerable populations often face intense social marginalization that is compounded by gender (WHO, 2015).

### 1.2.2 Socio-cultural barriers in TB

Socio cultural determinants play a vital role in perception, behavior and attitudes of a population towards disease control and treatment activities. Research from South East Asian religion (McArthur, Bali, & Khan, 2016) and African region (Vecchiato, 1997) have reported the impact of socio cultural barriers on TB diagnosis and treatment. Freedom to travel by own is limited for women in Islamic communities, which in turn greatly affect their access to health care services to detect and treat TB (Khan, Walley, Newell, & Imdad, 2000).Furthermore, Gibson, Cave, Doering, Ortiz, & Harms (2005) conducted a study to determine the socio-cultural factors influencing the prevention and treatment of TB among the 10 highest risk immigrant and Aboriginal communities in Canada. The study reported social barriers due to culture and religion in these communities.

In depth analysis in to socio cultural barriers for TB prevention, Hudelson, (1996) suggested that socio-economic and cultural factors are of importance in many ways: firstly, they may play a role in determining overall gender differences in rates of infection and progression to disease, and secondly, they may lead to gender differentials in barriers to detection and successful treatment of TB. Persistent socio-cultural challenges in public health interventions for TB management and treatment were reviewed by Vissandjee & Pai (2007) which emphasis the necessity of integration of gender sensitive TB preventive and control statgies intopublic health sysytems in the world.

### 1.2.3 Human Rights Dimensions of TB

Promotion and protection of the human rights of people affected with TB is a legal, ethical and moral imperative (Stillo, Frick and Cong 2020). Declaration of the Rights of People Affected by TB has identified the right of life and dignity, right to health, freedom from torture and cruelty, equity and freedom from discrimination, freedom of movement, right to security and liberty (The

Global Fund, 2020). In relevance to TB care provision and health services, people affected by TB have the right for privacy and family life, right for confidentiality, information, informed consent. People with TB are rightful of their preference in education, work, adequate food, housing and sanitation in similar to unaffected population. The society should respect their right to social security, freedom of expression, freedom of assembly and association, participation. Society is bound to protect them with righteous justice and should be allowed to enjoy the benefits of scientific progress too (Citro et al., 2016).

However, TB transmission, prevention, treatment, care and support have long raised, and continue to raise, a wide range of human rights concerns and human right violations. Vulnerability of infection and spread of TB is indefinitely associated with lack of an adequate standard of living, including individuals in detention (UN, 2010). The Universal Declaration of Human Rights (UDHR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) describe a right to an adequate standard of living that includes food, clothing and housing, and the improvement of living conditions (UN, 1948). However, when these basic human rights are not met, and individuals live and work under crowded, unsanitary and inadequate conditions, the spread of TB is fuelled up. In addition, the close connection between HIV and TB epidemics magnify and complicate the human rights issues involved. Stigma and discrimination and associated myths and beliefs in the community, enhance human right violations of people who are affected by TB (Myers et al., 2006).

Children affected by TB face many social challenges. Hence, human rights-based approaches to children affected by TB is a timely need, owing to global increase in Pediatric TB ( Roy et al., 2016).

Human rights violation of patients living with TB can occur at the vicinity of TB service delivery and follow up too. Late detection of TB can lead to undetected transmission and poorer health outcomes. Hudelson, (1996) suggests that socio-economic and cultural factors may be important in two ways. Firstly, these factors may play a role in determining overall gender differences in rates of infection and progression to disease, and secondly, they may lead to gender differentials

in barriers to detection and successful treatment of TB. Both have implications for successful TB control programs.

# Chapter 2: Objectives

## 2.1 General Objective

To describe gender, socio cultural and human rights related barriers in reaching TB prevention, diagnosis and treatment services in Sri Lanka

## 2.2 Specific Objectives

1. To describe the gender related barriers in reaching TB prevention, diagnosis and treatment services

2. To describe the socio cultural barriers in reaching TB prevention, diagnosis and treatment services

3. To describe the human rights related barriers in reaching TB prevention, diagnosis and treatment services

# Chapter 3: Methods

A cross sectional descriptive hospital and community based study was carried out using qualitative study approach in selected target groups. Focus group discussions (FDG) and in-depth interviews (IDI) were carried out to describe socio economic , gender, human right barriers and factors associated barriers in reaching TB prevention, diagnosis and treatment services among adult TB patient in Sri Lanka.

## 3.1 Study design

A qualitative study design with Focus group discussions (FDG) and in-depth interviews (IDI) in hospitals and general population was conducted.

## 3.2 Study setting

Preventive and curative TB services in Sri Lanka are carried out in all 26 districts in Sri Lanka through a comprehensive network which is decentralized to the Provincial Health services and further to Regional Director of Health Services. There are 26 District Chest Clinics (DCC) in each of 26 districts headed by District Tuberculosis Control Officers (DTCOs) play a vital role in TB activities.

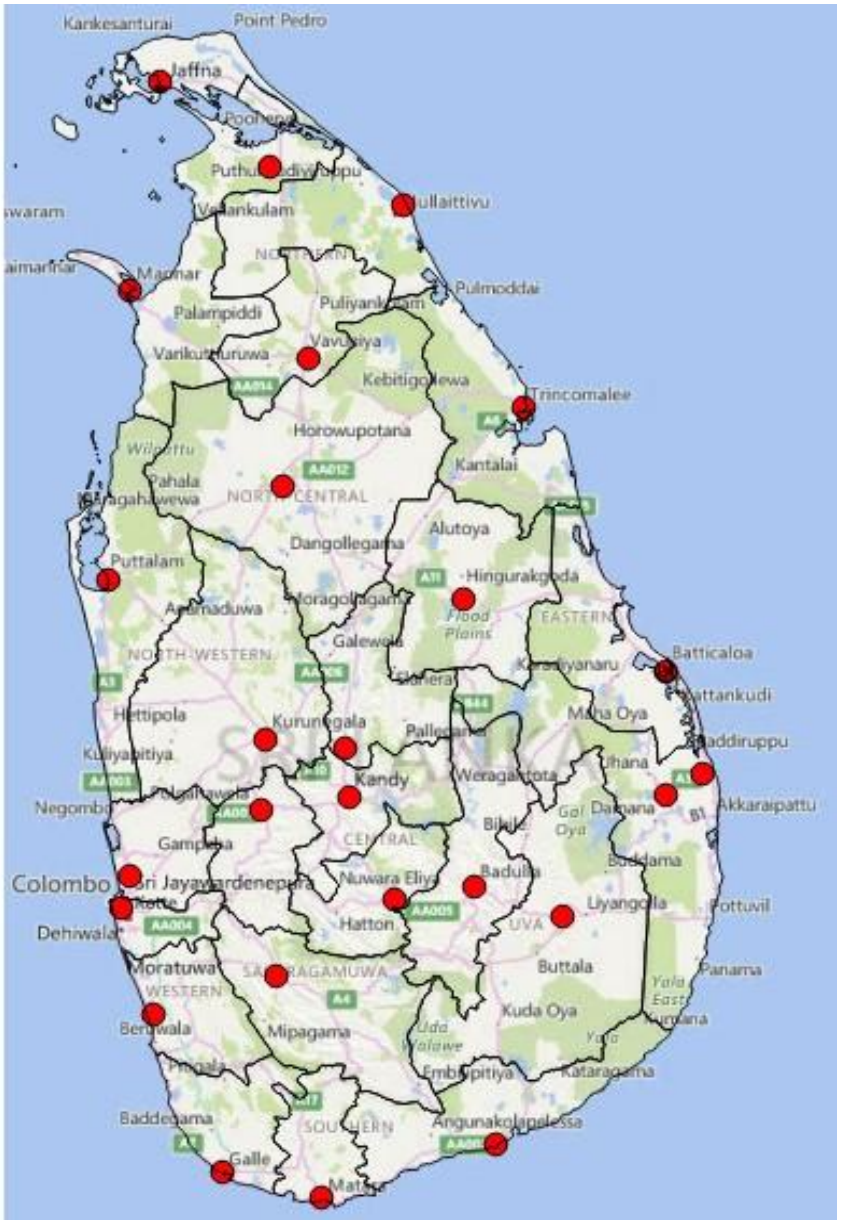



**Figure 3.1 – Distribution of District Chest Clinics (DCC) in Sri Lanka**

## 3.3. Study population

Study population for the present study consists of three groups;

1. Health care workers (HCWs) group
2. Community group
3. Patients group

### 3.3.1 Health Care Worker Group

Health care workers (HCWs) group consist of medical officers, nursing staff and Public Health Inspectors (PHII) .To represent perceptions from curative health staff, OPD Medical officers and Nursing officers from Medical ward were included in the study population. DTCOs and PHII from the District Chest Clinic represented the preventive health care sector. Medical Officers, Nursing Officers, DTCOs and PHII were considered to have an equal level of understanding and expected to gather equal levels of information through this research. Therefore, in-depth interviews were conducted among hospital staff (OPD Medical officers and Nursing officers in the medical ward) and staff from District chest clinics (DTCO and PHII).

### 3.3.2 Community Group

Community Group was further sub grouped as

1. General public (estate workers)
2. Community workers

Community Workers Group consists of the public in the community. A diverse community group with representations from all sectors in the community including Gramasewa officers, Child Welfare Officers (CWO), Development Officers (DO) from social service department in the area, religious leaders, Non Governmental organization (NGOs) and Community based organizations (CBO) etc was comprised in the Community group.

General public (estate worker) sub group of Community Group consist of Child Welfare Officers (CWO) and Development Officers (DO) who work in the plantations.

### 3.3.3 Patient Group

Patient groups consist of "Diagnosed TB patients who have completed intensive phase of treatment up to treatment completed stage; (NPTCCD, 2018) attending to chest clinics for treatment and follow-up".

### 3.3.4 Inclusion criteria

1. Patient Group - Male and female TB patients who have been residing in the Colombo, Jaffna Nuwaraeliya, Ampara and Kalmunaei districts during the past one year.
2. Community Group –Those who are not diagnosed to have TB in their life time and may or may not be stakeholders of TB care at community level
3. HCWs Group - Medical officers, Nursing officers and DTCOs and PHII; those who are working in a hospital OPD/medical ward or chest clinic during the past one year.

### 3.3.5 Exclusion criteria

TB patients who were mentally unsound.

## 3.4 Study Period

Study was carried out from May 2020- October 2020.

## 3.5 Sample Size

Purposive sampling method was applied until a sufficient number of study participants were included.

## 3.6 Sampling Technique

A stratified sampling technique was applied to select five districts.

1. In the first stage out of nine provinces in Sri Lanka, four provinces were randomly selected. Selected Provinces were Western, Eastern, Northern and Central Provinces.

2. In the second stage, selected provinces were further stratified as Urban and rural ;Urban strata included Western Province and Northern Province, while Central Province, Eastern Province were included in the rural category.

3. In the third stage geographical location such as slum/estate, ethnic distribution and inclusion of marginalized population was taken into account.

Hence, the following districts were selected in adherence to the criteria given above.

Colombo district was selected into the study setting to represent urban slum population while Kalmunai district was selected on the basis of ethnic varied rural population representation. Ampara district was selected on the basis of inclusion of Sinhala speaking rural population representation in the study sample. Jaffna district was selected on the basis of incorporation of Tamil speaking urban population while Nuwaraeliya district represented the estate population of Sri Lanka.

Finally a purposive sampling method was applied as it allowed selection of the potential participants who were willing to speak about their experiences and issues and ability to provide rich and valuable information.

## 3.7 Data collection tool

The conceptual framework was developed to describe the effect of gender, human right and socio cultural barriers on treatment seeking behavior, treatment adherence, and treatment completion among TB patients in Sri Lanka. Based on the conceptual framework an In Depth Interviewer (IDI) guide (Annex I) and FGD guide (Annex II) were prepared in English, Sinhala and Tamil languages. IDI were carried out based on the IDI guide among the HCWs group. Semi-structured questions were formulated using open-ended, non -threatening and non-embarrassing words.

FGD guide with inclusion of TB case scenarios based on experiences of DTCOs from the field were developed by PI and carried out among the Community Group and the Patient group.

### 3.7.1 Translation of an In-depth Interview Guide and Focus Group Discussion Guide

The IDI guide and FGD guide were prepared by the PI in English and translated into Sinhala and Tamil languages. The back translation was done and semantics were cross checked with the original English questionnaire by two bilingual experts independently.

**Pilot study**

Pilot study was done at Kalutara district in cooperating similar institutional vicinity.

## 3.8 Data Collection

### 3.8.1 Variable Definition

FDGs and IDIs were carried out based on the following main thematic areas which were identified as barriers in reaching TB prevention, diagnosis and treatment services in Sri Lanka. Themes are

1. Gender related barriers
2. Human right related barriers
3. Socio cultural related barriers

### 3.8.2 Data Collection method

#### 3.8.2.1 Mode of Data Collection

The mode of data collection consisted of Focused Group Discussions (FGD) and IDIs. HCW group was approached via IDIs, in order to obtain a deeper analysis of barriers regarding TB prevention and treatment. Furthermore, conduction of IDIs for the HCWs group was methodologically feasible due to their busy working conditions. HCWs ideas and perceptions regarding development of action plans to address barriers in TB prevention and treatment were effectively achieved through IDI Technique. IDIs were conducted among HCWs from five districts until the PI was satisfied on completion of the theoretical data saturation point.

The data collection technique of FGDs was applied for both Community and Patient groups. Each focus group consisted of ten persons from each specific group (community group and patients). One FGD per group per district was planned to be conducted .However, FDGs were conducted until the PI was satisfied on achievement of theoretical data saturation point. Therefore 11 FDGs ( five in the Community group, five in Patients group and one in Pediatric TB patient group were conducted) .

Study participants in Community and Patients groups were selected in adherence to similar socio-economic characteristics such as age, level of formal education and economic status,

hence, within each group; participants were more likely to express themselves freely. Therefore, homogeneity within groups was maintained .Sub groups representing urban, rural, estate, Tamil and Muslim areas were formed within a focused group based on their availability, willingness to participate and their ability of communication.

DTCO of the concerned area assisted the research group in selecting suitable participants.

Data collection technique is summarized in Table 3.1.

***Table 3.1 Data collection Technique.***

| District | Categories of study population | Data Collection Technique | Study setting |
|---|---|---|---|
| **Colombo** | HCWs (Doctors & Nurses) group | Indepth Interviews | National hospital Sri Lanka-Medical Unit & Borella Chest clinic |
| | Community group | FGD | Group from CMC area |
| | TB patients Group | FGD | Patients attending to chest clinic Borella |
| | Pediatric TB Patients group | FDG | Patients attending to Pediatric chest clinic Borella |
| **Jaffna** | HCWs (Doctors & Nurses) group | Indepth interviews | Teaching hospital Jaffna, Medical Unit & chest clinic |
| | Community group | FDGs | Group from Jaffna Provincial council held in Kopai District Hospital |
| | TB patients group | FDGs | Patients attending to chest clinic Jaffna |
| **Kalmunai** | HCWs (Doctors & Nurses) group | Indepth interviews | Teaching hospital Kalmunai Medical Unit & chest clinic |
| | Community group | FDGs | Group from Kalmunai Provincial council |
| | TB patients Group | FDGs | Patients attending to chest clinic ,Kalmunai |
| **Ampara** | HCWs (Doctors & Nurses) group | Indepth interviews | Teaching hospital Amapra - Medical Unit & chest clinic |
| | TB patients group | FDG | Patients attending to chest clinic ,Kalmunai |
| **Nuwaraeliya** | HCWs (Doctors & Nurses) group | Indepth interviews | District General Hospital Nuwaraeliya Medical Unit |
| | Community group | FDGs | Group from estates in Dikoya |
| | Community group | FDGs | Group from estates in Rikillagaskada |
| | TB patients Group | FDGs | Patients attending to chest clinic, Nuwaraeliya |

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#### 3.8.2.2 Selection of Moderator and Recorder

A Consultant Community Physician conversed in all three languages and two Senior Registrars in Community Medicine attached to NPTCCD acted as moderators for all FGDs and IDI. A Medical Officer took notes and recorded all relevant interviews.

#### 3.8.2.3 Administrative clearance

Prior to data collection, permission and approval was obtained from provincial and regional directors of health services in the respective districts and relevant Hospital Directors and in charge of the chest clinics. The date of data collection was decided upon, following discussions with hospital directors and relevant administrative authorities in-order to prevent disruption of routine health care services of the institutions and prevent logistic inconvenience. Date of data collection was informed to all hospitals, district chest clinics and community settings prior to data collection.

#### 3.8.2.4 In-depth interviews (IDIs) procedure

IDIs were conducted as semi structured interviews of 45 minutes to one hour duration in hospital and district chest clinic premises. A place with minimum interruption was selected to conduct the interview to ensure participant's privacy. Confidentiality was maintained. Information sheets were provided to the study participants and informed written consent was obtained. All interviews were recorded digitally (audio and video) with the consent of the participants and simultaneously additional notes were taken. Later, digital (audio and video) recordings were copied into statements. The interviewer noted the nonverbal responses during the interviews.

#### 3.8.2.5 Implementation of the FGD

The selected participants were informed by the PI one week prior and reminded one day before the discussion about the date and the venue. The FGDs were conducted in a comfortable place with adequate lighting and space and privacy was maintained.

Information sheets were provided to tall study participants and sufficient time period was given in order to go through the information sheet and clarify their doubts. Written informed consent

was taken. In the event where the diagnosed TB patient is within 15-18 year age group parent consent form and assent form were given. Parent consent form was used for the pediatric age group (TB patients less than 15 years of age) and the consent was obtained from the parent/guardian.

#### 3.8.2.6 Closure of session

At the end of each interview, clarifications were made on clarity of contents in the interviews and issues were settled.

#### 3.8.2.8 Analysis of Qualitative interview data

Data analysis was conducted as a cyclical process starting with the first FGD /IDI and carried out simultaneously with the data collection. Data collection was done from June to September 2020. Data analysis is a cyclical and ongoing process throughout the data collection phase (Braun & Clarke, 2006) and thematic analysis method was applied.

### 3.9 Ethical clearance

Ethical review committee of University of Kelaniya granted ethical clearance for the study in May 2020.

Annex III –Ethical clearance certificate

### 3.10 Data Analysis

Framework analysis Technique of Qualitative research was applied for analysis of data. Following three steps was applied.

**Step 1 -Developing and applying a coding system**

Coding was done manually and following three types of coding were applied

a. *Open coding*. The initial organization of raw data to try to make sense of it.
b. *Axial coding*. Interconnecting and linking the categories of codes.
c. *Selective coding*. Formulating the story through connecting the categories.

**Step 2 - Identifying themes, patterns and relationships**

Following effective methods of qualitative data interpretation were applied.

a. ***Word and phrase repetitions*** – scanning primary data for words and phrases most commonly used by respondents, as well as, words and phrases used with unusual emotions.
b. ***Primary and secondary data comparisons*** – comparing the findings of in depth interviews and FGDs with the findings of literature review and discussing differences between them.
c. ***Search for missing information*** – when several aspects of the issue was not discussed or mentioned by respondents, although PI is expected them to be mentioned.
d. ***Metaphors and analogues*** – comparing primary research findings to phenomena from a different area and discussing similarities and differences.

**Step 3: Summarizing the data**.

Summarize the noteworthy quotations from the transcript in order to highlight major themes within findings and possible contradictions.

# Chapter 4 : Results

## 4.1 Demographic data

### 4.1.1 Patients Group

The age distribution of the Patients Group is illustrated in Table 4.1.1.

**Table 4.1.1 Distribution of Patients Group according to Age**

| No | Age category | Number | Percentage(%) |
|---|---|---|---|
| 1 | 0-14 years | 4 | 6.2 |
| 2 | 15-19 years | 5 | 7.8 |
| 3 | 20-29 | 12 | 18.7 |
| 4 | 30-39 | 17 | 26.6 |
| 5 | 40-49 | 13 | 20.3 |
| 6 | 50-59 | 4 | 6.2 |
| 7 | 60-69 | 5 | 7.8 |
| 8 | 70-79 | 1 | 1.5 |
| 9 | 80 and more years | 3 | 4.9 |
| | Total | 64 | 100.0 |

Patient Group sample had 30-39 year age group at the highest percentage of 26.6% (n=17) and the lowest percentage was of 70-79 years age group (1.5%, n=1)

The male /female ratio of the Patient group is given in Table 4.1.2.

**Table 4.1.2 Distribution of Patients Group according to sex**

| | Sex | Number | Percentage |
|---|---|---|---|
| 1 | Female | 28 | 43.7 |
| 2 | Male | 36 | 56.3 |
| | Total | 64 | 100.0 |

Male participants in the Patients group was at a slightly higher percentage (56.3%, n=36).

The distribution of the ethnicity of the Patients group is given in Table 4.1.3.

**Table 4.1.3 Distribution of Patients Group according to Ethnicity**

| No | Ethnicity | Number | Percentage (%) |
|---|---|---|---|
| 1 | Sinhalese | 26 | 40.6 |
| 2 | Tamil | 22 | 34.4 |
| 3 | Muslim | 14 | 21.9 |
| 4 | Others | 2 | 3.1 |
| | Total | 64 | 100.0 |

Ethnicity composition of the Patients group comprised 40.6% Sinhalese, 34.4% Tamils, 21.9% Muslims and 3.1% Malay/Burgers.

The Distribution of Level of highest ideational atonement among Patients group is given in Table 4.1.4.

**Table 4.1.4 Distribution of Patients Group according to level of highest educational attainment**

| No | Level of highest educational attainment | Number | Percentage (%) |
|---|---|---|---|
| 1 | No schooling | 9 | 14.1 |
| 2 | Primary (Year 1-5) | 21 | 32.8 |
| 3 | Year 6-11( Up to O/L) | 20 | 31.2 |
| 4 | Passed O/L | 8 | 12.4 |
| 5 | Year 12-13 (Upto A/L) | 1 | 1.6 |
| 6 | Passed A/L | 2 | 3.1 |
| 7 | Diploma | 1 | 1.6 |
| 8 | Degree | 1 | 1.6 |
| 9 | Post Graduate Degree | 1 | 1.6 |
| | Total | 64 | 100.0 |

The largest group (32.8%) were educated up to Grade 5 only and 14.15(n=9) were with no schooling among the Patients group.

Employment status of the study population in the Patients Group is given in Table 4.1.5.

**Table 4.1.5 Distribution of Patients Group according to current employment status**

| No | Currently Employed | Number | (%) Percentage |
|---|---|---|---|
| 1 | Yes | 30 | 46.9 |
| 2 | No | 34 | 53.1 |
| | Total | 64 | 100.0 |

Of the study sample in the Patients group, 46.9 % were employed and 53.1% were not employed at the time of data collection.

Distribution of patients who are currently employed in the patients group according to the job category is illustrated in Table 4.1.6.

**Table 4.1.6 Distribution of Patients Group according to Job Category (n=30)**

| No | Job category | Number | Percentage (%) |
|---|---|---|---|
| 1 | Professionals | 1 | 3.3 |
| 2 | Clerks and Clerical support workers | 1 | 3.3 |
| 3 | Services and Clerical Support Workers | 4 | 13.4 |
| 4 | Skilled Agriculture ,Forestry and Fishery Workers | 8 | 26.7 |
| 5 | Elementary Occupations | 15 | 50.0 |
| 6 | Armed forces | 1 | 3.3 |
| | Total | 30 | 100.0 |

Of the patients who were employed at the time of data collection, majority were of Elementary Occupations (50.0%, n=15) and 26.7% (n=8) were occupied in skilled Agriculture, Forestry and Fishery work fields.

Distribution of Patients group according to monthly income is given in Table 4.1.7.

**Table 4.1.7 Distribution of Patients Group according to Monthly Income**

| No | Average monthly household income (Rs) | Number | Percentage (%) |
|---|---|---|---|
| 1 | Less than Rs 10,000/- | 5 | 7.8 |
| 2 | Rs 10,000/- 19,999/- | 15 | 23.4 |
| 3 | Rs 20,000/- 29,999/- | 22 | 34.7 |
| 4 | Rs 30,000/- 39,999/- | 10 | 15.5 |
| 5 | Rs 40,000/- 49,999/- | 5 | 7.8 |
| 6 | Equal or over Rs 50,000/- | 7 | 10.8 |
| 7 | Total | 64 | 100.0 |

Highest income category in the Patients group was in the Rs 20,000/- to 29,999/- category (34.7%, n= 22).

Table 4.1.8 illustrates the civil status of the patients which is also an important demographic variable to describe a population.

**Table 4.1.8 Distribution of Patients Group according to Marital Status**

| No | Civil status | Number | Percentage (%) |
|---|---|---|---|
| 1 | Single (never married) | 22 | 34.7 |
| 2 | Married(currently married) | 30 | 46.8 |
| 3 | Living together | 2 | 3.1 |
| 4 | Divorced | 2 | 3.1 |
| 5 | Separated | 3 | 4.6 |
| 6 | Widowed | 5 | 7.7 |
| 7 | Total | 64 | 100.0 |

Currently married comprised the largest group at 46.8 % (n=30) and living together and divorced groups were the smallest at 3.1%.

Distribution of the patients group according to the patient's family size is given in Table 4.1.9.

**Table 4.1.9 Distribution of Patients Group according to Family Size**

| No | Family size | Number | Percentage(%) |
|---|---|---|---|
| 1 | Less than 4 | 25 | 39.0 |
| 2 | 5-7 | 33 | 51.6 |
| 3 | 8-10 | 6 | 9.4 |
| | Total | 64 | 100.0 |

Family size of 5-7 members in the family comprised the largest group (51.6%, n=33) while family size of 8-10 members were 9.5% (n=6).

### 4.1.2 Community Group

The age distribution of the Community Group is illustrated in Table 4.1.10.

**Table 4.1.10 Distribution of Community Group according to Age**

| No | Age category | Number | Percentage(%) |
|---|---|---|---|
| 1 | 20-29 | 4 | 7.5 |
| 2 | 30-39 | 23 | 43.4 |
| 3 | 40-49 | 15 | 28.3 |
| 4 | 50-59 | 6 | 11.4 |
| 5 | 60-69 | 4 | 7.5 |
| 6 | 70 and more years | 1 | 1.9 |
| | Total | 53 | 100.0 |

Community Group sample had 30-39 year age group at the highest percentage of 43.4% (n=23) and the lowest percentage was of 70 years and more group (1.9%, n=1).

The male /female ratio of the Community group is given in Table 4.1.11.

**Table 4.1.11 Distribution of Community Group according to sex**

| | Sex | Number | Percentage |
|---|---|---|---|
| 1 | Male | 28 | 52.8 |
| 2 | Female | 25 | 47.2 |
| | Total | 53 | 100.0 |

Male participants in the Community group was at a slightly higher percentage (52.8%,n=28).

The distribution of the ethnicity of the Patients group is given in Table 4.1.12.

**Table 4.1.12 Distribution of Community Group according to Ethnicity**

| No | Ethnicity | Number | Percentage (%) |
|---|---|---|---|
| 1 | Sinhalese | 24 | 45.3 |
| 2 | Tamil | 18 | 34.0 |
| 3 | Muslim | 11 | 20.7 |
| 4 | **Total** | 53 | 100.0 |

Ethnicity composition of the Community group comprised 45,3% Sinhalese, 40.0% Tamils, and 20.7% Muslims.

Table 4.1.13 illustrates the distribution of Community group according to their designation.

**Table 4.1.13 Distribution of Community Group according to Designation**

| No | Designation | Number | Percentage (%) |
|---|---|---|---|
| 1. | Gramasewa Officers | 3 | 5.7 |
| 1 | Samurdhi Officers | 4 | 7.5 |
| 2 | Child Development Officers | 8 | 15.1 |
| 3 | Development Officers | 10 | 18.9 |
| 4 | Drug Rehabilitation Officer | 2 | 3.8 |
| 6 | Priest/monk | 2 | 3.8 |
| 7 | Community Organization Members | 10 | 18.9 |
| 8 | Non Governmental Organization Representatives | 9 | 17.0 |
| 9 | Retired Officers/teachers | 5 | 9.3 |
| | Total | 53 | 100.0 |

Majority of the Community group (18.9% respectively) were Development Officers and Community Organization members by their designation.

### 4.1.3 Health Care Workers Group

The age distribution of the HCWs Group is illustrated in Table 4.1.14.

**Table 4.1.14 Distribution of Health Care Workers Group according to Age**

| No | Age category | Number | Percentage(%) |
|---|---|---|---|
| 3 | 20-29 | 5 | 16.7 |
| 4 | 30-39 | 14 | 46.7 |
| 5 | 40-49 | 7 | 23.3 |
| 6 | 50-59 | 3 | 10.0 |
| 7 | 60 and more | 1 | 3.3 |
| | Total | 30 | 100.0 |

HCW Group sample had 30-39 year age group at the highest percentage of 46.7% (n=14) and the lowest percentage was of 60 years and more group (3.3%, n=1)

The male /female ratio of the HCW group is given in Table 4.1.15.

**Table 4.1.15 Distribution of Health Care Workers Group according to Sex**

| | Sex | Number | Percentage (%) |
|---|---|---|---|
| 1 | Male | 13 | 43.3 |
| 2 | Female | 17 | 56.7 |
| | Total | 30 | 100.0 |

Female participants in the HCW group was at a slightly higher percentage (56.7%, n=17).

The distribution of the ethnicity of the HCW group is given in Table 4.1.16.

**Table 4.1.16 Distribution of Health Care Workers Group according to Ethnicity**

| No | Ethnicity | Number | Percentage (%) |
|---|---|---|---|
| 1 | Sinhalese | 17 | 56.7 |
| 2 | Tamil | 5 | 16.7 |
| 3 | Muslim | 8 | 26.6 |
| 4 | Others | 30 | 100.0 |

Ethnicity composition of the HCW group comprised 56.7% Sinhalese, 26.6% Muslims and 16.7% Tamils.

Table 4.1.17 illustrates the distribution of HCW group according to their designation

**Table 4.1.17 Distribution of Health Care Workers Group according to Designation**

| No | Designation | Number | Percentage (%) |
|---|---|---|---|
| 1. | DTCO | 5 | 16.7 |
| 2 | Medical Officer –Chest Clinic | 5 | 16.7 |
| 3 | Medical Officer- OPD | 2 | 6.7 |
| 4 | Matron | 1 | 3.3 |
| 5 | Nursing Officer- Chest Clinic | 6 | 20.0 |
| 6 | Nursing Officer- Medical wards | 3 | 10.0 |
| 7 | Public Health Inspector | 8 | 26.6 |
| | Total | 30 | 17.0 |

Majority of the HCW group (26.6%, n=8) were Public Health Inspectors attached to District Chest Clinic in Sri Lanka.

## 4.2 Patients Group

Six Focused Group Discussions were carried out among 64 patients.

### 4.2.1 Gender based barriers

**Difference in health seeking behaviours among men and women**

Five patients shared their own had experiences on gender based difference in health seeking behavior. However, majority were in the opinion that gender based difference in health seeking behavior exist in the community.

Twenty nine year old female patient from Jaffna said "as females, we have to work a lot in the morning like cook, get children ready for school. I have to finish all house hold work by 8 am and then go to work in the estate. After work I have to pick my children from school and take to them for tuition classes. So in comparison to males women do not have time to access health care services easily. I was diagnosed as TB 2 weeks back and was advised to self – isolate. But it was difficult to self isolate from my family as I had to look after the family". Another female patient in her late twenties from Jaffna said that she had a two weeks delay in coming for treatment as she was afraid that if she goes to hospital there won't be anyone to look after the children and she might have to hire someone to look after them which she can't afford. It was the opinion of an older female patient in her seventies from Jaffna that since she is separated from his husband and lives with her son ,daughter in law and 3 children she presented late for treatment ,due house hold difficulties and delayed presentation made her symptoms worsened.

Most of the male patients agreed that, it is more difficult for women to seek medical treatment due to their household work and lack of money for transportation to health care facility. In comparison, men could easily go out of their houses and often enjoy economical freedom.

A 35 year old house wife from Kalmunai stated that "I was suffering from cough and difficulty in breathing and seek treatment from 5-6 private practitioners .Each of them gave me various types tablets and finally the $6^{th}$ doctor was able to diagnose my condition. Nobody did an X ray or sputum examination except the last occasion. My husband works in Saudi Arabia. Because of

that I could not go to a government hospital as I was not in a position to get admitted into a hospital due to the household responsibilities. It took 5 months from the onset of my symptoms to diagnose my disease. I did not know that choric cough, might be TB".

On the contrary, 35 year old male patient from Ampara, who is a chef by profession, stated that he got delayed in seeking medical treatment due to commitments and responsibilities in his job and he could not get leave of absence from his work place.

**Lack of awareness about the disease**

Majority of patients said that they were scared as they thought that TB is a killer disease and were not aware that treatment exist which can offer complete cure. However, majority of the patients agreed that their doubts and fear was resolved after coming to chest clinic for treatment.

A 50 year old unmarried female TB patient from Kalmunai stated that "I have a previous history of TB, where I was cured after 6 months of complete treatment. However, this time I did not have any symptoms such as cough or fever but had abdominal discomfort. I went to three Private practitioners during this episode where they treated me with different types of drugs. Recently I got shortness of breath and came to the chest clinic for treatment. I'm unmarried and live in my sister's house. There are 7 members in that house. My brother takes care of the whole family by running a grocery shop of his own. I could not get married because I didn't have money to build a house and give it as a dowry. I don't know about the side effect of TB drugs."

A 20 year old barber who works in a saloon in Kalmunaie for 15 years was suffering from on and off cough for 2 month. He thought that it's due to the air conditioning in the salon. Later the cough developed into chronic, un-resolving in nature and a client who came to the salon had informed to the PHI of the Nindawoor MOH office. The area PHI had visited his salon and had left a message for the patient to meet him. Later the PHI had referred the patient to Samanthuraie hospital for sputum examination. Four days after starting TB medication his urine became red in color. He was not informed about the side effects of TB drugs. He claims that he was given a leaflet which was written in English language and states that he could have understood if it was given in Tamil language.

**Limited access to health care services**

Gender based disparity in access to health care services was mentioned by 76 year old male TB patient from Colombo .He stated that "I feel that women, especially older women find it difficult to stay in queues in hospitals. So it is better if there are separate queues for women. In addition, young mothers leave their children in nursery/ school to attend clinics. So women should be given priority unlike men". The wife of an 80 year old TB patient from Colombo agreed that standing up in the queues for a long time is difficult for older women.

**Female dependency**

A 75 year old wife of an 80 year old TB patient mentioned that "we live alone and I take care of my husband. But if I get TB there is no one to look after me and take to treatment".

**Marriage**

Around ninety percent of participants agreed that TB condition does not affect the marriage for females. A young girl from Nuwaraeliya stated that "no discrimination from the family of my boyfriend after I was diagnosed as TB. They treated me well after diagnosis. Marriage will not be affected".

However, a 45 year old male patient from Kalumai stated that when his daughter's wedding was planned, he had asked PHI to visit not only his house but several nearby houses as well, in order to show it is a common gesture to the community. He was scared and worried that the bride groom's party might get to know about his illness that they might call off the wedding.

### 4.2.2 Human rights related barriers

**Stigma and discrimination**

Every patient participated in the present study agreed that stigma and discrimination towards TB persists in the society and it is a great barrier in diagnosis and treatment of TB in Sri Lanka. Twenty one patients claimed that they did not disclose their TB status to their friends/ neighbors in the fear of been stigmatized and two patients claimed that after knowing about their TB condition neighbors completely stopped visiting their homes. The majority of patients in the study

group stated that when PHI visit their homes in the PHI uniform and vehicle whole neighborhood get to know about their TB condition and all patients agreed that they prefer the possibility of PHI visiting their homes without his uniform in casual wear. A male patient from Colombo said that he comes all the way from Avissawella to Colombo, bypassing the Avissawella chest clinic, because he doesn't want anyone known to him in his village to find out that he is suffering from TB. An elderly patient from Colombo agreed and said that "once when I met a friend in the bus, I showed him the card while closing the word TB, as I didn't want him to know".

Five male patients from Colombo stated that their friends know about his TB status but however they do not discriminate him, rather support him by keeping up his morale.

However, except six patients, all others said that there is no discrimination from their respective families. Absence of stigma from family members may be due health education and awareness provided by the PHI on the disease. One patient from Jaffna said that "my wife is scared that she and others in the family will get infected, so she treats me differently, by giving me a separate place in the house and separate utensils". However, another patient from Jaffna said "my family doesn't treat me differently, but I use separate utensils for my meals as I believe TB can be spread from sharing utensils. An elderly male currently with EPTB who has a past history of Pulmonary TB in 1991 from Jaffna said "I live with my son. My grandchild likes to play with me. But my son and his wife don't like it. When the child comes to my room, I close the door as I am afraid that I might infect the child"

One patient from Colombo said that "stigma in the community is due to lack of awareness about TB in the community. You need to increase awareness through media. People are not scared of Leprosy anymore as there was an extensive campaign and people know about Leprosy management". Another patient agreed this opinion stating "society is scared about TB as no awareness that TB can be cured by 6 weeks medication".

Finally, it is worthwhile to note that a patient from Colombo declared that "I have told no one about TB. Telling the name Welisara is enough to get stigmatized in the community as it is a dedicated hospital for TB".

**Loss of right to adequate standards of living**

A 35 year old male patient from Kalmunai stated " I was employed as a chef in Qatar for 2 years .Following return I was diagnosed as TB and I was unemployed for last 2 months . Now I live by pawning jewelries. I could not go to the Grama Niladari to get the TB allowance because I am worried that the Gramasewa Officer might spread the news among the villagers".

**Myths and Taboos**

A MDR-TB patient who escaped from Welisara hospital said that other patients told that there are many side effects in anti TB medication and to escape from the hospital and seek indigenous treatment. A male patient aged 35 years from Kalmunai stated that "there is a belief among villagers that a person get TB due to "yaka gahanawa"(stricken by the devil or satan) and some villagers follow superstitious rituals given by astrologers without going for treatment"

**Inadequate conditions in inmates and detention facilities**

A 23 year old male drug addict, from Jaffna said that he was diagnosed with TB while he was in the remand prison. His wife is pregnant with their second child she is not aware about his disease. Furthermore, in the prison he is isolated and kept in a separate cell and nobody comes to his cell and food is supplied to him in parcels. Patient was upset about it.

**Structural gaps in health care services**

When asked about their experiences in health care services in relevance to TB management, a 72 year old male patient from Colombo said that "I went to a General Practitioner (GP) with complaint of loss of weight and I was sent to Homagama government hospital (GP told me that there is no TB in Sri Lanka anymore and it is eradicated now.) At the OPD in Homagama hospital a doctor told me that there was no problem with me and sent me home without testing me. So again I went to GP and he sent me to Sri Jajayawardenapura hospital where I stayed for one week and was diagnosed as TB". Similar experience was reported by a 40 year old businessman from Kalmunai who is a PhD holder. He had been suffering from a chronic cough 2 years back and was diagnosed as Bronchial Asthma by a private practitioner. Following

treatment for Bronchial Asthma he went to India for studies in October 2019 and returned to Sri Lanka in July 2020.After return to Sri Lanka, his cough worsened and he received over the counter medication from a pharmacist. Since, no improvement he went to a GP again where GP had asked him to check sputum. Then he had gone to a leading private hospital in Colombo, necessary investigations was not done. Since, no improvement, a doctor who is known to him had suggested him to go to Welisara Chest Hospital where he was diagnosed as a case of TB.

Majority of patients agreed that there was a significant delay in identification of TB status.

**Stigma & discrimination among health care staff**

One patient from Jaffna stated that he was stigmatized by the hospital staff in Jaffna hospital when he got diagnosed as TB. Apart from him, all other participants agreed that they did not face stigma and discrimination from health staff.

**Maintenance of confidentiality by health staff**

All participants agreed that health staff maintained patients' privacy and confidentiality. Nevertheless, when PHI visits their homes in his uniform they felt that everyone around gets to know about their disease status and feels exposed.

### 4.2.3 Socio –cultural barriers

All patients stated that religion and ethnicity were not barriers in TB diagnosis and treatment services in Sri Lanka.

**Occupation**

Occupation was mentioned as a barrier for TB treatment. One patient from Jaffna said that he works from 3 am to 8.30 pm and because of his work load he doesn't have time to seek treatment. During the weekend he has to go to Colombo for classes .Another female patient from Jaffna said "when I applied for medical leave for TB other staff in my office got to know about my disease condition. Now I am worried how my co-workers would behave towards me when I go back to work". A 35 year old Air Conditioner repairman from Colombo said "I cannot tell my clients about my TB condition as they will get scared and I will lose jobs. Outside people are

scared and they don't even drink from the same cup which we drink. We can't tell in public and, we can't tell our employer as we will lose my job".

A 20 year old male patient from Kalmunai who is a barber stated that "I'm taking TB treatment for 2 months. I did not go to the salon for last 2 months. Owner told me to that I need to completely cure my disease before coming back to work. When I go to work to talk to the owner, nobody came near me nor talked with me. I was given a separate plate and a cup to eat. I am worried that the owner might employ another person at the salon and I might lose work there. Still the owner has not informed me whether he keeps or removes me from the job".

### 4.3 Sub Group- Pediatric TB Patients

A 30 year old mother of a child aged 10 years with TB from Kalmunai stated "My child was admitted to Ashroff Memorial Hospital (government hospital) twice with fever and cough during last 2 months. Both times, chest x rays was not done and only basic blood tests was done. Then my child developed severe chest pain in the left side of the chest and I took him to a cardiologist at the private sector. The Consultant Cardiologist ordered a chest x ray and then he diagnosed my child as a TB patient. After that, my son got admitted to Ashroff Memorial Hospital (government hospital) and treatment was started. Following his discharge he was asked to attend chest clinic Kalmunai. I told my neighbors and relatives that I went to the hospital because my child is having a heart problem. But, a nurse from the hospital ward where my son was admitted, had divulged information about my son's disease to my neighbors and now no child in the school or neighborhood comes to play with my child. My child is so unhappy and cries at the night while telling me these things. My child and I both are in distress".

Three children diagnosed with TB from the Pediatric Chest Clinic Borella shared similar experiences. They were two girls and a boy aged 15, 14 and 12 years old respectively. All children stated that they had not disclosed their disease even to their best friend. It was a notable fact that, though the 15 year old girl child and 12 year old boy child were diagnosed as EPTB, they were scared to disclose their disease condition to their friends and neighbors. All three agreed that they were shocked to hear about their diagnosis as they thought TB is does not exist

in Sri Lanka and they did not have any idea that TB is a curable disease at the onset of their diagnosis.

A 27 year old mother of a child diagnosed with TB lymphadenopathy 2 weeks back, burst in to tears during the FGD. The family was in denial of the disease of their child as they though TB is no longer in the community. The mother thinks that the as the child played with sand from the construction site in their house , workers sometimes spit on the floor , hence the child caught the bug while playing with infected sand. Mother blames herself for letting the child to play with sand and feels that the rest of the family including her husband and the in-laws too blame her for the disease of their child. Furthermore, it was noted that pediatric chewable anti TB drug was out of stock for 2 weeks and the child was supplied with adult tablet and was asked to crush and give to the child. Mother complained that the 4 year old child refuses to drink the bitter, crushed medicine, empty stomach in the morning. Therefore, she needs the help of the father of the child to hold the child tightly until she forcefully input the crushed medicine to the child's mouth. The child cries out aloud and during the last week his behavior had changed. The child is restless, angry, quarrels with other siblings during the course of the day especially in the mornings. His 2 elder sisters who are aged 5 and 7 years respectively are stressed too. All three children throws temper tantrum episodes since the diagnosis of the younger child. This situation has affected the economy of the family too, as the child's father who is a lorry driver cannot go on long trips to earn his living as he is expected to be in the house in the mornings to hold the child while giving the medication.

Mother of a 7 year old child with Pulmonary TB, who is a nurse by profession, said that the family blames her for the disease status of the child as they believe that the mother brought the TB causing bacteria home from the hospital. Both mothers from Colombo Chest Clinic stated that their child's disease had affected their marriage as the blame for the child's disease is pointed towards them.

## 4.4 Community Group

Five Focused Group Discussions were conducted among 53 community members.

### 4.4.1 Gender Based barriers

**Geographical areas such as plantations, slums, rural areas**

Geographical areas such as plantations in the estate sector contribute as a barrier in TB care seeking and management. Community member from Rikillagaskada stated that "Estate sector believe that they will not get disease ( non acceptability).Due to lack of awareness about the diseases ,loss of daily wage, patients from estate sector will not go to hospital rather would take some home remedies and stay at home".

Different views were revealed from Community members from and around the capital, Colombo. A 42 year community participant from Colombo who is a president of a Community housing scheme said that, in the housing scheme where he lives that there are about 10,000 populations. So when someone gets TB can spread easily. It was the view of a another community member from Colombo, that almost about 30% eat from hotels outside and in Colombo specially in area such Pettah hotels use same cups and utensils. This may be the reason to spread in the community.

It was worthwhile to highlight a fact arisen in the discussion that, Sri Lankans are not scared about diseases due to less awareness of the magnitude of the disease. The best example is that even amidst Corona, large number of people are crowded and crushed in queues in clinics at National Hospital of Sri Lanka.

**Smoking, alcohol, illegal drugs**

The effect of alcohol, smoking and illegal drugs on TB diagnosis and management was mentioned by several community members during the discussion. Experiences of community members from estate sector were that alcoholics do not adhere with treatment and continuation of medication.

Community members from Colombo were of similar opinion regarding defaulters. The Community leader from a housing scheme in Colombo said that "I know three TB patients from the scheme where I live who are drug addicts. They do not take TB medication properly. They only take TB drugs for few days until cough subside and then stop medications. When they don't have drugs they come to the clinic .They abuse TB medication and use them as substitutes for Heroin when Heroin is not available. All 3 are males. I have not seen any female patients in the scheme. I don't know why? Maybe I see only males because I associate them the most. I see them near houses coughing and emaciated. May be women are there but I don't see them. Women don't go out of the house much, so may be TB female patients are there but we don't see them".

A 39 year old female Drug rehabilitation officer, from Colombo had the same opinion about drug addicts infected with TB, "Drug addicts who are TB patients come for treatment only when they are feeling very bad. Once they are better they go back to drugs. There is no follow up for these patients even by PHII. Most of them do not care about the disease and some say now it is time to die. Drug addicts never complete treatment. Drug addicts, when they don't have Heroin they go back to DCC and get anti TB medicine and use them as substitute. Drug addicts steal other medications from dispensers when they come to get medicine. They are very clever in doing that. I am 100% sure that drug addicts do not complete treatment. Duration of treatment of 6 months is the problem as if can introduce an injection then compliance will increase and stigma and discrimination will be more."

A 75 year old father of a Christian church from Jaffna stated that, in Jaffna area addiction to illegal drugs is becoming a major public health problem. Mothers in the area tend to neglect their children due to their personal work and many of them are searching for employment to overcome poverty. He feels that pediatric population in Jaffna is increasing as and drug addiction has become a huge problem.

All community members agreed that drug addicts are more prone to get infected with TB due to their nature of risky behavior and sharing of drugs among a group.

**Difference in health seeking behaviors among men and women**

Most of the community participants from Rikillagaskada mentioned that there is no difference between health seeking behavior among males and females in the area. Both males and females use remedies for cough for few days before approaching health care facilities.

However, a 52 year old female Child Development Officer from Dickoya, in Nuwara Eliya district feels that the health seeking behaviors is comparatively better among men when compared to females in Dickoya. On the similar grounds, a 35 year old female, a District Coordinator for a community organization agreed that there is a difference between males and females in regards to treatment seeking behavior. Reason for this difference is that usually when a female get a disease they take Paracetamol and avoid going to a hospital to get treatment due to household works.

However, few participants from the same area noted that default rate is higher among males; reason being according to their opinion may be stubbornness (does not listen to family/wife advice). They suggested that health staff can encourage a child in adolescence to provide regular medication to their fathers/family similar to the practice in Diabetes clinics in Nuwara Eliya district.

A different perspective is observed for children despite the gender. According to a 40 year old community member from Jaffna, when a child develops a cough parents seek treatment without delay. But when a parent gets a cough they don't bother about getting treatment due to household works.

**Marriage**

Community group participant from Colombo stated that she had come across couples during her marriage counseling sessions, who confine in her stating that " my wife previously had TB.I didn't know that and I got to know about it later. Now I don't have children. And I think it is due to my wife previously suffering from this deadly disease. I don't like to even look at her now. She is disgusting". She further stated that similar to COVID 19 quarantine completion certificate, TB patients do not get a nice card or certificate as a proof to declare that they don't have

TB this disease anymore. If they get such document it will aid patients to declare their good health status. She had many experiences where she has seen families being broken up due to TB infection both in the present and the past. She further stated her experiences where partners of TB patients feel disgusted by the present/ past TB status of the patient and ultimately leave the TB infected spouse.

Child Development Officer from Dikoya stated that "people fear that TB spread by generation to generation. If the grandmother had TB then it will be passed on to their children. The next generation also lives in fear. However I think a girl can marry once she cured from this illness."

**Access to free healthcare**

All community members agreed that both genders have equal access to health services. However, lack of bus fare and money for expenses during travelling is the main problem especially for women. Sometimes due to lack of money for transportation, women tend to wait at home until their disease condition becomes severe. Some women default clinic visits due to money problems.

It was of the opinion of the community group that "when symptoms get better, many patients stop medication. In addition, some think, after taking medication for a prolonged period it can lead to other diseases and side effects. People think like other Upper Respiratory Tract Infections, TB will also be cured after taking medication for few days. Lack of awareness about the disease is the main problem".

Some community participants mentioned that "DOT provision is a problem for the community as giving DOTs daily to a patient is a big commitment and it is a problem for their daily life.

A Child Development Officer from Dickoya stated that there is a need to educate and empower females to take nutritious foods. Women tend to eat leftover remaining food stuff following consumption of other members in the family mainly men and children. She suggests arranging screening programs and awareness programs during weekend or a time of the years where less tea leaves generation in the estate which is period where workers have some leisure time.

**Level of Education**

Community members from Kalmunai, stated that in some areas in Kalmunai where TB incidence is very high, level of education of women is very low. Therefore, awareness about TB is low in such areas.

Members from Rikillagaskada community agreed with this fact and stated" education level among women in the estate sector is very poor, which might be the reason for low awareness about the diseases"

**Gender Barriers in Treatment seeking**

A Child Development officer from Dickoya community, aged 37 years stated that though males are engaged in their jobs it is not a barrier for TB treatment. Currently both males and females occupy in various types of jobs to earn money for living and females have to put more effort to do their jobs when compared to males. This opinion was complemented by another Child Development Officer who stated that "Females think more about their family, children and expenses of the family. When the need arise for women to go to hospital, they need to stop all their normal day activities and domestic work. Most of the women cannot spare even a single day. They tolerate their symptoms until it become unbearable while doing the job. They work till morning to evening in the estates, some do overtime in the factory at night and even Sundays they are working. They don't like to get admitted to wards." However, other Child Development officers from the same community disagreed with this comment .It was their opinion that though females are engaged with household works they do not miss any opportunities for getting TB treatment. They agreed that normally working males present late for treatment and once male TB patient is asked to get admitted to a ward they think about job, income loss etc. This economic responsibilities lead men to miss their next visit.

District coordinator from a Community Organization, EXPO from Jaffna stated that patients are reluctant to come to hospital because they have to stay hospital for few days. Therefore, they seek treatment from private practitioners. Consultant Respiratory Physician in Jaffna usually admits the TB patient initially for first week to monitor side effects of anti TB drugs. The

Catholic father from Jaffna community stated that “females are engaged with other household work and they don’t have time to go get treatment for an illness. Therefore, treatment seeking among females in Jaffna is poor”.

**Gender Barriers in treatment continuation**

The Secretary of Hospital Welfare Society in Kopai hospital was in the opinion that males get defaulted more than females and alcohol and drug addiction can be the culprit for this situation.In addition, some males start their treatment from one place and then shift to another place after some time. Some male patients feel that they get cured after taking treatment for some period. These may be the reasons for defaulting.

It was agreed by other community participants from Jaffna that most of the patients do not prefer frequent hospital admissions which can be the reason for getting defaulted for treatment. In addition, it was noted that as the anti- TB medications are powerful and difficulty to tolerating may be another reason for defaulting treatment. In support of this view, the 75 year old Catholic father from Jaffna stated that as some of the males in Jaffna are addicted to drugs they tend to change their addresses frequently. Because of these reasons men tend to get defaulted where usually females continue their treatment properly.

### 4.4.2 Human Rights barriers

It was the general opinion within the community group that stigma and discrimination towards TB exist in the community, somewhat lesser than the past .The community is not aware of the disease burden, treatment availability and the fact that TB is a curable disease. “Most people don’t know about TB. So there may be more actual TB patients than this declared known number. People are ashamed of TB, unlike Diabetes and Hypertension .People are ashamed to even take TB allowance from the social services .Although awareness is there, people are scared about TB. Both Leprosy and TB carries stigma in the community.” Seven Child Development Officers from Dikoya, who provide DOTS to patients and engage in their activities voluntarily, stated that they have noted that there is fear for TB in the community. They feel that the society should not stigmatize patients as TB patient had a right to live freely in the society and they

should empowered to talk about their human rights. In most of the places patients' utensils are not used by others. So people feel ashamed and embarrassed. A former school principal from Rikillagaskada community shared an experience where parents not allowing their children to associate a child with TB/ or a child in a family with a TB patient. Children reject such child with TB /child with a TB patient in the family, even when treatment is available and such child becomes marginalized in school.

Majority of community participants agreed that as it is a norm to wear face masks at present, discrimination due wearing the face mask for TB patients is reduced. Previously when a patient wearing a face mask gets in to the bus he gets the attention, but now such patient do not draw special attention as everyone else wear face masks regularly. Previously people did not even sit near a patient who is wearing the face mask in public transport. Therefore, compulsory attire of face masks in public places has helped to diminish stigma and discrimination at large.

A 40 year old female Gramasewa officer from Dikoya stated that people do not have disciplines which should be taught since childhood. The community today don't behave properly even towards COVID infection which the authorities need to force them to put a face mask on. It's not the language, the problem but it is the disciplines. If we can increase the awareness on TB we can reduce stigma towards TB patients. Child Development Officer from Dikoya agreed on this view and further said that awareness on TB can be increased by showing films especially in Tamil language in the estates.

A male district coordinator from a Community organization in Jaffna agreed that there is lack of awareness on TB in Jaffna. When a person gets TB, society is not likely to keep connections with him. The way society treats TB patients leads them to default their treatment further. Nobody comes closer or talks to TB patients without fear. Therefore the patient feels alienated. Furthermore he stated while conducting media campaigns, it's better to use a person who had TB and who got cured following treatment. This will enhance the trust among people towards the TB program.

**Loss of right to adequate standards of living**

The view of Secretary of Hospital Welfare Society in Kopai hospital was that people from Jaffna do not have nutritious foods at their homes. Patients cannot tolerate strong TB drugs without nutritious foods. Patients receive a diet high in protein during their hospital stay. At Kopai hospital TB ward they provide egg, milk, twice a week chicken, fish, green gram, and cowpea and when they get high level of protein they can tolerate drugs. Lack of proper nutrition and intolerance to TB treatment are reasons for defaulting treatment among poor patients.

**Prejudice and Coercion**

TB is regarded as diseases of the poor and highly contagious in nature, while Diabetes is a disease of rich and non-contagious in nature. Sometimes relatives come to get the allowance as patients can spread the disease and officers in social services also prefer that relatives comes to take allowance due to fear of contacting the disease from the patient .

**Vulnerability**

Bed ridden patients and women of extreme age groups are less likely to seek treatment for TB. Community from Kalmunai stated that, in Kalmunai and Ampara, there are elderly women, living alone in remote areas, as their children had died during the time of war. Therefore, such people do not have anyone to take care of them. Some develop cough and lose weight and die without seeking treatment. Therefore, there may be vulnerable pockets in the population, where TB treatment facilities have not been reached.

**Myths and Taboos**

A retired principal from Rikillagaskada community stated that people believe that TB is hereditary and all types of TB are contagious in nature.

A Child Development Officer from Dikoya stated that in general, estate sector people initially tries out all sort of traditional remedies such as thovil, mantara, gurukam, nool bedili and when these doesn't work then seek medical help. People believe that these rituals can cure diseases such as TB. Their thinking pattern and behavior is largely affected by Indian teledrama.

**Structural gaps in health care services**

Community members from Rikillagaskada are of the view that "Patients are not aware about the available services in the government sector in Sri Lanka and people are more prone to go to private sector for convenience. There is a large time lag between onset of the disease and diagnosis of diseases, at most times, about 2 and half months or more. Furthermore, knowledge on TB among the health staff is not satisfactory .Most of them are not aware of the disease. .Investigation facilities are not readily available in most of health care facilities".

Community members in the Colombo group complained that "PHI or any officer don't follow up whether patient continue medication or not"

A child welfare officer from Dikoya stated that health education posters should be pasted not only in hospitals but also in community places such as offices of Gramasewakas, crèches like crowed places. Furthermore posters and leaflets should contain more elaborative art work and lesser wordings as person who cannot read can understand the pictures.

**Confidentiality**

It was the opinion of Development Officer from the Additional Secretary Office in Jaffna that violations of the confidentiality of patients occur at the time of receiving TB allowance.

The female Gramasewa Officer from Dikoya stated that it is difficult to keep the confidentiality in estates sector. Since, the whole community lives in close vicinity when a vehicle goes to the estate everybody come and gather around it. Everybody knows all information about the others and news spread easily among the estate population. Nobody go visit the house of a TB patient. They look at it from faraway keeping a substantial level of distance.

**Community Expectations**

The view of a 45 year old district coordinator of a community organization from Rikillagaswewa stated that most of the patients do not know that TB is 100% curable. Therefore, at the point of diagnosis, mostly patients become mentally and physically upset. Hospital and health authorities need to rebuild the trust and self confidence among patients.

### 4.4.3. Socio cultural barriers

**Religion**

Community members from Kalmunai mentioned that "Some Muslims believe that it is Allahs wish and thinks that it is beyond their control".

**Occupation**

Community members from Rikillagaskada stated that TB patients face problems invariably in their work place and in gatherings. However, at most times their jobs are not affected by TB status. Nevertheless, private sector, estates and garments do not grant leave for patients go to clinics.

A female Child Development Officer from Dikoya stated that they do not have any experience in incidences where TB patients had completely lost their jobs; it's for a short period until they complete the treatment.

**Social Support**

Gramasewa officer from Dikoya stated that "NGOs are doing the projects of their own need. They request data and reports from us. When we discuss with them we feel like that NGO s have the ability to help us but they don't do anything. There is lot of things which they can do to help TB patients, economically and physically. But they do not do that "

## 4.5 Health Care Worker Group

Thirty IDIs were conducted with HCWs.

### 4.5.1 Gender based barriers

**Geographical areas such as plantations, slums, rural areas**

Nursing staff from Rikillagaskada and Nuwaraeliya felt that people from plantation areas, which the majority are Tamils, face geographical difficulties in visiting to health facilities. They often visit their estate medical practitioner and gulp up any medication which he provides to them. Reason behind can be, less knowledge about the disease, language barrier and difficulties in attending clinics. There is a need to conduct mass awareness programs in estate. Despite any in-

formation given by the health care staff to educate them patients/ community, they do not have a clear understanding about the disease. Though nursing staff talk to them in Tamil language, (so language is not a barrier), it might be due to their low education level. Furthermore, estate population does not get leave when they are sick to attend health care facilities.

PHI from Nuwaraeliya district described the situation as "we provide DOTs via volunteer Child Development officers (CDO) who work at crèches in the estate sector who work in the estates. Patient who live at walking distance to these crèches arrive at this place in the morning to take drugs before leaving to their job. We issue drugs to CDOs for first 2 months. We visit once a month to this crèches and sometimes we visit twice a month as time permits. When CDO informs us about patients who default their treatment we inform the range PHI in the respective area. Sometimes range PHII is busy with their work. We continue DOTs service for whole 6 months to estate workers .When a patient with good education level like teachers, bank officers we provide drugs directly to them to be used by their own. They can continue treatment while keeping their dignity. When family members do not attend for contact screening, we normally inform the Thaliewer (leader of the estate) of that estate. These workers listen to the word of Thaliewer, not listen to our words"

PHI from Ampara had a different opinion "Ampara is an area with lot of paddy fields and patients engage in agriculture related activities. Most of them continue their medication and we invariably encourage them to take treatment. We keep contact numbers of one of their family members either their spouse of children and contact them when needed. Since most of them cultivate in their own land attending for treatment is not a problem to them".

**Smoking, alcohol, illegal drugs**

Alcohol usage in estate population is very high among both male and female population. PHI from Nuwara Eliya stated that "In Nuwaraeliya district males and females both drink alcohol daily. Major part of their earning spends on alcohol. They get paid according to the weight of their plucked tea leaves and roughly one earns around1000 rupees per day. However, due to their drinking habits and very poor money management skills, mostly at the end of the day they don't have money to travel to hospital".

Alcohol is the main reason for defaulting treatment among males .DTCO from Nuwaraeliya share experience as “as I can remember there was a family in Nawalapitiya. Husband who is a welder by profession and he did not take treatment properly. His wife had died due to an unknown illness and his nine year old child got TB too. He was a heavy drinker and addicted to alcohol. Main reason for defaulting of treatment among males is alcohol abuse.” PHI from Nuwaraeliya agreed with the fact and stated that “the main agenda of the day for most of the males in Nuwaraeliya estate sector is drinking alcohol in the evening. They do not care about our advices. They give more priority to drinking alcohol, than to getting treatment for TB”

Experience of doctors from Colombo is that smoking prevalence is higher among males in Colombo district. Hence, due to smoking TB may be naturally more prevalent among males than females.

Furthermore, experiences from PHI from Colombo states that “addiction to illegal drugs leads to treatment failure and can predominately be seen among males .Drug addicts infrequently miss clinic dates and do not adhere to treatment. Employment such as driving contributes further to treatment failure among males in Colombo district. ”.In agreement, PHI from Amapara states that “most male patients declare that they have stopped taking alcohol with treatment. Though, it is highly doubtful, on 95% of the times their children confirm that their fathers do not continuing alcohol”.

**Marriage**

Nursing staff from Nuwaraeliya stated that previously TB was a barrier in marriage where there was an incidence where a female patient committed suicide due to TB related problems in her marriage. Some husbands blame wives for getting the disease and scold her (saying got this by going around and getting out of the house). Nevertheless, nowadays TB is not a barrier for marriage as definitive treatment is available. There was an instance where the boyfriend/husband left the patient when she was in a critical state. Nowadays few patients face problems in marriage, but most of them take care of the spouse despite TB infection. In agreement, PHI from Dikoya stated that in Poodaluoya area there was a couple where a deaf and dumb female was married to an ordinary man. Later on when the husband got TB, the wife though deaf and dumb

left that fine, ordinary man." DTCO from Kalmunai stated that some of the patients were asked to stay out of their house by the family until TB is complexly cured. There were instances where some husbands live in a temporary place outside the house or some sleeps in corridors. Meals were provided outside of the house for the patient. It is sometimes not due to lesser affection by the wife, rather practical problems such as houses are too small to provide separate lodging for the TB infected husband.

PHI from Nuwara Eliya gave a different perspective with regards to marriage in the estate sector. He states that the culture is different in the estate sector in comparison to other places. Most males don't have a formal family life. They like living together as a couple without consummating marriage. There are 172 estates in Nuwaraeliya and some of the males have the habit of living together with one female from one estate for some period and move on to live with another partner in a different estate. When such people default treatment we, find great difficulty in locating them. Even the wife of the given address does not know the whereabouts of her husband/civil partner. Most of them do not care about their family life and it's not a problem to females as well. Number of divorce cases is lesser in the estate community due to this reason.

**Difference in health seeking behaviors among men and wome**n

Health care staff in the Nuwara Eliya were in the opinion that, among people who come to OPD most are women, while among patients who are suspected or diagnosed with TB most are males. The reason behind detection of more males among diagnosed and suspected TB patients is due to their habit of smoking. Smoking and its complications and associations of smoking such as smokers cough and COPD can mask symptoms of TB. But for female patients chronic cough is not a common symptom, so they present to hospital early. Furthermore, when a woman falls ill they do not seek medical treatment until they become very sick, some stays for months and months until they are very sick. Men have lesser level of tolerance, so for minor symptoms men present early while women tolerate a present late to health facilities. Nursing officer at DCC Nuwaraeliya for 5 years shared her experience as " women present late may be due to their house hold work. Last week 22 year old female patient died after 1 day of starting treatment. She

was only 22 kg in weight, we could see when she came she was not well, OPD referral, we did sputum check immediately and started treatment. But she presented very late to us".

PHI from NuwaraEliya shared his experience as "when they start treatment after for 2-3 weeks they feel comfortable. Large majority of males and females in Nuwaraeliya work in Colombo. Once they complete 2-3 week treatment they do not inform to us, they just disappear to Colombo, we don't know what happened to them. Once the condition become worsens with lot of difficulties they come back to us. Eighty percent of patients living in Nuwaraeliya have a history of working in Colombo at some period of their life time. In 2019 there were 3 female patients who left for Colombo by interrupting their treatment and we were unable to trace them back". Furthermore "Some males ask us to issue all the drugs at once as they want to travel to Colombo for the jobs. Most of the time males are the ones who interrupt treatment. Majority of female adhere to treatment. Occasionally some females make arguments with CDOs".

Furthermore, PHI describe the effect of the leader of the estate over treatment provision in patients as, "we have a Tamil speaking HCW who provides health education to patients who cannot understand Sinhala. At one occasion, though he instructed a male patient to take the 4 tablets at same time in the morning in Tamil the patient kept on taking only one tablet in the morning, one in day time, one in the night. When I visited the patient on a regular DOT visit, I realized that some tablets were left with this patient. When I inquired from him the reason for leftover tablets, he disclosed the way he used to take tablets and admitted that at times he forgets to take a tablet at daytime. They are not obeying our instructions. He said "Thaleiwar" who is the leader of the estate; instruct him to take tablets in that way. They don't care us. They are work according to the "Thaleiwar".

In Colombo, treatment adherence among women is more satisfactory in comparison to males. However, barriers due to family commitments are commonly seen among fameless which obstructs them and prevent them from reaching health care facilities.

According to DTCO from Ampara, most of the male's patients who attend their clinic continue treatment without many interruptions. There are males who were used to drink alcohol prior to start TB drugs. But once they start TB treatment, every one of them stopped alcohol

consumption and continued TB medication properly. There are some patients who have stopped alcohol consumption permanently. All the females in Ampara continue treatment properly.

However, according to chest clinic Medical Officer from Kaluminai chest clinic, few problems have arisen among TB patients from the locality who was engaged in agriculture related jobs. Since they were daily paid workers, some days they had to travel out of the area to earn their living. Due to this reason, some patients are reluctant to take daily DOTS. Hence, in Kalmunaie daily DOTS are not practiced regularly. We issue drugs for 1-2 weeks at a instance according to the level of compliance of the patient. If the patient has a good level of drug compliance, then we issue drugs for 2 weeks. When a patient fail to attend clinic after 1 week of commencement treatment we immediately trace them .However, at the moment we provide strict daily DOTs for 2 patients unless which they would default without doubt. Earlier we had 46 DOT centers in Kalmunaie. However, none of the centers are functioning properly at the moment.

**Access to free healthcare**

Patients from estate sector face issues in regards to access to health care facilities. It is mostky due to presence of mountainous areas and poor transport system. PHI from Nuwaraeliya district shares his experience "there is a estate called "Maraiewatta" close to Adams peak, Nallathaniya situated in uphill. When a patient from this estate needs to attend Nuwaraeliya chest clinic at 9 am he has to start his journey at 3.30am from his home. He came only once and did not come to give his sputum for 2$^{nd}$ month or for chest x-rays on a separate day. Therefore, we had to send ambulances to his house. Our Ambulances could go only up to Nallathaniya and we had to walk 5-6 km on foot to reach his home. Even though we provided drugs , collected his sputum and performed portable chest x-rays once, thereafter either he has to visit chest clinic know or one of us have to climb the hill to collect his sputum. Sometimes we forcefully bring the patient down". He further added another situation where,"there is another place called "Kotthallena" situated close to the "Sapthakanya" mountain. In that area one patient died from TB due to treatment interruption. He went to Colombo following default and we couldn't trace him. When we received the news that he returned back to village we visited his home, but alas! His funeral was

going on! No vehicle can go in that road leading to his house. It's very difficult to even to walk in those roads"

Chest Clinic Medical Officer from Nuwaraeliya stated that "there are old women in the villages, remote areas in mountains who a had been coughing for some time, severely emaciated but no care giver to take them to hospital. Therefore they suffer and die, we don't know if it is due to TB or not". PHI from NuwaraEliya furthermore added to this comment as, "in Nuwaraeliya district more than 50% of the patients face problems in access to treatment facilities. There are places even we cannot reach by our office vehicle, when we go for provision of DOTS. Some houses are situated in the hills while some doesn't have a proper road. Some times when a patient doesn't have access to get our facility we send an office vehicle to them and somehow collect their sputum investigations and Chest x-rays. Some patients live in estates in Nuwaraeliya, and within these estates big buses does not function .Small vans, three wheels and lorries are used for transportation of estate workers.

PHI from Kalmunaie mentioned about areas with lesser access to health care facilities within his territory. There are some remote areas in Kalmumai, where there are no means of public transportation. There is an area called "Central camp" where only one or 2 buses are run in from the Kalmunai center back and forth for the whole day; one bus travels in the morning and the other in the evening. We have arranged DOT center in that area where a nurse from the closest divisional hospital or a midwife acts as the DOTS provider. Currently we issue drugs for the initial two months through the DOTS provider. However, since the defaulter rates are high in these areas we find difficulty in DOT provision.

Similar limitations in access were reported from Amapra "There are 2 places in Uhana area like that. When they travel 1km distance they will get a Bus. They can even travel in a bicycle".

**Level of Education**

Level of education among women in estate sector is relatively very poor. PHI from NuwaraEliya recalls his experience as "depending on the weight of the patient, number of tablets is varying from one patient to the other. Some patients have to take 4 tablets per day. Their literacy rate is so low that when we inquire about the number of tablets they take per day they count fingers and

show us. When we instruct them they listen, but they cannot keep important things in their memory and forgets easily. Even when we inquire about the number of members in the family they show by counting their fingers. They are having very low literacy rate. I do not agree on the statement that language a barrier. When we explain them in even in Tamil language they don't understand. We used to explain things via a person who was fluent in Tamil but was not helpful in their treatment adherence."

PHI from Colombo shred his experience about workers who lift goods "natthami" presented with most of the time no primary level education and concurrently poor treatment adherence.

However, it was worthwhile to note that most patients from Amapara district who are invariably farmers by profession though having low level of education attainment, they obey to instructions of health care team and they get a very good family support as well.

**Taboos and myths**

Taboos and myths persist in the estate sector predominately. Most of them believe TB is hereditary in nature, and also many believe that TB is can spread by cloths and believes in demonic presence in the causality.

**Difference in treatment adherence among men and women**

PHI from Nuwaraeliya explained that "almost all defaulters in the area are males. Females are scared to discontinue treatment. Once we explain about treatment females usually continue it. But males give various excuses for not continuing treatment such as going to Colombo or any other faraway places". In addition, ,males invariably default their treatment due to occupational related factors such as transfer from place to place, alcohol addiction and not caring for advices given by health care providers.

Chest Clinic Medial Officer from Nuwara Eliya who had served the area for 4 years agreed on the statement given above. However, he recalls that in the year 2019 there were 3 females who went missing after for 2$^{nd}$ month and 5$^{th}$ month sputum clinic visits respectively. They were grandmothers in their late seventies and did not care for advice of the TB management team.

Later, the doctor had to spend his personal money to get them down to the clinic for completion of treatment.

DTCO from Ampara gave a notable fact that females from Ampara, who majority is of Sinhalese's ethnicity, invariably attend the chest clinic accompanied by another family member. Thus, such accompanying family member is an encouragement agent so that they continue the treatment without interruption. Lose of daily wages due to attending chest clinic is not a problem for TB patients from Ampara area. Furthermore, women intensively listen to medical advices given by the health staff.

Similar picture can be seen from Kalmunai where, the percentage of treatment adherence among females is satisfactory. Similarly, they have adequate money as most of them work in the paddy fields and earn their living.

**Delay in presentation**

Delay in presentation to health care facilities is invariably higher among males. PHI from Rikillagaskada stated that many of the men from area are alcoholics and most of them travel to Colombo for their occupation. According to his experience "these estates have Estate medical assistants (EMAs).Estate workers usually seek treatment from them for minor diseases and alignments. Main income of these health workers are through private practices. Since they want their daily income running on, they do not refer TB suspected patients to hospital or proper health care facilities. EMAs keep on treating suspected TB patients with symptomatic treatment for a long time without refereeing them to a proper place in order to continue earning their income. Therefore, these poor patients present to chest clinics late with worsened symptoms. There are some good EMAs who refer patients early to chest clinics. There was an instance where one EMA had been treating a 30 year old female TB patient for 1 and half years. She presented to us with severe form of TB infection and died immediately after commencement of TB mediation by us. We have trained EMAs recently."

Chest clinic nursing officer recalled an unfortunate event where the recent death of a 22 year old patient named "Priya". "Last Monday she came to our office to give her sputum. She was an

emaciated girl who weighed only 22 kg!. On Tuesday we saw that the result was positive. I asked her to attend to the clinic on Wednesday to start treatment. She took the treatment for one day and died on Thursday. She has gone to several places for treatment before coming to chest clinic". Delay in presentation is evident in Ampara and Kalmunai . Most of the patient present in delay. We were found cases that have delay 8-9 months", explained by DTCO Ampara.

### 4.5.2 Human Rights related barriers

**Stigma and Discrimination**

The majority of HCWs interviewed in the present study stated that stigma exist in the community at large scale. However, it was a common agreement that there is absence of gender preferences when it comes to stigma and discrimination towards TB in the community. Many agreed that one good thing due to Corona infection is that as everyone wears masks in the society, TB patients do not feel stigmatized as before.

A 60 year old medical practitioner attached to Chest Clinic Colombo disclosed that, he could give many examples where TB patients get discriminated in the community. He said that in one occasion, 17 year old female patient was severely discriminated by neighbors where she felt greatly ashamed and humiliated that she couldn't even come out of the house where she tried to commit suicide . More than 50% of cases patients are separated in the vicinity of their house and given a separate room. Stigma is greatly seen in Colombo and suburbs, which lead to wide array problems including school/ Montessori admission of children from TB family, work place discrimination in some government work places etc.

DTCO from Kalmunai was in agreement with the fact of existence of stigma and discrimination in the community. He stated that social stigma is high in Kalmunaie and patients confine in him that when neighbors get tom know about their diseases condition they refuse and meal/food/drink or even water from the patient's house. The patient's house becomes isolated in the community. There were patients who said that they are unable to attend chest clinic because their daughter's wedding is arranged and if the other party gets to know about patient's TB condition the marriage proposal would break off. Some patients even hide their disease condition

from their spouses in the fear of being discriminated. He feels that stigma is higher among Muslims and Tamils in Kalmunai area in comparison to Sinhalese population. There were some incidents where patients were asked to leave their houses due to TB among the Muslim community.

Doctor from Nuwaraeliya reported that patients confine in him that when a person daily attends to a DOT center in a village, the neighbors get suspicious about "why this person attends to this place daily?". In one instance in a DOT center in Nuwaraeliya when the villagers got to know about the disease condition of the patient, he wanted to change the DOT provider as he could not stand the stigma and discrimination he faced in his locality.

PHII from Nuwaraeliya district have similar view on stigma and discrimination .They recall many instances where TB patients were marginalized in their locality. One incidence was in Kalawadeniya village where both a school boy and his father suffered from TB and villagers discriminated the family, even village priest. Nobody in the village agreed to be a DOT provider, hence home DOTs had to be given for them. However he felt that stigma and discrimination is more prevalent in the Sinhalese community in comparison to Tamil and Muslim locality. Muslims are more open and discreet about their disease. However, there was an incidence in 2017, where in a Tamil family the wife left the husband when husband was diagnosed of TB.

PHI from Ampara recalls an incidence where one patient was adamant to continue his TB mediation without informing his wife. Therefore, the range PHI had to arrange a separate screening programme in the area to cover up the whole family of contacts without informing about the patient.PHI from Kalmunai staed that there are times that PHI visit patient's house without uniform as patients are reluctant thinking that their neighbors will find out if PHI visits in their official attire. He feels, somehow there is no gender difference in stigma.

**Prejudice and Coercion**

PHI from Colombo Chest clinic stated that children do not like to keep their parents who are suffering from TB in their houses. Therefore, it had become a great social issue for elderly TB patients in Colombo district.

**Poor infection control and vulnerability to infection in health care settings**

It was the opinion of OPD medical officer from Rikillagaskada District Hospital that "Although triage is done in OPD I feel that probable cases may be missed at the OPD due to high turnover and number of patients. No mechanism to trace whether patients detected in the OPD has gone to DCC or not. Patients complain that when they were given a cup for sputum sample, health staff did not provide enough information to them".

**Loss of right to adequate standards of living**

DTCO from Nuwaraeliya stated that according to the patients leave granted to them is in adequate. "Usually government servants are given 3 months of paid leave (28 X 3) and after that we refer them to a medical board. Another complaint from patients was that the monthly allowance of 500 rupees given to them not adequate even to cover their transport expenses. Some district provides 5000 rupees per month as TB allowance. I hope go get the allowance increased up to Rs 5000 rupees for patients from Nuwaraeliya district as well. One of my friends from Kandy said they had given a proposal to governor to increase this amount and I shall do the same "

PHI from Ampara stated that In Ampara patients get Rs 5000 per month for 6 months. However, some patients refuse this allowance assuming that Gramasewa officer of his area may divulge his disease condition to the society.

**Myths and Taboos**

Nursing officer from Nuwaraeliya stated that "Hindu people engage in ritualistic activities like yaga homa and hadihooniam. However, these rituals are less common among Sinhalese and non-existence among Muslims. Quacks who trick people by saying will cure disease by booth balawega are there".

**Inadequate conditions in inmates and detention facilities**

According to PHI from Colombo, high risk areas such as slums and prisons get adequate TB services. However prisons are overcrowded, thus increase the spread of TB

**Structural gaps in health care services**

Matron from Rikillagaskada states “I have seen only one TB patient. I do not see very serious TB patients getting admitted to ward. This may be because of good diagnosis system patients are less presented to the wards.”

Furthermore, nursing staff from Nuwaraeliya shares their experience as “There can be delays in OPD due to high work load and these days due to fear of COVID 19 people with cough does not present to hospital, they stay at home and take remedies for cough. But once they come to DCC we immediately check their sputum so there is no delay”. She added further that , the Diagnosis of TB invariably get delayed in incidence when patients do not directly come to DCC doctors in many private and government places lease suspect of TB and referrals get delayed as health care staff in those places are not aware about TB”.

It was the opinion of the chest clinic MO in Nuwaraeliya that since inevitable delay happen in OPD system, a direct link between OPD and chest clinic should be implemented. In Nuwaraeliya there is roughly around 500 m distance between Hospital OPD and Chest clinic. When patient is referred to chest clinic from OPD, the patient has to walk on foot this distance. When an inward patient in the hospital was ordered for a gene expert sample, gene expert facility is within hospital microbiology lab. But that sample has to go to registration purposes to chest clinic prior to the investigation at hospital. Digital Xray facility is available at chest clinic, but due to technical error until it is being sorted out patients are sent to hospital for chest x rays. Presumptive TB patient’s referral from the OPD is currently not done properly.

PHI attached to Nuwaraeliya chest clinic further complemented this statement as “currently we receive 0.5% of OPD referrals to chest clinic. We should get at least 2 % of OPD referrals. Nowadays we arrange ring surveys around newly detected patients’ residence. Normally these screening programs are being carried out during the weekends because these estate workers do not like to miss their 1000 rupees salary. Hence, the collected sputum samples will be checked at the chest clinic on following Monday. Often the results are negative. But when we repeat the sample by asking the patient to come to chest clinic and give their samples then the result becomes positive. This type of incident occurred in Gorokoya area. We suspect that the error in

sample may be due to the time gap between sputum collection and microscopy as well as some problem occurs while carrying in our vehicle. In addition we get low number of referrals from GPs. During the first quarter in 2020 only one patient was referred to us from a GP .We have noted that around 60% of our patients had gone to GPs prior to coming to us. Most of the GPs accept that they do not refer any patient to us. We have conducted numerous amounts of awareness programs for GPs in our locality, however still they do not refer patient to us. Even for suspected cases GPs give symptomatic medication and send them to home without referring to us for an x-rays.

PHI from Ampara stated about treatment delay with regards to NTRL. Weekly, Ampara, Samanthuraei and kalmunaie Chest Clinics collect sputum samples for culture send to NTRL,Welisara. The vehicle from samples from all 3 places and leave to Welisara on every Friday. Some occasions, due to lack of vehicles, sputum samples are being kept at the clinic for more than 2 weeks after collection .When we handover one culture bottle to the Welisara lab, they issue a new bottle to the chest clinic. Therefore, there are times that culture bottle are not available in the clinics due to one to one replacement mechanism opted by the NTRL. Furthermore, he added that during some months of the year referrals from central dispensaries decreases, though DTCO visit these central dispensaries and aware them. Similar situation is observed among several GPs in the area. Lack of awareness through TV advertisements is a great obstacle in enhancing awareness on TB.

DTCO further described the situation as he pointed out the fact as there are lesser number of patients to GPs in Kalmunai area, they tend to keep the patients by giving a cough syrup or salbutamol. GPs do not like to refer patients to a proper place as it will affect their income. He added further that in Kalmunaie district there are 7 base hospitals situated close vicinity and rectified the matter stated by his PHI on sending sputum culture samples to NTRL Welisara. He is doubtful on the status of live bacilli in the samples when reaching Welisara as there is a delay in sending samples following collection of 1-2weeks.He is of concern on the reason for getting most of the culture samples which they send as negative samples by NTRL. His concern is further complicated by the decision of Consultant Respiratory Physician in Kalmunaie. The

consultant does not prefer community screening as it is his opinion that if the patient is symptomatic they will come to the health sector. He questions the need "why we want to increase the number of cases by doing unnecessary investigations?" The overriding the authority of DTCO by the Consultant Respiratory Physician of the area is a great concern in Kalmunai which has affected TB screening services in the district.

DTCO Kalmunai faces many administrative issues too. He complained that the medical Administrators in Kalmunai give priority to physical improvement of the hospital e rather than trace defaulters. Medical authorities in variably try to send PHII attached to Chest Clinic to various other duties. Lack of a permanent radiographer is a systemic problem as the covering up radiographer from BH Samanthurae attends for 2 hrs per 4 days in a week. Patients who come in other 2 days to the clinic or in the afternoons do not get access X ray facility.

**Stigma & discrimination among health care staff**

There have been no complaints on stigma and discrimination of health are staff to DTCOs and matron in the hospitals."When I came to this job I was scared to TB. Those days I was staying away from the patients. Now I don't feel any difference "as mentioned by PHI from NuwaraEliya.

PHI from Ampara shared his experience about a 75 year male patient who had interrupted TB treatment for 1 and half month. The patient refuses to accept the fact that he is having TB as he still has the energy of a bull. When he went to the hospital to get treatment he was not provided a bed to stay. Hospital staff told him that they can get TB from him and ask him to stay at a separate area. He said he was harassed by the hospital staff. He running a tea shop of his own and it was ultimately closed due to illness. People in the area stopped coming to his boutique following knowing he had got TB. After that incident he doesn't like to continue treatment. According to him, information was leaked to the village through the hospital staff. Though PHI has visited his house several times and explains the situation to his children still the patient does not listen and default the treatment. PHI had encouraged him to Rs 5000 per month allowance from social services. Ultimately range PHI of the area accepted to provide DOTS to him.

PHI from Ampara stated that they maintain the confidentiality and dignity of the patient. "Normally prior to house visit we collect all the information from the patient whether he like us to pay him a visit at home, the directions to go to the house without asking anybody from the area, color of the house, landmarks, color if the gate, whether we can come in uniform or not. By this war we can protect the privacy of the patient. If the patient request from us doesn't come to their house then we will not go to that place".

Nursing Officer from Nuwaraeliya stated that hospital staff does not stigmatize TB patients at the ward. A matron working in the medical word in Rikillagaskada DH stated that "when we suspect a person as a patient with TB, we isolate him/her the ward and give a face mask. Most of the times the patient feels discriminated. But when we explain the reason to them, some understand this but some people mentally becomes low even after when we explain. There is no stigma from staff towards TB patients. There have been no complaints from patients even about minor staff"

**TB in health care staff**

Matron from Rikillgaskada states that "If pt is allowed by doctor and she is well enough to work while continue medication there is no problem. She will not be discriminated by staff as a matron I will help her by giving an easy appointment .We had one midwife with EPTB, which no troubles were arisen. Nevertheless, we had to face some difficulties at the time when one nurse in the hospital was diagnosed with TB. The particular nurse refused to wear a face mask, hence other staff got worried. We anyway conducted a mass screening for the staff and no one found positive"

**Unequal access to treatment**

Unequal access to treatment services were identified as stated by PHI "Some of the patients living in Nuwaraeliya request to take drugs from Colombo due to easiness of doing their jobs. First 2 months in the intensive phase we don't transfer patients to Colombo. Depending on the behavior of the patient when we feel he has good treatment compliance after 2 months of treatment, if the patient is strongly requesting, we take actions to transfer them to Colombo chest clinic".

**Keeping Confidentiality at health sector**

PHI was certain on maintaining confidentiality of patients "We don't leak any personal information of patients to outside. But when RDHS office request data we will provide them. All our health assistant staff is worked here for 5-6 years. They knew very well about this."

"During our training period we were taught that don't go to the TB patient house first when we do the field visit. First we visit 2-3 other houses and then go to the TB patient house. Then the village people will not suspect particular patient and particular patient not getting stigma".

Sputum collection booth is in a very busy place where lot of people move around with so privacy of patients who give sputum sample is not maintained.

Villages such as Padukka, more concern about confidentiality. But in CMC area not bothered about confidentiality. To maintain confidentiality of contacts PHI visit in normal clothing. There was an occasion that university student had to leave private boarding without maintain confidentiality. Contact tracing becomes difficult as contacts are not disclosed properly due to confidentiality issues.

**Reluctant for contact tracing**

DTCO from Kalmunai stated that there were few problems arisen during contact screening where the patient doesn't divulge the information to their spouses.

### 4.5.3 Socio- cultural barriers

**Religion**

Estate sector population predominantly consists of the Tamil population. Since they live in closely approximated houses which are adjacent to one another in the estates known as "line rooms" ,contagious disease such as TB spreads with ease within this locality. However, DTCO Nuwaraeliya stated a different opinion "There is generally no cultural barriers in Nuwaraeliya".

PHI from Kamunai stated that he doesn't have any information on cultural barriers among Muslim society on continuing treatment .Most of patients from Samanthuraei, Kalmunaie areas

are Muslims by ethnicity. DTCO from Kalmuani mentioned that some Muslim patients do not listen to health care staff when we ask them to use the tablets properly or when we ask them to put mask at their homes. They say that everything is happening according to the wish of the god.

**Ethnicity**

Stigma and is more commonly seen among Tamil population and difficulty in contact tracing more commonly seen among Tamils. In comparison, stigma is comparatively less among Muslims, and most of the time they bring all of their contacts for screening. The probability of TB spread among Tamils is higher because they live in line rooms which are crowded to ether, poor ventilation. EPTB is more commonly seen among Sinhalese. Tamils do not care much about diseases, they think that they live for little time, marry early, have children and die. So health seeking behavior is less among Tamils so I think Tamil people present to health facilities later than Sinhalese people.

In Nuwaraeliya, majority of patients are Tamil speaking people. Some of our health staff is fluent in Tamil. There is a language barrier between Sinhala speaking HCWs and patient on some extent. But we try our maximum to explain them on treatments and follow-up by get help of a translator.

Chest Clinic Medical Officer from Nuwaraeliya stated that Sinhalese population doesn't like to disclose that they suffer from TB. When we disclose about heir diseases condition, most of Sinhalese patients start to cry but Tamils do not cry on disclosure.

DTCO Kalmuani stated that" Disease spread is more among Muslims because their health seeking behavior is low. Treatment adherence is low among Muslims and Muslims live in crowded places, kids more, so disease spread is more".

**Economic factors – poverty levels, transportation**

In the plantation sector TB is a common disease entity. Therefore, normally people do not lose their jobs. But lose daily wages when attending clinics or treatment which is a great economical problem to the patient. People don't like to disclose to employment in the fear of losing their work due to their illness. According to PHI in Nuwaraeliya bringing all contacts for contact screening an economical burden on poor patients from the estate sector due to money and loss of

daily living. Money, transportation, distance to health facilities and loss of daily wages is a problem. People don't have money for bus fare even, when we ask them to fill out income column some starts crying as no income, mainly these days due to COVID situation. When we ask to bring contacts, sometimes per contact expenditure is Rs 100 rupees and to bring 10 contacts you need Rs 1000 rupees, though we ask them to bring contacts, they can't bring them as they don't have money with them. Estate workers ask for a clinic date immediately after their pay day of the factory. "There was a daily paid driver in Nuwaraeliya. He was scared of losing his job, because of that he was not attending for treatment" .Males and females equally engaged with a job due to poverty in Nuwaraeliya estates.

Economic factors, level of education matters a lot .In Colombo among "Manning" market laborers, drug addicts treatment interruption is very high.

In this estates SIM cards are provided free of charge. Therefore the patients tend to change their phone SIM cards frequently. In an emergency we are not be able to contact them due to this problem. Most of the time phone numbers get changed by the time they come for their 2 month sputum conversion.

PHI from Nuwaraeliya reports employment as a main barrier in TB treatment "when we ask from them why you have not attended to the clinic on particular day they said that they don't have money. I'm not agreed to that doctor. We are giving them a social allowance of 500 rupees per month. They can use that for travel to clinic. Some of them use that money to bring food to the house. Most often give my own money to attend clinic. Nevertheless, they default clinic visit despite us giving them money. Therefore sometimes I feel that it's their behavior problem and not due to lack of money". In addition PHI stated that "usually when estate worker get TB the estate owner tried to keep him in the job. But we asked them to refrain going to job for at least 2 month period. I don't know about whether they getting salary r not for that period".

PHI from Colombo Chest Clinic stated that employment is a barrier in TB management." mutta kara gahan aya", daily wages people can't come to take medicine due to loss of income. Therefore, PHI tries to decrease default by giving medicines to them at their homes.

**Family support**

It was the opinion of health staff in Rikillagaskada, Nuwaraeliya that the family support for TB patients was not satisfactory .In comparison to Sinhalese population ,Tamil people don't have much family support.PHI –Nuwaraeliya further stated that "there is one male defaulter at Bagawanthalawa hospital who has been taking inward treatment for 6 months. Earlier to his admission he had defaulted TB treatment for several times. Though he has a house he and his wife lived separately for last 14 years. His wife does not take him to inside of the house. He used to sleep outside of the house and in the morning again go to the town for manual work (lifting goods).He is addicted to alcohol. That is his life".

# Chapter 6 :Discussion

## 6.1 Gender based barriers

### 6.1.1 Geographical areas such as plantations, slums, rural areas

It was the opinion of HCW group that geographical areas such as plantations, slums, rural areas enforce as a gender based barrier in TB care provision in the country. Geographical location in the estate sector renders transportation difficulties. Lack of proper road system, convenient and comfortable modes of transportation to health care facilities are few of contributing factors for geographical barriers in TB outreach services. Gender is risk factor since; females find it more difficult to climb up and down in mountainous areas and women are further burdened with security issues in travelling alone in these remote areas. Remote areas with low population density lead to isolated communities which are seen in the post war era in the Eastern part of the country. Lonely old women with no families render in these pockets and often do not have means of approaching health care facilities. Hence, it was the opinion of community members from rural areas that such patients may be dying of TB without proper diagnosis and treatment.

### 6.1.2 Smoking, alcohol, illegal drugs

Alcohol, smoking and illegal drugs in an isolated and combined can act as barriers in TB diagnosis and management as perceived by community members in the study population.

Experience in community members from estate sector was that invariably alcoholics do not adhere with TB treatment and continuation of medication. Perception of community members from Colombo was that male drug addicts invariably default TB treatment and often misuse anti TB drugs as substitute for illegal drugs .Similarly, it was the opinion of the Community group from Jaffna, that rising threat of addiction to illegal drugs associated with neglect of children due to female employment might be barrier in TB treatment in the future. It was the unanimous agreement that drug addicts are more prone to get infected with TB due to their nature of risky behavior and sharing of drugs among a group.

Perception of the HCWs on the current issue was that diagnosis of TB among men can be delayed due to smoking and related complications such as smokers cough and COPD. Alcoholism is accompanied with treatment non adherence and ultimate treatment failure among TB patients. Alcohol intake is predominantly seen among males; however, there are reports on female alcohol consumption from the estate sector in Sri Lanka. Factors such as cold weather, less educational level, low social expectations facilitate to alcohol intake in the community.

### 6.1.3 Difference in health seeking behaviours among men and women

The general opinion among the TB patients in the study group was that gender based difference in health seeking behavior exist in the community. Female patients described an inevitable delay in presentation to health care facilities due to their domestic and child rearing responsibilities. Most of the male patients agreed on this opinion stating, that seek for medical treatment is poor among females , due to their household work and lack of money for transportation to health care facility. In comparison, men have easier accessibility to health care facilities due to their social and economical freedom.

However, majority of the community members in the study group were of the opinion that gender is not a barrier for health seeking behavior among males and females in the area. They felt that both sexes use remedies for cough for few days before approaching health care services, except for female Child Development Officers from estate sector had a different consensus. They were in the opinion that time between onset of symptoms and presentation to health care facilities was shorter among males in comparison to females, however, the defaulter rate is higher among males; reason being according to their opinion may be stubbornness (does not listen to family/wife advice) .

A different perspective was observed for children in spite of the gender. Parents/careers immediately seek medical treatment for a child with minor ailment such as cough where as adults at most times do not bother to seek medical attention due to domestic responsibilities.

It is noteworthy that HCW group in the current study was in the opinion that perceived delay in presentation to health services exists predominately among females in the community. This may be a result of domestic responsibilities, high level of pain threshold and monetary difficulties such as money for transportation and expenses. Hence, males present to health care services at earlier stages of diseases in comparison to women who present fairly late to health facilities .Difference in opinion was found among estate sector HCWs in the study sample who described that among OPD attendees most are women, while among patients who are suspected or diagnosed with TB most are males. The reason behind detection of more males among diagnosed and suspected TB patients is due to their habit of smoking. Smoking and complications and associations of smoking such as smokers cough and COPD can mask symptoms of TB. But for female patients chronic cough is not a common symptom, so they tend to present to health care facilities earlier than men. Furthermore, men have lesser level of tolerance, so for a minor symptom a man present may present earlier, while a woman tolerate for a longer period and present at late stages of the disease.

### 6.1.4 Lack of awareness about the disease

Lack of awareness about the diseases was a major finding in the present study. Many patients in the study sample were not aware about disease pattern, burden and current treatment for TB in Sri Lanka. Many patients were not aware on availability of IEC materials .Language barrier, owing to majority of available IEC material are printed in English language, was an added barrier for patients from Tamil speaking areas and rural areas.

### 6.1.5 Limited access to health care services

Gender based disparity in access to health care services was mentioned by patients in the study group. Patients from both sexes were in favor of provision of prioritized service to women in health care facilities to address the delay.

Majority of community members were in agreement that both sexes have an equal access to health care services. However, women are often faced with lack of bus fare and money for expenses for travelling to health care facilities and subsequently women present to health care facilities at severe or terminal state of their disease condition.

.Community members from estate sector proposed arrangement of screening programs and awareness programs during weekend or a time of the years where less tea leaves generation in the estate which is period where workers have some leisure time as a solution to increase TB case detection in the plantation sector.

### 6.1.6 Gender Barriers in Treatment seeking

It was the opinion of the Estate community that , though both sexes are equally employed at present , females often need to put more effort in their occupation in comparison to males .It was their opinion that working females are often burdened by domestic work and child care responsibilities, hence when the need arise for women to go to hospital, they struggle to find alternative measures for their normal day activities and domestic work as most of the women cannot spare even a single day. Hence, women tend to tolerate their symptoms until it become unbearable for them to cope up.

The community group from Jaffna were in agreement stating that women are engaged with household work and they often do not have time to seek treatment for an illness.

### 6.1.7 Gender Barriers in treatment continuation

The opinion from the community group from Jaffna was that males get defaulted more than females due to alcohol usage, drug addiction, internal migration and notion of complete recovery after initiation of treatment and subsequent relief of acute symptoms. In addition, dislike for hospital admission and perceived intolerance to the anti- TNB medications can be associated factors for reason for defaulting TB medication.

Satisfactory treatment adherence to TB medication is predominantly seen among female population in all five study settings. Despite many obstacles in reaching TB management, once the diagnosis is made and treatment is started, females tend to adhere to treatment schedule. On the other hand treatment adherence by males is comparatively less in the community. Factors associated with low level of treatment adherence may be due to alcohol usage, employment barriers, stubbornness and non acceptability of the disease condition.

### 6.1.8 Female dependency

It was noted among elderly TB patients in the study sample that male dependency on their female partner in the old age provides a sense of insecurity towards the females as in the event when the wife gets TB , they face non availability of a person to provide care.

### 6.1.9 Marriage

It was the opinion of the patients in the study group that TB is not a barrier marriage for females at the present day. However, there were few reported incidences where the notion of insecurity in the community on marriage to a patient or a family suffering from TB in the community.

It was the general opinion in the community group that marital disharmony associated with disgust and blame towards the TB affected partner, mostly towards the wife, still persist in the community.

HCW group in the present study was in consensus that, role TB in the marriage has a vital role in the current society. There is hesitancy in marriage, with a diagnosed TB patient or into a family with a TB patient. Young girls with TB often face problems in love affairs/ marriage. TB status leads to disharmony in marriage life. Resentment towards the TB infected partner is commonly seen in the community. Both genders face problems in marriage due to their TB condition.

### 6.1.10 Level of Education

Community members from Kalmunai were of the opinion that in certain parts of Kalmunai where TB incidence is very high, level of education of women is very low. Therefore, awareness about TB is low in such areas. Members from estate community agreed with this fact that the poor education level among women in the estate might be a contributing factor for low awareness of TB in the area.

Furthermore, it was opinion of the community members from estate sector that the knowledge and awareness on nutrition is poor among females. They emphasized on the need to educate and empower females to take nutritious foods as women tend eat leftover food stuff following consumption by others members in the family mainly men and children.

The opinion from HCW group in the current study was that level of education plays a prominent role in continuation of TB treatment. In estate sector, both genders invariably get a low attainment in education. Similarly, in the Muslim community in the eastern province, in some pockets female education level is level is low.

## 6.2 Human Rights Based Barriers

### 6.2.1 Stigma and discrimination

Stigma and Discrimination plays a vital role in TB management services in Sri Lanka. Stigmatization towards TB patients and their families among estate, urban and rural populations were reported in the present study. One third of the TB patients in the study group revealed that TB patients and their families are ashamed of their disease condition; rather they refuse to disclose their disease condition to their family and neighbors. Patients further declared that due to stigmatization, they bypass chest clinic in their locality in order to avoid possible encounter with known personnel.

Society marginalizes and rejects TB patients from the society. Patients face stigmatization within their own families. It was stated by the HCW group that, EPTB patients face similar stigmatization as Pulmonary TB patients .It was their view that main causative factor for this condition is lack of awareness about TB in the community. Furthermore HCWs in the study group stated that the knowledge and awareness on TB among health care staff is not satisfactory. Private practitioners and OPD doctors are unaware on the disease burden of TB in the Sri Lankan society. Medical practitioners from Colombo and suburbs believed that TB is a eradiated diseases in Sri Lanka. TB does not pop up in the list of differential diagnosis for chronic cough and low grade fever among many of medical practitioners in Sri Lanka. Hence, a significant number of probable TB cases might be missed out in the community.

It was the general opinion within the community group that stigma and discrimination towards TB exist in their localities, somewhat lesser than the past. The community is not aware of the disease burden, treatment availability and the fact that TB is a curable disease.

### 6.2.2 Loss of adequate standards of living

TB can lead poor families to more depths in poverty. Loss of employment and means of living is the main factor which leads TB patients and their families towards poverty. Pawning of jewelry and taking loans from neighbors are reported remedies in adaptation for loss of standards in living.

Nutrition plays a vital role in cure and management of TB. It was the opinion of the community members from Jaffna that TB patients cannot tolerate strong anti TB medication without nutritious food and often people do not receive nutritious food at their homes.

It was the opinion of healthcare workers Nuwaraeliya, Colombo and Jaffna that TB allowance provided to the TB patients was insufficient while provision in Ampara and Kalmunai areas was reported as sufficient, In summary , a uniform amount of money ; Rs 5000 rupees per month as the minimum was proposed by HCWs for TB patients in all districts where the study was conducted.

### 6.2.3 Structural Gaps in the health care services

In the present study vital structural gaps in the health care services were identified. Significant delay in time of presentation to health care services until the time of diagnosis and treatment was reported from patients in the study sample. Majority of patients in the study sample has initially gone to Private Practitioners as they could not afford to lose day's wage by attending government hospitals. As stated, at most instances, TB was not among top three differential diagnosis of chronic cough, low grade fever or loss of weight/appetite. It led to significant delay in diagnosis of TB. Most of the Community members in the present study agreed on the fact that patients are more prone to go to private sector for convenience due to delay in service provision in the government sector. Further, they agreed on the existence of a significant delay from onset of symptoms until the diagnosis of diseases which at most times was about 2 and half months or

more. In addition, they stressed on the importance of display of health messages outside health care institutions in the community.

HCWs in the study group agreed that there is an inevitable delay in OPDs in government sector in TB diagnosis due to overcrowding of government sector OPDs. In addition, practical issues in TB laboratory diagnostic services were reported in the study sample.

### 6.2.4 Stigma and Discrimination among health staff

In conclusion, majority of study participants were of the opinion that health care staff treat TB patients with dignity and do not discriminate them or their families. All participants in the patients group agreed that health staff maintained patients' privacy and confidentiality. Nevertheless, when PHI visits their homes in his uniform they felt that everyone around gets to know about their disease status and feels exposed. Majority of HCW s in the study sample Patients were not stigmatized by health care staff.

### 6.2.5 Vulnerability

Bed ridden patients and women of extreme age groups are less likely to seek treatment for TB. Community from Kalmunai stated that, in Kalmunai and Ampara, there are elderly women, living alone in remote areas, as their children had died during the time of war. Hence, they do not have care providers. There are instances where, they develop cough and lose weight and die without seeking treatment. Therefore, there may be vulnerable pockets in the population, where TB treatment facilities have not been reached.

### 6.2.6 Myths and Taboos

All three study groups in the present study agreed on the persistence of taboos and myths in the community, however the incidence is rapidly decreasing. Urban, Sinhala dominant areas such as Colombo has almost eliminated taboos and myths on TB from the community. Nevertheless, remote areas such as Ampara, Kalmunai and Nuwara eliya, taboos on TB prevention, which leads to ritualistic approaches such as bali, thovil, yaga homa can be still found in occasional basis. The community group were in the opinion that in general, estate sector people initially even at present beliefs and ritualistic approaches play a significant role.

### 6.2.7 Prejudice and Coercion

It was the opinion of the patients group that, TB is regarded as a disease of the poor and highly contagious, where Diabetes is a disease of rich and non-contagious. In addition, HCW group were in an opinion that, in Colombo, children of elderly TB patients do not like to provide for their parents, hence TB among elderly has become a social issue within the community in Colombo district.

## 6.3 Socio cultural barriers

### 6.3.1 Ethnicity

According to the perceptions of the study participants in the current study, TB is more common among the estate population in Sri Lanka. This may be due to the fact that they live in close proximity in the estate sector, lack of awareness about the disease and low socioeconomic conditions within this group. In addition, health seeking behavior, low educational level and lack of good living conditions among this ethnic group contribute to barrier in TB diagnosis and management among this ethnic group.

### 6.3.2 Occupation

Occupation plays a major role in TB control activities in the community. Occupations such as garment factories have a higher risk in transmission of TB. Occupation invariably leads to lack of proper adherence to treatment. It was the opinion among HCWs in the study group that since TB is a common disease in the plantation sector, normally people do not lose their jobs, but loses of daily wages when attending clinics or treatment which is a great economical problem on the patients. Hence, patients do not disclose their TB status to their employment in the fear of losing their work due to their illness.

## 6.4 Pediatric sub group

Pediatric TB patients and their families face many barriers in their day to day life. Acceptance of the diseases condition in a child is difficult for the parents and this embarks a great pressure on the marriage life of the parents. Mother of the child invariably becomes a subject of guilt and blame receiver for the causality of the child's disease condition. Thus, this leads to gender based violence and difficulties towards the mother of the child and leads to marital problems and disharmony.

Older children and adolescents are ashamed of the diseases and in almost all cases refuses to disclose to their close friends. These children suffer secretly, over the stigma and discrimination which is created by the society, thus leads to behavioral problems and has an effect on their education.

## Chapter 6: Conclusions

1. Gender plays a vital role in TB diagnosis and management services in Sri Lanka. Barriers in access to free health care services is seen among females in Sri Lanka, mainly due to factors such as domestic responsibilities, concurrent employment and monetary factors such as lack of money for transportation**.**
2. Geographical areas such as plantations, slums, rural areas enforce a gender based barrier in TB care provision in the country. Plantation sector population face transportation difficulties owing to geographical location. Lack of proper road system, convenient and comfortable modes of transportation to health care facilities are contributing factors in geographical barriers in TB outreach services. Gender is risk factor since; females find it more difficult to climb up and down in mountainous areas aided with security issued while travelling alone in these areas.

3. Smoking, alcohol and illegal drugs are barriers in TB treatment. Diagnosis of TB among men can be delayed due to smoking and related complications such as smokers cough and COPD. Alcoholism is accompanied with treatment non adherence and ultimate treatment failure among TB patients. Alcohol intake is predominantly seen among males; however, there are reports on female alcohol consumption are reported from estate sector. Factors such as cold weather, less educational level, low social expectations in the community leads to alcohol intake in the community.

4. Marriage is invariably affected by TB status of a patient or the family. Marital problems due to refusal and disgust of the partner are reported in the society.

5. Delay in treatment seeking behavior is evident among females in the society. Factors for the delay lie with domestic responsibilities, low education level and lack of awareness about the diseases.

6. Treatment adherence and completion is relatively higher among females. Once presented and diagnosed in the health facility, women tend to adhere to advice given by health care

providers and continue medication, hence, defaulter rate is low among females in the community.

7. Stigma and discriminations persist in the society. Lack of awareness on TB care including prevention, diagnosis, treatment and follow up in the community as it leads to stigma and discrimination, concealment of their disease condition from the locality and subsequently poor treatment adherence. However, in depth Interviews revealed that stigma and discrimination is rarely seen among health professionals in the areas where the present study was conducted.

8. Structural Gaps in health care services is invariably seen in the community. Majority of TB patients' first level of contact in the health care service is identified as private practitioners due to perceived delay in treatment provision within the government sector. Substantial amount of delay is evident in the health care from the time of first contact up to being diagnosed as TB. Inadequate knowledge on current status of TB and newer treatment modalities among health care professionals may be the causative factors for this delay in the study population.

9. TB is more common in the estate population in Sri Lanka, for the reasons being living in close proximity in the estate sector, lack of awareness about the disease and low socio – economic conditions within this group.

10. Larger family size of TB patients is a notable factor in the present study.

11. Perceived discrimination due to stigma among children affected by TB leads to concealment of their disease condition from the friends and psychological trauma at early ages in life. Pediatric TB patients and their families face social manifestations which reflect as gender based violations towards the mother of the child. Lack of awareness and knowledge on TB was reported in the pediatric sub sample in the current study.

## Chapter 7: Recommendations

1. Lack of awareness on TB care including prevention, diagnosis, treatment and follow up persist in the community at large. It leads to stigma and discrimination, concealment of their disease condition from the locality and subsequently poor treatment adherence. Hence, culture appropriate, language feasible and easy to understand and grasp sort of media coverage and IEC material provision to general public as well as health providers is recommended.

2. Future TB prevention and control interventions should be Gender sensitive, targeting outreach to the vulnerable pockets in the community. Advocacy Communication and Social Mobilization (ACSM) strategy in TB prevention should be targeted at marginalized populations.

3. Gender sensitive approaches such as designated clinic hours for older/disabled women can be implemented at the District chest clinics.

4. Advocacy Communication and Social Mobilization (ACSM) strategy in TB prevention should specifically reach rural and estate communities. When preparing for future TB preventive health messages, importance in materials in Tamil language based communication should be emphasized, strengthened and highlighted .ACSM strategy should place optimal emphasis on less educated persons. Health education materials should be more focused on visual media such as Tamil films which can be views in the estate locality.

5. Awareness on TB burden in Sri Lanka and treatment modalities should be extended beyond Chest clinics. Extensive awareness programs should be implemented in collaboration with other professional colleges such as College of General Practitioners in Sri Lanka and awareness on TB burden and management should be extended to other medical professional including Private Medical Practitioners.

6. Community-based and/or family supervision models of the DOTS strategy may be more successful in achieving treatment compliance and positive outcomes among women as well as men who may be unable to visit treatment centers on a daily basis.

7. Targeted interventions according to different communities should be set in consideration of the district situation ( family size, extended families)

8. Behavioral Change Communication (BCC) to sensitize children towards social values, empathy and empower them to interact with discrimination is recommended though incooperaion of life skills and coping strategies techniques in to school curriculum. Counselling facilities in all DCCs for children with TB and their families is a necessity.

9. Quantitative studies targeting factors associated with treatment seeking behaviour for TB in the estate sector, pockets in the rural sector and high risk communities such as drug addicts infected with TB in the urban sector and prisoners are recommended.

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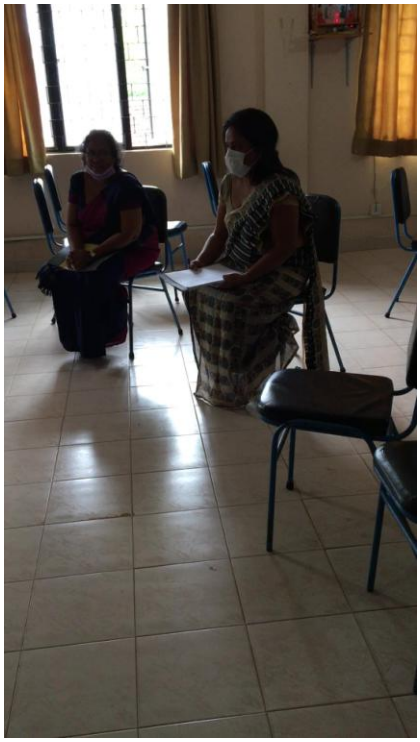
# Pictorials

## FDG – Patients Group-  Chest Clinic Jaffna


**FGD –Patient Group- Jaffna District at Chest Clinic Jaffna**

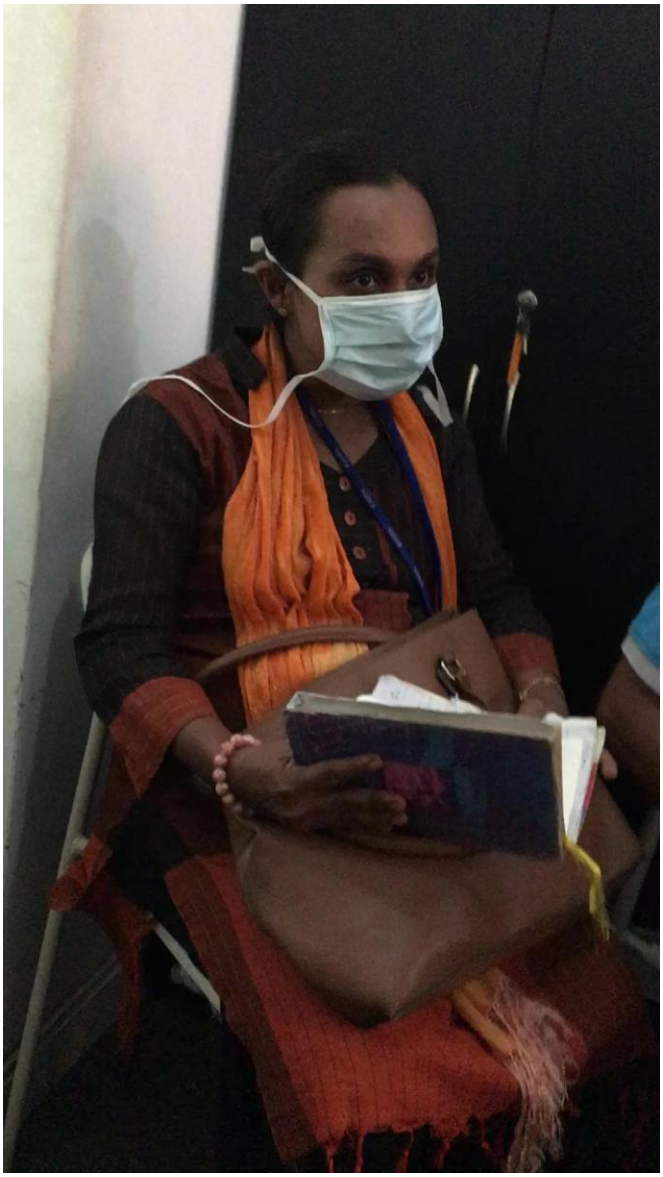

**FGD – Community Group Discussion Jaffna(Kopai)**

**FDG – Community Group- Rikillagaskada MOH office**



**FDG- Patients Group- District Chest Clinic Colombo**

FGD  Community Group Chest Clinic Colombo



**FDG – Community Group- Chest Clinic Kalmunai**

## Annexes

## Annex I

## Interviewer Guide for In-depth interviews for Health care workers (District TB Control Officers (DTCOs) and Public Health Inspectors (PHII) attached to DCC )

**Introductory Questions:**

1. Can you tell me a bit about you and your role in this health facility?
    **a.** Age, service period, main duties

**Gender related barriers:**

1. What do you think about the TB treatment seeking behavior of the male patients in your area?
2. Do you think that male patients in your area have constraints in treatment seeking as they are the breadwinners of the family?
3. What is your opinion on TB treatment adherence of male patients? If you find non-adherence, is it because they are on daily wages/ they become unemployed?
4. What do you think about the TB treatment seeking behavior of the female patients in your area? is it restricted because of their family commitments/ house hold chores?
5. What is your opinion on TB treatment adherence of female patients?
6. What is your opinion on treatment outcomes of male and female patients? If there any difference what is the reason for that?
7. Do you find any difference in treatment seeking/adherence between male and female patients in your area?
8. Do you feel that females are diagnosed late compared to male patients? If yes, what are the reasons?
9. Do women and men have equal access to health facilities? Are there any restraining factors affecting women?

**Human rights related barriers:**

1. How do you feel about the TB diagnosis in your institution? Are the majority of the patients diagnosed early or mostly its late presentation? If you believe it's mostly delayed presentation, in your opinion what are the possible reasons for that?
2. What is your opinion about access for TB care for the patients in your districts? Have you established adequate diagnostic services in high risk areas/difficult to reach areas/ plantation sector?
3. Are OPD doctors referring the patients as outpatient for the diagnosis or they tend to admit and make the diagnosis? Please share your experience. Do you think that when a suspected TB patient is admitted to the ward they are diagnosed promptly? Or any delays in diagnosing? Do you think that suspected/diagnosed TB patients receive adequate inward care during the stay in the hospital?
4. What is your opinion about maintaining privacy of TB patients in the DCC? Do you think that diagnosed TB patients are stigmatized/ discriminated in the DCC? Do you believe that proper care, including counselling and health education is provided to TB patients by the staff at DCC? Do you think that confidentiality of contacts of TB patients are protected in the current setting?
5. Have you ever come across a TB patient facing discrimination in their household, society and workplace? Any incidents ending up in losing jobs, family disharmony, marital disruption?
6. Do you believe that current contact tracing mechanism is creating more social discrimination? Have you ever come across an incident where patients' personal details are leaked out due to erroneous behavior of public health staff?
7. Do you think that TB suspects, diagnosed patients and their contacts are given an opportunity to complain in an instance where their human rights were violated?

8. What is your opinion about supportive services for TB patients? TB leave, TB allowance and nutrition support. Are patients entitled for these services getting the required services without any difficulties? Share your experience.

**Socio cultural barriers**

1. Do you think that ethnicity, religion and cultural beliefs are affecting TB treatment seeking behavior of the community in your area?
2. Do you think that ethnicity, religion and cultural beliefs are affecting TB treatment adherence of diagnosed TB patients?
3. What is your opinion on treatment seeking and treatment adherence behavior of the community in relation to economic status and level of education?
4. Do you think that substance abuse is affecting TB patient's treatment adherence in your area?
5. What is your opinion about adequacy of family support for TB patients to continue treatment?
6. Do they have Taboos and myths? Are there any other barriers which we are not discussed so far?

## Annex II

# Focused Group Discussion Guide

**Patients diagnosed with TB**

**Socio cultural related barriers**

1. What is your highest level of education?
2. How much is your monthly income? How many meals per day you take? Do you feel that you have enough food?
3. Where do you live? How many rooms are there at home? How many people including children live at your home?
4. What is you occupation? What is the impact of TB on your job? What were the difficulties you had to face with TB treatment at your work place?
5. Are there any taboos/myths which had delayed you to seek treatment for TB?
6. How far is it to nearest hospital? Do you have accessible roads? What are the difficulties you face to travel from home to hospital?
7. What is your religion? Ethnicity? Do you think that your ethnicity, religion and cultural beliefs had effected your TB treatment seeking behavior?
8. Do you smoke/take alcohol/illegal substances daily?

**Gender related Barriers**

1. How did you present with TB to health facilities? Do you feel that your diagnosis was delayed at some point at the hospital? Do you think that you being a woman has an effect in delayed diagnosis and treatment?

2. Do you think women have difficulty in access to free healthcare? What kind of obstacles do you face as a woman in accessing TB treatment services? Do you think that being a woman has affected your mode of transportation to health care facilities?
3. Did you face any difficulties to access to TB health care services because you are a woman/ man?
4. Being a woman did you face obstacles in diagnosis of TB? Did the rople you play as a mother/wife /daughter in your family effect your treatment seeking behavior?
5. Are you married? Did you get married before or after you were diagnosed with TB? What was the impact of TB on your marriage? Do you have problems regarding marriage due to your TB status?
6. After diagnose with TB, how did it affect your family life? Did you face any refusal for care, threat and stigma from your family members? What was their action towards your diagnosed TB status?
7. Do you adhere well to your TB treatment schedule? If you find that you cannot adhere to treatment, is it because you are a woman?
9. Since you are a male, do you think that you have constraints in treatment seeking as you are the breadwinners of the family?

**Human rights related barriers**

1. Do you feel ashamed/ unhappy that you are diagnosed as TB?
2. Do you feel any harassment/ undignified approach in TB treatment?
3. Do you think that confidentiality of you and your contacts in regards to TB treatment was secured?
4. In an instance where your confidentiality/ dignity were violated, were you given an opportunity to complain/ review with your care providers?

5. What do you know about your TB treatment schedule? Did doctors/ nurses explain to you about the etiology, impact of your disease? Were you given an opportunity to clarify your doubts, questions regarding TB disease and control?
6. Do you receive DOT treatment- Who is your DOT provider? Are you happy with DOT treatment you received? Do you feel threatened about DOT provision? How does DOT provision effect your occupation, family life?
7. Did your contacts were traced and investigated for TB? Do you feel that contact tracing mechanism had caused any social discrimination for you? Did you have any incident regarding contact tracing such as breach in confidentiality ?Are you satisfied with the procedure or do you feel that your personal details were leaked out due to erroneous behavior of public health staff?
8. Do you have any more barriers than these in relation to seeking treatment for TB?

**Case scenario 1 –Poor access to TB treatment facilities**

Rani is a 55 year old female estate worker who lives in X village in Nuwaraeliya. She was diagnosed as a case of pulmonary TB three months back. To get monthly TB drugs she has to attend district chest clinic Nuwaraeliya. She has to get 3 buses to reach that and it takes 2.5 hrs for that. To get a bus she has to walk 3 miles in the estate and she is travelling to the road by walking. Bus starts at 7am from the estate and reaches chest clinic around 10 am .Mostly she comes back to his house around 2.30pm in the evening following his TB treatment. She doesn't get his daily wage on the days which she visits the chest clinic since she is a daily paid worker. She is the sole bread winner of the family of which consist of her elderly parents and an unemployed son. Her husband is suffering from cancer and she is unable to go for work.

1. Did you experience same kind of problems when attending for your treatment?
2. Do you think that Rani should have a DOTS provider to provide her with treatment?
3. What are the causes do you think that Rani must be having for not getting a DOTS provider?
4. Do you have experiences of this kind of patients in your area?

5. Being a female what are the difficulties Rani would have regarding access in getting TB treatment?
6. What kind of a support do you think that the community can provide for her?

**Case scenario 2 -Stigma within Health care premises**

Mr Appuhamy 60 year old laborer had cough for 2 weeks. He went to meet general practitioner in the area to get treatment for this. Then Doctor gave him some drugs and asked him to visit the hospital if symptoms did not resolve? After 1 week, still Appuhamy was having cough. Then he went to the nearest Hospital OPD for treatment. He stayed in the queue for one hour to get a number to meet doctor. Within the OPD, hospital staff blamed him that "why you came here"? You have to go to the chest clinic for cough? You came to here to spread the disease to us? Don't you have a mask to wear? Please don't come to this place hereafter? The poor fellow felt shame because health staff blamed him in front of large gathering in the OPD. He came out from the hospital and asked the three wheel driver about the location of the chest clinic. Three wheel drivers said chest clinic is situated 10 kms away from this hospital.

Mr Appuhamy did not have enough money to go to the chest clinic by bus on the same day. Furthermore he felt too tired and thought to go home and come another day to the chest clinic.

1. Do you agree to the behavior of the health staff? In which way the quality should improve?
2. Did you face to the similar kind of experiences in the past?
3. If the patient is a woman what sort of further difficulties would she face than Mr Appuhamy?
4. Do you think a female patient may face stigma in the community with regards to being diagnosed as a TB patient?

**Case scenario 3 – Marriage & family life**

35 year old Kamal is a Bank Officer from a reputed family in the area. He has 2 kids aged 6 yrs and 8yrs.He was diagnosed with pulmonary TB the last week and he kept it as a secret and didn't tell to his wife or family.

1. Did you ever come across such situation?
2. If you are Kamal, would you to hide the diagnosis from wife and the family?
3. What is your view on Kamal's family members? Do you think that his family members have a right to know Kamal's condition and undergo testing for contact tracing?
4. If Kamal has told his family members what would happen?
5. Do you think a female patient may face more problems when disclosing their TB status to their family?
6. What was the reaction of your family members when they were informed about your disease? How did you cope with the situation?

**Case scenario 4 – Occupation**

25 years old Nayana is a village girl from Monaragala who is currently working in a garment factory in Biyagama. She was suffering from low grade fever, weight loss and loss of appetite for 2 months duration and was presented to district chess clinic following a referral from a private Practitioner. She was later diagnosed with Pulomanary TB. She does not want to disclose this to Her work place and refused to give details about her contacts.

1. Have you come across such incident in your life or have you heard about it?
2. Do you think having Pulmonary TB would affect Nayana's occupation and job safety?
3. What do you think Nayana should to about her occupation? Should her continue to work?
4. What should Nayana do during the course of her treatment?

**Case scenario 5 – Taboos and Myths**

Soma, a 30 year old female patient was presented with low grade fever, cough, loss of appetite and loss of weight to district chest clinic and was diagnosed as a patient with pulmonary TB. She is from a remote village in Monaragala and was suffering from above complaints for more than six months. When the DTCO was asking for reasons for delay in seeking medical treatment, she said that she was told by villagers that it is a seasonal disease and will pass away. Some others have told that this must be 'Kase' which is incurable and no treatment available for it.

1. Are you aware of any taboos and myths regarding TB in the society?
2. Do you think that Soma, being a woman was more vulnerable in her community?
3. Do you think that the community plays a role in decision making power of women in the community?

**Community**

**Gender related barriers**

1. Are you aware of gender disparity in seeking treatment for TB in your community?
2. Do you think men and women get equal opportunity for diagnosis and treatment for TB?
3. What do you think about the TB treatment seeking behavior of the male patients in your area?
4. Do you think that male patients in your area have constraints in treatment seeking as they are the breadwinners of the family?
5. What is your opinion on TB treatment adherence of males in the community? Do you think that non-adherence of TB treatment among males are because they are on daily wages/ they become unemployed?
6. What do you think about the TB treatment seeking behavior of the females in your area? is it restricted because of their family commitments/ house hold chores?
7. What is your opinion on TB treatment adherence of female patients?
8. What are the gender related barriers in relation to seeking treatment for TB?

9. What can be done to empower women in the community regarding treatment seeking behavior for TB?

**Human rights related barriers**

1. Do you look down at people with TB? Or are you ashamed if you or your family member is diagnosed with TB?
2. Do you believe that TB is curable? Would you associate a TB patient on treatment with respect?
3. Do you think people who are following TB treatment to be freely mobile in the community? or do you think that they need to be hidden away from the society?
4. Do you think people with TB should have a voice to rise?
5. If you were diagnosed with TB, do you think you should be given a fair and equal opportunity to receive treatment?
6. Would you support a colleague /friend/ neighbor with TB with their physical /psychological needs?
7. What is the role which NGOs can play with relevance to TB diagnosis and treatment services in the community?

**Socio cultural related barriers**

1. How can you help to reduce stigma and discrimination, which is associated with TB in the community?
2. Do you think a girl who had undergone TB treatment can marry and have a normal family life like others?
3. If anyone in your family wants to marry a girl who had undergone TB treatment what would be your reaction towards it?
4. If you are an owner of a company/institute would you hire an employee who is undergoing TB treatment? or if you get to know that one of the employees are diagnosed as TB what would be your reaction regarding it?

**Case scenario 1 –Poor access to TB treatment facilities**

Rani is a 55 year old female estate worker who lives in X village in Nuwaraeliya. She was diagnosed as a case of pulmonary TB three months back. To get monthly TB drugs she has to attend district chest clinic Nuwaraeliya. She has to get 3 buses to reach that and it takes 2.5 hrs for that. To get a bus she has to walk 3 miles in the estate and she is travelling to the road by walking. Bus starts at 7am from the estate and reaches chest clinic around 10 am .Mostly she comes back to his house around 2.30pm in the evening following his TB treatment. She doesn't get his daily wage on the days which she visits the chest clinic since she is a daily paid worker. She is the sole bread winner of the family of which consist of her elderly parents and an unemployed son. Her husband is suffering from cancer and she is unable to go for work.

1. Do you think that Rani should have a DOTS provider to provide her with treatment?
2. What are the causes do you think that Rani must be having for not getting a DOTS provider?
3. Do you have experiences of this kind of patients in your area?
4. Being a female what are the difficulties Rani would have regarding access in getting TB treatment?
5. What kind of a support do you think that the community can provide for her?

**Case scenario 2 –Taboos & Myths**

1.Mr.Saranapala was started on treatment for TB 5 months back. He was given a separate cup and plate to use and separate room to stay by his family. Now even his family members are scared to come near him because they think that they will get the disease from him.

2.Samudra is a 22 year old unmarried lady, who had completed 6 months of TB treatment and her last sputum smear was negative for TB. Her boyfriend had refused to marry her because he is scared to get TB from her.

1. What do you think about Mr.Saranapalas story? Are you agreeing the way his family treat him? Do you think TB can be spread from one person to another after 5 months of treatment? Did you experience similar kind of incidence in your area?
2. Do you think Mr. Saranapala could have objected for this type of treatment from his household?
3. If, this is a case of a woman, what further obstacles do you think that her might have to face at her home ? Do you think a woman is more vulnerable in such a situation?
4. Do you agree with Samudra's boyfriend's decision? What is your opinion? Have you ever experienced similar kind of incidence in your area?
5. Do you think different ethnicities; different religions have different beliefs on TB or its treatment? Please share your experiences.
6. Are there any other taboos and myths on TB and its treatment in your area?

**Case Scenario 3 – Substance abuse**

There was a 26 year old drug addict with 2 children, living in a slum area who was diagnosed to have TB and on treatment .His initial compliance was good during the first 2 months of treatment .In the later phase an interruption of treatment noticed by the DTCO.

1. Alcohol and substance abuse increases the risk of TB in the community. What is your opinion about it?
2. What is the impact of interruption of TB treatment on his family?
3. In the event of female drug abuser, what more obstacles do you think would she have to face in TB diagnosis and treatment?

**Case scenario 4 – Occupation**

25 years old Nayana is a village girl from Monaragala who is currently working in a garment Factory in Biyagama. She was suffering from low grade fever, weight loss and loss of appetite For 2 months duration and was presented to district chess clinic following a referral from A private practitioner. She as later diagnosed with Pulmonary TB. She does not want to disclose

This to her work place and refuse to give details

1. Have you come across such incident in your life or have you heard about it?
2. Do you think having Pulmonary TB would affect Nayana's occupation and job safety?
3. If you are Nayana's employer what would you do?
4. Do you think Nayana is safe to be employed in a overcrowded place like a garment factor?
5. What do you think about Nayana's accommodation? What can you offer to improve contact tracing of Nayana?

**Case scenario 5- Structural Gaps in Health care services**

Fathima is a 40 year old female patient who recently travelled to Sri Lanka from Dubai. She was suffering from low grade fever and a persistent cough for 2 months prior to her return. After coming to Sri Lanka, she attended a private practitioner who treated her with a course of antibiotics. She felt bit relieved but her condition worsened in April first week. She was taken to the nearest hospital and was diagnosed as a case of Bronchial Asthma. She was started on inhalers and sent home. Her condition did not improve and had several admissions to nearby hospital which she was treated with nebulization. Later she was investigated for TB and was found positive for Pulmonary TB. There was a delay of 3 months in her diagnosis.

1. What do you think about the situation?
2. Do you feel that that there are gaps in health care service provision? Do you have any experiences regarding similar situations?
3. What can be done to avoid such situations in the community?
4. Do you think if the patient was a male similar delay would happen? If not what are the reasons behind it?

## Annex III - Country level Action plan to address Gender, Socio Cultural and Human Rights related Barriers in reaching Tuberculosis Prevention, Diagnosis and Treatment Services in Sri Lanka

| | **Key findings** | **Strategic Objectives** | **Key activities** |
|---|---|---|---|
| 1 | Lack of awareness on TB care including prevention, diagnosis, treatment and follow up in the community as it leads to stigma and discrimination, concealment of their disease condition from the locality and subsequently poor treatment adherence. | 1. Awareness to generate demand for prevention, diagnosis and treatment among different sections of the targeted populations including addressing stigma issues.<br>2. Social Mobilization to ensure community participation and active involvement in TB care. | 1.Targeted approaches focusing each specific groups after studying their needs, level of education and beliefs , taboos persist with in those communities |
| | | | 2.Use of Community based organizations such as Funeral societies, women societies to involve members from the same community to empower TB patients to adhere to TB management |
| 2 | Inadequate knowledge on current status of TB and newer treatment modalities among health care professionals | Expand service delivery through fully empowered health care staff with prevention practices at work and foster stigma free TB treatment & cure as change agents in communities | 1.collaboration with other professional colleges such as College of General Practitioners in Sri Lanka, Sri Lanka Medical Association, Government Medical Officers Association etc. and include monthly TB updates in their website/ news letter. |
| | | | 2.Incooperation of TB into existing training /awareness programs of health care specialties other than respiratory physicians |
| | | | 3.Establishment of WhttsApp/Viber groups by DTCOs for GPs in his district and periodical update on current status of TB and newer treatment modalities |

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|---|---|---|---|
| | | | 4. Recognition and Provision of GPs as secondary DOTs providers where home DOTs cannot be done under M&E of DTCOs. |
| | | | 5. Adult and Pediatric TB algorithms to be distributed to all OPDs, private hospitals and GPs and M&E by DTCO for the sustainability. |
| 3 | Perceived discrimination due to stigma among children affected by TB leads to concealment of their disease condition from the friends and psychological trauma at early ages in life. | Behavioral Change Communication (BCC) to sensitize children towards social values, empathy and empower them to interact with discrimination | 1. In-cooperation of life skills and coping strategies techniques in to school curriculum. |
| | | | 2.Availabilityof counselling facilities in all DCCs for children with TB and their families. |
| 4 | Need to future research | Quantitative studies targeting factors associated with treatment seeking behaviour for TB in the estate sector, pockets in the rural sector and high risk communities such as drug addicts infected with TB in the urban sector and prisoners | 1.Research surveillance, quantitative analysis and advocacy to Identify policy gaps , health inequities , social determinants, gender and human resources barriers in TB management |
| | | | 2.Continouse M&E to identify policy gaps , health inequities , social determinants in TB care provision |