PERCEPTIONS, STIGMA AND TREATMENT PATHWAYS AMONG TUBERCULOSIS PATIENTS IN WEST POKOT COUNTY, KENYA

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DECLARATION

Declaration by candidate

This thesis is my original work and has not been presented for a degree in any other University.

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DEDICATION

I dedicate this work to the memory of my late Dad Francis Mbuthia. His sacrifices to see me through education and his zeal to see me succeed in academics has gotten me this far.

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ABBREVIATIONS AND ACRONYMS

AIDS   Acquired immune deficiency syndrome.

CARTA   Consortium for Advanced Research Training in Africa

CINAHL   Cumulative Index to Nursing and Allied Health Literature

DLSPH   Dalla Lana School of public health

DOTS   Directly Observed Treatment, Short-course.

DOT   Directly observed therapy

DLTLD   Division of Leprosy, Tuberculosis and Lung Disease

FGDs   Focus group discussions

HIV   Human immunodeficiency virus

IDIs   In-depth interviews

KNBS   Kenya National Bureau of Statistics

MDG   Millennium development goal

MOH   Ministry of Health

NTLD   National Tuberculosis Leprosy and Lung Disease

PTB   Pulmonary tuberculosis

SDGs   Sustainable development goals

TB   Tuberculosis

WHO   World Health Organization

ABSTRACT

Despite being a curable disease, tuberculosis (TB) is the leading cause of death among infectious diseases globally, surpassing malaria and HIV and AIDS. Delay in TB diagnosis and initiation of treatment is a major obstacle that hinders the success of TB control. The delays increase the infectiousness of the disease thus sustaining transmission within the community. Lack of awareness and stigma associated with TB are some of the main reasons why people delay to seek treatment. This study was carried out among a selected sample of TB patients in West Pokot County, Kenya. The objectives of the study were: to assess the knowledge and perceptions of tuberculosis among TB patients; to examine the level of stigma associated with tuberculosis and how it exemplifies itself among TB patients; to document the treatment pathways experienced by TB patients and to determine the level of delay and factors associated with the TB diagnostic delays. The Health Belief Model and Model of Pathways to Treatment were used as the empirical lens to understand perceptions, stigma and treatment pathways among tuberculosis patients. A mixed methodological approach was engaged to collect the data used in this study. The specific techniques used in data collection include an interviewer administered questionnaire which was administered to 208 purposively sampled TB patients in four public health facilities between July 2015 and March 2016, focus group discussions, longitudinal follow-ups and in-depth interviews. The study revealed that 68 % of the respondents had poor knowledge of TB however 76% of the respondents correctly perceived as a contagious and curable disease. The study revealed that TB patients held a lot of misperceptions about the cause and transmission of TB, as only 24% identified germs as its main cause. Majority of the respondents 73(35%) thought that TB was caused by smoking and drinking. Similarly, the study found high level of both perceived and felt sigma among the TB patients which was manifested through self and community isolation of TB patients, association with HIV and inadequate of social support. The study further revealed that health care system was pluralistic in nature with different players including herbalist, drug shops/chemist, traditional healers, private clinic and the public health care facilities. The patients experienced dynamic and complex health seeking trajectories as they switched from one provider to the other which resulted in delay in TB diagnosis and treatment. Three factors were identified as the main causes of delay: one, individual factors which include lack of knowledge, misinterpretation of symptoms, stigma and poor health seeking behaviour; two, socio-cultural factors which include cultural beliefs, gender roles, masculinity and male dominance and three, structural factors which include inadequate diagnostic facilities, distance to health facilities and lack of finances.

In conclusion, the study found gaps in TB knowledge, high level of stigma and high level of diagnostic delay in the study area. There is a need for the TB program to heighten patient education to improve patient knowledge and awareness on TB as well as implement more innovative approaches such as intensive case finding and sensitisation of the informal health care providers in order to enhance early patient presentation in the health facilities. There is also need to improve the diagnostic capacity of the health facilities in the County.

1.0 CHAPTER ONE: BACKGROUND TO THE STUDY

1.1 Introduction

Tuberculosis (TB) is an airborne infectious disease caused by an acid-fast bacillus, which belongs to the *Mycobacterium tuberculosis* complex. The disease affects the lungs in approximately two-thirds of cases, but almost all other organs can be the site of TB infection. The symptoms of TB disease depend on where in the body the TB bacteria are growing (Comstock, 2000). Pulmonary TB is more common and present with a persistent cough (lasting 2 weeks or longer), chest pain, coughing up blood or sputum, weight loss, fever, fatigue and chills (American Thoracic Society, 2000).TB is transmitted through droplet infection. When an infectious patient coughs, sneezes or talks, aerosols are formed in the lungs and expelled. These aerosols contain the micro-particles that carry the bacilli, and when inhaled by others can cause infection (American Thoracic Society, 2000; Comstock, 2000). However, exposure to the TB microorganism does not necessarily mean one will develop the disease. Currently, over two billion people in the world are infected with the *Mycobacterium tuberculosis*, but only 10% will go on to develop active tuberculosis disease (World Health Organization, 2015).

In biomedical terms, TB is a disease with known effective treatment for decades. However, in order to understand why the disease burden still persists in many parts of the world, there is need to examine TB as an illness and the illness behaviour among those affected by TB. This study draws from Kleinman (1980) elaboration of illness which he defines as the shaping of the disease into behaviours and experiences through personal, social and cultural reactions to disease. The study sought to establish TB illness behaviour which is used to refer to the way people monitor their bodies, define and interpret their symptoms as well as their actions in the quest to access care.

Studies have shown that limited knowledge about TB and poor health seeking practices among communities that favour the use of alternative medicine over biomedical approaches and TB stigma have hindered TB control under the DOTS strategy(Engeda et al., 2016; Gele et al., 2010; Sima et al., 2017). As outlined in the WHO end TB strategy, timely diagnosis and notification is one of the global priorities in the control of TB (Uplekar et al., 2015). However, early case detection not only depends on the diagnostic capacity of the health facility but also the health seeking practices of the patients.

In Kenya, as in the case of other Low-Income Countries, TB control programs rely heavily on passive case finding. The programs depend on individuals with TB to voluntarily get help and therefore patient's health-seeking behaviour is critical to the success of these programs.

Health-seeking behaviour refers to the actions taken by individuals who perceive themselves as ill to enable them to treat or cope with their symptoms (Ward et al., 1997). It is a complex process (Chrisman, 1977) that entails patients interpretation of their symptoms and then making choices on treatment actions to adopt depending on the available options. Health-seeking behaviour is therefore a product of cognitive and non-cognitive factors that call for contextual analysis (Olenja, 2003). Previous studies have documented health-seeking practices of TB patients in Kenya (Ayisi et al., 2011; Liefooghe et al., 1997), however, none has focused on TB patients in the pastoralists communities. The current study sought to address this knowledge gap.

1.2 Global and national burden of tuberculosis

Tuberculosis is a major global health concern (Yuen et al., 2015). It is the most common infectious cause of mortality worldwide surpassing malaria and Human Immunodeficiency Virus and

Acquired Immune Deficiency Syndrome (HIV and AIDS) (World Health Organization, 2016). An important factor in the persistence of tuberculosis as a global health problem is the co-epidemic with HIV. In 2014, an estimated 12% of people with tuberculosis were co-infected with HIV and 74% of these people were in Africa (World Health Organization, 2015). TB causes ill-health among millions of people each year and ranks together with the human immunodeficiency virus (HIV) as a leading cause of death worldwide (World Health Organization, 2015). The global targets and indicators for TB control have been developed within the framework of the Millennium Development Goals (MDGs), Stop TB partnership and WHO's World Health Assembly (Raviglione & Uplekar, 2006; Stop TB Partnership, 2006). The targets were developed to halt and reverse TB incidence by 2015, half prevalence and death rate by 2015, while by 2050, a total elimination of TB as a public health problem with one case per one million population insinuated. Worldwide, there has been major progress in reducing TB cases and deaths in the past two decades. According to WHO, the 2015 MDGs target of halting and reversing TB incidence has been achieved, with TB incidence falling globally for several years and declining at a rate of 2.2% between 2010 and 2011(World Health Organisation, 2012). Globally, the 2015 MDGs targets of reducing TB mortality and TB prevalence by 50% were almost met with a reduction of TB mortality rate and the TB prevalence of 47% and 42% respectively.

However, even with this encouraging progress and availability of highly efficacious treatment for decades, the global burden of TB remains enormous. Globally, there were an estimated 9.6 million incident of TB cases in the year 2014. Among them, 1.2 million (12 %) were people living with HIV and AIDS. Further, there were 1.5 million deaths associated with TB. Among these deaths, there were an estimated 190,000 deaths from Multi-drug resistant tuberculosis (World Health

Organization, 2015). The number of TB deaths is unacceptably high given that with a timely diagnosis and correct treatment, TB has high cure rates. From 2016, the goal is to end the global TB epidemic by implementing the End TB Strategy whose targets are linked to the newly adopted Sustainable Development Goals (SDGs) (World Health Organization, 2015). The strategy aims to reduce the number of TB deaths by 90% by 2030 (compared to 2015 levels) and reduce the TB incidence by 80% to <20 per 100,000 population (Uplekar et al., 2015).This implies that worldwide, the burden of TB is enormous and more studies on the challenges hindering the control of TB are therefore justified.

Sub-Saharan Africa bears the greatest burden of tuberculosis and HIV pandemic and more than 50% of the TB patients are co-infected with HIV. Although Africa represents about 16% of the world population, a third of the total global TB cases that occurred in 2015 were from the region (World Health Organization, 2016). The number of people dying of TB is alarmingly high particularly in Sub-Saharan Africa (Nyasulu et al., 2016).

Kenya is ranked 13th on the list of 22 high-burden TB countries (countries with a 100 or more TB cases per 100,000 population) in the world and has the fifth highest burden in Africa (World Health Organisation, 2013). TB takes the greatest toll on the most productive age group of 15 to 44 years (World Health Organisation, 2009). The number of reported TB cases had increased tenfold from 11,625 in 1990 to 116,723 cases in 2007 and declined to 103,981 in 2011 and 89,760 cases in 2013 (Division of Leprosy Tuberculosis and Lung disease (DLTLD), 2011; National Tuberculosis Leprosy and Lung Disease (NTLD), 2015). According to Division of Leprosy, Tuberculosis and Lung Disease (2013), Kenya achieved treatment success rate of 87%. This puts Kenya amongst countries that have achieved the WHO-recommended treatment success rate of 85%. Coupled with

the improved case detection rate of 82% amongst all forms of TB cases, Kenya stands to improve on TB control targets beyond set targets (Division of Leprosy Tuberculosis and Lung disease (DLTLD), 2011).

Despite the successes of the TB control program, the country had a case notification rate of 217/100,000 population cases reported and therefore, more effort is needed to control the disease (National Tuberculosis Leprosy and Lung Disease (NTLD), 2013). To halt the tuberculosis epidemic, transmission must be stopped to prevent new infections and new cases. This can be achieved through early diagnosis and prompt initiation of effective treatment to render the TB patients non-infectious (Yuen et al., 2015). Yuen et al. (2015) argue that trying to eliminate tuberculosis without stopping transmission would be like trying to empty a basin full of water without first turning off the tap that fills it.

1.3 Statement of the problem

Effective drugs for TB have been available since the 1940s, but the burden of TB remains enormous especially in low-income countries (Dye et al., 1999) and thus the need to explore challenges hindering TB control. Delays in presenting for treatment has been identified as a major challenge in TB management in resource-constrained settings where health services are not well developed (Juniarti & Evans, 2011; Thomas, 2002). Tuberculosis patients go through different challenges during treatment which may hinder early diagnosis and adherence. Studies have shown that hidden costs of treatment, poor access to care, stigma, discrimination and prior maltreatment by the health system are some of the challenges TB patients face which may lead to delayed diagnosis and treatment abandonment (Godfroid et al., 2013; Greene, 2004; Sagbakken et al.,

2008). However, the experiences of TB patients and the challenges facing them during diagnosis and treatment in West Pokot County have not been explored. The paucity of data on patient's experiences and factors associated with delays among patients in West Pokot County and other regions in the country has serious implications on the success of any interventions aimed at addressing TB control.

According to WHO, lack of knowledge about TB and stigmatisation causes underutilization of the services, delay in seeking diagnosis, and poor treatment adherence (Stop TB Partnership and World Health Organization, 2006). Consequently, creating general awareness about TB among communities and initiating community participation in the control of the disease makeup one component of the 6 basic components of the "Stop TB Strategy" of the WHO (Raviglione, 2006). However, Kenya is one of the many countries where the level of awareness and community perceptions of TB is not well documented.

Tuberculosis is a social disease of public health importance whose control is not possible through biomedical focus only. For effective control of the disease, there is a need for qualitative research to understand the social factors hindering TB control in order to complement the biomedical emphasis on better drugs, vaccines and new diagnostic tools. Anthropological studies to bring out the experiences and treatment pathways that may be causing delayed diagnosis among TB patients are important as this will inform the TB control program on areas of improvement to control the transmission of the disease. The purpose of this study therefore, was to explore some of the social behavioural factors that hinder timely diagnosis and treatment of TB.

1.4 Research questions

The following research questions guided the study

1. What is the knowledge and perceptions of TB among the patients in West Pokot County?

2. What is the level of TB stigma and how does it exemplify itself among TB patients in West Pokot County?

3. What treatment pathways do TB patients experience in West Pokot County?

4. What is the level of diagnostic delays and what factors are associated with these delays in West Pokot County?

1.5 Research Objectives

1.5.1 General objective

To explore the knowledge, perceptions, and the treatment pathways TB patients experience in West Pokot County, Kenya.

1.5.2 Specific Objectives

1. To assess the knowledge and perceptions of tuberculosis among TB patients in West Pokot County

2. To examine the level of stigma associated with tuberculosis and how it exemplifies itself among TB patients in West Pokot.

3. To document the treatment pathways experienced by TB patients in West Pokot County.

4. To determine the level of delay and factors associated with the TB diagnostic delays in West Pokot County.

1.6 Assumptions of the study

The study assumes that TB patients in West Pokot County experience different treatment pathways that lead to delays in diagnosis and treatment of TB. The study also assumes that TB patients have low level of knowledge on TB and face high level of stigma in West Pokot County.

1.7 Justification of the study

Tuberculosis has been termed as a typical social disease, that requires both biomedical as well as social science research approach for effective control (Mason et al., 2015; Saunders & Evans, 2016). Tuberculosis tends to affect the disadvantaged groups such as the poor, the marginalised and minorities in the community and therefore, emphasis on detailing and tackling the structural and social determinants of TB has widely been recommended (Hargreaves et al., 2011; Lienhardt et al., 2005; Lonnroth et al., 2010). The purpose of this research was to approach TB diagnosis and treatment from a medical anthropological approach and examine the lived reality of TB infection and further understand the socio-cultural factors patient's encounter that may hinder timely TB diagnosis. This study is important in informing policymakers in the TB program on areas of improvement in the control of TB in West Pokot County. The study documents the treatment pathways and stigma experienced by TB patients in West Pokot County and illustrates a theory of factors leading to TB delays. This is crucial in informing the development of more patient-centred approaches to improve early diagnosis and treatment of TB. The information gathered from the study will not only inform the TB program on areas of improvement in TB services delivery in West Pokot County and other parts of the country but also in other pastoralist communities in Africa. The study also provides baseline information for future intervention studies aimed at addressing delayed diagnosis and stigma among TB patients in pastoralist communities.

1.8 Scope and limitations of the study

This study explored the experiences of TB patients in West Pokot County. The study focused on the perceptions about TB and the experiences of the patients with the illness. The study sought to find out whether patients experienced stigma and the health seeking practices adopted by the patients after the onset of TB symptoms. The study also sought to estimate the level of delay in diagnosis and determine factors leading to the delays.

The study had some limitations; first the use of IDIs and FGDs to study patients' lived experiences with TB was not sufficient to yield a detailed account of the patient's experience. A method such as ethnography which does not focus on reports about activities but is driven by the interest of being there and observing events as they occur (Flick, 2015) would have been more appropriate. However, conducting ethnography was not possible due to limited time and funds available for the study. Nevertheless, triangulation of different methods was done to tease out the research questions. Similarly, longitudinal follow-ups in the community were done with four informants in order to get a detailed account of their experiences with TB diagnosis, treatment, and stigma at the community level.

The limited time and funds for the study also affected the recruitment of study participants since the research team could only be in the field at specific times. As result, it was not possible to apply a random sampling framework on all the TB patients in the County. Only patients seen during specific recruitment days had a chance to take part in the study. However, to ensure good representation proportionate recruitment was done in four different hospitals serving the County.

Secondly, the assessment of treatment pathways during diagnosis and stigma scales used were based on self-reporting by patients who may tend to report what is socially acceptable. This may

have introduced social desirability bias which could affect the data validity (Nederhof, 1985; Randall & Fernandes, 1991). To improve the accuracy of the information, the respondents were assured of confidentiality and anonymity. The questionnaires were anonymous with no names and were identified by the use of arbitrary numbers. The study also triangulated methods to tease out the degree to which the findings differed or agreed.

Another weakness of the study is the dependence on patients' recall for the data on treatment pathways and delays. Self-reporting on its own is not exact; it depends on the ability of individuals to recall past events. However, this has been used in similar studies and hence the comparison of findings from other locations was valid. Similarly, only newly diagnosed patients in the first two months of treatment were included in the study to reduce the recall bias.

Finally, the study focused on individuals affected by TB only and not the community. This could only document the affected individuals' self-perceptions of TB but not the views of the general community.

1.9 Operational definitions of key terms

Stigma- Stigma refers to exclusion, rejection, blame or devaluation resulting from experience or reasonable anticipation of an adverse social judgment' because of having a certain condition. In this study, stigma associated with TB refers to prejudice, maltreatment and negative attitude directed to TB patients as a result of their diagnosis.

Perceptions – Beliefs or opinions about something often held by many people. In this study, this will refer to the understanding or the opinions held by the TB patients about Tuberculosis.

Delays in TB management– This refers to the time from the onset of TB symptoms to the time of initiation of TB treatment. The delay is classified as either patient delay, health system delay or total delay

Patient delay - This refers to the time between the onset of clinical symptoms of TB to the first visit to professional healthcare provider.

Health system delay- This refers to the time from patient's first consultation with the professional health care provider for the symptoms of TB until the date of diagnosis.

Total delay - This refers to the sum of the patient delay and the medical provider's delay

Adherence/ Compliance- Adherence or compliance refers to the extent to which patients follow the instructions they are given for prescribed treatment.

2.0 CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter presents a critical review of the relevant anthropological literature on TB and the theoretical framework that guided this study to its logical conclusion. The chapter is divided into four sections. The first section reviews literature on community perceptions of TB highlighting different communities understanding of TB including names used to refer to the disease. The second section analyses the anthropological literature on TB awareness and the importance of TB knowledge in the health-seeking behaviour and prevention. The focus on the third section is on treatment pathways experienced by TB patients during diagnosis and treatment and the health-seeking behaviours which lead to delays in diagnosis and treatment. The fourth section reviews literature on TB related stigma and its impact on delays in diagnosis and treatment. The fifth section presents the health seeking model and model of pathways to treatment as the main theoretical and conceptual framework that not only informed this study but also served as background to the anthropological contribution of this study.

2.2 Community's perceptions about Tuberculosis

Ethnomedically, tuberculosis has different local names in different communities in Kenya. In the Kiswahili language TB is referred to as *Kifua kikuu* which implies an extraordinary disease affecting the chest. Among the Kalenjin community (the main tribe consisting of the Pokot speakers of West Pokot among others), TB is referred to as *Chebuonit* which means 'a disease based in the lungs and the lungs can swell until they can finish someone'. In the same community, TB is also called *Kiploleit* which means 'coughing or continuous coughing' Other local names used to refer to TB by different communities are as shown in the table 2.1(Liefooghe et al., 1997).

Table 2.1: Local names for Tuberculosis

Community	Local term	Meaning
Turkana	*Itirian*	Coughing without stopping until you do not have space for breathing or even sleeping.
Luo	*Kahera*	That cough that never clears. A disease that never disappears. It can be in the chest.'
Luhya	*Olwera*	'A disease that usually affects the lungs and chest'
Bukusu	*sifo ba syangarasha*	'A kind of disease where one keeps coughing for a long time or you can even end up dying'
Bunyala	*obulwai ba sirifu*	'Disease associated with the chest … problems with breathing system, Western Province 'the results being thin, coughing and…death.'
Kikuyu	*Murimo*	Refers to the consequences of isolation, you could not greet somebody with your hand when you had this disease'.

Studies have shown that community's lay perceptions are important in explaining why people adopt different health seeking practices (Cramm et al., 2010). The perceptions about TB also shape the attitude towards the TB patients which results in patient being accepted or being shunned in the community. The local names used to refer to TB imply that the different Kenyan communities perceive the disease as a fatal chronic chest infection.

2.3 Awareness of Pulmonary Tuberculosis

Awareness of tuberculosis is important in TB control and prevention as it determines people's health-seeking practices. Improving community's knowledge on TB is essential in the TB Control strategy as it shapes their health-seeking behaviour (Bam et al., 2014; Koay,2004; Legesse et al., 2010). Several studies have shown that dearth of knowledge about the etiology, cardinal symptoms, route of transmission as well as appropriate treatment of TB may lead to delayed or inappropriate health-seeking practices, thus sustaining the transmission of the disease within the community (Auer et al., 2000; Gele et al., 2009; Legesse et al., 2010; Lienhardt et al., 2005; Melaku et al., 2015; Mesfin et al., 2009; Mushtaq et al., 2011; Tolossa et al., 2014; Yimer et al., 2005). Awareness of the causes, routes of transmission, treatment, and prevention of TB allows individuals to assess symptoms and seek the necessary treatment in good time. However in a study done in rural Southern Ethiopia, Melaku and team found out that majority of the people in the rural areas do not seek early diagnosis because they may not suspect TB upon appearance of early symptoms such as a cough and fever rather they wait until severe symptoms such as weight loss and haemoptysis appear (Melaku et al., 2015). Mushtaq and colleagues also reported similar findings among patients in rural Pakistan (Mushtaq et al., 2011). With the emergence of drug-resistant strains, Gregory et al note that TB programmes are now faced with a more critical challenge of controlling the spread of multidrug-resistant and extensively drug-resistant TB, which relies upon promptly making the diagnosis and initiating appropriate treatment (Gregory et al., 2014).

According to Mondal et al. (2014), although people often have a general idea of what TB is, gaps in knowledge on transmission, treatment, and prevention leads to diagnostic and treatment delays among people living with TB. The authors argue that patients with low knowledge about TB are

less likely to seek healthcare and get diagnosed rather they often turn to self-medication and traditional healers which lead to delays in diagnosis and appropriate treatment (Mondal et al., 2014). The use of traditional herbs not only delays health care seeking but also enhances the spread of the infection to the healthy population (Storla et al., 2008; Tolossa et al., 2014). In Ethiopia, Abebe and colleagues found that lack of awareness on TB contributed to the late presentation of suspected TB patient in the health facility (Abebe et al., 2010).

Community members do not differentiate the cause of TB and the risk factors for disease development. Poverty and lack of awareness are considered the most important factors that increase the risk of exposure to TB while factors such as HIV and AIDS, smoking, malnutrition, increased susceptibility of infants and the elderly and increased virulence and/or increased dose of bacilli have been recognized as important contributors to the development of the disease and its epidemiological burden (Cegielski & McMurray, 2004; Hassmiller, 2006; Legesse et al., 2010; Lienhardt et al., 2005). However, previous studies have documented misconceptions about the cause, treatment, and prevention of TB. In a study done in western Kenya region, Liefooghe et al found that TB is a well-known disease in the community that is perceived as a contagious disease that is fatal. Nevertheless, the respondents attributed the cause of TB to factors such as smoking, alcohol, hard work, exposure to cold air and sharing utensils with TB patients. In the same study, many participants believed that TB was hereditary. This may be due to the fact that TB is an airborne illness, which often spread among people living in close proximity and therefore, may seem to affect people from the same families. While some of the respondents believed that TB should be diagnosed and treated in a hospital and not at the periphery level others felt that traditional treatment was equally effective and took much shorter time compared to modern TB treatment (Liefooghe et al., 1997).

Similarly, studies done in Ethiopia showed a low level of knowledge about the cause of TB. In a study involving community members in rural areas of Southern Ethiopia, Melaku et al, (2015) found that only 9.2% of the respondents knew that bacteria is the causative agent of TB. The majority of the respondents felt that TB was caused by factors such as dust, poverty, exposure to cold air, lack of enough food, poor hygiene, smoking and drinking alcohol. The findings are consistent with those of other studies done in different parts of Ethiopia (Abebe et al., 2010; Legesse et al., 2010; Tolossa et al., 2014). The misconception about the cause of TB is of concern since it could affect the health seeking behaviour and the preventive methods for the disease.

Community's understanding of the human transmission of infection by the TB patients is absolutely critical to the control of the disease. TB is a contagious, communicable disease that spreads to non-infected individuals when an infected patient expels droplets with TB microorganism to the surrounding environment as aerosol when coughing (Kompala et al., 2013). It is important for the TB patients to know the mode of transmission of TB as this can influence their behaviour such as cough etiquette, respiratory hygiene as well as seek early treatment, which is critical in preventing TB transmission (Legesse et al., 2010; Longtin et al., 2009; Mondal et al., 2014). Several studies have shown that majority of the patients know TB as a communicable disease (Tolossa et al., 2014). Nevertheless, they hold misconceptions about the route of transmission. In their study Tolossa et al. (2014), found that while 80% of the respondents knew TB was transmissible, 35.6 % of the respondents thought that sharing utensils with a TB patient was a route of transmission for the disease. In another study among a pastoral community in Ethiopia, respondents felt that avoiding sharing utensils and sexual contact with TB patients would

prevent the disease transmission (Legesse et al., 2010). These misconceptions are likely to misinform the community on the control and preventive measures they ought to institute. The current study sought to establish whether such misconceptions exist in West Pokot County.

2.4   Stigma associated with Tuberculosis

The term stigma was originally described by Goffman as a devalued or undesirable social attribute that arouses negative feelings and subsequently causes the individual to become excluded from social relationships (Goffman, 1963). Stigma involves "exclusion, rejection, blame, or devaluation resulting from experience or reasonable anticipation of an adverse social judgment" because of a particular condition (Weiss & Ramakrishna, 2006 : 536). According to Link and Phelan (2001: 377),"stigma is present when: … elements of labelling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them" (Link & Phelan, 2001). Similarly, stigma refers to a social process in which people out of fear of the disease want to maintain social control by contrasting those who are normal with those who are different (Parker & Aggleton, 2003). Depending on the 'root or cause' authors have alluded to two types of stigmatisation conditions (Falk, 2001; Moya et al., 2014). Stigma could be existential referring to a situation whereby the individual did not cause the stigma or has little or no control over it. It could also be 'achieved' stigma when a person earns the stigma because of conduct or because the individual contributed to attaining it (Falk, 2001). The stigmatised individual often assumes the sense of disvalue and embraces a set of self-regarding attitudes about the denounced characteristic including shame, disgust, and guilt (Goffman, 1963). According to Yang et al. (2007) for the stigmatised, stigma amalgams suffering while for the stigmatiser, stigma is an effective and natural response that emerges as an act of psychological defence and moral experience that one is being

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threatened. Stigma is, therefore, a social determinant of health. When a disease is stigmatised, individuals may be unwilling to seek treatment due to fear of the social and economic consequences following diagnosis (Courtwright & Turner, 2010).

Different forms of stigma have been described by different theorists. Stigma may be enacted, felt, or both (Gilbert & Walker, 2010; Parker & Aggleton, 2003; Scambler, 2004; Weiss & Ramakrishna, 2001). Enacted stigma refers to exclusion or rejection by others against those with a certain condition based on beliefs of social unacceptability or inferiority (Chang & Cataldo, 2014). This form of stigma manifests through physical and spoken processes and can be witnessed. Felt/perceived stigma refers to the shame associated with having a condition and to the fear of being discriminated stemming from the anticipation of adverse judgment related to the stigmatised condition (Chapple et al., 2004). This form of stigma is important in causing TB delays as it may lead to patients hiding their diagnosis for fear of being stigmatised. Stigma leads to feelings of shame, and tainted identity and may increase the stress associated with illness and contribute to psychological and social morbidity (Chapple et al., 2004). The experience of stigma is often based on a perceived combination of the two forms of stigma.

The emergence of the HIV pandemic has been shown to complicate TB-related stigma. Historically, TB has been stigmatised because of its contagious nature and also due to incorrect knowledge of its cause, transmission, or treatment, as well as its association with marginalized group (Baral et al., 2007 ; Christodoulou, 2011; Jaramillo, 1999; Kipp et al., 2011; Sengupta et al., 2006). Three decades into the HIV and AIDS pandemic, stigma remains a significant challenge for HIV and AIDS and TB control programs. Tuberculosis and HIV and AIDS stigma often overlap

due to the high co-infection rate (Abney, 2011). Tuberculosis has been perceived as a marker for HIV positivity (Ngamvithayapong et al., 2000). In Sub-Sahara Africa where the prevalence of HIV and AIDS is high, a patient with Tuberculosis is often assumed to have HIV/AIDS as expressed by one participant in a study by Abney (2011:16) who had this to say; "Sometimes they think that because you have TB you also are HIV-positive". Similarly, a study done in South Africa showed that association of new TB cases with HIV and AIDS was the main cause of stigmatisation (Møller et al., 2011). The symptoms of HIV and AIDS which is associated with perceived sexual misconduct is often confused with TB and with the increased awareness of the link between the two diseases among the general public, TB patients are perceived as a high-risk group (Van Rie et al., 2008). The stigma associated with HIV and AIDS, therefore, amalgams TB stigma (Bond & Nyblade, 2006; Kipp et al., 2011) and may result in a delay in seeking care (Møller et al., 2011; Ngamvithayapong et al., 2000; Van Rie et al., 2008). Tuberculosis has been and still is often considered a ''dirty disease'', ''a death penalty'' or as affecting ''guilty people'' (Aryal et al., 2012:48). This may serve as a deterrent to TB cases from seeking treatment promptly posing risks of transmitting the disease to others.

Understanding the source of TB stigma is integral to reducing its effects on poor health-seeking behaviour that often lead to delayed diagnosis. Empirical evidence shows that there are geographical and cultural variations in the explanation for stigmatising TB patients (Courtwright & Turner, 2010). However, most authors identify the perceived risk of transmission from TB-infected individuals to susceptible community members as a leading cause of stigmatisation (Courtwright & Turner, 2010; Dodor et al., 2008; Gelaw et al., 2001; Kurspahić-Mujčić et al., 2013; Sharma et al., 2007). In Ghana, research shows that some of the main causes of TB-related

stigma are fear of infection, TB's association with HIV and AIDS, health staff's own fears, self-stigmatization by TB patients, and the blaming and shaming of TB patients by the public (Dodor & Kelly, 2009).

The stigma associated with TB has been widely shown to be a major setback to the success of TB control globally. Social stigma is not only a hindrance to seeking TB treatment early (Ahsan et al., 2004; Auer et al., 2000; Li et al., 2013; Skordis-Worrall et al., 2010) but also treatment adherence. Stigma around TB can make people reluctant to stick with their course of treatment over the many months as required for fear of being 'found out'. Poor adherence, in turn, may lead to drug resistance. The consequences of stigma can be seen affecting care-seeking behaviours, as people have been known to hide their TB status to family or friends, out of fear of being ostracised (Mathew & Takalkar, 2007). Research has demonstrated that in some cases, personal rejection occurs as a result of the strong stigma surrounding TB. Some of the causes of self-discrimination identified include fear of transmitting TB, avoiding gossip and potential discrimination (Baral et al., 2007).

Stigmatisation is a process involving institutions, communities, as well as inter and intra-personal attitudes and often result in negative social and economic consequences. The most common result of TB stigma is isolation from other community members. As result, TB stigma can considerably impact on economic opportunities of those affected. For instance in Ghana, TB stigma resulted in the prohibition of TB-infected individuals from selling goods in public markets and attending community events (Dodor et al., 2008). Tuberculosis patients in Thailand perceived tuberculosis as a dreadful, disgusting disease that leads to death and as a result isolated themselves (Sermrittirong et al., 2015). In India, a significant number of women become homeless after being

diagnosed with TB (HealthDev.net, 2008). In Pakistan, stigma associated with TB lessens the likelihood of getting marriage partners for the young tuberculosis patients and their family members (Liefooghe et al., 1995). Evidence both in research and practice shows that stigma associated with TB is universal. However, the effect of stigma on promptness to seek TB treatment has not been well quantified (Kipp et al., 2011).

Different authors have cited disease-related stigma to be a difficult concept to measure (Gilbert & Walker, 2010; Macdonald et al., 2015; Moya et al., 2014; Yang et al., 2007). According to Macdonald et al. (2015), questioning people about deep-rooted prejudices and opinions is difficult in that, direct questioning may immediately alienate the respondent and hinder information. On the other hand, using indirect questions is likely to mislead the respondents. The other challenge with stigma research relates to the research methodology. While stigma is evident in a post-event narrative, it is unlikely for a researcher to witness a stigmatising encounter and therefore, the researcher lacks first-hand knowledge of stigma. The subjective stigma encountered by patients remain locked in a past verbal narrative (Macdonald et al., 2015).

Although TB stigma is recognised as a serious problem, it has been difficult to describe the magnitude and the public health importance of the problem probably due to lack of quantitative measures of stigma in the African context (Marangu et al., 2016; Visser et al., 2008; Yang et al., 2014). Despite being recognized as an important social determinant of health, difficulties in characterising and monitoring stigma over time has made it difficult to justify the allocation of resources to interventions aimed at dealing with the problem (Courtwright & Turner, 2010). This

study utilized stigma scales developed and validated in Thailand because within the African context there is no scale that has been developed to measure stigma.

There is a need to have a better understanding of the determinants of TB stigma and the level of stigma experienced in order to devise ways to minimise it and its effects. Due to lack of an instrument to measure TB stigma in Kenya at the time of our study, we examined the adaptability of the TB stigma scales previously developed and validated in Thailand. This study sought to measure TB stigma using stigma scores and through statistical analysis to determine whether the level of stigma has an association with patient delays in seeking medical care. Further, narratives from specific selected individuals were used to understand TB stigma from patient's own perspectives and lived experiences.

2.4.1 Role of TB stigma in delays in diagnosis

While a lot of research focusing on HIV and AIDS stigma has been done, there is little research on TB stigma and its impact on TB diagnosis and treatment (Courtwright & Turner, 2010). Stigma is a social determinant of health that affects the ability to access care often leading to delayed diagnosis. Stigma associated with TB has been termed as a barrier to prompt diagnosis and treatment compliance (Buregyeya et al., 2011; Chileshe & Bond, 2010; Courtwright & Turner, 2010; Jaramillo, 1998; Liefooghe et al., 1997; Munro et al., 2007; Murray et al., 2013). Due to the fear of being identified as TB patients, individuals may not seek health care services for a TB diagnosis (Arcêncio et al., 2014), leading to delays in diagnosis and therefore, increased transmission of the disease in the community (Golub et al., 2006; Kurspahić-Mujčić et al., 2013).

Although TB stigma has been viewed as an important factor that increases delays in TB diagnosis and treatment, there have been mixed findings on the subject. Studies done in Syria, Zambia and Uganda showed that stigma associated with TB was not a predictor of delays in diagnosis and treatment of the disease (Godfrey-Faussett et al., 2002; Kiwuwa et al., 2005; Maamari, 2008). This is contrary to the findings of other studies that showed that TB stigma hinders individuals from being screened for TB and seeking treatment (Buregyeya et al., 2011; Jaramillo, 1998; Noyes & Popay, 2007). In their systematic review, Noyes and Popay (2007) examined the experience of stigma and public discourses around TB. The authors concluded that due to TB stigma, people will be reluctant to seek a diagnosis or to be seen to be receiving treatment or may keep the TB diagnosis as a secret. This is likely to result in delays in diagnosis and poor adherence to treatment. Similarly, Buregyeya and colleagues in a study done in Uganda found that fear of stigmatisation was a hindrance to early diagnosis of TB (Buregyeya et al., 2011). In another study done in Cameroon, Cambanis and colleagues found that perceived TB stigma was a significant predictor of delays of more than four weeks, but the association disappeared after multivariate adjustment (Cambanis et al., 2007).

Judging from these divergent findings indeed, the effect of stigma on promptness to seek TB treatment has not been well quantified (Kipp et al., 2011). Therefore, there is a need for more studies to determine the impact of TB stigma on diagnostic delays.

2.5 Treatment pathways experienced by TB patients during diagnosis and treatment

The sequential nature of health seeking behaviour, as described by Chrisman (1977), provides a useful key to understanding the different pathways and experiences patients follow in seeking diagnosis and treatment. According to Chrisman (1977), health seeking behaviour has five

different stages that patients go through during their illness. These stages include the 'symptom definition' stage which deals with how patients perceive the physical changes produced by the disease; 'illness-related shifts in the role behaviour' which refers to the way in which the evolution of symptoms influence how patient relate to their peers; 'treatment actions' which refers to the activities undertaken by patients to remove the burden of the illness; the 'lay consultation' stage refers to the exploring of peer's opinion about patient symptoms and suggestions for dealing with them; 'adherence' means those activities taken by patients for following treatment and medical advice (Chrisman, 1977). Understanding the way in which the patients interpret the TB symptoms, as well as the behaviour and treatment actions they adopt, are important in developing strategies for controlling an infectious disease like in the case of TB. This is because the main contributing factor to TB transmission is the presence of untreated patients in the community. Studies have shown that delays in seeking TB treatment prolong the infectiousness of the disease and therefore, early diagnosis of TB and rapid initiation of treatment is a prerequisite for the control of TB (Gele et al., 2009 ; Golub et al., 2006; Montavon et al., 2013; Otwombe et al., 2013; Sagbakken et al., 2010; Storla et al., 2008).

 In his work on patient and healers in the context of culture, Kleinman (1980) recognises illness and disease as a social construction that is heavily influenced by the culture and beliefs of the community. He acknowledges that the health care system has multiple players and that people's cultural beliefs and practices influence their health seeking practices. According to Kleinman, health care system has three sectors that closely overlap and are important in the study of socio-cultural issues in health care (Kleinman, 1980). These include the professional, folk, and the popular sectors. The professional sector refers to the institutionalised health care system that we all recognise while the folk sector refers to the alternative medicine that includes sacred and secular

forms of treatments. The popular sector refers to the individuals and community beliefs and practices. According to Kleinman, healthcare system includes people's beliefs and practices which are mainly governed by their culture. People or actors from the three sectors of health care system interpret the same symptoms of illness differently and are likely to act differently in the quest to manage the symptoms. For infectious diseases, like it is in case of Tuberculosis this may lead to delayed diagnosis and treatment which prolongs the infectiousness of the disease in the community.

There is no single definition of prolonged or acceptable delay from the onset of symptoms to the initiation of anti-tuberculosis treatment. Some authors have defined prolonged delay as 1–2 months (Gele et al., 2009; Otwombe et al., 2013; Storla et al., 2008). One month is quite a long time to have a TB patient coughing and releasing the disease microbes to the air hence infecting others (Baral et al., 2007). In the present study, prolonged patient delay will be defined as having symptoms for at least one(1) month prior to seeking treatment while prolonged health care system delay will be defined as starting anti-tuberculosis treatment at least one (1) week after the visit to the health care provider.

Depending on the origin or the one causing TB delays, there are different forms of delays. According to Jaramillo, misinterpretation of symptoms can lead to actions that hinder timely diagnosis and treatment of disease (Jaramillo, 1998). The misinterpretation of the symptoms can either be by the patients who may associate prolonged cough to something else other than a serious disease requiring formal health care or by health workers who may treat a TB patient with antibiotics before making the right diagnosis which in both cases results in delays in diagnosis and treatment. Delays in TB treatment and diagnosis have, therefore, been categorised into either patient delay, health care system delay and the sum of which is the total delay. Where patient delay

is defined as the number of days between onset of TB symptoms and the first contact with a professional health care provider, while system delay is defined as the number of days between patient visit to the health facility and initiation of anti-tuberculosis treatment (Gele et al., 2009; Otwombe et al., 2013 ; Sagbakken et al., 2010; Storla et al., 2008).

Both the patient and the health care provider contributes to delays in TB diagnosis, however, it is not clear which of the two contributes most to the total delays. In a cross-sectional study done among TB suspects in South Africa, Meintejs and colleagues showed that delays in TB diagnosis are mostly as a result of provider and not patient delay. In the study, the provider delay was double that of patient delay among those diagnosed with TB with a mean of 30 days and 14 days respectively (Meintjes et al., 2008). According to Meintjs et al. (2008) the delays in primary health care facilities were mainly due to the tendency of patients to visit multiple health care providers hence lack continuity of care. This was likely to lead to an incorrect investigation and thus, prolonged health provider delay observed in the study. Similarly, a study done in Vietnam showed longer mean provider delay of 7 weeks compared to mean patient delay of 3 weeks (Lönnroth et al., 1999). Other studies with similar findings were in Uganda (Kiwuwa et al., 2005) and Ghana (Lawn et al., 1998) where the health provider delay was double the patient delay. Lawn et al noted that private practitioners have insufficient TB diagnostic skills and this contributes to the high provider delays (Lawn et al., 1998). This is contrary to the findings from South Africa that showed patients who visited the public sector clinics experienced more provider delays as compared to those who visited the private general practitioner (Meintjes et al., 2008). However, both studies agree that provider delay reflects the inefficiency of the health system in diagnosis of pulmonary TB whether at the periphery public facilities or among the private practitioners.

Nonetheless, other studies have shown contrary findings where patient delay is the main cause of delay in TB diagnosis. Studies done in Tanzania (Mfinanga et al., 2005), Nigeria (Odusanya & Babafemi, 2004) and Thailand (Ngamvithayapong et al., 2001) showed that patient delay was longer than the provider delay. The authors attribute the longer patient delay to lack of awareness about TB and poor accessibility of TB services. According to Ngamvithayapong et al, patients with high health insurance coverage and easy accessibility of health services had a short patient delay (Ngamvithayapong et al., 2001).

Whether patient delay or provider delay contributes more to the total delay is an aspect that is likely to vary in different set ups depending on the prevailing factors. If the patients have easy accessibility to TB services, are knowledgeable about the disease and adopt good health seeking behaviour, this is likely to reduce patient delays. Similarly, if the health providers both public and private are well equipped with knowledge, skills and have sufficient diagnostic facilities, this is likely to lead to shorter provider delays and vice versa. However, it is important to note that where TB patients present early for diagnosis (short patient delay), the patient may only have fugue symptoms (Mfinanga et al., 2005) and sputum smear may not be ordered or might not yield positive results in the early stages of the disease and this may lead to misdiagnosis thus longer provider delay. But in cases of longer patient delays, patients come in advanced stages of the disease and diagnosis is unlikely to be missed hence short provider delay. Therefore, longer provider delay may not always reflect the inefficiency of the health system. However, patient's health-seeking behaviour is key in determining delays in TB diagnosis. A patient who visits the right health care providers consistently may allow for further investigation and proper diagnosis and thus less diagnostic delays.

Different factors ranging from social, demographic, cultural, and economic predisposes TB patients to diagnostic delays. In a systematic review, Storla et al. (2008) allude to different factors that may lead to delays in diagnosis and treatment of TB. The authors noted that delays are caused by factors affecting either the patient or the health care worker resulting in either patient delays or health system delays. While some factors influence either the patient or the health system delays, other factors affect both delays. Demographic characteristics such as gender and age as well as social economic factors such as poverty and low education level were associated with diagnostic delays. This is in agreement with the findings of Jaramillo who noted that economic difficulties experienced by TB patient while seeking help for their symptoms may contribute to delayed diagnosis and even treatment interruption (Jaramillo, 1998).

While gender is believed to have a strong influence on healthcare attitudes and behaviour, its impact on delays in TB treatment is disputed in the literature. The health-seeking behaviour of female patients tends to be different from that of males. According to Johansson et al, both genders show delays in seeking TB treatment but for different reasons. In their qualitative study, they found that the main factor contributing to delays in TB treatment among women is fear of social isolation from the family or the community while among men the main factor has been shown to be fear of individual costs of diagnosis and treatment of the illness (Johansson et al., 2000). In other study done in Ethiopia, Asefa and Teshome found that female patients were less likely to experience total delay than their male counterparts [AOR =0.34, 95%CI: 0.18–0.62](Asefa & Teshome, 2014). These findings affirms those of Kiwuwa et al. in a study conducted in Uganda among smear positive TB patients which showed that males were more likely to experience delay in treatment [AOR = 1.83, 95%CI: 1.02–3.29] (Kiwuwa et al., 2005:122). This gender difference in health seeking behavior with women being more likely to seek care faster than men has also been

documented in other studies in South Africa (Meintjes et al., 2008), Uganda (Buregyeya et al., 2014), Ethiopia (Madebo & Lindtjørn, 1999), India (Rajeswari et al., 2002) and California (Norcross et al., 1996). However, other studies have shown contrary findings, with female gender being more likely to experience diagnostic delays compared to male patients (Asch et al., 1998; Bai & Xiao, 2004; Guneylioglu et al., 2004; Lawn et al., 1998; Legesse et al., 2013; Li et al., 2013; Long et al., 1999; Mfinanga et al., 2008; Needham et al., 2001; Ouedraogo et al., 2006; Pirkis et al., 1996; Ward et al., 2001; Yamasaki-Nakagawa et al., 2001; Yang et al., 2014). Some of the reasons cited for longer delays among female patients are the fact that women have low decision-making power and are heavily loaded with various domestic chores and care of young children at their homes. These burdens deprive them of the time and opportunity to visit distant government medical facilities. Nevertheless, other studies conducted in Ethiopia (Belay et al., 2012; Mesfin et al., 2009; Yimer et al., 2005) , Nigeria (Odusanya & Babafemi, 2004), Spain (Diez et al., 2004), and Brazil (dos Santos et al., 2005) did not show any association between the gender of the patients and delays in seeking treatment. The role of gender in delays in TB diagnosis and treatment, therefore, seem inconclusive and more extensive studies should be done to determine which gender is more likely to experience delays in TB diagnosis and treatment.

The influence of another important demographic factor associated with TB diagnostic delays, the patient's age, is also disputed. Several studies have shown old age to be a risk factor of TB delays (Ayuo et al., 2008; Farah et al., 2006; Gagliotti et al., 2006; Godfrey-Faussett et al., 2002; Lienhardt et al., 2001; Sherman et al., 1999; Ward et al., 2001; Yimer et al., 2005). This has been attributed to the fact that many of the old patients have co-existing illness which makes TB diagnosis difficult (Farah et al., 2006; Mathur et al., 1994) and that they often rely on someone

else to take them to the health facility (Yimer et al., 2005) which may lead to delays. However, other studies have shown contrary findings (Demissie et al., 2002; Enkhbat et al., 1997). According to their findings, old age is not a risk factor for delays in TB diagnosis and treatment. Further research is important to establish the association between age and TB delays.

Unlike gender and age, the importance of the level of literacy as a factor that influences people's health-seeking behaviour is scarcely contested. Educational status of patients has been shown to have an association with TB treatment and diagnostic delays. Studies have shown that patients with improved educational status are less likely to experience delays in TB diagnosis and treatment (Asefa & Teshome, 2014; Hinderaker et al., 2011). This could be due to the increased awareness of the signs and symptoms and the importance of early diagnosis and treatment of TB reinforced by good health-seeking practices among educated people. Similarly, low education level and/or low level of awareness about TB has been documented as a risk factor for delays in TB diagnosis and treatment (Agardh et al., 2012; Bai & Xiao, 2004; Demissie et al., 2002; Farah et al., 2006; Guneylioglu et al., 2004; Li et al., 2013; Madebo & Lindtjørn, 1999; Mfinanga et al., 2005; Needham et al., 2001; Okur et al., 2006; Saly et al., 2006).

Poverty has also been shown to be a risk factor for delays in TB diagnosis and treatment. According to Jaramillo economic difficulties experienced by TB patient while seeking help for their symptoms may contribute to delayed diagnosis and even treatment interruption (Jaramillo, 1998). These findings are in agreement with studies done elsewhere which showed that low‑income predisposes one to TB diagnostic delays (Altet Gomez et al., 2003; Cambanis et al., 2005; Gagliotti et al., 2006; Lewis et al., 2003; Masjedi et al., 2002; Okur et al., 2006; Sasaki et al., 2000; Sherman

et al., 1999). The delays among the poor are mainly due to their inability to meet the public transport costs and other charges imposed at the health facilities (Barter et al., 2012).

Other studies found patient delays to be as a result of poor perception of the health services (Godfrey-Faussett et al., 2002), fear of stigmatisation and traditional beliefs (Buregyeya et al., 2011 ; Nicholls et al., 2005). False beliefs about curability of TB and its causation by evil spirits (Mochache & Nyamongo, 2009) results in delays in seeking treatment, as patients often seek traditional or divine healing for such illnesses before turning to formal health care. Storla et al also identified stigma to be an important factor in causing delays. This is because patients are likely to shy away from visiting the TB clinic in fear of being seen by other people as this would inform the public that they have TB. The authors also note that in countries where TB is linked to high prevalence of HIV and AIDS, effects of stigma are even worse as being seen in the TB clinic would be interpreted to mean one has HIV and AIDS (Storla et al., 2008).

Difficulties in access to health facility also influence the health-seeking behavior. Studies show that health facility being far is associated with TB diagnostic delays (Fatiregun & Ejeckam, 2010; Legesse et al., 2013; Wang et al., 2006; Yimer et al., 2005). As a result of the limited access to health facilities, residing in the rural area has been documented as a risk factor for delays in TB diagnosis and treatment (Huong et al., 2007; Li et al., 2013). According to Storla et al. (2008) easy access to the TB clinic designated by the national TB program was important in reducing patient related delays.

There are other factors that either increase the time spent on diagnosis or the time after diagnosis to the start of treatment resulting in health system delays. Storla et al. (2008) identified these factors

to be; other forms of tuberculosis other than pulmonary TB, clinical features such as co-existing chronic cough, the absence of blood in the sputum and negative sputum smear. When a patient has these characteristics, the doctors are less likely to suspect TB and commence treatment hence delays in diagnosis and treatment. They further observe that health care delay is also influenced by poor health care infrastructure. This includes poorly trained personnel and limited diagnostic tools which is a common phenomenon in most rural health facilities in low and middle-income countries. They also noted that low suspicion of TB among the doctors and misdiagnosis of the chest X-ray is common in TB low endemic countries and is a major cause of health care delays in the management of TB. Similarly, they recognise the role of the health-seeking behaviour of the patients in causing health care delays. They see the main cause of TB delays as being due to repeated visits at the same level of health care facility without a correct diagnosis. The health providers who mainly contribute to this vicious circle are mainly the primary level government health facilities, the private practitioners and the unqualified quacks and traditional healers (Storla et al., 2008).

Primary level government health posts and private practitioners have widely been shown to contribute to delays in diagnosis because of the limited diagnostic capacity. The primary facilities are run by junior nurses and low-level health staff whose primary training is not to diagnose serious diseases but to manage minor ailments and promote preventive activities (Anastasatu et al., 1989; Lawn et al., 1998; Lienhardt et al., 2001; Needham et al., 2001; Okur et al., 2006; Rojpibulstit et al., 2006; Steen & Mazonde, 1998; Yimer et al., 2005). Similarly, empirical evidence has shown that patients who seek the first care from private practitioners and traditional healers are likely to experience more delays because most of the private practitioners are likely to be less familiar with

diagnosis and treatment of TB (Kiwuwa et al., 2005; Lawn et al., 1998; Li et al., 2013; Lienhardt et al., 2001; Needham et al., 2001; Odusanya & Babafemi, 2004; Pirkis et al., 1996; Rojpibulstit et al., 2006; Skordis-Worrall et al., 2010; Steen & Mazonde, 1998; Storla et al., 2008; Wandwalo et al., 2004; Yamasaki-Nakagawa et al., 2001). However, in most countries, private practitioners are preferred by patients due to the promptness of services they give and therefore, are consulted first as opposed to the government facilities which are likely to have the qualified personnel and the necessary diagnostic tools but often poor customer service. Studies have shown that private practitioners are preferred because a majority of the public view them as more effective, more accessible, more understanding and more likely to respect confidentiality than the governmental health care workers (Auer et al., 2000; Skordis-Worrall et al., 2010). This contributes greatly to health care delays in diagnosis and treatment of TB. However, this is not the case with all private practitioners as there are major private hospitals with well-trained personnel and are well equipped and TB patients may not necessarily experience delays. In South Africa Meintjes et al. (2008) found that delays in TB diagnosis were associated with public sector clinics compared to the private general practitioners. It is likely that the general practitioners were well equipped with knowledge and skills to diagnose pulmonary Tuberculosis which may not be the case in other countries that have shown contrary findings. To reduce the diagnostic delays as a result of private practitioners and primary health care facilities, it would be important for the national TB program to sensitise these health care providers about TB and encourage them to refer patients to the right public facilities in time.

Studies done elsewhere, have shown that delays in TB treatment and diagnosis is a major problem in the TB control program which may have contributed to the high burden of TB in the country

(Asefa & Teshome, 2014; Belay et al., 2012; Hussen et al., 2012; Mesfin et al., 2009; Mesfin et al., 2005; Sreeramareddy et al., 2009; Yimer et al., 2005). However, in the Kenyan set up there is inadequate documented data on the experiences of TB patients during diagnosis and treatment and whether they experience delays and factors attributed to the delays. This study therefore, applied the mixed methods study to fill the observed void in West Pokot County.

2.6 Theoretical Framework

In determining what theoretical framework to inform this study, two types of model were considered. The health belief model and the treatment pathway model were found useful in the current study.

2.6.1 The Health Belief Model

The Health Belief Model (HBM) was originally developed by Hochbaum who used it to explain the uptake of TB screening opportunities provided via mobile X-ray units (Hochbaum, 1958). This was in the early 1950s, when medicines for TB were becoming available and it was found that beliefs about susceptibility to the infection and the benefits of screening were strongly correlated with chest X-ray acceptance. Subsequent extensions of the model have been associated with efforts to apply it in other contexts, including not only other forms of screening but also immunisation and compliance with medical treatment for conditions such as diabetes, renal failure and hypertension (Becker, 1974; Janz & Becker, 1984; Rosenstock, 1974).

The focus of the HBM is to assess health behaviour of individuals through examination of perceptions and attitudes someone may have towards disease and negative outcomes of certain actions. The main construct of the model are perceived severity, perceived susceptibility, perceived

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benefits and perceived barriers (Janz & Becker, 1984). Recently, other constructs have been added to the HBM, this include cues to action, motivating factors and self-efficacy (Rosenstock et al., 1988). The HBM assumes that health behavior change is predicted by the existence of the four main perceptions either individually or in combination. This include perceived susceptibility, referring to one's subjective perception of the risk of contracting a condition or disease; perceived severity, associated with feelings about the seriousness of acquiring an illness in terms of medical and social consequences; perceived benefits based on beliefs regarding the effectiveness of the particular actions available in reducing the threat of disease/illness and perceived barriers, referring to the cost-benefit analysis which it is believed people undertake to weigh up a beneficial action and its opposing limitations such as costs, side-effects, time and inconvenience.

The HBM is useful in this study in explaining the health behavior of patients with TB symptoms. The components that concern perceived vulnerability to and severity of the disease as well as perceived benefits and costs of treatment that forms the basis of decision to seek health services. The motivation to seek early diagnosis and treatment depends on the perception of the patients on the vulnerability and severity of the disease. Seeking treatment early is an individual choice which is influenced by the patient's perception on the seriousness of the disease and other factors like availability of funds, accessibility of the health services, encouragement from the family and friends.

The HBM construct of motivating factors is also inspiring in the present study. Some enabling/supporting factors must be present to enable the predisposed individuals to seek or adopt the prescribed health behavior. Enabling factors such as accessibility of health services, financial status of the individual, the attitude of the health care workers, and support from the family

members may have positive or negative influence on the individual's motivation to seek TB treatment.

Social support is particularly very important when dealing with a stigmatized disease condition like in the case of TB. The kind of support a TB patient gets from the family members, health personnel and friends will impact either positively or negatively on the patient's ability to seek treatment early. In the present study, the author sought to determine how these factors interact and whether the level of stigma associated with Tuberculosis has an effect on care seeking practices.

Weaknesses of the theory

The theory's assumption that individual undertake health behavior consciously; lack of evidence to support belief-behavior relationship and its emphasis on individual factors without considering structural and environmental factors thereby encouraging victim blaming are some of the documented weaknesses of HBM (Roden, 2004). Although the theory is adequate in studying the factors leading patients to make decision to seek health care services the model is deficient in studying treatment pathways among TB patients since it does not incorporate the role of informal health care services such as self-medication and alternative medicine as part of the health seeking practices. The model does not match the complex dynamism of healthcare seeking behaviour and therefore not adequate to provide a clear framework for this study. As a result second theory of pathways to treatment (Scott et al., 2013) was incorporated in the study.

2.6.2 Model of Pathways to Treatment

The model of pathway to treatment as proposed by Scott et al. (2013) is a revision of the general model of total patient delay by Andersen and colleagues (Andersen et al., 1995). The model has

been used widely to study diagnostic delays in cancer treatment (Birt et al., 2014; Walter et al., 2012).

The model provides a descriptive framework that focuses on events, processes and intervals during care seeking and factors contributing to delays in the different stages (Fig 2.1). The events refer to key time points in the pathway. According to Scott et al, there are five events namely detection of abnormal changes in the body, making the decision to consult health care provider, first consultation with the health care provider, diagnosis and treatment commencement.

The intervals on the other hand, refer to the time between the different events. There are four intervals: i) appraisal interval refers to the time from detection of symptoms to making a decision to seek help from the health care provider; ii) help seeking interval which refers to time from when one make decision to consult to the first consultation with health care provider; iii) diagnosis interval which refers to time from the first visit to the health care provider to the time the diagnosis is made and iv) pre-treatment interval refers to the time between diagnosis and commencement of treatment.

The processes refer to the actions that occur within the intervals and whose outcome determines the next event. Some of the processes include actions such as self-medication which are key factors in causing delays in presentation to the health facility and thus delays in diagnosis.

Finally, the model describes the contributing factors as the features of the patient, health care system that may influence the processes and the timing of the events and the duration of the intervals. The model identifies three types of factors namely the patient, health system and disease factors as shown fig. 2.1 below.
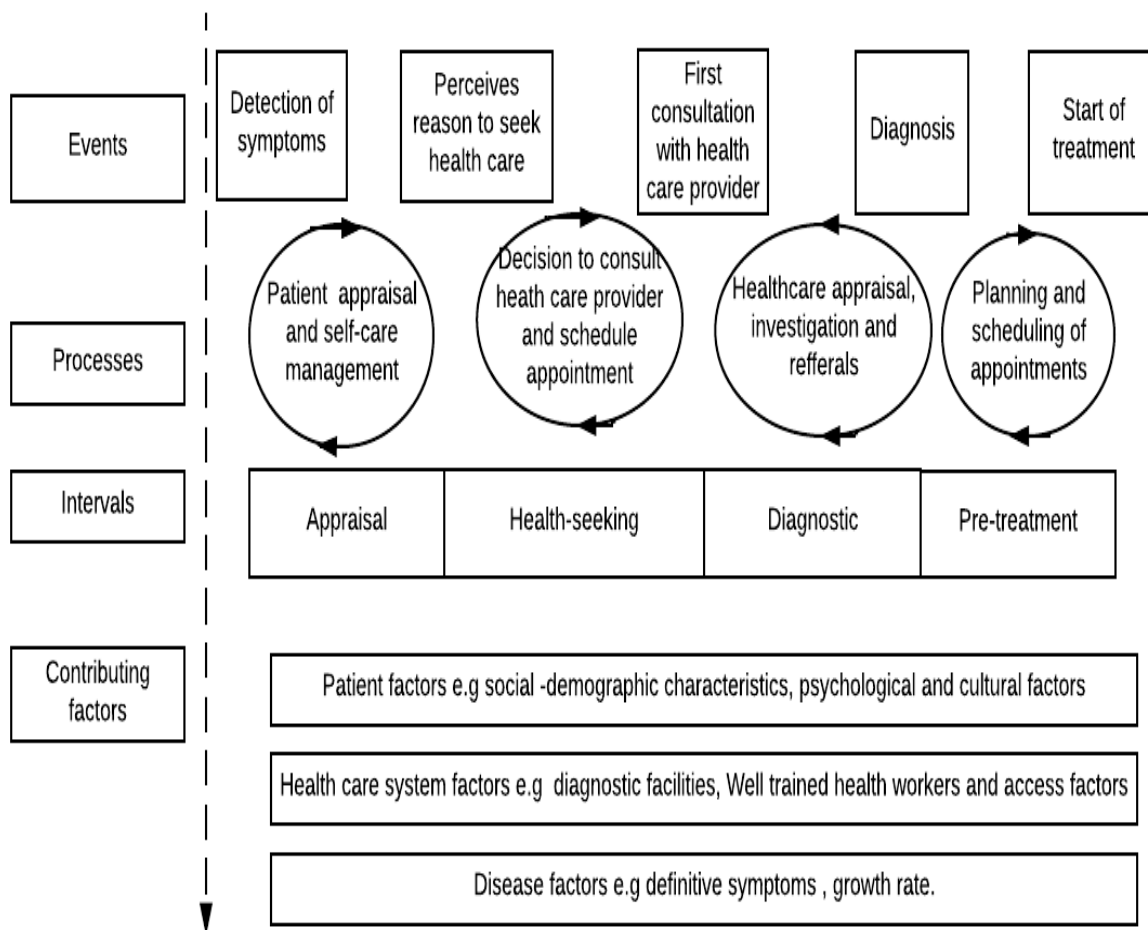
Figure 2.1 The model of pathways to treatment according to Scott et al. (2013)

The pathway to treatment theory sufficiently addresses the treatment pathway with emphasis on consultation of health care provider and processes that occur along the pathway which include lay consultation, self-medication as well as alternative medicine. The model was therefore, useful in informing the current study as it helps in understanding the different phases of health seeking pathway and factors that contribute to delays in diagnosis and treatment with an aim of identifying

targets for intervention to improve early presentation, diagnosis and treatment and therefore, reduce TB transmission.

The current study sought to study the perceptions, lived experiences and treatment pathways for TB patients. A conceptual framework for the study was as shown in fig 2.2.

Independent factors
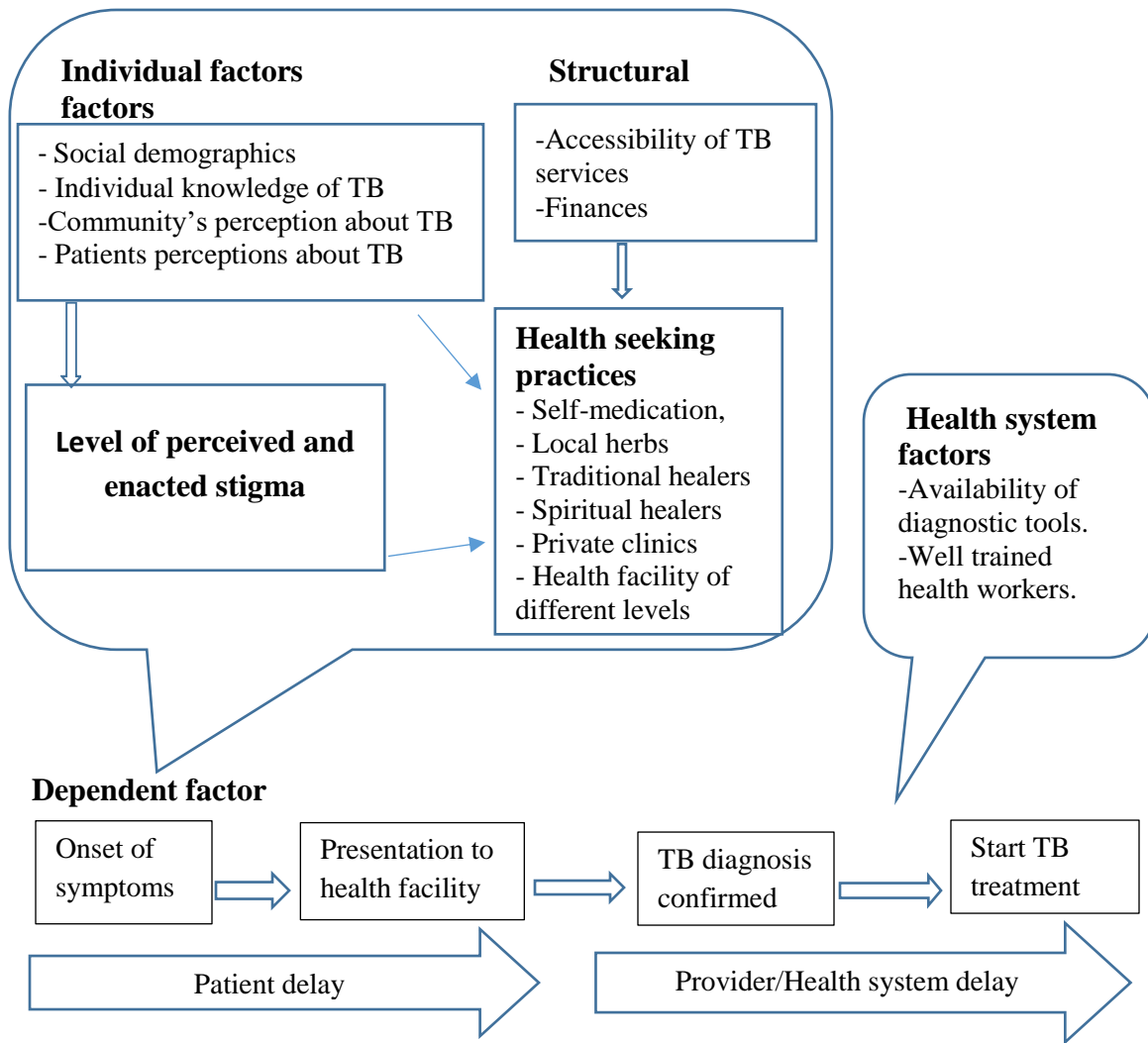
Figure 2.2: Conceptual framework for studying the treatment pathway and diagnostic delays among TB patients in West Pokot County, Kenya

This study conceptualised that patient delay in getting TB diagnosis and treatment was due to various factors which are mapped out in the conceptual model presented above. These factors include: individual factors such as social demographic characteristics people's perception about TB, TB knowledge, and level of felt and perceived stigma; structural factors such as accessibility of the health facilities and availability of finances to pay for the services. A combination of these factors affects the health seeking practices of the patients and ultimately the time it takes from the onset of symptoms to the time of diagnosis and treatment.

3.0 CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter describes the methodology used in the study. It includes a description of the research site, the research design, the study population, sample size, methods of data collection, data analysis and the ethical considerations.

3.2 Research Site

The study was carried out in the four health facilities in West Pokot County. West Pokot County is one of the administrative counties in Kenya and lies within Longitudes 34 ° 47´ and 35 ° 49´ East and Latitude 10 °10´ and 30º 40´North. The Map of West Pokot is shown in fig 3.1. It borders the following counties; Turkana to the North, Baringo to the East, Elgeyo Marakwet and Trans Nzoia to the South, and the Republic of Uganda to the West. The County is composed of four (4) Sub-counties namely West Pokot, North Pokot, Central Pokot and Pokot South. The County covers an area of 8,418.2 km^2 which fall within a semi-arid to arid ecological zone, characterized by recurrent droughts. Approximately 80% of the County is arid or semi-arid and 60% of the inhabitants are nomadic pastoralists while the rest of the population are agro-pastoralists (Huho, 2012). The County not only exhibits high levels of poverty and illiteracy in Kenya but is also served with relatively poor infrastructure. Some 512,690 lived in the County as of the 2009 census (Kenya National Bureau of Statistics (KNBS), 2010:140). The majority of the inhabitants are Southern Nilotic-speaking Pokot. The Pokot have led a fully mobile pastoralist lifestyle since the nineteenth century when they settled in this area. However, some have recently abandoned pastoralism and embraced sedentary agro-pastoralism. Rain-fed cultivation has over the last few decades emerged as a dominant livelihood in the well-watered areas (Nangulu, 2009).

The seasonal movement for the search of water and pasture for the livestock makes the population to have the least access to social amenities such as education and health services. Pastoralists are migratory people whose mobility can pose a challenge in adhering to TB treatment. Prompt diagnosis and treatment of pastoralist TB patients remain to be a challenge in TB control programs in many countries in Africa, where pastoralism is a common means of livelihood (Gele et al., 2009). In 2013, the case notification rate of TB in West Pokot County was high at 225/100,000 with a total of 1311 TB cases compared with the national rate of 217/100, 000 (Ministry of Health (MOH) Kenya, 2013). The marginalization of this County together with the high poverty index, the nomadic nature of livestock keeping, and general low health indicators could be the driver for the TB epidemic as these factors hinder the timely diagnosis and treatment (National Tuberculosis Leprosy and Lung Disease (NTLD), 2013).
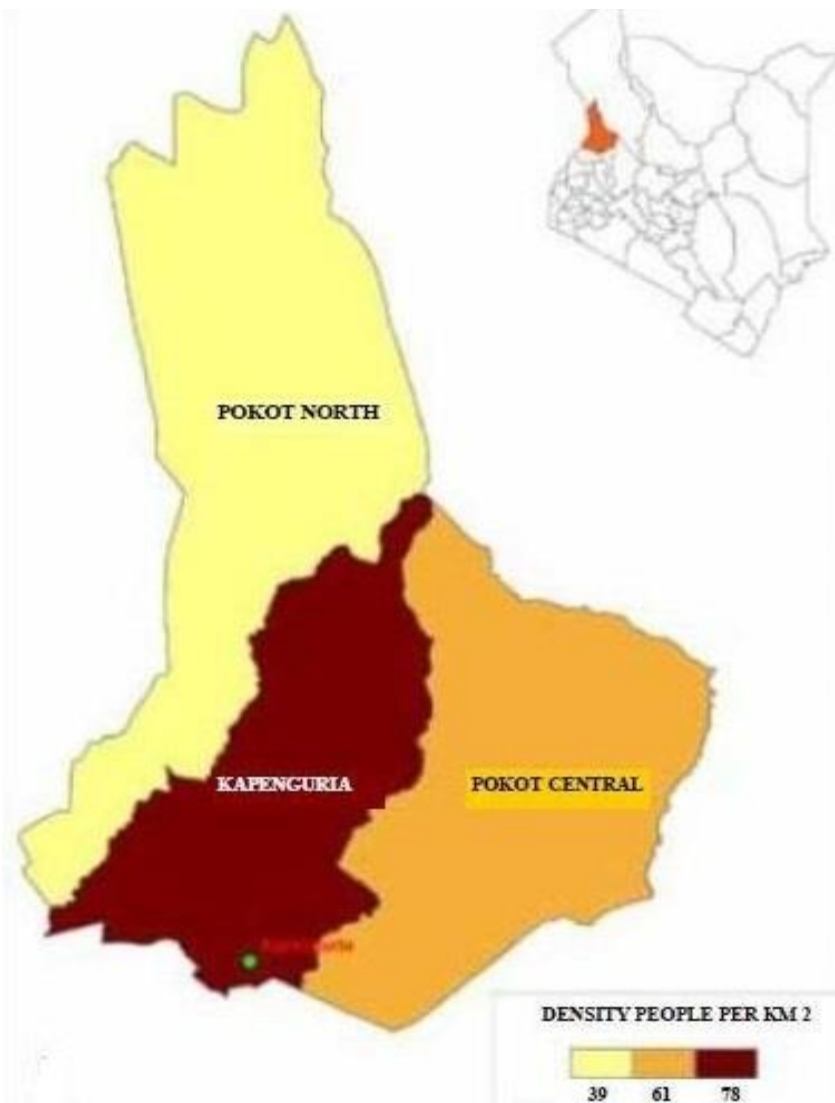
Figure 3.1 A map showing West Pokot County

(Adopted from http://softkenya.com/wp/content/uploads/2012/5/West-Pokot-County-Map)

3.3 Research design

This study combined quantitative and qualitative methods, leading to a mixed method approach (Creswell, 2013). An explanatory sequential mixed method approach was used where the study was conducted in two phases (Creswell & Plano Clark, 2011; Ivankova et al., 2006). Mixed

methods design refers to the process of collecting, analysing and combining both qualitative and quantitative data in the same stage of research in order to gain a deeper understanding of the research question (Creswell, 2005).

The qualitative research approach is based on naturalistic philosophies. According to the philosophers, ontologically there are multiple realities and knowledge is co-constructed through the interaction between the researcher and the research participants. In this paradigm, the investigator assumes a constructivist approach and uses inductive reasoning where participant's experiences and views are used to generate themes and ideas that are then used to build a theory. On the other hand, quantitative research is based on the post-positivist paradigm. In this paradigm, ontologically there exists a single reality which is objective. The philosophers in this paradigm believe that reality exists beyond their thinking and can be studied through scientific research methods. The researcher in this paradigm uses deductive approach to study a hypothesis or theory and collects data to either disapprove or verify the theory (Chilisa, 2012).

Though there has been debates on the incompatibility of mixing the two approaches due to their distinct ontologies and epistemologies, there has also been increased cognizance of the shortcomings of being bound by paradigmatic incommensurability (Newman & Benz, 1998; Teddlie & Tashakkori, 2003). The qualitative and the quantitative approaches should not be seen as dichotomous but rather should be viewed as an 'interactive continuum' where one approach builds on the other (Newman & Benz, 1998). The advocates of mixed methods believe that the approach is more applicable in studying complex research questions compared to the traditional qualitative or quantitative alone studies (Creswell & Clark, 2007; Teddlie & Tashakkori, 2003).

This is based on the argument that each method has its own limitations and the use of only one method is likely to yield biases and limited results. When used together, the methods complement each other and yield a more robust analysis of the problem under study (Greene et al., 1989; Miles & Huberman, 1994).

According to Greene et al. (1989) the mixed methods design is applicable in research for the following purposes: Triangulation – to seek convergence of the findings from the qualitative and quantitative data sets; complementarity –for interpretation and elaboration of the findings. Often, qualitative data is used to provide explanations to the patterns observed in the quantitative data; development of research -tools or results from one study can be used to inform the design of a second study; initiation – one design is used to lay the basis of another study to unveil emerging paradox and suggest areas of further research; Expansion – Another method is used to add breadth, richness, and detail.

The rationale for the mixed methods design in this study was triangulation. Triangulation refers to the use of different methods to study the same phenomenon with an aim of confirmation of findings in order to enhance the validity of the research findings (Greene et al., 1989). The explanatory mixed method approach allowed the use of methods with different strengths to tease out the research problem at hand. The first phase included a quantitative survey done using a questionnaire which enabled the researcher to quantify the level of TB knowledge, delays and TB associated stigma in the study area. The second phase was a qualitative study consisting of focus group discussions (FGDs) and in-depth interviews (IDIs) as well as community follow-ups of selected informants during the treatment period. The qualitative study was useful in providing explanations to the patterns observed in the quantitative phase. From the qualitative data, it was possible to get

details of the health-seeking practices leading to delayed diagnosis and how TB stigma exemplify itself among TB patients.

The research was conducted over a period of ten months. First, the survey was conducted by use of interviewer-administered questionnaire. Second, the informants for the qualitative study were then purposively identified based on their level of delay and TB stigma. The IDIs were done at the TB clinics. The patients were expected to narrate their lived experiences during the TB diagnosis and treatment. Similarly, six FGDs were conducted with patients seeking treatment in various TB clinics in the County. Community follow-up was also done with selected informants to gain a deeper understanding of the lived experiences of TB treatment.

In this study, the researcher assumed a pragmatic epistemological approach (Rescher, 2005). Mixed methods researcher advocate for this worldview because it uses many methods in data collection to study a phenomenon and its oriented on the premise of what works best to get the most appropriate results (Creswell & Clark, 2007). A post-positivist paradigm that tries to find meaning in empirical data was employed in the quantitative study while an interpretivist paradigm was applied in the qualitative study where the researcher sought to obtain an understanding of the data from an individual perspective (Crotty, 1998; Denzin, 2002). Both qualitative and quantitative data were collected and analysed separately and only merged in the final analysis in order to preserve the integrity of different paradigms of each method.

3.4 Study Population

The study population consisted of adult patients diagnosed with TB in West Pokot County.

3.4.1 Inclusion criteria

- Newly diagnosed adult Tuberculosis patients in West Pokot County willing to participate in the study.

3.4.2 Exclusion criteria

- Mentally ill TB patients

- Patients who had not completed 2 weeks of treatment

- Patients who were not residents of West Pokot County.

3.5 Sample size and participant recruitment

Fisher's formula was used to calculate sample size. A prevalence rate of TB diagnostic delays of 92.6% as documented in a study done among TB patient's in western Kenya (Ayuo et al., 2008) was used to estimate the sample size. Using this as a reference for a single proportion calculation with type 1 error of 5% and amount of discrepancy tolerated on p of 5% the minimum required sample was:

$$N = \frac{Z^2 p (1-p)}{d^2} = \frac{(1.96)^2 \, 0.926 \, (1-0.926)}{(0.05)^2} \quad 106$$

Where:

- N= sample size $\quad$ =106

- Z = standard normal score at 95% Confidence interval $\quad$ = 1.96

- p = Prevalence proportion $\quad$ = 0.926

- δ = level of discrepancy tolerated $\quad$ = 0.05

The minimum required sample for this study was 106. However, more respondents were recruited to increase the power of the study. To ensure representation of the entire County, patient's

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recruitment was done from the four main public health facilities offering TB treatment in each of the four sub-counties in West Pokot County. Proportionate allocation of patients was done based on the strength of each hospital as follows;

Hospital	Total new TB cases July 2015- Mar 2016	Total recruited
Kapenguria County Hospital	182	70
Kacheliba Sub-County Hospital	158	50
Sigor Sub-County Hospital	152	50
Chepararia Sub-County Hospital	143	50
Total	635	220

The questionnaires were administered as an exit interview at the TB clinics by the researcher and trained research assistants. Out of the 220 questionnaires administered only 208 were complete for analysis. Twelve questionnaires were excluded from analysis due to the incomplete information for various reasons such as; poor recall capacity for some of the respondents and difficult respondents who did not offer response to some of the questions making the information inadequate for analysis.

For the qualitative component, the study participants were composed of 61 patients purposively selected from the 208 patients who took part in the survey. Recruitment of the participants was done through the help of the nurses working at the various TB clinics. Only patients in the intensive phase (first two months) of TB treatment were included in the study. With the guidance of the nurses at the TB clinics, participants who met the inclusion criteria were purposively selected based on characteristics such as length of delay, gender, and place of residence. The selected

patients were briefed about the study and upon providing informed consent they were booked for the interviews during their appointment dates.

In order to gain a deeper understanding of the patient's health-seeking experiences as well as observe TB patients' interactions with the family and community, four informants were purposively selected for longitudinal follow-ups. The follow-ups were conducted through home visits until treatment completion.

3.6 Data Collection Methods

Several methods were used to collect information from the respondents, informants and participants. This section shows what methods were used to collect what kinds of information.

3.6.1 Quantitative data

3.6.1.1 Questionnaire survey

The main tool for primary data collection was an interviewer-administered questionnaire (Appendix 2). The questionnaire with both open and closed-ended questions was divided into four sub-sections namely socio-demographic characteristics; awareness on tuberculosis; duration taken during diagnosis and treatment and stigma scales. Questions addressed socio-demographic characteristics, knowledge on tuberculosis, health seeking practices, time of onset of TB symptoms and time of the first visit to a health facility- patient delay, time of the first visit to facility to the date of diagnosis – health system delay.

The questionnaire also contained a validated stigma measurement scale that was developed in Thailand to quantitatively measure stigma associated with TB (Van Rie et al., 2008). The items in the TB stigma assessment scale were mainly on, attitudes toward TB patients, fear of disease

transmission, association of TB with HIV and AIDS and disclosure of disease status. The scale contained 12 items which were used to measure experienced and felt TB stigma. The items were used to assess the experiences, opinions, and feelings of TB patients (e.g. "Some people who have TB feel hurt of how others react to knowing they have TB; "Some people who have TB feel lonely"). The scale also comprised of another 11 items that were used to measure perceived TB stigma. This was done by considering the TB patients' perception on how the community feels and behaves towards people suffering from TB (e.g. "Some people try not to touch others with TB"; "Some people keep their distance from people with TB"). Responses were summed up for each scale to create stigma scores, with higher responses indicating higher stigma.

The questionnaire was translated into Kiswahili which is commonly spoken by the majority of the West Pokot residents. The research assistants were also drawn from the local community to assist in translation in cases where patients required to be interviewed in the local dialect.

3.6.2 Qualitative data

3.6.2.1 In-depth interviews

In-depth interviews were used to collect data on patient experiences and treatment pathways facing them during tuberculosis treatment. The interviews were done with fifteen TB patients drawn from the four main TB clinics in West Pokot County. A semi-structured interview guide (Appendix 3) was used to collect the information. The probing questions were adjusted in the consecutive interviews to probe on new emerging themes from the previous interviews. Each interview lasted for about 60-90 minutes. The IDIs were conducted in Kiswahili language at the TB clinic. The IDIs were tape recorded and later transcribed verbatim (Creswell, 2005). Data collection was stopped at 15 IDIs.

3.6.2.2 Longitudinal follow-ups

In addition, longitudinal follow-ups were done with four purposively selected informants from the IDI cohort in order to obtain narratives on the lived experiences of TB patients. These were 2 males aged 32, and 61 years as well as 2 females aged 30 and 36 years. With the help of the community health worker attached to the TB clinic, I visited the four patients to their homes to further understand their lived experiences with TB and TB treatment and observed their interactions with the rest of the family members.

3.6.2.3 Focus Group Discussions

Six FGDs were conducted as follows; three with males consisting of 7, 8 and 10 participants and three with females consisting of 6, 7 and 8 participants. The participants shared their perceptions and experiences of health care seeking for TB symptoms. FGDs were meant to complement the IDIs. Compared to individual interviews, group interaction allows participants to agree and disagree thereby revealing the participant's real perceptions on the subject of interest (Barbour & Kitzinger, 1998; Liefooghe et al., 1997). The FGDs were constituted based on gender. Gathering ideas and cultural beliefs surrounding TB was possible through this method of data collection. An FGD guide (Appendix 4) was used to collect the data. The probing questions were elevated in the consecutive FGDs to include emerging themes. The FGDs took place at the TB clinic with each FGD lasting between 90 to 120 minutes. The principal investigator moderated the discussion as the research assistant recorded notes during the discussion. The FGDs were conducted in Kiswahili language at the TB clinic and were audio recorded and later transcribed verbatim.

3.7 Data processing and analysis

3.7.1 Quantitative data

Stata computer statistical packages were used for data entry and analysis. During data collection, data were entered daily into the database which was created at the beginning of the study. Data checks were carried out and incomplete questionnaires were excluded from analysis. The database was password protected and was only accessed by the researcher. Hard copies of the questionnaires were kept under lock and key.

Univariate categorical variables were analysed in frequency and percentages and presented in tables. The univariate continuous variables were analysed using measures of central tendency and dispersion. Bivariate categorical variables were analysed using chi-square test. The test was also used to examine the association between socio-demographic factors and level of stigma. Multivariate analysis was carried out using logistic regression to establish the relationship between socio-demographic characteristics and delays in TB diagnosis. Statistical significance was set at $P<0.05$. The data is presented in tables and text.

The composite measure of patients' knowledge was measured by the total number of correct answers to 8 items on knowledge of TB. These included knowledge about the cause of TB, signs, and symptoms of the disease, curability, mode of transmission, risk factors for TB and availability of free treatment in government hospitals. The scale was then dichotomized into two categories (good or poor knowledge) using the median as the cut-off.

Patient delay, defined as the period (in weeks) from the onset of the first symptom(s) possibly related to pulmonary TB to the date when the patient first contacted qualified primary health care services as a result of the symptoms, was the focus of interest. Patients were expected to remember

the duration of their symptoms and when they first sought treatment from the health facility. Patient delay was calculated as the time between these two points. The provider delay was also estimated from the time of the first visit to the health worker to the time TB treatment was commenced. In order to determine the effect of TB stigma on the length of the delay, TB stigma was correlated with the categories of the delay.

3.7.2 Qualitative data

The information gathered from focus group discussions, narratives and in-depth interviews were transcribed by the researcher. Transcripts were analysed with the aid of the N-vivo (version 11) qualitative data analysis software. Data collection and data analysis were done concurrently. During this process, the principal investigator wrote memos and reflections of what had been learnt in each narrative, IDI and FGD. Theoretical sampling was done by formulating more probing questions that would be asked in the consequent FGD or IDI to clarify emerging concepts.

Thematic analysis was done by reading the transcripts multiple times and identifying, coding, and categorizing meaningful patterns into themes and sub-themes. Three levels of coding, that is open, axial and selective as used in grounded theory were applied during the analysis (Strauss & Corbin, 1998). Open coding was done by reading the transcripts word by word many times and identifying codes from the data. A total of 17 codes emerged. Related codes were then grouped together into sub-categories during the axial coding. Axial coding refers to the process of relating codes or categories to each other through inductive and deductive reasoning while selective coding is the process of choosing one category that relates to all the other categories to serve as the core category (Strauss & Corbin, 1998). The sub-categories were then integrated into theoretical constructs in the selective coding which lead to the core category of pathway of delay in TB diagnosis. 'I suffered for a long time' was a sub-category under delays which was expressed by the informants

as a summary of their experience in seeking TB diagnosis. The axial and the selective coding were used to explore the relationships between the sub-categories and tie the concepts together to generate a conceptual framework of factors leading to delays through comparative analysis (Strauss & Corbin, 1998). Data were presented in a textual form and where possible, verbatim quotes used to amplify the voices of the informants. The qualitative and quantitative data were compared to relate the information from the two data-sets.

A visual model of the sequential mixed methods used in this study is as shown in fig 3.2. Mixed methods literature recommends graphical representation of methods used to help the researcher visualise the sequence of data collection, the linking and mixing points of the two approaches used within the study (Creswell, 2005; Tashakkori, 1998).

Phase	Activity

Quantitative data collection
- Questionnaire survey

  N=208

Quantitative data analysis
- Stata software version 13
- Descriptive statistics
- Multivariate analysis

Connecting the qualitative phases
- Purposively selecting participants for IDIs, FGDs and longitudinal follow-ups based on their level of delay and gender.

Qualitative data collection
- Semi structured in-depth interviews n=15
- Focus group discussion 6-10 participants in each   n=6
- Longitudinal follow-ups n=4

Qualitative data analysis
- N-vivo software
- Thematic analysis

Integration of quantitative and qualitative
- Interpretation and discussion of both quantitative and qualitative data.
  The survey provided results on the level of TB knowledge, diagnostic delays and the level of TB stigma while the qualitative data provided details of participant's perceptions of TB, health-seeking practices and their experiences of TB stigma.

Figure 3.2 Model summary of the explanatory sequential mixed methods approach

3.8 Ethical Considerations

The research proposal was approved by Moi University School of Medicine / Moi Teaching and Referral Hospital Institutional Research and Ethics Committee (IREC) (Appendix 9 and Appendix 10). Permission to conduct this study was sought from the County director of health in West Pokot (Appendix 11) and the hospitals administration. Authorisation to carry out the research was also sought from the National Commission of Science and Technology Innovations (NACOSTI) (Appendix 12). Recruitment of respondents was based on informed consent. They were briefed on the study and each respondent asked to sign the consent forms without any coercion. The right of the participants to withdraw from the study at any point in time was communicated to them and observed. Respondents were assured of confidentiality and anonymity of any information they gave. The questionnaires and the qualitative data from the participants were identified using code numbers and pseudonyms. Participation in the study was voluntary and free of any coercion. Findings of the research will be communicated through a feedback process to the various participating hospitals. The results of the study will also be disseminated to the larger scientific community through publications in scientific journals and the thesis copies deposited in the University of Nairobi Libraries as well as the repository.

4.0 CHAPTER FOUR: KNOWLEDGE AND PERCEPTIONS OF TUBERCULOSIS

4.1 Introduction

The findings of this study are presented in this and the subsequent three chapters. Each of the four data presentation chapters answers one of the key research questions posed in the study. This chapter provides the results of the first research question: how do patients perceive TB and what knowledge do they have about the disease in West Pokot County?

4.2 Characteristics of the respondents

In this study, it was deemed imperative to know about the people who participated in the sample survey to determine how representative they might be of the general population. They were also important for the purpose of identifying possible intervening and confounding factors that may affect patient's perceptions and experiences of TB illness. These included gender, age, marital status, religion and the occupation of the respondents.

Out of the 208 respondents who took part in the survey, the majority (63.5%) were male. This is consistent with the pattern of the national TB registration which shows more males than females presenting with Tuberculosis. Similarly, recent national tuberculosis survey showed that the prevalence of TB in Kenya was much higher in males at 809 per 100,000 population compared to females at 359 per 100,000 (Ministry of Health (MOH) Kenya, 2016). The respondent's age ranged from 18- 61 years with a mean age of 38.8 (SD$\pm$16.1years). More than 80% (81.3%) of the respondents self-identified as Christians. Only 23.5% of the respondents had attained secondary school education. Slightly more than half of the respondents (50%) depended on pastoralism as the main source of income. Other characteristics of the respondents are shown in Table 4.1 below.

Table 4.1: Socio-demographic characteristics of TB patients in West Pokot County

Variables	Male n=132 n (%)	Female n=76 n (%)	Total n=208 n (%)
Age group			
18-20	17(12.9)	13(17.1)	30(14.4)
21-30	29(22)	21(27.6)	50(24)
31-40	29(22)	16(21.1)	45(21.6)
41-50	23(17.4)	14(18.4)	37(17.9)
>50	34(26.7)	12(15.8)	46(22.1)
Religion			
Christian	103(78)	66(86.8)	169(81.3)
Muslim	8(6)	4(5.3)	12(5.7)
No religion	21(16)	6(7.9)	27(13)
Level of education			
No formal education	60(45.5)	25(32.9)	85(40.9)
Primary	44(33.3)	30(39.5)	74(35.6)
Secondary	28(21.2)	21(27.6)	49(23.5)
Marital status			
Married	85(64.4)	40(52.6)	125(60.1)
Single	32(24.2)	24(31.6)	56(26.9)
Divorced/windowed	15(11.4)	12(15.8)	27(13)
Occupation			
Pastoralists	69(52.3)	35(46.1)	104 (50)
Businessman	25(18.9)	15(19.7)	40(19.2)
Formal Employment	23(17.4)	14(18.4)	37(17.8)
Others	15(11.4)	12(15.8)	27(13)

(Source: Results from survey data)

4.3 Patients perceptions and knowledge of TB

Tuberculosis was commonly referred to as "*TB*" by the study participants. When asked the local name for the disease, the participants reported that among the Pokot community, TB was known as *Semewo takat* meaning disease of the chest. Ethnomedically, TB was perceived as a curable chronic chest infection. The local traditional healer was referred to as *chepsakitian* and *Chepangur* was one of the common herbs used in the treatment of chronic cough.

To determine the respondents' knowledge of TB, a composite score of the level of knowledge was calculated by allocating one point to every correct response on the question about the cause, symptoms, curability, transmission, prevention and risk factors for tuberculosis. The total score was 17 points. The knowledge score ranged from 1-15 with a mean of 7.3 (SD 2.8). The knowledge score was then dichotomised into poor and good level of knowledge. Scores above eight were considered good level of knowledge and those with a score below eight were considered to have poor knowledge. Slightly less than a third of the respondents 65(31.2%) had good level of knowledge while 143 (68.8%) had poor level of knowledge.

4.3.1 Causes of TB

From the survey data, only 50 (24%) of the respondents attributed germ/bacteria as the causative agent of TB. One of the probing questions on knowledge about TB in both narrative guide and focus group discussion guide was "What causes TB?" The data from both the narrative and the focus group discussions showed that participants had different explanations as to what causes TB. Only two participants in the focus group discussion indicated that TB was caused by germ or bacteria. Majority of the respondents 73(35%) thought that TB was caused by smoking and drinking. This was further illustrated by the findings from the FGDs and IDIs. The respondents particularly those who had the habit of drinking alcohol and smoking cigarettes found this as the

only explanation as to why they acquired TB. The following are some of the views expressed by

different FGD participants and IDI informants:

> "TB is caused by drinking alcohol and smoking cigarettes. If you look keenly, you will find those who take a lot of illicit brews get TB. I used to take alcohol and that's how I got the disease but now I have stopped". (Extract from the 2nd female FGD).

> "TB is caused by alcohol and smoking and may be dirty environment. I used to drink a lot and smoked a lot that's how I got this disease."(Male 32 years).

> "I don't work at night when it is cold but I used to take alcohol. I suspect it could be the alcohol. I highly suspect it was alcohol that caused my TB." (Male 40 years).

While smoking and drinking alcohol may serve as risk factors for developing TB, they do not

cause TB. The findings were consistent with those of a study done in Malawi (Nyasulu et al., 2016)

and Ethiopia (Abebe et al., 2010) that showed misconceptions about the cause of tuberculosis. The

mistaken beliefs on the causes of TB are likely to affect the control and preventive measures the

community may advocate for. According to the respondents, since drinking alcohol and smoking

was a major cause of TB, one of the measures suggested to reduce the burden of TB in the County

was that the government should ban the consumption of illicit brew and cigarette smoking. This

was illustrated by the following FGD participants and IDI informants;

> "TB is caused by drinking and cigarettes smoking. To reduce this problem the government should ban smoking and stop consumption of all illicit brews."(Extract from 2nd male FGD).

> "I think that TB can be reduced if people stopped smoking and drinking alcohol completely..." (Male 32 years).

> "I agree that drinking and smoking brings TB. And people should stop drinking so that we can finish this disease from our community."(Extract from 3rd male FGD).

Data from both the survey and qualitative study revealed that respondents attributed dust and cold

air to be the cause of TB. From the survey, 43(21%) thought TB was caused by dust while 34(16%)

believed TB was as a result of the cold air. According to the FGD participants, dusty environment

and the dry weather predominant in West Pokot was the cause of the increased cases of TB in the

area. According to them, TB mainly affected people who were exposed to dust due to the nature of their jobs. Some of the respondents had this to say;

> "It affects those people who smoke and those who work in dusty places. This place is dry and thus why we have a lot of TB in our area."(Extract from 2nd male FGD).

> "TB is a lot in this region because of the dry weather and a lot of dust…" (Extract from 1st female FGD one).

Others attributed cold air to be the cause of tuberculosis. In one of the FGDs, one of the participants disagreed that TB was not caused by dust but rather by cold air. This was based on her own experience. This is what she had to say about the cause of TB;

> "I think that TB is caused by cold and not dust. This is because when I started having cough and chest pains it was during the cold season."(Extract from 1st female FGD).

Other participants felt that TB was as a result of both cold air and dust as indicated by one of the male participants;

> "TB is caused by dust and cold air. I was working in a very dusty place and had to report to work early in the morning. That is how I fell sick."(Extract from 1st male FGD).

From the survey data, only a minority of the respondents 10(5%) thought that TB was inherited. However, from the qualitative data, TB was widely viewed as a disease that runs in families. According to the participants, this was the explanation for having more than one person from the same family suffer from TB. Although most of them termed TB as a contagious disease, they did not attribute transmission to be the reason why members of the same family can suffer from tuberculosis. According to the participants, having a member of the family suffer from TB was expected since this was an inherited disease. This was demonstrated by some of the participants who had this to say;

> "From what I know TB is hereditary. It is a family disease like in my case most of the members have been treated for TB. It runs in our family. Even when they told me I had the disease I was not surprised."(Extract from 3rd female FGD).

*"...*if someone from your family has suffered from TB, then automatically someone else in the family will have to suffer from TB. That is, they say that there are some families/clan who have had this disease from olden days and it will continue like that even in future generations."(Extract from 1ˢᵗ female FGD).

"..this is a disease that runs in the family. If your grandparents had the disease, the disease will affect the later generations."(Female 39 years).

"TB often affect people from the same family. If one has TB if you follow closely you will find the parent or the parent or even the grand-parent had TB at some point in time. So TB runs in some families and sometimes by bad luck one can get TB even if it was not in your family initially.*"*(Male 28 years).

The misperception of TB as a hereditary disease may be due to the fact that TB is an airborne illness, which often spread among people living in close proximity to each other and therefore, may seem to affect people from the same families.

From the survey, 8(4%) attributed curse to be the cause of TB. Similarly, one of the key questions in the FGD guide was 'What are some of the traditional explanations to the causes of TB?' In response to this question, the participants indicated that TB was a curse or a bad omen that can befall anyone.

"…..people say TB comes as a result of a curse or a bad omen. This can affect anyone and there is little you can do other than seek for traditional healer's intervention…" (Extract from 3ʳᵈ female FGD).

"…. Most people here think that it is witchcraft. When one gets a disease that is not getting cured fast, then they believe they have been bewitched."(Extract from 3ʳᵈ male FGD).

From the survey data, contact with domestic animals particularly goats was not mentioned as a cause of TB. However, from the FGDs and the IDIs TB was seen as a zoonotic disease that spread from the goats to humans as alluded to by some of the informants;

"In this region, we think TB is common due to the dry weather, a lot of dust and also the practice of rearing goats where some people sleep in the same room with the goats. This may be causing the many cases of TB."(Extract from 3ʳᵈ female FGD).

"TB is a disease that affects the chest mainly and it is brought by the close contact with goats. Living in the same room with goats can bring the infection to the humans" (Male 61 years).

This could be attributed to the fact that participants were mainly pastoralists. They believed that their interaction with the domestic animals was a source of TB. Due to animal theft, communities in the region often share room with their goats and sheep. To some of the participants, this was one of the causes of tuberculosis.

For others, TB was as a result of trauma to the chest. Some of the participants associated their illness to be as a result of trauma that they had suffered at some point before the TB symptoms set in. Several patients recounted that their chest problems started after some injury to the chest which was later diagnosed as tuberculosis. This is what the FGDs participants had to say;

> "TB occurs after one has been hurt. I got TB after I had fallen from a height and my chest began to cause me problems from that time."(Extract from 2nd male FGD).

> "One can get TB when you suffer from trauma. My problem with TB started when I fell from a tree and hurt my ribs. After some time I started coughing and that is how my problem all started."(Extract from 3rd male FGD).

The study revealed that there were false beliefs and opinion about the causes of TB in the study area. The findings are consistent with those of a study done in rural Uganda among TB patients and community leaders where witchcraft, hereditary factors, heavy labour, sharing of utensils and smoking were the causes of TB (Buregyeya et al., 2011). Similarly, in a study done Tanzania, participants attributed TB to smoking and drinking alcohol, witchcraft, and genetic factors (Wandwalo & Mørkve, 2000). The misperceptions about the cause of TB should be targeted through patient education and awareness creation in the community.

4.3.2 Signs and symptoms of TB

A minority of the respondents 10(5%) did not know any sign/symptom of TB. Tuberculosis identified by the respondents included chest pain 87(42%), weight loss 65(31%), cough 60(29%), bloody sputum 40(19%), fever and night sweat 31(15%), lack of appetite 24(11%).

Similarly, the IDIs informants identified the common signs of TB as prolonged cough, weight loss, chest pain, fever and night sweats.

> "The signs of TB are cough and loss of weight. I lost a lot of weight myself. If one finds out that they are having chest pain and coughing despite taking the cough syrups then they are likely to have TB."(Male 40 years).

> "The signs of TB include sweating a lot and losing weight and having poor health. And then one doesn't feel like eating and so doesn't grow fat they just grow thin."(Female 28 years).

4.3.3 TB transmission

From the survey, the majority 158(76%) of the respondents were aware that TB is infectious while 28(13%) indicated that TB could not be transmitted from one person to another and 22(11%) were not sure. Slightly less than a half 91(44%) of the respondents indicated that TB is transmitted through coughing and sneezing.

Similarly, the FGDs participants and the IDIs informants perceived TB as a contagious disease that can easily spread from one person to the other. Participants correctly indicated that TB is an airborne disease and emphasised the need to observe cough etiquette to prevent transmission. The participants had this to say;

> "No, TB is contagious. It is usually spread from one person to the other…" (Extract from 1st male FGD).

> "I have heard that TB is transmitted to another person through coughing. The doctors here tell us to cover our mouths when we are coughing so that we don't pass the disease to the other people."(Extract from 1st female FGD).

> "TB can be transmitted through air when you cough or sharing utensils."(Male 45 years).

Although the participants correctly perceived TB as contagious, they had a lot of misperceptions on TB transmission. This is of concern since it is likely to affect the preventive and control measures adopted by the community. The survey data showed that 72 (35%) indicated that TB is

spread through sharing of utensils and while 19 (9%) thought that TB was spread through sexual contact with a TB patient. Almost all the participants in both the FGDs and the IDIs informants indicated that TB is transmitted through sharing of utensils. They noted that they all had their utensils set aside from the rest of the family to avoid transmitting the illness. This was confirmed during the longitudinal follow-up with TB patients. The patients had their utensil set aside and were not to be cleaned or stored with the rest of the family utensils. The participants had this to say concerning TB transmission;

> "The disease can be transmitted through sharing of utensils. That is why it is always good to have your own cup, spoon, plate and even *sufurias* (cooking pot) ...I don't know of any other route because like now I sleep with my wife but I have not infected her…"(Male 40 years).

> "TB is transmitted if you share utensils with an infected person."(Female 38 years).

> "If you have TB, you are supposed to have your cup, plate, spoon, cooking pot and even beddings isolated from the rest in the family. You must not share with the others."(Extract from 2nd female FGD).

For others, TB was transmitted through casual contact with an infected person. According to the participants, TB was transmitted through casual contact such as shaking hands, eating and drinking together with TB patients. In order to prevent transmission, they advised that an infected person should avoid associating with the rest of the family including having their own utensils and house. This often led to acts of isolation as described by the FGD participants.

> "When one has TB he/she should not shake hands with the healthy people until one completes the treatment."(Extract from 2nd female FGD).

> "TB is also transmitted when you eat and drink with a person who has TB. People with TB should have their own utensils and should not share house with the rest of the family."(Extract from 3rd female FGD).

> "As a TB patient, you have to be isolated. Especially the utensils used by a TB patient should not be shared by others. That is what I experienced. Also when it comes to eating together, when people know that you have TB they are not willing to share food with you…" (Extract from 1st female FGD).

4.3.4 Curability of TB

The survey data showed that most 202 (97%) of the respondents were aware that TB is a curable disease. Similarly, the qualitative data revealed that patients correctly perceived TB as curable. They were also cognisant of the fact that for one to be cured of TB, they needed to adhere to treatment for a long period of time. The fact that the patients were aware of efficacious drugs against TB made it less stressful for the patients to learn that they were suffering from TB. Two IDI informants had this to say;

> *"… TB is curable but one has to be persistent and take drugs for a very long time…"* (Female 30 years).

> "I wasn't scared at all because TB is a disease that is treatable as well as curable. So why should I get scared…" (Male 32 years).

Patient's previous experiences were key in shaping their perceptions about TB. A male aged 28 years expressed how devastated he was to learn that he had TB which according to him was a fatal disease. He believed that TB can be fatal particularly if one does not seek and adhere to the doctor's instruction. His experience of having witnessed a patient die of TB in his village made him worried about his illness. However, he found relief after the nurse explained to him that TB was curable and showed him evidence of people who had been treated and cured of TB. This reinforces the importance of patient education by the health workers in creating awareness on facts about tuberculosis. This was illustrated by the IDI informant in his response to the question, how did you feel after being told you were suffering from TB?

> "When they told me I had TB, I got scared that I might die and leave my children without a caregiver since their grandmother cannot be able to take care of them but the nurse reassured me that it is a treatable disease and that I will get cured when I take the drugs well. I was scared because I used to have a neighbour who had TB, he was told to stop taking alcohol and to stop smoking but he continued until he died…. I was encouraged by the doctor who gave me an example of 5 people

who had TB and yet they recovered so I was told not to stress myself and this gave me hope."(Male 28 years).

Most patients thought that TB was a severe disease that mainly affects the chest and has an insidious onset which makes it hard to diagnose. Participants were concerned about the frustration one has to go through before getting the correct diagnosis and treatment. Due to the onset of symptoms which mimic other respiratory tract infections, patients are often treated with different medications without improvement. This was illustrated by the following sentiments;

> "… with TB life is complicated, some of us have gone to so many hospitals before being told the problem is TB. When you start coughing you will think it is a common cold but things get worse…" (Extract from 3rd female FGD).

> "TB is a bad disease it hides in the body and it is not easy to know that you are suffering from TB. Because it starts just like a common cold with a cough …" (Female 49 years).

> "It is a disease that does not respond to treatment…" (Extract from 2nd male FGD).

> "TB is a disease of excess cough, which even if you try to take medicine from the chemist or even from the hospital it doesn't respond…" (Extract from 2nd female FGD).

The respondents perceived TB as a source of great suffering to the patient. Several respondents agonised how difficult it was to go through the experience of having TB. They recounted how TB caused them a lot of pain and discomfort which left them very weak and unable to lead a comfortable life. Some of the informants and participants had these to say;

> "I have suffered, I am usually fatigued. You know I am very weak. I used to vomit a lot after taking that drug."(Female 38 years).

> "When you have TB you suffer a lot and you experience a lot of chest pains and you also cough a lot. It is a bad disease that sucks the body making you lose weight… It makes someone to vomit a lot and lose appetite and this makes you very weak."(Male 28 years).

> "TB the way I know is something that makes you lose weight, *'inakunyonya kama kupe' (*it sucks you like a tick) it sucks you until you become very weak and everyone can notice you are unhealthy."(Extract from 1st female FGD).

The Participants were cognisant of the fact that TB is fatal without treatment. Both the FGDs participants and the IDIs informants seemed to agree that TB is a severe illness whose remedy exists in hospitals. They termed TB as 'a very bad disease' which requires medical attention.

According to the informants, if one has TB they should seek the right treatment from what they referred to as 'big hospital' meaning the County hospital.

> "When one has that disease, he should go to the hospital because it is a very bad disease."(Extract from 1st male FGD).

> "TB is a bad disease that is hard to treat, when you get it then you are in great trouble, you will require to search for treatment otherwise the disease can finish you."(Extract from 2nd female FGD)

> "TB is a bad disease that can finish you and the best thing is to look for treatment in a big hospital like this one so that your problem is discovered early and cured."(Male 28 years).

The participants alluded to the prolonged therapy as a major challenge in dealing with the disease. This was illustrated by some of the quotes from the IDIs participants.

> "TB can be treated and cured if one follows the doctor's instruction. The only problem is that the treatment is for a very long period of time."(Male 61years).

> "The challenge is that of having to take the drugs daily without fail for a very long period of time."(Male 30 years).

However, some of the patients indicated having abandoned treatment prematurely after their health had improved. This only resulted to more suffering as the disease recurred and patient forced to restart a full treatment regimen. This may be attributed to lack of knowledge about TB treatment among some of the TB patients in West Pokot County.

> "The problem with TB is that you have to take treatment for a very long time and sometimes you give up. Personally, I swallowed the drugs until I felt I had recovered. I swallowed for one and half months and I felt I had improved and so I stopped the medications."(Extract from 2nd female FGD)

> "Even me I swallowed the drugs for some time until I had improved and so I stopped the treatment. But after one and a half years, I started coughing badly and I had to come back here. They tested me and I was told to start the treatment again."(Extract from 2nd female FGD).

4.3.5 Preventive measures

From the survey, a majority of the respondents thought that they should avoid sharing cups with a TB patient 81(40.7%). Other preventive measures were cough etiquette 70(34%), avoiding spitting

carelessly 31(15%) having a separate room for patients 34(16%), early treatment for affected patients 40(19%).

Similarly, the FGD participants and the IDI informants attributed casual contact such as greetings, sharing meals with an infected person as modes of TB transmission. As means of preventing TB, nearly all the respondents reported the need for TB patients to have their own utensils which shouldn't be shared with the rest of the family members. The findings of the current study are consistent with those of a recent study done among pastoralist communities in Ethiopia that showed significant knowledge gaps about the causes, signs and symptoms, mode of transmission, prevention, and treatment of TB among the community members (Sima et al., 2017). While patients may have a general idea about TB, lack of knowledge about the causes, risk factors, modes of transmission and prevention may negatively affect the efforts geared towards reducing the burden of TB in the community. The misconceptions about the causes and transmissions affect the kind of preventive methods adopted by the community members.

4.3.6 Risk factors for TB

The respondents noted groups at risk of acquiring TB to be the very old 153(76.9%), those with chronic illness such HIV and AIDS 126(63.3%), those facing food shortage 74(37.2 %) and children below five years 74(37.2%).

The FGD participants thought that TB could affect anyone in the community.

> "Everyone is at risk of getting TB be it men, women, and children, the disease affects everybody."(Extract from 3rd male FGD).

However, they recognised that children, the old and those facing food shortages were predisposed to suffer from TB more than any other category of community members.

"TB just like many other diseases is more likely to affect the children, the old or those who do not have enough food."(Extract from 2nd female FGD).

Although HIV and AIDs is a main risk factor for TB, the FGD participants and IDI informants did not identify it as a risk factor for TB. This could be attributed to the stigma attached to HIV and therefore, it is possible that the informants avoided discussing HIV as a risk factor of TB.

4.4 Summary

Understanding patient's perceptions about TB as illness is integral in studying social factors affecting TB control. The current study sought to document patient's knowledge and perceptions of TB through the survey, focus group discussions and in-depth interviews with TB patients. While the survey was useful in quantifying the level of knowledge, the illness narratives were a helpful tool in understanding the context within which TB occurs and the meaning through which patients understood their conditions (Mason et al., 2015).

Data from both qualitative and quantitative study showed that the survey respondents, in-depth interview informants as well as the focus group discussion participants correctly perceived TB as a contagious disease that is curable if one seeks the right treatment. However, there were a lot of misconceptions about the causes and transmission of tuberculosis. The misconceptions are of great concern as they often lead to wrong opinions on control and prevention of TB thereby making it difficult to reduce the burden of TB. Lack of awareness about the causes, transmission, and treatment of TB has been associated with the poor health care seeking behaviour as well as delayed diagnosis and treatment since it often leads to first consultation of traditional healers or non-health professionals (Mondal et al., 2014). Improving community's knowledge of TB is, therefore, an essential component in the TB control strategy as it shapes their health-seeking behaviour thus reducing delays in diagnosis and treatment (Bam et al., 2014).

5.0 CHAPTER FIVE: LEVEL AND MANIFESTATIONS OF STIGMA ASSOCIATED WITH TUBERCULOSIS

5.1 Introduction

The focus of this chapter is on the second specific objective which sought to explore the level of stigma and its manifestations among the TB patients in West Pokot. The chapter also covers discussions of the findings on TB stigma in West Pokot in relation to other studies done in other setups.

5.2 Level of TB stigma

Through the survey, the study sought to quantitatively measure the level of both felt and perceived stigma among newly diagnosed TB patients using two scales focusing on patients and community perspectives towards TB.

5.2.1 Tuberculosis stigma scale characteristics and scores

Cronbach alpha internal consistency reliability coefficient was used to determine the validity of the TB stigma scales. The internal consistency for the two scales that is Cronbach's coefficient alpha of 0.89 and 0.88 for the 11-item and 12-item scale was satisfactory. The study shows that the stigma measurement scale developed in Thailand and adopted in the current study had good overall internal consistency, reliability, and psychometric characteristics among TB patients in Kenya.

The summed stigma scores were normally distributed with mean scores of 20.1 for the experienced/felt stigma and 16.3 for the perceived TB stigma (Table 5.1).

Table 5.1: Stigma scale characteristics and scores

Tuberculosis stigma	Cronbach's Alpha	Mean summed stigma score (SD)
Patients with TB: experienced and felt TB stigma (12 items)	0.88	20.1 (5.89)
Patients with TB: perceived TB stigma (11 items)	0.89	16.3 (5.56)

(Source: Results from the survey data)

5.2.2 Tuberculosis stigma scale loading value and scores

Factor analysis showed high loadings (>0.40) for all the items in both the perceived stigma scale and the felt stigma scale (Table 5.2 and 5.3). Items with absolute loading value of ≥ 0.40 are considered important in the scale (Raubenheimer, 2004).

The TB stigma assessment scale covered areas such as fear of disease transmission, attitudes toward TB patients, association of TB with shame and judgment, and disclosure of disease status. Items covering association of TB and HIV and AIDs such as "Some people who have TB are afraid to tell others that they have TB because others may think that they also have AIDS" (mean stigma score of 2.10) were rated highest in the experienced stigma scale. Similarly items covering fear of disclosure such as "People with TB choose carefully who they tell that they have TB" (mean stigma score of 1.92) were rated high. Other items with high stigma score were those linked to fear of getting TB through casual interaction such as "Some people may not want to eat or drink with friends who have TB" (mean stigma score of 1.70)

Table 5.2: Absolute loading values for the perceived TB stigma scales by item

Community perspectives on tuberculosis (assessed by patients)	Mean (SD)	Loading value
Some people may not want to eat or drink with friends who have TB	1.70	0.51
Some people feel uncomfortable about being near those with TB	1.72	0.68
If a person has TB, some community members will behave differently towards that person for the rest of his/her life	1.45	0.61
Some people do not want those with TB playing with their children	1.49	0.67
Some people keep their distance from people with TB	1.59	0.69
Some people think that those with TB are disgusting	1.35	0.67
Some people do not want to talk to others with TB	`1.35	0.70
Some people are afraid of those with TB	1.5	0.66
Some people try not to touch others with TB	1.44	0.72
Some people may not want to eat or drink with relatives who have TB	1.50	0.69
Some people prefer not to have those with TB living in their community	1.60	0.66

(Source: Results from the survey data)

Table 5.3: Absolute loading values for felt TB stigma scales by item

Perspectives of TB patients on tuberculosis (felt stigma)	Mean	Loading values
Some people who have TB feel hurt of how others react to knowing they have TB	1.66	0.60
Some people who have TB lose friends when they share with them they have TB	1.61	0.68
Some people who have TB feel lonely	1.61	0.76
Some people who have TB keep their distance from others to avoid spreading TB germs	1.70	0.51
Some people who have TB are afraid to tell those outside their family that they have TB	1.78	0.65
Some people who have TB are afraid of going to TB clinics because other people may see them there	1.33	0.61
Some people who have TB are afraid to tell others that they have TB because others may think that they also have AIDS	2.10	0.71
Some people who have TB feel guilty because their family has the burden of caring for them	1.50	0.61
Some people who have TB will choose carefully who they tell about having TB	1.92	0.63
Some people who have TB feel guilty for getting TB because of their smoking, drinking, or other social behaviours	1.61	0.45
Some people who have TB are worried about having AIDS	1.89	0.67
Some people who have TB are afraid to tell their family that they have TB	1.32	0.55

(Source: Results from the survey data)

5.2.3 Level of felt stigma

The respondent's summed felt stigma scores were classified into three categories. A majority 127(61.1%) of the respondents had high level of felt stigma while 54(25.9%) and 27(12.9%) had very high and low level of stigma respectively (Figure 5.1).
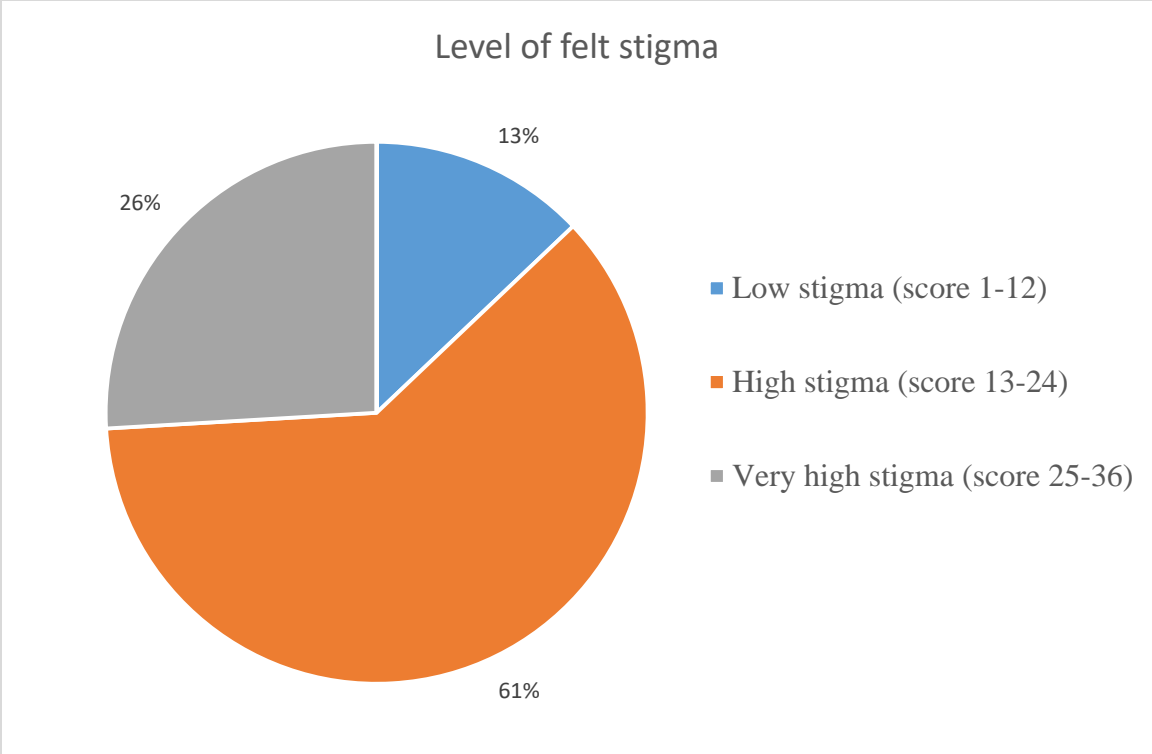
Figure 5. 1: Level of felt stigma among TB patients in West Pokot County

(Source: Results from the survey data)

5.2.4 Level of perceived stigma

Similarly respondents summed perceived stigma scores were grouped into three categories. Results show that a majority 121(58.2%) of the respondents had high level of perceived stigma while 32(15.4%) and 55(26.4%) had very high and low level of stigma respectively (Figure 5.2)
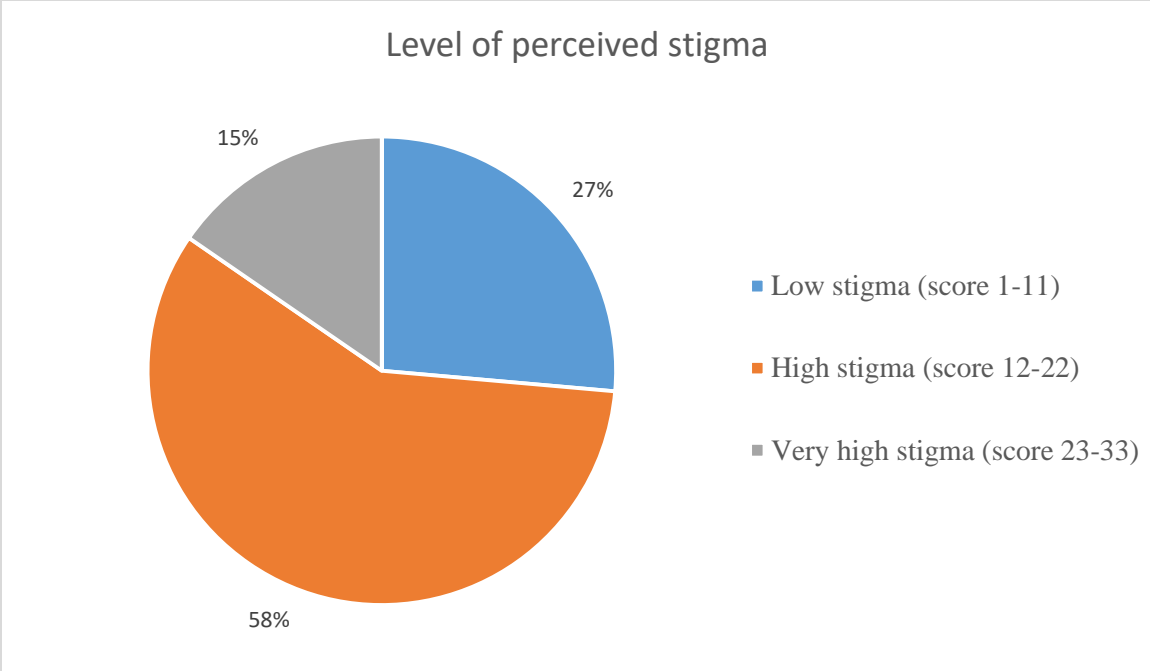
Figure 5. 2: Level of perceived stigma among TB patients in West Pokot County

(Source: Results from the survey data)

5.3 Manifestation of stigma among TB patients

In-depth interviews and focus group discussions were used to further understand how stigma manifests in the lives of TB patients. The findings show that tuberculosis stigma was a problem among tuberculosis patients in West Pokot. Under the theme stigma, there were five sub-themes emerging from data namely; self-isolation, isolated by others, association of TB with HIV and AIDS, fear to disclose TB diagnosis and lack of social support.

5.3.1 Association of TB with HIV

The respondents revealed that when one has TB, they are considered to have HIV as well. The community seemed to accept TB as a disease that occurred due to natural causes and did not blame the patient for having the disease. However, in the case of HIV, the patient is blamed for having

acquired the infection. This often resulted in ill-treatment from the community. This was alluded

to by a 28 years old IDI informant as follows;

> "The reason why they treat you like that is because they thought that because I had TB, I had HIV
> as well and they would say it was my fault, I brought the disease to myself. That is what I passed
> through until I told myself now in this world may God help us because when you have TB you can
> be isolated and suffer so much."(Female 28 years).

Similar to other studies (Abney, 2011; Moya et al., 2014; Van Rie et al., 2008), the current study

found that the association of TB and HIV and AIDs increased TB stigma. A female aged 30 years

had this to say;

> "I didn't get stressed because I knew TB has a cure. Some people said I had HIV and this made me
> feel very bad. They wanted nothing to do with me."(Female 30 years).

In Sub Sahara Africa where the prevalence of HIV infection/AIDs is high, a patient with TB is

often assumed to have the HIV virus (Møller et al., 2011).This was the case for a 49 years old IDI

informant;

> "But when I told people I had TB, they did not believe me they said that I had HIV. And when I
> started my TB treatment and had gained weight they said I was taking ARVs and the drugs had
> made me gain weight."(Female 49 years).

This could be due to the high co-infection rate of HIV and TB as well as the similarity of symptoms

such as loss of weight, fatigue and body weakness (Bond & Nyblade, 2006; Ngamvithayapong et

al., 2000). Previous study done in western Kenya showed a high co-infection rate of 42%

(Nyamogoba et al., 2012). The assumption that a TB patient was likely to have HIV was by both

the community members as well as the health workers. This could be due to the fact that TB is an

opportunistic infection in HIV and AIDs patients and the high co-infection rate, which necessitates

testing of all TB patients for HIV and AIDs. A study done in South Africa revealed that the

community viewed TB and HIV and AIDs as one and the same disease (Skordis-Worrall et al.,

2010). In the current study, items such "Some people who have TB are worried about having

AIDS" and "Some people who have TB are afraid to tell others that they have TB because others may think that they also have AIDS" rated highest. This was also confirmed by the IDIs where patients with TB feared to disclose their diagnosis so as not to be labelled as HIV positive. Therefore, apart from the role of HIV and AIDS in shaping the epidemiology of TB, it also influences the social experiences, attitude, and perceptions of TB patients (Bond & Nyblade, 2006).

Participants found it difficult to refer to HIV and AIDs by its name and used terms such as 'the big disease', 'the other one' 'the other bad disease'. This implies that there is high stigma associated with HIV which spills to TB since the two diseases are associated.

> "Yes that is true when one has TB, people just conclude that you have **the other one**."(Extract from 1st male FGD).
>
> "When you have TB you don't want to tell everybody because when they know, they start suspecting that you have the **other bad disease**."(Female 30 years).
>
> "My mother would tell me, my daughter nowadays they say there are drugs, why don't you test for **the big disease**."(Female 38 years).

5.3.2. Fear to disclose diagnosis

From both the qualitative and quantitative data, the current study has shown that TB stigma manifests among the patients through fear of disclosure of the disease status. The IDI informants reported that they preferred to keep their TB diagnosis a secret. One would choose carefully whom to tell that they were suffering from TB. The main reason why the respondents feared disclosing their diagnosis to everyone was so as not to be suspected of having HIV and AIDs. The patients didn't dread having TB since it is a curable disease. The fear of the patients was to be associated with an incurable disease such as HIV and AIDs as alluded to by a 39 years old female informant;

> "..but when you have TB people think that you have HIV as well and so you don't go telling everybody that you have TB because they will say you have AIDs as well." (Female 39 years).

According to Goffman (1963), individuals with stigmatizing attributes resist stigma by manipulating the information they share with others through negotiated disclosure. In the current study, maintaining the diagnosis of TB confidential was rated very high as measured by items such as 'Some people who have TB choose carefully who they tell about having TB'. Only close friends and family members were supposed to know that the patient is suffering from Tuberculosis. The patients preferred to keep their TB status to themselves due to fear of being socially diagnosed as HIV and AIDs patients. To some, being seen at the TB clinic was a problem as this would make them to be labelled negatively.

> "Even coming to this clinic makes me very stressed because when people see you here they will start gossiping and saying that you have HIV…I know of people who avoid coming here. "(Female 28 years).

This association and the attendant stigma is likely to affect TB control because the fear of being identified as TB patient makes individuals not to seek health care services for a TB diagnosis (Arcêncio et al., 2014), leading to delays in diagnosis and therefore, increased transmission of the disease in the community (Golub et al., 2006; Kurspahić-Mujčić et al., 2013).

5.3.3 Isolation by others

Data from the survey revealed that fear of contagion through casual transmission was a significant determinant of TB stigma. Items in the stigma scale linked to fear of infection through casual interaction, such as "Some people keep their distance from people with TB" were rated highly.

Similarly, the IDI informants narrated how the community isolated them as a result of their TB diagnosis. In some instances, even friends and family did not want to associate themselves with

the TB patient. It was distressing to the patient to find that the people they counted for support secluded them as well. The IDIs informants painfully recounted the experiences they had to go through:

> "….even now no one wants to get close to me. My sisters isolated me and everyone was busy with their own activities. Even my friends who used to come and laugh with me and eat with me were no more no one wanted to be close to me. The ones we could spend time together and eat together left me… I suffered a lot."(Female 38 years).

> "I was isolated from friends and families and also the doctors because initially we used to eat together but when they got to know that I had TB, no one came near me."(Female 36 years).

> *"*But the neighbours stopped coming to my home and were only talking ill about me."(Female 49 years).

> "My friends deserted me and my siblings did not want anything to do with me."(Female 36 years).

> "When I learnt that I had TB, I felt very bad. People could see me and run away. They could bring me food and leave me to stay alone in a separate Manyatta. When there were *wazee Barazas* (male gatherings). I was barred from attending so as not to infect others."(Male 42 years).

The community's understanding of the infectious nature of TB often lead patients to see themselves as disease vectors as reflected by the item "some people who have tuberculosis keep their distance from others to avoid spreading TB germs". Similarly, through IDIs, the patients confirmed having faced social isolation from the community and in extreme cases from their loved ones.

During the longitudinal follow-up, isolation of TB patients was evident from the interaction between the patient and the rest of the family. A female aged 27 years indicated that from the time she was diagnosed with TB, none of her siblings wanted her close to them. She had her utensils set aside and had a separate room to sleep. She recounted her experience as follows;

> "Am happy you came to visit me. With this disease, I have been so lonely. Even my sisters do not want to see me near them. We used to share a bedroom but now I was asked to sleep alone in that room out there. I cook my own food…" (Female 27 years).

Social isolation of tuberculosis patients is common and dates back to the ancient times where those considered to be in advanced stages of tuberculosis were not attended to by the health

professionals but were instead sent to the temple and sea voyage to be cured from there. While these were used as forms of treatment, the real intention was to isolate them from the rest of the population to prevent disease transmission (Lauer, 2017). Evidence has shown that perceived risk of transmitting TB to the healthy community members is a leading cause of stigmatization among TB patients (Courtwright & Turner, 2010; Dodor et al., 2008; Gelaw et al., 2001; Kurspahić-Mujčić et al., 2013; Moya et al., 2014; Sharma et al., 2007). Tuberculosis patient instils fear in others due to the risk of infection. The current study showed that, in an attempt to deal with the risk of infecting others, the patients observed various social taboos such as avoidance of sharing of meals and kitchen dishes, sharing a room or having sexual relationships after one had been diagnosed with TB and treatment commenced. Due to the lack of information among community members, the fear of infection was often exaggerated and commenced after the diagnosis and persisted even after completion of treatment. However, this kind of stigma is due to incorrect knowledge about transmission of TB. Although smear-positive TB patients are highly infectious and spending prolonged time with them pose a great risk of TB transmission, it is important to note that after two weeks of treatment, such patients are no longer infectious and are not likely to transmit the disease (World Health Organisation, 2003).

5.3.4 Self-isolation

Self-stigmatisation was also evident in the study. The respondents self-isolated themselves in fear of infecting their loved ones particularly children and to avoid being shunned or being subject of gossip by neighbours. A female aged 49 years narrated why she had to move from the main family house to live in a separate house though in the same compound;

> "….it is now more than five months. I don't want to pass the disease to my family so I prefer to stay away from them."(Female 49 years).

Participants seemed to understand that children were more vulnerable to TB infection due to their weakened immunity. Cases of TB patients sending their children to live with the grandparents were common among both female and male TB patients. A participant in the first female FGD, aged 28 years reported that she could not stay with her children while taking TB treatment. She was forced to take them to her mother where they were supposed to stay until the time she would complete her TB treatment.

> "For my case when I knew I had TB, I had to isolate my children. I took them to their grandmother where they will stay until the time I will complete my treatment….. They will stay there until the doctor tells me the disease is over."(Extract from 1st female FGD).

Similarly, a 45 years male FGD participant stated that his children had stayed with their paternal grandmother parent for a period of one year in an attempt to protect them from being infected with TB.

> "It is important to avoid mixing with the rest of the family so as not to infect them. In my case, I sent the children to their grandmother so that they don't get infected. They have stayed there for one year now."(Extract from 2nd male FGD).

The isolation is done for a prolonged period of time, some for the whole treatment period and others for more than a year. Self-Isolation was both at the family level and at the community level. Participants avoided interacting with the rest of the community so as not to be blamed for infecting them. This was alluded to by a female aged 30 years as follows;

> "… most of the time you will find me alone at home I prefer to stay home with my disease so that they don't say I passed the disease to other people."(Female 30 years)

Apart from protecting the children from being infected, cases of patients avoiding spouses so as not to infect them were common. A male aged 42 years explained why he had to stay in a separate house so as to protect his wife from being infected with TB.

> "This disease can be transmitted when one coughs. And so I decided to stay far from my family so that I wouldn't infect them. All that time I was taking my treatment, I used to live in a separate house from that of my wife. I did not want to infect her."(Male 42 years).

The extreme cases of self-isolation were not necessary in the prevention of TB transmission. Common measures such as cough etiquette and treatment of those infected was sufficient to protect the family members from TB infection.

5.3.5 Social support

Respondents indicated the importance of social support during their illness. While the neighbours and in some cases friends abandoned the patient, the unconditional love of the family members remained a key source of social support. The love of the family members encouraged patients to complete their treatment. This was illustrated by a 28 year old male informant during the in-depth interview;

> "Throughout the period I was sick, it's only my family that remained close to me. They encouraged me to go for my medicines and keep on swallowing them but most friends abandoned me and had less and less company."(Male 28 years).

On the other hand, lack of social support from family and friends was a source of TB stigma.

"My sisters isolated me… I would find myself all alone…. I suffered a lot." (Female 38 years).

5.4 Factors associated with TB stigma

Chi square (χ^2) test was done to determine socio-demographic characteristics associated with high level of stigma. Gender was significantly associated with high levels of both felt and perceived stigma (p= 007 and 0.005 respectively) as shown on Tables 5.4 and 5.5. The age, religion, level of education, marital status and occupation did not show significant association with both the level of perceived and felt stigma.

Similarly, in the qualitative study, more female patients reported having faced discrimination as result of their illness compared to their male counterparts. The female patients verbalised having been isolated more than the male patients. One of the male respondents when asked whether he faced any kind of isolation or discrimination had this to say:

"…I live in my own home why would anyone isolate me?"(Male 41 years).

This could be attributed to the fact that males were in a better position to resist discrimination, particularly in the family setup due to their greater sense of belonging.

Table 5.4: Bivariate association of level of felt stigma and socio-demographic characteristics

Variables	Level of felt stigma			χ^2 p-value
	Low n (%)	High n (%)	Very high n(%)	
Gender				
Male	17(62.9)	90(70.8)	25(46.3)	0.007
Female	10(37.0)	37(29.1)	29(53.7)	
Age				
18-20	5(18.5)	76.2(32)	16.7(7)	0.22
21-30	7(25.9)	50(22)	40.9(18)	
31-40	7.1 (3)	64.3(27)	28.6(12)	
41-50	9.8(7)	67.6(48)	22.5(16)	
>50				
Religion				
Christian	19(11.2)	103(61)	47(27.8)	0.19
Muslim /No religion	8(20.5)	24(61.7)	7(17.9)	
Education Level				
No formal education	13(48.2)	53(41.7)	19(35.2)	0.53
Primary	7(25.9)	43(33.6)	24(44.4)	
Secondary and College	7(25.9)	31(24.4)	11(20.4)	
Marital status				
Currently married	18(66.7)	73(57.5)	34(62.9)	0.80
Single	7(25.9)	35(27.5)	14(25.9)	
Windowed/ Divorced	2(7.5)	19(14.9)	6(11.1)	
Occupation				
Agro-pastoralists	13(48.1)	59(46.5)	32(59.3)	0.33
Self- employed	6(22.2)	26(20.4)	8(14.8)	
Formal employment	2(7.4)	27(21.3)	8(14.8)	
Others	6(22.2)	15(11.8)	6(11.1)	

(Source: Results from the survey data)

Table 5.5: Bivariate association of level of perceived stigma and socio-demographic characteristics

Variables	Level of perceived stigma			Test
	Low	High	Very high	χ^2 p-value
Gender				
Male	45(76.3)	72(63.2)	15(42.8)	0.005
Female	14(23.7)	42(36.8)	20(57.1)	
Age				
18-20	11(18.6)	19(16.7)	4(11.4)	0.36
21-30	11(18.6)	23(20.1)	12(34.3)	
31-40	13(22.0)	24(21.1)	8(22.8)	
41-50	12(20.3)	17(14.9)	8(22.8)	
>50	12(20.3)	31(27.2)	3(8.5)	
Religion				
Christian	46(77.9)	86(81.1)	30(88)	0.47
Muslim/No Religion	13(22.0)	20(18.8)	4(11.8)	
Education level				
No formal education	22(37.3)	52(45.6)	11(31.4)	0.08
Primary	19(32.2)	36(31.5)	19(54.3)	
Secondary/ College	18(30.5)	26(22.8)	5(14.3)	
Marital status				
Currently married	37(62.7)	66(57.9)	22(62.8)	0.77
Single	17(28.8)	31(27.2)	8(22.8)	
Windowed/ Divorced	5(8.5)	17(14.9)	5(14.3)	
Occupation				
Agro-pastoralists	25(42.4)	62(54.4)	17(48.6)	0.22
Self- employed	13(22.0)	16(14.0)	11(31.4)	
Formal employment	11(18.6)	21(18.4)	5(14.3)	
Others	10(16.9)	15(13.2)	2(5.7)	

(Source: Results from the survey data)

5.5 Summary

The study showed that the stigma measurement scale developed in Thailand and adopted in the current study had good overall internal consistency, reliability, and psychometric characteristics among TB patients in Kenya. Understanding the source and the magnitude of TB stigma is an

important step towards reducing its effects on poor health-seeking behaviour that often leads to delayed diagnosis. There was a high level of both felt and perceived stigma in the study area. TB stigma manifested through association of TB with HIV, fear to disclose TB diagnosis, shunning of TB patients, and lack of social support as well as self-isolation.

6.0 CHAPTER SIX: TB PATIENTS TREATMENT PATHWAYS

6.1 Introduction

This chapter addresses the third research question: What treatment pathways do TB patients follow in West Pokot County? The chapter covers both qualitative and quantitative findings on the health seeking pathways adopted by TB patients in West Pokot County.

6.2. Treatment pathways

One of the key questions in the survey the study sought to answer was, "What forms of care did you seek before you obtained a TB diagnosis?" The findings on the health-seeking pathways adopted by the patients are as illustrated in fig 6.1. The figure shows that there were multiple actors in the provision of healthcare and respondents had different priorities as their first points of care. More than a third (35%) of the respondents opted for traditional healers, 25% opted for self-medication while only 6% and 4% respondents opted for the Sub-County and County hospital respectively as their first point of care. All the 208 respondents reported having obtained their TB diagnosis at the Sub-county or the County hospital where they finally obtained the TB diagnosis. In Kenya, dispensaries and health centres are the first points of entry into health and mainly offer primary health care services. As result, nearly half of the respondents (45%) started at this point of care. However, most of the primary health care facilities do not have the right capacity to diagnose tuberculosis and therefore, the patients ended up in the Sub-County and the County hospitals where TB diagnosis was done.
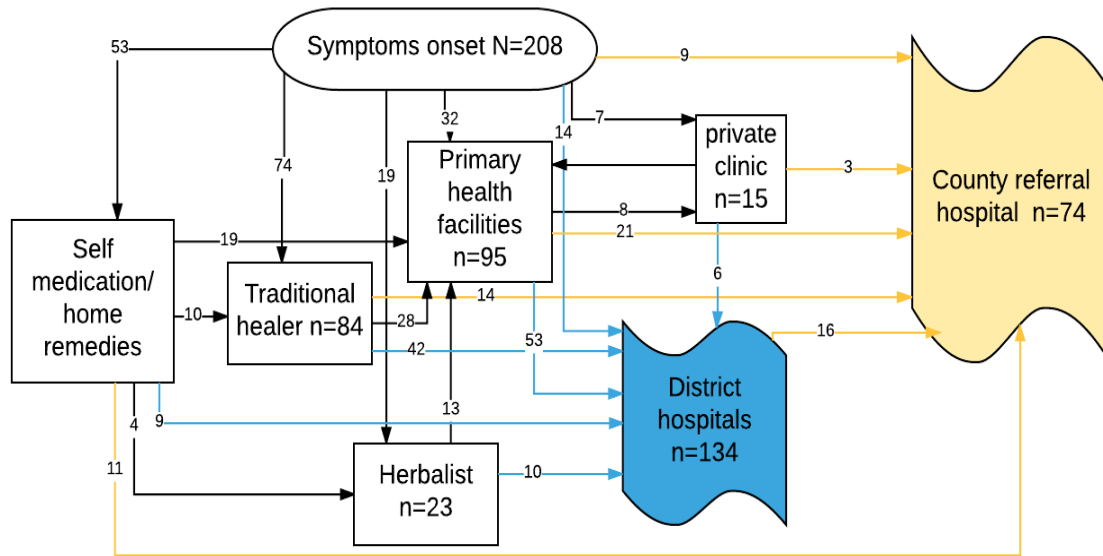
Figure 6. 1 Schematic model of treatment pathways followed by patients in West Pokot County.

(Source: Results from the survey data)

The findings from the survey portrayed almost linear health-seeking pathway as opposed to the convoluted health-seeking pathways observed in reality. The responses from the survey did not reflect zigzag paths involving a back and forth pattern which was reported during the IDIs, FGDs and observed during the longitudinal follow-up of the informants. Although the survey was limited in studying the treatment pathways, it was useful in highlighting the key players in healthcare provision in the community and the priority points of care for the TB patients in West Pokot County. However, to gain a better understanding of the patient's care-seeking pathways data from FGDs, IDIs and longitudinal follow-ups were used.

One of the key questions in the interview guide was "What actions did you take when you started experiencing TB symptoms? The findings from the qualitative study revealed that the informants had multiple pathways of care. The IDI informants and the FGD participants reported having

sought care from different providers. These included: traditional healers, herbalists, drug shops/chemist, private clinics and the public health care system. Participants reported dynamic health seeking trajectories. They switched from one provider to another in search of relief of symptoms as illustrated by the following verbatim quote;

> "In my case, I was sick for almost 2 years. I tried many things; I bought medicine in the shops, I went to the local medicine man who gave me some herbs, but this did not help. I also went to the dispensary many times but they treated me for other things. I kept taking the different local medicines as well as drugs from the chemist without much improvement. But for the severe cough, I had it for two months after which I came here and my sputum was tested and they found TB."(Extract from 2nd female FGD).

> "...at first, I thought it was just a normal cold and so I didn't take any action. But after some time the cough became persistent and I bought some cough syrups. Later I decided to seek treatment from the dispensary. I also went to the local herbalist. I used the herbal drugs for a period of one year. You know they are of different types from different trees so what we do we try this one when it fails you try the other. I also went to the dispensary now and then but got treated for something else other than TB. All this time, nobody told me I had TB. After taking the medicine for a long time, I realised the problem was still persisting. When I realised it was not helping, I came to the County hospital."(Female 39 years).

Although TB symptoms were experienced, patients did not relate to them as TB and resulted to self-medication by buying medicine from the chemist or over the counter drugs from shops. The participants indicated that they thought the illness was a mere common cold and did not seek proper health care but relied on self-medication as the first option. They either bought painkillers and cough syrups from the shop and chemist or used local herbs from the market or the farms. Some of the patients reported having tried several herbs before seeking healthcare from the health facility. After symptoms got worse, the patients sought treatment from the health facility. This was pathway was illustrated by a female aged 36 years as follows;

> "And you know when this disease sets in, you will start coughing continuously so you don't stop and you buy drugs from the chemist every now and then because you are always ill. You keep changing the drugs but you realise you are not getting well. So one month passes and another one passes you are still coughing that's when now you are forced to come to the hospital..." (Female 36 years).

From the survey data, more than a quarter of the respondents opted for self-medication as the first priority option of care. This point to the significance of drug shops and chemists as the first point of care that can be utilised to improve referral. Previous studies have demonstrated the importance of drug shop as the first contact of healthcare (Bonadonna et al., 2017; Mesfin et al., 2009; Satyanarayana et al., 2016). Global studies have shown that pharmacies and drug shops owners seldom refer patients for specialised medical treatment (Kiwuwa et al., 2005; Lönnroth et al., 1999).

The decision to seek treatment was determined by the therapeutic managers who were men in cases where the patient was a married woman and the parents in the case of children.

> "As a woman, it is good to ask for permission from your husband and if it is the child who is sick the mother may also decide to take the child to the hospital after informing the husband if he is at home."(Extract 1st Female FGD).

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However, according to the participants in the male FGD, there was no need for women to ask for permission to go to the hospital as alluded to by some of the participants;

> "When one feels they are very sick, they just decide to go to the hospital it is not a must for a woman to ask for permission from the husband. And if you are weak then whoever is available even if it is the neighbour should take you to the hospital."(Extract from 1st male FGD).

The findings from the longitudinal follow-up of the female patients indicated the contrary. The study found that a woman would be considered disrespectful if she decided to seek healthcare without the knowledge of the husband. The women, on the other hand, took great care of the sick husbands by reminding them to swallow their medicines. Men admitted that their wives had been supportive during their illness. A male aged 45 years recounted his experience as follows;

> "My wife has been very supportive; she is the one who encouraged me to go to the hospital. I don't forget to take my medicines because she always reminds me to take the drugs as instructed by the doctor." (Male 45 years).

For 74 (35%) of the participants, the cultural explanation of disease causation highly influenced the treatment pathway they adopted. The patients believed that severe illness was seldom caused by natural causes alone but rather bad omens, evil spirits, and witchcraft had a role to play. According to the respondents, such illnesses should be treated by a traditional healer because seeking modern medical care for such illnesses could result in death. For this reason, they always visited the traditional healer first before seeking care from the contemporary health facilities.

> "Most people here before going to the hospital have to go to the traditional doctor. Our community believes that for many diseases, there are some evil spirits that bring the problem and so before even seeking hospital treatment, it is good to remove these spirits for better results" (Extract from 2nd male FGD).

> "It can be sickness due to witchcraft. Such a person must go to the traditional healer for the problem to be cured. Otherwise, if they rely on the hospital medicine for such sickness they will just die. But after getting the traditional therapy, if the sickness continues then the person can go to the hospital for another form of treatment." (Extract from 3rd female FGD).

When self-treatment failed 15(7%) respondents sought treatment from private clinics. However, none of the respondents reported having been diagnosed with TB from the private clinics. It was only after developing severe symptoms that the respondents sought treatment from either the Sub-County or the County hospitals where TB diagnosis was done.   A male aged 27 years had this to say;

> "I had started coughing long before but I only bought medicines from the shops. I did not improve and when it got worse I went to a private clinic in January where I was told that it was Pneumonia. …But my illness got worse...I therefore decided to seek treatment in a bigger hospital and came to … hospital…and I was found to have TB." (Male 27 years).

While for 95 (45%) of the participants/ informants primary health care facility was their first contact with the health care system, TB diagnostic facilities were not available at this level. Informants reported having visited the primary health care facilities severally without improvement. The findings are in agreement with recent patient-pathway analyses in five countries that showed that more than 40% of TB patients initiated care in low-level facilities that did not

have TB diagnostic capacity (Hanson et al., 2017) . At the primary health facilities, patients were mainly treated for upper respiratory tract infections, typhoid, and malaria.

> "I have suffered a lot with this illness ...I went to the dispensary and was given medicine but I did not get well. I went back to the same dispensary more than twice and was given another medicine each time but still, I didn't get well. After I got very sick, my children took me to … County hospital and there I was tested for TB and it was negative…they tested me again they said I had TB."(Male 45 years).

Previous research has shown that vicious cycle of repeated visits at low-level healthcare facilities is a major cause of delays in TB diagnosis (Storla et al., 2008). The healthcare providers contributing to this vicious cycle are mainly primary health care posts and private practitioners with limited training (Kiwuwa et al., 2005; Yimer et al., 2005). This kind of vicious cycle at the private clinic was illustrated in the following quote;

> "With TB life is complicated some of us have gone to so many hospitals before being told the problem is TB. When I started coughing I started by going to the Hospital. But these were private clinics. I went from one private to the other but I never improved. Each time they treated me for a different disease at time malaria, pneumonia but they never tested my cough for tuberculosis."(Extract from 3rd female FGD).

The healthcare workers at the primary health care facilities did not refer the patients for TB services until the patient opted to go to the Sub-County or the County hospital. While some respondents were diagnosed with TB without delay, some of the patients reported having gone to the hospital on several occasions but were treated for other diseases other than TB. Some were offered a TB test which turned out to be negative, only to be diagnosed with TB much later. This pathway was illustrated by a male informant aged 32 years;

> "After trying so many options my children finally brought me here when my cough had become too much (County Hospital). But the disease was still hiding in my body. I was tested for TB twice but it was negative. I was confirmed to be TB positive on the third test after several months of suffering."(Male 32 years).

For other patients, when self-treatment and traditional medicine failed they sought treatment from the private clinic. However, none of the patients reported having been diagnosed with TB from the

private clinics. These were only a source of further delay in the diagnosis and treatment of TB patients. It was only after developing severe symptoms that the patients sought treatment from either the Sub-County or the County hospitals where TB diagnosis was done.   A female aged 28 years had this to say;

> "I realised the drugs from the shop were not helping me and so I went to a private clinic. I was told that I had Typhoid and was given 6 injections. I asked them why they said it was typhoid because I used to cough a lot and I could have chest pains even when yawning. They changed my treatment and I was given 3 injections and medicine to swallow. After the treatment, I had some relief and could go out a bit but later it got worse and I went back to the same clinic since I still had Sh. 1500 left. I was given another 3 injections. After a while, I got worse and decided that I will not go to any other private clinic but I will go to the County Hospital." (Female 28 years).

Nearly half of the respondents (45%) had their first contact with the health facility at the primary health care centers and the private clinics. However, they all ended up in the County or Sub-County hospitals for TB diagnosis much later. This is mainly because the dispensaries and private clinics especially those in rural areas do not have trained personnel and diagnostic infrastructure necessary to manage TB patients. In Kenya, most dispensaries are managed by community health nurses and do not offer laboratory services and therefore, TB diagnosis is not possible. Similarly, private practitioners are inadequately trained and have a limited diagnostic capacity to manage TB. This often leads to delay in TB diagnosis. These providers are crucial in the referral system necessary for timely TB diagnosis and should be sensitised on the need to refer any patients with a prolonged cough for a TB test.

Some of the patients reported that they went directly to the Sub-County hospital/ County hospital and were offered TB diagnosis without delay. The respondents on this pathway had shorter health system delay because more often they came to the hospital in very advanced stages of the disease with symptoms suggestive of TB. The sputum smear for such patients was likely to be positive

and therefore, TB diagnosis able to be obtained without delay. When asked what actions he took after falling sick, a 32 year old male informant had this to say;

> "I just stayed home because I didn't know what problem it was. That time it was not very bad. I stayed home for like one month after which I started feeling very weak and decided to go to the hospital. I came to the County hospital and was diagnosed with TB.... By the time I came to the hospital I was coughing blood and the doctors right away suspected I had TB…" (Male 32 years).

6.3. Summary

The study found that the health seeking pathways were quite dynamic. Timely diagnosis and notification is one of the global priority in the control of TB as outlined in the WHO end TB strategy (Uplekar et al., 2015). However, early case detection not only depends on the diagnostic capacity of the health facility but also the health seeking practices of the patients. In Kenya, just like most developing countries (Lienhardt et al., 2001), the TB control program relies heavily on passive case finding which is dependent on patient presentation to the health facility and thus health-seeking behaviour becomes critical. In the present study, tuberculosis patients followed different pathways to seek diagnosis and treatment available in their communities. These complex pathways led to a huge shortfall in the number of patients who presented for timely diagnosis to health facilities.

7.0 CHAPTER SEVEN: PATIENT DELAYS IN TB DIAGNOSIS AND TREATEMENT

7.1 Introduction

This chapter outlines the findings from both the survey and the qualitative study in relation to delays in TB diagnosis. The chapter addresses the fourth research question and its related sub-sections; what is the level of delays and what factors are associated with the TB diagnostic delays in West Pokot County. The chapter also covers discussion of the findings on TB delays in West Pokot in relation to other studies done in other setups.

7.2 Length of delay in TB diagnosis

Using the survey data, three types of delay in TB diagnosis and treatment commencement were estimated in days. The study revealed a mean patient delay of 66 days. The mean health system delay was 38 days while the mean total delay was 110 days. The median patient delay, system delay and total delay was 66(IQR: 34-92), 31(IQR: 7-58) and 101(IQR: 68-137) days respectively (Table 7.1).

The WHO treatment guidelines recommend that anyone with a cough lasting more than two weeks should have their sputum tested for TB (World Health Organization, 2010). However, in the current study, the median total delay from the onset of TB symptoms to treatment initiation was 101 days (IQR: 68-137). The delay in TB diagnosis in West Pokot region is unacceptably high. This is a great public health concern due to the fact that each case of active TB patient dispenses several tubercle bacilli in the air infecting many susceptible individuals in the community.

The median delay in the present study compares to that of studies done in Mozambique (150 days) (Saifodine et al., 2013),Tanzania (136 days) (Mfinanga et al., 2005), Uganda (112 days) (Buregyeya et al., 2014), Ghana (104 days) (Osei et al., 2015). However, it was much higher than the median delay observed in Kenya in a referral hospital setting (44 days) (Ayuo et al., 2008) and

other African countries such as Ethiopia (45 days) (Asefa & Teshome, 2014), South Africa (60 days)(Meintjes et al., 2008) and Malawi (80 days) (Makwakwa et al., 2014).

In the present study, patient delay was the main cause of TB delay with a mean of 72 days compared to 38 days for system delay (Table 7.1). The findings are in agreement with those of studies done in Kenya (Ayuo et al., 2008), Ethiopia (Asefa & Teshome, 2014), Tanzania (Mfinanga et al., 2005), Nigeria (Odusanya & Babafemi, 2004), Nepal (Basnet et al., 2009) and Thailand (Ngamvithayapong et al., 2001) that showed longer patient delay compared to provider delay. Conversely studies done in Uganda (Buregyeya et al., 2014) and South Africa (Meintjes et al., 2008) showed health system as the main contributor to total delays.

Whether patient delay or provider delay contributes more to the total delay is an aspect that is likely to vary in different settings depending on the prevailing factors. If the patients have easy accessibility to TB services, are knowledgeable about TB and adopt good health seeking behaviour this is likely to reduce patient delays. Similarly, if health providers both public and private are well equipped with knowledge, skills and have sufficient diagnostic facilities, this is likely to lead to shorter provider delays and vice versa. However, it is important to note that where TB patients present early for diagnosis (short patient delay), the patient may only have fugue symptoms (Mfinanga et al., 2005) and sputum smear may not be ordered or might not yield positive results in the early stages of the disease and this may lead to misdiagnosis thus longer provider delay. But in cases of longer patient delays, patients come in advanced stages of the disease and diagnosis is unlikely to be missed (Gele et al., 2009) hence short provider delay. Therefore, longer provider delay may not always reflect the inefficiency of the health system. However, patient's health-seeking behaviour is key in determining delays in TB diagnosis. A patient who visits the right

health care providers consistently may allow for further investigation and proper diagnosis and thus less diagnostic delays.

Table 7.1: Delay in TB diagnosis among TB patients in West Pokot County

Type of delay	All patients N=208	Male n=136	Female n=76	p value
Patient delay in days				
Mean (95% CI)	72(64-80)	79(71-88)	60(44-75)	*0.01
Median	66	77	48	**0.002
IQR	34-92	45-102	15-75	
System delay in days				
Mean (95% CI)	38(32-43)	31(25-37)	49(40-59)	*0.001
Median	31	26	40	**0.02
IQR	7-58.5	6-43	26-67	
Total delay in days				
Mean (95% CI)	110(101-119)	111(100-121)	109(92-127)	*0.89
Median	101	103	96	**0.54
IQR	68-137	74-138	59-136	

P value based on t test for mean comparison   IQR -Interquartile range.

**P value based on Bootstrap test for median comparison

(Source: Results from the survey data)

7.2.1 Social and demographic factors associated with patient delay

Gender χ^2 =14.2; p= < 0.001, level of TB knowledge χ^2 =5.6; p= 0.01, felt stigma χ^2 =9.1; p= 0.01 and perceived stigma χ^2 =8.4; p= 0.01 were significantly associated with patient delay. The age, marital status, religion and the occupation of the patient had no association with the patient delay (Table 7.2).

Table 7.2 Delay in TB diagnosis among TB patients in West Pokot County

Variables	Patient delay		χ^2 p-value
	No (n=38)	Yes (n=170)	
Sex			
Male	24(63.2)	52(30.6)	**0.000**
Female	14(36.8)	118(69.4)	
Age			
18-20	7(17.9)	23(13.6)	**0.42**
21-30	11(28.2)	39(23.1)	
31-40	5(12.8)	40(23.7)	
41-50	8(20.5)	29(17.2)	
>50	8(20.5)	38(22.5)	
Religion			
Christian	30(81.1)	132(81.5)	0.96
Muslim/No religion	7(18.9)	30(18.5)	
Education level			
No education	15(38.5)	70(41.4)	0.91
Primary	15(38.5)	59(34.9)	
Secondary and College	9(23.1)	40(23.7)	
Marital status			
Currently married	18(47.4)	107(62.9)	0.19
Single	14(38.8)	42(24.7)	
Windowed/ Divorced	6(15.8)	21(12.4)	
Occupation			
Farmer	16(41)	88(51.7)	0. 15
Businessman	11(28.9)	29(17.1)	
Formal employment	4(10.3)	33(19.4)	
Others	7(18)	20(11.8)	
Level of TB Knowledge			
Good	18(47.4)	47(27.6)	**0.01**
Poor	20(52.6)	123(72.4)	
Felt stigma			
Low stigma	14(36.8)	13(7.6)	**0.000**
High stigma	16(42.11)	111(65.3)	
Very high stigma	8(21.1)	46(27.1)	
Perceived stigma			
Low stigma	19(50)	40(23.5)	**0.002**
High stigma	12(31.6)	102(60.0)	
Very high stigma	7(18.4)	28(16.47)	

(Source: Results from the survey data)

After adjusting for confounding factors poor tuberculosis knowledge (AOR=3.34; p=0.02), male

gender (AOR=6.23; p=<0.001), high level felt stigma (AOR=10.8; p=<0.001), and high level of

perceived stigma (AOR=6.28; p=0.001), were independent predictors of patient delay (Table

7.3).

Table 7.3 Adjusted multivariate logistic regression model for factors associated with patient delay

Variables	Patient delay			
	AOR	SE	95%CI	P-value
Sex				
Female	Ref			
Male	8.13	4.4	2.82-23.4	**0.000**
Age				
18-20	Ref			
21-30	0.46	0.36	0.09-2.20	0.33
31-40	1.51	1.46	0.22-10.0	0.66
41-50	0.87	0.87	0.12-6.25	0.89
>50	0.44	0.48	0.06-3.49	0.47
Religion				
Christian	Ref			
Muslim/No religion	0.88	0.56	0.25-3.10	0.84
Level of education				
No education	Ref			
Primary	0.77	0.53	0.20-2.95	0.71
Secondary and college	2.04	1.59	0.44-9.44	0.36
Marital status				
Currently married	Ref			
Single	0.40	0.26	0.11-1.46	0.16
Windowed/divorced	0.29	0.22	0.06-1.28	0.10
Occupation				
Farmer	Ref			
Businessman	0.86	0.59	0.22-3.32	0.83
Formal employment	1.42	1.16	0.29-7.07	0.66
Others	1.27	1.11	0.23-7.01	0.77
Level of TB knowledge				
Good	Ref			
Poor	4.05	2.13	1.44-11.4	**0.008**
Felt stigma				
Low stigma				
High stigma	9.3	5.88	2.70-32.1	**0.000**
Very high stigma	9.15	6.86	2.10-39.7	**0.003**
Perceived stigma				
Low stigma	Ref			
High stigma	7.7	4.53	2.42-24.4	0.001
Very high stigma	6.1	4.82	1.29-28.7	0.022

(Source: Results from the survey data)

In the study, the mean patient delay was significantly higher among males (79 days compared to females 60 days p=0.02). Conversely, system delay was significantly higher among females (49 days) compared to males (31 days p=0.001). However, there was no significant difference in the total delay among the sex groups. Different from the patient delay, the mean system delay was significantly higher for women compared to that of men. The results are in agreement with the findings of other studies that showed that females were more likely to experience health system delays compared to their male counterparts (Lawn et al., 1998; Long et al., 1999; Mfinanga et al., 2008; Ngamvithayapong et al., 2001).Thorson argued that longer diagnostic delays among females may be attributed to biological differences in symptom presentation between males and females making a suspected female TB patients at higher risk of not getting suitable diagnostic investigations, on the basis of being female (Thorson et al., 2007). However, a study done in Ethiopia showed contrary findings. Females were less likely (AOR =0.34, 95% CI: 0.18–0.62) to experience diagnostic delays compared to males (Asefa & Teshome, 2014).

7.3 Reasons leading to patient delay

The study revealed that 81.7% of the respondents delayed in seeking diagnosis and treatment. Therefore, one of the key questions the survey sought to answer was "What factors hinder TB patients from seeking early diagnosis and treatment from the health facility?" According to the respondents, the main reasons causing delays in diagnosis and treatment of TB was misdiagnosis, distance to the health facility, and lack of awareness on the need for early diagnosis, easily accessible traditional medicine and lack of finances to meet the cost at the health facility (Table 7.4).

Table 7.4: Reasons leading to delay in TB diagnosis among TB patients in West Pokot County

Reasons for delay	Frequency (%)
Being treated for other problems before testing for TB (Misdiagnosis)	101(48.6)
The distance to the health facility is far	82(39)
Lack of awareness about TB and the need for early treatment	80(38.5)
Traditional healers are more accessible.	65(31.3)
Lack of finances to meet the cost of treatment at the health facility	51(24.5)
TB is a curse and traditional healers have a role play in the treatment	18(8.7)
TB is not curable therefore did not see the urgency in seeking treatment.	5(2.4)

(Source: Results from the survey data)

7.4 Conceptual model of factors associated with delay in TB diagnosis

From the qualitative study, a total of 17 codes emerged from the open coding. During the axial and selective coding, the related codes were then grouped together into 11 sub categories which were then grouped into three major themes (categories) (Strauss & Corbin, 1998). The in vivo code "I suffered for a long time" was used to link the three themes and formed the core category in the pathway of delay (Table 7.5).

Table 7.5: Codes and categories emerging on factors leading to delay in TB diagnosis in West Pokot County

Codes	Sub Categories	Category	Core category
I suffered for a long time	Delay/ consequences		"I suffered for a long time" pathway of delay
I stayed home	Delay		
Thought it was a mere cough	Interpretation of symptoms as less severe	Individual factors	
The uneducated prefer traditional medicine	Low education		
Self-medication	Poor Health seeking behaviour		
Religion			
Herbalist and Traditional healer			
Lacked time / to continue earning a living	Gender roles	Socio-cultural factors	
Needed permission from husband/husband wouldn't give me transport	Male dominance and Masculinity		
Men should persevere first/ need not seek help for minor problems			
Some illness are as result of witchcraft	Cultural beliefs		
Health facility was far	Distant facilities	Structural factors	
Didn't have money for transport and to pay at the hospital	Lack of finances		
Treated for the wrong disease at dispensary	Poor diagnostic infrastructure		
Treated for the wrong disease at private clinics			
Misdiagnosis sub-County/ County hospital			
Misdiagnosis at County hospital			

(Source: Findings from FGDs and IDIs)

From the categories and sub-categories, a conceptual framework of factors leading to TB delays was developed. The study revealed the pathway to TB diagnosis was complex with the interplay of different factors which resulted in a long period of suffering for the patients. The health seeking

experiences of the patients can be summed up in a conceptual framework of pathway of delay that illustrates the interaction of factors that lead to delayed TB diagnosis in Kenya (Fig 7.1). The framework demonstrates three types of factors that influence patient's health seeking practices following the onset of TB symptoms. The categories are individual, socio-cultural as well as structural factors. The consequences of the interaction of these factors were delayed diagnosis, increased transmission and prolonged period of suffering.
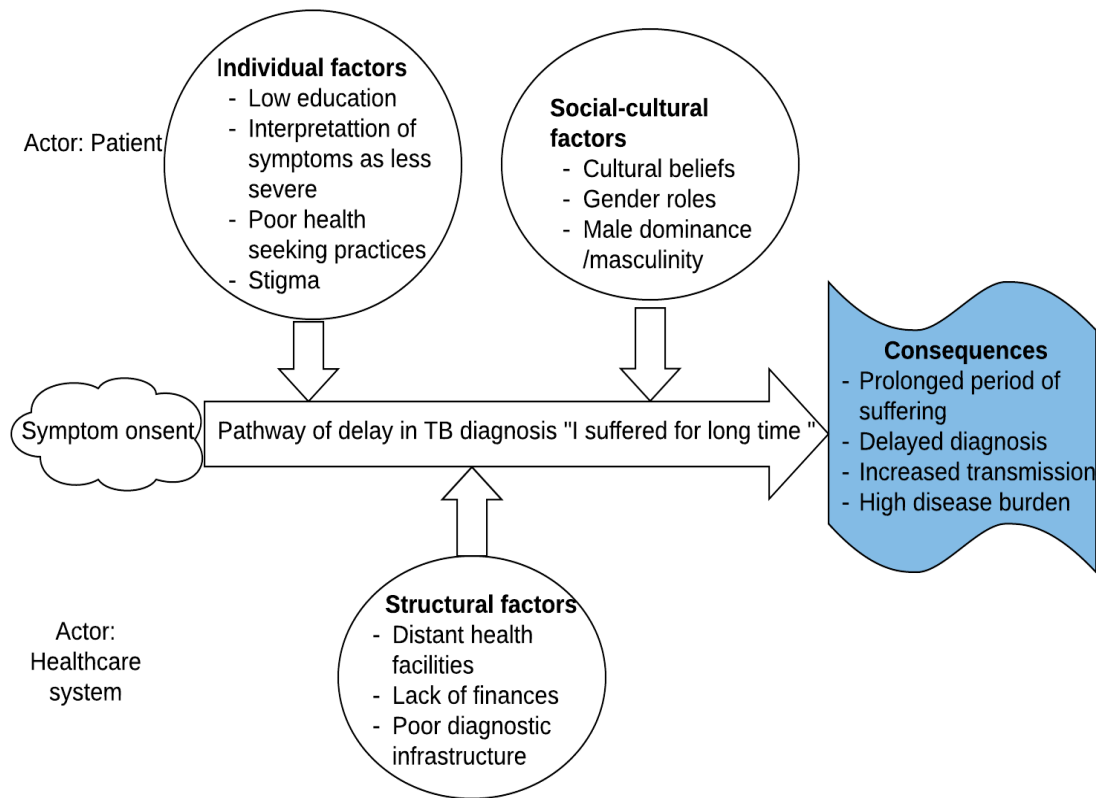
Figure 7.1 Conceptual framework of factors leading to delay in TB diagnosis in West Pokot

(Source: Results from qualitative Data)

7.4.1 Individual factors

Individual factors included a low level of education, lack of awareness of severity of the TB symptoms and poor health seeking practices.

Low level of education

According to the respondents, lack of education contributes to poor health seeking practices with people without formal education preferring alternative medicine. This often led to delayed presentation in the health facility and thus delayed diagnosis. A 61-year-old retired teacher had this to say;

> "Some people take time to come to the health facility. This is mainly the uneducated people who seek this alternative medicine. For me, I came to the hospital as the first option but it took time before they discovered that I as suffering from TB."(Male 61 years).

Lack of the knowledge was a contributing factor to people turning to alternative medicine and only presenting to the health facilities after severe symptoms set in. Participants argued that there was no need to seek hospital treatment following symptoms onset since good alternative medicine was locally available. According to them people turn to modern medicine due to lack of indigenous knowledge on how to make use of the herbal medicine which according to them is without side effects. This was alluded to as follows;

> "If you go to the markets you can get good local herbs. They help a lot. When you start coughing you don't run to the hospital immediately. There are good locally available herbs. These do not have side effects like the medicine from the Whiteman. The time of our grandparents the medicine we have today was not there but people still used to be treated. But right now because we don't know how to make use of the available medicine like our great grandparents did then, we find it not helpful and we end up in the hospital and we have to take the medicines from the white people." (Extract from 3rd female FGD).

Similarly, the quantitative study showed that good TB knowledge was associated with shorter patient delay (Table 7.4). When individuals are aware of common signs and symptoms of TB and the risk of transmission, they are likely to seek health services promptly and vice versa. Evidence from other studies have also shown that gaps in knowledge on transmission, treatment, and prevention lead to diagnostic and treatment delays among people living with TB (Abebe et al., 2010; Gele et al., 2009; Mondal et al., 2014; Nyasulu et al., 2016; Saifodine et al., 2013). Similarly,

a study done in Ethiopia found that lack of awareness on TB contributed to late presentation of suspected TB patient in the health facility (Abebe et al., 2010).

Interpretation of symptoms as less severe

In response to the question "What action did you take when you started experiencing TB symptoms? Majority of the respondents reported that they did not seek treatment since they assumed this was a normal common cold that would resolve on its own. Others said they only bought over the counter painkillers or cough syrups or used local herbs to sooth the cough. It was only after the respondents experienced serious symptoms such as coughing blood, severe chest pain, that they sought TB treatment from the hospitals. Majority of the respondents narrated how they experienced flu-like symptoms such as cough, fatigue, fever and lack of appetite for a prolonged period of time. They did not find the need to seek medical treatment as they believed this would resolve on its own or would be cured through local herbs or self-medication. They only sought biomedical attention after experiencing more severe symptoms such haemoptysis, weight loss and chest pain. This is what some of the informants had to say;

> "It started last year and at first I thought it was just a normal cold and so I didn't take any action. But after some time the cough increased and I decided to seek treatment."(Female 39 years).

> "At first it started just like a normal cough which I assumed. I used to think it is a cold or it was as a result of my smoking."(Male 32 years)

> "I had coughed for almost one year. I thought it was just a normal cough that will go away…when I started coughing blood I realized the disease might finish me. That is when I decided to come here and was tested for TB and it was positive."(Extract from 2nd female FGD).

One of the key emerging themes from the qualitative data on delays was the interpretation of symptoms as less severe. This is mainly because signs and symptoms in the initial stages of TB are indistinct from other diseases. This is consistent with the findings of a study done in South Africa where TB patients interpreted cough as a flu that would resolve on its own and therefore

delayed seeking care (Kerrigan & West, 2017). In the current study, patients waited for severe symptoms such as haemoptysis and loss of weight for them to seek health proper attention. These are signs of advanced disease which implies a great risk of continued transmission of the disease in the community.

Poor health seeking behavior

The respondents had poor health seeking practices which contributed to delayed TB diagnosis. After experiencing TB symptoms patients opted for other forms of treatment before seeking treatment from the health facility. Some of the health-seeking practices among the community members included:

i.   *Self-medication*

After experiencing TB symptoms, majority of the participants used over the counter medication from the chemists and shops. These were mainly antibiotics, painkillers, and cough syrups. However, this only brought temporary relief, after which the patients had to seek other forms of treatment. Participants from the second female FGD had this to say;

> "Like that for me the whole year it was a matter of buying Amoxil because that malaria had affected the chest, that malaria is bad."(Extract from 2nd female FGD).

> "In my case, I was sick for almost 2 years. I tried many things I bought medicine in the shops, I went to the local medicine man who gave me some herbs but this did not help". (Extract from 2nd female FGD).

ii.   *Herbalist and traditional healers*

Respondents indicated that there were many herbalists and different types of local herbal medicine available in the community. They often tried different herbs which did not cure them and finally ended up seeking health care in the health facility.

> "Yes in this place there are many herbal preparations that we try before going to the hospital. One is called *Chepangur* which I used but it was not helpful."(Female 36 years).

"I used the herbal drugs for a period of one year. You know they are of different types from different trees so what we do we try this one when it fails you try the other. But after taking the medicine for a long time I realised the problem was still persisting. When I realised it was not helping I came to the hospital."(Female 39 years).

"There are many herbalists who will give all sorts of medicines. Sometimes they help but other times they don't. We try them but we end up coming to the hospitals". (Extract from 2nd female FGD).

The patients indicated that they preferred herbal medicine due to the fact that it was readily available with some herbalist willing to deliver the medicine to the patients unlike in the case of conventional medicine where one has to travel to the hospital. They argued that even before the conventional medicine was made available the local herbs were used to cure diseases. According to them, the herbs have no side effects. The respondents had this to say:

"The reason people prefer the traditional medicine is that it is more accessible and it is cheaper. Before you can get the money to travel to the hospital you want to try something that is available close to you."(Extract from 2nd female FGD).

Even after using the herbal medicine, none of the respondents reported to have been cured but rather the TB symptoms got worse and finally, the patient had to seek treatment in the health facility

"I also tried herbs but my cough got worse and I started coughing blood. I had also lost so much weight that everyone was worried I would die."(Extract from 2nd male FGD).

Some of the respondents were advised that the prolonged cough was as a result of the uvula and went to the traditional healer to have the uvula removed. However, this did not cure the problem and the patient finally had to seek other forms of treatment. On being questioned why they continued to seek treatment from the traditional healer yet none of the respondents reported having been cured through the traditional medicine, they indicated that traditional medicine was preferable because it had no side effects and was more accessible.

iv) Religion

Although some of the respondents mentioned religion as one of the determinant of health seeking practices, this did not result in delay in health-seeking as most of the patients saw this as complementary. None of the respondent reported having avoided the hospital to rely on prayers but rather they sought for prayers while still undergoing treatment.

"I went to the dispensary and the priest prayed for me to get healed as well" *(Female 38 years).*

The role of religion in the treatment pathway was further explored during the longitudinal follow-up. Despite the fact that the informants were following the doctor's prescriptions for TB treatment, they believed that their healing would only come as result of divine intervention. This was illustrated by a female aged 36 years who reported that, in addition to making visits to the hospitals to collect her medications, she also needed to fast and pray often and visit the church for prayers for her to be cured of her illness;

> "I am following my treatment as instructed I have never failed to pick my medicine and haven't missed to take my medicine even a single day. But I believe it is only God who can cure me from this diseases so I fast and pray often and ask God to heal me. I also go to my pastors for payers. I believe God will cure me of this bad disease."(Female 36 years).

The narrative in most communities which is also supported by the confessions of most doctors is that they can only treat but it is God who heals. This therefore, means that prayers or the call for divine intervention remains a common theme in treatment seeking patterns.

7.4.2 Social and cultural factors

Socio-cultural factors were also key in influencing the time taken from the development of symptoms to the time the patient sought health care. These included; cultural beliefs, gender roles, masculinity and related male dominance.

Cultural beliefs

In the Pokot community, traditional medicine had a role in the management of all illnesses including TB. According to the respondents, some of the illnesses are caused by evil spirits or witchcraft and can only be treated through traditional medicine. As result, when one experienced TB symptoms, they visited the traditional healer (commonly known as *chepsakitian* among the Pokot community) before seeking medical treatment. The community believed that an illness which is as result of evil spirits can lead to death when treated with conventional medicine. It was therefore, necessary to rule out evil involvement before seeking treatment from the hospital. If one noted no improvement after the traditional medicine, they would then seek treatment conventionally. This often led to delayed diagnosis and treatment of TB. In one of the focus group discussions, all members admitted having visited the *chepsakitian* before seeking medical care. Each of them described different types of therapy they had to undergo some taking as long as six months before giving up on the therapy and seeking treatment from the hospital. Some of the respondents pointed that;

> "..you know most severe disease come as a result of curses and witchcraft, It is only *Chepsakitian* (traditional healer)…who can cure you of such. When I went I was asked to slaughter a goat and then we went to the bush to cast away the evil spirits. In the bush they removed the intestine and tied it on my head then I was given herbs to take for one month. The intestines were to stay on my head for one week. After that I still continued coughing and so I bought drugs which I took and improved a bit but finally I came here and was told I had TB." (Extract from 2nd female FGD).

> "They are very many. Almost in every village you will find one. And most people before going to the hospital they have to go through the traditional doctor before going to the hospital. Our community believes that for many diseases, there are some evil spirits that bring the problem and so before even seeking hospital treatment, it is good to remove this spirits for better results…Everybody here must have gone to *chepsakitian*."(Extract from 1st female FGD).

Some of the patients argued that as Christians they don't believe in rituals as a remedy to the evil spirits. According to them, if one is possessed by the evil spirits then they should seek prayers.

They indicated that hospital treatment was the only solution and termed the traditional medicine as ineffective. Respondents from the first female FGD pointed that:

> "In my view, hospital medicine is the only effective treatment for TB. But when it comes to the traditional herbs it is all lies. I don't think it helps. Even the rituals done in the village are useless, those who drink those concoctions most of the time they end up getting sick." (Extract from 1st female FGD).

The current study revealed that tuberculosis patients delayed seeking health care from the health facilities while receiving care from the informal health care providers. Similar findings were documented in Ethiopia (Derseh et al., 2017), Malawi (Nyasulu et al., 2016), Tanzania (Verhagen et al., 2010), Nepal (Baral et al., 2007) and Ghana (Lawn et al., 1998). Cultural explanations of the causes of TB led the patients to turn to alternative approaches such as traditional healers and herbalists as opposed to seeking treatment from the health facility. Easy accessibility of the alternative medicine compared to the health facilities also made it appealing to some of the patients. TB patients from a pastoralist community in Ethiopia also cited easy accessibility of traditional medicine as the reason for not seeking care from the health facility (Gele et al., 2010). This often leads to delays in TB diagnosis and treatment which results in continued transmission in the community. Nyasulu et al. (2016) found that cultural and traditional practices as well as beliefs in witchcraft as causes of illness were major causes of delay in TB diagnosis. Similarly, a study done in rural South Africa found that community members associated breaking cultural norms to be the cause of TB whose remedy was traditional medicine (Edginton et al., 2002).The preference for traditional medicine is therefore, based on misconceptions about the causes and treatment of TB. Such myths and beliefs should be targeted through awareness creation since they often lead to delayed treatment, increased transmission of TB in the community as well as a risk of development of multi-drug resistant strains.

Gender roles

The males were seen as the heads of the family and were supposed to provide and take control of the family. Similarly, the female assumed their submissive roles and they were not supposed to go to the hospital without their husband's approval. When dealing with their own sickness, male patients didn't view early TB symptoms as a reason to skip work and go for healthcare. According to the participants, male patients lack time to seek healthcare as they are busy earning their daily living. Some of the respondents had this to say;

> …But with us men when you fall sick with a minor problem like coughing we don't act fast. We usually persevere first because you have other things to do to earn a living... *(*Male 37 years)

> "You have to ask for permission. You can't go like that. Like me before I came here my husband had told me "Why can't you go and pick Amoxil from the chemist"….They don't see the need for us to go to the hospital."(Extract from 1st female FGD).

Masculinity and male dominance

Male dominance was a key factor contributing to delay in seeking TB treatment among the female patients. The females were economically disadvantaged as they relied on the male partners to provide finances to seek care. This was not granted freely, therefore, resulting in delays.

> "We quarrelled with him until he gave me money for transport. I told him to allow me to go and have my chest checked because it had deteriorated. "(Extract from 1st female FGD).

The participants reported that masculinity was a hindrance to timely management of TB. For the males, the act of seeking immediate medical attention was seen as an act of weakness and instead they are supposed to persevere. They only sought treatment when the condition got worse. This was alluded to by several participants;

> "I didn't buy medicine but I stayed two months before going to the hospital because I didn't know what the problem was. That time it was not very bad. As a man, you don't fall sick today and tomorrow you are in the hospital. We go to the hospital when it is very bad."(Male 32 years).

"You know most of the time a man is known to persevere. First, it's hard for men to go to the hospital."(Extract from 1st male FGD).

Social and cultural factors such gender roles were therefore, key in influencing the time taken from the development of symptoms to the time the patient sought health care. Gender refers to the behaviour, expectations, and roles within a social, economic and cultural context ascribed to being male or female. Evidence has shown that social construction of gender greatly influences the health-seeking behaviour (Mason et al., 2015). There is need to understand how gender is constructed, performed and challenged in the social spaces where TB diagnoses are revealed and concealed in order to promote social inclusion of all TB patients in the provision of TB services. In the present study, the qualitative data showed that masculinity was a source of delay in seeking health care for male patients and male dominance was a source of delay for the female patients who were required to ask for permission and financial support from their male counter parts. However, the quantitative findings showed that total delay was not significantly different across gender. This is consistent with other studies done in Tanzania (Mfinanga et al., 2005), Nepal (Basnet et al., 2009), Ghana (Osei et al., 2015), Ethiopia (Mesfin et al., 2009) and Nigeria (Odusanya & Babafemi, 2004). Concerning patient and health system delays, the current study found significant differences across the gender. The quantitative data showed that males experience longer patient delays compared to the females. Similar findings were illustrated by the respondents during the FGDs and IDIs. Both genders confirmed that male patients do not seek treatment from health facilities promptly compared to females. The findings of longer patient delay among males are consistent with those of other studies done in Uganda (Buregyeya et al., 2014) and South Africa (Meintjes et al., 2008). This may be a contributing factor to the higher burden of TB among males compared to females. Empirical evidence has shown that there is a higher burden of TB among males which may be as a result of the interplay between a true higher incidence of

the disease among men and their poor interaction with primary health care facilities as well as longer delays in seeking treatment for various illnesses including TB (Kumwenda et al., 2016). In the Pokot community, men viewed themselves as strong and seeking treatment promptly was viewed as an act of weakness. Male patients are supposed to persevere until the symptoms are severe.

This form of masculinity where men are viewed as people without emotions and lack vulnerability is culturally instigated. It leads to male delay in seeking health care and as result being underserved by the health care system (Borgdorff et al., 2000; Chikovore et al., 2015; Emslie et al., 2006; Moynihan, 1998). Evidence has shown that men are more likely to have a late TB and HIV diagnosis and to die during the treatment (Ayles et al., 2009; Corbett et al., 2004; Johnson et al., 2013; Mibei et al., 2016; White & Cash, 2003). Chikovore et al., (2015) rightfully argue that, unless health care system adopts a more male inclusive approach, they will continue to serve as a reservoir for TB transmission in the community.

7.4.3 Structural factors

Structural factors include distant health facilities, lack of finances to access the health care as well as poor diagnostic infrastructure that result in misdiagnosis.

Distant health facilities

When asked why they delayed seeking treatment for TB symptoms, some of the patients reported that the health facilities were far and this hindered them from seeking treatment in good time. According to the respondents, this was also a contributing factor to non-adherence to treatment as alluded to by the informants;

> "Some of us live very far from the hospital and have to come all the way."(Female 39 years)

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> "Some of us come from far and there is no hospital nearby, even the dispensary is very far and you find you have no fare to get to the hospital and you are already sick and are supposed to go get the drugs. So although the TB treatment is free in the government hospital, we still encounter a lot of challenges."(Extract from 1st female FGD).

The vast terrain in West Pokot County coupled with the pastoralist livelihood of the participants was a hindrance to access and adherence to TB treatment. Male participants reported having missed to make the required subsequent visits to the TB clinic while tending to their livestock.

> "Some of us like me come from very far and the other time I went out to find pasture for my goats and my medicines got finished and so I had to miss my medicines. Now I came back and I had to start the medicines again." (Extract from 1st male FGD).

Lack of finances to go to the hospital

Some of the respondents indicated that lack of money to pay for transport and investigations required at the health facilities was a hindrance to prompt care seeking. Some of the participants opted for local herbs or self-medication which to them was more accessible. This resulted in delayed diagnosis. Although TB treatment is offered free of charge in the government health facilities in Kenya, patients often incur direct and indirect costs while seeking for TB diagnosis. The patients are required to pay for registration fees, investigations such as chest X-ray and the sputum examination as well as incur transport costs to access the health facilities. For some of the patients, raising the finances is a challenge and this often leads to delay in accessing TB services. When asked why he delayed seeking care from the hospital male aged 32 years pointed that:

> "The hospital is very far from my home and therefore, my problem was that I didn't have fare to go to the hospital. Apart from that I knew when I come to the hospital I will be required to pay for the card and X-rays."(Male 32 years).

The cost of accessing TB services is a challenge for patients in developing countries. Despite the availability of free TB medication, patients and families face a lot of direct and indirect cost

while seeking TB treatment hindering access to timely diagnosis and treatment (Mauch et al., 2013).

Poor diagnostic infrastructure

The participants reported that misdiagnosis was one of the factors contributing to delay in TB diagnosis. According to them, getting a TB diagnosis was a frustrating experience. Even after the patient had sought healthcare, they were treated for other ailments other than TB. Mostly patients were treated with antibiotics for pneumonia, malaria or upper respiratory tract infection. For some respondents, despite presenting with a prolonged cough, they were never offered a TB test. This leads to delay in diagnosis. A female aged 30 years had this to say;

> "They couldn't realize I had TB, I suffered a lot. I went from one hospital to another and still could not find TB. You know TB is a bad disease. It hides in the body and it finishes someone slowly by slowly. The first time I went to the hospital and was told that I had pneumonia, then meningitis. I was given medication but the cough did not stop. I was treated for the wrong disease."(Female 30 years).

Misdiagnosis was mainly in the dispensaries and the private clinics. Those who sought care at the dispensaries and private clinics were mainly treated with antibiotics and were neither offered a sputum test nor referred for sputum test in the Sub-County or the County hospitals. Repeated visits to the dispensaries caused delayed TB diagnosis. It was only after the respondents noticed severe symptoms that they sought treatment at the Sub-County and County health facility where they were offered a sputum test and chest x-rays. This is as evidenced by some of the participants who said the following:

> "When I feel sick I went to the dispensary and was given some drugs which never helped me. I kept going back to the dispensary but they never checked my sputum. I later went to the private clinic where I was given Injections, I improved a little but later I got worse and came to the hospital. I got admitted and they said I had pneumonia. After that, they tested my sputum and I was told I had TB."(Extract from 3rd female FGD).

"I started coughing last year and was treated at the local dispensary three times. When I noticed my health was getting worse I came to the County hospital in January and explained to them. They requested me to take the sputum test and I agreed. At that point it was confirmed that I had TB and started the treatment." (Male 30 years)

For the majority of the respondents, their first contact with the health facility was at the dispensaries and the private clinics. However, all the respondents reported having obtained their TB diagnosis from either a Sub-County or the County hospital. This is mainly because the dispensary and private clinics especially those in the rural areas do not have trained personnel and diagnostic infrastructure necessary to manage TB patients. In Kenya, most dispensaries are managed by community health nurses and do not offer laboratory services and therefore, TB diagnosis is not possible. Similarly, private practitioners particularly those in the rural areas are inadequately trained and have limited diagnostic capacity to manage a TB patient but because they are money minded they may handle the patient repeatedly without referring them to the appropriate health facilities. This often leads to delay in TB diagnosis.

"I had been treated in the dispensary for like a year with Amoxil, septrin and even injections but when I came here … I was asked to have my sputum tested and have chest X-ray done and this is when they said it was TB."(Extract 1st female FGD).

"It is good to look for treatment in a big hospital like this one so that your problem is discovered early and cured."(Male 28 years).

However, seeking health care at the Sub-County or the County health facility did not guarantee timely diagnosis. Some of the respondents who sought treatment from the hospitals reported having been tested for TB and the test was negative and were treated for other conditions before finally being confirmed to have TB. This was illustrated by the following respondents;

"even when I came here [County hospital] I was tested but they said I didn't have TB and later on my chest was bad and I was coughing a lot and they tested me again and found that I had TB" (Extract from female 3rd FGD).

"I was tested for TB twice but it was negative but the third time I was confirmed TB positive."(Female 30 years).

Misdiagnosis was therefore, a major cause of delay even in cases where patients sought care in good time. This could be due to the fact that the standard diagnostic technique for TB in Kenya is by sputum examination and cultures which are not sensitive enough to capture disease in the early stages. Since the discovery of TB in 1882, sputum microscopy has remained the cornerstone for TB diagnosis in low and middle-income countries (Perkins & Cunningham, 2007). Although sputum microscopy is economic and convenient it has low sensitivity and only detects cases with high bacterial load and advanced cases (Boehme et al., 2011; Cox et al., 2014; Perkins & Cunningham, 2007; Steingart et al., 2007). Chest X-ray offers a fast and sensitive test for diagnoses of TB, however, it requires specialized manpower and therefore not available in the primary health care facilities. More sensitive tests such as radiography, molecular diagnosis that can capture the TB cases early enough are expensive and inadequate. The West Pokot County was served by one X-ray machine and one gene X-pert machine both centrally located at the County referral hospital. Currently, Kenya has at least one gene X-pert machine per County and only re-treatment cases are subjected to molecular diagnosis which is more sensitive to detect the bacteria even in early stages of the infection.

7.5 Summary

There was high level of delay in TB diagnosis in the study area. The delays were as result of the interplay between individual, socio-cultural and structural factors. The findings imply that the biomedical emphasis on better drugs, vaccines and sophisticated diagnostic methods is not adequate in the fight against TB. In order to reduce delays there is need for interventions targeting

not only structural factors hindering timely diagnosis among the pastoralist communities but also creating awareness and reducing TB stigma.

8.0 CHAPTER EIGHT: SUMMARY, CONCLUSION, AND RECOMMENDATIONS

8.1 Introduction

Given the importance of research on social determinants of health in the control of infectious diseases such as tuberculosis, the purpose of this thesis was to examine the lived experiences of TB patients with an aim of understanding their pathway to care and factors associated with delayed TB diagnosis. Specifically, the study sought to find out the knowledge and perceptions of TB among the patients, and the level of TB related stigma and how it exemplifies itself in the lives of the patients. The study also examined the health seeking practices adopted by the patients for TB symptoms and the length of resulting delays in diagnosis as well as factors contributing to these delays. The focus of the study was TB patients from West Pokot County which is partly a marginalized county with the majority of the residents depending on pastoralism as a source of livelihood.

This chapter offers the summary of findings, a conclusion of the thesis by revisiting the research questions as well as the recommendations emanating from the findings. In addition, the chapter offers some thoughts on future research in the subject matter.

8.2 Summary of the findings

In chapter four, the first research question 'What is the knowledge and perceptions of tuberculosis among TB patients in West Pokot County' has been addressed. Respondent's responses to the questions on the causes, signs and symptoms, transmission, risk factors for TB infection and curability of the disease were used to determine TB knowledge. From the survey data, a composite score was used to group the respondents with poor and those with good knowledge. The survey showed that more than a third of the respondents had poor knowledge of tuberculosis. Through the FGDs and IDIs, the study sought to further understand the respondent's perceptions about TB. The

study showed that TB was correctly perceived as a curable disease and a contagious one. According to the respondents, it was also a serious disease that is hard to diagnose and treat based on the experiences they have had to go through.

Findings from both the survey and the qualitative data revealed that majority of the patients held misconceptions and myths about the cause and transmission of TB. Only 24% of the respondents attributed germ to be the cause of TB. Others attributed the cause of TB to genetic factors, drinking alcohol and smoking, cold air, trauma, dusty environment as well as bad omens. From the survey, majority (76%) of the respondents were aware that TB was infectious, however, the qualitative data illustrated mistaken ideas on the mode of transmission where sharing of utensils and casual contact were seen as the main routes of transmitting TB.

In Chapter five, the thesis addresses TB stigma by answering the question "What is the level of stigma associated with tuberculosis and how does it exemplifies itself among TB patients in West Pokot? The section covers findings on the level of felt and perceived TB stigma as measured using two different Likert scales with statements focusing on patients and community's perspectives towards TB. The summed stigma scores in each scale were used to categorise the respondents into three categories of low, high and very high level of TB stigma. The study revealed that a majority (61.1%, 58.8%) of the respondents had a high level of felt stigma and perceived stigma respectively. From the qualitative findings, the study showed that TB stigma manifested through fear to disclose TB diagnosis, the association of TB with HIV and AIDS, lack of social support from the family, isolation by others as well as self-isolation.

In chapter six, the question "What treatment pathways do TB patients experience in West Pokot County?" is answered. In this section, the thesis examines the health seeking practices of the

patients, their experiences through the journey from the onset of TB symptoms to the point of TB diagnosis and treatment. The study reveals a pluralistic health care system for TB patients with different stakeholders such as drug shop owners, private clinics, traditional healers, herbalists as well as the formal public health care system. Respondents adopted dynamic health seeking trajectories and switched from one health care provider to the other. Cultural explanations for the causes of TB were a major factor that contributed to delayed access to TB services from the health facilities. Patients preferred to seek care from the informal health care sector before going to the health facilities which resulted in delayed TB diagnosis.

Finally, chapter seven addresses the research question on the level of delay and factors associated with TB diagnostic delays in West Pokot County. The study revealed that a majority (81.7%) of the respondents experienced delayed TB diagnosis. Three types of delay in TB diagnosis and treatment commencement were estimated in days. The study showed a median patient delay, system delay and total delay of 66, 31 and 101 days respectively. The logistic regression analysis showed that the male gender, high level of stigma and poor TB knowledge were associated with high level of TB delays. Similarly, the qualitative findings revealed that the pathway to TB diagnosis was lengthy and complex with an interplay of three types of factors namely individual, socio-cultural and structural factors. Individual factors contributing to delay included issues such as low level of TB knowledge and poor health seeking practices while socio-cultural factors included gender roles, masculinity, and male dominance as well as stigma. In this chapter, the health seeking experiences of the patients has been summed up in a conceptual framework of the pathway of delay whose consequences was a prolonged period of suffering for the patients. This was depicted by one of the in vivo code *"I suffered for a long time"*.

8.3 Contribution of the Study to Knowledge

The research sought to shed light on perceptions, stigma and treatment pathways of TB patients by exploring their lived experiences with the disease. The study showed poor TB knowledge among the respondents which was associated with delay in presenting to the health facility. Although the respondents correctly perceived TB as a contagious disease, they did not understand the correct mode of transmission and this is of concern since it affects community's choice of TB control and preventive strategies. Similarly, respondents had high level of both felt and perceived TB stigma. The stigma was mainly driven by mistaken beliefs about the disease transmission and its association with HIV. There is need to engage the affected communities in addressing stigma through support groups as well as health education to demystify misconceptions surrounding TB transmission that often lead to discrimination. Above all, the TB awareness and prevention measures must be part of the community health care initiatives at the grassroots level if the widespread misconceptions are to be dealt with.

Delay in diagnosis and treatment of TB is high in the study area. Patient delay is the main contributing factor to the total delay. This is of great concern in the fight against the TB epidemic. Research has shown that airborne transmission is not only responsible for the spread of drug sensitive TB but has also lead to the rapid increase of extensively resistant tuberculosis (XDR-TB), previously thought to be as a result of non-adherence to multidrug-resistant TB (MDR-TB) treatment (Shah et al., 2017).

A recent national tuberculosis prevalence survey showed that Kenya is home to double the number of cases previously notified by the TB program. According to the survey, 40% of TB cases remain undetected (Ministry of Health (MOH) Kenya, 2016) . The findings of this study are important in

explaining the missing TB cases. The study show that TB patients spend a lot of time seeking alternative medicine before getting to the health facilities for diagnosis and treatment.

The findings emphasize the need for early diagnosis and treatment of TB to prevent transmission of both drug sensitive and resistant strains of the disease. Approaches geared towards timely diagnosis are recommended so as to avoid the consequences of the pathway of delay in TB diagnosis which includes prolonged period of suffering to the patient and increased disease transmission. There is need to raise TB awareness in the community on the need for timely diagnosis. The TB program should address the structural factors by increasing the number of facilities offering TB diagnosis and improve the diagnostic capacity of the facilities by scaling up radiography services and molecular diagnostic facilities. There is also need to improve timely diagnosis through collaboration with the informal health care sector in order to improve timely referral of patients. Similarly, innovative approaches such as intensive case finding as described in a recent study in South Africa (Kerrigan & West, 2017) should be incorporated in the TB program. The results also show a need to expand the diagnostic capacity of the health facilities and incorporate innovative approaches such as intensive case finding in the TB program.

8.4 Conclusions

The respondents demonstrated a low level of TB knowledge and held mistaken beliefs about TB. This is despite the fact that these were patients on treatment whom according to TB program guidelines should have received TB education from the health facility. This could imply the level of TB knowledge is worse in the general community. Tuberculosis awareness is crucial to the success of control and prevention of TB and therefore, the TB knowledge gaps in West Pokot should be addressed.

There was a high level of both felt and perceived TB stigma among TB patients in the study area. Fear of infection through casual transmission was a significant determinant of TB related stigma that lead to shunning of TB patients. The community's understanding of the contagious nature of TB often led patients to consider themselves disease vectors. The respondents self-isolated themselves in fear of infecting their loved ones particularly children and to avoid being shunned or being the subject of gossip by neighbours. This calls for a need to design effective strategies to reduce TB stigma and its effects in the West Pokot community.

Tuberculosis patient adopted complex and dynamic treatment pathways that resulted in delay in TB diagnosis. In Kenya, TB control program depend on individuals with TB to voluntarily seek treatment (passive case finding) from the health facilities and therefore, patient's health-seeking behaviour is critical to the success of the program. Health-seeking trajectories showed that patients started with services closer to them such as self-medication, herbal remedies, traditional healers, and primary health care facilities and went to the hospital only after experiencing severe symptoms.

Delay in diagnosis and treatment of TB was high in the study area. Delays in TB diagnosis were as result of the interplay between individual, socio-cultural and structural factors. Concerted efforts should be taken in order to improve health seeking practices of the community on TB. There is need to not only focus on biomedical control of TB through better drugs, vaccines, and new diagnostic techniques but also socio-behavioural factors affecting patients' presentation to the health facilities must not be ignored for effective TB control.

8.5 Recommendations

- The TB program should heighten patient education to improve patient knowledge and awareness of TB and put more effort to dispel misinformation about the causes and mode of transmission of the disease.

- There is need to implement more innovative approaches such as intensive case finding in order to enhance early patient presentation to the health facilities.

- To address the structural factors, there is need to improve the diagnostic capacity of the health facilities in the County.

- There is a need for TB programmes to collaborate with the informal health caregivers for purposes of sensitising them on patients' referral in order to improve timely diagnosis.

8.6 Suggestions for future research

- Community interventions research aimed at reducing both TB and HIV stigma are recommended.

- Research on the informal sector and the public healthcare system partnerships should be piloted to establish their effectiveness in improving timely referrals and diagnosis.

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APPENDIX 1: INFORMED CONSENT FORM

TITLE: Perceptions, stigma and treatment pathways among Tuberculosis patients in West Pokot County, Kenya

Principal investigator: Grace Mbuthia

Introduction:

Good morning/afternoon?

My name is Grace Mbuthia and I am here with my research team to conduct a study on the perceptions and the experiences TB patients go through in West Pokot County. I am a PhD student from the University of Nairobi. I would like to seek your permission, please read the consent form below. I would be very grateful if you will assist me by agreeing to be a participant in my study.

The purpose of the study

The aim of this study is to explore the lived experiences of TB patients in West Pokot County. The results of this study will help in the formulation of patient centred approaches in the management of tuberculosis in West Pokot County and the Nation at large.

Procedure

The purpose of this form is to obtain your consent to participate. If you choose to participate, a questionnaire will be administered to you and the interview will take approximately 40 minutes to complete. Participation is voluntary and you can choose not to answer any individual question or all of the questions. However, we hope you will participate in this interview since your views are important.

Benefits

There are no direct benefits to you by choosing to participate in this study. However, the results of this study will be communicated to the national leprosy and tuberculosis program to help in generating policy aimed at improving TB treatment and control.

What are the risks of the study?

Apart from the inconveniences caused by taking part of your time, the process is safe and there are no risks involved. However, we will try as much as we can to make sure we save on your time. Failure to participate also does not have any effects on you or your treatment of TB or access to any facility.

What about confidentiality?

All the information obtained will be strictly confidential and data will be stored safely and will only be accessed by the Principal Investigator. The forms used to collect the data will not bear the names of the participants in the study.

Contact information

For any enquiries in the event of any research related questions, comments or complaints, the following persons will be available for contact:

Principal Investigator: Grace Mbuthia

> **Telephone:** 0722 287 196

> **Email:**   **gmbuthia2002@yahoo.co.uk**

> **The Director,**

> **Institute of Anthropology, Gender & African Studies,**

At this point, do you want to ask me anything about the study?

Subject permission:

I, the undersigned, have read and understood the above information which has been fully explained

to me by the investigator. I have agreed to voluntarily consent to participate. I was given the chance

to ask questions and I received satisfactory responses.

Name of Participant or respondent...

Signature..   Date...

Signature of the person obtaining consent ……………………….. Date …………………

(Must be signed by the investigator or individual who has been designated to obtain consent).

APPENDIX 2: SURVEY QUESTIONNAIRE

Questionnaire for assessing perceptions, stigma and treatment pathways among Tuberculosis patients in West Pokot County, Kenya

District…………………………………………..

Health Facility……………………………………

Patient No…………………..

Type of tuberculosis (Check from records)………………………………..

Part I: Socio- demographic characteristics of the respondents

1. Sex: a. Male   b. Female

2. Age (Years): …………………………….

3. Religion

a. Roman Catholics Christian

b. Protestants Christian

c. Traditional Africans

d. Muslim

e. Other specify …………………………………

4. Marital status

a. Married

b. Single

c. Divorced

d. Widowed

5. Educational status:

a. Illiterate

b. Primary

c. Secondary

d. Other (specify)…………………………………………

6. Occupation (main source of income):

a. Farmer

b. Business man

c. Formal employment

d. Other (specify) …………………………………………………………..

Part II. Awareness on TB.

7. What do you think is the cause of TB? **(do not read the alternatives but circle it if the respondent will mention it)**

a. Bacteria/germ

b. Cold air

c. Curse or bad omen

d. Shortage of food

e. Smoking and drinking

f. Hot climate g. Sun light

h. Dust

i.Any other …………………………………………………

8. What are some of the common symptoms of TB? (**do not read the alternatives but circle it if the respondent will mention it**)

a. Cough more than 2 weeks

b. Sputum with blood

c. Weight loss

d. Loss of appetite

e. Fever andnight sweats

f. Chest pain

g. Any other…………………………………………………..

9. Do you think that the disease can be transmitted from a patient to another person?

a. Yes

b. No

c. Do not know

10. If yes, how is the disease transmitted from patient to other person? (**do not read the alternatives but circle it if the respondent will mention it**)

a. Through cough, sneeze &breathe

b. Through sharing of utensils

c. Through contact with patients (body, cloth , sweat etc.)

e. Any other …………………………………………………………………….

11. What measures do you think can be taken to prevent transmission of TB from patient to another

person? **(do not read the alternatives but circle it if the respondent will mention it)**

a. Avoid sharing cups with a patient

b. Do not cough/ sneeze at other people

c. Do not spit everywhere

d. Use separate room for patient

e. Early treatment for affected patients

f. Do not know

g. Any other …………………………………………………………………………….

12. Does TB have treatment?

a. Yes

b. No

c. Do not know

13. In your area, what types of persons are likely to develop TB?

i) Young children below five years

a. Yes

b. No

c. Do not know

ii) The very old (above 60 years)

a. Yes

b. No

c. Do not know

iii) Those that have problem of shortage food:

a.Yes

b. No

c. Do not know

iv)Those who suffer from other diseases like HIV and AIDS:

a. Yes

b. No

c. Do not know

v) Those who are under stress:

a. Yes

b. No

c. Do not know

vi. Any other ………………………………………………

Part III. Duration and factors associated with delayed diagnosis and treatment of TB patients (to be completed for TB patients on treatment).

14. When did you start experiencing symptoms for your current illness (Date) ………………………………………………………………………………………

15. What care did you seek until the time of diagnosis of TB (document different forms of care sought by the patient in order?)

a.…………………………………………………………………………………………….

b.………………………………………………………………………………………………

c.……………………………………………………………………………………………..

d.………………………………………………………………………………………………

16. When was your first visit to a health facility concerning your current illness? (Date).....................................

17. What factors make TB patient delay in seeking treatment at a health facility? (**Do not read the alternatives but circle it if the respondent will mention it)**

   a) Lack of awareness about TB and the need for early treatment to prevent transmission.

   b) Lack of finances to meet the cost of treatment at the health facility

   c) Traditional healers are more accessible.

   d) TB is a curse and traditional healers are preferable

   e) TB is not curable therefore did not see the urgency in seeking treatment.

   f) Even when one come for treatment early they treat other problems and not TB (misdiagnosis)

   g) Others factors

…………………………………………………………………………………………………

…………………………………………………………………………………………………

(**To be confirmed from out-patient cards, TB registration books**).

18. When was the TB diagnosis made (Date)……………………………….

19. When was the TB treatment commenced (Date) …………………………..

PART 1V: Stigma scales (Van Rie et al., 2008)

A. Community perspectives toward tuberculosis

Statement	Strongly disagree (0),	Disagree (1)	Agree (2),	Strongly agree (3)
Some people may not want to eat or drink with friends who have TB				
Some people feel uncomfortable about being near those with TB				
If a person has TB, some community members will behave differently towards that person for the rest of his/her life				
Some people do not want those with TB playing with their children				
Some people keep their distance from people with TB				
Some people think that those with TB are disgusting				
Some people do not want to talk to others with TB				
Some people are afraid of those with TB				
Some people try not to touch others with TB				
Some people may not want to eat or drink with relatives who have TB				
Some people prefer not to have those with TB living in their community				

B. Patient perspectives toward tuberculosis

Statement	Strongly disagree(0)	Disagree (1)	Agree (2),	Strongly agree(3)
Some people who have TB feel hurt of how others react to knowing they have TB				
Some people who have TB lose friends when they share with them they have TB				
Some people who have TB feel alone				
Some people who have TB keep their distance from others to avoid spreading TB germs				
Some people who have TB are afraid to tell those outside their family that they have TB				
Some people who have TB are afraid of going to TB clinics because other people may see them there				
Some people who have TB are afraid to tell others that they have TB because others may think that they also have AIDS				
Some people who have TB feel guilty because their family has the burden of caring for them				
Some people who have TB will choose carefully who they tell about having TB				
careless behaviours Some people who have TB feel guilty for getting TB because of their smoking, drinking, or other				
Some people who have TB are worried about having AIDS				
Some people who have TB are afraid to tell their family that they have TB				

APPENDIX 3: SEMI STRUCTURED IN-DEPTH INTERVIEW GUIDE.

(a) What do you know about TB (cause, predisposing factors, signs and symptoms, curability and transmission)

(b) I would like to know about the experience you have gone through since you started ailing from Tuberculosis. (Probes when did you come to suspect that you had TB? What actions did you take (the health seeking practices in chronological order) when you started experiencing TB symptoms, how long was the period between the time you started coughing and the time you got a TB diagnosis? What did you go through before the diagnosis process and commencement of treatment? Why do people delay before seeking TB treatment from the health facility?

(c) How did you feel to realise you had Tuberculosis

(d) How did those around you treat you when they knew you had TB? Probe on social support system from family, friends, the community, the neighbours or health workers/facilities.

(e) Did you experience any form of discrimination/stigma before, during and after treatment?

(f) What are some of the available traditional forms of treatment for TB

(g) Is there any other information regarding TB you would want to tell me?

APPENDIX 4: FOCUS GROUP DISCUSSION GUIDE (TB patients)

a) Let us talk about TB. What do you know about TB? probe on cause, curability, transmission, signs and symptoms, risk factors

b) What is it like to be a TB Patient, what kind of experience does a TB patient through?

c) What actions do TB patients take when they start experiencing TB symptoms?

d) Do TB patients seek treatment promptly from the health facility immediately they suspects they have TB? What other form of health care are available in this community?

e) What are some of the traditional explanations to the causes of TB?

f) Do TB patients face any form of discrimination (do they isolate themselves or are they isolated by others? Why?

g) How do TB patients interact with the rest of the family /community?

h) Are there any traditional medicine/herbs or treatment for TB in the community?

i) How does the family/community members expect TB patients to conduct themselves? Are there any restrictions imposed on TB patients?

j) What social support did you receive from family/community?

k) What cultural beliefs about TB exist in your family/community?

l) Is there any other issue regarding TB in the community that you would wish to share with us?

FORM YA IDHINI

JINA: Maarifa, unyanyapaa na njia za matibabu wanazofuata wagonjwa wa kifua kikuu katika West Pokot County.

Mpelelezi mkuu: Grace Mbuthia

Habari za asubuhi / mchana?

Jina langu ni Grace Mbuthia na mimi niko hapa pamoja na timu yangu kufanya utafiti juu ya unyanyapaa na njia za matibabu wanazofuata wagonjwa wa kifua kikuu katika West Pokot County.

Mimi ni mwanafunzi katika chuo kikuu cha Nairobi na utafiti huu unahusiana na masomo yangu.

Nangependa kuomba ruhusa yako, tafadhali soma fomu ya idhini ifuatayo. Ningeshukuru sana kama wewe utukubali kuwa mshiriki katika utafiti wangu.

Madhumuni ya utafiti

Lengo la utafiti huu ni kuchunguza unyanyapaa na njia za matibabu wanazofuata wagonjwa wa kifua kikuu katika kata hii ya West Pokot. Matokeo ya utafiti huu yanatarajiwa kusaidia katika uundaji wa mbinu za kusaidia na zinazojali mgonjwa wa kifua kikuu.

Utaratibu

Madhumuni ya fomu hii ni kupata idhini yako ya kushiriki katika utafiti wetu. Kama utakubali kushiriki, utahitajika kujibu maswali kadhaa na mahojiano itachukua takribani dakika 60 kukamilisha. Ushiriki ni kwa hiari yako. Hata hivyo, tunatarajia utakubali kushiriki katika mahojiano haya kwa sababu maoni yako ni muhimu kwetu.

Faida

Hakuna faida ya moja kwa moja kwako wewe kwa kuchagua kushiriki katika utafiti huu. Hata hivyo, matokeo ya utafiti huu itawasishwa kwa taasisi inayohusika na matibabu yako. Pia itakuwa muhimu katika kutunga sera za kupunguza kifua kikuu.

Utafiti unaleta hatari gani?

Mbali na usumbufu unaosababishwa na kuchukua muda wako, utafiti huu ni salama na hakuna hatari ya kushiriki.

Hata hivyo, sisi tutajaribu tuwezavyo kuokoa muda wako.

Nini kuhusu siri?

Habari zote zitakazo patikana zitakuwa siri na zitawekwa na mtafiti mkuu na kutumika kwa ajili ya utafiti pekee. Wshiriki katika utafiti huu hawataweka majina yao.

Mawasiliano ya habari

 Kwa maswali yoyote katika tukio lolote na maswali kuhusiana, na utafiti, maoni au malalamiko, watu wafuatao watakuwa wanapatikana kwa ajili ya kuwasiliana.

    Mpelelezi Mkuu Grace Mbuthia

   Namba ya: 0722 287 196

  Barua pepegmbuthia2002@yahoo.co.uk

       AU

  Katibu

  Hospitali ya kitaifa ya Kenyattaya   bodi ya maadili ya utafiti

  Sanduku la posta

  Barua pepe:

Katika hatua hii, unataka kuuliza mimi chochote kuhusu utafiti huu?

Idhini ya Mshiriki

Mimi, niliyetia sahihi , nimeelewa habari kuhusu utafiti huu ambazo zimeelezwa kwangu na mtafiti . Mimi nimekubali kwa hiari yangu kushiriki katika utafiti huu. Nilipewa nafasi ya kuuliza maswali na nikapokea majibu ya kuridhisha.

Jina la Mshiriki ....

Sahihi .... Tarehe ....

Sahihi ya mtu anayechukua idhini .... Tarehe ....

(Lazima itiwe sahihi na mtafiti mkuu na mtu ambaye amekuwa mteule wa kupata idhini)

APPENDIX 6: KISWAHILI TRANSLATED SURVEY QUESTIONNAIRE

Dodoso kwa ajili ya kutathmini maarifa, unyanyapaa na njia za matibabu wanazofuata wagonjwa wa kifua kikuu katika West Pokot County.

Wilaya ....

Kituo cha Afya ....

Nambari ya Mgonjwa ....

Aina ya kifua kikuu (Angalia kutoka kumbukumbu) ....

SEHEMU YA KWANZA: Sifa za kijamii za washiriki

1. Sex a. Kiume b. Kike

2. Umri (miaka) ....

3. Dini

a. Mkristo

b. Muislamu

c. Nyingine (eleza)…………………………..

4. Hali ya ndoa

a. Ameolewa

b. Hajaolewa

c. Talaka

d. Mjane

5. Hali ya Elimu

a. Hawajui kusoma na kuandika

b. Shule ya msingi

c. Sekondari

d. Nyingine (eleza) ....

6. Kazi unayoitegemea kwa ajira ya kila siku.

a. Mkulima

b. Wavuvi

c. Biashara ya kibinafsi

d. kuajiriwa rasmi

e. Nyingine (eleza)

SEHEMU YA PILI: Maarifa kuhusu kifua kikuu.

7. Unafikiria nini ni sababu ya kifua kikuu? (usisome njia mbadala lakini utie alama ikiwa mhojiwa

ataitaja)

a. Bakteria

b. Hewa baridi

c. Laana

d. Uhaba wa chakula

e. Kukunwa pombe na kuvuta sigara

f. Hali ya hewa yenye joto

g. Jua

h. Vumbi

i. Nyingine ....

8. Je, unazijua baadhi ya dalili gani za kifua kikuu? (usisome njia mbadala lakini tia alama kama

mhojiwa atataja)

a. Kikohozi zaidi ya wiki mbili

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b. Kikohozi chenye damu

c. Kupungua uzito

d. Kupoteza hamu ya kula

e. Joto na Kutokwa na jasho usiku

f. Maumivu ya kifua

g. Mengine yoyote ....

9. Je, ugonjwa wa kifua kikuu unaweza kuambukizwa kutoka kwa mgonjwa hadi kwa mtu mwingine?

 a. Ndiyo

 b. Hakuna

c. Sijui

10. Kama ndiyo, kwa nini ugonjwa kuambukizwa kutoka mgonjwa mtu mwingine? (usisome njia mbadala lakini utie alama ikiwa mhojiwa ataitaja)

a. Kwa njia ya kukohoa, kupiga chafya na kupumua

b. Kwa njia ya kutumia vyombo sawa na mgonjwa wa TB

c. Kwa njia ya kugusa mwili, nguo au jasho ya mgonjwa wa kifua kikuu

e. Nyingine yoyote ………………………………………………………………….

11. Ni hatua gani unafikiri zinaweza kuchukuliwa ili kuzuia maambukizi ya TB kutoka kwa mgonjwa hadi kwa mtu mwingine? (usisome njia mbadala lakini utie alama ikiwa mhojiwa ataitaja)

a. Epuka kushirikiana vyombo vya chakula na mgonjwa wa TB.

b. Usikoholee au kupiga chavya katika watu

c. Usiteme mate ovyo ovyo

d. Mgonjwa atumie chumba tofauti na watu wengine

e. Tiba ya mapema kwa wagonjwa walioathirika
f. Sijui
g. Nyingine yoyote …………………………………………………………………

12. Je, ugonjwa wa kifua kikuu uko na tiba?

a. Ndiyo

b. La

c. Sijui

13. Katika eneo hili, ni aina gani ya watu wako hatalini sana sana ya kuungua ugojwa wa kifua

kikuu ?

 i) Watoto wadogo chini ya miaka mitano.

a. Ndiyo

b. La

c. Sijui

ii) Wazee (zaidi ya miaka 60)

a. Ndiyo

b. La

c. Sijui

 iii) Wale wenye tatizo la uhaba wa chakula

 a.Yes

b. La

c. Sijui

iv) Wale ambao wanakabiliwa na magonjwa mengine kama UKIMWI.

a. Ndiyo

b. La

c. Sijui

v) Wale ambao ni chini ya dhiki.

a. Ndiyo

b. La

c. Sijui

vi. Wengine …………………………………………

SEHEMU YA TATU: Muda na mambo yanayohusiana na kuchelewa kwa utambuzi na matibabu ya wagonjwa wa kifua kikuu

14. Ulianza kuhisi dalili za ugonjwa wa kifua kikuu wakati gani (Tarehe)…………………

15. Hatua gani ulichukua (Usisome majibu lakini tia duara kama mgonwa atataja majibu haya)

 a. Nilitumia dawa za mitishamba

 b. Nilitembelea kituo cha afya

 c. Nilitafuta msaada kutoka kwa mganga wa jadi

 d. Nilitafuta uponyaji wa Mungu

16. Wakati wa kwanza wewe kutafuta matibabu kwa kituo cha afya kuhusu ugonjwa huu ilikuwa lini (Tarehe) ....

17. Mambo gani alifanya wewe kuchelewa kutafuta tiba katika kituo cha afya (Usisome majibu lakini tia duara kama mgonwa atataja majibu haya)

    a) Ukosefu wa ufahamu juu ya kifua kikuu na haja ya matibabu ya mapema ili kuzuia maambukizi.

    b) Ukosefu wa fedha za kugharamia matibabu katika kituo cha afya

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c) Waganga wa jadi ni rahisi kupatikana.

d) Kifua kikuu ni laana na waganga wa jadi wana ufanisi zaidi kuliko kituo cha afya

e) Ugonjwa wa kifua kikuu hauna tiba kwa hivyo sikuona umuhimu katika kutafuta matibabu.

f) (Thibitisha kutoka kwa kadi ya mgonjwa na vitabu vya usajili wa kifua kikuu).

18. Wakati upimaji wa ugonjwa wa kifua kikuu ulifanywa (Tarehe)....................................

19. Wakati matibabu ya kifua kikuu ilianzishwa (Tarehe)...............................

SEHEMU YANNE: Mizani ya kupima unyanyapaa (Van rie, Sengupta et al. 2008).

A. **Mitazamo ya wanajamii kuhusu kifua kikuu**

Taarifa	Sikubali kabisa(0)	Sikubali (1)	Nakubali (2)	Nakubali kabisa(3)
Baadhi ya watu hawataki kula au kunywa na marafiki ambao wana kifua kikuu				
Baadhi ya watu huwa na wasiwasi wakiwa karibu na wale walio na kifua kikuu				
Kama mtu ako na kifua kikuu, wanajamii watahusiana na yeye tofauti na kawaida kwa maisha yake yote.				
Baadhi ya watu hawataki watoto wa wale wanaungua kifua kikuu kucheza na watoto wao.				
Baadhi ya watu hukaa mbali na watu wenye kifua kikuu.				
Baadhi ya watu wanadhani ya kwamba wale walio na kifua kikuu wanaudhi sana.				
Baadhi ya watu hawataki kuzungumza na mtu ambaye anaungua kifua kikuu.				
Baadhi ya watu hujaribu kutogusa wengine na walio na kifua kikuu.				
Baadhi ya watu hawataki kula au kunywa na ndugu ambao wana kifua kikuu.				
Baadhi ya watu hawapendi wale wanaoungua kifua kikuu wakiishi katika jamii yao.				

B. **Mitazamo ya wagonjwa kuhusu kifua kikuu**

Taarifa	Sikubali Kabisa (0)	Sikubali (1)	Nakubali (2)	Nakubali kabisa(3)
Baadhi ya watu ambao wanaungua kifua kikuu wanakwazika na jinsi watukujua wao kuwa na kifua kikuu				
Baadhi ya watu ambao wanaungua kifua kikuu hupoteza marafiki wanapokiri kuwa wana kifua kikuu				
Baadhi ya watu ambao wanaugua kifua kikuu huhisi upweke.				
Baadhi ya watu ambao wanaungua kifua kikuu hujitenta na watu wengine ili kuepuka kueneza wadudu wakifua kikuu.				
Baadhi ya watu ambao wanaungua kifua kikuu wanaogopa kuwaambia watu walio nje ya familia zao kwamba wana kifua kikuu				
Baadhi ya watu ambao wana kifua kikuu wanaogopa kuwaambia wengine kwamba wana kifua kikuu ili wengine wasifikiri kwamba wao wako na ukimwi pia.				
Baadhi ya watu ambao wanaungua kifua kikuu huwa na hofu ya kwenda kliniki ya kifua kikuu ili watu wengine wasiwaona huko				
Baadhi ya watu ambao wanaungua kifua kikuu hujilaumu kwa sababu ya kuletea familia yao mzigo wa kuwatunza.				
Baadhi ya watu ambao wana kifua kikuu huchagua kwa makini watu wakuwaeeleza kuwa wanaungua kifua kikuu				
Baadhi ya watu ambao wanaungua kifua kikuu hujilaumu na kuona walipata ugonjwa kwa sababu ya uvutaji sigara , kunywa pombe, au tabia mbaya nyingine.				
Baadhi ya watu ambao wana kifua kikuu huwa na wasiwasi kuhusu kuwa na ukimwi.				
Baadhi ya watu ambao wana kifua kikuu wanaogopa kuwaambia familia zao kwamba wana kifua kikuu.				

APPENDIX 7: KISWAHILI TRANSLATION OF THE IN-DEPTH INTERVIEW GUIDE

a) Nengependa kujua yale unayofahamu kuhusu ugonjwa wa kifua kikuu (nini inasababisha huu ugonjwa, unaenea namna gani, nani yuko hatarini kupata huu ugonjwa)

b) Nieleze kwa kina uliyoyapitia baada ya kupata ugonjwa wa kifua kikuu mpaka sasa.(Jinsi ulivyo kuja kushuku ulikuwa na ugonjwa wa kifua kikuu, hatua ulizozichukua kutafuta matibabu, uliyoyapitia kabla ya utambuzi wa ugonjwa, Ilikuchukua muda gani kujua ulikuwa unaungua kifua kikuu, Kwa maoni yako kwa nini watu huchukua muda kabla ya kwenda hospitalini wanapo pata dalili za kifua kikuu)

c) Ulihisi namna gani ulipogundua ulikua na ugonjwa wa kifua kikuu?

d) Msaada gani ulipata kutoka kwa familia, marafiki, jamii, majirani au wafanyakazi wa afya ?

e) Ulikubana na unyanyapaa kabla, wakati wa na baada ya matibabu ?

(f) Katita kijiji hiki kuna matibabu ya kiasiri ya kutibu kifua kikuu?

g) Taarifa yoyote ingine kuhusu kifua kikuu na madhara yake.

APPENDIX 8: KISWAHILI TRANSLATION OF THE FOCUS GROUP DISCUSSION GUIDE

(a) Ni yapi jamii hii inaelewa kuhusu kifua kikuu?.(Kiini, ueneaji, dalili, walio hatarini ya kupata huu ugonjwa)

(b) Mtu anapoungua huu ugonjwa wa kifua kikuu, anapitia yapi katika hii jamii?

(c) Wagonjwa wanapopata dalili za kifua kikuu wanachukua hatuua gani?

(d) Je, wagonjwa wa kifua kikuu hutafuta matibabu mara moja kutoka kituo cha Afya wanaposhuku wako na ugonjwa wa kifua kikuu? Aina gani nyingine ya huduma za afya ambazo mgonjwa wako alitafuta?

(e) Je, kuna maelezo gani ya kiasiri kuhusu kiini cha kifua kikuu.

(f) Je, wagonjwa wa kifua kikuu hutegwa au hujitenga wenyewe?

(g) Wagonjwa wa kifua kikuu wanatengamana na watu wengine namna ganikwa familia / jamii?

(h) Je, kuna dawa za jadi / dawa za kienyeji au tiba ya ugojwa wa kifua kikuu katika jamii yenu?

(i) Familia / wanajamii huwatarajia wagonjwa wa kifua kikuu kufanya mambo gani?Je, kuna vikwazo vyovyote zilizowekwa kwa wagonjwa wa kifua kikuu?

(j) Msaada gani wa kijamii unaotolewa kwa wagonjwa wa kifua kikuu katika familia/jamii yako?

(k) Ni tamaduni gani kuhusu kifua kikuu zipo katika familia yako / jamii?

(l) Je, kuna mengine ya utamaduni wa ugonjwa wa kifua kikuu katika jamii ungependa kutueleza?

APPENDIX 9: ETHICAL APPROVAL

INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE (IREC)

MOI TEACHING AND REFERRAL HOSPITAL
P.O. BOX 3
ELDORET
Tel: 33471//2/3
Reference: IREC/2014/224
Approval Number: 0001349

MOI UNIVERSITY
SCHOOL OF MEDICINE
P.O. BOX 4606
ELDORET

12th February, 2015

Ms. Grace Mbuthia,
Moi University,
School of Nursing,
P.O. Box 4606-30100,
ELDORET-KENYA.

INSTITUTIONAL RESEARCH &
ETHICS COMMITTEE

12 FEB 2015

APPROVED
P.O. Box 4606-30100 ELDORET

Dear Ms. Mbuthia,

RE: FORMAL APPROVAL

The Institutional Research and Ethics Committee has reviewed your research proposal titled:-

"Challenges Facing Tuberculosis Patients in Baringo County Kenya"

Your proposal has been granted a Formal Approval Number: **FAN: IREC 1349** on 12th February, 2015. You are therefore permitted to begin your investigations.

Note that this approval is for 1 year; it will thus expire on 11th February, 2016. If it is necessary to continue with this research beyond the expiry date, a request for continuation should be made in writing to IREC Secretariat two months prior to the expiry date.

You are required to submit progress report(s) regularly as dictated by your proposal. Furthermore, you must notify the Committee of any proposal change (s) or amendment (s), serious or unexpected outcomes related to the conduct of the study, or study termination for any reason. The Committee expects to receive a final report at the end of the study.

Sincerely,

PROF. E. WERE
CHAIRMAN
INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE

cc	Director	-	MTRH	Dean	-	SOP	Dean - SOM
	Principal	-	CHS	Dean	-	SON	Dean - SOD

APPENDIX 10: PROPOSAL AMENDMENTAPPROVAL

INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE (IREC)

MOI TEACHING AND REFERRAL HOSPITAL
P.O. BOX 3
ELDORET
Tel: 33471//2/3

MOI UNIVERSITY
SCHOOL OF MEDICINE
P.O. BOX 4606
ELDORET
Tel: 33471/2/3

Reference: IREC/2014/224
Approval Number: 0001349

6th May, 2015

Ms. Grace Mbuthia,
Moi University,
School of Public Health,
P.O. Box 4606-30100,
ELDORET-KENYA.

Dear Ms. Mbuthia,

RE: APPROVAL OF AMENDMENT

The Institutional Research and Ethics Committee has reviewed the amendment made to your proposal titled:-

"Challenges Facing Tuberculosis Patients in West Pokot County"

After review of the above. We note that you are seeking to make an amendment as follows:-

1. To change the study site from Baringo County to West Pokot County.

The amendment has been approved on 6th May, 2015 according to SOP's of IREC. You are therefore permitted to continue with your research.

Note that this amendment approval will expire on the date of expiry of your Formal Approval. If it is necessary to continue with this research beyond the expiry date, a request for continuation should be made in writing to IREC Secretariat two months prior to the expiry date.

You are required to submit progress(s) regularly as dictated by your proposal. Furthermore, you must notify the Committee of any proposal change(s) or amendment(s), serious or unexpected outcomes related to the conduct of the study, or study termination for any reason. The Committee expects to receive a final report at the end of the study.

Sincerely,

PROF. E. WERE
CHAIRMAN
INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE

cc: Director - MTRH   Dean - SPH   Dean - SOM
    Principal - CHS   Dean - SOD   Dean - SON

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APPENDIX 11: PERMISSIOM FROM THE COUNTY DIRECTOR OF HEALTH

MINISTRY OF HEALTH

Telephone: 0202394760
Email: kapenguriad@yahoo.com
When replying please quote.

KAPENGURIA DISTRICT HOSPITAL
P.O BOX 63,
KAPENGURIA

Ref: KAPE/ADM/62/15

20th July 2015

To Grace Mbuthia
Moi University
P.O Box 4606-30100
ELDORET-KENYA

Dear Madam

RE: PERMISSION TO CARRYOUT RESEARCH IN WEST POKO T COUNTY

This is in reference to your request to carry out research in West Pokot County.

Permission is hereby granted for you to carry out research on challenges facing in T.B Patients in West Pokot County.

Thank you.

Dr. Limo Abraham
Ag. Director of Health West Pokot County
WEST POKOT COUNTY

APPENDIX 12 : NACOSTI PERMIT

NATIONAL COMMISSION FOR SCIENCE, TECHNOLOGY AND INNOVATION

Telephone: +254-20-2213471,
2241349, 310571, 2219420
Fax: +254-20-318245, 318249
Email: secretary@nacosti.go.ke
Website: www.nacosti.go.ke
When replying please quote

9th Floor, Utalii House
Uhuru Highway
P.O. Box 30623-00100
NAIROBI-KENYA

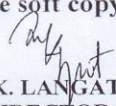Ref: No.

Date:
30th June, 2015

NACOSTI/P/15/2156/6271

Grace Wambura Mbuthia
University of Nairobi
P.O. Box 30197-00100
NAIROBI.

RE: RESEARCH AUTHORIZATION

Following your application for authority to carry out research on *"Challenges facing tuberculosis patients in West Pokot County,"* I am pleased to inform you that you have been authorized to undertake research in **West Pokot County** for a period ending **1st May, 2016.**

You are advised to report to **the County Commissioner, the County Director of Education and the County Coordinator of Health, West Pokot County** before embarking on the research project.

On completion of the research, you are expected to submit **two hard copies and one soft copy in pdf** of the research report/thesis to our office.

DR. S. K. LANGAT, OGW
FOR: DIRECTOR-GENERAL/CEO

Copy to:

The County Commissioner
West Pokot County.

The County Director of Education
West Pokot County.

National Commission for Science, Technology and Innovation is ISO 9001: 2008 Certified