

**LIVED EXPERIENCE OF TB PATIENTS: INSIGHTS FROM NAIROBI CITY
COUNTY**

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Dedication

This work is dedicated to all people coping with TB and other diseases

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LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
DOT	Directly Observed Treatment
DTLD	Division of Tuberculosis and Lung Disease
EPTB	Extra-pulmonary Tuberculosis
HIV	Human Immunodeficiency Virus
MDR-TB	Multi-drug Resistant Tuberculosis
MOH	Ministry of Health
PTB	Pulmonary Tuberculosis
TB	Tuberculosis
WHO	World Health Organization

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ABSTRACT

Tuberculosis is a global health problem with serious health and social implications which produce unique experiences for the patients. Understanding the lived experience of TB patients is important for appropriate TB intervention and management. The study sought to describe the lived experience of TB patients in Nairobi City County, Kenya. It was a qualitative study using 40 narratives of TB patients, 40 home observations, and key informant interviews with 4 TB health care providers using a phenomenological approach. The 40 TB patients were interviewed twice, first at the healthcare facility with a follow-up interview in their homes.

The findings showed that the TB patients' daily experience is characterized by socio-economic, structural and medication-related factors. Patients experience stigma and perceptions, lack of family and social support. The patients also face financial constraints in the treatment process and their daily life is undesirably altered in the treatment experience. Although there is good patient-healthcare provider relationship, patients have to deal with long treatment regimens and the long queues when seeking treatment services in the health facilities. Collectively, the patients experience social exclusion and low quality of life.

The study concludes that TB management programs should account for factors that influence the lived experience of TB patients to facilitate effective treatment. The factors are barriers to effective treatment and management. Provision of social and family support, addressing stigma and counseling and structural barriers may influence the patients' positive experience and promote treatment adherence for successful TB management.

CHAPTER ONE: BACKGROUND TO THE STUDY

1.1 Introduction

Tuberculosis (TB) is an infectious disease caused by *Mycobacterium tuberculosis* (M. tb). *Mycobacterium tuberculosis* was first identified and described by Robert Koch, a German physician in 1882 (Kazda, 2000). Before Koch's work, TB was thought to be caused by unhygienic environment and that prevalence was dependent on the community's folklore. Treatment in the early times focused on healthy diet, good hygiene and exposure to fresh air.

Although significant gains in TB management such as the introduction of Directly Observed Treatment (DOT) strategy have helped address the problem, the disease's prevalence is high and is a leading cause of morbidity and mortality. The 2016 World Health Organization TB report shows that 2-3 billion people are infected with *M.tuberculosis* but only 5-15% of these develop TB (WHO, 2016). In 2015, there were 10.4 million new TB cases worldwide and 1.4 million TB deaths (WHO, 2016).

In addition, poor resource countries such as those found in sub-Saharan Africa contribute to more than 80% of TB morbidity and mortality (Kim *et al.* 2017). This has led to the view that tuberculosis is a social, economic and political disease and that it shows whenever there is neglect and poverty. In Kenya, the notification rates of cases of TB have increased significantly in the past 2 decades. WHO (2016) attributes this increase to the impact of HIV. According to Sitienei *et al.* (2013), Nairobi is one of the areas hardest hit by TB epidemic.

Tuberculosis is classified into two major clinical forms: pulmonary TB (PTB) and Extra-pulmonary TB (EPTB). PTB is the commonest form and accounts for about 80% of all TB cases (MOH, 2009). PTB affects the lungs while EPTB occurs outside the lungs. EPTB can develop in any part of the body (except the nails, hair and teeth). TB patients are classified into four categories. Category 1 involves new cases- patients who have never been treated previously or used anti-TB drugs for less than one month. Sputum smear positive PTB, sputum smear negative and severe forms of EPTB belong to this category (MOH, 2009). Category 2 consists patients previously treated sputum smear positive PTB. This can occur due to relapse, failure or default of treatment (smear positive re-treatment). This category has high risk of developing drug resistance hence MDR-TB (Muture *et al.* 2011). Category 3 comprises patients with new but less

severe cases. Sputum smear negative and extra-pulmonary TB belong to this category (MOH, 2009). Category 4 is for patients with chronic and MDR-TB.

Although everyone is vulnerable to TB, there is high prevalence in resource poor countries. This inequality partly illustrates the lived experience of TB patients in these countries and settings. The factors that lead to the inequality add to the lived experience. For example the patients may experience poor access to health facilities in what Farmer (2004: 307) calls “structural violence”. The experience for TB patients is further shaped by the unique nature of the disease especially in social setting. Women would cope with the disease differently from men based and their experience would be shaped by gender issues within the society (Essendi and Wandibba, 2011). For instance, despite free TB services in all government health facilities, fewer women than men access the services (Essendi and Wandibba, 2011).

Other than the gender dimension, lived experience for TB patients occurs within wider social system. The social environment in which TB patients are subjected to is important in determining how the patients cope. Social stigma, social support structures, economic factors and such variables are important in shaping experience. The co-morbidity of HIV/AIDS and TB does not only contribute to stigma but also shape the lived experience uniquely. In most cases, a positive tuberculosis diagnosis prompts HIV test (MOH, 2009). The living conditions (housing) and places of residence (densely or sparsely populated) are other factors that contribute to the overall experience that TB patients undergo and greatly determine healing. The interaction with healthcare providers and awareness in regard to treatment centers further shape the experience for TB patients.

1.2 Statement of the Problem

Tuberculosis is not only a public health problem but it is also a social problem. This is because of the social variables associated with infection, diagnosis, treatment and subsequent healing. Such variables include poverty, access to treatment, interaction with healthcare providers and social stigma. Thus, TB experience takes place in a social context and the social variables that operate within that context significantly shape the lived experience. The experience fundamentally shapes how patients cope with the disease and how healing comes about. Depending on the nature of experience and the variables therein, it is thus conceivable that treatment and healing can be demoted or promoted.

The social context that shapes the lived experience for TB patients dictates how treatment and its adherence are exercised. Poverty for instance is cited as the cause and consequence of TB. As a consequence of TB, poverty may hinder successful and sustained treatment. Although the cost of drugs is significantly subsidized or free in government health facilities, there are embedded costs such as traveling and food that may thwart sustained treatment. This way, defaulting may result and thus negatively affect healing. Further, social stigma is part of experience and may affect how patients cope with TB psychologically and how treatment is sought and sustained. This is because of the association of TB with HIV/AIDS (Sitienei *et al.* 2013). Presence or absence of supportive social structures and networks influences how TB patients cope and adhere to treatment.

According to Helman (2007; 196), treatment and the “total drug effect” take place within a macro-context: the “social, cultural, political and economic milieu in which use of drug takes place.” The socio-economic climate such as poverty and unemployment is part of the macro context and as noted above, it influences treatment. Further, social grouping where drug use takes place influence the intention to go for treatment and sustaining it. Such social groupings include the family, friends and members of the society. In the case of TB, these social groupings that constitute the social networks may encourage or discourage treatment and adherence. A study conducted by Muture *et al.* (2011) showed that defaulting treatment is a factor of poverty, the side effects of TB drugs and lack of social support for continued intake of the drugs. Lack of the social networks and support compounded by the social stigma contribute to delay in treatment and defaulting. This may increase risk of death, the spread of disease and pose difficulties to TB management because of multi-drug resistant TB. TB is easily treatable when

detected early while poor adherence to sustained treatment as in DOT (Directly Observed Treatment) strategy may contribute to development of multi-drug resistant TB.

The heaviest global burden of TB is in the sub-Saharan Africa. Kenya is ranked 13th among 20 countries hardest hit by TB. Further, according to the Ministry of Health (2009), major urban areas- Nairobi, Mombasa and Kisumu have the highest TB prevalence rates compared to other parts of the country. This may be attributable to the social context associated with urban areas that produce a unique lived experience for the patients. TB prevalence for example in Nairobi is high despite the concerted efforts for TB management. TB diagnosis and treatment is provided for free in government health facilities and there are public health campaigns on TB. These focus on creation of awareness that TB is treatable and that diagnosis and treatment is free.

In Kenya, TB control programmes have subscribed to the internationally accepted WHO's DOT strategy and tuberculosis regimens (Muture *et al.* 2011). The DOT strategy is deemed effective in treating TB and requires patients to take anti-tuberculosis drugs for at least six months (Muture *et al.* 2011). Despite the efforts, TB prevalence in Nairobi City County remains high. The current TB management approach as in the DOT strategy relies on provision of the drugs and passive case findings. The approach also depends on whether and when people go for treatment. However, it does not focus on the subjective and lived experience that may influence TB treatment and healing. The approach does not focus on the role of other social variables which shape the lived experience for TB patients and which can demote or promote healing.

There is therefore a gap between provision of TB health services and their access as well as utilization for successful treatment and healing. This gap is conceivably responsible for the high TB incidence in Nairobi City County. There is need therefore to describe and understand the lived experience of patients that create this gap. This study thus sought to describe the lived experience of TB patients in Nairobi City County and answer the following questions:

1. How does the lived experience of TB patients in Nairobi City County influence treatment and healing?
2. What is the role of social networks in the management of TB, by TB patients in Nairobi City County?

1.3 Research Objectives

1.3.1 General Objective

To describe the lived experience of TB patients in Nairobi City County.

1.3.2 Specific Objectives

1. To establish how the lived experience of TB patients in Nairobi City County influence TB treatment and healing.
2. To determine the role of social networks in improving the lived experience of TB patients in Nairobi City County.

1.4 Study Assumptions

1. The subjective experience of TB patients in Nairobi City County impact access to treatment and healing subsequently.
2. Social networks are important supportive structures regarding how TB patients in Nairobi City County cope with the disease.

1.5 Justification of the Study

The research will describe the lived experience of TB patients in Nairobi City County. Treatment and healing for TB takes place within the entire lived experience. It will thus contribute significantly to the understanding of the factors that influence TB management. The findings will thus be useful to TB control programs.

The research is also qualitative in nature. It will thus provide qualitative aspect on TB research to compound the quantitative aspect. Further, the research will be part of literature on the lived experience of TB patients. The findings will thus be used for literature review by future researchers.

1.6 Scope of the Study

The study purposed to describe the lived experience of TB patients. It specifically sought to establish how the lived experience of TB patients in Nairobi City County influence TB treatment and healing. It also sought to determine the role of social networks in improving the lived experience of TB patients in Nairobi City County. This is because the lived is experience of the TB patients was assumed to influence treatment and hence healing. It was also assumed that the support from the social circles or networks are important in improving the lived experience and hence promote treatment and healing.

The study was conducted within Nairobi City County. The informants were TB patients who had been on treatment for at least three months and had stayed in Nairobi for one month prior to the study. The study informants were recruited from Ngara Health Centre and Mbagathi Hospital where sought treatment. Since the study was largely qualitative, it targeted 40 TB patients who were interviewed at the health centres and then followed to their places of residence for further interviews. In addition, the study targeted 4 healthcare providers from the two centres. The healthcare providers were used as the key informants. The study used phenomenological theoretical perspective to guide the description of the TB patients' lived experience.

1.7 Limitations of the study

The study used phenomenological theoretical approach that seeks to describe the lives and events of people as they subjectively experience it. By being guided by this theoretical approach, the study's data were entirely qualitative. However, it was the aim of the study to collect qualitative data and the results were not affected or skewed by little quantitative data. The sampling procedure was a potential source of bias in the study. The study used purposeful sampling where only TB patients who were under treatment were included. Thus, those who were not under treatment or had completed and had relevant information to the study were not included. In addition, the study targeted those who had lived in Nairobi for at least one month prior to the study. It is conceivable that there are those who would be recruited but do not come from Nairobi. This limitation was however, addressed at the time of recruitment where patients were asked whether they lived in Nairobi and seeking treatment. The study targeted patients who were 18 years and above. This meant that the patients who are below 18 years and had pertinent information to the study were not included. However, the informants who met this criterion of inclusion provided the information that the study sought to gather.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This literature review captures the aspects associated with TB disease process and which lived experience is contextualized. These aspects essentially shape the experience that patients undergo. The literature review focuses on social experiences that are embedded within TB diagnosis, treatment and coping within the social and economic environment. It will also capture the relationship between TB and HIV/AIDS in order to bring out the wider scope of TB patients' experience.

2.2 TB Exposure and Infection

Every individual is prone to infection but susceptibility to tuberculosis is under the influence of discrete factors. The variation in these factors can be used to explain the differential prevalence of TB across the globe. The aggregate impact of these factors forms the initial experience that TB patients undergo. WHO (2016) estimates that 2-3 billion people are infected with *M.tuberculosis* and roughly 5-15% of these people develop the disease. Thus, although everyone is susceptible to the bacilli, not everyone develops TB and its severe consequences including death. This situation forms part of the experience that TB patients have since they are subjected to social and economic environments that build up the experience.

Further, there are factors that determine the physical exposure to *M. tuberculosis*. The kind of housing and settlement pattern for instance determine exposure to the bacteria. Well-ventilated houses in sparsely populated residential areas are more likely to prevent TB infection than the crowded, poorly ventilated houses such as those found in urban informal settlement (slums). TB can thus be said to be a disease caused by poverty.

2.3 TB and HIV/AIDS

HIV/AIDS and TB exert much weight on disease burden (Helman, 2007). Both diseases have highest prevalence especially in poor resource settings such as the sub-Saharan Africa. The two diseases are not only public health problems but are also social diseases, perpetuated within a social context. They occur in similar socio-cultural and economic contexts and equally have similar socio-cultural and economic ramifications. For instance, the two diseases and their management are associated with poor-resource settings. Another way that HIV/AIDS and TB are related concerns their concurrence. Prevalence of HIV/AIDS significantly influences prevalence

of TB. One of the factors that have presented real challenge and barrier TB control is its concurrence with HIV/AIDS. The HIV/AIDS pandemic has greatly contributed to prevalence and threat of TB, especially in Southeast Asia and Africa. According to Comstock (2000), the human immune system is weakened significantly by HIV/AIDS and the challenges of developing active TB are much higher. High prevalence of HIV/AIDS is associated with high prevalence of TB as exemplified by sub-Saharan Africa. Although TB can occur independently, its diagnosis prompts testing for HIV/ AIDS. This is because TB manifests in many cases of HIV/AIDS as an opportunistic infection.

According to Helman (2007; 392), although sub-Saharan Africa constitutes only 10% of the world's population, it is home to 60% of global HIV/AIDS infections. Tuberculosis is also highest in the region accounting for more than 80% of the world's TB infections. This implies that there are certain factors associated with these diseases and that the factors are common in sub-Saharan Africa. The bottom line, however, is that high prevalence of the two diseases show an intricate correlation between them. Corbertt *et al.* (2006) observe that in 2008, of the 9.4 million new cases of TB, 1.2-1.6 million (representing 13-16%) were HIV positive. According to WHO (2001), incidence of TB closely relates with the estimated HIV prevalence especially in Africa.

Although TB can occur independently, most cases of TB are associated with HIV infection. This means that TB patients experience double disease burden, when the two diseases are concurrent. Further, patients have to contend with persistence of TB since its management becomes complex in the face of HIV/AIDS. In addition, the comorbidity subjects TB patients to social stigma. Tuberculosis is highly stigmatized in social settings. People in the social set-up may fear of possible infection from infected persons and would isolate themselves. Such isolation thwarts the coping ability of TB patients. The level of stigma increases when people in the social settings associate TB with HIV/AIDS. TB patients are often thought to be HIV positive, even when they may not have AIDS (Mochache & Nyamongo, 2009). Because of the stigma, TB patients may lack important social support for treatment that is fundamental for healing (Mochache & Nyamongo, 2009).

2.4 TB Stigma and its Impact

According to Farmer (1997), there is a general consensus over the universal social stigma attached to TB. The comorbidity of TB with HIV/AIDS increases the magnitude and chances of the stigma. The stigma contributes to worsening quality of life for the TB patients (Hudelson, 1996). In addition, stigma plays an integral role in most stages of disease process. It determines the extent to which acknowledging of symptoms and seeking care takes place. Research has revealed that it is through identifying the consequences of stigma that effective intervention practices and management of TB can be implemented (Nair *et al.*, 1997; Shrestha-Kuwahara *et al.*, 2002). TB patients have a genuine fear of being socially ostracized because of their health status and this is a reason they would hesitate to disclose their TB status to family or friends (Shrestha-Kuwahara *et al.* 2002). In these studies, it was found that many TB patients would fear disclosing their TB status because this would adversely affect their relationship with family, neighbours and friends. The social consequences of stigmatization cause long delays in seeking care as well as poor adherence to treatment. A study done by Mata (1985) showed that the strong stigma associated with TB made some patients prefer death to social rejection. This is because TB was linked to family rejection and loss of friends.

Dick and Schoeman (1996), Liefoghe *et al.* (1995), Uplekar and Rangan (1996) have shown that there is shock of being diagnosed with TB and this may send patients and their families in search of a different diagnosis. Uplekar and Rangan (1996) observed that some medical practitioners would avoid disclosing a positive TB diagnosis for the fear that the patients would not return for treatment. Rubel and Garro (1992) came up with similar observation in a study among the South African Zulus. Essentially, people diagnosed with TB stopped attending the clinic when this status was revealed to them. The social stigma that TB patients face can also lead to loss of employment or fear about that and thus thwart disclosure or delay diagnosis, care seeking and effective treatment (Johansson *et al.*, 1996; Shresth-Kuwahara *et al.*, 2002).

Women particularly may be on the receiving end of social stigma especially in societies where women occupy a lower social status. The social consequences of TB diagnosis may result in increased mortality and under treatment (Hudelson, 1996). Nair *et al.* (1997) conducted research in India and observed that married women would delay treatment or avoid disclosing their positive TB diagnosis to their husbands because of fear of being deserted. Essendi and Wandibba (2011) observe that TB is the cause of most deaths for women than other causes of maternal

mortality combined. In addition, single women with a history of TB may attract fewer marriage partners (Jaramilo, 1998). This is because it is feared by their potential husbands that the women may not be productive at home because of sickness. Further, the relationship between TB and HIV makes the men shun marrying such women (Jaramilo, 1998). Such stigma may hinder compliance to treatment as the patients attempt to conceal their TB status for fear of the social consequences such as rejection. Jaramilo (1998) asserts that healthcare givers at clinical settings can also perpetrate that stigma. Accordingly, the patient-healthcare provider interrelationships are influenced by negative perceptions of TB patients held by healthcare providers. This form of stigmatization creates unfavourable environment and discourage patients from adherence to treatment. Dick *et al.* (1996) found that many TB patients preferred interacting with considerate paramedics or community volunteers since they perceived nurses and doctors as figures of authority. Studies have also shown that women patients seek care for TB from healthcare providers that they are comfortable with than seeking treatment and care from government hospitals or clinics (Long *et al.*, 1999; Thorson *et al.*, 2000). Mochache and Nyamongo (2009) have shown that stigma as embedded in socio-cultural and superstructural forces is one of the factors that influence treatment seeking. The fear of stigma can hinder treatment seeking among TB patients. Stigma thus remains an important experience that TB patients go through and which influences healing.

2.5 TB and Poverty

According to Kim *et al.* (2005), TB is both a cause and consequence of poverty. In this case, TB is a cause of poverty because of the way poverty precludes primary health care. The high prevalence of TB in sub-Saharan Africa can partly be explained by the region's low-income status. This is where most people live in congregated areas. Such living conditions increase the chances of TB infection. The houses are also likely to be poorly ventilated, thereby inhibiting free circulation of air, thereby increasing the chances of the bacilli in the air. Further, these areas may already have people with active TB but due to lack of financial resources for hospital admission or fear of stigma, they stay in the congregated areas. This leads to infection of others with TB. Poverty thus forms an important aspect of experience of TB patients in relation to infection and treatment (Muture et al. 2011).

2.6 TB Diagnosis

Early diagnosis (followed by effective treatment) is an important aspect of TB management. This is because early diagnosis paves way for early treatment. The dynamics involved in testing and diagnosis are complex and varied and form the experience of TB patients. The knowledge of people regarding TB influences testing. The knowledge of TB symptoms may influence testing and thus early treatment. The intention to go for testing is subject to the influence of the social context within which individuals are tested. According to Helman (2007; 196), there are factors at the macro level that determine response to signs or symptoms. The macro level factors in question include the family, friends and other people in social relations. In relation to TB, even when one is diagnosed with active TB, one may be reluctant to disclose this to family or colleagues. Such fear may compromise early onset of treatment and adherence.

The perception of TB in regard to the cause, development, symptoms and treatment affects the intervention measures employed and decision to go for testing (Mochache & Nyamongo, 2009). In a study done by Mochache and Nyamongo (2009; 897) in south-west Kenya, respondents attributed TB to various causes including heredity, AIDS and risky behaviour (such as smoking, alcohol consumption and unprotected sex). Other causes cited were the environment (extreme cold), supernatural causes, air (poor ventilation, bad air), poor hygiene (dirty utensils, uncooked food) as well as malnutrition (Mochache & Nyamongo, 2009; 897). This shows the varied perception in relation to TB causes. The perceptions influence treatment choice. According to Mochache & Nyamongo (2009; 898) such treatment choices would be self-treatment with patent drugs, divine intervention, hospital for tests and treatment as well as local providers for traditional medicine. In the list of treatment choices, only hospital (for tests and treatment) choice facilitates effective treatment. It can therefore be said that the dynamics surrounding diagnosis shape the wide experience of TB patients. In addition, the understanding of TB symptoms influences the decision to go for testing or other interventions.

2.7 TB Treatment

Infection and diagnosis are the aspects of TB where initial experience for the patients is shaped. In general, the decision to seek treatment occurs within a socio-cultural and economic framework (Helman, 2007). In relation to TB, there are many dynamics in treatment that form the challenges faced by patients. The social environment including the family and other players in the social context, may promote or discourage treatment and adherence thereof (Helman, 2007). Access to

health centres also determine how treatment is sought and access barriers including structural violence (Farmer, 2004). Good social networks and support structures within the society promote treatment and adherence. Financial challenges affect treatment and may result in default of treatment, thereby leading to the development of multi-drug resistant TB (Muture *et al.* 2011).

2.7.1 DOT Strategy

According to WHO (2009), Kenya has adopted the internationally recognized and WHO recommended DOT strategy as an effective TB treatment strategy. The strategy employs five key elements. It encompasses sustained political commitment to increase human and financial resources and integrating TB control into the national health system. It also ensures access to quality assured TB sputum microscopy. In addition, it emphasizes standardized short course chemotherapy to all diagnosed cases of TB and case management under DOT. In addition, DOT ensures uninterrupted supply of quality assured drugs with reliable procurement and distribution systems. Finally, the strategy encompasses recording and reporting system enabling outcome assessment of each patient and overall assessment of the programme. The strategy requires TB patients to observe treatment for at least 5 months without default (Muture *et al.* 2011). However, adherence to treatment is influenced by financial abilities of the patients among other factors. Muture (*et al.*, 2011), for instance, found that patients may default treatment not only because of cost for treatment but also because of side effects of the anti-tuberculosis drugs. Default was also attributed to sheer ignorance, feeling better and travelling away from treatment site. The study also indicated that the rate of defaulting was highest during the initial two months, which is the intensive phase of treatment (Muture *et al.* 2011).

2.7.2 Financial Challenges in TB Treatment

In the treatment of TB under the DOT strategy, patients are required to observe medication for at least five months without interruption. However, default often happens and one of the reasons for this is affordability of the anti-tuberculosis drugs. The link between TB and poverty manifests again when TB patients become less economically productive due to illness. On the other hand, the household economies may not sustain regular TB medication. Other than the cost for anti-tuberculosis drugs, there are embedded costs such as travel to the health centres as well as costs for food even at household level (Weller *et al.* 1997).

2.7.3 Access to TB Treatment

Access to TB treatment is not only a function of the social forces that influence the decision to seek medication (such as family or colleagues) and financial abilities of the patient. Rather, treatment also depends on the availability of health care facilities and TB support centres as well as their proximity. The decision to seek treatment is influenced by how easily the health and support centres for TB are available. According to Farmer (2004; 307), tuberculosis is one of the diseases whose dynamics are influenced by what he terms as “structural violence.” Structural violence encompasses the kind of neglect perpetrated by political process. The rights of the people in relation to good healthcare are violated and there is no structural and institutional commitment for TB control, hence posing access barrier (Farmer, 2004). Structural violence encompasses the failure of public health programmes and pertinent stakeholders such as the Ministry of Health to coordinate efficient and effective TB treatment. Muture *et al.* (2011; 701) point out that default of treatment may be attributed to traveling away for the treatment sites. Such default can be facilitated by sporadic TB treatment and support centres that are far away from the patient’s reach.

In Kenya, TB control programmes have been institutionalized under the Division of Tuberculosis and Lung Disease (Sitienei *et al.* 2013). DLTLD has faced the challenge of providing integrated TB and HIV services. As a poor resource country, the available resources for TB control are negatively skewed in the face of high prevalence. The threats about the emergence of MDR-TB have posed challenges in the fight against TB (WHO, 2009; 18). These obstacles have been compounded by unfavourable socio-economic environment. In response, the MOH through the DLTD has identified certain areas for increased support. These include decentralization of TB control services to the community level in order to improve access and strengthening of human resource institutional capacity (WHO, 2009). Private public partnership is another area and is supposed to increase the number of private providers incorporated in the TB service provider network and partnerships between TB and HIV control programmes for promotion of integrated TB/HIV services were other areas (WHO, 2009). Public education campaigns for dissemination of awareness on early care seeking and adherence to treatment have also been embraced in the fight against TB. However, as Muture *et al.* (2011) show, there is a proportion of TB patients frustrated in treatment by poor structural and institutional arrangement.

2.5 Theoretical Framework

2.5.1 Phenomenological Theoretical Perspective

Phenomenology is the study of subjective experience. It is a school of thought useful in qualitative studies because of its focus on the context on which behaviour and experience take place. From a phenomenological perspective, human experience and behaviour are understood as they occur in the context of relationship with things, people, events, and situations. Phenomenology as a discipline may be conceptualized as the study of structures of experience or consciousness. It has its roots in the philosophical work of Edmund Husserl. The perspective has evolved into the science of describing what is perceived, senses and contextual awareness and experience. Husserl conceptualized phenomenology as the descriptive, non-reductive of what appears, in the manner it is appearing in the subjective and intersubjective (Husserl, 2014; 464).

Phenomenology encompasses knowledge and experience as they appear to an individual's consciousness; and the experiencing self is the person or self. Experiences, feelings, and emotions are deeply embedded in an individual's life worlds- spatial, corporeal, temporal, and relational (Husserl, 2014). The basic assumption of this framework is that there is an essence to shared experience. Understanding people's experience is often through description rather than explanation or analysis. Phenomenologists argue that every perception occurs within a certain landscape of a person's mind. An individual's view of the world is not based on generic known truths. Rather, perceptions are experienced within mental landscape. Phenomenology seeks to explore the conscious lived experience of phenomena; the particular ways in which phenomena are perceived in day-to-day life (Husserl, 2014). The perspective is concerned with understanding an individual's life world. It is held in phenomenological theoretical perspective that the way to knowledge is to back the experience of everyday life.

The lived experience of the everyday world is revealed through consciousness and this is the primary inquiry of phenomenology. Lived experience presents to the individual the truths and realities of life (Husserl, 2014). Through accessing the lived experience, researchers are able to gain an understanding of the meanings and perceptions of another person's world. This is because by use of phenomenological theoretical perspective, it is possible to study the conscious experience as experienced from the subjective or first person viewpoint.

Researchers using phenomenological approach seek the central underlying meaning of the experience- the essential, invariant structure. There is emphasis on the intentionality of

consciousness where the experience have both outward appearance and internal consciousness. The evidence obtained from phenomenological research is often derived from first-person reports of life experience. The theoretical perspective seeks to determine what an experience means for the holders and are in a position to provide a comprehensive description regarding that experience. These premises of phenomenological perspective make it relevant to form the theoretical framework that informed this study.

2.5.2 Relevance of the Theory to the Research

The study sought to describe the lived experience of TB patients in Nairobi City County. Its aim was to describe the subjective experience the patients. This inquiry was well reflected and explained by the phenomenological theoretical perspective. This theoretical perspective emphasizes on obtaining knowledge by focusing subjective experience for individuals and seeking what an experience means for the holders. From the theory therefore, the study extracted the meaning and experience of having TB from the subjective level as represented in the patients' narratives. This is based on the assumption that there are central underlying meanings of experience that researchers can understand in order to describe the lived experience of the people. By understanding an individual's life world, researchers can discern the experience as the TB holders see them. This theory was thus useful in the study since it will involved understanding and describing the lived experience of TB patients. Their subjective stories and experience formed the focal area of interest. The narratives were important in understanding and hence describing the "life worlds" and therefore able to understand what it means to live through TB phenomenon.

2.5.3 Conceptual Framework

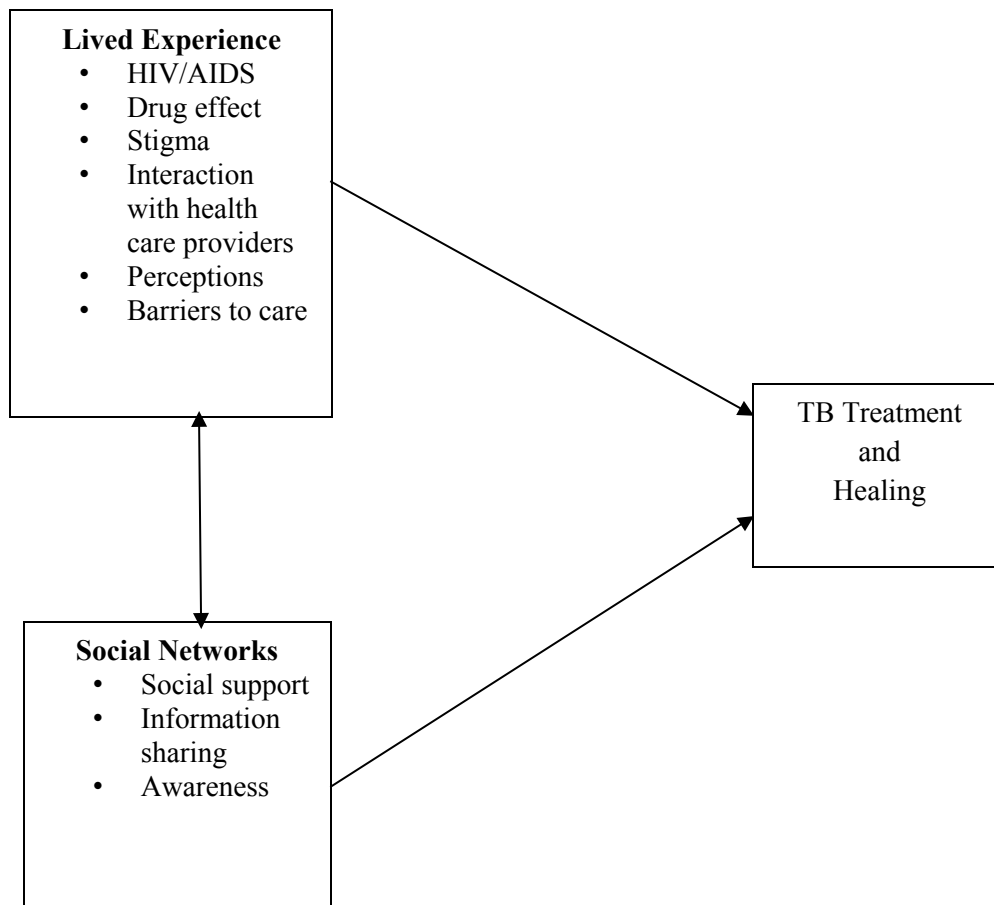


Figure 2.5: Conceptual Framework

The conceptual framework above shows the relationship between the independent variable (TB treatment and healing) and the dependent variable (lived experience). The framework also shows how the social networks (dependent) influence both the lived experience and treatment and healing. Essentially, the nature of patients' lived experience promotes or demotes treatment and healing significantly by posing either supportive or disabling. For instance, social stigma, existing barriers to care, and poor patient-provider relationship demote TB treatment and healing by providing the disabling factors. Addressing the barriers and factors would however promote TB healing and treatment.

Social networks provide the other set of dependent variables and have effect on the lived experience. The conceptual framework shows that there is a link between social networks, lived

experience, and treatment and healing. Poor social support and weak networks demote the lived experience of the patients and hence demote the lived experience, with ripple effects on treatment and healing. However, strong social networks promote the lived experience and support treatment and healing consequently.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This section outlines the methodology used for this study. It includes the description of the research site, research design, and the study population. It also describes the sample population and provides details regarding the sampling technique employed and the procedure thereof. The section further provides details about data collection methods used, and the data processing and analysis. It also includes the ethical considerations for the study.

3.2 Research Site

The study was conducted in Nairobi City County (Fig. 3.1) at Ngara Health Centre and Mbagathi Hospital. The health facilities acted as the recruitment centers and on the basis of providing TB services, with fully fledged TB clinics. Ngara Health Centre is Local Authority health centre within Ngara location, Starehe Constituency, Nairobi County. In relation to the study, the facility provides Tuberculosis diagnosis services, laboratory, and Tuberculosis treatment. On the other hand, located in Golf Course location, Kibra Constituency, Nairobi County, Mbagathi Hospital is a district hospital operated by the Ministry of Health. Formerly known as the Infectious Diseases Hospital (IDH), the hospital provides TB diagnosis and treatment service in its TB clinic and handles multi-drug resistant TB cases.

Nairobi is a metropolitan area and the largest county nationally in terms of population. According to the Kenya Population Data Sheet (2011), Nairobi County's population is 3.3 million; covers a total area of 696km² and has a population density of 4800/km². This hints the incidence of TB due to deplorable conditions associated with crowding. Actually, Nairobi is one of the urban areas cited in Kenya with high incidence and prevalence of TB (MOH, 2009). According to MOH (2015), TB prevalence per 100,000 people in Nairobi is 405 while the TB incidence per 100,000 people is 156. However, this is an improvement from 2012 where the county TB prevalence and incidence stood at 475 and 167 per 100,000 people respectively (MOH, 2015). Nevertheless, the current trends in Nairobi contrasts sharply with the national TB prevalence and incidence that stand at 208 and 79 per 100,000 people respectively, making Nairobi a high TB burden county (MOH, 2015).

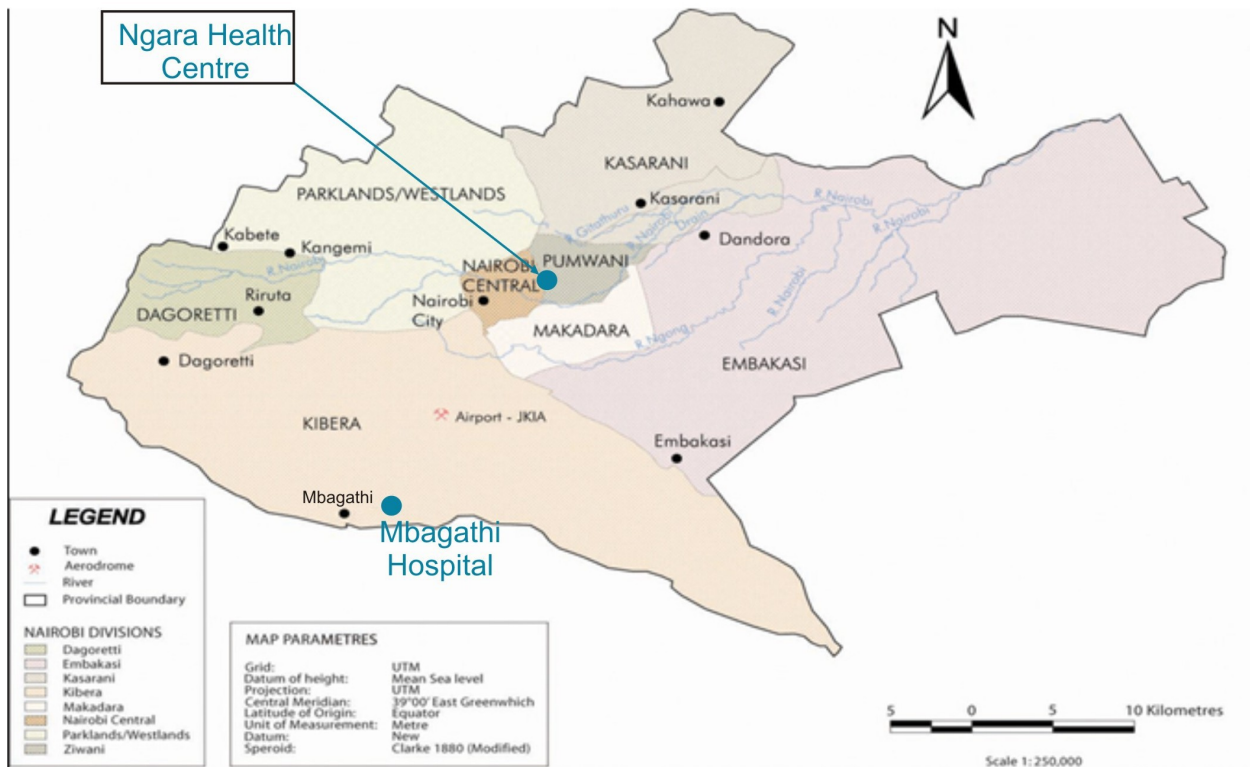


Figure 3.1: Map of Nairobi City County

Courtesy of Google maps

3.3 Research Design

This study used a descriptive-exploratory research design which allows description of phenomena at one point in time. The design was appropriate since there was an idea about the experience of TB patients that need to be explored. According to Blanche, *et al.* (2006), descriptive studies aim to describe phenomena, and this study sought to describe the lived experience of TB patients. Descriptive studies describe phenomena through narrative-type descriptions (Blanche *et al.* 2006). This was the aim of the study.

3.4 Study Population

The study population for this research was people suffering from clinically diagnosed tuberculosis from Nairobi City County.

3.5 Sample Population and Sampling Procedure

The sample population was drawn from the study population following the sampling procedure described below.

The study informants were sampled from the two health facilities. The patients must have been clinically diagnosed with TB and in their at least third month of treatment. They were asked relevant questions pertaining to this criterion of inclusion. If they met the criteria of inclusion, they were selected as study participants. The study targeted 20 TB patients from each facility for a total of 40 TB patients. Purposive sampling was used to select the health facilities. However at the individual/patient level, convenient sampling was used. If the patient met the criteria of inclusion, solicitation for participation was sought and when granted, interviews were conducted.

Each of these patients was informed prior to recruitment that there would be a follow-up interview to be conducted at their homes. The follow-up interviews would clarify emerging issues from the first interview. In addition, as explained in section 3.6.3 below, the home visits helped conduct direct observation.

The key informants were purposively chosen from the health facilities and the study targeted 2 key informants from each facility. This was based on their profession as healthcare providers particularly for TB and must have had been exposed to TB patients. The key informants were then selected through solicitation for participation or volunteering.

3.5.1 Inclusion and Exclusion Criteria of Study Participants

The study informants were persons with clinically diagnosed TB who had been under treatment for three months prior to the study. In addition, all informants were aged at least 18 years by the time of the study. The TB patients had to be from Nairobi City County or had lived there for at least one month prior to the study.

In the exclusion criteria, patients who did not have clinically diagnosed TB did not qualify for recruitment. Further, the TB patients who had completed treatment or had not been in treatment for three months prior to the study were not included even if they meet other criteria. The TB patients aged below 18 years were excluded. Additionally, the TB patients who did not come from Nairobi City County or had not lived there one for month prior to the study did not qualify for inclusion and the determination of the same was made through inquiry prior to recruitment.

3.6 Data Collection Methods

3.6.1 Narratives

Narratives, according to Good (1994), “report and recount experiences or events, describing them from the limited and positioned perspective of the present” (P. 139). It is a form in which

experience is represented. The study used this qualitative data collection method because of its ability to uncover the lived experience of TB patients through the stories they gave.

The narratives were collected by use of a narrative guide (Appendix 4). The guide had key themes where the patients were asked to narrate their experience with TB in terms of treatment, interaction with family, healthcare providers, and the society. With the patients' consent, the narratives were tape-recorded using a digital recorder. The narratives were then transcribed to text for analysis. The taped records were permanently deleted after transcription and confirmation of the transcripts.

3.6.2 Direct Observation

Direct observation is a qualitative data collection method. In this method, a researcher observes processes, physical structures, behaviour, or events. In this study, 40 observations were made. The method was used to observe the conditions under which TB patients live in and linked the information to the stories they gave. An observation checklist (Appendix 5) was used as a tool for data collection. Direct observation augmented responses from other methods. The method was particularly useful when the informants were followed to their homes.

3.6.3 Key Informant Interviews

Key informant interviews (KIIs) involved interviews conducted with persons who were knowledgeable and offered perceptive information on the topic of study. In this study, key informants were the TB health care providers: clinical officers and nurses. There were Four key informants used, two from each centre. The key informants were asked questions that sought to describe the experience of TB patients. An interview guide (Appendix 3) was used to focus on the relevant themes. The key informants were included in the study to corroborate the patients' narratives and provide medication-related facts. However, the patients' narratives and observation remained the major methods in describing the lived experience of the patients.

3.6.4 Secondary sources

The thesis development involved secondary information obtained from journal articles, books, the internet, government reports and WHO reports. The information from these sources was continuously sourced in the process of enriching the research.

3.7 Data Analysis

The research used qualitative techniques of data analysis. The audiotaped data obtained from key informant interviews and narratives was transcribed verbatim into English. Codes and themes

were developed from the transcripts through inductive content analysis. Coding entailed breaking down data into their component parts and the parts given labels. Thematic analysis was conducted to extract the emerging core themes. Further analysis entailed searching for recurrences of the sequences of the coded text within and across cases as well as looking for links between different codes. Direct quotes that illustrated important themes were extracted for presentation in the thesis. Data from the observation checklists was also subjected to thematic analysis where core themes were extracted.

3.8 Ethical Considerations

Prior to the start of the research, ethical approval to conduct it was sought and received from Kenyatta National Hospital/University of Nairobi Ethical Review Board (REF: P635/10/2015). Informed consent was sought at the initial contact prior to recruitment. The researcher did this by providing informants with informed consent forms. Before signing, they read the form to understand its details. The study did not encounter informants who were not competent in either English or Kiswahili. Thus, there was no need to seek the services of interpreters.

In the consent forms, the informants were informed about the aims of the research, duration of the interview, and the associated/possible benefits and risks. The procedure that was used in the research was explained to them. They were also informed that participation in the research was voluntary and that they were free to withdraw at any stage and that such withdrawal would not attract penalties or disfavor whatsoever. There were two consent forms for the patients and for the key informants.

Another aspect of ethical considerations was confidentiality and anonymity. In this case, the informants were assured that the information that they would give would remain confidential and would not be used for other purposes other than the ones stated. In anonymity, the participants were assured that their identity would remain undisclosed. Any information that would potentially identify the participants or their families was removed while the other information will remained true to the data. This upheld the privacy of the participants. The audio-taped records were permanently deleted after the transcription and confirmation of the transcripts.

The researcher had contacted the health facilities where the patients were recruited and they agreed to support the study. The patients would be referred to a health professional within the facility for counseling if any of the questions raised emotion or stress. Furthermore, in minimizing discomfort, the researcher asked questions in a way that reduced any likely stress or

discomfort. The informed consent forms (Appendices 1 and 2) have details of the ethical considerations.

3.9 Problems faced and their solutions

Tuberculosis is a highly stigmatized disease and I had anticipated resistance for participation and nondisclosure. However, I liaised with the healthcare providers at the two health facilities who persuaded the patients to cooperate in the research. Further, I requested the management of the health facilities to link me with their respective community health workers (CHWs) working with TB patients and who already knew the patients as well as their physical addresses. This helped solve the problem of resistance and nondisclosure and locate the homes of the patients for observations and further interviews.

CHAPTER FOUR: LIVED EXPERIENCE OF TB PATIENTS IN NAIROBI CITY COUNTY

4.1 Introduction

This chapter presents the research findings in two sections. The first section summarizes the socio-demographic characteristics of informants. These characteristics include sex, age, level of education, marital status, occupation, and religion. In the second section, data on the lived experience of TB patients in Nairobi City County and role of social networks is presented. Data pertaining to how TB patients cope with positive diagnosis and treatment of tuberculosis was collected. The questions generated information to help understand the factors or elements that shape the experience of TB patients after diagnosis and throughout the treatment period. The emerging themes are related to socio-economic factors, treatment/medication-related factors, and service provision factors. The interviews took place at the health facilities with a follow-up interview at the patients' place of residence.

4.2 Socio-demographic Characteristics of the Informants

A total of 40 narratives and 40 observations were conducted among informants with varied demographic characteristics. These included sex, age, marital status, education, religion, and occupation and are shown in Table 4.1.

The study included both males and females patients, whose age varied significantly. However, majority of the informants were aged between 18 and 29 years (Table 4.1). There were no informants who reported 50 years or above. The informants reported different marital statuses. Out of the 23 males, 8 (34.7%) were single, 10 (43.4%) were married, 2 (8.6%) were widowed, and 3 (13%) were separated while out of 17 females, 11 (64.7%) were married, 2 (11.7%) were single, 4 (23.5%) were widowed and none was separated (Table 4.1).

In terms of education, only a few (4) informants had attained University or College education and most of the informants had either primary or tertiary education. Ten informants reported that they have secondary education. Further analysis showed that there are differences in level of education based on gender. More women than men had tertiary and secondary education, while more men (8) reported that they have primary education than women (5).

The classification of the occupation informants was done depending on the type of job each informant reported. There were four major categories: Jobless, Informal employment, Business,

and Formal employment. In terms of breakdown of the categories, jobless category included informants who reported not to having any source of income and this group accounted for 20% of all informants. Informal employment category included informants working in non-permanent sectors such as cleaning, cooking, garage assistants, and other casual occupations whose payment was daily or weekly (wage). This group accounted for 30% of all the informants. Informants who reported to own and operate businesses such as vending food, vegetables and fruits, operating informal hotels/eating joints, or selling second-hand clothes (*mitumba*), and operating shops were classified under self-employed (business). This group constituted 37.5% of all the informants (Table 4.1). The formal employment category included those informants who reported to work in formal sector such as teachers and nuns and accounted for 12.5% of all the informants.

Under religious affiliation, the informants were Catholics (40%), Protestants (27.5%), Muslims (12.5%), or belonged to other religions (20%).

Table 4.1: Socio-demographic characteristics of informants

	Male N(%)	Female N(%)	Combined N(%)
Sex	23 (57.5%)	17 (42.5%)	40 (100%)
Age			
18-29	8(34.8%)	9(52.9%)	17(42.5%)
30-39	7(30.4%)	7(41.2%)	14(35%)
40-50	8(34.8%)	1(5.9%)	9(22.5%)
Education			
Primary	10(43.5%)	5(29.4%)	15(37.5%)
Secondary	4(17.4%)	3(17.6%)	7(17.5%)
Tertiary	7(30.4%)	7(41.2%)	14(35%)
University/College	2(8.7%)	2(11.8%)	4(10%)
Marital Status			
Single	8(34.8%)	2(11.8%)	10(25%)
Married	10(43.5%)	11(64.7%)	21(52.5%)
Separated	3(13%)	0(0%)	3(7.5%)
Widowed	2 (8.7%)	4(23.5%)	6(15%)
Religion			
Catholic	8(34.8%)	5(29.4%)	13(32.5%)
Protestant	10(43.5%)	4(23.5%)	14(35%)
Muslim	1(4.3%)	2(11.8%)	3(7.5%)
Other	4(17.4%)	6(35.3%)	10(25%)
Occupation			
Formal	2(8.7%)	2(11.8%)	4(10%)
Informal	8(34.8%)	5(29.4%)	13(32.5%)
Business	6(26.1%)	7(41.2%)	13(32.5%)
Jobless	7(30.4%)	3(17.6%)	10(25%)

4.3 Lived Experience of TB Patients

4.3.1 Patients' Experience of Stigma

Findings indicated that TB patients' daily life is characterized by the experience of stigma and labeling. Stigma was reflected in the actions people take in dealing with TB patients. These were noted to be either direct or indirect. Patients experience stigma within the family and the society at large. This stigma forms an important aspect of patients' own lived experience. Consider the following two quotes from patients in Ngara (aged 36 years) and another in Kibera (aged 30 years).

I lost close friends when they realized that I had TB. Some even asked me why I could not tell them all along because they knew about it when I was in my fourth month of treatment. I can say that the reason why they left me is because they did not want to be associated with sick people like me. However, I did not lose hope and I am hoping that I will heal so as to revive the relationships although I am not sure that they will accept me back. (Patient 22, Female, 36 years, Ngara Area)

People fall sick but with TB, this sickness is not normal. It is the worst experience because every time I walk in the estate, people start speaking in undertones while whispering. I feel uncomfortable because I know they say bad things about me yet I did not choose to be sick. I only get relief from my husband and children who understand me well. (Patient 05, Female, 30 years, Kibera)

Direct actions by other people against TB patients perpetrate stigma. Patients feel depressed and may have suicidal ideation as exemplified by a male patient.

There is a time I felt like committing suicide. I was in public transport vehicle when I coughed uncontrollably and some people left the *matatu* [public transport vehicle]. The conductor told me that I will pay for that because I made him lose customers. I understood that they did not want to be infected, but I felt bad about both myself and the conductor because he ought to have been lenient on me. (Patient 24, Male, 31 years, Ngara Health Centre)

Some patients may not have experienced stigma directly, but at the inter-subjective level, stigma against TB patients is real as shown by the following quote.

My friends and family are supportive and accommodative and I do not experience much stigma. However, I met a lady at the clinic who complained a lot. She told me that her neighbour changed place of residence when she told her that she was taking TB drugs. (Patient 36, Male, 40 years, Eastleigh)

The above excerpts from patients' narratives indicate that their experience is riddled with stigma that worsens their experience with the disease. The reality of stigma, as part of the lived

experience for patients, is reinforced by the healthcare providers as illustrated by the following quote.

There is a lot of stigma attached to TB. In fact, one of the barriers to treatment and the reason why some patients may default is because of stigma. People in the society do not want to be associated with TB patients because they think that they will get infected. People need to be educated about TB to reduce stigma and include the patients in the society. (Provider 01, Clinical Officer, Female, Mbagathi Hospital)

Stigma is not perpetuated by society alone. The family, like society, also perpetuates stigma. This is where the actions against the patients are suggestive of the underlying feeling of fear, shame, or dishonor. Consider the following two quotes from patients.

At home, people are suspicious about me to the extent of questioning my behavior since they think that there is something wrong I did and they think I put the family in negative light by acquiring TB. (Patient 29, Male, 21 years, Ngara Health Centre)

When my mother brought me to the hospital and doctors came with positive TB diagnosis, she bought cups, plates, and other utensils specifically for me. This was despite the fact that the doctor said the diagnosis was done early enough and my mother should not worry about infection. That is when I felt that although she was trying to be careful, she regarded me as a threat already and feared my encounter with others. (Patient 10, Female, 26 years, Ngumo)

The role of the family in perpetuating stigma to patients is expressed by the healthcare providers as demonstrated by the following quote.

There is a 24-year-old boy who came here and we started him on TB treatment. When he went home, the boy was separated. He was told to start living alone in a different room for almost two weeks. When he came next he said that the family members are asking whether he can join them in the main room. So we wondered where he had been living and he said that they had separated him. This means there is still fear. He did not go on well. He even refused taking the drugs and we could not follow up on him anymore. He ran away from the family (Provider 02, Nurse, Female, Mbagathi Hospital)

Not all patients reported a negative experience from the family members as shown by the excerpts below.

I have supportive family and friends who have been with me for close to four months now. Sometimes I forget that I have TB because there are no constant reminders associated with stigma. (Patient 25, Male, 29 years, Ngara Health Centre).

Although some community members resent me, the encouragement I get from my siblings and parents is overwhelming. It has seen me through hard times of self-denial and through that, I believe I will heal completely. (Patient 15, Female, 25 years, Mbagathi Hospital)

Stigma from the family or larger society erodes the support that TB patients need and is a causative factor for default as evidenced by the case of the 24-year old boy. This stigma within the family compounds stigma from the larger society to worsen the experience of TB patients. However, lack of stigma at home or in the society provides hope for the patients and gives them fortitude to cope with the disease. The quote below substantiates this statement.

I have been coping well. My friends are still the same, they have not changed. My employer is also understanding...My family is also very supportive, my mother wakes up early to prepare porridge, milk and *weetabix* [Whole grain food]. I am now almost completing medication through their collective effort. (Patient 3, Male, 30, Mbagathi)

The patients are living in the social environment that stigmatize them because of their TB status. Stigma shapes the experience of the patients and has dramatic consequences on treatment and healing. In order to avoid stigma, adherence to treatment is compromised through poor storage. The quote below from a key informant in Mbagathi Hospital illustrates this well.

Another reason why patients may default is storage. The other day we were talking to a lady about adherence and we noticed that she skipped taking the drugs. When we asked her how she stores her drugs, she told us that she stores them in different places so that the family members do not come across them. This is stigma. She does not want the family to know that she is taking the drugs. So when she keeps them in different places, she forgets and may skip to take them. (Provider 02, Nurse, Female, Mbagathi Hospital)

When asked whether they would take medicine in public, some patients cited the problem of stigma and that they would rather postpone taking the drugs. The following excerpts illustrate this view.

No. I cannot dare. Once you do that [taking TB drugs in public], you will see people looking at you suspiciously. I would rather skip and take the drugs when I am alone. (Patient 31, Female, 28 years, Ngara Health Centre).

I would be afraid to take medicine in public and that is why I prefer taking them at night when I am at home. People will start looking at you with bad eyes, some thinking that you will infect them so you just take medication later. (Patient 14, Male, 31 years, Ngumo)

However, other patients would not interrupt treatment because of stigma as shown by the following quote.

...why not? I can take the TB drugs even in *matatu* [public transport vehicle] people may not know where you are suffering from although TB drugs have a characteristic shape and color and people may recognize them. I once sat with a person who I saw taking anti-retroviral drugs without caring that I was looking at her. So I can also take TB drugs. It is my disease not theirs. (Patient 20, Female, 30 years, South C)

4.3.1.1 Insensitivities Arising from Perceptions

TB patients experience impervious attitude arising from local perceptions, knowledge, and stereotypes on TB, its perceived causes and/or links, symptoms, and consequences. This was particularly evident in the connection between TB and HIV/AIDS. One of the reasons cited for persistence of stigma is the perceived link between TB and HIV/AIDS. Although TB can occur independently, most people believe that it is caused by HIV/AIDS. It was found out that TB patients were perceived to have HIV/AIDS and were thus seen within the lenses of HIV carriers and with the capacity to not only infect others with TB but also with HIV/AIDS. This was one reason for social isolation. The narratives from the patients showed that the perceived link between HIV/AIDS and TB shapes the attitudes people have against TB patients.

It is hard for the people in the community to understand that you can have TB alone. They think that when you have TB, you the other one [HIV/AIDS] and they can discriminate you on this reason. I had to convince my boss (by showing him the results) that I don't have AIDS to keep my job because he can fire you when you have that disease [HIV/AIDS]. (Patient 8, Female, 38 years, Highrise)

The perception on TB-HIV/AIDS relationship is even more devastating for the patients themselves since they are afraid of the results and how their families would think of them.

I was afraid when the doctor told me that I had to undergo HIV test. You know people say that you are sexually promiscuous when you have HIV. Although I expected this since people say that HIV/AIDS causes TB, I was afraid since I did not want my people to know that doctors also suspected that I had HIV. (Patient 40, Male, 45 years, Mathare)

The connection between HIV/AIDS and TB inclines patients to doubt their HIV status even when they have tested negative as disclosed by a 34-year old patient.

There is a time I visited my friend and his son heard me say that I was diagnosed with TB. Then the boy said innocently that I have HIV. I felt so bad because I knew that he had heard this from the people in the community. Although I was negative, I felt like I actually had HIV because of his statement. (Patient 18, Female, 34 years, Kibera).

TB patients may be isolated because they are thought to have HIV/AIDS and are labeled as such as substantiated by the sentiments of one patient.

People say that TB does not come alone. It comes with HIV/AIDS. Thus, when you see people avoiding you when they know you have TB, they suspect you have HIV/AIDS. It makes you feel labeled and bad especially when you know that you do not have AIDS. Even if you have HIV/AIDS, it is a disease like any other and people should not discriminate against you because of that.” (Patient 02, Male, 40 years, South C)

The reality of the TB-HIV/AIDS co-infection is demonstrated by instances when patients lose intimate partners because of fear of infection.

I had a female partner when I was working in town. One day, she saw me take TB drugs and I confessed that I had TB. I had not told her before that I had TB since I feared that she would leave me. She told me that TB is normal. After some time, she left me for another man. When I asked her friend why she left me, I was shocked by the response. Apparently, she thought I had HIV when she learnt about my TB status. (Patient 11, Male, 28 years, Mbagathi Hospital)

Healthcare providers reinforced the stigma that results from the link between TB and HIV/AIDS.

Most think that if have one has TB, he/she has HIV, but which is true mostly because 60% of TB patients have HIV. But usually when the patients get TB they think they have HIV. They are scared because of the stigma.(Provider 01, Clinical Officer, Female, Mbagathi Hospital).

Most of them say that when they have TB, they have HIV. I think it is like a myth since it is not always true. But we tell them to test. (Provider 03, Clinical Officer, Male, Ngara Health Centre).

Apart from HIV/AIDS connection, TB stigma is also embedded within the perceptions regarding its supernatural cause.

TB patients are isolated because TB is thought to be a result of transgression (going against the wishes of the dead) and thus lead to a curse. Patients are thus thought to have sinned and therefore subjected to isolation that reflects stigma. The excerpt below sheds light on this issue.

... when the results came positive, people started saying that it was a curse from my grandfather because I refused to name my baby after him. Others started saying that my enemies had bewitched me and they avoided me. This really scared me since in our culture, people do not associate with the cursed and the bewitched lest they fall in the same [misfortune]. However, the doctor told me not to worry about it... (Patient 05, Female, 30 years, Kibera)

TB healthcare providers support the above association between TB and supernatural causes.

Some patients say that they have been bewitched. Some say that it is *Chira* (curse) and believe that they have to contend with this. (Provider 01, Clinical Officer, Mbagathi Hospital)

The discourse in relation to TB consequences compounds makes the experience for patients difficult. The sentiments from the patients' narratives show that what people in the society perceive to be the consequences of TB increases stigma and hopelessness among the patients.

I called my mother in the rural home to tell her that I had TB. Immediately, she started crying because she knows TB is incurable and had been told that by other people in the community. This discouraged me a lot (Patient 21, Male, 23 years, Mathare)

Other beliefs and stereotypes that people have in relation to TB add weight to TB patients' experience as illustrated by the statement of one Female patient.

People in the estate say that I will not bear children anymore because I have TB. Although I know this is not true, it is a negative statement especially when you hear people say it in your presence. (Patient 32, Female, 31 years, Ngara Health Centre)

When asked about the questions patients ask frequently, one key informant said that most patients ask whether they will be cured and this reflects the perception and fears about TB in the society. The following quote captures the fear.

The major question they ask is whether TB is curable. They think it is a dangerous disease which can kill them. Some are even hostile verbally. You talk to them and respond very rudely. It is like they have given up hope. (Provider 02, Nurse, Female, Ngara Health Centre)

Perceptions and knowledge regarding the cause of TB form part of the patients' experience and influence treatment and healing. The connection between sorcery or curse and TB illustrate this view well. On this breath, the local understanding of TB may influence treatment because some

patients may resort to non-biomedical measures as treatment options. A key informant from Mbagathi Hospital shed more light on this.

Others say that it is inherited. That TB runs in the family. So they think that it is genetic. Others think that it is a myth. So some of them go to witchdoctors because they believe they have been bewitched. Some of those we put on treatment say that TB is about sorcery so they must go home to see a sorcerer. (Provider 01, Clinical officer, Female, Mbagathi Hospital)

The influence of the local perceptions, knowledge, and stereotypes on TB is manifested in stigma. People's beliefs and perceptions on the cause of TB and its consequences influence the TB experience since some patients are labeled, isolated, stigmatized, and discriminated against. Perceptions on the cause of TB also incline some patients in Nairobi City County to resort to treatment options that correspond with the beliefs, hence negatively influencing treatment and healing.

4.3.2 Coping with Medication

In their daily lives, TB patients have challenges in medication process. In the study, patients reported experiencing high pill burden, long duration regimen, and debilitating side effects. The way patients cope with the experience determines completion of medication and healing.

According to the universally adopted treatment procedures as in the DOT strategy, the duration regimen takes up to six months. The findings showed that for the patients in Nairobi City County, it is a challenge to take the drugs routinely, each day for six months. When asked to narrate the experience in treatment, patients cited the cumbersome nature of taking the TB drugs because of the long duration regimen.

I was told that TB treatment takes six months, and I felt that it is a long time. Now I have gotten used to them although it is difficult because you have to carry the drugs when you are travelling. (Patient 26, Male, 37 years, Ngara Area)

Taking the drugs routinely for a long time inclines some patients to quit as it becomes boring in the face of side effects as evidenced by a young patient.

... I was about to quit taking the drugs because it was cumbersome to take the drugs each day. It becomes boring and sometimes disgusting especially when I experience unbearable headaches and dizziness. (Patient 07, Male, 26 years, Mbagathi Hospital)

A healthcare provider puts the issue long regimen into perspective.

We usually start treatment immediately after diagnosis according to the standardized regimens for TB. We use pyridoxine which needs to be along the drugs. Then we do HIV testing and counseling to verify whether they are HIV positive or not. If they are found to be HIV positive we put them on septrin. We also give them vitamin A to boost the immunity. Then we refer them to CCC [Comprehensive Care Centre] for follow up if they are HIV positive. (Provider 01, Clinical Officer, Mbagathi Hospital)

This procedure may put patients in two different medications and the experience can be devastating. Even in the event that there is no co-infection, TB patients still experience hardship in taking the drugs and observing the routine. The quote below puts this view into focus.

For my case, to say the truth, I take the drugs because the doctors and people who observe me insist. If I were let alone, I would quit because the drugs can really burden you. (Patient 29, Male, 21 years, Ngara Health Centre)

TB treatment takes a long duration, you find them defaulting, it is like they have lost hope. So they need to be counseled for them to take the medicine for the needed duration. Patients also feel burdened. TB drugs are like five drugs in one but the government has tried to put them in a fixed dose combination.(Provider 01, Clinical Officer, Mbagathi Hospital)

The challenge associated with taking the TB drugs routinely and for a long time is intricately associated with defaulting, which form part of the experience for the patients while under treatment. The patients were found to experience debilitating side effects from the drugs. This worsened their experience and prompted some of them skip taking the drugs in an attempt to avoid the side effects especially when they have busy schedules. Reports from the key informants showed that many patients skip and eventually default medication primarily because of the side effects. The excerpts below substantiate this statement.

One of the barriers that the TB healthcare is facing is defaulting because of the side effects, although other factors such as general deviance cannot be overlooked. (Provider 04, Nurse, Female, Ngara Health Centre)

They may have TB drugs, septrin, and antiretroviral drugs so they feel burdened. This may make them to default. They can even choose which drugs to take among those because they say that they feel more sick when they take certain drugs. So they may choose to take the ones that make them feel better. So the issue of side effects becomes major. The side effects are many. When they get the side effects, it becomes difficult to continue with medication. (Provider ,03, Clinical Officer, Male, Ngara Health Centre)

The side effects they can get include the skin cutaneous hypersensitivity (they start itching all over the body) because there are drugs which can cause this. They also get jaundice. They also get abdominal cramps, peripheral neuropathy (affects the nerves especially when they lose vitamin B6)- severe joint pains and patients are unable to walk. They can pass reddish urine. But we tell them that this is normal because when the drug is excreted, the color of the drugs comes out. But it really scares them. (Provider 01, Clinical Officer, Female, Mbagathi Hospital)

The patients also reported discrete side effects of the TB drugs although the effects varied from individual to individual, with others reporting multiple effects. The commonly cited side effects included headache, dizziness, colored urine, jaundice, abdominal cramps, loss of appetite, restlessness, and nausea.

4.3.3 Interactions with Healthcare Providers

Apart from the side effects of TB drugs, TB treatment was also found to be characterized by positive experience at the healthcare facilities. Findings indicated that the patients experienced good interaction with healthcare providers in the healthcare facilities. When asked about the experience in the consultation rooms, patients responded that there is warm reception in each visit and drugs are always available. The patients experience positive caring relationship with the TB health-care providers. The patients' cited creating good rapport with the healthcare-providers. The latter are also listening, caring, and support the patients emotionally through encouraging and advising them accordingly. The TB healthcare providers also maintain high levels of confidentiality. The following quote show the patients' good experience in this part of service delivery.

The health care providers here are good people who treat us like their own people and they seem to understand my culture well. In addition, I get TB drugs every time without being turned back. (Patient 31, Female, 28 years, Ngara Health Centre)

The patients are also happy with the friendliness and confidentiality demonstrated by the health care providers as exemplified by this male patient.

The doctor answered all the questions I had and was very pleased with her friendliness. She knows how to keep secrets. (Patient 06, Female, 46 years, Kibera)

The following quote also shows that the healthcare providers are patients' friends.

They [healthcare providers] are very understanding people here...Most of them are my friends now (Patient 34, Male, 32 years, Huruma)

The positive relationship is also demonstrated between the patients and the healthcare workers or volunteers. This relationship was found to reinforce treatment as the CHWs make follow-ups and keep contact with the patient to ensure regular treatment. The excerpts below illustrate the positive relationship and its role in promoting treatment.

There is one [CHW] who visits me at home. She is concerned about me and encourages me to take the drugs even when I feel like giving up. I do not let her down (Patient 39, Female, 28 years, MlangoKubwa)

My sister [the CHW] here even calls me sometimes to know how I am doing. *Yeye ni kama daraja yangu na hospitali* [She is the bridge between me and the hospital] (Patient 13, Female, 30 years, Highrise)

The healthcare providers also claimed to empathize with patients and accord them care as required as shown by the excerpts below.

You look at patients and you cannot afford to be rude. We also have to follow the ethical code of conduct and respect the patient (Provider 03, Clinical Officer, Male, Ngara Health Centre)

Some of them [patients] have come here many times and we even know their names. One way to help them is to show them love and care and that is what we do. They can lose hope if not supported well. (Provider 02, Nurse, Female, Mbagathi Hospital)

4.3.4 Delays in Service Provision

However, despite the perceived good patient-healthcare provider relationship, patients reported delays when they come for drugs or other visits. It was found out that patients make long queues and stay for a long time before being served. Many attributed this to low healthcare provider-patient ratio. Apparently, some patients stay in the facilities where they pick their drugs for up to 4 hours, when according to them, they ought to spend a maximum of one hour. Comparatively, this was found to be a long time especially when they had forego other duties in order to go to the health facilities. For those with tight schedules, they experienced challenge in balancing work and treatment. The following quotes demonstrate this issue.

It becomes tricky when I have to go to the hospital to pick the drugs and I have to report to work at the same time. When I come to pick the drugs, I get late at work but my boss understands. (Patient 27, Female, 30 years, Eastleigh)

... like today, I came here at 7.30 am. Look it is now 11.30 and they [healthcare providers] have gone for a break. You feel like going away without the drugs since you have other things to do. (Patient 9, Male, 36 years, Mbagathi Hospital)

The key informants confirmed these sentiments.

We also get overwhelmed. We are few and there are many patients to be attended to. (Provider 04, Nurse, Ngara Heath Centre)

Delays in service provision are compounded by inconveniences that patients may go through when certain health facilities have to make referrals.

Some facilities lack enough TB drugs and therefore refer some patients here [Mbagathi] and some may not even bother to come because of the inconvenience. (Provider 02, Nurse, Mbagathi Hospital)

I can go to get drugs or other services in other facilities close to my place but I come here [Mbagathi] directly because those other facilities may not give me what I want. (Patient 01, Female, 31 years, Mbagathi Hospital)

Due to this delay and inconveniences, patients recommended that the stakeholders ensure there is sufficient number of TB healthcare providers for quicker delivery of services. Others suggested on the possibilities of having local dispensaries equipped with comprehensive TB treatment capacities to avoid referrals and travelling long distance to seek treatment. Therefore, although structural issues such as good healthcare provider-patient relationship and payment for treatment are enabling, others such as slow delivery of services are not and they collectively shape patients' experience.

4.3.5 TB Awareness and Sensitization

The findings indicated that there are public health campaigns and programs carried out by the Ministry of Health that seek to sensitize people on TB. This means that TB patients live through information sufficiency in regard to TB services. Public sensitization was particularly evident in the healthcare facilities where posters with comprehensive information on TB are strategically placed in TB clinics. The messages on the posters/stickers create awareness about free TB service provision. Sensitization also seeks to inform the people about the symptoms that should warrant clinical diagnosis and further actions to take. Below are some of the images from the health facilities showing sensitization on TB and awareness on TB service delivery.

Plate 1: Sticker creating awareness on TB services at Mbagathi Hospital's TB Clinic

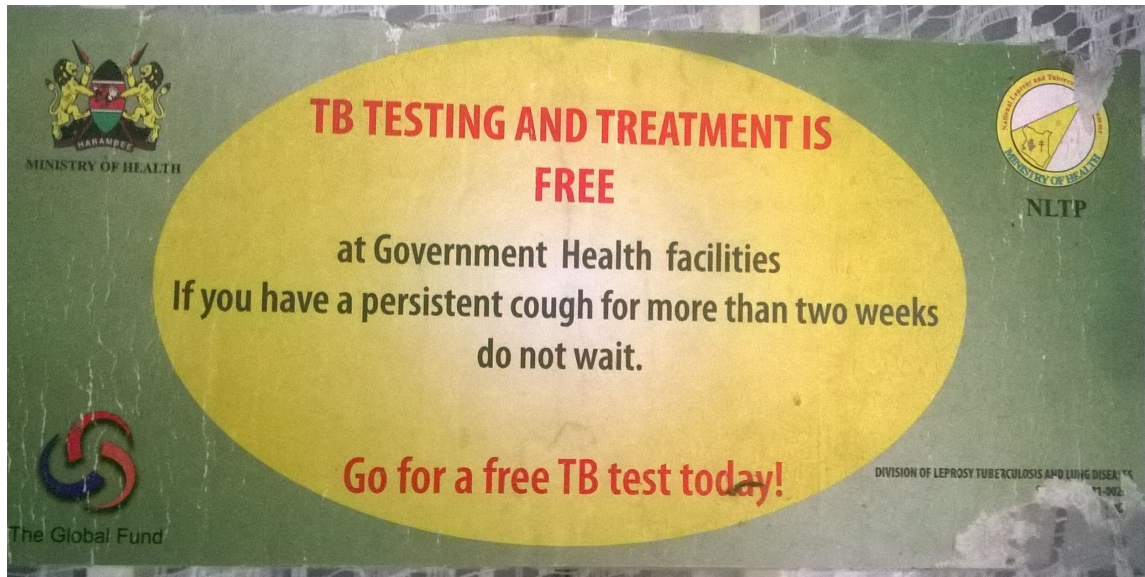
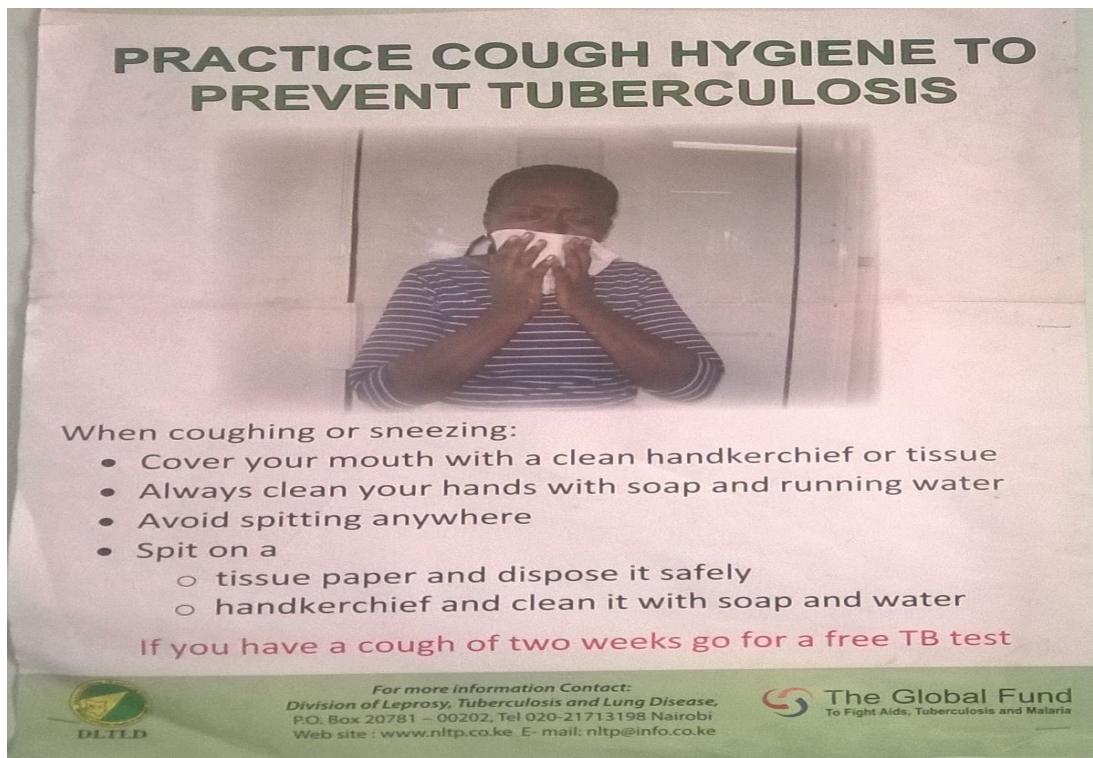
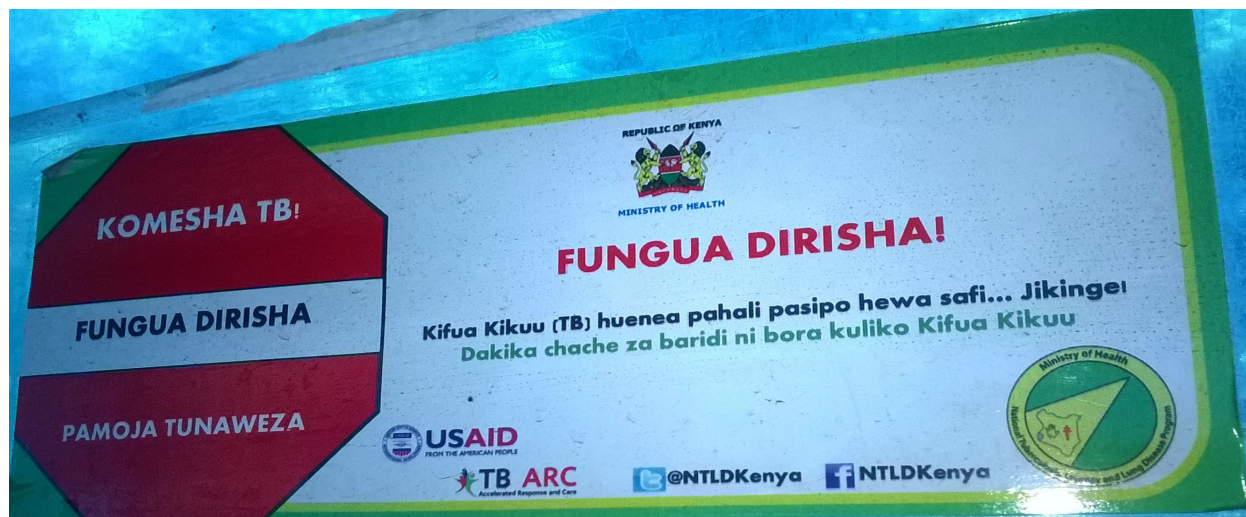


Plate 2: Poster sensitizing people on TB prevention at Ngara Health Center



The awareness has also been extended to the public transport vehicles where there are messages on TB prevention and management. The image below was taken on a public transport vehicle heading to one of the patients' home.

Plate 3: Sticker sensitizing people on TB prevention on a public transport vehicle



The sensitization programs also use the mass media where the Ministry of Health creates TB awareness on radio and TV. The following two quotes from patients substantiate this view.

Nowadays is not like before. People have information on TB and are told what to do on radio in order to avoid infecting others and how to get drugs from hospitals. (Patient 20, Female, 30 years, South C)

I learnt about TB clinics on TV where the government said that it offers TB treatment for free. That is when I stopped fearing that I would spend a lot of money if I went to hospital. (Patient 32, Female, 31 years, Ngara Health Centre)

Thus, patients and other members of the public have access to information through the sensitization programs and campaigns that target to create awareness.

4.3.6 Financial Burden

The experience of TB patients in Nairobi County was found to be shaped by the social and economic factors in regard financial capabilities and social support. The information on this thematic area was obtained primarily during the observations and follow-up interviews. TB testing/diagnosis and treatment services are free in all public hospitals countrywide. However, patients in Nairobi City County were found to face financial difficulties that worsened treatment experience. There are embedded costs that put financial strain on the patients, thereby negatively

shaping their experience. These costs mainly include transport, food, and other miscellaneous expenditures. According to the patients' narratives, the healthcare providers issue them with nutritional advice and tell them to have enough food in balanced diet. The aim is to overcome the side effects of the TB drugs as substantiated by the following quote.

After talking to me... the doctor advises me to eat well because the drugs cannot be taken with an empty stomach. When you take the drugs before eating, you feel dizziness and you cannot work. (Patient 11, Male, 41 years, Dagoretti)

However, most of the patients come from poor socio-economic backgrounds or settings that do not support medication requirements adequately and sustainably. Some patients reported challenges in meeting the feeding requirements and opted to skip medication as shown by the excerpts below.

Sometimes it is hard to eat well because as you know good food requires money. So I am unable to eat according to the doctor's advice and I think that is why I experience headaches. When I do not have enough food, I do not take the drugs to avoid more headaches (Patient 07, Male, 26 years, Mbagathi Hospital)

I have two children who need to eat but the doctors tell me to eat well as well. I spend the little money I have on food and when there is no money to buy enough food, I let the children eat first...I postpone taking the drugs until when I get enough food. You may collapse if you are hungry and take the drugs like that [when hungry]. (Patient 32, Female, 31 years, Ngara Health Centre)

Most of the patients interviewed were either unemployed or engaged in businesses with low income as shown in Table 4.1. One patient put this view into focus.

...when my husband died in 2005, I was left with no stable means of income. I had six children to take care of but two died along the way. Feeding myself and the remaining ones became a problem because I was also falling sick from time to time. I opened a kiosk to sell *mandazi* [bans]. This is the business that has sustained me with little income although I do not make sales when I am sick. When I was very sick last December, I went to the hospital and they told me I had TB and put me on treatment. I still rely on the small business and well-wishers for food and other necessities. (Patient 6, Female, 46 years, Kibera)

Patients also face challenges in meeting transport costs amid opportunity cost. Some patients would prefer to take feed themselves and their families and forego regular visit to the clinic as illustrated by the following excerpts.

...When me and my family have enough food, that does not worry me a lot because I can take the drugs comfortably but now I may fail to go there

[Mbagathi] to collect more drugs. It is far from here and you cannot just walk especially when you are weak. (Patient 08, Male, 41 years, Dagoretti)

Many times, I walk to Ngara, if I have to go there. The reason is that when I calculate properly, it is easier to walk than to spend the money for fare and then lack food in the evening. (Patient 34, Male, 32 years, Huruma)

The observations also showed that most of them lived in Nairobi's sprawling informal settlements. These areas are densely populated and housing is in bad condition and poorly ventilated. This poses risk of spread of TB including re-infection especially in the event of defaulting. The possibilities of infecting others are even more pronounced given that the average number of people living with the patient in the same room/housing was five. This perpetuates the cycle of disease burden.

4.3.7 Social Support

TB patients in Nairobi City County face declining social and family support although TB acceptability and support are gaining momentum. The excerpt below shows lack of family and social support.

I live alone. My wife ran away and I depend on my uncle since I cannot resume work because of sickness. My uncle does not give me money to buy food and does not support me. He does not care about me at all. When I borrow money from other people, they say that I am a bother so I just decide to stay with my hunger (Patient-16, Male, 46 years, Kibera)

Despite there being an average of 5 persons living with the patients in the same room, observations indicated that only 12 (30%) of the patients had someone specifically assigned to observe them. All patients relied on their memory (or observers') to remember to take TB drugs. Nevertheless, despite the poor conditions of living/housing, drugs were observed to be kept in clean, dry, and strategic places for remembering. This is an indication of commitment to treatment.

In addition, the patients reported relatively poor social networks and support systems and this is attributable to stigma at family and community level. When asked about whether they were affiliated to social groups that offered support for TB patients or at least the members, it was found out that only 10 (25%) had at least one functional welfare or social group that assisted them emotionally and financially to cope with TB and TB treatment. Incidentally, all the patients who had at least one support/women group (*chama*) were women. For the groups with women TB patients, they shared information on prevention measures such as covering the mouth when

coughing and opening windows in public transport vehicles. They also liaise with other organizations for public campaigns and creation of awareness in a bid to address stigma and lack of knowledge. They pledge to continue with the groups even after healing. Below is a quote from one woman who was the chairperson of her women group.

In my group, we have women with TB and the ones without. Having TB did not prevent me to become the chairperson. In fact, other women supported me... In the group, we discuss various matters and more so on how to tackle TB since it is a very common disease here among women... although our focus is to sensitize everyone not women alone. The group has been of major help to many who have TB...and I believe even in future, it will help many more. (Patient 05, Female, 30 years, Kibera)

Men did not report having any active and beneficial relationship with such welfare and support groups. The patients (whether attached to social and welfare groups or not) urged authorities to look into ways on how such welfare groups for TB patients can flourish and said that they would join in large numbers. One man summed up with the following quote when asked about joining welfare and support groups.

I know such groups exist... even the ones with healthy people [without TB]. Women are good at this and have actually benefitted. I would not hesitate to join if I found one. (Patient 34, Male, 32 years, Huruma)

Thus, TB patients live in an inclusive social and economic environment that is not enabling and that shapes their experience for worse. The stigma, financial strain, structural gaps, and wavering social networks and support system provide reasons for the persistence of TB despite efforts to lessen its burden in terms of epidemiology.

4.4 The Role of Social Networks in Improving the Lived Experience of TB Patients

The study sought to establish the role of social networks in improving the lived experience of TB patients. Social networks encompass the relational ties that people have in the community. The findings indicated that strong social ties support adherence to treatment hence promoting healing. The quote above from the 46-year old male patient from Kibera demonstrates the gap created by lack of strong social networks. However, the narratives from women who are members of a welfare group reveal that having wider networks alleviates the challenges that shape patients' lived experience. The patients' narratives showed that they would prefer social groups including the welfare groups in order to get support and improve their lived experiences as exemplified by the quote below.

I know such groups exist... even the ones with healthy people [without TB]. Women are good at this and have actually benefitted. I would not hesitate to join if I found one. (Patient 34, Male, 32 years, Huruma)

The role of social networks can be seen in addressing defaulting, reducing stigma, and lessening the financial burden.

4.4.1 Adherence to treatment

The medication related factors such as pill burden and the side effects were noted to contribute significantly to defaulting. However, the findings indicated the social networks and links that patients have play a great role in sustaining medication. Adherence to the long course of TB treatment is a complex phenomenon and the social relations that patients have in the community help improve sustained treatment. The following three quotes illustrate this view.

When a person [TB patient] is left alone, it is easy for him or her to decline to take drugs. However, with someone who encourages you even when the side effects are too much, you cope well (Patient 29, Male, 21 years, Ngara Health Centre)

When we give them [TB patients] drugs, we ensure that there is someone at home to observe them because some can even forget to take the drugs. I can say that social networks help the patients cope with medication effects. You realize that those who default mostly lack the support and have unsupportive networks. (Provider 02, Nurse, Female, Mbagathi Hospital)

Thus, patients may partly default because of lack support that comes from the networks. However, strong social networks, as illustrated by the quote below, facilitate treatment completion and healing.

I have been coping well. My friends are still the same, they have not changed. My employer is also understanding...My family is also very supportive, my mother wakes up early to prepare porridge, milk and *weetabix* [Whole grain food]. I am now almost completing medication through their collective effort. (Patient 3, Male, 30, Mbagathi)

This implies that social networks play a critical role in the treatment process by supporting patients cope with undesirable medication effects including the long drug regimen and side effects.

4.4.2 Stigma Reduction

The findings showed that a well knot social fabric is supportive and help either reduce social stigma directed towards the patients or help them overcome the effect. TB is a highly stigmatized

disease. However, affiliation with social groups encourages patients to come out and share experiences as well as encourage each other. Having wider social networks increase the individual interactions and acceptance in the community. Consider the quote below.

People fall sick but with TB, this sickness is not normal. It is the worst experience because every time I walk in the estate, people start speaking in undertones while whispering. I feel uncomfortable because I know they say bad things about me yet I did not choose to be sick. I only get relief from my husband and children who understand me well. (Patient 05, Female, 30 years, Kibera)

The quote shows the place of social networks in the context of social stigma. The family in this case is part of the individual social links that provide hope and support to TB patients when the same is not available from the wider community.

Increased acceptability in social groups help improve patients' lived experience as it alleviates stigma. Patients feel loved and accepted, thereby gaining fortitude to cope with the disease. This is shown by the following quotes.

I have supportive family and friends who have been with me for close to four months now. Sometimes I forget that I have TB because there are no constant reminders associated with stigma. (Patient 25, Male, 29 years, Ngara Health Centre).

Although some community members resent me, the encouragement I get from my siblings and parents is overwhelming. It has seen me through hard times of self-denial and through that, I believe I will heal completely. (Patient 15, Female, 25 years, Mbagathi Hospital)

The patients attribute their ability to cope with the disease to friends and family who form part of the social networks.

4.4.3 Easing Financial Constraints

The findings show that although TB services are provided in public health facilities free of charge, patients experience embedded financial constraints. However, this experience can be offset by the social ties that individual patients have. The idea of welfare groups encompass both human and social capital that patients obtain from such associations. Further, the study found out that some women have groups that support TB patients morally and financially. Consider the quote below.

In my group, we have women with TB and the ones without. Having TB did not prevent me to become the chairperson. In fact, other women supported me... In the group, we discuss various matters and more so on how to tackle

TB since it is a very common disease here among women... although our focus is to sensitize everyone not women alone. The group has been of major help to many who have TB...and I believe even in future, it will help many more. (Patient 05, Female, 30 years, Kibera)

Although lack of money among patients is a serious problem in TB management program, most patients are increasingly overcoming this problem through establishing groups with savings and loans schemes. We also encourage them to join welfare groups and increase friends who can support them financially. I would say social networks help address such [financial] issues. (Provider 01, Clinical Officer, Female, Mbagathi Hospital)

Patients can ease financial pressures they face from their networks in the community. This encourages adherence to treatment and patients' feeling of support and belongingness.

The section focused on the description of the demographic characteristics of informants and their lived experience. The lived experience was described along the themes of stigma, drug effects, social support, financial constraints, relationship with healthcare providers, time use in the clinic, and public awareness and sensitization. These provide the wide spectrum on which lived experience for TB patients takes place. Each of the factors further influences the sustenance and effectiveness of TB treatment, depending on the way it influences the lived experience. For instance, stigma inhibits disclosure and negatively affects adherence to treatment. On the other hand however, good healthcare provider-patient relationship promotes adherence to treatment. In some cases, gender differences may affect the influence of these factors on lived experience and treatment. For instance, men are less likely to experience elaborate or strong social networks and this may negatively affect how they cope as well as the treatment outcome. In addition, public awareness and sensitization programs are strategically designed to reach wider audience as in the use of private and public spaces.

In the analysis and interpretation of the data, it is evident that the lived experience of TB patients in Nairobi City County significantly influences the incidence and prevalence of the disease. This is by influencing the extent to which treatment is successful hence healing. The data shows that majority of the patients live in a social world where exclusion takes place and the patients are segregated and labeled on the basis of having TB. Due to the magnitude of the stigma, the patients may fail take drugs to avoid labeling and this constitutes default. Patients may also feel unwanted and isolated and therefore lead low quality of life, with low self-esteem, and with no

fortitude to heal. Further, the findings show that although TB services are provided free of charge in public health facilities, patients experience financial difficulties because of the embedded costs of food and travel. When some patients report postponing to take drugs because of the difficulties to obtain food and travel to health centres, treatment interruption is inevitable. Interruption of medication implies that the patients prolong their infectiousness to other people in the community. By interpretation, it means that more people are exposed to the bacteria and hence high risk of infection. Further, the more people are exposed to TB infection, the higher the likelihood of new cases of TB, hence high disease incidence and burden in the County. This trend is well supported by the Ministry of Health statistics that put TB incidence rate in Nairobi at 156 per 100,000 people. The observations showed that most patients live in crowded and deplorable conditions, with most houses having inadequate ventilation. Thus poses risk of new cases arising from the lived experience. TB prevalence is also hinged on the patients' lived experience. Defaulting not only increase the treatment and healing period, hence having many people living with TB, but also increases the chances of developing multi-drug resistant TB (Muture et al. 2011). Weak social networks characterize patients' lived experience as they face stigma and exclusion. Lack of support from the family and society imply that patients are not positioned to heal and are likely to default treatment. However, strengthened social networks have the capacity to reduce stigma, promote treatment adherence and help offset financial challenges that TB patients face.

CHAPTER FIVE: DISCUSSION, CONCLUSION & RECOMMENDATIONS

5.1 Discussion

The discussion is guided by the specific research objectives, namely, (i) to establish how the lived experience of TB patients in Nairobi City County influence TB treatment and healing and (ii) to determine the role of social networks in improving the lived experience of TB patients in Nairobi City County. The study findings indicate that whereas TB treatment services are free in government health facilities and other private sector facilities, other aspects of the lived experience of TB patients in Nairobi City County affects TB treatment and healing. Further, there is incredible role played by social networks and social support to improve the lived experience of TB patients. The experience of TB patients in Nairobi City County is shaped by medication-related factors, service provision, and socio-economic factors. The discussion describes how these factors influence TB treatment and healing.

5.1.1 Stigma and Influence on TB Treatment/Healing

The TB patients in Nairobi City County face stigma and this adversely affects their experience and undermines adherence to treatment significantly. Study findings indicated that stigma from the family and the society contributes to default in medication among the patients. Stigma also plays a role in discouraging the patients and erodes support for sustained treatment. This way, stigma creates a disabling environment on which the patients cope with the disease and adhere to treatment. According to Farmer (1997), there is universal social stigma attached to TB. A study conducted by Essendi and Wandibba (2007) in Nairobi showed that there is high stigma linked with TB and that it is a major barrier to care seeking. Jaramillo (1999) asserts that stigma contributes to the worsening of the quality of life for TB patients. Moya and Lusk (2013) observe that stigma adversely shapes the experience of TB treatment and recovery. This is through posing barrier to quality of life and healthcare access. This shows the impact of TB in shaping the experience of the patients and its negative influence on treatment.

In the study, it was found out that stigma inhibits disclosure and that patients would skip medication in order to avoid the stigma associated with TB. Patients reported keeping the drugs away and concealing their TB status for fear of isolation or labeling. In fact, in one case, one patient reported avoiding taking TB drugs in presence of his partner and reported fear of disclosing his TB status for fear of desertion. It was also found out that patients would misplace drugs in attempts to hide them from the family and this compromised treatment. Other patients

reported to prefer skipping drugs than revealing TB status because of fear of being stigmatized. This can contribute to defaulting and shows the extent to which stigma can affect treatment. Shrestha-Kuwahara *et al.* (2002) report similar findings where they observe that TB patients show denial or reluctance in disclosing their TB status to family or friends because of the fear of isolation and ostracism. In relation to treatment, such fear demotes treatment as the patients conceal TB status and isolation thwarts family and social support that help TB patients cope with other factors that adversely shape their experience.

The impact of stigma on TB is exacerbated by the TB-HIV/AIDS link. The study findings show that the link between TB and HIV/AIDS is pervasive in the society and this adds weight to stigma. In one case, a patient was deserted by a partner because of the perceived link between HIV and TB. Many patients cited stigma because they were thought to be HIV positive. HIV/AIDS is itself stigmatizing and its link with TB further negatively shapes the experience of TB patients in terms of stigma since it is assumed that TB patients also have HIV (Mochache and Nyamongo, 2009). This compounded stigma affects disclosure and medication adherence, hence affecting treatment as shown above. In addition, the co-infection with HIV is also independently associated with irregular treatment and defaulting (Muture *et al.* 2011).

5.1.2 Perceptions, Beliefs and Influence on TB Treatment

The study found out that there are different beliefs and perceptions regarding TB in Nairobi City County. These include beliefs on causality and the perceived TB-AIDS link. It was found out that people believe that TB is caused by supernatural causes and that people with TB have HIV. These beliefs and perceptions pose barrier to treatment in two major ways. On one hand, they dictate treatment options and they add weight to stigma on the other hand. On the beliefs on causality, some patients attributed TB to curses, heredity/genetic factors, and others believed that TB is caused by supernatural causes such as sorcery/witchcraft and would resort to supernatural curative measures such as visiting the witchdoctors. Similarly, Mochache and Nyamongo (2009) and Liefoghe *et al.* (1997) found out that in Kenyan communities, there are several beliefs on TB causality including genetic factors/hereditary disposition and supernatural causes/witchcraft, which affect care seeking. In health-seeking behavior, Helman (2007) asserts that the perceived cause of a disease prompts appropriate therapy choice among the available options. In health-seeking behavior pathway models, Good's model (1987) show that the perception of illness dictates therapy choice such as traditional healer, self-treatment or biomedical practitioners. This

implies that if the cause of TB is perceived to be witchcraft/sorcery, patients may resort to non-biomedical choices such as traditional healer or a witchdoctor. Nyamongo (2002) elaborated a descriptive model for treatment sequences of Malaria and included herbal, public, self, or private therapy choices depending on various factors including beliefs on causation. However, in biomedicine, it is known that not all therapeutic choices are effective in disease management.

The perceptions and beliefs on TB causation such as association with HIV, witchcraft, and curses was found to add weight to stigma in Nairobi City County. This limits disclosure and increases vulnerability to defaulting as in removal of family and social support. On the perceived link between TB and HIV, Mochache and Nyamongo (2009 p.897) observe that the flawed “link makes many patients conceal their TB status.” Further, TB patients may prefer self-treatment or traditional healers as therapy options since HIV screening is usually done in TB management and the patients would not want to know their HIV status. Mochache and Nyamongo (2009) assert that HIV-related stigma is the driver of the fear than the test result and that fear of stigma can hamper treatment among TB patients.

5.1.3 Medication Effects

The lived experience of TB patients in Nairobi City County is also shaped by the medication related factors: High pill burden and the drug side effects. The study findings indicate that patients feel burdened by the long duration regimen as in the DOT strategy. This is aggravated by high pill burden especially in case of co-infection (with HIV/AIDS). Although TB drugs were found to present pill burden for patients, co-infection aggravates the burden. According to Gebremariam, Bjune and Frich (2010), concomitant treatment leads to a higher pill burden. Drug-drug interactions, paradoxical reactions, and overlapping drug toxicities complicate concomitant treatment (Kwara, Flanigan, and Carter, 2005; Dean *et al.* 2002; Corbett *et al.* 2006).

Patients’ experience was found to be negatively shaped by TB treatment’s high drug pill and this may affect effective treatment and recovery. This is because the experience becomes a predisposing factor to treatment interruption or defaulting. Since patients do not want to be burdened by daily intake of drugs and may be required to travel with them, they may skip or default completely. Various studies have strongly associated TB poor treatment adherence or default with high pill burden. Gebremariam, Bjune and Frich (2010) and Shargie and Lindtjorn, (2007) found out that pill burden is one of the key barriers to TB treatment adherence. Further,

the link between poor adherence and pill burden is associated with regimen complexity and the larger extent on which the regimen affects patients' daily life (Munro *et al.* 2007; Ingersoll and Cohen, 2008; Shargie and Lindtjorn, 2007). Thus, in both single infection and co-infection, TB patients face the risk for decreased adherence to treatment. In fact, Gebremariam, Bjune and Frich (2010) observes that co-infected patients on concomitant treatment may be at risk of poor adherence to either or both treatment.

The other aspect that was found to shape patients experience in treatment was the drugs' side effects. Most patients cited undesirable experience with the side effects that prompted distorted adherence. The side effects were found to overwhelm many patients who cited abandoning the drugs in order to avoid the effects. When patients have engagements that would be frustrated by the side effects, they prefer to skip taking the drugs. This is an indicator of poor adherence and a gateway towards defaulting. Studies have shown that one of the key drivers to poor adherence is the TB drugs' side effects (Deshmukh *et al.* 2015; Gebremariam, Bjune and Frich, 2010 and Muture *et al.* 2011). Such low adherence to TB treatment is not only detrimental to recovery and healing but also leads to increased risk of prolonged infectiousness, death, relapse, and drug resistance hence MDR-TB (Muture *et al.* 2011; Gebremariam, Bjune and Frich, 2010). Thus, the experience in TB treatment (high pill burden and side effects) negatively influences TB treatment and recovery by being a barrier to treatment compliance.

5.1.4 Interactions with HealthCare Providers and Influence on Treatment

The study found out that there is a good patient-provider relationship in Nairobi City County. Patients and providers alike reported forging good therapeutic relationship with each other. This positively shapes the experience of the patients as they obtain emotional support and counseling from the providers. Notably, such good relation and healthcare practices cultivate a culture of patients' commitment to treatment or adherence. The patients also feel motivated to turn up for subsequent visits. This is a significant enabling factor in promoting sustained treatment and healing. Gebrimariam, Bjune and Frich (2010) cited lack of adequate communication with health professionals as a barrier in TB treatment adherence. Similarly, Deshmukh *et al.* (2015) observe that lack of provider support is a barrier to treatment adherence. It is thus conceivable that with open communication as facilitated by good patient-provider relationship, adherence and hence recovery are enhanced. This is because the patients would receive combined support to improve the experience with TB.

5.1.5 Delays in Service Provision and Influence on Treatment

Although the patients reported good interaction/relationship with healthcare providers, they also registered dissatisfaction in the long time they spend at the facilities before they are attended to. This illustrates a structural gap that may demote treatment. Apparently, patients wait for long hours in the queue awaiting services. This can be a barrier towards treatment as it discourages the patients to turn up for appointments or when their drugs run out. According to McLean (2003), long waiting times form part of the healthcare factors that for non-adherence to TB treatment. The patients may opt to pursue other beneficial engagements such as going to work instead of “wasting” time at the facility. This may negatively affect sustained treatment and encourage defaulting as some patients may fail to refill their drugs due to the delays in service provision at the facilities. The patients linked this delay to the shortage of TB healthcare providers attending to them. Further, it was found out that some facilities may lack TB drugs for various reasons and therefore refer patients to major facilities such as Mbagathi. This may discourage the patients because of additional costs of travel and other inconveniences. Such gaps pose detrimental effects on sustained and effective TB treatment and consequently, healing.

5.1.6 TB Awareness/Sensitization and Influence on Treatment

Study findings indicate that TB patients in Nairobi City County live in an environment of awareness where information on TB and related services is available. Indeed, according to Essendi and Wandibba (2011), awareness level of TB in Nairobi is above average although there are gaps. Both in the healthcare facilities and in social settings, there is awareness as manifested by the distributed sensitization materials. Particularly, the awareness and sensitization has been extended to public spaces such public transport vehicles and use of Swahili, implying a strategy for wider outreach to the clientele of *matatus* and other members of the public. For the patients, availing information on TB services and the affordability thereof is a factor contributing to adherence. Ayisi *et al.* (2011) assert that TB patients might discontinue their treatment before completion because of lack of awareness regarding duration of TB treatment and others may stop treatment once the symptoms subside. Essendi and Wandibba (2011) observe that gaps in awareness/knowledge regarding TB treatment form a barrier towards care seeking and poor treatment adherence. Muture *et al.* (2011) observe that inadequate knowledge on TB is a factor contributing to defaulting among patients. However, regular and comprehensive information on TB as disseminated to patients increase knowledge on TB and this may prevent defaulting

caused by lack of knowledge/information. In addition, patients are aware of where they can get treatment or other TB services. Awareness also contributes significantly to the identification of symptoms so that patients can seek testing/treatment immediately. Through sensitization, TB patients are also aware of prevention measures to avoid infecting others.

Sensitization also plays a significant role of increasing community awareness on disease transmission and prevention. According Matebesi and Timmerman (n.d) widespread dissemination of precise information on the causes and prevention of TB may help counteract misconceptions and myths on TB. This would help counter the disease etiology that may cause stigma or inhibit effective treatment. Thus, raising public awareness on TB in Nairobi City County is important in promoting treatment and improves patients' lived experience as well.

5.1.7 Financial Constraints and Influence on TB Treatment/Healing

TB patients in Nairobi City County face financial constraints that hinder compliance to treatment requirements. Although TB diagnosis and treatment services are offered free of charge in public health facilities, patients incur embedded costs such as for transport and food that put pressure on the existing financial strain. In the study, most patients interviewed did not have stable and adequate income and work in small-scale businesses and reported financial strain in sustaining treatment requirements such as nutritional. Due to shortage of food, some patients may skip medication to avoid the side effects. In several studies, financial constrain or low income is cited as one of the barriers to adherence (Deshmukh *et al.* 2015; Gebremariam, Bjune and Frich, 2010; Muture, *et al.* 2012).

The interplay between TB and poverty is well established and documented. Kim et al. (2005) asserts that TB is both a cause and consequence of poverty and high TB burden in low-income settings such as sub-Saharan Africa is an indication of the intricate relationship between poverty and TB. TB places high financial burden on families and this forms an important part of the patients' experience (Wyss, Kilima and Lorenz, 2001). According to Essendi and Wandibba (2011), poverty is a major barrier to care access especially among the economically disadvantaged people in the society such as women. Financial constraints undermine treatment by posing certain barriers such as lack of food and transport to the health facilities (Bjune and Frich, 2010; Weller et al. 1997). Bjune and Frich, (2010) suggest that adherence can be encouraged by provision of food and financial support and this shows the extent to which financial constraints engrained in poverty affects treatment and recovery.

The social conditions are also debilitating as most of patients live in congested informal settlements. This may explain the high prevalence of TB in such low-income and informal settings because with congestion, those with prolonged infectiousness and defaulters may infect others while being at risk of re-infection/relapse. When the health facilities are far from patients' place of residence, the travelling costs increase the financial burden and in the opportunity cost, the patients may forfeit or postpone going to the facilities, thereby undermining treatment.

5.1.8 Social Support and Influence on TB Treatment/Healing

Although healthcare providers provide support for patients, lack of strong social and family support is a major issue that shapes the experience of patients in Nairobi City County. This is despite the positive effect of social support in promoting treatment adherence (Baral *et al.* 2014; Deshmukh *et al.* 2015; Essendi and Wandibba, 2011; Gebremariam, Bjune and Frich, 2010). Support here refers to encouragement to take drugs as requires, provision of food and other necessities and moral back-up to cope with lengthy treatment. Research findings show that a small number of patients in Nairobi City County have links to social groups and networks that provide financial or emotional (encouragement) support. This is worse for men who do not have such social networks as community-based, gender-based or welfare groups. Such patients do not accrue the benefits associated with such group affiliations and do not have strong networks or links to provide the necessary support.

In addition, family and social support is not available to many patients as evidence by lack of persons specifically assigned to observe the patient. This is despite the fact that most patients live with at least five people in the same room/house. Ayisi *et al.* (2011) found that lack of family support is an important barrier towards treatment compliance. Lack of strong social networks and support system is attributable to the impact of stigma from the society and even the family (Moya and Lusk, 2013). However, this has dramatic and severe consequences on treatment and healing. Without strong networks, patients succumb to the drugs' side effects and may default when there is no support and encouragement from the networks or links to manage the undesirable experience. According to Baral *et al.* (2014), TB patients with combined support (society, family, and health centre) show treatment adherence than those without support. Thus, lack of strong social networks negates the support that patients need to sustain effective treatment.

5.1.9 Role of Social Networks in Improving Patients' Lived Experience

There is compelling evidence from the study that the role of social networks in improving the lived experience of TB patients in Nairobi City County cannot be underestimated. Social networks and links entail having key persons, groups, entities, resources and accessing structures that offer support in terms of availing various needs (Deshmukh *et al.* 2015). Social networks are about providing an enabling environment to the patient in order cope and overcome barriers to access and sustenance of treatment (Baral *et al.* 2014). According to Helman (2007), treatment takes place in a macro environment and within a social unit composed of friends, family, and community members who may discourage or encourage adherence to treatment. Patients whose networks support adherence to treatment and are accommodative have fewer chances of defaulting and not stigmatized.

In the study, patients with such networks showed great fortitude and sustained treatment. The patients who reported strong family and social support also reported few challenges when coping with the disease. This stands in sharp contrast with patients who reported to have weak family and social relations. The women who had support groups experienced no financial difficulties in treatment because of the support from their groups. In addition, men admitted that women get support from their social networks and desired to have such networks too. The role of social networks is thus to help lessen or mitigate the barriers and burden associated with treatment that characterize patients' experience. Social networks also help overcome the devastating impact of stigma. Having wider and strong social networks means that patients have gained substantial acceptance and do not therefore suffer from hopelessness, isolation, and labelling that comes with stigma.

Successful TB treatment as well as management is dependent on the subjective or lived experience of patients. Further, social networks play a significant role in improving the lived experience and thus promoting treatment and healing. In Nairobi City County, apart from the good provider-patient relationship and TB awareness, other elements that shape the lived experience demote treatment and healing. Despite the role of the social networks in improving the lived experience and treatment, patients (particularly men) do not have strong or elaborate social links/networks for social support. Lack of such social networks and support increases the impact of stigma, drug effects, perceptions, as well as financial constraints. These negatively

shape the lived experience for TB patients and have adverse consequences on treatment and healing.

In summary, the lived experience of TB patients in Nairobi City County is characterized by factors that demote or promote sustained and effective treatment. The elements that shape patients' experience are socio-economic, medication-related and structural or service provider related. On one hand, socio-economic and medication related factors have negatively shaped the patients' experience by creating unfavourable environment for coping. TB patients in Nairobi City County have to contend with long duration regimen associated with TB management. The long duration regimen exerts pressure and is burdensome especially in case of co-infection with HIV/AIDS. Patients feel burdened by the fact that they have to take the drugs daily for six months. This burdensome nature of treatment is compounded by the adverse drug effects (the side effects) that patients have to experience. The drugs have debilitating side effects that may compromise patients' schedules. Resultantly, some patients prefer to skip medication or quit completely (default).

Further, the socio-economic context exacerbates the patients' experience where patients live in a social environment that is not supportive. Social stigma is an issue that the patients in Nairobi City County have to confront for sustained treatment. Patients also lack effective social and family support and this negates the positive impact of social networks and supportive structures or systems. In addition, despite the free TB service provision, the patients experience financial constraints because of the embedded costs associated with treatment. Many patients have low income and live in informal settlements with poor living and housing conditions.

On the other hand, the patients experience good relationship with the healthcare providers. The healthcare providers are cited to be supportive, encouraging, understanding, friendly, and observe confidentiality. TB drugs are also available freely to patients. However, there are gaps in service provision where low healthcare provider-patient ration. Patients thus experience long waiting time in the queue before they are served. In other instances, some facilities do not have comprehensive TB service provision capacities and refer patients to higher-level facilities, hence inconveniencing the patients.

5.2 Conclusion

The analysis and reflections advanced in the study lead to conclusions that can be drawn from the lived experience of TB patients in Nairobi City County. The study investigated how the lived experience of patients influences treatment and the role of social networks in improving the lived experience. The study established that patients are in a socio-economic environment that negatively produce and shape their experience, thereby demoting treatment and recovery. High prevalence of TB in Nairobi City County is thus attributable the factors that shape patients' subjective experience and which undermine successful treatment.

TB patients face stigma from the society and family. Stigma seems to be embedded within the etiology on TB and its association with HIV/AIDS. Although the disease is itself stigmatizing as patients are labelled and isolated, the perceptions on the cause and consequences of TB aggravates the stigma. Stigma plays a central role in inhibiting support for the patients as pressure from other factors shaping patients' experience piles up.

Further analysis showed that medication-related factors such as long regimen, pill burden and side effects form part of patients' experience and hence lower quality of life. In many cases, the impact of these factors inclines patients to default or interrupt treatment. This points to the importance of observed care and support for the patients for successful TB treatment.

Although TB services are provided free of charge in public and private facilities, patients face financial constraints. These are attached with their demands of daily life as well as the requirements for treatment such as food sufficiency. Most TB patients have low income and the ensuing financial constraints contribute to discontinuation of treatment. The socio-economic status of the patients also perpetuates the disease due to infection and re-infection experienced in crowded informal settlements.

In service provision, the study found out that there is a good relationship between healthcare providers and the patients. This provides a form of support for the patients and encourages adherence to treatment. This is however countered by the long waiting time patients spend on clinics. Patients feel discouraged and may decline or postpone to go for treatment in order to save time. However, patients have information on availability of TB free services due to the sensitization campaigns in public health. Nevertheless, this does not address the subjective experiences of patients.

Social networks play critical role in improving the experience for TB patients and seem to offset negative factors such as stigma and financial constraints. Social networks increase patients' fortitude and promotes adherence to treatment. It is through social networks that patients find support, encouragement, hope, and resilience to cope with the disease.

The study has established disconnect between free TB services and sensitization campaigns on one hand and successful treatment and healing on the other hand. This is because the subjective experience of patients demotes treatment and healing.

5.3 Recommendations

1. The study findings show that there are structural gaps in TB service provision. Although TB services are provided freely in public health facilities hence affordability, the healthcare providers attending to the patients are few and do not match the increasing number of the patients. This is evident in the patient-reported long waiting time and the providers' feeling of being overwhelmed by an expanding clientele. Thus, for comprehensive TB management, it is recommended that the public health and hospital authorities increase staff and service provision capacity in TB clinics. This will not only relieve the providers pressure in order to serve the patients well, but also increase patient satisfaction.
2. The lived experience of TB patients has been found to be negatively shaped by social stigma and lack of social support/networks. Although there are existing public sensitization campaigns, they need to be reinforced with community support messages. Public health officials would tailor this sensitization to address the need of alleviating social stigma through education that seeks to demystify existing beliefs, perceptions, and stereotypes. Public health sector also needs to devise patient support and community advocacy programs that would diversify patients' social networks.

5.4 Areas for Further Research

On the lived experience of TB patients from Nairobi City County, it has been found out that patients lack or do not have strong social networks for social support. However, men are hardest hit on this issue. Unlike the men, women seem to have stronger affiliations to community and women groups that provide emotional and financial support for TB patients. There is need for further investigation on how men's social networks may be made more supportive to the patients. On the same topic, it is also important to investigate the impact of such loose social networks for men in TB management among them.

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APPENDICES

Appendix 1: Informed Consent Form for TB Patients

LIVED EXPERIENCE OF TB PATIENTS: INSIGHTS FROM NAIROBI CITY COUNTY

Investigator: Alex Muriithi Gateri

Introduction

I am Alex Muriithi Gateri from the Institute of Anthropology, Gender and African Studies, University of Nairobi. I am conducting a study on

LIVED EXPERIENCE OF TB PATIENTS: INSIGHTS FROM NAIROBI CITY COUNTY.

The study is being done in Mbagathi Hospital and Ngara Health Centre and further data collection will take place at the patients' home.

You have been selected to participate in this study because you are a TB patient and in at least third month of treatment and you live in Nairobi. Thus, the information you give will be critical in describing the lived experience of TB patients in Nairobi City County. The interview will take about 30 minutes.

Purpose

The study seeks to describe the lived experience of TB patients from Nairobi City County.

Procedure

If you agree to participate in the study, you will be asked various questions here at the hospital and the investigator will accompany you to your home for further interview and observation. The questions will be about your experience from the time you were diagnosed with TB and the treatment process. Although you will be asked certain specific questions, you will be free to provide more information that is relevant to the themes being addressed.

Risks/Discomfort

There are no risks in participating in this study. However, you may experience discomfort or psychological distress because of the personal nature of some of the questions asked. However, you are free to decline to answer the questions that you are uncomfortable with. Further, the

questions will be asked in non-emotive way and you will be asked in a friendly way. In case of any psychological distress or discomfort, I have liaised with the hospital management so that you will get help immediately.

Benefits

Although there will be no direct or immediate benefit for participating in the study, the investigator will assist in answering questions that you may have. Further, the study aims at describing the lived experience of TB patients and the findings of this study will be of benefit to the patients and the society since they will be used to inform the best practices to improve patients' experience and enhance treatment and healing.

Confidentiality and Anonymity

Your confidentiality will be maintained at all times during the study. The information provided will not be used for other purpose than the one stated. The names or identifiers of participants will not be used in the report or publications which may arise from the study. True identification of participants will be concealed at all times.

Compensation

There will be no direct compensation for your participation in the study. This is because you have not incurred expenses for primarily coming for the study and that you have not left unattended duties purposely for this study. The study is also for academic purpose (Masters Degree). However, there will be indirect compensation for loss of your position in the queue. I will liaise with the healthcare provider to give you priority for consultation when we finish the interview.

Voluntariness

Participation in the study is voluntary. You will be free to withdraw at any stage of the study and doing so will not attract any penalties or discrimination whatsoever. However, I humbly request for your cooperation, which will be highly appreciated.

Persons to contact

If you have any questions regarding the study, you can contact Alex Muriithi Gateri through telephone number 0728399757.

You may also contact the KNH/UoN/ERC Committee-0735-274288/0721-665077.

I would like to know whether you have a question to ask now. If no, would you like to participate in the study? If Yes, please sign the space below.

I _____ hereby voluntarily consent to participate in the study. I acknowledge that a thorough explanation of the nature of the study has been given to me by Mr./Ms. _____. I clearly understand that my participation is voluntary.

Signature _____ Date _____

Signature of Reseacher/Assistant _____ Date _____

Appendix 2: Informed Consent for Key Informants

Investigator: Alex Muriithi Gateri

Introduction

I am Alex Muriithi Gateri from the Institute of Anthropology, Gender and African Studies, University of Nairobi. I am conducting a study on

LIVED EXPERIENCE OF TB PATIENTS: INSIGHTS FROM NAIROBI CITY COUNTY.

The study is being done in Mbagathi Hospital and Ngara Health Centre and further data collection will take place at the patients' home.

You have been selected to participate in this study because you are a professional in TB healthcare provision and that you work in this facility. Thus, the information you give will be critical in describing the lived experience of TB patients in Nairobi City County. The interview will take about 30 minutes.

Purpose

The study seeks to describe the lived experience of TB patients from Nairobi City County.

Procedure

If you agree to participate in the study, you will be asked questions on various thematic areas on TB. Some of the questions will be about your personal and professional opinion and experience in handling TB patients. Although you will be asked certain specific questions, you will be free to provide more information that is relevant to the themes being addressed.

Risks/Discomfort

There are no risks in participating in this study. However, you may experience discomfort or psychological distress because of the personal nature of some of the questions asked. However, you are free to decline to answer the questions that you are uncomfortable with.

Benefits

Although there will be no direct or immediate benefit for participating in the study, the findings will benefit the TB healthcare providers in understanding further the experience of TB patients

and knowing employing the research-based best practices for improving the experience. This will help to properly manage the disease.

Confidentiality and Anonymity

Your confidentiality will be maintained at all times during the study. The information provided will not be used for other purpose than the one stated. Your names or other identifiers will not be used in the report or publications which may arise from the study. True identification of participants will be concealed at all times.

Compensation

There will be no compensation for your participation in the study. This is because the study is for academic purpose (Masters Degree). However, your participation will be critical, as it will contribute to the understanding of the lived experience of TB patients which will in turn help respond to TB management and improve the patients’ experience.

Voluntariness

Participation in the study is voluntary. You will be free to withdraw at any stage of the study and doing so will not attract any penalties or discrimination whatsoever. However, I humbly request for your cooperation, which will be highly appreciated.

Persons to contact

If you have any questions regarding the study, you can contact Alex Muriithi Gateri through telephone number 0728399757.

You may also contact the KNH/UoN/ERC Committee-0735-274288/0721-665077.

I would like to know whether you have a question to ask now. If no, would you like to participate in the study? If Yes, please sign the space below.

I _____ hereby voluntarily consent to participate in the study. I acknowledge that a thorough explanation of the nature of the study has been given to me by Mr./Ms._____. I clearly understand that my participation is voluntary.

Signature _____ Date _____

Signature of Reseacher/Assistant _____ Date _____

Appendix 3: Key Informant Interview Guide

Introduction

Hallo, my name is Alex, a Master of Arts in anthropology student at the University of Nairobi. I am conducting research on the lived experience of TB patients in Nairobi City County. This is part of the requirements for my Masters degree. You are one of the respondents chosen for this study as a health care provider with insights on the experience associated with TB. Your name will not appear anywhere in this study and the information you give will be handled with utmost confidentiality. You are also free to withdraw from the interview if you feel uncomfortable. However, I ask for your cooperation and your responses to the questions will be highly appreciated. If you agree to participate in the interview, we may begin.

Questions

1. From experience, what are some of the predisposing factors for infection that patients in Nairobi City County understand?
2. What do the patients perceive to be the cause of TB and how do they understand some of the symptoms?
3. How do the patients understand the relationship between TB and HIV/AIDS and how does the relationship affect them?
4. What are some of the treatment procedures when patients are diagnosed with TB?
5. What can be the barriers for adherence to treatment? Why would patients default treatment?
6. What are common side effects and how do patients commonly handle them?
7. What are the main questions that patients ask about TB?
8. According to experience, main problems patients face during treatment
9. In your opinion, what is the role of social stigma, exclusion in the community and support structures/social networks in improving the lived experience, treatment and healing?

10. What would you suggest for improvement of experience, treatment and healing for TB patients?

Appendix 4: Narrative Guide for Patients

Informant Code.....

Introduction

Hallo, my name is Alex, a Master of Arts in anthropology student at the University of Nairobi. I am conducting research on the lived experience of TB patients in Nairobi City County. This is part of the requirements for my Masters degree. You are one of the respondents chosen for this study as a patient with experience associated with TB. Your name will not appear anywhere in this study and the information you give will be handled with utmost confidentiality. You are also free to withdraw from the interview if you feel uncomfortable. However, I ask for your cooperation and your responses to the questions will be highly appreciated. If you agree to participate in the interview, we may begin.

Demographic Information

Age.....

Place of Residence.....

Highest Level of Education Attained

1. Primary
2. Secondary
3. Tertiary
4. University
5. Other (Specify.....)

Occupation.....

Sex

1. Male
2. Female

Marital Status

1. Single
2. Married
3. Divorced
4. Separated
5. Other (Specify.....)

Religion.....

Questions

1. Were you aware of TB as a disease before?

Probes: The causes, symptoms, consequences? What were your other perceptions about TB? What is the perception of the community in relation to TB? What do you know now about TB? What do people in your community say about it now? Why?

2. How did you know that you have TB?

Probes: Did you experience certain symptoms and did you recognize them as TB symptoms? Did you go for normal treatment and the doctor recommended a test?

3. Let us talk about testing/diagnosis.

What prompted you to go for testing? Did you tell anyone- the family, friends, neighbors that you are going for TB testing?

What was their reaction and what did they say? How did they support you? How were you feeling about their response/reaction and the entire testing procedure?

4. Who were you living or interacting with before diagnosis. Did they continue living or interacting with you after that diagnosis? Why or why not?

5. Tell me something about the experience at the hospital and interaction with the doctor.

Were you afraid for testing? What did the doctor tell you about TB? Did you meet other people who came for similar services as you at the hospital? What was your feeling about testing?

6. Let us talk about treatment. Did you get the treatment after testing or you waited? If you waited, why and for how long?

Probe: What did the doctor tell you about the treatment?

Probe: Defaulting, duration of intake? Other instructions? How did you feel about that information?

7. Tell me about sharing information about treatment.

Probe: Who do you stay with now while taking the TB drugs. Why?

Who knows that you are under treatment? Who have you told or declined to tell. Why or why not? How did they react?

8. How do you remember to take the drugs?

Probe: There is someone who watches or reminds you. Do you have a schedule/reminder?

9. If there is someone who observes you as you take the drugs, who is he/she where does he/she live?

10. Is there a day you can remember that you did not take the drugs? What happened so that you forgot?

Have you defaulted treatment (missed taking TB drugs). Why or why not? If yes, for how long? Do you know someone who has ever defaulted? Why?

11. Let us talk about the problems you face in treatment? What are they? Cost, schedule?

Probe: Do you forfeit other duties because of going for medication?

12. What side effects do you experience if any, because of taking the TB drugs?

How do you feel about them? How do you deal with them? Who helps you to deal with them?

13. Are you free to take the drugs in public? Why or why not?

14. Do you have a community forum or network for TB patients where you meet and discuss your affairs? If yes, how has it been of benefit to you?
15. In your opinion, what would you like to be done to address the challenges you face? What would be done to enhance your experience at the hospital, community, and family levels?

Appendix 5: Observation Checklist

Informant Code.....

Observation Number	
Area of residence	
Settlement pattern	1=Densely populated 2= Sparsely populated
Housing	1= Good condition and well ventilated 3= Poorly ventilated and Poor condition
The number of people living with the patient in the same house/room	
Is there someone specifically assigned to observe the patient?	1. Yes 2. No
Does the patient have a written schedule or reminder for taking TB drugs?	1. Yes 2. No
Are the drugs kept in clean, dry place	1. Yes 2. No

Specify other observations

.....

