

**SELF-EFFICACY, PERCEPTION OF DISEASE, PERCEPTION  
OF HEALTH SERVICE AMONG NON-ADHERENCE TB  
PATIENTS LIVING IN SLUM AREAS OF HLAING THAR YAR  
TOWNSHIP, YANGON, MYANMAR**

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OF THE REQUIREMENTS FOR THE DEGREE OF  
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2015**

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ABSTRACT

Tuberculosis (TB) is a major public health problem in Myanmar. Myanmar belongs to the global list of 22 high TB burden countries along with having a major MDR-TB problem and is also one of the 41 countries with a substantial TB/HIV problem. Trying to understand the health behaviors, related to a particular group of people, is important for addressing their health problems and needs and to improve their health status. This study aimed 1) to describe the socioeconomic factors of non-adherent TB patients and 2) to understand their self-efficacy, perception of TB disease, and perception of the health service.

This research is an explanatory qualitative research study and it was conducted in Hlaing Thar Yar Township, Yangon, Myanmar over a period of four months. In-depth data was obtained through 12 purposively selected non-adherent TB patients for in-depth interviews, 7 key-informant interviews, and participant observations. The field data was saturated during the final interviews of patients. After that, the data was translated into English and analysed by using a manual data master sheet.

The findings showed that 1) non-adherent TB patients perceive TB as a common illness, an infectious disease that can be transmitted by air, a disease that requires following a medical prescription, and a disease that has social, financial, and physical impacts on them. However, most of them do not perceive TB as a curable disease; 2) they perceive available health services as unavailable, inaccessible to them, and insensitive to their socioeconomic and cultural contexts; and 3) non-adherent TB patients who are restarting or planning to restart their treatments, as newly categorized patients, have high self-efficacy. Patients who haven't restarted or who have no desire to restart their treatment have low or poor self-efficacy. By providing affective and efficient health education about the potential side-effects of anti-TB drugs, experiences during treatment, and the outcomes of improper treatment along with reassessment of health education, facilitating procedures for receiving treatment for TB patients, and treatment adherence of TB patients who are living in the township might be improved.

KEY WORDS: NON-ADHERENCE/ TUBERCULOSIS (TB) PATIENT/  
PERCEPTION/ SELF-EFFICACY/ SOCIOECONOMIC

115 pages

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## LIST OF ABBREVIATION

ASEAN	The Association of Southeast Asian Nations
DOTS	Directly Observed Treatment Short Course
DR-TB	Drug Resistant TB
HIV	Human Immunodeficiency Virus
LMIC	Low and middle income country
MDG	Millennium Development Goals
MDRTB	Multi-drug resistant TB
NTP	National Tuberculosis Program
TB	Tuberculosis
WHO	World Health Organization
XDR-TB	Extensively drug-resistant TB

## **CHAPTER I**

### **INTRODUCTION**

#### **1.1 Background of the study**

Tuberculosis (TB) is one of the preventable and curable documented infectious diseases and remains a major public health problem today. Infected persons present symptoms in different ways depending on the site of the body affected. If treatment is taken incorrectly or incompletely, resistance to anti-TB drugs can be developed and treatment later on becomes much more difficult and complicated. The World Health Organization (WHO), in 1993, declared TB as a “Global Emergency” due to a remarkably increase in prevalence and rise in multidrug resistant infectious cases all over the world.

In 1882, Robert Koch, a German physician and microbiologist was able to identify and isolate the causative organism *M. tuberculosis* (McKinney et al., 1998). As well that the genetic examinations of tubercle bacilli from East Africa had shown that *M. tuberculosis*, has a progenitor species about 3 million years old (Gutierrez et al., 2005). In truth, evidence of tuberculosis have been found in the spines of mummies of Egyptians and South American that were dated to be more than 6000 years old (McKinney et al., 1998). The public’s reaction to the TB health crisis during the 1950’s was alarming in its resemblance to the HIV/AIDS epidemic today (Rosenstock et al., 1994).

Passing through the times, there were a great number of professions from different fields not only studying the etiology and epidemiology of infection but also trying to discover the effective drugs to counteract the infection. It was found that TB was transmitted from one person to another by means of respiration (air borne infection). When a person with pulmonary TB cough up, sneeze or spit, they propel the sputum or droplet contaminated with the bacilli exposed into the air. The inhalation of droplets is the most common mode of TB transmission. A person needs to inhale only a few of these to become infected.

The problem of TB continues to exist as a global public health problem since it was declared as a global emergency in 1993. In 2012, an estimated 8.6 million people developed TB and 1.3 million people died from the disease (including 320,000 deaths among HIV-positive people) (Global Tuberculosis control, 2012). The number of people who died with TB is accountably considerable given that most are preventable.

Nearly 20 years after the WHO declaration of TB as a global emergency, the main heading progress towards 2015 is to achieve global targets within the context of the Millennium Development Goals (MDGs). Two years in advance to the date, the Global Tuberculosis Report 2013 and accompanying supplement Countdown to 2015 examine progress towards the 2015 targets and defined the five top prioritized actions needed to attain the goal.

During 1948 to 1963, due to the fact that people discovered effective chemotherapeutic agents, many TB control programs were established in developed countries, which contributed to a substantially drop in the prevalence of the disease occurrence. On the other hand, however, when this was implemented in the developing world where the burden of the disease was highest, this did not result in the same decline as witnessed in the developed countries (Raviglione and Pio, 2002).

The case detection rate was static, even though, the epidemiological pattern of TB incidence showed the greatest amount of active TB cases were found in developing countries especially in Southeast Asia, accounted for 41% of the world's total number with over 3 million cases per year; and in the African nations where there were 1.6 million new TB cases each year, in contrast with nations having privileged backgrounds witnessed roughly 100,000 cases (WHO, 2001).

In addition, there is an interesting fact that although the numbers of cases steadily decreased in developed countries, TB infection in those countries disproportionately affected low-income groups, for example, substance users, people come from low socioeconomic status, the elderly, and residents of congregate facilities, such as homes for the aged and chronically ill centers (ATS, 1992; CDC, 2000; Grange, 1999).

Moreover, in 2012, WHO predicted that about 1.1 million (13%) of the estimated 8.6 million people were co-infected with HIV infection, the African Region

is the place where about 75% of those cases mostly happened there. It is not unusual to see TB as co-infection with HIV nowadays. Since, over the period of 1990s, about eight million out of the estimated 88 million new cases of TB and 2.9 million of the 30 million people predicted to die of TB was attributable to HIV infection (Dolin et al., 1994).

In recent times, TB infection still plays a critical role in leading cause of death among HIV patients not only in Asia and Africa (amounted to 40%)(WHO, 1999), but also in the United States presenting as a major opportunistic infection for those people (CDC, 2000).

In 2009, with 9 million incident cases and 2 million deaths of TB remained unchanged to cause significant morbidity and mortality, especially in the low and middle income countries (LMIC) as WHO identified as the 22 “high TB burden” nations in which Myanmar is also included.

The impacts of TB on poor people more fuel with problems of malnutrition, ill health, HIV co-infection, repeated childbirth, fear, stigma attached to the disease and the delay in seeking medical care and drug incompliance. Additionally, Multi Drug-resistant TB (MDR-TB) is also a potentially catastrophic challenge to TB control programs in many areas of the world. Since 1994, throughout the world, the beginning of the project of Anti-tuberculosis with chemo therapy: Directly Observed Treatment, Short-course (DOTS) has focused attention and strictly monitors progress in order to achieve the set targets value (Raviglione, 2003).

After exponentially spread of multidrug-resistant tuberculosis (MDR-TB), defined as disease caused by strains resistant to at least isoniazid and rifampin, in the early 1990s, drug resistant to infection rose awareness as a global problem. MDR-TB now threatens the inhabitants of countries in Europe, Asia, Africa, and the Americas (20% of new cases and more than 50% of treated cases). In low-prevalence countries, drug resistance is generally more common in foreign-born populations or marginalized people or people come from less privileged backgrounds, most likely reflecting inadequate treatment programs and inaccessible to the health service (Broekmans, 2000).

WHO projected as amounted to 3.6% of new cases in 2012 and about 20.2% of previously treated cases have MDR-TB. On top of these, extensively drug-

resistant cases (XDR-TB) have been informed by 92 countries in 2012 accounted to 9.6% of MDR-TB. Action to MDR-TB depends on prompt recognition and treatment with at least 3 drugs to which an isolate is susceptible.

Furthermore, current epidemiological findings of TB fail to support the target. This is because of significant gaps in multi levels of national- and-international-directed TB-control efforts. All NGOs, INGOs, government organizations need to address these economic and social obstacles in order to meet with the goals of MDGs (Jassaland Bishai, 2010).

Most of the disease control program such as DOTS require seeking of health care by patients themselves actively, even though, there are much of difficulties to do so by people especially in resource-poor countries. TB can lead to catastrophic out-of-pocket expenditure and cause patients to lose an average of 3 to 4 months' wages due to illness-related absence from work (World development indicators. Washington, DC: WBG; 2009).

Furthermore, in controlling the TB disease, treatment adherence or drug compliance to treatment is composed of multi factorial factors including the structures of the health care system, patients-providers relationship, people perception about services and providers, patients' underlying socioeconomic status, access to service and withstanding to social rejection and interaction (Ailinger& Dear, 1998; Liam, Lim, Wong, & Tang, 1999; Rubel&Garro, 1992; Sumartojo, 1993; Thomson & Myrdal, 1986).

The extreme variability of access to care, such as money spent on daily wages for health seeking days and diagnosis, drugs, charges for investigations, and transportation fees are amongst the factors of social context that profoundly affect the ability of control programs to implement policy effectively (Lienhardtand Ogden, 2004).

Hence, there could be cases defined as incomplete case or missed case by WHO (2013) encompassed that nearly 3 million people were missed by national notification systems. To cover these cases, it is needed to find people with the illness and ascertain that they get the right treatment and care through health systems underpin by the providence of collaborative governmental and nongovernmental organizations, community workers and volunteers. All these tasks are required to

achieve the goal of TB eradication along with the collaboration of public hospitals, collaboration of private health facilities and better data concentration.

## **1.2 Significance of the study**

One-third or about 4.9 million cases of the global burden of tuberculosis is found in the WHO South East Asia Region (<http://www.who.int/about/regions/searo>). Moreover, the disease is mainly affecting the young adult people who have been infected in their most productive period. It can largely impact on not only the building of human resources for the countries concerned but also their economic booster. Tuberculosis (TB) is still a major health problem in Myanmar. Myanmar belongs to the global list of 22 high TB burden countries along with one of the 27 countries of high MDR-TB problem and 41 countries of high TB/HIV problem (<http://myanmarredcrosssociety.org/tuberculosis/>).

Based on a nationwide TB prevalence survey of Myanmar conducted in 2009-2010, the notification rate of 274 per 100,000 population is the second highest in South East Asia (ASEAN) countries after Cambodia (286 per 100 000) as well as in the WHO SEA Region after Timor-Leste (432 per 100 000). Myanmar has the TB prevalence rate with 525 cases per 100,000 population, compared to the global average of 178 cases per 100,000 population. WHO estimated that TB prevalence in 2013 was 473/100,000 population and TB mortality was 49/100,000 population. It is estimated that 230,000 new TB patients develop every year (Global Tuberculosis control WHO report, 2011).

In accordance with the Human Development Index 2011 which includes education, income, health related measures, the World Bank categorized Myanmar as a low-income country, ranking 149 out of 187 countries. Over 32% (about 20 million) of the people live in poverty, causing it one of the poorest countries in Southeast Asia.

Therefore, trying to understand the health concerns, beliefs, social situation and health behaviors related to a particular group of people is important to address their health problems, needs, and also, it is sensible to say that it can prevent unwanted health consequences to a certain extent. By studying the actual needs of slum people

with TB disease in receiving healthcare, there are surely certain benefits to improve outcomes of health including improvements in health care effectiveness in term of,

1) It will help to increase awareness in providing and planning for health care services, preventive programs and diagnosis algorithms efficiently and affectively in dealing with the people needs and wants.

2) It can fill up the gaps between the providers and patients' needs, which in turn, result in increased accessibility to the health care services, good quality of health care services and promote well-beings of people.

3) It can also reduce self-medication & drug-resistance problems, misunderstanding and barriers in tackle the issue of non-adherence among people especially from less privileged backgrounds.

4) It can be useful for better health promotion in health care deliveries and improve slum people's health status and the quality of their lives.

5) The results can be applied for health care providers in NGOs, INGOs of all organizations and state policy makers in providing and planning for comprehensive health care services.

### **1.3 Objectives of the study**

1) To describe the socioeconomic factors related to accessibility of health care service among non-adherence TB patients living in slum areas of Hlaing Thar Yar Township, Yangon, Myanmar.

2) To understand the self-efficacy, perception of disease, perception of health service among non-adherence TB patients living in slum areas of Hlaing Thar Yar Township, Yangon, Myanmar.

## **1.4 Research Question**

### **1.4.1 General Research Question**

How perception of slum TB patients on disease, health service and their self-efficacy influence their non-adherence behavior to health care service in Hlaing Thar Yar Township, Yangon, Myanmar?

### **1.4.2. Specific Research Questions**

- 1) What are the demographic and socioeconomic data of the non-adherence TB patients who live in slum areas of Hlaing Thar Yar Township, Yangon, Myanmar?
- 2) How do the non-adherence TB patients who live in slum areas perceive TB disease?
- 3) How do the non-adherence TB patients who live in slum areas perceive health service?
- 4) How do the non-adherence TB patients who live in slum areas perceive their self-efficacy?
- 5) What are the reasons why they do not adhere to the health care service concerning with their perception of disease, perception of health service and their self-efficacy?

## **CHAPTER II**

### **LITERATURE REVIEW, THEORETICAL PERSPECTIVES AND CONCEPTUAL FRAMEWORK**

This chapter presents a review of theoretical and empirical literature of previous researches which contribute to the concepts in the study. The purpose of the study is to study the non-adherence behavior of TB infected people living in slum area and those people' perception of the disease, perception of health service and their self-efficacy related with their socio-economic conditions. The geographical environment, social participation, and local dynamics of health systems in which the slum people are living could be potential factors affecting the above mentioned as well. In this review of the literature, the researcher work towards an understanding of this independent and dependent variables, relationship between these variables and its outcomes can be developed in a practical and experiential way.

#### **2.1 Tuberculosis in Yangon**

Since 1990s, the impact of the tuberculosis (TB) and its consequences is a public health challenge in Myanmar particularly in high prevalence congested areas. Not only they are more vulnerable to the disease because of their living and working conditions, they are also plunged deeper into poverty as a consequence of TB, which points to wider problem in society.

The TB prevalence rate is higher in urban areas in Myanmar. Among them, Yangon is the most affected city occupying 25.3% of the total number of diseased people, which are mostly concentrated in urban slum area. The prevalence rate (525 per 100,000 population) as well as a high notification rate (384 per 100,000) in Myanmar points out a significant incidence and that needs to be addressed (National TB program of Myanmar, 2011).

Most prevalent TB cases in the community do not present with classic symptoms which are detected via screening criteria. This causes most of these cases to be missed by the national notification system. The current NTP definition of TB suspects: cough for consecutive two or three weeks, can catch up only one third of smear positive and one fifth of culture-positive TB cases (Review of National Tuberculosis prevalence survey, 2009-2010).

## **2.2 Drug adherence in Tuberculosis treatment**

Issues of health-related behaviors and its determinants are at the center of the heated debate under the titles of both communicable and non-communicable diseases. Thus, there is a great deal of health behaviors studies done in various health-related fields with divergent perspectives and different scopes of studies resulting in colorful corollaries. The type of health related behaviors was classified by Pender (1987) into primary preventive behaviors and secondary preventive behaviors.

Primary behaviors involved straightforward activities to reduce the chances of illness or malfunction in people from an individual level to community as a whole safekeeping from casual matters. Unlike primary behaviors, secondary behaviors are composed of activities for diagnosis, instant treatment taking or intervention to stop the disease phenomenon; leading to decreased sufferings and getting back quick recovery, and regain normal conditions.

Due to biomedical improvements, DOTS therapy was affective in TB disease controlling and intervention in 1970s with five distinct components. Furthermore, thanks to the commitment of WHO and its partners, the whole course of DOTS treatment is properly delivered to the patients free of charge in the public sector with the intentions of ascertaining that all patients receive complete treatment, and to stop drug resistance and its sequel in high prevalence community (Gwatkin, 2000).

Moreover, because TB is generally assumed as disease of poverty and the duration of treatment is quite long, the free DOTS therapy also aims to promote the access of the poor to the treatment. Therefore, this TB control strategies with DOTS therapy contributes to cost-effective and is devoted to reducing the prevalence rate to a great extent (the World Bank's *World Development Report*, 1993).

However, in spite of substantially noticeable improvements in therapeutic measures for TB with DOTs strategy, the epidemiological pattern of TB incidence showed that there is an unequal distribution throughout the world. The greatest amount of active TB cases and drug resistance were found in developing countries especially in Southeast Asia, accounted for 41% of the world's total number and in the African where there were 1.6 million new TB cases each year, in contrast with nations having privileged backgrounds witnessed roughly 100,000 cases (WHO, 2001).

There are many underlying causes that can explain the prevalence and disease patterns of TB in high prevalence community by the efforts of studies related with cultural beliefs, living conditions, life experiences of Tuberculosis patients, and patterns of disease. Nevertheless, TB is still the leading infectious cause of death. Thus, Osterberg & Blaschke (2005) projected that the extent of the people following the medical advice is a primary concern in success of intervention to the diseases especially for infectious cases.

Jakubowiak *et al.*, (2008) investigated the social and psychological factors which may have impact or hinder a patient to be in touch with the health care system and to improve the quality of TB control programs with the objective of identifying how the people with TB disease' social and psychological factors impact on their drug adherence behavior. They studied that compared with regular compliance patients, non-compliance clients were mostly male, non-occupied, have a bad social history like imprisonment, uneducated, had apparently no worry to transmit their disease to other family members.

Furthermore, though they were taking medical treatments, they did not know the duration of treatment. One catchy point was a remarkably numbers of people had not only pessimistic views of the medical staffs, also they all felt that this medical personnel felt pity for them which they totally dislike. Along with it, they did not believe that they could be fully healed back and did not want to proceed treatment any more.

Likewise, patients' perception about the effectiveness of available health facilities have also impacts on those people' drug compliance in both positive and negative ways. As an instance, in Pakistan, Khan *et al.*, (2005) studied about the benefits difference between direct observed treatment taking and self-administered

treatment taking of TB patients. They observed that there was no difference between them. The reason was direct observed patients had perceived providers' attitude towards them were poor and not much paid attention to their symptoms, and they faced many obstacles in access to direct observed treatment in the trial period, which can impact on the drug compliance of the direct observed patients.

Correspondingly, the study done by Marra *et al.*, (2004) observed that the adherence of anti-TB drugs in patients had directly association with patients' perceived the positive views on available health service and good attitudes towards health care providers as they believed that health care providers can support them timely medication with good care. However, although there was high drug compliance in studied patients, the rate of missed dose among patients was high because of patients' alcohol intake and drug abused.

In addition, with the reason of TB patients just relieved their sufferings like coughing, fever, breathlessness and felt being well during taking treatment, non-adherence to the treatment occurred among those patients. They thought that they had been cured, and they decided themselves not to take treatment furthermore. So that they stopped the continued treatment taking before the end of the prescription (Khan *et al.*, 2000 and Menegoni, 1996).

Nichter's (1994) study of people with Tuberculosis' experiences in the Philippines revealed that participants believed tuberculosis could result from germs, fatigue, poverty, exposure to cold or wind, or any factor that seriously weakened their lung. The term "weak lung" was used by not only people but also physicians to avoid negative attitude towards people.

It would encourage the patients either to treat themselves or delay seeking necessary treatment and even, caused poor drug compliance in receiving anti-TB treatment. Nevertheless, it revealed that the vast majority of participants who were currently taking treatment had a view that tuberculosis could be cured by a doctor using medication. Most participants did not know the length of treatment, however.

There are many studies about Tuberculosis patients concealed their diagnosis due to being afraid of socially rejection from their friends, relatives and people from the surroundings. This concealments led them to delay and non-adhere to the treatment taking in timely. As instances, Carey *et al.*,(1997) reported that 77% of

the TB infected Vietnamese migrants in US mostly never expressed that they had the disease due to being afraid of facing avoidance from others and difficulties in finding employment. This worry at social difficulties further caused them to easily noncompliance to the treatment.

Furthermore, Barnhoorn and Adriaanse (1992) studied to compare treatment completer and non-completer TB patients related with their health beliefs in taking medications such as the perceived severity of the disease, costs and benefits of the treatment regimen and respective self-efficacy. They studied that 67% of completer had at least one person who can help them to take medication while only one third of non-completer had like that.

Compared with non-completer, completer reported they can more control their health, answered less difficulties for taking drugs, significantly perceived the treatment benefits, and regain health. Non-complete patients had less belief in their doctors, treatment and more complaint about health and social problems. In comparing self-efficacy, there was statistically significant higher in completers than non-completers.

In controlling the TB disease, treatment adherence is composed of multi factorial factors including the structures of the health care system, and quality of service provided. Besides, in order to utilize the service and good drug compliance of treatment, the location, time taking to go there and travel charges to the health center, access to service and proper withstanding to social rejection and interaction to take medication are playing an essential role in sticking to the treatment (Ailinger & Dear, 1998; Liam, Lim, Wong, & Tang, 1999; Rubel & Garro, 1992; Sumartojo, 1993; Thomson & Myrdal, 1986).

These findings are also proved as true by a study of Orr (2011), in which a systematic and analytic review of previous literature for drug adherence of TB patients. In the study, the system of the health service available, patients' socioeconomic context and social factors functioned as barriers to drug adherence in TB patients. Surplus, difference in patients and providers' beliefs about the disease and treatment further caused in drug incompliance to the patients.

As well, in the study of Liefoghe *et al.*,(1997) projected that due to the near distance and needed to pay treatment fees to the traditional healers just only after

relieved the symptoms attracted the TB patients more closer to the traditional healers than western medical centers. Likewise, the use of jargons and complicated terms for symptoms and explaining in prescription by health care providers can result in many problems with TB infected Ethiopian refugees in Israel, which was leading towards the drug incompletion in many patients and failure of the controlled programs in Israeli TB clinics (Chemtob, Weiser, Yitzhak & Weiler-Ravell, 2000).

In addition, studies done in the US for understanding the high prevalence rate of Tuberculosis in foreign-born people by Ailinger and Dear (1997, 1998) & Mitnick, Furin, Henry, & Ross (1998) observed that the main cause of treatment compliance was based on family encouragement and social support. However, in this study, researchers found that protective behaviors in other family members were hindered by their poor economic and socially disadvantaged situation. Such effective and efficient findings from the study could improve health care delivery system in US and its providers to achieve the reduction in the prevalence rate.

Thus, some literatures have stressed the role of drug adherence of TB patients and its determinants in controlling the infection because if people's perception about disease and treatment available is not enough, or if they cannot be able to use the health facilities, people cannot be compliant to drug taking, which leading increased treatment failure and DOTs system cannot fulfill the target rate although it can be available with free of charge (Sumartojo, 1995). Furthermore, DOTS is just mere the one impressive approach, not an elixir for the Tuberculosis patients. DOTS therapy will be completely successful if it is accessible and treatment is adhere to the patients.

Hence, the issue of drug adherence and its negative consequences has become important not only for diseased people but also for the whole society. Thenceforth, people from different fields studied how to solve this problem with a better way. By reviewing literature for this issue, there is a small numbers of literature which are studied about the perceptions of patients to drug non-adherence. Besides, despite the fact that the role of self-efficacy has been documented in many studies of health behaviors, there is a small number in study of behaviors of TB patients' non-adherence to treatment.

To be able to better understand the drug non-adherence behaviors of TB patients, it is still needed to find psychological correlation with those behaviors.

Jaramillo (1998) also suggested that applying different methods and study styles can contribute well in providing the different points of view and scopes for broadening the horizons to find out the solutions in studying the human health-related behaviors.

## **2.3 Theoretical Review**

### **2.3.1 Health Belief Model**

The Health Belief Model (HBM) is one of the social cognition models which were firstly developed in 1950s by a team of social psychologists to explain the reason why people could not take part in activities to prevent or to test diseases (Hochnaum, 1958; Rosenstock, 1960, 1966, 1974). After time passed, the model was modified to apply in people's response to symptoms Kirscht (1974) as well as to their behaviors in response to diagnosed illness, especially for drug compliance in long term therapy (Becker, 1974). Three decades later, the model has become one of the most wide spread psychological models in explaining health related behaviors.

Cognitive theorists stressed the role of subjective hypotheses or expectation grasped by the subject. In this perspective, behavior is critical of the subjective value of an outcome. Such mental process: thinking, reasoning, expecting are essential contributions of all cognitive theories. However, despite the fact that both cognitive theorists and behaviorists were convinced that rewards or benefits of behavior are crucial, it is true for cognitive theorists that such rewards conveyed by the influencing expectations from situation rather than by dominant behavior directly (Bandura, 1977a).

Over passing the time, further literature expanded the Health Belief Model and figured out a great deal of investigations with basic assumption of an individual's health-related behavior based on an individual's perception of their social environment and motivation. Actually the model was developed for health education programs (Rosenstock, 1974). However, (Kirscht, 1974; Becker, 1974; Becker and Maimam, 1980; Janz and Becker, 1984) classified the range of behaviors into three broad areas as preventive health behaviors, sick role behaviors and illness behaviors.

Generally, it is sensible to say that different people will take the different action to resist, to find out, or to face unwell-being situations in them if they assume themselves as susceptible to the surrounding happenings, if they were convinced that there is a tendency to avoid serious results in them, if they take a specific change in behavior will be a benefit by resulting in a valued outcomes (i.e. the disease will be effectively prevented or cured by taking action), and if they are certain that the supposed barriers (e.g. cost, inconvenience, pain, embarrassment-impeding) to taking the action are outweighed by its benefits (Rosenstock *et al.*, 1988). The following definitions and mentions generalize the key variables in broaden views.

**Perceived susceptibility:** The scope of perceived susceptibility refers to individual's subjective belief of the tendency of contracting to a certain illness (how susceptible am I to this illness?). Relating with medical illnesses, the dimension has been expanded to encompass the agreement with the diagnosis, and susceptibility to illness in common.

**Perceived severity:** Being aware of the severity of an illness if no action is taken (How severe would the outcome be if I had this disease?) including not only medical and clinical consequences (pain, deformity, death) but also potential social impacts likes job loss, impaired social networks with others.

**Perceived Threat:** it consists of a combination of perceived susceptibility and perceived severity of illness.

**Perceived barriers:** In order to take the recommended behavior for a particular health action by a person may be hindered the adverse view of those actions or perceived barriers. A type of less conscious, cost-benefit reasoning is assumed to happen where the individual out-balances an effectiveness against perception that it may be harmful, notorious (having unwilling results or reaction), repulsive, inconvenient, time-wasting and so on.

**Perceived benefits:** The belief in effectiveness of strategies designed to reduce the threat of illness. This assumption relies on beliefs regarding the effectiveness of the available actions in lowering the risk of disease, or the perceived benefits of doing action. Hence, the degree of belief in susceptibility and severity of an individual would not be estimated to accept or reject no matter if this action was perceived as reasonable and formally effective.

Therefore, “The combination of susceptibility and severity contributed the strength to act and the sum of benefits and barriers provided a better way to act” (Rosenstock, 1974, p.332). In spite of the fact that these factors are the essential components of the model, research based on it has indicated that other factors are involved to a certain extent as well.

In addition, one’s behavior is likely to be influenced by cues that can trigger to take action. It may be internal (e.g., symptoms) or external (e.g., mass media, illness experience of others, already educated about illness). Moreover, although all these factors are major components of the model, many researches based on it have proved that other factors need to be taken into consideration as well. They called those are demographic variables (e.g., sex, age, race, ethnicity), social psychological factor (social class, group pressure) and structural variables like poverty and religious norms. These variables, especially socio-demographic factors of levels of education, can impact indirectly on perceived threat and benefit (Becker & Maiman, 1975).

A person is far more likely to stop his health behavior when he doubts his ability to do so with the thought of distrust, or comes to the conclusion that the costs of pursuing are too much of a burden (Bishop, 1994). For example, individuals with a disadvantaged status are more likely to feel than people from a privileged background that affording the charges or seeing doctor is very troublesome for them.

### **Related literatures for Health Belief Model**

Efficient relevant findings can be found for health related behaviors by applying the Health Belief Model. In 1977, Marshall Becker and his colleagues (Becker, Maiman, Kirscht, Haefner, & Drachman, 1977) found that by correlating the measures of perceived vulnerability, benefits or barriers, and motivation, the model conveyed the accurate predicting whether people keep taking appointments throughout the treatment period and followed the prescription till to attain the result.

Furthermore, the Health Belief Model are efficiently useful in treatment taking as well as following preventive measures such as screening for Human Papilloma virus in women (Hennig & Knowles, 1990), practicing in examination of breast to be awareness of abnormal mass in breast (Calnan & Moss, 1984; Champion, 1990) and joining the preventive activities to HIV infection (Wilson, Lavelle,

Greenspan, & Wilson, 1991), the components of the model can successfully explain the relationship between practices and perception variables.

The research by Sukhon (2002) analyzed the tetanus prevention health education program among pregnant women applied with health belief model consisted of knowledge about tetanus infection, perceived susceptibility to mother and infant, and perceived severity, and also, perceived benefits to prevent infection by taking tetanus toxoid injection at the tetanus toxoid mobile clinic.

They studied the data collected before, one month after health education and after accomplished and compared between studied group and comparison group. They observed that the health education program applied with health belief model significantly improved women' perception particularly in knowledge, all the components perception of model and, costs for antenatal care in studied women.

The study of "In search of factors responsible for noncompliance among tuberculosis patients in Wardha District, India" done by Barnhoorn and Adriaanse (1992) compared completer and non-completer TB patients related with their health beliefs in taking medications such as the perceived severity of the disease, costs and benefits of the treatment regimen and respective self-efficacy. In presenting physical symptoms, completed patients expressed more severe symptoms than non-completed patients while the latter mentioned their health condition was more worsening at the time of treatment taking.

One significant finding was education related problems of knowledge about disease; causes and mode of transmission and benefits of drug regimen was significantly associated with compliance behavior. Likewise in other studies, getting satisfaction in health care providing resulted in totally continuation of treatment taking.

However, in predicting the health behaviors, the components of the Health Belief Model are relevant factors, even though, the HBM does not take into consideration determinants such as past experiences of the people, complications of mal-practiced action, and perceived control etc. As an instance of this, AIDS which is associated with particular people such as the poor, homosexuals, drug addicts, in this case, persons who do not consider themselves into these groups will be difficult to think themselves as vulnerable to this disease. Likewise, studies in the diarrhea

outbreak areas found that people in this area accepted the diarrhea as a way of “body cleansing” and vomiting was perceived as “a signal of relief” instead of severity of the disease (Hausmann-Muela *et al.*, 2002 and Nyamongo, 2000).

Glazer-Waldman, Hart, & Le Veau (1989) studied physical therapists’ health beliefs and behaviors related with health among them. The findings of this research are that even though physical therapists favored practicing good health habits, their health beliefs were not strong enough to predict their health behaviors such as drug taking or medications. Those are positively correlated with health beliefs, but not remarkably consistent to estimate for health behavior whether the therapists will do or not.

Hence, results from empirical studies clearly showed that the Health Belief Model can be effectively applied and predicted that people will be ready to take action when they come to realize that they are at risk of contracting or suffering from the disease and when they believe that the disease has serious affects. On the other hand, people are highly unlikely to take action when the likeliness of the disease is perceived to be less or it has only impact minor affects.

In conclusion, such perceptions lead the individuals to avoid or counteract the disease by selecting the best alternatives, balancing between advantages and disadvantages, and barriers or cost of specific alternatives with taking into consideration of demographic and psychosocial factors.

### **2.3.2 Self-efficacy**

Self-efficacy refers to an ability of someone to achieve something, to produce the intended result. A psychologist Albert Bandura (1977) has defined self-efficacy as “one’s belief about his ability to organize and succeed in particular situations based on its own cognition”. Self-efficacy contributes to significant differences in how people feel, think and act to attain the target result. This concept is most widely used and coordinated into a great deal of theories and models.

A strong sense of personal efficacy is related to better health, higher achievement, and more social integration. A low sense of self-efficacy in people, on the other hand, is associated with ill health without achieving accomplishments and personal improvements. This concept has been applied to such diverse areas as school

achievement, emotional disorders, mental and physical health, career choice, and sociopolitical change. It has become one of the key variables in Social Cognitive Theory (Bandura, 1977, 1986, 1991, 1992).

Actually, the statement of self-efficacy is that confidence in one's ability to conduct a particular task or behavior, which is vice versa, strongly related to one's actual ability to perform that behavior. People can get hold of a sense of efficacy via their own achievement and loss, witness of other's experiences, and assessing their ability by communicating with others.

On the other hand, in order to start or change behavior of someone, perceived self-efficacy of those has a connection to the outcome expectation and, this connection has, in turn, influence on making decision by those people. It is difficult to separate self-efficacy from expectations of an outcome. People's view of an outcome reveals their ability in that behavior.

Albert Bandura (1977) hypothesized that "personal action control or agency is determined by three classified outcome expectancies: (a) situation-outcome expectancies which is people's belief about what will result in future if they take no action to change, (b) action-outcome expectancies in which people convince that if they take action to change, something will be happened in future, in other words, outcomes derive from personal action (c) efficacy-expectancies which is presented people perceive their own capabilities to perform a specific action required to meet with a desired outcome."

Efficacy expectations are changing and heightened by four mechanisms:

(a) Mastery experiences – it is believed that the most effective way to develop the self-efficacy in people, and will encourage the people to believe themselves in their capability to have enough skill and to be flourished in their lives.

(b) Verbal persuasion – enhance people's ability verbally. Thus, they try their best to succeed in their lives and to hit to their targets. But, on the contrary, if there is too much verbal persuasion leads people to give up all their hopes as they may not do it well.

(c) Emotion arousal – by doing psychological or physiological stimulus cause the people to know their ability. Positive emotional support enhances and builds positive self-efficacy but opposition induces negative results. Likewise, physiological

arousal like pain, exercise and psychological distress likes anxiety and blame are associated with lesser ability. Thus, it should try to taper the tension and shift negative emotion to positive in order to develop self-efficacy.

(d) Vicarious experience – by noticing and seeing the individual who looks like them so that these individual's actions might be influenced on them to mimic. For instance, the model efforts to do something till success that made him being afraid, loss something. Therefore, he can also breed the desire to do as much as the same with the model because both are in same condition. However, it may be not going to be enough to change or follow, if the model has different characters or conditions.

Thus, self-efficacy supports that the individual who has high self-efficacy and outcome expectations, they are more likely to engage in health behaviors to prevent, to conserve, and to recover from illness. Differently, a person who has low self-efficacy show poor engagement in health behaviors related with their illness. So much so that self-efficacy plays an essential role in adaptation and maintaining of health behavior to a certain extent.

In order to commence and stick with health related behaviors, one has his own abilities and strength to convey the actions needed. A great deal of researches has projected the scope of optimistic self-beliefs as a forecast of changes in people's behavior in the health context (Bandura, 1992; Maddux, 1993; O'Leary, 1992; Schwarzer, 1992). They make decisions to take action in accordance with the belief that if they act in a desired way it would contribute to a favorable outcome. They also make decisions based on their belief that the behavior can be maintained until the end or until the expected outcome is achieved.

People with a strong self-efficacy, therefore, experienced little psychology and physiological strain in combat to stressors rather than those with a weak sense of efficacy (Bandura, Reese, & Adams, 1982; Bandura *et al.*, 1985; Holahan, Holahan, & Belk, 1984). Moreover, during early childhood, parents and family members are crucial to developing a process of strong sense of efficacy in the children as models of behavior, as a vector of reinforcement, and as a standard of comparison (Harterm, 1983).

Consequently, when children start their school lives, the role of peers are exclusively important for them to compare themselves with their friends in the fields of

academic ability, talents, failure and success and so on. Hence, in general, people can build strong self-efficacy for activities and situations in which they passed through successfully. On the contrary, failure leads people tend to get low self-efficacy (Bishop, 1994).

Furthermore, the connection between a stressful life and unhealthiness is strongly reduced in people with a high level of self-efficacy (cf. Holahan, Holahan, & Belk, 1984). Hence, in order to be strong in self-efficacy is dependent on how a person perceives and interprets their emotional experiences.

### **Related literatures for self-efficacy**

Many pieces of research have found that self-efficacy does influence people's health, illness, and sick-role behavior. Di Clemente, Prochaska, & Gilbertini (1985) deduced that cigarette smokers who had no belief that they can quit smoking were incapable of trying to stop smoking. Obviously, smokers who believe themselves that they can do quitting the smoking can change their smoking habit. Moreover, patients with chronic respiratory disease can take prescribed drugs and exercise if they believe themselves they can do well, so also, they are more likely adhere to the instruction than those who have less or no self-efficacy (Kaplan, Atkins, & Reinsch, 1984).

The study by Morris, McAuley, & Motl (2008) projected that in elderly people, their perceived satisfaction with neighbors lead them to change in doing walking physical behavior, which is promoted by their perceived self-efficacy. This means that elderly people with higher satisfaction with their nearby people can overcome obstacles to do physical activity over time due to their high levels of self-efficacy although they have some limitations in functional movements of their extremities.

Hence, in the study, we can observe that self-efficacy has a positive association with physical workout in older people who have impaired bodily locomotion. In addition to this, self-efficacy can be not only performing as a mediator in joining physical activities and promoting quality of life of elderly people but also playing an essential role as reinforcement of physical activity and indicator of quality of life (White, Wojcicki, McAuley, 2011).

Pedersen et al., (2012) investigated that participants who were technicians working in both private and public industrial productions with the objectives to determine the effects of exercise-specific self-efficacy on compliance to particular strengthen exercises at their working hours. Self-efficacy was found to be a predictor of compliance during 20 weeks in the private sector company, but not in the public sector company. Thus, work-place specific self-efficacy differences might be present.

Additionally, people with high self-efficacy believe themselves that they are dare to overcome any barriers to achieve the targets. Barriers towards exercising might be lack of time, lack of support from company leaders and colleagues, work load, limited break time and so forth. This study did not find baseline self-efficacy to be a predictor of compliance to training over time in the intervention as a whole.

The set of determinants such as knowledge of health risks and benefits, perceived self-efficacy, expectancies about the consequences of one's actions, personal goals, and perceived impediments other than self-efficacy may play a role regarding exercise participation. A specific worksite atmosphere as well as social and cultural factors, like social class, peers, and environment, may better explain barriers or motivation for exercise than initial self-efficacy. Moreover, interactions between participants and social support from group members influence a person's health behavior (Bandura, 1997).

Ungcharoensap (2001) studied about Tuberculosis patients' behaviors after applying to self-efficacy theory and community network at hospital located in Suphanburi Province by dividing patients into experimental group and comparison group. After the program, the self-efficacy levels of experimental group were statistically higher than their counterpart although there was no difference in self-efficacy between two groups before the study. Moreover, during study, group discussion and sharing information within experimental group using role model and demonstration can result in increased their perceived self-efficacy, knowledge about Tuberculosis, and understanding the effects of good medical practice which enabled them to recover within definite period as well as their drug compliance behavior.

However, a study of Griva, Myers, and Newman (2000) have found that the relationship between self-efficacy and good blood sugar control seemed to be more practical than the linkage of self-efficacy and treatment adherence in adolescents and

young adults with insulin dependent diabetes mellitus. This means that patients' perceived self-efficacy have direct relation with metabolic control likes dietary avoidance, doing physical exercise rather than compliance with treatment.

Arias (2010) analyzed determinants of self-efficacy among HIV positive individuals in seeking care for Tuberculosis treatment in Honduras for the reasons of an increased rate of prevalence, reactivating, mortality and also, high rates of treatment defaulters in those people. In this study, people with high self-efficacy had found that no history of appointment with physicians within one year, and they had optimistic view on health personnel.

Surplus, their perceived benefit to treatment was also reason for high self-efficacy in them. In other words, it is sensible to say that people who perceived severity of TB have higher self-efficacy to complete the treatment than those who viewed TB as a less severe form. This is the beneficial finding for behavior changing in TB patients.

The research done for drug compliance and treatment adherence of African American hypertensive patients by Brathwahe and Feldman (1985) studied that the higher in perceived self-efficacy level in hypertension patients, the greater their compliance with medications. Based on this study result, Uzoma and Feldman (1989) also investigated self-efficacy level in diabetic patients who were controlled their blood sugar level with insulin, and also repeatedly proved that self-efficacy was a strong predictor in self-reported treatment compliance in patients.

On the other hand, in the study of "The Impact of Self-Efficacy, Perception of Severity of Illness, and Psychosocial Adjustment to Illness on Glycemic Control Among African Americans with Type II Diabetes Mellitus" accomplished by Mc Vea (2004) showed that there was no predictive value for glycemic control by self-efficacy, perceived illness severity and psychosocial adjustment in the diabetic patients.

Diabetic women with lower self-efficacy in the study revealed their disease severity as more serious than men, reporting with more difficult in participating vocational circles, suffering severe form of psychological distress. Older diabetic patients came out with difficult sexual relation, difficult time adjusting to control diabetes. More educated people reported as they have high level of self-efficacy as

well. Nonetheless, on other side of coin, the studied blood sugar level in studied diabetic patients did not alter in line with age, gender, and educational level.

In a nut shell, even though a considerable amount of literature about self-efficacy in health related behaviors have made invaluable contributions in explaining and predicting health-related behaviors of people to a certain extent, concerning with Tuberculosis disease, there is a gap still present to explain non-adherence behaviors of patients particular with the context of urban slum people. Requiring data on self-efficacy for the TB infected people living in slum area does necessarily mean that additional research on this concept needs to compel to fulfill the gap.

#### **2.4. Conceptual Framework and explanation for study**

The review of literature and frameworks of previous studies contribute to the theme of conceptual frame for this investigation. Components of the Health belief model and self-efficacy will form a substantial basis for this study. The Health belief model tries to explain different health-related behaviors of different people which were expounded as differing perceptions in interactions (William, 1998). Rosenstock, Strecher & Becker (1988) did addition self-efficacy to the model. Correspondingly, personal efficacy is related to better health, higher achievement, and more social integration (Bandura, 1977, 1986, 1991, 1992).

This study tries to understand and explore how non-adherence TB infected people who living in slum area perceived the available health service, perceived their disease related with their socio-economic conditions and their self-efficacy for treatment taking. In the study, TB patients will be diagnosed and known about their disease by medical practitioners when they go to the hospitals or private clinics, and take the necessary investigations for their sufferings.

The diagnosed patients have to receive anti-TB drugs from health care center at their living township. Although some of them are diagnosed at private clinics, both the medical practitioners and TB patients have to inform respective health care center which deliver the anti-TB drugs. Therefore, as to be participants in this study, diseased people who are not taking the drugs totally for their TB disease since they have known their diagnosis, or diseased people who are missed to take drugs at a

certain period of time and retake the drugs regularly or some patients who quit from treatment taking.

Perceived about disease in the study refers to an explicit cognitive approach to explain behaviors of the TB patients based on their perception for TB (cause, infectious, curable, and complication, perceived benefit of taking TB treatment, and perceived barriers to overcome to get TB treatment and impacts of disease to their socioeconomic status).

Perception of services encompasses patients' perception of available health service for TB disease and their accessibility to it. Perception for available services includes in terms of quality of service related with providers at the center, investigation, supportive drugs and process of the health center. Accessibility to the service covers distance, time taken to go there, charges for the transportation, accompanying person, income for health seeking days, out-of-pocket expenditures for some unsupportive drugs and investigations.

The geographical environment, living and working conditions, social participation, and local dynamics of health systems in which the slum people are living could be potential factors affecting the above mentions as well. Self-efficacy of TB patients refers to how much belief non-adherence TB patients have in their ability to comply with their medication as prescription, performing under unfavorable situations with managing time available.

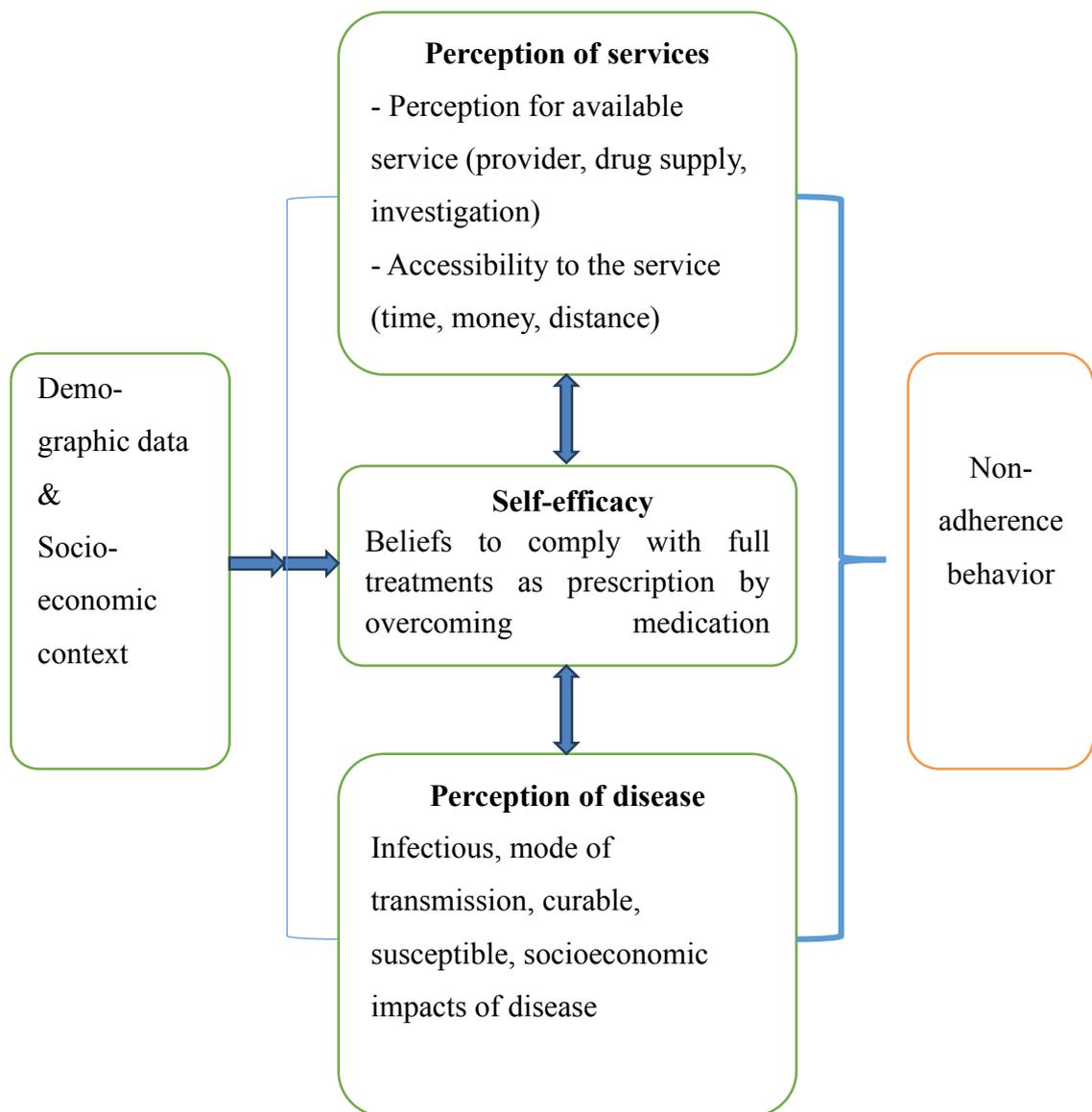
In other words, self-efficacy contextualized in the study as TB patients' beliefs in their ability to start to take treatment and comply with treatment facing with barriers and managing time to take anti-TB drugs regularly until the end of their prescribed period. The self-efficacy of the patients will be assessed based on taking drugs properly, in terms of: type, dosage, timely consumption of the medication and attending the clinic at the appointed time (Suksawat, 2002).

Health care providers, family members, other currently taking or completed patients would be motivators through verbal persuasion. Patients require to believe that if they adherence with TB treatment properly, they can be cured (outcome expectations).

Lenz & Shortridge-Baggett (2002) proved that people with high levels of self-efficacy are more perseverant to encounter the difficulties than those with lower in

self-efficacy, controlling themselves for facing negative things toward them. Furthermore, the former people can be able to recover quickly after an adverse event.

By studying the association between these perceptions of the slum TB infected people and their self-efficacy for drug adherence will provide and promote the better delivery of health care facilities to the people especially from less privileged backgrounds and to improve their health status and quality of lives.



**Figure 2.1 Conceptual framework**

## **CHAPTER III**

### **RESEARCH METHODOLOGY**

This chapter presents how the researcher conducted the research consistently in pursuance of achieving the reliable results to meet the objectives of the study. This study described the socioeconomic factors related to accessibility of health care service among non-adherence TB patients living in slum areas of Hlaing Thar Yar Township, Yangon, Myanmar and also tried to understand self-efficacy, perception of disease, perception of health service among non-adherence TB patients from their emic point of view by using explanatory qualitative research design with in-depth interviews, observation and key-informant interviews.

#### **3.1 Research Site**

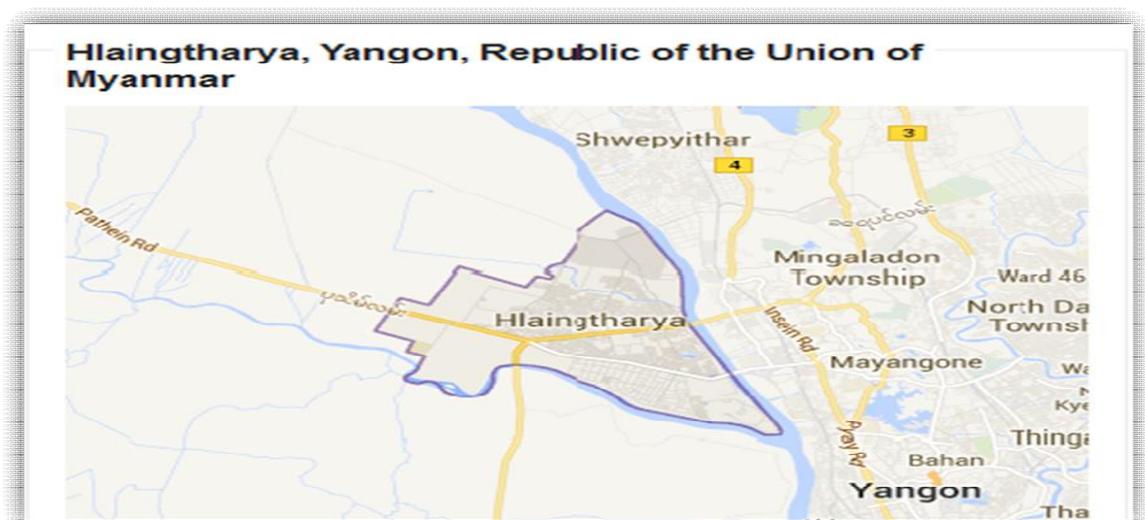
This study was done in Hlaing Thar Yar Township, located in western part of Yangon, the ex-capital city of Myanmar with an estimated population of 407,490 in total area of 83.33km<sup>2</sup>. The people living in the township have to take at least three hours to reach to the downtown area of Yangon where most of their works located. Typical jobs for people living there are manual labors like constructions, home industries, garment factories and fisheries, shops, or street vendors. Many people in the community are living in unprosperous conditions. Typically, sanitation is a critical issue as there is very limited access to clean water, toilets and house are as congested as each other. Electricity can be accessible irregularly especially in hot season. Furthermore, due to dense population in the area and lack of factual documents hide some unlawful acts and make the area to become the place where some offenders' hiding place. About half of all the roads in this part of the country are not passable during the rainy season.

There are 20 wards, 18 villages and 9 village Tracts in Hlaing Thar Yar Township. For health facilities for Tuberculosis in the township, Shwe Lin Ban station

hospital, one primary health center, one secondary health center and one Yay Oak Kan rural health center. Moreover, there are six sub-health centers (SHC) (Yay Oak Kan, Nyaung Ywar, Kalargyi Su, Shan Chaung, Shwe Lin Ban and 18) in the township. These health facilities for Tuberculosis are cooperating with international NGOs such as World Vision, MSI, WHO (Unicef). These INGOs interrelated with local NGOs such as Myanmar Maternal and Child Welfare Association (MMCWA), Myanmar Medical Association, Red Cross, Nurses Association, Health Assistant Association. Some local community based organizations (CBO) and sub-help groups (SHG) are also functioning to help Tuberculosis patients in their respective wards.

Since many people are living in underprivileged conditions, it is hard to determine their factual documents not only in Hlaing Thar Yar also in other many slum areas in Myanmar. Scanty infrastructures and limitation in access to resources are large-scale stumbling blocks for fundamental building of health and education services.

Moreover, Hlaing Thar Yar area is a densely populated slum area and is including in one of the slum areas of having a remarkable incidence rate TB (1673 in 2013 & 1917 in 2012) in country so that it can be more possible to find the informants easily. In addition to this, the researcher is native of the city and the usage of the language is the same with the local people. These factors make this geographic region a good choice as the research site for this study.



**Figure 3.1 Hlaing Thar Yar township (map from google)**

### **3.2 Entering the Research Field**

After accepting approval from Mahidol University's ethical committee for health social sciences research, the researcher went to the field area and thenceforth, greeted and met with the respective health personnel in the township and then, community members, some philanthropic groups' leaders in the community, and community development facilitators and TB specific community providers from World Vision. The researcher explained them about the purposes and objectives of the study in detail and requested permission from them after explaining how to recruit informants as the inclusion's criteria. As well as the researcher requested for their cooperating to be able to get contacts, to identify the informants, and to involve in this study as key-informants as well.

After that, with the help of the community development facilitators and behavioral change facilitator from World Vision and youth network of the study area, the researcher made appointments with the informants, selective key-informants for in-depth interviews separately at their convenient time and explained the objectives and purposes of the study. Thereafter, the researcher requested them to participate in the study.

However, since the main informants for this study were daily wage workers, they cannot give enough time to answer the questions. Thus, the researcher frequently visited to each informant and had to make many appointments in advance throughout conducting the study. Sometimes, although they made appointments with the researcher, they suddenly went out for other places for their job purposes or other matters. Similarly, in their appointed date and time, they were busy for other household chores and needed to wait till their available times in trying to get trustful data.

Surplus at first, a few patients were inconvenient to participate and answer for interviewing because they thought that it was something wrong about their stopping of drug taking. The researcher explained in detail the purpose the research, benefits of the study and strongly granted them for data security. After that, the researcher can convince them to get rapport. Finally, they were willing to cooperate and participate in the study till the end of data collecting.

### 3.3 Respondents

The targeted samples for this study were TB patients who have been diagnosed and known about their disease by medical practitioners when they go to the hospitals or private clinics, and took the necessary investigations for their sufferings.

In the community, as informants for this study, TB patients who are above 18 years of age, living in slum areas of the research site, and diagnosed as Tuberculosis patient by the registered medical practitioner, and TB patients who are not taking the drugs for their TB disease since they have known their diagnosis, or TB patients who are missed to take drugs at a certain period of time and retake the drugs regularly or TB patients who quit taking drugs before the end of prescribed period.

Total informants were 14 non-adherence TB patients including the 12 informants for in-depth interviews who were recruited according to their willingness, availability of their times and information richness to express.

By using in-depth interview, health care providers, TB specific community provider, close friend and family member of the TB patients and behavioral change facilitator were interviewed as 7 key-informants for the study. Participant observation was also done during and after in-depth interviewing.

Before doing interviewing, rapport and mutual understanding was built by visiting their homes and greeted and introduced them as a student and explained in detail about the study, and made them to ease and reliable to discuss and describe their feelings, experiences and sufferings. All the interviews conducted in the places and time that each interviewee felt free, convenient and had enough privacy. The researcher paid first priority to privacy in every single step of the conduct for the sake of the informants and data security so that every interview carried out in keep quiet, convenient and safe places. During interviewing, the informants were treated as unique individuals throughout the whole process.

After getting full and detail explanations about the research purpose, nature and possible outcome of the research, informants as well as their family members gave written informed consent voluntarily for their participation in the study.

### **3.4 Research method**

The non-adherence TB patients were purposively selected who are voluntarily participated in the study by giving informed consent and the recruitment process was done through the youth network of the township. Sample size was 12 non-adherence TB patients living in the study site.

### **3.5 Data collection methods**

The researcher carried out data collecting by listening carefully, revealing sympathy and empathy, displaying understanding and following the ethical manners and behaviors of the researcher. In responding to their expressed feelings which concerned with their health and experiences, something related with their background status, lives problems and sufferings, the researcher followed paying respect to the informants as unique individuals during the whole process.

The following data collection methods were used in conducting this qualitative study in order to collect rich enough data to be beneficially answering the research questions.

**3.5.1 In-depth interview** is the main part of the study and carried out to disclose the insider views of non-adherence TB patients related with their experiences which came across during their medication, their socioeconomic conditions and their perceptions of their disease and available health service. With the help of the staffs from World Vision and youth network of the study area, the researcher recruited 14 non-adherence TB patients and purposively selected 12 patients as informants. The researcher approached them with TB community providers and explained about the study, and then, invited them to willingly participate in the study.

Reciprocally, the researcher did answer what they want to know more about the research, the health knowledge about their disease and others, and private life of the researcher and other personal interests to reduce social gaps between the researcher and the respective communities. By doing so, the researcher built rapport and trusting relationship with them to be able to conveniently express their perceptions and concerns related with their health and lives. Furthermore, the researcher did

friendly visiting to their homes and participating in their social and ritual activities with paying respect to the other people in their families and communities.

In addition, the researcher's background study and previous working experiences as a medical doctor made the researcher more facilitated in building trusting relationship and rapport with patients and local people as a holistic approach. The detailed information of data collection, study process and confidentiality of data were explained and granted before getting informed consent from them. And also, the researcher let them know to keep participation till the end or quit from any step of data collecting. After building rapport, the time for interviews were set and all the interviews were carried out the place where the informants felt free, safe and enough privacy. Mostly the interviews were done at the houses of the informants.

**3.5.2 Key-informant interview.** In order to better understand about the living conditions, social grounds, TB patients' experience the researcher recruited 10 people and collected data from 7 key informants including health care providers, social worker, close friend and family member of the patients and TB providers to participate in this study in their available time, place where they thought that their privacy and confidentiality is maintained and their preferred situation.

Each and every participant felt free to open-up their views, concerns, experience related with the TB patients as well as let them well know the purposes and processes of this study by the researcher. After introduction, talking for general personal information and getting informed consent from them, the interview conducted by covering all guideline questions for required information and data.

As a key informant would like to stop in taking part during data collection, the researcher paid priority to the informants' rights to withdrawal in any step of study process and did not disturb anything.

**3.5.3 Participants Observation** was used as a learning for the researcher to gain closer insider views of the slum people' living conditions, their surrounding environment, their daily activities, which can be provided their socioeconomic contexts, perceptions and their self-efficacy related with their drug taking. It helped the researcher to realize the real experiences that the slum TB patients' natural lives,

living conditions, and experiences during their taking medication, which cannot be observed without participating.

Thus, during and after interviewing, together with informants, some participatory observations were done such as participating in health education sessions, some community activities together with informants, their families and friends, and some philanthropic activities in the community. This technique was used only after permission from the informants.

### **3.6 Data collection tools**

The following tools were used in collecting data with paid full attention and priority of the informants' benefits and potential risks due to research processes after taking both verbal and written informed consents.

- 1) Participant observation guidelines
- 2) In-depth interview guidelines and questions
- 3) Diary, field-note, pen, pencil, and eraser
- 4) Voice recorder
- 5) Digital camera
- 7) Laptop computer

Field note was written throughout conducting the field. The laptop was used in data entry, summarizing and interpretation.

### **3.7 Data processing and analyzing**

The researcher did the collection and recorded all the data. These all recorded data were analyzed in Myanmar language, and thenceforward expanded and translated into English language. It was categorized into the perception of disease, perception of health service and self-efficacy related with the drug taking of non-adherence TB patients. After each in-depth interview, key-informant interview and observations, jotted notes, memorized events and answers of informants and all the recorded data was kept in secret place. Subsequently, this recorded data were reviewed, rechecked, described, summarized and interpreted in line with thematic

analysis of research findings by using a data master sheet. As an ongoing process, the researcher analyzed the findings in answers of research questions, checked with objectives and finding out missing and other necessary information and then, asked again if it was. After processing the data in translating, entering and interpreting, all recordings, memos and jotted notes were destroyed completely for the sake of informants' privacy and confidentiality.

### **3.8 Validity and trustworthiness of data quality**

#### **3.8.1 Data triangulation**

Data triangulation was applied to be reliability, affirmatory and validity of data on the same research issue and also, engaging more than one various research methods to be consistent with each other and to balance effects of each particular method such as in-depth interview, key-informant interview, and participant observation.

Before doing each interview, all the informants for both in-depth and key interview were explained thoroughly the objectives of the study, recruitment process and processes of conducting research to build rapport and trusty worthiness between the researcher and informants by avoiding unethical manners during conducting the interviews with neutral and natural ways.

#### **3.8.2 Reflexivity**

Although the researcher's background professional experiences and educations were medical doctor, the researcher behaved utmost throughout the study as a researcher of social science to fulfill the purposes of the study and to pay attention to what all seen and listened to the informants' saying in all processes and fields of data collecting.

Not only that, but also related with data analyzing, the researcher paid full of attention of this study which was dealing with informants who were suffering TB diseases with particular socioeconomic conditions to be able to have the least influences from health care providers and professional person. Furthermore, the

researcher tried to use only knowledge and experiences of integrated; psycho, social, bio and individual approaches to all the informants in order to be improving mutual understanding, trusted relationship and gaining valid data in conducting throughout this research, but not as a concrete medical profession.

Furthermore, the researcher put much of efforts to achieve insiders views of disclosed data and experiences which shared by the informants in dealing with their real situations, sufferings, beliefs, behaviors and socioeconomic conditions in respective community. By doing so, the researcher performed as a neutral person to see the reality with psychological perspective but not with outsider's and health care provider's point of views to fulfill the purpose of the study. In addition, the researcher was aware that the importance of adaptation and ethical manners with sympathetic ears to the Tuberculosis patients who are living in slum areas and their difficulties for taking medication.

### **3.9 Ethical Consideration**

On all accounts of conducting the study, the researcher did try not to cause physical, social, emotional impacts on the informants by following the three basic principles of research ethic issue such as respects for persons, the beneficence and the principle of justice from before starting the field conducting till the end of the publication. Moreover, the researcher took into concerns all ethical considerations throughout the study.

**(1) Informed consent:** By thoroughly explaining about the study's purpose, benefits and potential risks to informants in the study and well replying all the questions of informants by using simple words and local terms, the informed consents written in Myanmar language obtained from both patients and key-informants before starting to collect the data. Interviews and observation began with their secure permissions and voluntary participation for the study.

**(2) Privacy:** The researcher paid first priority to privacy in every single step of the conduct for the sake of the informants and data security so that every interview carried out in the safe places and time that each and every informant felt free, convenient, and had enough privacy. Throughout and during ongoing process of

data collection, the researcher let them to choose their convenient time and places. Surplus the researcher prioritized the informants' rights to keep participation till the end or withdrawal in any step of study process and so on.

**(3) Confidentiality:** All attaining information, data, photos and evidences of the informants for this study was made sure with their approvals, remained confidential and used only as fictitious names to protect and prevent from any social, emotional or physical harm to the informants. All the recorded things were used only when getting permission from them to do so. After doing data entry and analysis of the study, all notes, records, recordings and photos were completely destroyed.

**(4) Beneficence:** The informants were thankfully given some kind of gifts such as tonic and foods and some contribution as an immediate benefit to show acknowledgment for their time and actively participation. In addition, the researcher shared their emotional feelings, experiences with the informants by listening patiently and without giving any comments and disturbing.

The researcher expected to apply in distributing of anti-TB drugs to the patients not only in the research area but also other areas across Myanmar, which can contribute well in promoting and upgrading the health status of local people who come from less privileged backgrounds.

**(5) Reciprocity:** The researcher provided health education to the informants and local people in their needed times and replied their questions with a good manner and patiently. As well as, the researcher lent sympathetic ears to them to relieve their emotional sufferings. Moreover, demonstrating, teaching and encouraging them the easy and effective ways to prevent the respiratory tract infections by sharing knowledge with them about how to make good ventilation and lighting in the house, how to clean their surroundings, how to prepare nutritious food, and providing tonics, pamphlets and protective masks.

## **CHAPTER IV**

### **RESEARCH FINDINGS**

In this chapter, the study's findings on the psychological, social and economic experiences encountered by slum TB patients will be presented. These findings are collected from informants and key informants by interview and observation.

#### **4.1 Context of the study area**

The study area is Hlaing Thar Yar Township, one of the new set-up townships founded in the 1980s. It is located in the western part of Yangon, ex-capital city of Myanmar. Total area is 83.33km<sup>2</sup> with an estimated population of 407490 and the density of population is 14948/km<sup>2</sup>. The township is connected to other parts of Yangon across the Yangon river by the Aung Zeya Bridge and the Bayinnaung Bridge including Htantabin Township in the north and west, Insein Township, Mayangon Township and Hlaing Township in the east and to Twante township in the south across the Pan Hlaing river by the Pan Hlaing Bridge.

Generally, the region has fair weather. In the rainy season (June to September), flooding in the lower areas of the township is not uncommon. Even though there are some wealthy parts like the FMI City and Pun Hlaing Garden Residences in the southeastern parts of the township, many parts of township are occupied by the mobile manual workers. After Nargis Cyclone (2008) had occurred, the township significantly experienced a skyrocketing in population due to the movement of people from many parts of Myanmar in order to seek employment without establishing the necessary infrastructures.

The people living in the township have to take public transportation at least three hours to reach the downtown area of Yangon where most of their works are located. Typical jobs for people living there are manual labors like construction,

garment factory, home industry, shops, or street vendors. As a result, many people in the community live in non-prosperous conditions. Typically, sanitation is a critical issue as there is very limited access to clean water, toilets and congested housing. Around 40 percent of the population is living in over-crowded area making children and families vulnerable to preventable disease.

Since many people are living in underprivileged conditions, it is difficult to determine their factual documents not only in Hlaing Thar Yar but also in other many areas in Myanmar. Scanty infrastructures and limitation in assessment to resources are large-scale stumbling blocks for fundamental building of health and education services.

Merely 27% of the population can access adequate electricity. This is 20 times lower than the global average. Similarly, people who live in the slum areas cannot access to drinking water (The World bank, Feb 2014). About half of all the roads in this part of the country are not passable during the rainy season. This area is also a densely populated suburban slum area and not far away from downtown area. These all factors make this geographic region a good choice as the research site for this study.

In term of health context related to TB in Hlaing Thar Yar Township, there are 20 wards, 18 villages and 9village tracts. Health facilities for Tuberculosis are progressing by Township Health Center and Specialist Hospital in Insein Township which are cooperating with international NGOs such as World Vision, MSI, WHO (UNICEF). These INGOs interrelated with local NGOs such as Myanmar Maternal and Child Welfare Association (MMCWA), Myanmar Medical Association, Red Cross, Nurses Association, Health Assistant Association. Some local community based organizations (CBO) and self-help groups (SHG) are also functioning to help Tuberculosis patients in their respective wards.

Among them, World Vision is mainly providing half of the total number of wards for both community development and specific diseases controlling like TB, HIV by raising awareness and facilitating in treatment taking via behavioral changed facilitators (BCF) and community TB providers who have been received Basic Health Education training, how to conduct in both individual awareness and facilitate on community group discussions. Furthermore, World Vision's field works are

coordinated with Township Health Office and Hospitals for referral TB patients from any parts of the country in their responsible wards.

#### **4.2 Demographic and socioeconomic background of the informants**

The age of the informants in the study is ranged between 25 years and 55 years. All of the female informants are elderly whereas the majority of male participants are not as old as female informants. All are 8 men and 4 women. All the informants' ethnic group is Bama except one woman is Arakanese, the eldest informant. The duration of their moving to this area is between 3 to 7 years. The levels of the education are quite varied from one to another. Most of the informants reached secondary school level, two of them have high school level, and one informant is high school graduated while two others are non-educated.

It can be seen that only one female informant is a single and has highest education level compared with all informants. Most of the male participants are married. Furthermore, it is not uncommon to see that more male informants are smoker, drinker compared with female ones.

Generally most of the informants are living in small detached houses which have not enough light and ventilation. Concerning about family backgrounds, 8 informants are from extended families, other four informants are from nuclear families in their own homes or rented house.

Simply extended family is more crowded than the nuclear one. Some of the informants have poor condition of housing, water supply, latrine, and have no electricity but the majority of female informants are still living in a good condition. Most informants come from underprivileged backgrounds and quite large family size with at least 4 family members. Apparently, there are only three women informants are living in the families which their family incomes are stably earning (monthly regular income). The rest are not.

Most of the informants are daily wage workers. They need to support their families whether they are living in nuclear or extended family type. However, when they are taking treatment, some of them cannot work at all, and become dependents in their families. Even though some are working during their treatment taking, they

cannot go for working daily resulting in lacking of income for that day. Their family incomes are also unstable in most of the informants' families; they cannot earn enough money to cover for monthly or daily expenses.

**Table 4.1 Summary of demographic and socioeconomic backgrounds of the informants**

<b>Fake Name</b>	<b>Age</b>	<b>Gender</b>	<b>Education</b>	<b>Alcohol, Smoking</b>	<b>Types of Family</b>	<b>No.of family members</b>	<b>Family income (Stable/ Unstable)</b>
<b>1. Ko Myo</b>	32	Male	7th grade	Ex-social drinker, social smoker. Betel chewer.	E	4	Unstable
<b>2. U Thar</b>	47	Male	6th grade	Alcoholic, Betel chewer, non-smoker	N	4	Unstable
<b>3. Daw Hla</b>	55	Female	5th grade	Chronic smoker	E	4	Stable
<b>4. Ko Tin</b>	25	Male	5th grade	Non-smoker, non-alcoholic, betel chewer	N	6	Unstable
<b>5. Daw Mar</b>	52	Female	9th grade	Non-smoker/alcoholic/ non-betel chewer	N	5	Unstable

**Table 4.1 Summary of demographic and socioeconomic backgrounds of the informants (cont.)**

<b>6. U Tun</b>	50	Male	6th grade	Non-smoker/alcoholic/ non-betel chewer	E	7	Unstable
<b>7. U Hla</b>	46	Male	Non-educated	chronic smoker, Chronic alcoholic	E	5	Unstable
<b>8. Daw Thoung</b>	55	Female	Non-educated	Non-smoker/alcoholic/ betel chewer	N	2	Stable
<b>9. Daw Myint</b>	47	Female	passed matriculation exam	Non-smoker/alcoholic/ non-betel chewer	E	7	Stable
<b>10. Ko Swe</b>	36	Male	6th grade	Ex-chronic drinker, social smoker. Betel chewer.	E	5	Unstable
<b>11. Ko Zaw</b>	41	Male	5th grade	Social alcoholic, ex-smoker.	N	5	Unstable
<b>12. Ko Win</b>	33	Male	10th grade	Alcoholic, ex-smoker	E	7	Unstable

Ko Myo is male, 32 years old, single and dependent. He had been a farmer before he got back bone TB disease. Now he cannot work for six months and totally bed-bound for 2 months. He is living with his aunt's family, and the whole family only depends on his uncle-in-law's income which is normally just enough to eat for whole family. Now, he cannot walk to anywhere as his back bone is not in a straight line and too weak to stand upright position. Thus, when it is needed to go out, he has to use taxi or trishaw.

The reason why he stops his drug taking was that his disease has to be long term treated which consumes much money but he cannot afford. He frequently needs to call doctor to relieve his ache and pain in the back and lower limbs and he has to pay for 6000 kyats each time he call the doctor. Furthermore, he needed to take some nerve tonic and other drugs which are beyond his reach. Moreover each and every time to go to health care center, he has to pay for 4000 kyats for taxi fares as he cannot walk. His family also cannot support him every time, thus he has to borrow money from other people. He may get support from other relatives but sometimes. Unfortunately, his uncle feels unwilling to pursue support because he is just an uncle-in-law, not a close relative. Moreover, the uncle himself is now facing difficulties because of having lost his job for 2-3 months.

U Thar is male, 47 years old, married, chronic and alcoholic, 5<sup>th</sup> grade of education. He is 2 times treated as supported patient from NGO. Last 10-11 years ago, he had severely injured in his left leg and left arm. Since that time, he cannot work well. His wife and his two daughters are supporting for house expense. But for his charges to take alcohol, he does not need to ask them. By helping others in the township do washing dishes, cleaning house, carrying heavy objects, he can earn some amount of money for drinking alcohol every day. Before treatment stopping, He had done all necessary investigations to start his treatment, only few times absent to go. The last time his wife gave warning him to go together with her, but he went to liquor house with his friends and came to house in drunken state. Thus, his wife was too angry to him and set fire to all of his medical records in which it makes him stay away from treatment taking. Hence, he hasn't started his treatment yet.

Daw Hla is female, 55 years old, 5<sup>th</sup> grade of education, and dependent. She is a supported Cat I TB patient from World vision. She regularly took her

treatment to 5<sup>th</sup> month of duration. After 5 months of her drug taking, she stopped to continue taking drugs by her own self because she had to go to take care of her daughter and grandchildren who are living in another province. There was a severe flood in their province, all their families' farms and crops were sunk under flood-water. Thus, she had to take her grandchildren especially her grandson to Yangon for matriculation exam. This help is so urgent that she can't pay attention to take drugs regularly and absent from her treatment taking including sputum and CXR examinations for assessment.

Ko Tin is male, 25 years old and 4<sup>th</sup> grade of education. His father passed away since he was young. The rest of his siblings are students. He is a head of his family and earns money by riding trishaw for his whole family. His younger brother is also riding trishaw by hiring it from others to help his brother in order to cover the whole family expenses. He took his first treatment without any problem till two months. During drug taking, he cannot ride his trishaw every day so his younger brother had to work both day and night to cover the family's expense. After 1 month of drug taking, he can withstand breathlessness and can ride his trishaw well.

Daw Tun is female, 52 years old, a mother of 3 sons and dependent. She is an ordinary housewife. Every day, her husband and her two sons have to go to open their stationary shop in the bazaar. Her youngest son has to go to school as well. Thus, there is nobody to take care of her.

U Tun is male, 50 years old, carpenter, and 6<sup>th</sup> grade of education. Now he is living with his daughter's family. He is unable to work for nearly two months and now bedridden. There are 7 family members in his family, but only 3 members are working as daily-wage workers in garment factories and construction site. He has been diagnosed to be both Type II Diabetes and TB diseases, and prescribed to receive anti-TB treatment as Cat II patient and drugs to control his blood sugar.

There is no other family member to take care of him because all of them have to go for work to cover the family expense. His wife and his family members have no idea how to do it. They can't decide whether they should suggest him to continue his treatment or not. If he continues his drug taking due to their suggestion, they have no money to support. On the other hand, although they are afraid of

prolonging disease, they also feel afraid of the side effects of drug because they have seen their father's suffering due to it.

Finally, although he had got anti-TB drugs with free of charge, he decided himself not to continue his drug taking because of lacking of enough money to treat his co morbid diseases and feeling fear from side effects of anti-TB drugs.

U Hla is male, 46 years, married, and uneducated person. He is earning money by bringing passengers from one side of river to another side by rowing his boat. Although he has one son and one daughter, they are not living with him. His wife is also an ordinary housewife and staying at home to take care of her 89-years-old mother-in-law. His son and daughter never provide any support to him. His daughter who is working in a garment factory cannot bring him to the hospital because she is afraid of reducing her amount of overtime fees. His income is reduced during taking drugs because he can't do anything after taking drugs. He will feel drowsy and need to take rest till afternoon. Not only that, because of his work nature, it is difficult for him to follow appointed time treatment with health staff.

Daw Thoung is female, 55 years, widow, and non-educated. She and her daughter moved to Yangon for her daughter's job finding last about 2 years ago. They are living in the small rented attached-house in the study area with 45,000kyats per month. Her son who is working in the other city provides them for daily expenses. Though they have moved to Yangon for more than 2 years, her daughter cannot get the job yet. This is because her daughter has to take care of her who has TB, Diabetes, stroke and hypertension throughout that period. Even though, rice, pea, oil, transportation charges, and other medical care are provided by the NGO, they are facing difficulty for their daily basic needs after her son got married and can no longer provide her for daily expense. Thus, she and her daughter decided to go back to their native town, Sittway.

Daw Myint is female, 47 years, single, and passed matriculation exam. She is living in a quite big concrete-based wooden house with her two siblings and a couple of her niece who are earning money from their stable jobs. During this time (third time) of drug taking, she had to stop her business of binding books in which she can previously do it well because of her general debility. However, during all the times of taking treatment, she had no financial difficulties because she has her own money

and her family can provide her with enough money too. For this time of drug taking, she gets monthly support from NGO and also get transportation charges about 5000kyats every time she goes to the health center.

Ko Swe is male, 36 years old, married and a daily wage worker as a bus conductor mechanic. He has two children. His family is now living with his mother because he cannot afford to pay for housing rent since he was ill. His mother is selling green grocery at the bazar to cover the expenses for the whole family. His wife is busy with two young children at home.

Now he is taking his second time treatment. Due to his illness, he can't work every day or do the whole day and he has less income as a result. The day he cannot work or go to health center, sometime, he has to borrow money from others or pawn his belongings. His boss is quite disappointed for his frequent absence and now he is looking other person to replace him.

Ko Zaw is male, 41 years old, married and ex-carpenter. Although he is a head of his family, now he is totally dependent because of his illness. His one daughter is also taking anti-TB drugs as Cat I patient. They are living in a very small attached house in which space is too narrow for five family members. The sanitation measures are not good enough to live healthy. Houses are too closed to each other.

Due to his disease and anti-TB drugs' effects, he can't work. Thus, his wife has to earn money for the family by selling the grocery especially soap oil at the bazar. His daughter, the one who is taking anti-TB drugs, is also working in a garment factory. Though he cannot work as a carpenter, he helps his wife in selling soap oil by non-stop stirring the big bowl of chemical mixing for 3-4 hours each time to make it. His son who is now attending high school, also helps his mother by doing all household chores. All family members have to fulfill the needs of the whole family.

Ko Win is male, 33 years old and single. He is living with his brother and his younger sister's family and earning money by riding his own trishaw. All his family members have good income. He is a chronic alcoholic. The reason why he misses his anti-TB drug taking is due to oversleeping after drinking alcohol. He is also a supported patient from one of the NGOs as both TB and HIV co-infected patient. All his family members know about his diseases. One of his sisters who do not live with

them supports him when he has to go to the hospital or health center. His sister who is living with him prepares food, money and clothes for him.

### 4.3 TB experiences of the informants.

After carrying out in-depth interview with 12-informants and 7-key informants, the researcher could learn the experience that TB patients passed through before, during and after taking their treatments. Likewise, the reasons why they stop to take their medication, restart or not to take their treatment again are also studied. In addition to this, the durations of their drug taking before stopping are varied among the patients as well as their underlying causes of stopping drugs are also different from each other.

Depending on the number of disease happenings and sputum results, TB patients have been divided into category I, II, and IV or MDR-TB patients. For Cat I categorized patient, they need to take only oral drugs for 6 months. For Cat II patients, they need to take 8-9 months of drugs including 2 months of daily regular injection. For Cat IV patients, they require at least 6 months of daily regular injection and up to 2 years of drug intake. Hence, according with their TB categories, the duration of treatment takings that they had to accomplish are also different from each other among the informants.

**Table 4.2 Summary of the TB experiences of the informants.**

Name	TB status (when they stopped drug taking)	Currently Taking anti-TB or not	Associated Diseases +/-	Total months of drug taking. (start - stop)	Supported patients or not
1. Ko Myo	Special TB (Back Bone TB)	<b>No</b>	<b>No</b>	25 Days	Not supported.
2. U Thar	MDRTB	<b>No</b>	<b>No</b>	Not started	Supported.
3. Daw Hla	Cat I (sputum Neg)	<b>No</b>	Asthma	5 months	Supported.

**Table 4.2 Summary of the TB experiences of the informants (cont.)**

Name	TB status (when they stopped drug taking)	Currently Taking anti-TB or not	Associated Diseases +/-	Total months of drug taking. (start - stop)	Supported patients or not
4. Ko Tin	Cat I (sputum +)	<b>No</b>	<b>No</b>	2 months	Not supported.
5. Daw Mar	Cat II (sputum Neg)	<b>No</b>	<b>No</b>	1 month	Not supported.
6. U Tun	Cat II (sputum +)	<b>No</b>	Type II D M	1 month	Not supported.
7. U Hla	Cat I (sputum neg)	<b>No</b>	<b>No</b>	2 month	Not supported.
8. Daw Thoung	MDR-TB	<b>No</b>	Hypertension, Type II DM, Stroke.	22 months	Supported.
9. Daw Myint	Special Regime patient	<b>Yes</b>	<b>No</b>	20 months	Not supported.
10. Ko Swe	Cat I	<b>Yes</b>	<b>No</b>	4 months	Not supported.
11. Ko Zaw	Cat I (sputum +)	<b>Yes</b>	Air way??	Nearly 6 months	Not supported.
12. Ko Win	Cat I (sputum Neg)	<b>No</b>	HIV (+), Liver abscess	3 months	Supported.

(Names are fictitious)

As their TB status at which they stopped to continue their treatments, the informants in the study are classified as 6 Cat I TB-patients, 2 Cat II TB-patients, and the rest 4 are prolong treatment taking patients including one back bone TB patient and one is already diagnosed as MDR-TB patient but hasn't taken his treatment yet. Three out of 12 informants are now taking their treatment again as new categorized patients when the researcher conducted the study, 2 from Cat I and 1 from MDR-TB.

Other 3 patients from Cat I want to retake medicines or consult the doctor again as they are still suffering from their symptoms. Similarly, some patients from MDR-TB want to retake treatments as well but it depends on conditions. However, 2 Cat II TB-patients have no desire to take drugs again no matter what it is. The durations of their drug taking are also not the same among the informants; it varies from 3 weeks to nearly 6 months. Their sufferings and their illnesses affect not only on themselves but also on their family members in terms of physical, social, financial and emotional impacts.

In spite of the fact that it is hard to define only one reason behind their discontinuing drug takings, majority of patients do not adhere to their treatment related with their underlying socioeconomic conditions. Some patients in the study have problematic issues with health staffs. On the other hand, for all Cat II patients, their suffering from side-effects of drugs and health service factors are the main reasons for stopping their drug taking. In prolong treatment-taking group, the reasons behind their stopping or not starting treatment are different from each other.

**Informant no. 1, Ko Myo.** He is a back bone TB diseased patient. He stopped his drug taking after 25 days from starting. He was an ex-farmer. When he was doing as a farmer in the farm, he began suffering from back pain. At first, he thought that it was due to his working nature and he had not paid attention it as a big issue so that he just applied burn oil on his back in the night times. But, it was not relieved and he became gradually worsen to nearly bed-bound for 2 months. Thus, his aunty took him to an orthopedic hospital to consult with specialists and did necessary investigations. Later, he knew that he had TB disease in his back bone and was prescribed to take anti-TB drugs as Cat I patient.

However, his ache and pain in both legs were more and more severe during night times. It was so painful that they needed to call the doctor in some nights. It is too expensive for him to call the doctor to their home. Moreover, he also needed to take other nerve tonics and some analgesic drugs to relieve his sufferings. He and his family could not afford to pay for these costs.

**Informant no. 2, U Thar:** He is two-time treated patient. His second-time treatment was completed last 3 months ago. Although it was nothing happened to him during his first-time drug taking but some worse thing happened to him when he was

taking his second time treatment. He had to lie in bed and could not even go to midwives for an injection every day. Both first and the second times, he was supported by NGO with transportation charges, anti-TB drugs, and medical services every month.

Now he has experienced cough, weight loss and easily fatigue. He thought himself that TB was happened to him again. Thus, he contacted TB specific provider and went to the hospital. After that, he knew that he had TB disease again as MDRTB. However, he is still absent to go to hospital to receive medication for 1.5 months because he cannot stop taking alcohol.

**Informant no. 3, Daw Hla:** One year ago, she experienced cough and tightness of chest off and on with low grade fever. She thought that she had common respiratory problems as she was a chronic smoker. Thus, she took some drugs by herself but she did not relieve. So she went to TB community providers in their ward, and followed her to the hospital. At the hospital, she came to know that she had TB disease and was prescribed to take anti-TB as Cat I patient. She took drugs regularly for 5 months before she urgently went to her daughters who were living in the other province. Now, she has stopped taking drug for 3 months and she is getting cough and suffocate again. Therefore, she wants to check up her health status and take anti-TB drugs if necessary.

**Informant no. 4, Ko Tin.** He is a first-time treated patient. Four months ago, after getting cold, he suffered from cough and chest pain. His cough was more severe in the night times. He took the drugs from drug store by himself, but he did not feel relieved. His neighbors suggested him to go to the health center. Thus, he called his mom and went there. After consulting with doctor and doing required examinations, he knew that he had TB. Afterwards, he started to take the drugs regularly. During drug taking, he cannot ride his trishaw every day.

After 1 month of drug taking, he can withstand breathlessness and can ride his trishaw well. According to treatment guideline, every patient needs to take sputum examination after 2 months of drug taking as reassessment. Based on this sputum reassessment, dose of the drugs have to be adjusted for the next 4 months. He forgot to do sputum examination. Thus, midwives scolded him and asked him to go to health

center directly for further treatment. However, he did not go to there and stopped his drug taking.

**Informant no. 5, Daw Mar:** After 6 months she completed her first treatment, she had cough again with back pain and loss of appetite. Therefore, she went to health center and discussed with the doctor. After doing required investigations, she knew that she had TB again and had been prescribed to take anti-TB treatment as Cat II patient. In spite of the fact that she had no special difficulties during her first time drug taking, she has been suffering severe dizziness and weakness in lower limbs during her second-time treatment. She also faced difficulties in finding place to inject every day. The midwife who was taking care of her in the ward was living quite far and she could not go to meet her with severe dizziness in every morning at regular time. Thus, she had to find difficultly other places for daily injection.

Sometimes, it took so long time to find clinic to inject because the clinics near her home were not opened every day. Thus, she had to find one clinic after another with a trishaw. It was very problematic for her because she could not even raise her head and could not remember on what ways she was going because of her severe dizziness. Additionally, there was no other to help her at home as well. Therefore, she was too afraid to continue her drugs because of severe dizziness and she no longer wanted to be troublesome for finding injection places every day. Thus, she has discontinued her treatment for 3 weeks. Now, she is taking traditional herbal medicine.

**Informant no. 6, U Tun:** Now he has been stopping his 2<sup>nd</sup>-time anti-TB drug taking for 10 days after one month from starting as Cat II patient. A year ago, he got TB disease first time and took his anti-TB treatment as Cat I patient for 6 months completely. During first time, he did not have any experience of being ill except evening fever and weakness in lower limbs. He could do well his job and took treatment regularly till the end of prescribed period. His sputum results were negative all the time.

After 4-5 months of his first time treatment, he started to cough, loss of appetite again especially at night, and had to sit up to relieve. He knew that it was the symptoms like his first time TB disease. So he went to the hospital.

For his 1<sup>st</sup> time treatment, he had no problem. Thus, he thought that this second time will become like that. But, after one week of his treatment, he had vomited just after 2-3 minutes of drug taking, severe dizziness, weaken in both limbs and could not walk well. Moreover, he had experience of loss of consciousness during that time. His blood sugar level was also uncontrollable and in addition, he cannot afford not only to monitor his blood sugar level every day but also to buy other required drugs. Thus, he felt depressed and too afraid to continue his treatment.

**Informant no. 7, U Hla:** He had cough off and on and felt ache and pain in all 4limbs for quite long time. He felt so uncomfortable that he had to go to health center and took CXR as his doctor instructed. The results showed there were spots in his CXR, and diagnosed as TB disease so he had to take anti-TB drugs.

During treatment, he could not do anything after taking drugs and needed to take rest till afternoon. He felt as no strength in his body at all and suffered severe dizziness. He was afraid of drowsiness during rowing his boat, and his family was worried about him as well. On the other hand, because of his work nature, he had difficulties to go to midwives to take drugs at the exact appointed time.

Staffs from health center informed him that his sputum was clear when it was reassessed after 2 months of his drug taking. Thus, he thought himself that his disease was treated and not so important so that he stopped his drug taking. He returned to his work of rowing the boat for a long time without caring about his disease anymore. He has stopped taking treatment for 3months.

Now, he is suffering from weakness, loss of appetite and weight loss. On the other hand, his wife attended health education session about TB disease and she would like him to reassess his disease. If his disease is still present, he also wants to restart taking treatment next time.

**Informant no. 8, Daw Thoung:** After 3-4 months of moving to Yangon, she had cough for 2 weeks and not relieved with any drugs. Hence, her neighbors suggested that she should go and take CXR at a clinic. Thus, she went to a private clinic and took CXR and sputum examinations. Afterwards, she knew that she had TB disease with sputum positive. So, she connected to TB providers from one of NGOs in her ward and then taking treatment as Cat I patient.

However, her TB disease was not improved after 6 months of treatment, sputum results were still positive so she had to continue her treatment as Cat II patient. After 8 months of treatment, her sputum results were still positive, and she was changed to take Cat IV continuously. Throughout her drug taking, she was supported from NGO with other necessary drugs, fees related with treatment, food, tonics, and nutrition.

She had no problem during taking Cat I and Cat II treatment, but sputum results were still positive. During Cat IV treatment taking, she was totally bed-bound due to hypertension, diabetes mellitus, and stroke. Whereas, she became to believe that all her sufferings are due to her being post-menopause, and if she stably overcame her post-menopausal period, she could be recumbent from all of her sufferings. Moreover, she came to believe that drugs could only cause harmful effects to her and cannot relieve her sufferings. Hence, she stopped her drug taking wholly.

**Informant no. 9, Daw Myint:** She is a chronic TB patient. Her mother and two siblings of her passed away with MDRTB. For the first time of treatment taking, she took drugs not only anti-TB but also other antibiotics as prescribed by doctor for nearly 1 year because she had a strong history of MDRTB. The outcome was satisfied.

Two years later, she got TB disease again, and took treatment at outside clinic with special regime. At that time, doctor prescribed her to take the drugs at least 2 years fully. Just 4 months left to complete her treatment, the doctor passed away. Thus, she didn't know how to do further. At that time, she was well-being, good skin complexion and cough-relieved. Thus, she assumed that it might be okay if she stop drug taking.

However, one year later, she was getting bloody cough, malaise and loss of her appetite again. Her family took her to the hospital for investigations. Then, she was taking treatment as Cat II patient uninterruptedly. Although her treatment was completed, her sputum was still positive and was sent for gene therapy. Now she is on Cat IV treatment as MDRTB patient with 6 months of injection.

**Informant no. 10, Ko Swe,** 36 years: During his 1<sup>st</sup> time treatment, he missed to take drugs about 4 months of drug taking due to his career. He had to go for car work-shop in which he had to spend all the day at that work-shop to repair the car.

After coming back, he fell asleep so that he absolutely missed drug-taking for 2 days. After that, he himself discontinued his drug taking.

Thereafter 2 months of stopping, he experienced the symptoms again, and had to receive treatment as Cat II patient. For this time, he tries as much as he can to receive injection daily together with oral drugs by bringing drugs with him. Even though he is getting fever, intense itchiness for the whole body, and severe headache during his treatment, he decided to take drugs regularly whatever it is.

**Informant no. 11, Ko Zaw:** Two years ago, he took treatment regularly as Cat I patient nearly 6 months. However, without accomplishing his prescription, he stopped his treatment because of his job and felt being well. At that time, he had to urgently go for a short-trip for job. He thought that 6 months of drug taking would be enough because he was gaining weight and totally relieved from other symptoms.

After year later, he is gradually unwell, off and on low grade fever and loss of appetite. Simultaneously, his elder daughter has similar sufferings. Both of them went to the hospital and knew that he has TB again and his elder daughter is also getting TB disease at the first time. Thus, he has to take drugs as Cat II and now, he has been taking treatment as MDRTB patient because his sputum results are still positive after reassessments. Now, he has been taking MDRTB treatment for five months.

**Informant no. 12, Ko Win:** co-infected with HIV infection. He did tattoo 4-5 years ago together with his 2 friends who have already passed away with AIDS. Before he got TB disease, he had already taken anti-retro viral (ARV) drugs as supported patient from NGOs. During that time, he had received treatment for liver abscess too. After 1 year, he had suffered with breathlessness and chest pain every day which made him unable to lie flat. So, he went to doctor and took necessary investigations. After that, he had been diagnosed as Tuberculosis patient and had to take the drugs as Cat I patient. He regularly took anti-TB for 3 months. Now he has stopped both ARV and anti-TB for 8 months.

The reason why he stopped taking drug was, after 3 months of drug taking, one day he overslept due to too much drinking alcohol with his friend for 2 consecutive days. When he woke up at 10 o' clock, he thought that time was over. So, he missed his drug taking for 2 days. After that, he went to the clinic to take the drugs

and he was scolded loudly by health staffs in front of other people there. Therefore, he felt so shameful and decided not to continue his treatment. However, health staffs from health center came to visit him and called him to come and take the treatment again. He decides not to return because he does not prefer to take treatment as Cat II patient in which he will have to receive regularly of 2 months injection. He thinks that he is unable to maintain the regular schedule of injection because he cannot give up his alcohol drinking and his work nature. Furthermore, he believes that anti-TB drugs can no longer be effective for him, and it can only cause more severe sufferings to him.

## **4.4 Perception about Tuberculosis**

### **4.4.1 Nature of TB**

#### 4.4.1.1 Tuberculosis as a common illness

As the study area is densely populated slum area and the majority of those populations are living in underprivileged conditions, some of the infectious diseases such as tuberculosis, HIV/AIDS, and seasonal infectious diseases such as diarrhea and dengue are commonly occurred. Thus, some governmental, non-governmental organizations, and local philanthropic groups are implementing the disease control programs for TB in the study area either by providing financial aids, health education through community providers and social workers, or supporting nutrition to the TB patients. On the other hand, TB patients who need to take long-term drugs from other parts of the country are also moving to this area in order to get the treatment. Hence, TB disease is not the peculiar for the local people. Surplus the local people also have their own experiences directly or indirectly with at least one TB patient in their lives as being residents of this area.

One key informant who is working as a TB community provider explained that *“people living in this ward are closed to each other and TB is not a strange matter for them because there is a new or old TB patient in every 2-3 house of our ward. That’s why I can easily find 3-5 TB suspected cases a month in my allocated area as directed by my organization. Local people well recognize TB*

*together with me. Furthermore, I help them not only for TB but also other illnesses so that when they are getting ill or something happening, they try to look for me.”*

Ko Zaw (Informant 11) explained *“It is so common disease here. I have moved here for 6-7 years ago. During this time, I met many people who are taking anti-TB drugs not only in the vicinity of my house but also in my working places. I have heard some of them passed away from this disease. Now my elder daughter is also taking anti-TB drugs as Cat I patient. I feel sorry about that whether she gets it from me or not.”*

Despite the fact that many people in the area familiarize the disease, most of them do not know what it is. *“I know TB just as a TB. I don’t know much about it. It is just an airborne disease. The reasons for getting disease in me... I have no idea about it too. I also feel strange why it happens to me again just after 6months of my first time treatment though I completed my drugs taking in this time.”* expressed by Daw Mar.

4.4.1.2 Infectious disease that can be transmitted through the air

Being aware of mode of transmission and following the practices to prevent play an essential role in controlling any infectious diseases. Similarly, knowing Tuberculosis as an infectious disease that can be transmitted through the air and taking measures to prevent the infection is a fundamental step in dealing with the disease. One fourth of the informants in the study do not have an attitude that Tuberculosis is an infectious disease which can be spread from person to person through the air as well as they have not been informed about if someone in the family has the disease, there is a potential to get infection in all of the family members.

*“I myself have no idea about it. I just about cough one week and I felt ache and pain in all limbs, so I went to health center and consulted with doctor. Then I had to take CXR. I was told that there were spots in my CXR, and I had TB disease so I need to take anti-TB drugs. That’s all”,* voiced by U Hla who was taking anti-TB drugs as Cat I patient.

Differently, one informant (Ko Myo) who has back bone TB disease has knowledge about TB can be transmitted through the air, but he does not convince that he can transmit TB to the others, *“I have heard TB can be transmitted*

*from one to another through the air. I cannot believe myself why I have TB backbone without happening in my lungs. But I don't think that it can be transmitted to others because TB occurs in my bone, not in my lungs".*

Daw Mar who took her second time treatment incompletely restated that *"They said to me that it can be transmitted to others so I keep my utensils separately, I don't give my food to other people. In my home, I also drink water from separate pot with my own cup and also, I told my sons not to eat left-over food that I have already eaten."*

However, by observation, the informants and key informants who know about TB infection and its mode of transmission hardly follow any barrier methods to prevent the disease transmission. In case of the community health providers, they communicate with TB patients without any protection because they want to make rapport and smooth communication with patients and their family members.

#### 4.4.1.3 Tuberculosis is a curable or an incurable disease.

Related with the disease curability, only half of the informants believe that their disease can be cured with anti-TB drugs. Two of the rest do not know whether their disease can be treated with anti-TB drugs or not. They have just to follow the instruction from hospital.

*"I am not sure that my disease is curable or not. Doctors said to me that I need to take anti-TB drugs at least 8 - 10 months. For me, it is not only to treat the disease, but also the disability. I am still young and I am a man. I need to do for myself and for my family. I hope that I can walk well"* expressed by Ko Myo who suffered backbone TB disease.

U Hla (informant 7) explained that *"I feel shame and afraid to say to you like that but I have no idea about my disease whether it is curable or not. It is very easy for me, they prescribed me to take the drugs, so I did. Now it seems pity for me, I should ask them about it."*

However, four informants do not believe that their TB disease can be cured by anti-TB drugs, one from those feel worsen during his drug taking, two informants have to take treatment again as Cat II patients although they have completed their first time treatments, and the last informant perceive that all of her

sufferings are due to her post-menopause and if she overcomes her post-menopausal period, she believes that she will recover from all her sufferings.

*“For my HIV infection, I need to take the ARV for life long. When I started to take my drugs, I felt well-being and I can sleep well at night. But for TB, I don’t think so because now I am more severely suffering from chest pain, vomit large amount of bloody sputum in every morning though I am taking the drugs regularly. Sometimes, I have to sit all the night because of chest pain. It makes me unable to sleep the whole night”* highlighted by Ko Win who has been infected with both HIV and TB.

4.4.1.4 Tuberculosis as a durable process (a disease that needs to strictly follow the medical prescription)

To combat their disease, every Tuberculosis patient needs to take the anti-TB drugs daily for at least 6 months (for Cat II and Cat IV patients, they need to take daily injection at regular time simultaneously with oral drugs intake for 2 months and 6 months respectively) at regular interval, regular time without interruption and there should be empty stomach and 2 hour apart from any meal according with treatment guideline. Thus, to be successfully treated Tuberculosis, each TB patient must have great effort to fully comply with the prescription. Furthermore, they need to take necessary investigations at exact time based on treatment guideline without missing to assess the improvement and to adjust the dosage of drugs.

*“I took the drugs regularly at 3-4am every day because after taking drugs, I have to go to river for rowing my boat. After 1-2 hour, I come back and eat something. I don’t know much about how long I need to take the drugs. If I know in advance, I didn’t do like that.”* explained by U Hla who stopped his treatment after 2 months from starting. The reason why he stopped taking drugs was when he was reassessed after 2 months of treatment, health staff said to him that his sputum was clear. He thought that his disease was already treated and it is not important to continue taking drugs.

Community worker expressed out *“health staffs try to explain them at least how to take the drugs, how long they have to take, what time they have to take investigations but they hardly concern about it. It is normal. It is not only him, but also people living in this vicinity are look like that. If there is a TB provider in*

*respective ward, it is no problem. They could follow up drug taking of TB patients. But if there is no provider in the ward, and TB patients are also alcoholics or smokers, and, they do what they want to do especially at the end of second month when they feel better. They don't care about their disease any more".*

A daughter of informant no.8 presented, *"doctors, nurses and this sister (TB specific provider) supported us and told many things about the disease. My mother accepted it at first and she continued her treatment taking from Cat I, followed by Cat II, and till now Cat IV for nearly 2 years uninterruptedly. But, her conditions were gradually worse and become bed-bound during Cat IV and her mood changed a lot. Now, she believes that all her unwell-beings are due to being a post-menopause. Not due to TB disease. No need to follow the medical prescription."*

The informants in the study have taken their drugs at right time, right dose at regular interval during their taking medication. Apart from this two informants, all the informants in the study have somewhat perceived about they have to fully follow the prescription for a long term in order to cure their TB disease even though they are not so sure what time they have to take investigation, what the changes in their prescribed drugs. However, they cannot adopt to behave till the end of prescription due to many reasons.

Besides, most alcoholic informants know that they need to avoid drinking alcohol as long as they take treatment. One of them discontinued his treatment due to his alcohol intake which it made him missed to take the drugs for two days. Another informant cannot start the treatment yet as he is drinking alcohol every day.

#### **4.4.2 TB susceptibility**

Being as a Tuberculosis patient, informants in the study are varied not only their TB status but also their susceptibility to the disease. They also suffer differently from symptoms such as prolonged cough, low grade evening fever, weight loss and easily being tired. Hence, about half of the informants, their neighbors and key-informants have susceptibility to their suffering. Whenever they feel suffering from the symptoms, they went to the health center or contacted to the community providers

who are working in TB specific organizations. Besides, some informants especially who have experienced are more aware of disease susceptibility.

U Hla (46 year) explained that *“When I got cough for 1 week, and felt easily tired, ache and pain in all limbs, I bought drugs from drug house by myself. However, I still cough and felt discomfort so that I thought that I might have TB. So, I went to the hospital and consulted with a doctor. After that I took chest X-ray and blood test, and came to know that I have TB”*.

Another informant: U Tun voiced that *“Last month, I started to cough especially at night times; sometimes I had to sit up right, and could not sleep well. So, I knew that it was the symptoms like my first time TB. So I went to the hospital.”*

Daw Thoung who moved from Rakhine division (western part of Myanmar) to the study area in order to find job for her younger daughter said that *“When I felt unwell with prolong cough for more than 1 month, my neighbors suggested that I should go to the clinic and consult with a doctor because I might get TB. At first, I didn’t because I had not enough money to do. But, when I got some money from my son, I went to a private clinic. I consulted with a doctor and took necessary examinations too. They said that I had TB abscess in my lungs, and my sputum had something happened what I didn’t know. They prescribed me to take anti-TB drugs for 6 months.”*

However, nearly half of the informants did not notice that their illness was related with Tuberculosis. Daw Hla presented that *“Before I go to hospital, I didn’t think that I have TB. I just thought that that I had common respiratory problems as I am a chronic smoker. So I go to TB community provider in our ward, and have taken CXR and then, I know that I have TB.”*

Another informant, 32 years old, Ko Win voiced, *“I thought that it was due to my viral infection so I did not concern my sufferings. One day, I coughed up with bloody sputum in the early morning and I was so afraid. Thus, I went to the hospital and had to receive the examination of biopsy and aspiration liquid from my lungs. Then, I knew that I have disseminated TB in both of my lungs. After that, doctors prescribed the anti-TB drugs for 6 months for me to take.”*

#### 4.4.3 Outcome of TB without treating properly

Significantly only one informant knows in details related with disease outcome if it is not taking drug properly or full course of prescription. She experiences that 3 members of her family passed away with multi-drug resistant TB. Thus, when she gets disease, she followed the prescription in every time. Now she is on the third time treatment as MDRTB patient.

*“I hope to be cut-off this disease in every time of my treatment taking. But, I am afraid for not to be like that. Because I saw my family members passed away with MDR TB disease and also, I failed to be successfully treated in last times although I took treatment with special regime for nearly one year in my first time, and twenty months in my second time. Thus, I am really afraid about it. Drug resistant TB is terrified and night mare for my family”.*

Ko Zaw mentioned that *“Now, I understand what drug resistant is and its wide ranged impacts. So, I decide to treat my TB disease till the end of prescription. I hope my sputum to be clear after 6 months of injection. I feel guilty for stopping my first time drug taking without finishing. If I would have entirely finished my treatment and cared about it, I had just continued taking drug for 2-3 months, and I may not be a MDRTB patient. Now, I have to take long-term treatment and have to get injection every day. Besides, it has an impact largely not only on me but also on my family. Now, my elder daughter is also taking drug as Cat I patient. I feel very sorry about it”.*

Now he is taking treatment as Cat IV patient, which continuous after Cat II treatment because his sputum results are still positive after reassessment. Even though he does not realize in his first time occurrence what the drug resistant TB is, now he knows well about it. His eldest daughter, 16 year-old, is also taking anti-TB drugs as Cat I patient.

The rest of the informants have known that if they do not treat their disease properly, they must take treatment with more prolong duration in the second time than that in the first time. Moreover, in spite of the fact that they have heard multi-drug resistant TB (MRDTB), they do not know exactly what it is, what the extent to and impacts on themselves and the community.

Ko Myo highlighted *“To be honestly, I don’t know well about what the meaning of drug resistant. But, I heard from others that if TB is needed to treat next time, people have to take drugs so long time. But, I’m not sure about it.”*

#### **4.4.4 The impacts of TB**

##### 4.4.4.1 The impacts on the informant

Most of the informants have not socially bad experience due to their disease because the people in the community are too familiar with this kind of disease. They are commonly closed with at least one TB patient in their lives. Hence, TB patients and people in the surroundings are lack of awareness to take care of themselves from this disease even they were informed about mode of transmission.

One leader of local philanthropic self-help group said *“People living in surroundings can easily know who has this kind of disease and who are taking anti-TB drugs as a nature of people living there. They do not take care about this disease. It may be some diseased persons who are treating their disease silently without letting other people know especially TB providers and local helping groups like us. Generally, people perceive TB as a disease that needs to take long term drugs.”*

*“All my family members treat me with good manners. There is nothing changes before and after knowing my disease. My better-half never says anything about the cost that I use for my disease.”*

Surplus two informants have difficulties with lacking of support from their family members not because of the disease but because of economic reasons.

*“My uncle-in-law does not speak to me during this 1-2 months. I know that it is because I cannot provide financial support not only to my aunty but also an extra cost of my medication. I am now in a very difficult condition. I understand that my uncle may not be pleased to take care of me because (1) I am not his sided-relatives, (2) I cannot provide money to the family now, (3) my disease has to be treated for long duration which need much of extra cost, and finally at this moment, he job is unstable”* expressed out by Ko Myo who is living with his aunt’s family.

However, not only the disease itself has a great deal of financial impacts on the informants but also the side-effects of anti-TB drugs can largely contribute financial hardships to informants. Significantly all most all of the informants cannot work well due to their disease either they stopped or restarted their treatment. During their treatment taking, they are more likely to drop out from their work.

Thus, apparently, some had to totally drop out from their job because of their physical illness. Some cannot work the whole day or cannot go to their job every day; consequently, they cannot earn enough money, which can cause them getting into trouble especially among non-supported informants.

*“Of course, my income was reduced because I can’t do anything after taking drugs and I needed to take rest till afternoon. I felt exhausted and dizzy. So, I was afraid of drowning, and also, my family worried about me too,”* expressed by U Hla who is earning money by rowing boat in the river from one side to another.

*“I can’t do my work after taking drugs especially after receiving injection. Each and every time of injection, my buttocks are very hard like iron and I can’t stand well. So, according to the side-effect of the drugs, how can I work? Therefore, I can’t work every day and this makes me getting less income. Furthermore, I have so intense dizziness and blurred vision that I have to stay as upside-down position in separated place after returning to my home. It is very intolerant suffering. Now, my boss is finding other people to replace me because of my frequent absence from the job. I have to find new job.”* (Ko Swe)

#### 4.4.4.2 The impacts on the family

Most informants come from underprivileged backgrounds; their family sizes are quite large with at least 4 family members. Most of the family incomes are also unstable and even, they normally do not earn enough money to cover ordinary expenses. As there are children and elderly people in the family, their families are facing a great deal of hardships especially in the families in which informants are heads of the family and cannot provide money to their family due to their illness.

Besides, in order to take care of informants, their family members cannot work well too, which is another important cause of family-income reduction.

*“The reason why we moved to here is to find the job for my younger daughter before my elder son is getting marriage. But, we has been here for nearly 3 years, we can’t do anything. My younger daughter is spending most of her time taking care of me till now. Now, my son is going to get marry and he can no longer provide money to us. So, how can we do? Yes, I am supported drugs and other necessary things from NGO, but, we have to eat every day. We have no income.”* Daw Thoung.

In addition, some informants’ family have to cost for other unsupportive drugs, charges to treat their associated diseases, transportation cost as an out-of-pocket expenditure. These all are contributing as financial burden for the informants’ family.

## **4.5 Perceptions about Health service**

Perceptions about services in the study include the availability of health service for TB disease and the accessibility to it. Perception about available services includes the quality of service related with providers at the center, medical investigation, supportive anti-TB drugs and the management of the health service. Accessibility to the service covers distance, time taken to go there, charges for the transportation, accompanying person, out-of-pocket expenditures for some unsupportive drugs and investigations.

### **4.5.1 Unavailability of Health Service**

According to the treatment guidelines, Cat I patients need to take drugs from the health provider twice a week, Cat II and Cat IV patients need to receive daily injection at regular time simultaneously with oral drug taking for 2 months and 6 months respectively. Thus, some of the Cat II informants have encountered difficulties in finding places for daily injection.

*“Sometimes, it took so long time to find a clinic for an injection every day because the clinic near my home is not opened every day as well as midwives for our ward is living so far away from me. I can’t go to her with this severe dizziness every morning which I really can’t withstand. However, I was afraid that if I don’t receive injection every day at the right time it may have negative impact to my illness. So I had to find a clinic one after another for an injection. It was so troublesome for me.”* expressed out by Daw Mar.

Daw Myint highlighted her troubles during her second time taking drugs as *“When I had TB for the first time, I consulted with an outside-clinic doctor though I took drugs from township health center. When I got disease at the second time, I also went to outside clinic. The doctor told me to take the drugs at least 2 years as I had a closed contact with MDRTB. After 2 months of taking drugs, I became feeling well, gaining weight and my sputum result was good. I was so happy for that. However, just 4 months left to complete my treatment, the doctor passed away suddenly. My treatment had not completed. So, I didn’t know how to continue. At that time, in Yangon, DOTS system was not started yet, and then I thought myself that it might be okay if I stop taking drugs. Thus, I stopped treatment by myself. One year after, I felt unwell again and I had some doubts to my symptoms. So, I had to go to Aung San Hospital and I was diagnosed as MDRTB.”*

Besides, some informants have problems with health staffs due to time constraint when they are taking drugs, as a result, they hold negative perception to the health staffs. The midwives have time constraint because they have to take responsibilities of at least 2-3 wards as allocation. Not only that, they have to undertake many assigned duties to accomplish in their allocated wards which are not only concerned with health related issues. Moreover, related with health issues, they have to tackle many tasks such as reproductive health, immunization, antenatal care, maternal and child health care, under 5 children and many infectious disease control programs. Thus, they need time partition to be finished all the tasks in time.

U Hla presented *“To be honest, I argued with the midwife here. She told me to come before 9am to take the drugs and every time I keep going at the right time. One day, I went lately to her because of my work. As you know I am a boat paddler, I*

*have to serve the passengers. I knew that it is late, I tried to explain but she never concerns. She told me to come back next day then I argued with her.”*

Community worker said, *“That the way it is. Midwives are so busy here, so they are used to appoint all TB patients to take drugs in the morning. One day, he was being late and midwives didn’t give him the drugs. So both husband and wife came to me and asked for help”.*

Furthermore, lack of available health services have largely impacts on the informants who have associated diseases like Hypertension, or Diabetes because they require not only to take anti-TB drugs but also to take other necessary drugs under the supervision of health personnel. Thus, those informants encounter many hardships during their drug taking although they can access service for their TB disease with free of charge.

#### **4.5.2 Inaccessibility to Health Service**

The location of health centers or hospitals are not far away from the informants’ houses. Howbeit, some informants are not easy to go there by bus or by walk due to their illness.

Moreover, because mostly they are daily wages workers, waiting for a long queue at the hospitals cause them lose time to earn money in that days. In addition, one informant has no one to take him to the hospital because his two daughters are busy with their works. Furthermore, despite getting anti-TB drugs, doctors’ fees, nurse and sputum examinations’ charges with free of charge, all most all the patients have to pay for chest X-ray and some contributions as donation. Although these amount of money are not too much and reasonable and, it does not a matter for supported informants, it is not really affordable for them.

In addition, not only drugs for TB but also drugs for their associated disease like anti-hypertensive, or drugs for heart disease etc., are needed. The drugs for their associated diseases are costly. Besides, those informants need to go to hospitals or clinics frequently for their associated diseases during their anti-TB treatment taking. These all matters contribute those informants not to access to health services because the charges for these services are beyond their reach and they have financial difficulties to access them as well as their families cannot support them.

Furthermore, even some informants have been provided with transportation charges, injection fees, other required medical measures as supported TB patients by local organizations in their wards and NGOs, they have difficulties to solve their daily basic needs.

#### **4.5.3 Insensitivity to socioeconomic and cultural contexts**

In spite of the fact that they acquire all services related with their TB disease, many informants can no longer adhere to fully finish their treatment with the reasons of their family affairs, working conditions, alcohol drinking habit and other social matters to follow prescriptions.

*“Since I started drug taking, I regularly attended any appointments and took all the drugs too. But, about 5 months of duration, I had to go to Bago Division where my two daughters are living there because at that time, there was a flood which largely affective many areas and all my daughters’ farms were sunk. And, I had to help them and bring my youngest grandson and granddaughter to Yangon. So, I was so rush that I could not continue my drug taking and did not pay attention to take drugs regularly. Since that time, I stopped drugs taking.”* explained by Daw Hla why she discontinued her drug taking.

*“I was so angry to him. I already gave him warning many times to go to take drugs. At that day, I waited him to go to health center to start his 3<sup>rd</sup> time treatment, but he went to liquor house with his friends, and came to house in drunken state. So, I was too angry with him and burned all of his medical records. After that, we are afraid to go to health center without any documents. He also could not stop drinking alcohol every day and cannot start his treatment yet. I told him to go alone, but he didn’t. He was very stubborn to stop drinking alcohol”* expounded by the wife of U Thar, the MDRTB patient, who has been suffering TB again as his 3<sup>rd</sup> time of getting disease. He was absent to go to hospital to start his MDR-regime for 1.5 months as he can’t cease his alcohol drinking.

*“When I took my first time treatment, I was working as a bus conductor. During that time, I went to car work-shop to repair my car. Then, I spent the whole day at that work-shop by taking part in repairing my bus. And, I didn’t remember to*

*take the drugs.” expressed by Ko Swe who is now taking treatment again after 2 months of his stopping drugs.*

*He continued, “For that day, and the following day, I totally missed to take the drugs because I felt so much worried about bus fixing. I was afraid that it would not be in a good condition to run. I remembered that I had not taken the drugs just after I came back home. But, time has gone. So, I stopped it. Now, I am bringing drugs in my bag. I am scared to miss to take drugs because of being afraid for taking treatment next time.”*

32-year-old Ko Win stopped his drug taking after 3 months from starting as he was overslept due to too much drinking alcohol at night with his friends for 2 consecutive days. When he woke up at 10 o’ clock, he thought that time was over. So, he missed his drug taking for 2 days. After that, he went to clinic and, he was scolded loudly by health staffs in front of other people at there. He felt so shameful and decided not to continue his drug taking.

Besides, one informant who was supported by NGOs stopped her medication during her Cat IV treatment taking. She continuously took her anti-TB as Cat I patient for 6 months followed by 8 months as Cat II patient and then, consecutively took treatment changed to Cat IV as her disease has not improved. During her Cat IV drug taking, she was totally bed-bound due to Hypertension, Diabetes Mellitus, stroke, which lead her to become to perceive all her all sufferings are due to her post-menopause. She also believes that she will be overcome this unhealthy conditions when she passes her post-menopausal period. Thus, she decided herself that she no longer need to take the drugs which can bring to her sufferings from its side effects on one hand, and did not help to her to recover from TB disease on the other hand.

*“At first, I believed in these drugs, and I thought that if I have taken the drugs, my disease would be cured. However, my beliefs were totally changed because it could not bring any good things to me, it can only cause harmful effects to me. I suffered harshly due to these drugs. Not only this, I believe that all of my sufferings are due to my post-menopause. So, I did not need to take anti-TB drugs. My symptoms would be fine itself after time was passing. Why I said so is because after stopping TB drugs, I felt very well, weight gain, my face is clear, and my blood sugar and blood*

*pressure all are within normal limit. So if I overcome my post-menopausal period, I will recover from all of this.”*

Some informants perceive that their symptoms are relieved especially after 2-3 months of drug taking. At that time, they can do their some routine works. Thus, some informants no longer take care to do things as their prescription and stop their drug taking when other factors are involved.

*“As throughout my drug taking, everything was okay. I forgot to send my sputum after 2 months of drug taking as reassessment, so I was late. She (health staff) scolded me and asked me to go to health care center immediately, but, I didn't go. Of course, just only one time that I said before, the staff and I had bad relationship. Now I know that she scolded me with good mind, because if I have no record for sputum examination, the doctor would not know how to continue my treatment with 4FDC or 2FDC”.*

His mother said, *“Health center is not far away from us. Yes, of course, she asked him to send his sputum himself in advance. As well as, she explained to me that whether he has to continue 4FDC or 2FDC depended on his sputum result and the decision of doctor from health center. It is so important for him. Thus, she asked him to go there to receive prescription from the doctor. However, he didn't go there. I could not urge him to do so. He was a silly one.”*

#### **4.6 Self-efficacy of TB patients related with anti-TB treatment taking.**

In this study, self-efficacy of the non-adherence TB patients related with their anti-TB drug taking is also studied. The term efficacy refers to an ability of someone to achieve something, to produce the intended result. Self-efficacy of TB patients refers to how much belief patients have in their ability to comply with treatment as prescription, performing under unfavorable situations with managing time available.

A strong sense of personal efficacy is related to better health, higher achievement and more social integration. A low sense of self-efficacy in people, on the other hand, is associated with depression, anxiety, and helplessness without achieving accomplishments and personal improvements.

As explained in literature review, people can get hold a sense of efficacy via their own achievement and loss, witness of other's experiences, and assessing their ability by communicating with others. Hence, self-efficacy contributes to significant differences in how people feel, think and act to attain the target result. In other words, self-efficacy contextualized as a method focusing on motivating the patient and refers to the patients' ability to start to take treatment and comply with treatment until the end of the prescribed period facing with barriers and hindrances.

Related with self-efficacy, it can be seen that those non-adherence TB patients who are now restarting their treatments as new categorized patients and who have desire to take their treatment next time have strong self-efficacy in taking medication to be accomplished. Additionally, their family members' scarified supporting and encouragements which improve their ability, supporting from NGO, their willingness, their own experiences of TB play an essential role in their self-efficacy for drug taking.

On the contrary, for the patients who haven't restarted or who have no desire to continue drug taking seem to have low or poor self-efficacy. They all have been harshly affected by the effects of anti-TB drugs as their previous own experiences. They failed to encounter those side-effects of anti-TB drugs (their loss experience), which lead them to have lack of belief to continue or restart their treatment. In addition to this, no effort to follow the prescription or no support from others or having other associated diseases speed up their poor self-efficacy.

#### **4.6.1 I need to restart my treatment**

*“During the days that I stopped taking drugs, I really felt unwell, easily tired, and could not work every day. I regretted for my carelessness. I believed that if I take drugs regularly, my disease can cure. Thus, I went to hospital to take drugs as second time. In addition, I had to move to my mom's house because I could not work well and could not afford for house rental fees. My mother had to work for earning income for the day that I could not work for the whole family. My wife was busy with two young children at home. However, they encouraged me to treat my disease completely cured. No need to worry for home. They can struggle. Thus, I decided*

*myself to strictly follow doctor's instruction whatever occur"* presented by Ko Swe why he determined to take the treatment for his disease.

He continued, *"For this time, I try as much as I can to get injection daily with oral drugs together. It is very difficult for me. I can't do my work after taking drugs and injection. Furthermore, I have intense dizziness and blurred vision. After returning to my home, I stay at upside-down position in separated place. It is very intolerant suffering. However, I must be stick with my drugs to take daily. Whenever I see my mother and my wife attempt to raise income instead of me, I feel unhappy. Thus I try my best to follow doctor's prescription regularly to improve my health. The midwives who inject me every day also encourages me to inject regularly till the end. Now, I am so happy because I have overcome my injection period, and my sputum results are also good. I just only need 1 month to complete my treatment. Now, I am bringing drugs with me in my bag as I am afraid of missing to take drugs."*

Another informant, Ko Zaw also highlighted his self-efficacy in retaking medication 2 months after stopping his first time treatment.

*"At first, I had to take the drugs only for 6 months. But, I stopped my treatment nearly 6 months of drug taking because at that time, I had to go for a short trip for my job. I thought carelessly myself that it was enough. However, when I came back here, after 2 months, my sputum result was not clear and CXR as well. Thus, I had to continue Cat II and now, I am treating as MDRTB patient because my sputum is still positive after 2 months of assessment."*

He kept on saying, *"Because of my carelessness, it made me in worsen condition. I really feel guilty for it. If I took my treatment completely, I would not need to take drugs next time. Now, I have to take long term treatment as a chronic TB patient. So, I strongly decided myself not to happen like that anymore and I try my best to take my medication regularly. I hope so my sputum results to be clear in next time reassessment."*

*"It has impacts on not only me but also my family. Due to my lack of income, my family encounters many difficulties. But, they always never blame to me anything. Sometimes, they solve problems silently without letting me know. I feel sad. But I can't help them. I can do only is to take the drugs regularly."*

*Besides, now, my elder daughter is also taking anti-TB drug as Cat I patient. I feel very sorry about it whether it is transmitted from me or not. Thus, I am more trying hard to take both drugs and injection regularly for my family.”*

Daw Myint, MDR-TB patient who is taking now her third time treatment also revealed her strong self-efficacy as she is energetic to treat her TB disease till totally clean up from her body.

*“I hope to be cut-off this disease in every time of my treatment, but, I am afraid of not being like that. Because I saw with my eyes that my family members passed away with this kind of disease and I failed to be successfully treated in last 2 times, thus I really afraid of it.*

*Although I feel afraid a bit of not treating my disease clearly, I really want to get rid of this disease from my body. So, I try to follow each and every instruction from health center. My family, World vision, Cat TB (NGO) and health center are helping me a lot in my treatment. I try my best to accomplish my drug taking.*

*I substantially hope so. So, I am taking regularly not only anti-TB drugs but also other additional drugs according to my doctor’s instruction. In this time, although hospital planned to cut my drug taking in 20<sup>th</sup> month, I want to take the drugs up fully to 24<sup>th</sup> month because I think it may be more powerful and clear to get rid of my disease”.*

Even though some informants are not restarted their treatment yet, they have strong desire to consult with doctor if the conditions are favorable for them. Moreover they also have strong self-efficacy to take medication for next time if it is necessary as they want to treat their disease totally; they believe that they can fully follow the prescription in next time. In addition, encouragements from their families and supports from NGOs are also the contributing factors for their self-efficacy.

*“Now I am re-suffering cough and breathlessness particularly in night times. So I would like to check up my health in order to know whether TB disease is still present in me or not. My family members also said that they were so sorry for discontinuing my drug taking, and they encouraged me to take drugs regularly if I still have TB.*

*Now, my grandchildren are settle in here. I no longer need to worry for them. The provider also urges me to take treatment next time when we meet each*

*other. I myself, I want to have this disease totally been cured. Thus, if it is so, I will take drugs fully completed” articulated by Daw Hla who stopped her drug taking for social reasons.*

Another informant, Ko Tin who forgot to send his sputum for reassessment after 2 months of drug taking and stopped his drugs taking for 1 months highlighted, *“I still suffer from cough with sputum, and fever every day particularly in the evening for one month. And also, I can’t ride my trishaw the whole day because of getting easy tiredness. I think that I need to treat my disease attentively next time.”*

He continued, *“Of course, I will surely take the drugs regularly in next time. Because of my disease, I cannot ride my trishaw well. My neighbor who had TB disease at the same time with me now can do his job well after finishing his treatment. I admire him. If he can do, why I cannot do? So, please help me to indicate where I should go and contact to whom. If I have to take the drugs this time, I will surely follow the prescription precisely.”*

#### **4.6.2 I must stop alcohol taking because it affects the treatment.**

Apparently, ability to stop drinking alcohol in alcoholic informants contributes to their self-efficacy for drug taking. Among non-adherence alcoholic informants, their alcohol drinking habit is either the reason in missing their drug taking or the reason for not starting treatment taking. Hence, informants who have decisive desire to stop alcohol taking in order to restart their treatment as prescription contributes to strong self-efficacy in alcoholic non-adherence informants.

U Hla expressed his strong self-efficacy as *“now I realized that my disease is not cured totally because I still feel unwell every day, dry coughing and easily tired, and also I can’t work the whole day. Furthermore, my wife had attended TB health education session in the ward and told back me and encouraged me to restart treatment. So I want to restart my treatment expectantly and stop drinking alcohol if necessary.”*

His wife said, *“Every morning he has to wake up at 3a.m. to upload grocers and their green-grocery. We are mainly earning money by doing it. Now, he still has disease symptoms and I’m worried about him. I asked World Vision’s provider and other people how to do it.”*

*He continued, “Now my boat is hired to others with monthly fees because this season is not good to work for transportation fees. So, I have monthly income and my elder son can now support our family with his salary. I hope that I can treat my disease well. Surely I hope so. I will follow as far as I can with the instructions from staffs at health center.”*

*U Thar who has not restarted his MDRTB treatment also expressed that “I believe myself can do take the drugs next time. I can do it last two times. The provider in our ward is also welcome to help me if I restart my treatment taking. I can stop my alcohol taking. No doubt to do that because for last two times treatment taking, I wholly stopped my alcohol. Why not for this time.”*

#### **4.6.3 I no longer withstand the effects of drugs. If I will die, let it be.**

On the contrary, it can be found that some informants from the study have poor or no self-efficacy in taking their medication. Noticeably, they all have been harshly affected by the effects of anti-TB drugs with or without having associated diseases even though their reasons for stopping drugs taking are different from each other. They have simply lack of belief that they can withstand the side-effects of drugs which they suffered as their own experience. So that, they assessed themselves they have no ability to take the drugs any more.

*Daw Thoung expressed her self-efficacy related with treatment taking, “The reason why we came to Yangon is my daughter and I will do something here. Before starting anything, I was diagnosed as TB patient. After that, I had taken anti-TB drugs for more than a year but my condition became worsen and worsen. Our money is depleting gradually. I was bed-bound, my daughter has to stay beside me and taking care of me till now. She can’t work. During that time, I thought that why their so-called TB was not relieved though I took the drugs continuously for long time. I became disbelieved that I have TB. It is due to being as a post-menopause of me. So, I decided not to take drugs anymore. After stopping drugs, I feel very well, weight gain, my face is clear, and there is nothing abnormal. How would I have this kind of disease? My decision is right.”*

*She carried on, “these drugs didn’t bring any good things to me. This can only cause harmful side-effects to me. I suffer severely due to these drugs. Due to TB*

*drugs taking without really having TB disease, I am being like that. Now I totally do not trust both TB disease and these drugs. It brings so many bad things to me. Now, I feel regret that I should not take this drug. I don't need to be bed-bound. When I feel well, my daughter will have a chance to find job in Yangon."*

She and her daughter are dependent on supporting from her son who is working in another town. Now, he has got married and can't support them. Her daughter can't work in Yangon as she has to take care other mother. Hence, they are now too difficult to continue to stay in Yangon and have to go back to their native town, Sittway.

Another informant, Daw Mar described her self-efficacy as *"After being diagnosed, the doctor said to me that I need injection daily. It was a big difficulty for me to find injection place every morning. Surplus I really can't withstand my severe dizziness and weakness of lower limbs. Just now, while I am speaking with you, I still feel blurred vision. I no longer care whether these drugs are effective or not. My husband and my sons also told me that I should stop to take drugs, it may be dangerous not because of TB, but because of drugs and injection. They saw that how much I was suffered and difficult in taking medication. Willingly, I decided myself not to continue my treatment. **If I will die, let it be.***

*I am so afraid of continuing my drugs taking because I really do not withstand this severe dizziness. There is no one to help me at home as well. Also, I do not want to be in trouble to find injection place every day."*

Daw Mar has been suffering from severe dizziness and weakness in both lower limbs as side-effects of drugs during her second time treatment as well as facing difficulties in finding place for injection at the right time every day. These difficulties make her lack of belief to continue and contributes her to be in poor self-efficacy for taking drugs.

In addition, informant 6, U Tun articulated with tears in his both eyes, *"I asked the doctor whether this drug is really good for me. I can't believe it. Before starting my drug taking, I can walk, I can do everything. Because of this disease and these drugs, I have to stay on the bed every time. How much it has impacts to me. Due to these drugs, I can't go anywhere. Furthermore, I have never been known that I have Diabetes. After taking these drugs, I get this disease and my blood sugar level is so*

*difficult to control. I can't afford to monitor every day, and can't buy other needed drugs for it. Due to this disease, I have to divide my I compound and sold it one part after one. Now, I had to move and stay with my elder daughter. But, I do not relieve from my suffering. I feel really afraid of continuing these drugs taking.*

*If somebody ask me whether they should treat their TB disease, I would tell them, especially those who are poor and helpless like me, that please think carefully before starting anything.”*

#### **4.6.4 I would no longer be troublesome for my family.**

In order to treat TB, family support plays an important role in accomplish treatment. There is a great difficulty for informants to continue their treatment taking without supporting from their family members either moral or financial support. These lack of support from their family not only cause poor self-efficacy in informants but also cause them to stop or not to restart their drug taking.

Ko Myo who needed to treat his disease for long-term voiced with very soft tone as *“I cannot work well for six months due to my back bone TB and nearly bed-bound for 2 months. Thus, our whole family only depends on my uncle-in-law's earning money which is normally just enough to eat for whole family. Not only that, but there is an extra cost for my medication as well.”*

*He carried on, “My uncle-in-law is not pleased to support me because I am not from his side relative, and I need frequently to go to the clinic. Furthermore, his work is not stable these days and his income is just only enough for daily expense, not enough for an extra cost. My back bone is not in a straight line and too weak to stand upright position so that I can't walk well. Ache and pain in both legs is more severe during night times. So, I needed to call the doctor in most night times. It can cost 6000 kyats each time. My aunty has to borrow money from others. So, how can I continue my treatment which may be long time? Moreover, I need to take the nerve tonic and some analgesic to relieve the pains which are also expensive for me. So, I abandoned my drug taking. I would no longer be troublesome for my family especially my aunty who always takes care of me as her son since I was young.”*

#### **4.6.5 I have both HIV and TB, I may have to take the TB drugs for longer duration than others and I don't think these drugs can be effective for me.**

After 32-year-old Ko Win stopped his drug taking, health staffs from health center visited him and called him to come and take the treatment again. But, he will not go there again because he did not like to take treatment for 8 months together with injection. Now he stopped it for 8 months. He has low self-efficacy for drug taking because he feels that he has two infections so that he may need to take drugs more than 8 months for second time. It is intolerant to him especially daily injection for two months regularly. Furthermore, due to the nature of his work, he does not believe himself to take drugs regularly. Moreover, he cannot withhold his alcohol drinking during drugs taking. In addition, he believes that anti-TB drugs can only bring bad things to him instead of soothing his sufferings.

*“Because I have both HIV and TB, I may have to take the TB drugs for longer duration than others. For me, I can't wake up early in the morning every day (he wakes up at 5am every day to take the drugs). As I said to you before, my work sometimes take time till midnight, or sometimes I drink alcohol at night, so how I can wake up early in the morning. Moreover, the drugs affect me so bad. I can't eat, I can't sleep well, I feel weak because of this drugs. I feel more severe tight of chest and I usually cough up with dark brown colored sputum in the morning. I don't think that these drugs have curative effect for me. As I said you earlier, my sufferings are more severe due to this drug taking.”*

#### **4.7 The reasons of non-adherence concerned with perception of disease, perception of health service and self-efficacy.**

The reasons or factors related with their noncompliance behaviors of the informants are multi factorial as well as their decisions or willingness whether to restart or not to restart their treatments are also diverse. It is obvious that no single reason of non-adherence to the health care service was found in the informants. The surrounding environment, living and working conditions, social participation and local dynamics of health systems in which slum people are living are also contributing to their behaviors.

Based on their socioeconomic backgrounds, non-compliance informants perceived their self-efficacy related with drug taking, perceived about available health service and perceived TB disease through encountering following experiences correlated with their treatment taking.

#### **4.7.1. TB is a common disease**

The study area is densely populated slum area and their living situation (congested housing, narrow space, poor light and ventilation, poor sanitation measures) are favored for infectious disease occurrence in the study area. Most of the people living there come from disadvantaged backgrounds. Hence, some infectious diseases like TB, HIV, malaria, Dengue is generally common and the local people also have their own experienced of TB patient in their lives as being residents of this area. Besides, a number of NGOs and local philanthropic groups are helping local people to control the diseases by providing health education to the wider public and other necessary measures in taking treatment.

On the other hand, TB infected people from other parts of the country are also moving to this area. Hence, most of the local people are too familiarized with TB disease not to be taking into account TB as a strange matter. As a result, informants and people in the surroundings lack of awareness to take care about this disease and mode of transmission of it although most of the informants perceived TB as an infectious disease that can be transmitted through the air.

Even though all the informants in the study have somewhat perceived that they have to fully follow the prescription (right time, right dose, right interval) for a long term, doing with necessary investigations in order to cure their TB disease, the most important point is they all do not perceive how much it is important to be successfully treated their disease. Furthermore, only half of the informants believe that their disease can be cured with anti-TB drugs. The last but not least, despite the fact that almost all of the informants have heard multi-drug resistant TB (MRDTB), they do not know exactly what it is, what the extent is and impacts of it to the community and being themselves.

#### 4.7.2 Consequences of disease

**Physically:** All most all of the informants suffer from physical weakness, listlessness to do something, cannot concentrate to anything, loss of appetite and more or less severe weight loss and feel effortless to do anything due to their illness. Not only their disease but also the effects of the drugs have great impacts on the physical status of the informants. They also cannot sleep well at night, severe dizziness, burning sensation in the chest, intense itchiness on the whole body which is troublesome for their physical appearance.

Moreover, in order to take or to inject the anti-TB drugs at regular time, most of the informants are uneasy to do daily because of their physical illness. In addition, some informants who have associated diseases like hypertension, heart diseases are more difficult to control their diseases during drug taking, which lead them to non-adhere to the prescription.

**Socially:** Even though some documented literatures stated that TB patients and their families have been avoided from social surroundings, or social activities. However, in the study, most of the informants have not experienced about it because the studied community is very accustomed to TB disease, closed with each other and people in the community have experienced with TB patients being as a resident of this area. Thus, they hardly practice to follow any barriers method to prevent or not to transmit the infection to others.

**Financially:** Significantly all most all of the informants cannot work well during their drug taking. Some had to entirely drop out from their job or some cannot work the whole day or cannot go to their job every day; consequently, they cannot provide enough money for their family. As lack or reduced family incomes, their families face many financial hardships especially in the families which the informants are head of their families. Not only this, these lack of effort to work make some informants became the burden of their families too. Furthermore, some family members cannot work well as they need to take care of informants, which is one of the financial impacts of the disease on the informants and their families.

### **4.7.3 Consequences of drugs**

Not only disease itself, but also the side effects of drugs also conveyed several undesirable effects to them, leading informants stop their drug taking. In spite of the fact that it can be varied in severity of suffering from side effects of drugs in informants, all the informants have been more or less affected by drugs' affects. As a result of this, some stop to continue their taking treatment. Some become bed-bound for long time; consequently, not only informants but also their families have been more overloaded by financial difficulties, which become the main reason in informants to halt their drug taking. Moreover, appalling to endure these effects of drugs lead one informant not to restart their treatment.

Furthermore, almost informants have perceived to take anti-TB drugs for long term to cure their TB disease but they do not perceive that how and what they may face with side-effect of anti-TB drugs particularly among first time treatment-taking informants. Simply, they think that if they have Tuberculosis, they have to take the drugs from health center for 6 months.

### **4.7.4 Lack of social/financial support from family**

The social or financial supports from family play an important role to accomplish the treatment taking in the informants. They need their family's helps in so many ways. Thus, the informants in the study who cannot be provided from their families had to stop their treatment taking.

Due to lack or inability to contribution of family members, some informants face many hardships during their drug taking in terms of drug taking, going to the health center, daily injection, cost for transportation, charges for unsupportive drugs, treatment cost for their comorbid diseases because they could not stand their own due to their illness during their drug taking. Thus, they have to stop drug taking.

### **4.7.5 Related with health system**

Even though the services for TB diseases like consultation with doctors and other health staffs, charges for anti-TB drugs, charges for sputum examination are free of charge, in the study, informants have perceived about available health services as either unavailable or inaccessible to them with some limitations based on their

encountering during their treatment taking, which is favored by their underlying socioeconomic status.

#### 4.7.5.1 Limitations related with health staffs

As any TB patients have to receive long term treatment, they have to communicate with health personnel for long time. The informants in the study also need to in-touch with health personnel throughout their drug taking. Some of them have argued with those people in case of following the drug regime and procedures to do investigation according with their respective prescriptions, which can lead them to stop their treatment taking, as a result of this, they hold negative perception about health staffs. In addition, some feel unease and inconvenience in relation with health staffs due to time limitation to meet with them.

#### 4.7.5.2 Unavailable health service

Though all the informants in the study get anti-TB drugs with free of charge, some have problems with available health service. As an instance of this, apart from Cat I informant, most of the informants need to take regular injection according with their prescription. Some encounter difficulties in finding the place to inject every day because of unavailable health service in their living.

#### 4.7.5.3 Inaccessibility to health service

Although the location of health centers are not far away for the informants, some have difficulties to go there especially for informants who require to take daily injection treatment and informants who have to take prolonged treatment as they cannot go there by bus or by walk due to their illness. They confront for taxi fares especially for informants who are not supporting from any organizations in the study area.

Furthermore, as they are daily wages workers, or their accompanying persons are daily wages workers, it would obvious that when they go to hospital and wait for long queue cause them lack of income generation for that days. Despite getting anti-TB drugs, doctors' fees, nurse and sputum examinations' charges with free of charge, all most all the patients have to pay for chest X-ray and some contributions as donation. Though these amount of money are not too much and reasonable, some participants are not really affordable to pay it.

In addition, some informants who have other diseases need to take some drugs plus anti-TB drugs like anti-hypertensive, drugs for their blood sugar control, etc. as well as they need to go to hospital or clinic frequently for their associated diseases during their anti-TB treatment taking. These all matters deter some informants from accessing to health services especially for non-supported informants.

#### 4.7.5.4 Their social and economic contexts as a barrier

Because of their illness, both informants and their families are facing many financial hardships as a consequent of reduced family income. Hence, sometimes, they try to do their work to fulfill the needs of their family without taking care to strictly follow the prescription till the end of the prescribed period.

On one hand, the supports from family play an essential role to accomplish the treatment taking in the informants. Due to lack of contribution or incapability to contribution of family members, some informants face many hardships and have to abandon their drug taking. `

Furthermore, alcohol taking is one of the factors which deter some informants directly or indirectly to continue or to restart medication particularly in male informants. 7 out of 8 male informants in the study are either strong alcoholics or social drinkers. Because of alcohol drinking, some informant in the study still cannot start to take his medication for quite a long time. Likewise, the reason for some informants miss their drug taking is due to their alcohol drinking.

## **CHAPTER V**

### **CONCLUSION, DISCUSSIONS AND RECOMMENDATIONS**

#### **5.1 Conclusion**

Purposes of this study are to describe the socioeconomic factors related to accessibility of health care services among non-adherence TB patients living in slum areas of Hlaing Thar Yar Township, Yangon, Myanmar and to understand the perception of non-adherence slum TB patients to the disease, available health service and their self-efficacy related with anti-TB drugs taking. An explanatory qualitative research design was used for this study by applying Health Belief Model and Self-Efficacy as lens to allow the patients feel free to express their perceptions and self-efficacy for drug taking throughout their medication based on their socioeconomic contexts.

Research spent four months for in-depth interviews, key-informants interviews and participant observations after getting approval from Institutional Review Board (IRB) committee of Mahidol University. 12 non-adherence TB patients who stopped or not started their anti-TB drug taking without completing their prescriptions are observed and in-depth interviewed at their convenient and available times after getting informed consents from them. In addition, 7 key-informants including health care providers, social worker, close friend and family member of the patients and TB providers are carried out as key-informant in-depth interviews.

To sum up, regarding with their encountering before, during and after treatment taking, it was found that these non-adherence slum TB patients perceive TB disease, available health services and their self-efficacy as following:

##### **5.1.1 Perception about Tuberculosis**

**Nature of TB:** Not only patients but also their families, people in their environments perceive TB as a common illness for them. In other words, they perceive TB as a disease that everyone can get once in their lives. On the other hand, apart

from a few patients, most patients in the study perceive that Tuberculosis is an infectious disease which can be transmitted to each other by the air as well as if someone in the family has the disease, there is a potential to get infection in all family members.

Apart from a few informants, all the informants in the study have somewhat perceived about they have to fully follow the prescription for a long term in order to cure their TB disease even though they are not certain what time they have to take investigation, what the changes in their prescribed drugs. Nonetheless, only half of the patients perceive their disease can be cured by medication.

**TB susceptibility:** many patients, some their neighbors and key-informants in the study perceive their susceptibility to the disease when patients have suffered symptoms like prolonged cough, low grade evening fever, weight loss and easily tired.

**Outcomes of disease without treating properly:** all most all of the patients do not perceive in details related with disease outcome of improper treatment taking. Moreover, they do not perceive about MDRTB exactly what it is, what the extent and impacts of it to the community and being themselves.

**The impacts of TB:** Apparently, all most all of the patients have not perceived that they have socially impacted by the disease either in their family or in their surroundings. On the contrary, a few patients have perceived that they have inadequate social support from their family members not because of their disease but because of economic reason.

However, on the other hand, all the patients and their families perceive that they have a great deal of financial impacts because of both disease and side-effects of anti-TB drugs. Significantly all most all of the patients cannot work well during their drug taking. Some have to entirely drop out from their job, some cannot work the whole day or cannot go to their job every day; consequently, less or no income in them and cannot provide enough money for their family. As lack or reduced family incomes, their families face many hardships especially in the families which the patients are head of their families. Not only this, these lack of effort to work make some of the patients become the burden of their families too. Furthermore, some family members also cannot work well as they need to take care of patients.

### **5.1.2 Perception about Health services**

Even though the services for TB diseases like consultation with doctors and other health staffs, charges for anti-TB drugs, sputum examination are free of charge, in the study, patients perceive about available health services as either unavailable or inaccessible to them based on their encountering during their treatment taking, which is favored by their underlying socioeconomic status.

In term of availability of health services, it is perceived as unavailable services for the patients because during their drug taking, they are facing difficulties in finding services to inject every day at a regular time, time constraints when they are taking drugs on an appointed day, unavailable free supervision of health personnel to the patients who need not only to take anti-TB drugs but also to take other necessary drugs for their associated diseases like Hypertension, Diabetes. As a result of this, they hold negative perception to the health staffs and health services as unavailable for them.

Concerning with access to the health services, it is perceived as inaccessible to the patients with some limitations based on their encountering during treatment taking, which is favored by their underlying socioeconomic status. The reasons why are (i) some patients are not easy to go there by bus or by walk due to their illness (ii) waiting as long queue at the health center cause lack of income generation in patients and their accompanied persons for that days (iii) even though all health services for TB can be available with free of charge, some patients who have associated disease perceive disparately as inaccessible because they require to take additional drugs for their associated disease and need to go to hospitals or clinics frequently for their associated diseases. These services cannot access with free of charge and they can't afford to pay it.

### **5.1.3 Self-efficacy of TB patients with their anti-TB treatment taking.**

Related with self-efficacy, it can be seen that non-adherence TB patients in the study who are now restarting their treatments as new categorized patients have high self-efficacy as **“I need to restart my treatment”**. Moreover, though some patients are not recommenced their treatment, they also have strong self-efficacy as **“I must stop alcohol taking because it affects the treatment”** to take full medication

for next time after consulting with doctors. Additionally, their family members' scarified supporting and encouragements, their own TB experience, supports from NGOs make them to believe their ability to take drug and have strong self-efficacy.

For the patients who haven't restarted or who have no desire to restart their drug taking have low or poor self-efficacy as they believe that they have no materialistic efforts to follow the prescription or they have no physical and emotional support from others as **"I no longer be troublesome for my family"** or they can't withstand the drug effects **"I no longer withstand the effects of drugs. If I will die, let it be"** or they do not believe that the drugs are effective **"I have both HIV and TB, I may have to take the anti-TB drugs for longer duration than others and I don't think this drugs can be effective for me."** In addition, their loss experience of failed to encounter the side-effects of anti-TB drugs during their drug taking also cause them to be low in their self-efficacy.

To sum up, the reasons or factors related with their non-adherence behaviors of the patients in the study are multifactorial as well as their decisions or willingness whether to restart or not their treatments are also diverse. It is obvious that no single reason of non-adherence to the health care service is found in the informants. As well as, the surrounding environment in which they are living, living and working conditions of both patients and their families, social participation and local dynamics of health systems in the study area are also shaping their perceptions about TB disease, perception for available health services and their self-efficacy for their non-adherence to the drug taking.

## 5.2 Discussion

Apparently, most patients are living in small detached houses in which usually contain only one room and kitchen, not enough space for all family members with poor light and ventilation. Even this small house cost average 40,000 kyats/month as a rent. All family members are using the same room for eating, living and sleeping. Moreover, the sanitary measures, water supply are not good enough and electricity is accessible irregularly. Majority are living as extended family type and their sizes of

family are large. It is discovered that these poor living situations lead them prone to get infection more easily.

According to the Health Belief Model, different people will take the different actions to resist, to find out, or to face unwell-being situations in them if they assume themselves as susceptible (perceived susceptibility) to the surrounding happenings, if they convince that there is needed to avoid serious results in them (perceived severity), if they take a specific change in behavior will be a benefit by resulting in a valued outcomes (perceived benefit) (i.e. the disease will be effectively prevented or cured by taking action), and if they are certain that the barriers (e.g. cost, inconvenience, pain, time) to take the action are outweighed by its benefits (Rosenstock *et al.*, 1988).

In addition, a person's behavior is likely to be influenced by cues that can trigger to take action. It may be internal (e.g., symptoms) or external (e.g., mass media, illness experience of others, education for illness). Moreover, the other factors such as demographic variables (e.g., sex, age, race, ethnicity), social psychological factor (social class, group pressure) and structural variables like poverty and religious norms have proved that need to be taken into consideration by many researches based on model. These variables, especially socio-demographic factors of levels of education, can impact both directly and indirectly on perceived threat and benefit (Becker & Maiman, 1975).

Self-efficacy refers to an ability of someone to achieve something, to produce the intended result based on its own cognition, which is in turn, strongly related to actual ability of someone (Albert Bandura, 1977). Self-efficacy of TB patients contextualized as how much TB patients believe in their ability to start to take treatment, comply with treatment until the end of the prescribed period facing with barriers and hindrances related with their anti- TB drugs taking. In other words, the stronger the TB patient's self-efficacy, the more likely they engage in their medication.

Based on the significant findings of the study of non-adherent slum TB patients in the Hlaing Thar Yar Township in Yangon, all non-adherent patients experience various conditions which are prominently rooted in their disadvantaged socioeconomic conditions. Thus, the reasons behind their non-adherence are

multifactorial. In addition, a complex net of health system and the role of community have largely contributed to their non-adherence to drug taking. These findings are consistent with previous studies of drug adherence in TB patients in Canada (Orr, 2011), and other infectious disease (Farmer, 1999).

In the study, regarding with nature of TB, most of the patients perceive that it is an air borne infectious disease as well as if someone in the family has the disease, there is a potential to get infection in all the family members. Likewise, when they suffer symptoms of TB, about half of the patients, some patients' neighbors and key-informants in the study have perceived about their susceptibility to the disease and they try to go to health center (contributed the strength to act), which is persistent with the Health Belief Model.

On one hand, few patients perceive their disease can be curable and they have not perceived what they might come across during taking medication in terms of physical, social and financial impacts. As a result of this, they have simply no proper measures in advances to face them, which can contribute them to easily stop their medication. Besides, all most all of the patients do not perceive in details related with disease outcome of improper medication; MDRTB and the wideness of its impact.

According to Health Belief model, the non-adherent TB patients in the study have perceived their susceptibility to the disease, but they have not perceived the severity of TB disease (MDRTB). For perceive benefit (disease curability), only few patients perceive as TB is a curable disease. Furthermore, they perceive that impacts (physical, social, financial) of the disease, side-effects of the drugs, unavailable and inaccessible to health services in them as barriers. On one hand, their socioeconomic status, comorbid diseases, ability of family support, role of NGOs in the area are considerable factors in their medication.

Related with self-efficacy, socioeconomic conditions of the patients also play an important role in their self-efficacy for drug taking. Socioeconomic conditions in which getting socially supports and encouragements from their families, sacrificed financial supports from their family members likely to contribute to improve their beliefs to take their medication in the patients. Additionally, by assessing their own experience in which they stopped their medication for their socioeconomic conditions such as stopping drugs for working conditions, family related reasons, arguing with

the health staffs, they believe themselves to overcome this socioeconomic barriers when they consider whether to retake their medication next time. Surplus getting financial support from local organizations also tend to improve their belief to take medication.

Hence, some patients in the study can hold high self-efficacy for drug taking when they get their family's support or supports from others or when they motivate themselves from their own previous experience or when they witness others' experience that makes admire them. These contribute them to believe their ability to take medication. Thus, due to their high self-efficacy, some TB patients are retaking their drugs with new regime. Some have desire to restart their drug by consulting with doctor or by cutting their alcohol drinking.

On the other hand, having experience of failure to encounter their sufferings from side-effects of drugs and socioeconomic barriers (their loss experience in previous medication) and lack of social or financial support or incapability to support from their families and others cause some patients to have lack of belief in themselves to continue or to restart their treatment taking. They do not believe themselves that they can withstand the side-effects of drugs or they can overcome their socioeconomic barriers or they can fully follow the medication by assessing their ability. This can lead them to have low or poor in self-efficacy. In addition to this, no effort to follow the prescription or having other associated diseases are contributing to their poor self-efficacy. Hence, patients with low self-efficacy have no desire to retake their drugs.

In structural and functional perspective, social institutes such as families, schools, community, institutes, etc. are interrelated and interdependently linking to each other, dominating the society. Likewise, in the study, TB patients and their adherence to the medication are affected and influenced by their families, the local community and the local health system respectively. And, there are some structural barriers to improve provision of health care to the TB patients in the study area.

Related with the health system, the number of health staffs for the area is inadequate to cover the needs of the TB patients, unavailable to support free or reasonable health services for TB patients who have associated disease, some gaps in messaging health education and lack of taking into consideration socioeconomic

factors of the patients in providing health services. These all things tend to contribute the non-adherence behavior of the TB patients.

In the urban slum context, it is necessarily need to consider not only the supply of formal health care, but the role of the community who also shape the health status of local people. In the study, the community are lack of awareness to the disease and its transmission as they perceive TB as a common illness as well as lack of awareness to take care of drug taking in TB patients. Furthermore, the lack of awareness about outcome of improper treatment in the patients by their community as a whole have affected to the drug adherence to the TB patients. In addition, most of the non-adherence TB patients in the study are non-supported from local organizations. Thus, it points out that it is needed to expand their providence to TB patients to cover the needs of the TB patients in order to adhere to their drug taking.

In addition to this, lack of effort or incapability to provide money to the patients by their family members as well as their less time spending for the patients in taking medication also largely contribute non-adheret to drug taking in TB patients.

### **5.2.1 Socioeconomic contexts contributed to non-adherence of treatment among TB patients**

Most of the patients and their family members are unstable daily wage workers and generally, their incomes are just enough for basic family expenditures. Furthermore, there are some dependent people in their families. Thus, when patients take their medication, their families face many financial hardships especially in the families in which TB patients are head of their families.

Significantly all most all of the patients cannot work well during their medication not just because of their illness by disease but because of suffering from side-effects of drugs. Therefore, some have to entirely drop out from their job because of their illness. Some cannot work the whole day or cannot go to their job every day; consequently, they cannot provide enough money for their family as well as they are facing the risk of losing their jobs.

Not only this, these lack of effort to provide money to their families also cause them to become the burden of their families too as their family members need to find more money to cover income of patients. In addition, some family members of the

patients cannot work well as they need to take care of them, which leading the whole family more deepening into financial difficulties. Hence, not only their disadvantaged socioeconomic condition cause them to easily get disease, they are also plunged deeper into poverty as a consequence of TB, running as a vicious cycle.

In addition to this, this study found that their level of education also plays an important role in their non-adherence to the treatment. Most of them are being poor and they have no chance to attend the school to the high school level so that their capacity to absorb all what the health staffs said is hardly possible. Besides, less privileged backgrounds of their lives deter them from getting knowledge about disease from other sources as they cannot afford to access other media like television channels, newspapers, networking. This can largely contribute them not to achieve required knowledge related with their disease and lead them to abandon their drug taking easily. This is also similar with studies in Zambia (Kaona *et al.*, 2004) and in Turkey (Halim, Rasyid & Ahmad, 2006) which observed that patient behavior is largely effective by the knowledge about their disease and outcomes in non-adherence patients.

As an instance of this, some patients who perceive that their sufferings are relieved, gain weight and good appetite after 2-3 months of drug taking are easily stop to take the drugs when they are suffering from the side-effects of drugs or encountering other socioeconomic hardships in them or in their families. This is the same with the study about TB patients in Indonesia which revealed that most TB patients stopped DOTS treatment when they are starting to feel better in combination with lack of money and can't withstand side-effects of drugs (Widjanarko *et al.*, 2009). It is also consistent with the study of improved knowledge about TB disease had been positively associated with treatment adherence of TB disease (San & Bothamley, 2000) (Dick & Lombard, 1997) (White *et al.*, 2002).

Other studies have proved that TB is social suffering disease because people perceived that TB is hereditary or it is a disease of poverty and one of the leading factors in non-adherence of TB treatment (Martin, Grace & Kelly, 2008). However, it is apparent that in the study, TB is perceived as a common illness and not a peculiar matter in the study area and social sufferings seem to play a less important role in drug adherence of TB patients in the study.

Next interesting point is that alcohol taking is one of the factors which lead patients directly or indirectly to stop or not to restart medication particularly in male patients. Because of alcohol drinking, some cannot start to take their medication for quite a long time as well as missed drug taking in the drunken days. These findings are also coherent with the studies about patients with tuberculosis in the Arkhangelsk region. The study also found that three context conditions (ineffective health system, alcohol taking, poverty) led to the four consequences; delayed in health seek, develop MDRTB, increased rate of drop-out & reduce the rate of recovery (kuznetsov *et al.*, 2013).

Last but not least, mostly their working natures are physically demanding and require to use much of their strength in patients. Besides, not only their disease but also the effects of the drugs have largely impacted on the physical status of the patients. They also cannot sleep well at night, severe dizziness, burning sensation in the chest, malaise, weakness of all limbs and body, intense itchiness on the whole body which is troublesome for their physical appearance in working. Thus, their physically demanding working nature also conveys their non-adherence to drugs when they necessarily need to work for money, instead of resting at home in order to relieve suffering from side-effects of drugs.

### **5.2.2 The role of the family and community in adherence of drug taking among TB patients**

Another reason for why they cannot adhere to their treatment is some patients have no family member either to take care of them or to go along with them to health center as all family members need to go for work to cover the family expense instead of the patients. Correspondingly, some family members who have stable job also cannot go along with them because they are afraid to lose their overtime fees.

Additionally, TB patients need their family's helps in so many ways during taking medication, for instances, in taking medication regularly for long term, financial assistance for transportation cost and some unsupportive drugs, preparing for something to eat to be withstanding the side-effects of drugs throughout long-term medication, and medical cost for their associated diseases. However, their families cannot adequately support the patients because they are dependents of the patients or

they themselves are unstable workers or they simply cannot find enough money to support the patients.

Due to lack of contribution or incapability of contribution by family members, TB patients in the study face many hardships during their drug taking. This can contribute to lack of confidence in patients to keep taking medication. These findings are persistent with the studies in which proved that the degree of treatment adherence in TB patients can be reliable on the levels of patients perception of materialistic and psychological supports from their families and closed persons (Garner & Volmink, 2006) (Chong & Lopez, 2005).

Another significant finding is not only the patients but also most of the local people in the community are too familiarized with TB disease not to consider TB as a conscious matter. The reasons behind are that TB is so common in that area and local people have their own experienced with at least one TB patient in their lives as being residents of this area. Additionally, many TB patients are moving to this area in order to take the treatment. Thus, they perceive TB disease as a common illness for people in this area.

As a result, patients and people in the surroundings have lack of awareness to take care about this disease and mode of transmission of it although most of them are informed about it. As well as, they hardly follow any barrier methods to prevent transmission of infection from one to another. Thus, when the patients start to take anti-TB drugs or stop their drug taking or complete their treatment, the community has no strange feeling for that. This can result in the patients not to take care of their drugs taking regularly till the end of prescription. Furthermore, this lack of encouragement from their community and family can also contribute to the patients lower in their self-efficacy and less likely to adhere to their drug taking till the end of prescription.

Thus, the community as a whole (1) do not perceive that what causes lead them to get infection, (2) perceive TB as a common illness (3) lack of awareness about outcome of improper treatment in the patients and (4) lack of awareness to take care of drug taking in patients and disease transmission naturally favor the conditions for the patients not to adhere to their drug taking. In addition to this, lack of effort to provide money and less time spending from the family members to the patients also largely contribute their non-adherence to drug taking in TB patients.

### **5.2.3 Constraints and gaps of health care services for TB patients**

Even though the services for TB diseases like consultation with doctors and other health staffs, charges for anti-TB drugs, sputum examination are free of charge, in the study, it was found that patients perceive about health service as either unavailable or some barriers to access to health care services and insensitive with their socioeconomic contexts grounded on their encountering during their treatment taking, which is fueled by their underlying socioeconomic status.

In the aspect of accessible to health care service, it was found that TB patients face barriers to get medical care such as out-of-pocket expenditures, time spending, transportation cost, charges of CXR and treatment cost for their associated diseases. Although the places of health services are not far away from their living, they need to charge for transportation cost as patients are not easy to go there due to their illness. Besides, waiting for long queue at the hospitals cause lack of income generation in patients and their accompanied persons for that days, as a result of this, they have to borrow money from others or they mortgage their belongings to solve income generation for that day. Thus, they perceive as inaccessible for them.

Treatment cost and charges for the drugs are also main barriers for patients who have associated diseases as they require to take additional drugs and need to get close monitoring with doctors during their anti-TB drugs taking. However, TB patients and their families cannot afford to pay for this medical fees and also, they cannot be supported it with free of charge from TB health care service. Hence, even though they can access health services for their TB with free of charge, they are inaccessible to health services for their associated diseases.

Besides, some patients have confrontation with health staffs due to time constraint when they are taking drugs from them, as a result of this, they hold negative perception to the health staffs. This is because time set by health staffs are not convenient for them as they have to go for work, or other their socioeconomic reasons.

On the other hand, the midwives in the study have to take responsibilities of at least 2-3 wards as allocation. Not only that, they have to undertake many assigned duties to accomplish in their allocated wards, which are not only concerned with health related issues. Moreover, only related with health issues, they have to tackle many tasks. Thus, they need time partition to be finished in time all the tasks.

In addition, this study found that all most all of the patients do not perceive what they may come across during taking medication, particularly with potential side effects of anti-TB drugs, outcomes of incomplete treatment and, its large impacts. Likewise, in some health education sessions mainly emphasize on message about symptoms of disease, and encourage people to come and take medication when they get symptoms of TB.

Thus, TB patients in the study try to go to health center when they suffer the symptoms, but they do not try to take full course of medication when they face difficulty that they perceive as a barrier. Thus, this information gaps tend to lead the patients not to adhere to their drug taking effortlessly. In other words, health staffs in the community can raise awareness of the local people about symptoms of TB. But, they are unlikely to convince TB patients to take fully medication.

Thus, it would appear that health staffs are insufficient in number and their assigned works are overloaded for them, which likely to cause them not to fully emphasize on management of TB patients, particularly in providing adequate health knowledge, drug taking and reassessment of it. There is needed to increase the number of health staffs at the study area in order to improve the drug adherence of TB patients. Thus, such weakness in quality of care fuel non-adherence behavior in TB patients. These factors have been commonly and consistently found in many studies (Martin, Grace & Kelly, 2008) (Munro *et al.*, 2007).

However, on the other hand, it is sensible to say that health personnel in the community tend to focus in behavior change or individual intervention to make people adhere to their medication but in fact, there are also needed to take into fully consideration their socioeconomic factors which play an important role in their daily lives. Surplus it seems to do social interventions in both patients and community in the health care program for the study area.

Next reason for why they do not adhere to their drug taking is that they are unsatisfying to the services and treating behaviors of the health staffs. Being shouted by health staffs in front of others and some manners of their treating to the patients discourage them to continue their treatment or to restart their treatment.

To sum up, health care services that is apparently available but in reality, it is not adequate, unavailable and not accessible due to not accordance with patient

needs (e.g., hours of operation, long waiting time, lack of income generation for the days going to health center, cost of transportation, out-of-pocket expenditure for unsupportive drugs and treatment cost for associated diseases). These are more enforcing by the less privileged socioeconomic contexts of the patients and leading them to not adhere to their drug taking.

### 5.3 Recommendations

**Recommendation for non-adherence TB patients:** non-adherence TB patients have perceived TB disease as a common illness; they have lack of awareness about disease transmission, and no perception about outcomes of improper treatment taking. These attitudes and perceptions should be changed for the sake of themselves, their family, and for the community as a whole.

**Recommendation for health care providers:** Treatment adherence of TB patients can be improved by providing efficient and affective health education including treatment duration, potential side effects of anti-TB drugs, devastating impacts of non-adherence, which can raise the awareness of both patients and local people. Furthermore, not only adequate comprehensive health care services which is responsive to the patients' actual needs but also facilitating procedures in receiving treatment for TB patients should be provided in order to improve the drug adherence of TB patients.

On the other hand, the health authorities concerned should support the adequate number of health care providers for the community to be adequately cover the health needs of the TB patients. Furthermore, the existing health care providers should have been supported with refreshment courses or some incentives to encourage or to facilitate them to provide health care services to the TB patients.

**Recommendation for community:** The community as a whole in the study area perceive TB disease as a common illness and lack of awareness about transmission of disease. By raising awareness and enhancing the practices of prevention to disease transmission in local people, the community can be advantageous because it can prevent the people in community from transmission of TB disease from one to another.

Moreover, the community should provide volunteers for TB patients to go along with them to health center or to inject every day. It can help TB patients to better adhere to their treatment regularly till the end of prescribed period on the one hand and it can help the patients' family members who are tired for taking care and finding money for the patients on the other hand.

**Recommendation for further research:** Further qualitative studies with different perspectives should be done in different times and different places especially in overcrowded areas where fundamental people are living in order to be narrow the gaps between available health care services and the needs and sufferings of the TB patients.

Moreover, by doing so, it will achieve more competent and supportive findings and more understand the actual requirements of the TB patients. This can contribute to improve not only in providence of drugs to the TB patients but also to promote the drug adherence of those patients, which can further prevent them from becoming resistant to anti-TB drugs.

#### **5.4 Limitation**

The patients were interviewed at their convenient times, places with enough privacy after getting informed consents. At first, some patients were inconvenient to answer because they thought that it was something wrong about their stopping of drug taking. But, later, they were quite at ease and willing to cooperate and answer well.

Furthermore, as most patients are daily wage workers, they cannot give enough time to answer the questions. Frequently visited to each informant and making many appointments in advance were done throughout conducting the study.

In addition, the researcher had high risk to get infection from the informants as they all are TB or MDR-TB patients.

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## **APPENDICES**

## **APPENDIX A**

### **GUIDELINES FOR IN-DEPTH INTERVIEWS**

#### **Introduction**

- Observe and look around situation, and choose appropriate condition in approaching informants.
- Explain the purpose of the interview.
- Ask for their consents for interview process by signing in informed consent after informants agree to participate in the interview. If the condition is not suitable for signing consent, ask for an oral inform consent first.
- Interview is conducted in volunteer manner, and not by force.
- The interviews will be done in proper ways, where informant find it comfortable and feel safe enough, in their convenience, appreciate their space and private life, and by taking initiative to be part of the activity while the interview take places.
- To interview less than an hour for each and the rest can be done informally.
- Ask permission to take a picture and record the interview.

#### **1. Demographic data and socioeconomic factors**

##### **A. Demographic data**

- How old are you?
- What is your highest education? To what standard?
- How many people can work in your family?
- How much do the whole family earn money per month?
- Is it stable income or not?
- Is your family type is nuclear or extended?
- Daily/periodically expenditures of informant and their family (not compulsory).

**B. Socioeconomic factors**

- Do your family/spouse/people in family/ people in your surroundings know your disease? If not, can you tell them?
- How did they response to you when they know your disease?
- Is there any changes in relation between you and them after being diagnosed?
- How did they help you in taking medication/ going to health center/ improving your health?
- What were the challenges/ difficulties to follow this medication (if you didn't have support from them)?
- Did you have to quit/change from your job after being diagnosed?
- Did you avoid or have you been avoided from social activities after being diagnosed?
- How did you go to health center? Was it easy to get there?
- How long have you take time to go there?
- How much did you need to pay for transportation charge for each time to go there?
- Did you need to call other people to go there?
- Did you need to pay for any extra cost to get there?
- How did you solve income generation for these days?

**2. Perception about health services**

- a) How long have you received treatment at there?
- b) Did you attend the appointment regularly?
- c) Did you need to wait for so long time to consult with providers, during drug taking, when doing investigation?
- d) Did you feel convenience, privacy during taking medication?
- e) If other people you know gets same symptoms, or same disease, do you want to bring him to this health service? (Why?)

**For Patients-provider relation**

- How many providers are there in health center? (Dr/ nurse/ technicians/ workers)
- What and how did they explain about your disease? ( what TB is, Diagnosis, Prevention, Available treatment, outcome)
- Did you understand their explanations?
- How do you think so that they treated you before, during, after treatment?
- When you ask them something, how did they usually reply to you?

**For treatment**

- How do you understand DOTs? (duration, manner, regularly)
- Did you think that anti-TB drugs are effective to relieve your symptoms or cure your disease?
- Did you understand how to take it? Is it easy for you to understand the regime?
- Have you known what side-effects you can get due to anti-TB drugs?
- Did you feel any illness due to drugs?
- Sometimes, did you forget to take drugs?
- Did you need to take any other drugs when you are receiving treatment? (If yes, why and how?)
- Did you get drugs regularly from health service center?
- Did you want to take the drug till the end of the full course at that time?
- Did you take drugs regularly as directed from health center?

**For investigation provided**

- What kinds of investigation have you done?
- Did you need to pay for investigations?
- Did you know why you have to take the tests? –was it easy to take?

- How your relations with service providers during taking examinations?

### **3. Perception about TB disease**

- a) How did you know that you have TB disease? What did you suffer from illness before it?
- b) Do you know how did you get TB?
- c) What other causes leading you to get TB?
- d) What are the symptoms of TB apart from your sufferings?
- e) How do you think that it can infect to other from you? (in what way)
- f) How did you think is it curable disease or not? (in what way)
- g) Did you think that your disease is cured by taking drugs regularly from health center?
- h) Have you known that what are the complications of improper treatment of TB?
- i) Have you had any difficulties for your socio-economic life when you have been diagnosed? (If yes, why and how)
- j) If this TB disease happens in other people, how do you treat to them?

### **4. Self-efficacy related with anti-TB drugs taking.**

- a) Do you believe that you can continue to take treatment if you felt side effects/ you have any socioeconomic related difficulties to take treatment / you have faced any inconvenience situation at the service center when you are taking drugs?
- b) Did you believe that your disease was needed to take treatment?
- c) Do you believe that DOTS therapy can cure your disease?
- d) Did you have any bad interaction between you and people surroundings?
- e) How did you overcome any barriers and financial difficulties if you had?
- f) Do you believe yourself that you can overcome this barriers till the end of the treatment?

- g) How can you manage time to take treatment regularly?
- h) Did you believe that you can take the drugs till end of the full course of prescription with correct dose, uninterrupted, at regular time? (related with socioeconomic difficulties, accessibilities to the service, any difficulties in receiving treatment)
- i) How do your family members help you to take treatment, to improve your health?
- j) What other conditions in you to keep going treatment taking?

## **APPENDIX B**

### **GUIDELINE FOR KEY-INFORMANTS INTERVIEWS**

- How far from the informants' homes to the service center?
- How many providers are there?
- What are the functioning hours of health center?
- What kinds of service available for the TB patients? (consultation, drugs, investigations)
- How to provide these services to the patients? (FOC, partial cost, full cost)
- How do you think so about quality of drug supplied/ investigations taking?
- What are the difficulties for patients during taking treatment at service center?

## **APPENDIX C**

### **GUIDELINE FOR OBSERVATIONS**

Location: Informants' houses and surroundings

- Observe the living condition of informants and surrounding
- Housing and environment condition of informants
- Observe the informants and other people relations
- Observe informants' process to visit health center
- Observe their daily activity, daily life
- Observe the medication intake (DOTS) or other medication along with anti-TB drugs (if they are taking anti-TB treatment).
- Observe the patients' record books.
- Observe patients' sputum smear results or CXR results.
- Attending the health education sessions to observe the patients-providers communication.

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