COMMUNITY UNDERSTANDING OF TUBERCULOSIS (TB) TREATMENT-SEEKING BEHAVIOUR AND ADHERENCE TO THERAPY: A CASE STUDY OF KIOGORO DIVISION, KISII CENTRAL DISTRICT, KENYA.

BY

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DECLARATION

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

Lameck Mochache — Date 28/6/2007

This thesis has been submitted for examination with my approval as university supervisor.

Prof. Isaac K Nyamongo — Date 28/06/2007.

DEDICATION

To my mother Jane Nyaboke and my uncle Jackson Onserio Omoke

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LIST OF ABBREVIATIONS

AIDS- Acquired Immuno-deficiency Syndrome

CBS- Central Bureau of Statistics

DOT- Directly Observed Therapy

FGD- Focus Group Discussions

GOK- Government of Kenya

HIV- Human Immuno-deficiency Virus

MDR-TB- Mult-Drug Resistant Tuberculosis

MOH- Ministry of Health

NLTP- National Leprosy and Tuberculosis Control Programme

SPSS- Statistical Package for Social Sciences

TB- Tubecule bacilli

WHO- World Health Organization

ABSTRACT

Tuberculosis (TB), one of the leading opportunistic infections in the face of HIV/AIDS is becoming a major problem. The Sub-Saharan Africa region is most affected due to high AIDS cases, which has facilitated the rising cases of TB. Literature on health-seeking behaviour and compliance to therapy indicates that people perceive this disease variously. They have their own views and beliefs about the causes, symptoms, mode of transmission and therapy choices, which probably affect their treatment-seeking behaviour. Therefore, the study sought to unveil these beliefs and perceptions.

The main objective of the study was to explore people's perceptions on TB and how these perceptions affect their treatment-seeking behaviour and adherence to therapy. Specifically the study sought to explore people's perception about the causes and symptoms of TB, examine factors that influence therapy choices and those that influence TB treatment compliance. A sample of 100 households was randomly selected from ten sub-locations in Kiogoro division. A standardized questionnaire was administered to household heads to gather quantitative data. Also focus group discussions, interview with key informants and case histories were used to collect qualitative data to enrich that collected through the survey. Because of the nature of data collected both qualitative and quantitative methods were employed in the data analysis.

The findings indicate that the majority of people (over 70%) are aware of the causes and symptoms of TB. However, some misinterpret the disease hence delayed action and wrong therapy choices. Besides the misinterpretation of the disease, other factors such as: distance, perceived effectiveness of a given therapy, cost and HIV/AIDS were found to have an effect on treatment-seeking behaviour of people.

On compliance to therapy, the study reveals that patients do abuse drugs and get re-infected. Some factors that lead to this behaviour include: long TB regimens, transportation cost, lack of knowledge about the risks associated with non-compliance to therapy, alcoholism, medicine sharing and stigma.

The study recommends that lay people should be educated on the causes of TB, its symptoms and how it is transmitted because even though the findings indicate that the majority are knowledgeable about TB, some hold misconceptions, which need to be corrected for an effective fight against TB. This should be done through public media, public seminars and schools/churches- the study found that public media, schools/churches play a major role in information dissemination. There should also be active case detection to ensure that treatment starts early. Finally, the government and other concerned bodies should make health facilities more accessible.

CHAPTER ONE:

BACKGROUND INFORMATION

1.1 Introduction

We entered the new millennium with tuberculosis being an even greater global problem than it was at the beginning of the twentieth century. Each year, close to nine million people develop active tuberculosis (TB) and nearly two million TB deaths occur worldwide (WHO, 2003). HIV/AIDS has contributed significantly to the resurgence of TB. Individuals with HIV/AIDS infection develop active TB rapidly after becoming infected with mycobacterial tuberculosis.

In sub-Saharan Africa where AIDS has spread rapidly, rates of tuberculosis are soaring and overwhelming fragile tuberculosis control programmes. Between 1998 and 1999, African countries severely affected by HIV/AIDS reported a twenty percent increase in the incidence of TB; this rise was largely responsible for the increase of TB globally. Africa region accounts for at least 25% of global TB cases and a 12% increase in new reported smear-positive pulmonary TB cases, the most infectious form (WHO, 2005)

Kenya has a large and rising tuberculosis disease burden and is ranked 12th among the world's 22 countries with a high tuberculosis burden (WHO, 2004). It is estimated that over 50% of the adult population over 15 years are infected with the germ that causes TB. However, only a small proportion of these, usually 5-10%, in the absence of HIV infection or close to 50% if there is co-infection with HIV, will develop TB disease. The TB burden in Kenya has been increasing at a rate of about 12-16% every year for the last ten years. In 2004, there were slightly over 106,000 cases of TB that were notified to the National Leprosy and Tuberculosis Control Programme of the ministry of Health (NLTP, 2004). According to the WHO, this may represent only about 50% of the true number of cases of TB that occurred. Therefore, it may be that as many as 200,000 cases of TB occurred in 2004.

Tuberculosis is an important disease to target in areas severely affected by HIV/AIDS because TB is curable and can easily be prevented. Although it is fuelled by HIV/AIDS, TB is an infectious disease that does not remain confined to HIV positive patients. It spreads to even HIV negative people. It spreads from person to person through the air when people with TB in their lungs or throat cough, sneeze, sing, or even talk. When tuberculosis is not treated fast enough, it can lead to very serious complications and even death. Delayed treatment facilitates the continuous spread of the disease and this can be dangerous, especially in densely populated areas.

Besides delayed treatment, there is another problem of wrongful drug administration which may result from self-medication practices where the patients administer drugs by themselves without consultation with medical professionals or, in many cases, as a result of individuals not understanding the directions of use as given by physicians. In this case, TB becomes resistant to the effects of some tuberculosis drugs. This has contributed greatly to the emergence of multi-drug resistant tuberculosis (MDR-TB), which is not only costly but also very difficult to treat.

Delaying treatment and the use of medicine by persons without sufficient knowledge on the dangers of non-adherence to therapy entail health risks for the individuals concerned, those around them and the wider community at large. Therefore, this study explored people's knowledge or perceptions on the causes, symptoms, and mode of spread of tuberculosis, how they go about treating the disease, from which provider they get treatment, and how patients are handled at home. The study also investigated factors that influence compliance to therapy. Further, it sought to assess people's knowledge regarding the relationship between tuberculosis and HIV/AIDS. Finally, the study made some recommendations on how to improve on the efforts of controlling tuberculosis, what should be done to ensure people seek treatment as fast as possible, how to ensure that patients adhere to therapy as required to avoid cases of multi-drug resistant tuberculosis hence reducing mortality rates and prolonging lives of HIV/AIDS patients.

1.2 Statement of the problem

Tuberculosis (TB) is one of the leading opportunistic infections in the face of HIV/AIDS. It is an increasing and major worldwide problem, especially in Africa where AIDS is rampant and thus facilitating the spread. It is estimated that nearly one billion people will become newly infected, over 150 million will become sick and 36 million will die worldwide by the year 2020 if control measures are not further strengthened (WHO, 2002).

Like many other diseases, tuberculosis affects anybody but some groups of people are at higher risk to get active TB. These groups include: people with HIV/AIDS infection, those in close contact with people known to be infected with TB and are not under proper medication, and malnourished ones. Control of tuberculosis has become difficult due to people's delayed appropriate action. Literature on health- seeking behaviour and adherence to therapy indicates that the perceptions of this disease vary and cannot be determined by any general criterion. Several studies have shown that people have their own views and beliefs about the causes and symptoms of tuberculosis, which probably determine the action to be taken in the event of illness. Still some people lack knowledge on the causes, symptoms and the ways in which this disease is spread.

Another problem arises from the fact that tuberculosis regimens are too long – it usually takes up to 8 months. This is a very long period, especially when one considers the predominantly illiterate or urban poor populations in developing countries. Since the treatment is prolonged, there is always the difficulty of persuading patients to continue or adhere to medication as prescribed by the physician. There is always a tendency by patients to withdraw from medication when they get better thinking that they have recovered fully. Some patients take medicine irregularly. This poses a severe problem because as soon as patients withdraw from medication, they become sick and infectious again and can spread the tuberculosis germs to those around them.

In other cases, due to poor medication, another form of tuberculosis – multi-drug resistant tuberculosis may emerge. This form is not only expensive, but also very difficult to treat and this leads to high mortality rates.

Because of the aforementioned problems, the spread of TB has continued to rise, thereby undermining the efforts to curtail the epidemic. This calls for more detailed qualitative and quantitative studies at the community level in order to come up with concrete recommendations on how the problem could be addressed.

This study undertook to answer the following questions:

1. What are the people's perceptions regarding the causes, symptoms and mode of spread of tuberculosis?
2. What influences people's choice of the available health care providers?
3. What factors influence people's compliance to tuberculosis therapy?

1.3 Study objectives

The overall objective was to explore the people's knowledge of tuberculosis and how this affects their treatment–seeking behaviour and adherence to therapy.

Specifically the study undertook to,

1. Explore people's perceptions about the symptoms and causes of TB.
2. Examine the factors that influence therapy choices.
3. Investigate factors that influence TB treatment compliance.

1.4 Rationale of the study

This study was conceived as a basic social science research and therefore it was mainly concerned with advancing the state of knowledge within the field of medical anthropology and related social science disciplines. However, the research findings may

also be used in solving tuberculosis problem by providing avenues through which the problem may be approached.

In general terms, the study was meant to add new knowledge to the available literature on treatment-seeking behaviour and compliance to treatment, benefit development planners, change agents, non-governmental organizations and other groups who are interested in improving the health of people and specifically those who are interested in fighting TB. Finally, the findings of this study may guide other researchers who might be interested in the same problem.

1.5 Scope and limitations

Tuberculosis is a global problem and everybody is concerned in one way or the other. It was therefore important to get views from all people concerning this disease and on how to deal with it. But because of some constraints (limited time and money), the study had some boundaries: It was delimited to Kiogoro Division, only the sampled population provided the required data, it was also delimited to the methods of data collection stated and finally the study was only concerned with achieving its objectives.

CHAPTER TWO:

LITERATURE REVIEW

This chapter is subdivided into seven parts. The first part deals with the nature of the disease, the second, third, and fourth tackle treatment-seeking behaviour, compliance to therapy and HIV/AIDS and TB co-infection respectively. The theory that guided the study is presented in the fifth part and finally, assumptions and definition of terms take the sixth and last parts in that order.

2.1. The nature of the disease

Tuberculosis, commonly called TB (Tubercule bacilli), is a chronic infectious disease and most common among all chronic respiratory diseases. It is among the important causes of morbidity and mortality in the world today. TB is caused by inhalation of airborne tubercule bacilli or ingestion of milk or beef from tuberculous cattle. It mostly attacks the lungs (more than 80% of all cases) but can attack almost any part of the body. For instance, it can attack the bones, joints, throat, and abdomen.

When people with TB in their lungs or throat cough, sneeze, sing or even talk, the germs that cause TB may be spread into the air and if another person breathes in these germs, there is a chance that he/she will become infected with tuberculosis. Repeated contact is usually required for infection to take place. There is a difference between being infected with TB and having TB disease. Someone who is infected with TB has the TB germs in the body but the body's defenses are protecting him and he is not sick. However, the one with TB disease is sick and can spread the disease to healthy people. To become infected with TB, usually a person has to be close (for a long period of time) to someone with TB disease and who is not under proper medication.

Symptoms indicating the presence of tuberculosis disease are seen about six to eight weeks after infection. However, a person with TB infection will show no symptoms but the one with TB disease may have any or all of the following symptoms: A cough that will not go away usually with a wheeze; feeling tired all the time; weight loss;

loss of appetite; low-grade fever; night sweats; sometimes coughing up blood; failure to gain weight; chest pains; headache or vomiting lasting more than three days; pain or stiffness in joints; and pneumonia that fails to resolve. Nevertheless, the surest way of making diagnosis is to take a laboratory test. This is because a person with TB disease may feel perfectly healthy or may only have a cough from time to time. Therefore, people are advised to get tuberculin test if they are living in close contact with people who are sick and are not under proper medication or if a member of their family has died of TB.

There are various TB tests. The first one is the TB skin test; this is a way of finding out if a person has TB infection. The preferred method of skin test is the use of the Mantoux test. For this test, a small amount of testing material is placed just below the top layer of the skin, usually on the arm and two to three days later, a healthy care worker checks the arm to see if a bump has developed and measures the size of the bump. To test whether one has TB disease and not just TB infection, several other tests, including chest X-ray and a test of a person's sputum, are used. Having TB test is very important because it ensures that in case of the disease, treatment starts early. This helps in preventing the disease from spreading to others since when one is under proper medication; he or she becomes un-infectious within few weeks. Therefore, case finding should be one of the strategies in the fight against tuberculosis. It helps to identify those who are infected to ensure they start treatment early in order to control this highly infectious and deadly disease.

2.2 Understanding Treatment-seeking behaviour

Usually when one falls sick, the reaction is to try to get better or to regain the normal health state. People react to different illnesses in different ways. Some would embark on the therapeutic process immediately at the onset of symptoms; others wait for longer periods while others do not seek treatment at all. Pearson (1989) acknowledges this fact that responses to illness are not uniform. From the time one realizes something is wrong to the time he/she decides to make, an initial corrective measure varies from individual to individual or from society to society.

Several studies have been conducted on treatment-seeking behaviour and various factors have been stated as the determinants of this behaviour. These factors include lay people's knowledge and categorization of the illness, illness characteristics and its perceived seriousness, religion, perceived symptoms, and expenses that are likely to be incurred for each treatment choice.

Anderson (1963) grouped these determinants into two:

i. Predisposing factors such as age, sex, marital status, family size, social status, education, and race.

ii. Enabling factors such as family income, health insurance, religion, and perceived sickness.

In testing predisposing factors, Anderson (1963) found that perception of symptoms and ability to pay, play an important role in determining the use of health services. On the other hand, Bice and White (1969) found perceived symptoms to be the principal explanatory factor for utilization of health facility or seeking treatment. These researchers have stressed that for an individual to seek treatment, he or she must be able to interpret the symptoms either as serious or not serious. Therefore, the issue of symptoms is very important in studying treatment-seeking behaviour of an individual or the community. For example, understanding how people interpret tuberculosis symptoms helps providers to understand why people may delay seeking treatment.

The recognition of symptoms as a problem and the patterns of appropriate action to deal with the symptoms are culturally determined. This means that people from different cultures may interpret symptoms differently even when dealing with the same illness. A research carried out by Rubel and Garro (1992) among the Mexican migrant workers in southern California found considerable delays between the onset of symptoms and the decision to consult a health care provider. Many of them misinterpreted their early symptoms – such as cough, fatigue, and loss of weight, headache, or running nose- as evidence of less serious conditions such as grippe or bronchitis. Many TB patients

attributed their fatigue and weight loss to hard work and lack of sleep and initially treated themselves by smoking and drinking less, going to sleep earlier, using patent medicine and leading what they perceived to be a healthy lifestyle. A study measuring the delay of presentation of symptoms in Ethiopia indicated that patients took a mean of 10 weeks from the onset of symptoms to diagnosis (Cambanis *et al.*, 2005). In Manila, Philippines, one fifth of the patients had symptoms for at least three months before they approached a health facility (Auer *et al.*, 2000). These researchers report that many of these patients link TB to drinking and smoking and thus delay their treatment seeking for "harmless" symptoms. Therefore, in the efforts to fight tuberculosis, understanding people's perception as far as the symptoms are concerned is very important. It will help explain how people go about treating TB and whether they delay their treatment, which as seen earlier, facilitates the spread of the disease.

The knowledge of the causes of TB has also a role to play in treatment-seeking behaviour. Cultural beliefs about the causes of TB may influence how people treat their symptoms and from whom they get treatment. In Ethiopia, respondents believed that TB and all other diseases were generally caused by imbalance in behaviours or diet, and were best treated by herbal remedies and "good" foods. Another study found that the Xhosa-speaking people of South Africa often associated TB with lack of hygiene and witchcraft, specifically the lightning bird, *Impundulu,* and sought care first from diviners. Only when traditional treatment failed did they seek western medicine (Kuwahara (ed), 2002). In general, in many societies, when witchcraft and sorcery are implicated as the cause of illness, then it is only treatable by indigenous curing methods. This can explain why TB cases are on the rise; many people associate TB with supernatural causes and so do not seek treatment early or get treatment from appropriate or right providers.

Religion has also been found to influence people's interpretation of the disease and the choices of health providers. Osero (1990) found that faith healing was a prominent feature in health-seeking behaviour of the residents of Siaya, Kenya. According to his findings, the basic philosophical assumption behind faith healing is that diseases or

illness is a manifestation of forces from outside the human body- it is beyond human control. Due to this, people pray or offer sacrifices to receive good health or healing.

In other cases, religion determines which health care facility is to be utilized when one is sick for example, Mwabu (1984) found that Christians had higher probabilities of choosing modern health care facilities over traditional healers than people belonging to the indigenous religious systems. In this study, the researcher explored people's religious affiliations and how these affect their classification of TB and the choices they make concerning the health care providers.

Socio-economic factors also play a major role in the health-seeking behaviour of people. Research has it that people in economically disadvantaged positions living in medically under-served communities are at increased risk of tuberculosis. These people are less likely to seek medical care. They are unable to meet the cost of treatment, transport to health centres and in most cases, are malnourished hence weak immunity system. Studies in South Africa found that blacks who belonged to low socio-economic class had significantly less access to health care and thus stood less chance of being diagnosed than their white counterparts (Andersson, 1990).

Other reasons for failure to seek treatment early relate to the health care system itself, and the ways TB clinics are organized. For example, arranging appointments at inconvenient times, seating people in overcrowded and poorly ventilated waiting rooms, seeing them rigidly in order of registration (and ignoring any extenuating circumstances) and physicians using technical jargon when talking to patients. All these may contribute to people's reluctance to come to a clinic for treatment or follow-up (Helman, 1994). Therefore, interventions are needed to ensure patients seek treatment early. In designing more effective interventions, Rubel and Garro (1992) suggest that one needs to assess people's knowledge and how they use it to interpret causes and symptoms of this chronic, debilitating disease and the time that they seek help. This will help or contribute to the efforts of controlling tuberculosis and adding life to HIV/AIDS patients and protecting the healthy population. The objective of this study was to explore people understanding

of TB; the knowledge they have as pertains to causes, symptoms and mode of spread, and how this affects their health-seeking behaviour and adherence to therapy.

2.3 Understanding TB treatment and compliance to therapy

Treatment of TB depends on whether one has TB disease or only TB infection. A person, who has become infected with TB but does not have TB disease, may be given preventive therapy aiming to kill germs that are not doing and damage now but can break out later. Treatment of TB disease requires many months of faithful adherence to dosages of prescribed drugs (usually up to 8 months) but for many reasons, cases of non-adherence to therapy have been reported. For example, a study in India showed that adult patients withdrew from medication after a few months of treatment; a dropout of 20% per year was recorded (WHO, 1999).

Several reasons have been given to explain the issue of non-adherence. Many social scientists have identified patient health beliefs or health culture as the main cause of non-adherence. Still some see the issue of non-adherence stemming from complex factors both within and beyond the patient's control. These factors include patients' confusion about the implications of symptoms, social stigma, perceptions of services and providers, cost of transportation, the high cost of medication, and service delivery problems (Kuwahara, 2002; Helman, 1994; Rubel and Garro, 1992; Andersson, 1990). A research conducted by Andersson (1990) in South Africa reveals that patients from low socio-economic class are unlikely to continue visiting health centres because they cannot afford paying for the medicine or they are unable to meet the cost of transportation to health facilities. This explains why some patients may withdraw from therapy. Another research among the Zulu of South Africa found that to suggest that sufferers from TB were infectious was tantamount to identifying them as witches or sorcerers, since these were the only people in that community with the power to cause illness to other people. Since successful completion of treatment is associated with good social support from family, the stigma associated with it may be one reason why patients abandon treatment before complete recovery. They fear that if they continue taking medicine people may

realize that they are sick hence be stigmatized or ostracized socially. Other possible causes of non-adherence are; long regimens, lack of knowledge, and the fact that some patients may forget to take their drugs regularly as required considering the illiterate population. Some of these illiterate populations may withdraw from medication when they feel better thinking that they have recovered fully.

There are risks of non-adherence to therapy. Failure to adhere strictly may result in TB destroying the lungs- it can punch holes in the lungs rendering them ineffective. When the lungs are destroyed, the TB may be treated but what remains is a scar tissue, which will not function properly. In this case, chances of survival are minimal because lung transplants are very complicated and expensive. A worrying trend associated with non-adherence to therapy is the emergence of TB germs, which are resistant to the effects of some TB drugs. This has led to the emergence of multi-drug resistant tuberculosis (commonly called MDR-TB), which is a very dangerous form of tuberculosis. Doctors say that a multi-drug resistant strain can either develop inside the individual's body or otherwise an individual infected with "ordinary" TB can prompt this ordinary TB to change, adapt or mutate into MDR-TB by not taking drugs appropriately as prescribed. The danger lies in the fact that multi-drug resistant TB like ordinary one, can spread from one person to another. In other words, a healthy person can be infected with this super strain form of tuberculosis.

The studies that have been conducted in Kenya show that the super strain form of tuberculosis (MDR-TB) is already with us. In their study (Chakaya *et al.*, 2004) to document the presence of multi-drug resistant tuberculosis strains in Nairobi showed that 11.4 percent of those who were tested had multi-drug resistant TB (MDR-TB) while 43.6 percent had an isolate resistant to one or more drugs. Another study carried out by Githui *et al* (2004) confirmed the presence of multi-drug resistant (MDR-TB) Beijing/ W type in Kenya. This shows that some patients might have misused their drugs, which has led to the emergence of this form of tuberculosis. The emergence of a multi-drug form of tuberculosis is a cause for concern. An outbreak may be catastrophic, creating not only

increased morbidity and mortality but also a tremendous strain on already limited health care facilities in developing nations.

Lack of effective policies for the treatment and management of TB and the unavailability of adequate diagnostic facilities (especially in rural areas) as well as lack of knowledge among most people, may increase its spread putting the large population in danger of contracting the disease. Many researchers have come up with several strategies to counter cases of non-adherence to therapy and the emergence of multi-drug resistant tuberculosis (MDR-TB). First, there is a need to come up with new drugs to improve the current treatment by shortening the total duration of treatment and/or by providing more widely spaced intermittent treatment. According to O'Brien and Nunn (2001), shorter regimens and those that require less supervision are highly required. This is because with long regimens, some patients get "tired" on the way and withdraw hence re-infection.

The other approach to deal with the issue of non-adherence to therapy is the involvement of community in primary health care. This is a recommendation of the World Health Organization, which monitors the prevalence of TB worldwide. In sub-Saharan Africa, WHO has already coordinated projects to evaluate community contribution to effect TB treatment at the community level. Community health workers have been found to play an important role in ensuring that patients complete their medicine as required provided that these workers receive adequate support, motivation, and incentives (Hadley, 2002). Community approaches to TB care have shown high rates of success in a variety of settings. One approach used successfully in South Africa and the Philippines for example, is for community members to act as direct observant in a method or an approach commonly called, direct observation treatment (DOT). In their study, Wilkinson *et al* (1996) found that this approach is very effective and is applicable especially when dealing with illiterate population who are likely to misuse their medicine. In Thailand, family members have been used to observe treatment, resulting into adherence to therapy hence high cure rates and lowered spread of the disease. This approach can be applied all over to improve on the control and treatment of the disease

(TB). This study undertook to explore people's behaviour as far as treatment is concerned, reasons why people sometimes do not adhere to therapy as required, and their knowledge as pertains to risks of non-adherence. The research has also given recommendations from respondents' perspective on what should be done to ensure people adhere to therapy as required.

2.4 The Double Burden of HIV infection and Tuberculosis.

As people live with HIV, they become vulnerable to a variety of opportunistic infections and other diseases. HIV causes a gradual decline in the body's ability to fight infections. This results in an increased susceptibility of the infected person to a variety of infections including those that ordinarily would not take hold if the defenses were normal. These infections are called opportunistic infections. One of the most important infections is tuberculosis (TB). In sub-Saharan Africa, this is the most important opportunistic infection observed among the HIV infected people because it occurs frequently, is transmissible to both HIV infected and un-infected persons. It may be the earliest sign of HIV infection.

By 1996, approximately 20.5 million adults were living with HIV infection or diagnosed AIDS. Around 8.7 million had both HIV/AIDS and TB infection: 59% of HIV/TB infection was in Sub-Saharan Africa (WHO, 1996). In Kenya, it is estimated that about 50-60% of all TB patients are HIV infected. On the other side of the coin; TB is a very common disease in HIV infected individuals. One in two or three people infected with HIV will develop TB in their lifetime (Ministry of Health, Kenya, 2005). Therefore, the care of HIV infected persons must include screening for and treatment of TB while all TB patients should be offered counseling and testing for HIV. This is important because even though the treatment of TB in HIV infected persons is highly effective, a lot more needs to be done for that individual who is also HIV infected to secure long term health and survival.

A number of studies have been conducted to ascertain the pandemic of HIV-associated tuberculosis in Kenya. [Currie *et al.*, 2003; Chakaya *et al.*, 2001; Odhiambo *et al.*, 1999; Kibuga *et al.*, 1999). The research carried out by Kibuga *et al* (1999) in 19 districts in Kenya to determine HIV seroprevalence among tuberculosis patients and the burden of HIV attributes among notified patients, found that the HIV epidemic has a profound impact on tuberculosis epidemic in Kenya as in other countries. It explains about 41 percent of the 94.5 percent increase of registered patients in the period between 1990-1994 and 20 percent of all registered patients in 1994. Another research by Odhiambo *et al* (1999) to assess the impact of the increased evidence of tuberculosis (TB) due to HIV infection among school children found that, tuberculosis infection prevalence rates increased strongly in districts where TB notification rates had increased before 1994 but did not increase in districts where notification had increased more recently or not at all. HIV prevalence rates in TB patients were found to be 50 percent in districts with an early increase in notification rates and 28 percent in the other study districts.

These studies among many others provide ample evidence that the emergence of HIV/AIDS has fuelled the increasing cases of tuberculosis (TB). This is because the HIV weakens the body defenses giving way to opportunistic infections to crop in where TB is the leading and frequently noticeable infection. The prevention of tuberculosis among those with HIV infection is a logical public health goal, given that such patients are at high risk of getting tuberculosis, which in turn is associated with increased mortality rates. Infact, addressing TB offers the opportunity for early HIV intervention. In their research, to compare the benefits of tuberculosis treatment with the prevention of TB and HIV for the control of TB in regions with high HIV prevalence, Currie *et al* (2003) found that even where the prevalence of HIV infection is high, finding and curing active TB is the most effective way to minimize the number of TB cases and deaths over the next 10 years. In countries where the spread of HIV has led to a substantial increase in the incidence of TB, TB control programmes should maintain a strong emphasis on the

treatment of active TB. To ensure effective control of TB in the longer term, methods of TB prevention should be carried out in addition to, but not as a substitute for treating active cases (Currie *et al.,* 2003). In supporting the role of preventive therapy, research in Uganda (Whalen *et al.*, 1997) reported that a six-month course of isoniazid among HIV-infected Ugandans with positive tuberculin skin tests reduced the risk of tuberculosis by about 70 percent after a mean follow up period of 15 months. The results of the study in Uganda support the administration of Isoniazid as preventive therapy for persons in sub-Saharan Africa who are infected with HIV and have positive tuberculin test. Therefore, in Sub-Saharan Africa, where there is little access to antiretroviral drugs, preventive therapy of tuberculosis may be the single most affordable intervention for the prolongation of a healthy life in HIV-infected persons. By preventing tuberculosis, these regimens will also help reduce the transmission of tuberculosis especially in developing countries.

Although the interrupting of the transmission of tuberculosis by curative treatment of infection cases should continue to be priority for tuberculosis programmes, efforts need to be made to ensure community understands what TB is in the era of HIV/AIDS, the dangers of delaying health care and risks of non-adherence to therapy. This will contribute to the efforts of fighting tuberculosis and prolonging the lives of HIV/AIDS patients.

2.5 Theoretical Framework

In the social sciences, several theories have been advanced to describe or explain illness behaviour. In this study, not all these theories were examined; only disease theory system was used to guide the study.

2.5.1 A Disease Theory System

A disease theory system was advanced by Foster and Anderson (1978). It embraces beliefs about the nature of health, the causes of illness, and remedies and other curing techniques used by practitioners. Therefore, the disease theory system deals with causality; the explanations given by people to account for loss of health- explanations

such as breach of taboos hence punishment from the gods, and upset in the hot-cold balance within the body, or the failure of a human organism's immunological defenses against pathogenic agents such as germs and viruses; therapeutic process; preventive measures and finally the theory tries to explain a "why" question.

The people's perceptions about the causes of a certain disorder, their experience and knowledge of a given health problem influence their health- seeking behaviour. For example, if an illness is defined as due to the intrusion of an object by a sorcerer, extraction of the object is essential to returning the patient to health. In western medicine, if a laboratory analysis of a throat culture reveals a streptococcus infection, the modern physician prescribes the appropriate antibiotic.

The function of a disease theory system is not limited to providing guide to therapy; there is always the nagging question "why did it happen to me, at this time, in this place?" If a good answer to this question is not forthcoming, the patient fears the return of the illness. So a disease theory system not only diagnoses cause and provide the logic for treatment, but it deals with the much wider problem of what has happened to disturb the patient's social relationships, what harmony inherent in nature may have been disturbed and why, with apparent capriciousness, fate has dealt this individual a blow. This theory therefore focuses on people's beliefs about the nature of health, when one is considered ill, the perceived causes and the approaches used for restoring and protection of health.

2.5.2 Relevance of Disease Theory System to the Study

The central aim of any theory is to explain and predict phenomena. In this study, people's knowledge on the causes, symptoms and mode of spread of TB and how these affect their treatment-seeking behaviour were explored. Therefore, the theory led the study in explaining the perceptions and beliefs of people concerning the causes of tuberculosis, what people consider signs and symptoms of this epidemic and how they go about treating the disease or the symptoms.

People have varying beliefs concerning the causes and symptoms of a given illness and this affects their health-seeking behaviour. Different studies which have been carried out show that people perceive tuberculosis in different ways. For example, in Thailand, research indicates that some people associate their TB symptoms with AIDS hence delaying their seeking treatment for fear of having AIDS. The theory therefore was crucial in guiding the study in understanding, or exploring people's beliefs on the causes of TB and whether they knew the symptoms that are associated with the disease.

Understanding how people interpret TB causes and symptoms helps providers understand why people may delay seeking treatment. Since the theory also deals with therapeutic process, it guided the study to explore the health care providers available in the area and from whom people get treatment – modern doctors or traditional practitioner. This is because if people perceive that tuberculosis is caused by witchcraft, they will seek help from traditional healers or diviners. Finally, the theory was important in investigating the different measures that people take to ensure that the disease is not spread from a patient to a healthy person and what they do to ensure no future cases of tuberculosis; in other words the preventative measures taken by people.

2.6 Assumptions

In this study, a number of assumptions were derived based on reviewed literature regarding the perceptions on TB causes, symptoms and mode of spread; the health-seeking behaviour of tuberculosis patients and adherence to therapy:

1. Some people due to lack of knowledge misinterpret the clinical causes and symptoms of Tuberculosis.
2. People's beliefs affect the choices they make regarding TB therapy.
3. Patients are likely to withdraw from medication before recovery hence endangering their lives and of those around them.

2.7 Definition of terms

Treatment-Seeking Behaviour: Refers to what people do in case of ill health; it includes time or duration they take from the onset of symptoms and visit to health care facility, and also the kind of health care provider they choose.

Delaying Treatment: -The act of postponing initial medical consultations or any other alternative measures over a period of time.

Symptoms: -Refers to any noticeable changes in the body or its functioning to indicate the presence of a disorder or a disease.

Knowledge: - It refers to one's awareness or conception of causes and symptoms as well as risk of delayed treatment and non-adherence to therapy. Those who subscribe to scientific explanations are considered knowledgeable while those who subscribe to other forms of explanations are considered least knowledgeable.

Therapy: -Used to denote treatment or healing process.

Religious Affiliation: - Membership to a particular religion, denomination or sect.

Drug: - Refers to any substance used for treatment or prevention of a disease.

Over-the–counter medicine:- Refers to medicine bought and used without medical prescription.

Literacy: Refers to ability to read and write at the very basic level

Occupation: - what people basically do for their livelihood.

Alternative health care system: - Any other medical providers outside the modern health care facilities.

CHAPTER THREE:

STUDY SITE AND METHODOLOGY

In this chapter, there is a description of research site, sampling procedure, and methods of data collection and analysis.

3.1 Research site

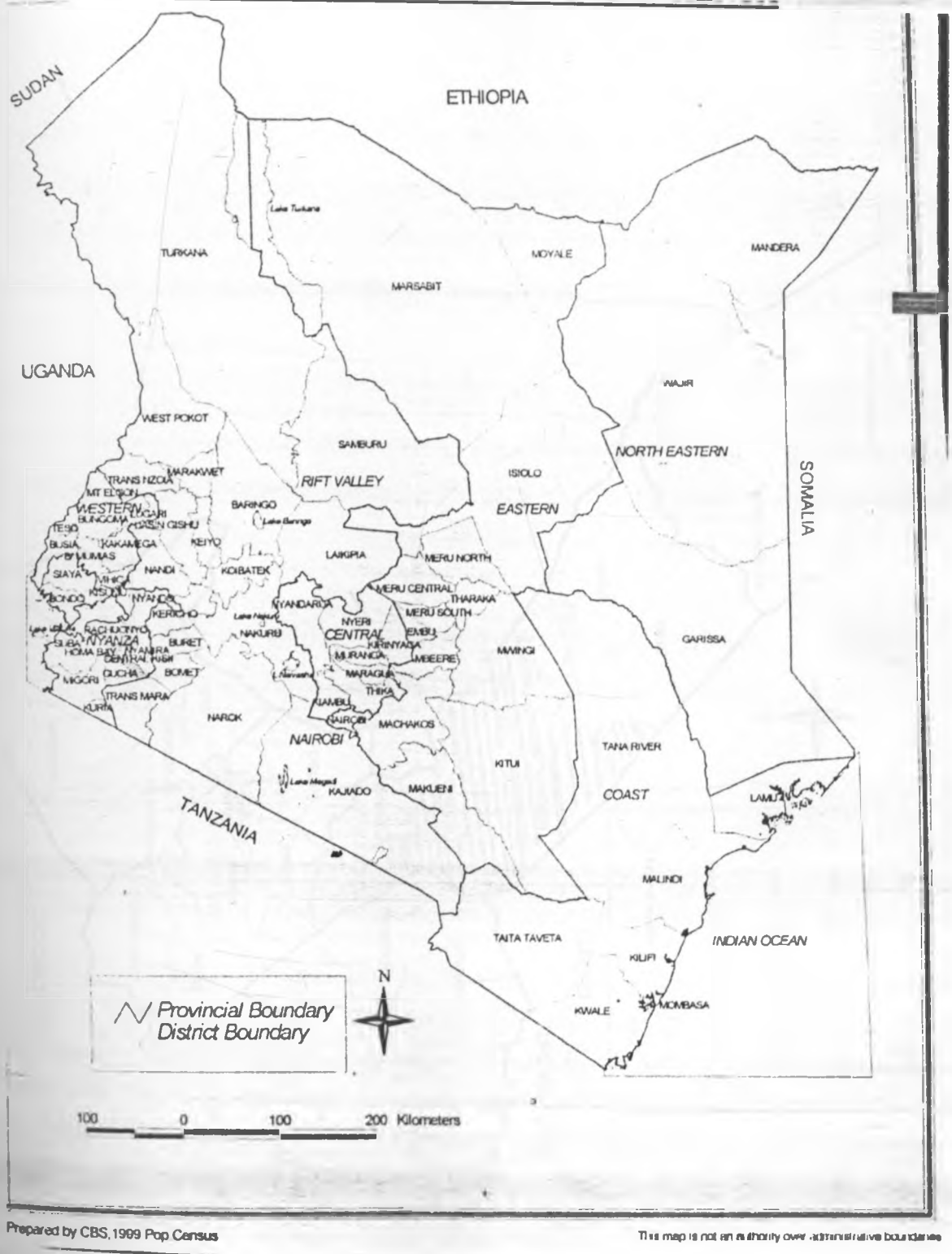
3.1.1 Location and size

The research was conducted in Kiogoro Division in Kisii Central district. Kisii Central district is one of the twelve districts in Nyanza province. It borders Nyamira district to the East, Gucha district to the Southwest, Migori district to the west, Rachuonyo district to the North and Trans Mara district to the South. The district lies between latitudes $0^{0}30'$ and $0^{0}58'$ South and longitudes $34^{0}42'$ and $35^{0}05'$ East. It occupies an area about 648.9 square kilometers (District Development Plan, Kisii, 2002).

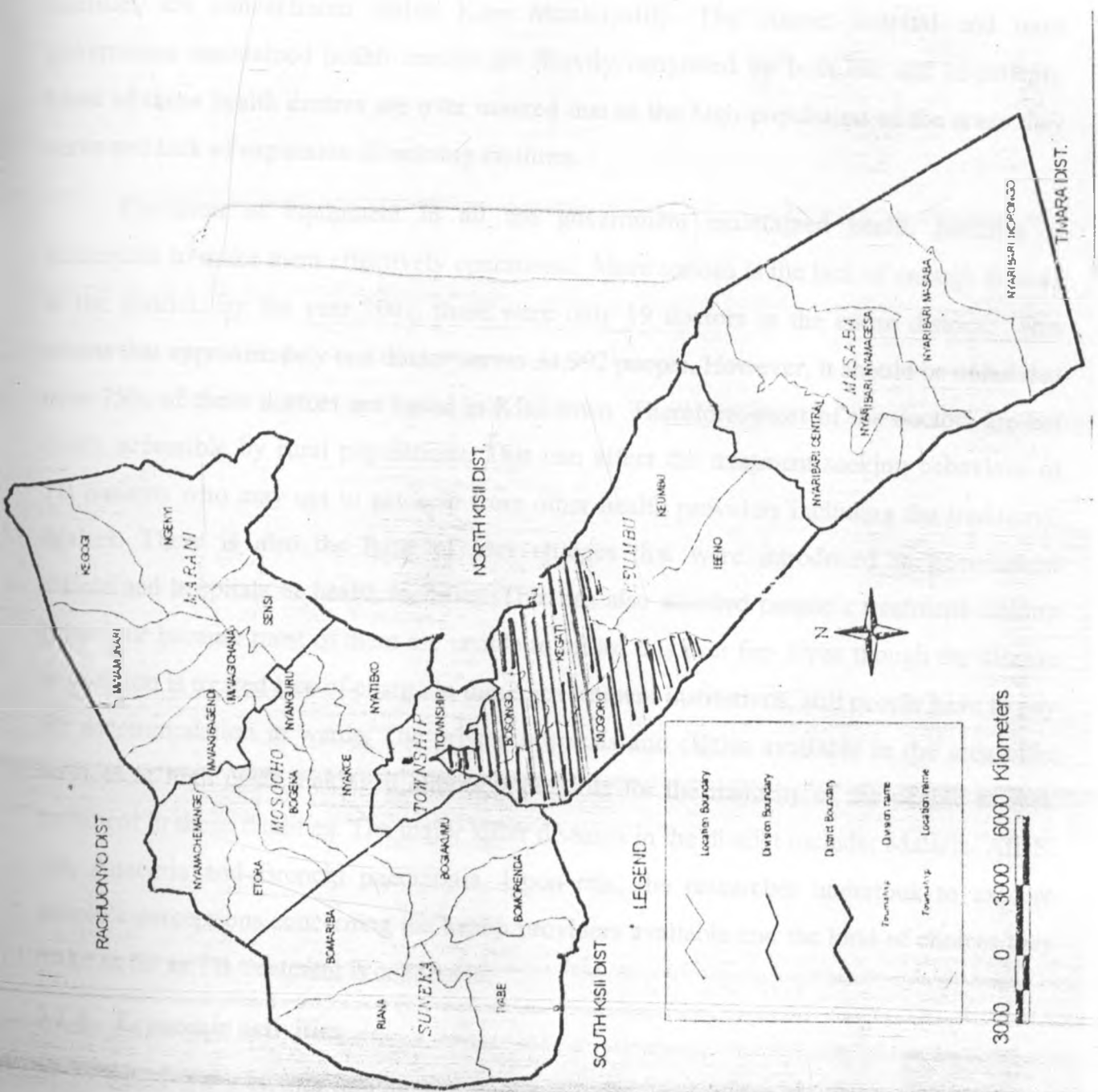
3.1.2. Population size and composition

Kiogoro Division is divided into three (3) Locations and ten (10) Sub-Locations. By the year 2001, the population in this division was estimated to be about 126,930 (District Statistics Office, Kisii, 2001). The division is largely occupied by Gusii-speaking people and it has the highest population density in the district. It was projected to be about 1,126 persons per square kilometre by the year 2004 (Central Bureau of Statistics, 1999).

LOCATION OF CENTRAL KISII IN KENYA



LOCATION OF KIOGORO DIVISION IN KISII CENTRAL



3.1.3. Health Facilities

Kiogoro Division has three GOK health centres and three private clinics. Most health facilities are concentrated within Kisii Municipality. The district hospital and most government maintained health centres are heavily congested by both out and in-patients. Most of these health centres are over utilized due to the high population of the areas they serve and lack of expansion of existing facilities.

Provision of equipment in all the government maintained health facilities is inadequate to make them effectively operational. More serious is the lack of enough doctors in the district. By the year 2001, there were only 19 doctors in the entire district. This means that approximately one doctor serves 34,992 people. However, it should be noted that over 75% of these doctors are based in Kisii town. Therefore, most of the doctors are not easily accessible by rural populations. This can affect the treatment-seeking behaviour of TB patients who may opt to get help from other health providers including the traditional healers. There is also the issue of user charges that were introduced in government maintained hospitals or health facilities. This has also affected people's treatment-seeking behaviour because most of them are unable to afford this user fee- Even though the disease in question is treated free of charge in these government institutions, still people have to pay for accommodation in wards. The private hospitals and clinics available in the area offer services at high costs making it almost impossible for the majority of the people to seek treatment in these facilities. The major killer diseases in the district include; Malaria, AIDS, TB. Anaemia and Bronchi pneumonia. Upon this, the researcher undertook to explore people's perceptions concerning the health providers available and the kind of choices they make as far as TB treatment is concerned.

3.1.4 Economic activities

Economic activities of a given community affect their health in one way or the other. They determine the kind of food people eat, their health-seeking behaviour, type of their dwelling units, education, in general they affect all aspects of their lives. Farming is the main economic activity in the district and specifically in Kiogoro division. The high and

well-distributed rainfall and good soils support farming of both cash and food crops. The main crops include coffee, pyrethrum, Bananas, maize, beans, sweet potatoes, finger millet, and sugarcane. Few farmers in this area practice both subsistence and cash crop production. The majority practice only subsistence farming. Farm holdings in the division are relatively small, ranging from 0.5 to 4.5 acres of land. This is due to the population pressure on land resulting in sub-divisions and fragmentation of the holdings. Livestock farming on the other hand is undertaken on small-scale basis. The livestock reared include cattle, sheep, goats, and poultry. Most of these are indigenous. This means that the production is low and the gains cannot fully support farmers in their daily needs.

3.1.5 Housing conditions

There is a strong relationship between housing conditions and exposure to diseases. Information on housing characteristics, such as access to electricity, source of drinking water, sanitary facilities, and flooring and roofing materials is key to explaining the interrelationship between the social and economic conditions of the household and likely exposure to and prevalence of diseases. The predominant flooring materials used by Kiogoro households are earth, mud, dung, and sand. More than 77 percent of the rural households use earth for flooring their houses (CBS, 2002). Data from the 1999 population census show that most populations in this division live in grass- thatched houses. There is also a rough measure of degree of household crowding. Most households (77 percent) have more than two persons sleeping together in a small single room. For cooking fuel, two-thirds of people in this area depend on firewood (CBS, 2002). TB spreads easily in overpopulated and poorly ventilated houses.

3.2 Study Design

The study was designed to elicit both qualitative and quantitative data. On this note, three methods were used in data collection: survey method, focus group discussions and interviews with key informants. In the survey method, structured questionnaires that contained both closed-ended and open-ended items were administered to all sampled household heads (100). The questionnaire was used to collect basic information about the

study issue. This included TB perceptions, treatment- seeking behaviour, knowledge of HIV/AIDS and TB co-infection, how patient are handled and adherence to therapy.

Three Focus group discussions and interviews with twenty (20) key informants were used in collecting qualitative data, which helped the researcher better understand the results by facilitating a fuller interpretation of the data. Interview guides were used during the interviews and focus group discussions.

3.3 Sampling

3.3.1 The universe

In this study, the sampling universe consisted of all households in Kiogoro Division. According to Central Bureau of Statistics (1999), there are 22,469 households in this culturally homogeneous division.

3.3.2 Unit of analysis

The unit of analysis was the household. This enabled the researcher to get the general view on TB without interviewing everybody. The definition of the household is based on that advanced by the United Nations (1973), which states that, the household is based on the arrangements made by persons, individuals or groups, for providing themselves with food and other essentials for living. It may be either,

a) one- person household- who makes provisions for living without assistance, or

b) multi-personal- who may be related or unrelated or a combination of both.

3.3.3 Sample selection

A small sample of 100 households was used and its choice was governed by some of the suggestions laid down by Bernard (1995), Gupta (1985) and Ghosh (1982). Bernard (1995) suggests that in a study of households, one should take a few households from each community (cluster), rather than study many households in a few randomly selected communities. According to Gupta (1985) and Ghosh (1982), large samples are needed when certain cadres of the respondents are likely to be uncooperative posting back the

questionnaires unfilled. The researcher administered the questionnaires personally. Also, a small sample was convenient due to limited resources (time and money). These scholars further state that if the population is homogeneous, a small sample may serve the purpose. In this particular case, the universe is composed of the Gusii people who share common social, administrative, and cultural background in a rural setting.

All the ten sub-locations in Kiogoro division were selected then; ten households were selected from each sub-location. In total, there were 100 households. Initially, it had been proposed that a list of all households was to be obtained from the Central Bureau of Statistics. This was not possible: It was found that population records for the community do not show individual households. Again, owing to the frequent shifting of boundaries and creation of new administration units, the official records are not up-dated immediately. It should also be noted that the last national census in Kenya was conducted in 1999 and therefore six years down the line so many changes might have taken place in terms of household composition. Because of this, the study adopted the WHO (1978) recommended cluster-sampling technique. This is the recommended method for rural areas where household lists are not available and it is not feasible to number each household in the village:

i) First, I precisely defined the limits of the sub-location.

ii) I selected a central location in the sub-location such as a market, school, or church.
iii) I randomly selected the direction in which the first household was to be located.

Single digits were allocated to each direction (e.g. 1 = N, 2 = S, 3 = W, 4 = E). The directions were selected randomly. This was done in each sub-location. Once the direction was selected, all the households existing along the directional line from the central location were listed. The second random numbers between one and the total number of households along the directional lines selected were drawn from each sub-location. The numbers, which were selected, identified the houses to be visited.

3.4 Methods of Data Collection.

3.4.1 The survey method

A standardized questionnaire was administered to the heads of all selected households (100). It contained both open-ended and closed items. The researcher administered the questionnaires personally. This instrument was used to gather information on various issues including: People's perceptions on the causes, symptoms and transmission of TB; how these perceptions affect their treatment-seeking behaviour; patients adherence to therapy; their attitude towards long regimens and what they think should be done to improve on the fight against TB.

3.4.2 In-depth Interviews

In-depth interviews with twenty (20) key informants were conducted. These consisted of medical personnel, local health providers, and elderly people who are considered wise in the community. All these were purposively selected. The community members were asked to identify the local providers and the wise people (those who are conversant with the beliefs and customs of the community). The interviews enriched data collected through the survey. The medical personnel and the local providers were also required to give information on their encounters with TB patients and what they think should be done to ensure patients take action immediately they get TB germs. These among other issues helped the research to achieve its objectives.

3.4.3 Focus Group Discussions

Three focus group discussions were conducted. Attention was paid to homogeneity of the participants to ensure free and open discussions. People who had suffered or still suffered from TB constituted their own group. On the other hand, elderly people were put together and finally, younger people constituted a third group. Subjects in these groups were purposively selected. These groups helped the researcher better understand the results by facilitating a fuller interpretation of the data.

3.5 Data processing and Analysis

After the field, the questionnaires were screened for responses and all answers to each question were listed down and manageable categories were established. Codes were given according to each category for easy computation. Both qualitative and quantitative approaches were used in data analysis. Data collected using the questionnaires were analyzed using the Statistical Package for Social Sciences (SPSS) computer program, counter-checked manually and presented in the form of frequency tables and percentages. On the other hand, descriptive method was used to analyze qualitative data collected through FGDs and in-depth interviews with key informants. Translated quotations, and selected comments from informants were also used.

3.6 Problems encountered in the field

Although the process of data collection was successfully conducted, certain problems were apparent. Scarcity of the means of transport was remarkable. The households that were visited in most cases fell far from the major roads. At times reaching the respondents entailed walking over long distances. This somehow slowed down the progress and only few households could be reached each day. Another problem was non-response, that is, the respondents could not be found or were too busy for the interviews. The solution here was to make callbacks or substitutions. All these meant spending more time and resources

Because of the link that exists between tuberculosis and HIV/AIDS, most people were reluctant to reveal their TB status because of stigma. Nevertheless, this was taken care of by assuring them that having TB does not mean one has HIV/AIDS and that even if that were the case, their responses would be confidential and they would remain anonymous.

It was also difficult to convince some people to be interviewed on TB. Most of the sampled informants wanted the researcher to address their problems, which included: malaria, asthma, STIs, and other many illnesses. According to these informants, TB was someone's problem and not theirs since they were not infected. Despite all these problems, the study achieved its goals.

3.7 Ethical Issues

Ethical principles, rules, and conventions distinguish socially acceptable behaviour from that which is considered socially un-acceptable (Burns, 1990). In this research, subjects were informed about the nature and purpose of the research, how they were selected and why it was important for them to cooperate so as to maintain representativeness. It was made clear to them that their participation was out of consent and would not be coerced to give information. They were assured that their responses to personal questions would be confidential and anonymous in that the reader of the research findings would be unable to deduce the identity of the individual. Participants in this research had also rights to discontinue or withdraw from the research at will. Finally, the informants were asked for permission for notes to be taken.

CHAPTER FOUR

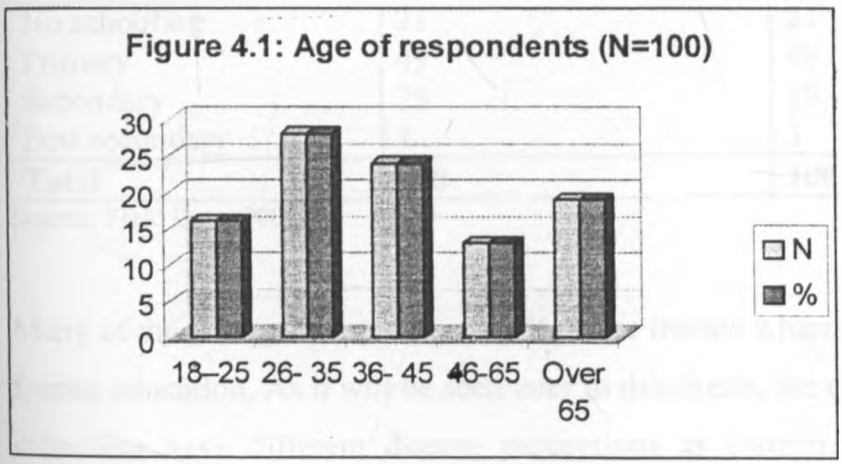
COMMUNITY UNDERSTANDING OF TB

This chapter is divided into two parts: The first part presents the socio-demographic information detailing the characteristics of the respondents and the second part deals with people's perceptions on TB. It presents findings on lay people's recognition of TB and what their beliefs are regarding the cause and the transmission.

4.1 Socio-demographic information

4.1.1 Age, gender, education, religion and economic activities

The respondents were household heads who were all over 18 years. The majority of these respondents were over 36 years (56%) whereas 44% of them were between 18-36 years (Figure 4.1).



In Kiogoro division and the Gusii community at large, the households are mostly headed by men (husbands) but in cases where men are not present, women take charge.
In this study, the majority (58%) of the respondents (household heads) were men and women were 42%. This reveals that many households in the division are headed by men. Women who are household heads are either widows or their husbands work and stay away from home for long periods.

Among the people of Kiogoro division the role played by the head of the household in health care decision is crucial: He or she is usually consulted when decision involving

monetary transaction are made. Logically, this is because he/she is the one that meets medical expenses. Therefore, with regard to health-seeking behaviour and therapy choices, the household head has a key role.

In studying people's perceptions of illness and their treatment–seeking behaviour, their educational background is very important. Sometimes, people with different levels of education hold different beliefs and perceptions with regard to illnesses and therapy choices. Table 4.1 indicates that 79% of the respondents at least had primary education and only 21% reported to be illiterate. The 21 % had no any kind of formal education meaning that they did not know how to read or write. Out of the 21 who had not been to school, 16 were over 65 years whereas the remaining five were between 36 and 65years.

Table 4.1 Education attained (N = 100)

Education	**N**	**%**
No schooling	21	21
Primary	49	49
Secondary	29	29
Post secondary	1	1
Total	**100**	**100**

Source: Field Data, 2006

Many of the younger people (over 80%) were literate whereas most of the old people had no formal education. As it will be seen later in this thesis, the older people who have no formal schooling have different disease perceptions as compared to younger people who are literate.

Religion is a factor in health-care seeking behaviour. In his research among different denominations is New York, Mechanic (1966) found variations among different denominations regarding therapy choices. This means that people from different denominations are likely to make different therapy choices. Most of the respondents in the division were Catholics (72%) the rest (28%) were protestants. This reveals that all participants were Christians. No Muslim, traditionalist or non- believer was sampled. In Kisii Central district, mosques are situated in town meaning that they are very far from

people. This can partly explain why no Muslim was sampled. On the other hand, no traditional religion that exists in the area. It was reported that a traditional religion, *emyamumbo,* used to exist but with the advent of Christianity, most people got converted. As mentioned earlier, religion affects people's actions and choices regarding therapy (this will be illustrated later in this thesis).

The majority of the respondents (38%) practice small-scale farming mainly for family consumption with only small portion for sale. 26% reported to own small businesses like the sale of onions, vegetables while others were hawkers. 11% of the respondents had salaried jobs, for example, teaching, and working in supermarkets, 4% practiced large-scale farming (coffee & Tea) and only 2% engaged in large-scale business. 6% had no any economic activity. Some of these depended on their close relatives for their daily needs including health care. Most of the respondents who fell in this category were over 65years. It is clear that most people in Kiogoro division had very low income (Table 4.2).

Table 4.2 Occupation (N = 100)

Occupation	**N**	**%**
Farming (small scale)	38	38
Business (small)	26	26
Casual work	13	13
Salaried employment	11	11
Farming (large scale)	4	4
Business (large)	2	2
None	6	6
Total	**100**	**100**

Source: Field Data, 2006

4.2 People's perceptions on TB

4.2.1 TB symptoms

The recognition of symptoms is often the start of action to counter an illness. Lay people learn to recognize illnesses on the basis of observable symptoms. The interpretation of symptoms varies from one person to another or from community to another even if dealing with same illness. The study sought to assess people's knowledge on the symptoms of TB and the findings show that most people (96%) recognize coughing as one of the symptoms of TB. These respondents reported that it is persistent coughing that makes them suspects that one might be having something more than normal common cold and more likely TB. The local term for TB is *Esese,* which literally means persistent coughing.

Wheezing/breathing problems were reported by 58%. This group reported that when one has TB, coughing is accompanied with wheezing. According to them, this is a sign that one is not suffering from normal common cold, but a serious disease – TB. 51% of the respondents mentioned loss of weight as a symptom of TB. They explained that when one has TB, he/she coughs a lot and the person does not eat well which usually lead to loss of weight. 28% mentioned general body weakness as a result of persistent coughing and poor appetite. When a person is weak, he/she is likely to retire from daily activities. Chest pains were also reported by 26% of the respondents and this was attributed to severe coughing. The claim was that due to persistent coughing the chest may be injured which subsequently would lead to " dead chest", *egekuba egeku.*

Other symptoms mentioned include: Fever (14%), sweating especially at night (7%), Breathing problem due to congested chest, vomiting, diarrhoea, pneumonia that fails to resolve and Headache among other many symptoms (see Table 4.3). The study reveals that the community classifies these TB symptoms as serious, less serious, or insignificant.

Table 4.3: Reported TB symptoms (N= 100, multiple responses)

Symptom	Frequency (f)	%
Coughing/sneezing	96	96
Wheezing/breathing problems	58	58
Loss of weight	51	51
General body weakness	28	28
Chest pains	26	26
Change of hair	18	18
Blood in sputum	15	15
Breathing problems	14	14
Fever	14	14
Vomiting	11	11
Chillness	10	10
Loss of appetite	7	7
Too much spitting	7	7
Abdominal pains	5	5
Thick sputum	5	5
Headache	3	3
Pneumonia	3	3
Diarrhoea	3	3
Rough skin	3	3
Skin darkens	2	2
Mouth turns reddish	2	2
Others (Pain in joints, Swollen legs, Lack of sleep and Poor eye sight)	4	4
No idea	1	1

Source: Field Data, 2006

Further, the respondents were asked to list the symptoms which they consider serious and which prompt them to seek treatment as soon as they appear. 37% mentioned persistent coughing and wheezing as serious symptoms. Their claim was that, these two create a lot of disturbance and discomfort and they lead to loss of water and difficulty in breathing which, makes one so weak to the extent of being unable to perform the daily duties. Blood in sputum was reported by 29%. These people had a belief that if blood appear in sputum that means serious chest injury. However, some had a view that blood in sputum reveals the

destruction of lungs. Vomiting (mentioned by 8%) and diarrhoea (5%) lead to loss of body fluids and if a patient is not treated quickly, may die. Other serious symptoms according to the informants include loss of appetite (5%), loss of weight (5%), chest pains (2%), too much sweating (2%), high fever (2%) and pneumonia (2%) (see Table 4.4).

Table 4.4: Serious TB symptoms (N = 100, multiple response)

Symptom	F	%
Persistent coughing and wheezing	37	37
Blood in sputum	29	29
General body weakness	12	12
Vomiting	8	8
Difficulty in breathing	6	6
Loss of appetite	5	5
Loss of weight	5	5
Diarrhoea	5	5
Chest pains	2	2
Sweating	2	2
Smelling sputum	2	2
High fever	2	2
Pneumonia	2	2

Source: Field Data, 2006

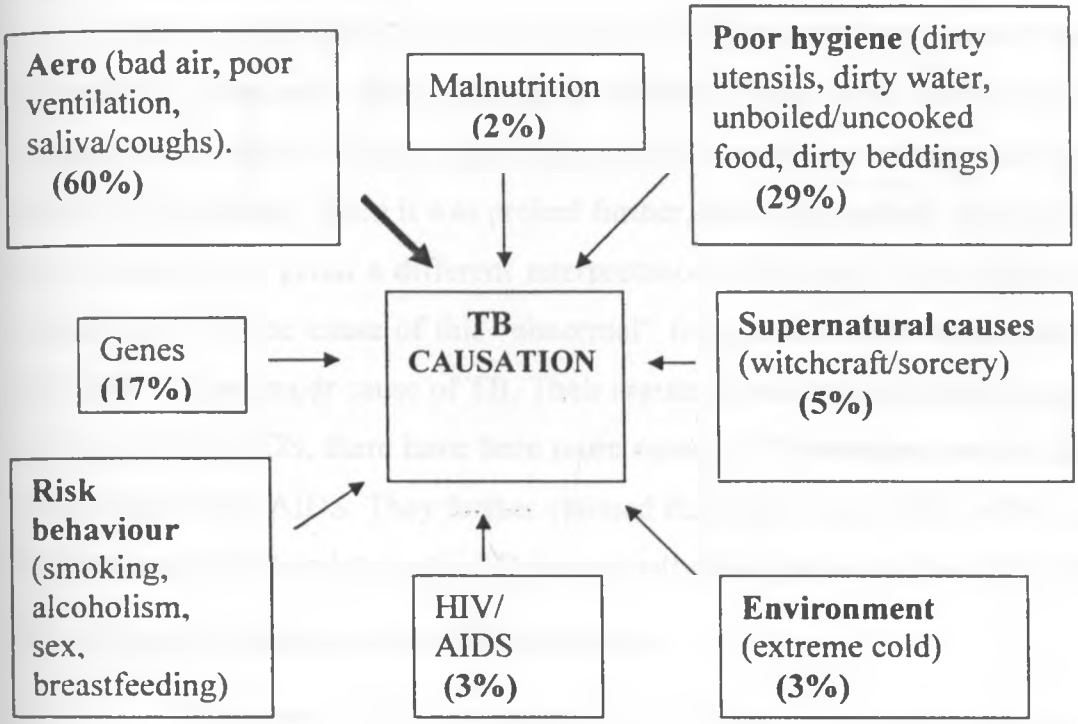
In general, understanding people's interpretation of symptoms is very important in studying the health-seeking behaviour of a given people. Clinically, TB is diagnosed when some of the symptoms given by informants are present. The symptoms mentioned by informants indicate that most lay people (95%) know TB symptoms. Only when people have determined that the symptoms indicate TB do they start treatment. Thus, their treatment-seeking behaviour would be based on their ability to correctly diagnose TB.

4.2.2 Perceptions of people on the causes of TB

This study reveals that people of Kiogoro division have different views and perceptions regarding the cause of TB. Some people place the etiology of TB within the individual; thus, it is caused by individual's own risk behaviour; others believe that the disease is caused by environmental agents such as air, extreme cold; other respondents hold

that poor hygiene greatly contribute to the disease; some associate the disease with supernatural forces, finally some informants think that the disease is hereditary. Figure 4.2 presents the summary of what people hold as the possible causes of TB.

Figure 4.2: Conceptual links of TB causation (multiple responses)



Source: Field Data, 2006

Figure 4.2 shows that people hold different beliefs regarding the cause of TB. The majority of the respondents (60%) mentioned "bad air" to be the cause of the disease. "Bad air" in this case means contaminated air with TB germs. These informants reported that the germs that cause TB are carried by air when an infected person coughs or sneezes and that this usually happens in poorly ventilated rooms. 43% of the respondents attributed the disease to risk behaviour. Cigarette smoking, alcohol consumption, sex and breastfeeding were few of the risk behaviour that the informants mentioned. These people reported that a person who smokes cigarette or *Ekebuesi* (pipe) is more likely to succumb to TB than a person who does not smoke. Likewise, heavy alcohol consumption especially local brew, *Ebusa* or *Echang'a* worsens the disease and that the person who drinks this stuff is unlikely to recover

from TB. Poor hygiene was also mentioned (29%) as one of the causes of TB. The respondents reported that people who do not observe cleanliness – their bodies and clothing, those who consume poorly cooked food/rotten food or drink dirty water are likely to get the germ that causes TB.

Some respondents (17%) reported that TB is a hereditary disease that can only be transmitted genetically from parents to children. Five (5%) attributed the disease to witchcraft or sorcery. These people claimed that sorcery or witchcraft could lead to any disease TB included. When it was probed further, these respondents reported that TB, which fails to resolve, is given a different interpretation and mostly the witches or sorcerers are implicated to be the cause of this "abnormal" form of TB. Two respondents believed that HIV/AIDS is the major cause of TB. Their argument was based on the ground that since the advent of HIV/AIDS, there have been more cases of TB meaning that the disease might be as a result of HIV/AIDS. They further claimed that most people who suffer from HIV/AIDS are likely to get TB and that; it is TB that actually kills people and not HIV/AIDS.

One of the key informants had this explanation:

> TB has been with us for long but it was different from what we see now. It used to be treated but today's TB is dangerous and it kills. I'm told that if you happen to have TB, the doctors test whether you have HIV/AIDS as well, that means this HIV/AIDS must be the cause of the severe TB...(female aged 78years)

Other perceived causes that were mentioned by informants include: bitter foods; poor ventilation in living rooms; sleeping in poultry houses and specifically in the presence of ducks; mothers passing the germs to suckling babies; carrying heavy load which damages the chest hence *Egekuba Egeku* (dead chest), extreme cold, malnutrition and many others. In brief, the findings show that the majority of the informants (over 60%)seem to be conversant with the clinical causes of TB. These are the respondents who mentioned "bad air", coughs/saliva and poor ventilation as the possible causes of the disease. These people actually knew that the bacteria that cause TB are carried by air when a person with the bacteria coughs, sneezes or spits. However, the research revealed some **misconceptions**. Some informants believed that TB is hereditary. Others thought the disease is caused by

witchcraft/sorcery whereas others (16%) had no idea as regards to TB aetiology. As it will be seen later, the beliefs people hold regarding the cause of TB affect their treatment–seeking behaviour and the kind of therapy choices they make. These beliefs also affect people's compliance to therapy.

4. 2. 3 TB transmission

In order to test people's knowledge regarding TB transmission, they were asked to state how it is transmitted. The majority (93%) of the respondents were aware that TB could be transmitted from an infected person to a healthy one. 4% reported that the disease does not spread and that a person can either get it genetically from parents or through the acts of witches or sorcerers. For example, one of the key informants reported this.

> TB, *Esese,* is a hereditary disease. If your ancestors had it, then you are likely to get it. You can share with others, cough or sneeze but still the disease cannot spread to others around you. It can only be passed on from parents to children genetically…(female, 72 years, no formal schooling)

The others who associated TB with witchcraft or sorcery claimed that the disease is meant for specific people only (the bewitched) and there is no way it can spread to others.

> The "saliva of a person is taken" *(Okourua amate*) by a sorcerer or a witch, thus causing TB to that specific person whose saliva has been taken. How can someone else whose saliva has not been taken get TB?... Reported by one of the informants. (Male, 76 years, no formal schooling).

Unfortunately, 3% of the respondents had no idea whether the disease can be transmitted. The same respondents had reported early that they did not know the cause of TB. These people had never suffered from TB or seen any TB patient. The 93 informants, who had knowledge that TB is transmissible, were asked to mention some of the ways through which the diseases could be transmitted. 54 (58.1%) of them believed that the disease is transmitted if one shares utensils with an infected person. The respondents mentioned spoons and cups as the most responsible for the spread since when one uses them; they come into contact with the mouth. That means if these utensils are shared, there is a possibility for the germ that causes TB, to be transferred from the mouth of an infected person to the mouth of a healthy person hence TB transmission. Therefore, to make the

utensils free from the germ, the respondents had an opinion that they should be thoroughly cleaned using hot water.

Coughing and sneezing were mentioned by 47.3%. These people reported that if an infected person coughs or sneezes the germs are spread into the air and if another person is present, he/she is likely to inhale the germs that cause TB. 29.0 % reported that sharing food or cigarettes could also facilitate the spread of TB. For example, a person smokes a cigarette and hands it to another to take a puff or takes a bite of a fruit or any other food and gives it to the other person. In this case if one person is infected with TB, he/she might pass the germs to the other person.

Sharing clothes and beddings was mentioned by 24.7 % of the respondents who believed that the patient is likely to leave his/her saliva or cough on the clothes or beddings and if another person uses the same, the germs may be contracted. 18.3% thought that TB was hereditary. Although these people had early reported that TB could be transmitted from a patient to a healthy person, they later explained that this could only be so genetically from parents who are infected to children. That means they shared the same view with those who earlier reported that TB does not spread through coughs or other means but genetically from parents to their children. That if the disease has been in the family, the chances of newborn babies having it are high.

Flies were also implicated as the carriers of TB germs. If a fly feeds on the coughs or saliva that has been dropped by an infected person, and the same fly lands on food, whoever eats the food is likely to be infected. One person believed that a mother could easily transmit the disease to her baby through breast–feeding. The respondent believed that the germs could be present in the mother's milk. Only 3% had no ideal on how the disease is transmitted even though they reported that the disease could be transmitted.

Table 4.5 How TB is transmitted (N = 93, multiple responses)

Mode of transmission	F	%
Sharing utensils	54	58.1
Coughing and wheezing	44	47.3
Sharing cigarettes and food	27	29.0
Sharing clothes and beddings	23	24.7
Hereditary	17	18.3
Kissing	14	15.1
Breathing to healthy people	12	12.9
Overcrowding in poorly ventilated rooms	5	5.4
Flies carrying the germs	2	2.2
Breast feeding	1	1.1
Dust	1	1.1
Don't know	3	3.2

Source: Field Data, 2006

From Table 4.5, it can be concluded that the majority of people (more than 80%) are knowledgeable as far as TB transmission is concerned. Only a few (18.3%) hold **misconceptions.** This is the group, which reported that the disease is only transmitted genetically from parents who have it to their offspring.

4.2.4 TB Prevention.

The researcher also undertook to assess the knowledge of people pertaining ways through which the spread of TB could be curtailed. It was revealed that a good number of them knew the ways to protect themselves and others from the disease. However, a few of the respondents thought that nothing could be done to curtail the spread (see Table 4.6). Out of the 93 informants who believed that TB could be transmitted, 62 (or 66.7 %) reported that the transmission could be stopped through isolating patients. This involves separating them in their own rooms, giving them their own utensils and beddings. By doing this, the respondents believed that the disease would not have a chance to spread to others. 14 (15.1%) mentioned early treatment as a way of ensuring that the disease is not transmitted. According to them, early and proper medication makes the patients to be non-infectious hence; they could mingle with others without transmitting the disease. These respondents

also added that early treatment means quicker recovery. 14% believed that cleanliness is crucial to prevent TB transmission. These respondents reported that observing hygiene, which, include clean/sterilized utensils, clean environment means, "clean" air- TB is contracted in dirty environment according to the informants.

Living in properly ventilated rooms was also reported to help in the fight against TB transmission. When people are overcrowded in poorly ventilated rooms, they are likely to get the disease especially if a patient is present in the same room. 8.6% believed that if those infected are advised to cough responsibly, then the disease could be curtailed. " Bad" foods, which include bitter and rotten ones, alcohol and cigarette were reported to fuel the disease's spread and that for people to protect themselves from this disease, they should avoid these " bad" foods. Compliance to TB therapy was mentioned by 6.5% who believed that if patients adhere to TB treatment as required they protect others from getting the disease. When people abuse drugs, they become infectious and can transmit the disease to others around them. 6.5% of the respondents reported to have no idea on how to stop the spread of TB and the other 6.5% believed that nothing could be done to stop the transmission. Some reported that since the disease is airborne, human beings have no ways of stopping air and therefore according to them, stopping an airborne disease from spreading is an impossible task. Commenting on this, an elderly informant reported that,

> TB is an airborne disease which we do not know or understand where it comes from neither do we know how to stop its transmission. This is the work of God; He is the only one who can help us...(female aged 67 years)

Table 4.6 How to stop TB transmission (N = 93, multiple responses)

How to stop the transmission	F	%
Isolation	62	66.7
Early medication	14	15.1
Cleanliness/hygiene	13	14.0
Encouraging people to cough responsibly	8	8.6
Ventilation	7	7.5
Avoiding "bad" food	6	6.5
Adherence to therapy	6	6.5
Avoiding mouth kissing	5	5.4
Boiling milk	2	2.2
Avoiding dusty areas	2	2.2
BCG vaccine	2	2.2
Putting on warm clothes	1	1.1
Infected mothers to avoid breast feeding	1	1.1
Nothing could be done	6	6.5
Don't know	6	6.5

Source: Field Data, 2006

4.2.5 Source of knowledge

Those respondents who seemed to have knowledge on the symptoms, causes and transmission of TB were asked how they acquired the information (the first source of information). Most of them reported to have acquired it from public media – radio, Television, whereas others got it from books. The rest learnt TB symptoms either by seeing TB patients or themselves suffering from the disease – past experience.

Table 4.7 Source of knowledge (N= 99)

Source	N	%
Public media	38	38.4
Books	26	26.3
Encounters with TB patents	16	16.1
Past experience	7	7.1
Others	12	12.1
Total	**99**	**100**

Source: Field Data, 2006

Table 4.7 shows that public media and books are the main source of information regarding TB symptoms. Therefore, they should be among the channels in educating people on matters pertaining TB: causes, symptoms, and transmission

The findings in this Chapter indicate that a good number of people are knowledgeable about TB. Most of them are aware of clinical symptoms, causes and transmission of the disease. As it was revealed, the majority knows that TB is an airborne disease that can be transmitted easily in poorly ventilated and overcrowded areas. Persistent coughing which is in deed the most common symptom of TB was mentioned by most of the informants. However, few respondents misinterpret the symptoms, causes and the transmission of TB, which leads to improper action and therapy choices endangering not only the infected people, but also those near them and the community at large. Therefore, it is essential that the TB campaigns be conducted for awareness and for effective TB management. If people are properly equipped with knowledge of TB, then it will be easy to realize the dream of a TB – free society.

CHAPTER FIVE

TREATMENT - SEEKING BEHAVIOUR

This Chapter presents findings on treatment-seeking behaviour: perceived severity of the disease, factors that influence therapy choices and course of action.

5.1 Perceived severity of TB

The informants were asked to rate the disease in terms of severity. The majority (95%) reported that TB is a very severe disease that kills if not well treated. 3% reported that even if TB kills, it takes long time for a patient to die if not treated, in other words it does not kill quickly. The remaining 2% had no idea whether TB is a dangerous disease or not. Most respondents seemed to know the risks associated with non-treatment or delayed action- destruction of lungs and eventually death.

On TB treatment, many informants (98%) believe TB is curable and only a few (2%) think otherwise. However, these respondents differ when it comes to a question on the course of action and therapy choice (will be discussed later). Two informants both females aged over 65 years believed that the available therapies are only meant to relieve pain and not to cure the disease. These respondents hold that when one has been infected with TB, there are no chances of survival.

5.2 Therapy choice and factors that influence these choices

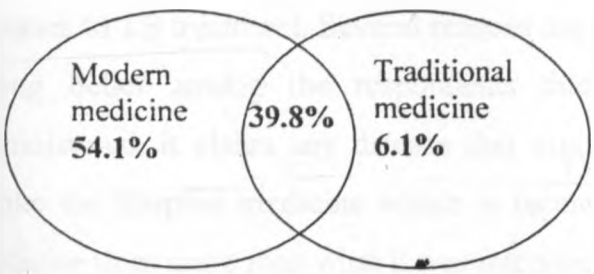
Kleinmann (1980) has suggested that in looking at any complex society, one can identify three overlapping, and interconnected sectors of health care: the popular sector, the folk sector and the professional sector. Each sector has its own ways of explaining and treating ill health, defining who is the patient and who is the healer and specifying how healer and patient should interact in their therapeutic encounters. People who become ill typically follow a hierarchy of resort ranging from self-treatment to consultation with others. As a first line of action, self-treatment accounts for a higher percentage. In this study, 86% of the respondents reported to treat themselves before making any consultation. Self-treatment falls under popular sector as suggested by Kleinmann. If people are not helped by self-treatment, they make choices about whom to consult in the popular, folk or

professional sectors for further help. As it will be seen later in this Chapter, these choices are influenced by the context in which they are made which include the types of helper actually available or accessible, whether the payment for their services has to be made, whether the patient or his/her sponsor can afford to pay for these services, and the explanatory model the patients use in explaining their ill health. This is the model that provides explanations for the aetiology, symptoms, physiological changes, natural history and treatment of illness. On this basis, patients choose what seems to be the appropriate source of advice and treatment for their conditions.

5.2.1 Therapy choice

The researcher sought to inquire from the informants what their choices were regarding TB treatment providers. Different views were given including the reasons for choosing a specific health care provider.

Figure 5.1 Therapy choice (N=98)



Source: Field Data, 2006

Figure 5.1 shows that the majority of the respondents (54.1%) preferred modern medicine as their first choice as compared to 6.1% who opted for traditional medicine. 39.8% reported that a combination of both modern and traditional medicine is the best choice since according to them, the disease TB, is "big" hence a combination of both therapies could effectively fight the disease. Those who prefer modern medicine still go for local/traditional medicine should the modern medicine prove ineffective (see figures 5.2, 5.3 and 5.4). Furthermore, those who prefer hospital or modern medicine still have to make choices as from which to receive treatment. There are three options: the government general hospital,

the government dispensaries and the private hospitals (see Table 5.1). People make different choices and these are influenced by various factors.

5.2.2 Factors that influence therapy choices

The study reveals that there are several factors that influence therapy choices or the switch between health care providers at the disposal of the patients or their sponsors. These included; perceived effectiveness of a given therapy (81%), recognition of symptoms, beliefs about the causes of TB, cost of treatment (38%), distance to the nearest health care provider (13%), cultural beliefs (mentioned by 6%), and HIV/AIDS.

5.2.2.1 Perceived effectiveness of a given therapy.

People switch between therapies because of the perceived effectiveness of a given therapy. When one health provider fails to bring about desired outcome, people tend to switch to what they consider more effective than the preceding one. Some of the informants believe that the local/traditional medicine is more effective than the modern medicine when it comes to TB treatment. Several reasons are given to defend their argument, first, there is a strong belief among the respondents that when the traditional medicine, *emete* is administered, it clears any disease that might be present and not only the target disease unlike the hospital medicine which is meant for a specific disease. That, the traditional medicine does more than what it was intended to do.

Secondly, the local medicine works faster. The informants reported that the local medicine cures TB within few weeks unlike the hospital one, which is taken for long periods in order to finish TB. Because of long TB regimens, some informants thought that this is a sign that modern medicine is ineffective and unable to finish TB within the shortest period. Thirdly, respondents complain that hospital medicine is bitter and sometimes it makes one very weak as compared to traditional medicine, which does not weaken the body. In other words, it is body-friendly to borrow one of the key informants' words.

However, most informants believed that hospital medicine is more effective hence; they go for it in case of an illness. These people reported that modern medicine is always given in right measures and after completing the dose; check-ups are done to ascertain

whether the disease has been completely treated. The local practitioners do not have any specific ways of testing whether one has TB. They just depend on manifest symptoms, which can sometimes mislead or they depend on tests done in hospitals. Furthermore, there is no proper measure of medicine. They administer the herbs and when the patient reports that he or she has felt better, the practitioner assumes the patient has recovered and therefore no more medicine. These are some of the reasons as to why some respondents (especially young respondents) reported to prefer modern medicine as compared to local. To them, the traditional medicine is ineffective and cannot be relied on. However, as shown in figures 5.2 to 5.4, these people will still utilize the local medicine if they do not recover.

Further, some respondents believe that only one kind of therapy is not effective to fight TB, which they consider "big". These people reported that for effective treatment, a combination of both modern and traditional medicine is used. Those who reported to start with hospital medicine could adhere properly but later embark on local herbs upon hospital medicine completion. This group reported that TB treatment is not finalized until some local herbs are taken. A key informant had this to say,

> TB is a big disease and we cannot rely on hospitals medicine alone. we use our local medicine too. So, even after finishing the medicine given by doctors, we take some herbs just to ensure the disease is completely and effectively treated...(male aged 56)

This shows that some people do not rely on hospital medicine even if they get cured; they still take some traditional medicine for "effective" healing. The case history revealed that some patients do not even wait to complete the hospital medicine before embarking on traditional medicine. They take both medicines simultaneously.

The informant reported thus;

> I used to take hospital medicine in the morning as prescribed by the physicians but at daytime after lunch, I could take local herbs, which I personally prepared. Local medicine made me feel better and I believed that combining them could make me recover quickly... and indeed, I did...(male 55 years)

This shows that whereas some patients adhere to modern medicine, finish it and start the traditional one, others take both therapies simultaneously. But the general agreement is that

using only one therapy (traditional or modern) is not enough to effectively fight and finish TB and that using both is the best choice.

5.2.2.2 Recognition of symptoms

From the discussions in Chapter Four, it is clear that the majority of the informants (more than 90%) are aware of the clinical symptoms of TB and only a few misinterpret these symptoms. In this section, I will discuss how these symptoms affect the health-seeking behaviour of people. Depending on the symptom that manifests itself, it is approached in different ways by different people. Many respondents reported coughing and wheezing. This is the most recognized symptom of TB by lay people. Even the local term for TB is *Esese*, which can be translated to persistent coughing or wheezing. Coughing, *ogokororalRikuba,* is not usually taken to hospital instead people treat themselves by the use of medicine they buy from kiosks or by use of locally prepared herbs. It is considered "a normal" phenomenon and therefore, nobody considers himself or herself sick when he/she has common cold. However, if the coughing persists, then it is considered "abnormal" and people seek help from the health centres or local herbalists depending on one's choice. If in case one coughs up blood, then the condition is taken seriously and one is rushed to practitioners. To some people, blood in sputum means destruction of the chest hence, *Egekuba Egeku* (dead chest) that is another local term for TB. In this case, the patient is considered very sick and therefore needs quick attention to safe his or her life.

Vomiting and Diarrhoea were also reported to be serious symptoms of TB. In both cases, it was reported that if quick action is not taken, the patient loses too much body fluids, which may lead to death. Traditionally, these conditions were treated by the use of herbs, which were meant to stop the vomiting, diarrhoea and replacing the lost body fluids. Loss of body fluids was reported to cause general body weakness, which the majority of the respondents mentioned as one of the serious symptoms of TB. It was considered serious in the sense that it makes people to abandon their daily activities. People in the study area depend mostly on farming for their livelihood so anything that prevents them from performing their daily duties is considered serious because it threatens their source of

livelihood and their very existence. This prompts people to seek help as soon as possible to safeguard their lives.

According to the findings, the symptoms of TB that can prompt people to seek treatment immediately in Kiogoro division include; those that make people abandon their physical activities, those that are so disturbing to the patients and those around them and the ones that threaten life. Most respondents reported that when the serious symptoms appear, action should be taken immediately lest the person will die. In other words, to some people, the serious symptom should appear before any action is taken. Zola (1966) found that Italian, Irish, and Anglo–Saxons differed in the type of symptoms they needed to have in order to seek medical aid. The Italians would be most concerned with symptoms that interfered with social and personal relations, Irish- Americas of Anglo–Saxon origin saw a doctor when the symptoms were considered to be interfering with their work or physical activity. Zola suggests that particular type of symptoms are more threatening to some people than others. This was the case with people of Kiogoro division. Some mentioned blood in sputum as the most threatening symptom of TB and which triggers them to seek treatment immediately. The 12% who mentioned general body weakness as a serious symptom reported that this makes them unable to perform their duties hence they embark on treatment immediately so as to get well and resume their daily activities. Therefore, to them, a symptom that makes them abandon their work is a serious one and needs quick attention. In brief, this study reveals that to the Kiogoro people, the serious symptoms are taken to practitioners immediately they appear whereas the ones considered less serious, people tend to delay taking action. This behaviour can pose problems because if people delay taking action for symptoms considered "harmless", it means at the time one takes a corrective action, many people around him or her might have contracted the disease. There is therefore a need to educate people at the community level on the importance of quick action when symptoms appear even those considered harmless by the community members.

5.2.2.3 Beliefs regarding the causes of TB

Lay people usually place the etiology of any ill health in one of the following sites: within the individual, in the natural world, in the social world or in the supernatural world (Helman, 1990). As it has been shown in Chapter 4, people have different perceptions regarding the aetiology of TB. These beliefs were found to have an influencing power on therapy choices or people's actions to prevent or treat TB. In this section, some of the major beliefs and how they affect treatment-seeking behaviour will be discussed.

People's bad habits such as the consumption of "bad" foods and cigarette smoking were considered to be among the causes of TB. Therefore, changing this behaviour (avoiding bad food and cigarette smoking) is considered appropriate in either treating or preventing TB. This is fuelled by the fact that usually when TB patients are under medication, are advised to avoid bitter foods, alcohol and tobacco smoking. Therefore, many informants believe that this might be the cause of TB and to protect oneself, a person should avoid these "foods". This makes other people to delay taking appropriate action because some think that by merely avoiding these foods and cigarettes, one would automatically be healed. These people are unlikely to go for any treatment and they opt for self-treatment, which is, changing one's eating habits and stopping tobacco smoking. This is a misconception which needs to be corrected and people should be informed that as much as changing one's behaviour contribute to the healing process, it does not bring or lead to recovery par se.

There are those who associated TB with witchcraft and as per the beliefs of many African communities, any disease that is caused by witchcraft or sorcery is never taken to hospital. Instead, people seek help from local "experts". These "experts" consist of diviners, seers or witch smellers, and witchdoctors. The underlying argument is that, even if the person is cured in hospital, a disease caused by a witch or a sorcerer will always come back if the "causer" is still alive with the powers intact. Therefore, the work of these local practitioners is to ensure that the disease once treated, does not come back. They ensure this by either killing the culprit or rendering his/her power ineffective.

Hereditary was also reported by some informants. When the disease is considered hereditary, people tend to be slow in taking action. Some believe that a hereditary disease has no cure and that the available therapies are only meant to relieve pain and add some life to a patient. Consuming donkey milk was mentioned by many as one of the therapies that reduce the severity of TB but not to cure it. Other respondents reported that a hereditary TB even though it kills, it does not kill quickly and that a person can live with it for many years. This can also lead to delayed action because people believe that the disease does not kill quickly hence there is no need for fast action. The rest had an opinion that a hereditary TB requires both traditional and modern therapy for effective cure. In general, beliefs about the causes of TB affect people's course of action and therapy choices. When "bad" foods are implicated on the cause, avoiding these foods is considered important for treatment, when witchcraft or sorcery is blamed, help is sought from local practitioners and when the disease is considered hereditary, people believe that it does not spread to healthy people around the patient. However, those with proper knowledge on the clinical causes of TB as the study revealed make right choices and their action is usually faster. They also take appropriate measures to protect themselves and those around them from the disease.

5.2.2.4 Cost of treatment

Cost of treatment was also revealed to play a role in the health-seeking behaviour of people. In Kenya today, TB tests and treatment services are offered free in government health institutions. This has been received with mixed reactions. Some believe it is the best way if TB is to be fought effectively whereas others think the scheme has created more problems. Following this, many people seek treatment from the government health institutions; others utilize the private hospitals and the rest go for traditional therapy. The majority (92.3%, N=92) preferred the district general hospital for various reasons free medication being one of them, 3.3% preferred government dispensaries and 3.3% had private hospitals as their choice.

Table 5.1 Modern health providers choices (N = 92)

Choice	N	%
Government Hospital	85	92.3
Government dispensaries	3	3.3
Private Hospitals	3	3.3
No response	1	1.1
Total	**92**	**100**

Source: Field Data, 2006

Free TB medication in the government institutions has acted as a pulling factor for tests and treatment. Many people reported to go early for tests and treatment because after all it would not cost them any money. During the study, most people were aware that these services were offered free in government health centres. They reported to have received the news from the public media, friends and those who had suffered and received these free services. The distance notwithstanding, informants reported that they travel all the way to the general hospital, which happens to be the only government institution in the area where tests and treatment of TB services are offered. This they could do as soon as they see or experience TB symptoms (the government dispensaries in the area do not carry out TB tests). In addition to free services, the respondents reported that unlike the dispensaries, the general hospital is well equipped and staffed. The local dispensaries, which include Kiogoro dispensary, Masongo dispensary and neighbouring Keumbu health centre are poorly equipped and under staffed, they do not carry out TB tests and treatment. Even if patients report to these health facilities for TB tests and treatment, they are referred to the general hospital. Therefore, many people decide to go directly to the district hospital. At the time of the study, Masongo dispensary had only one clinical officer and one nurse and Kiogoro dispensary had also one clinical officer and five nurses. There were also no wards in these institutions.

Those who reported to prefer the dispensaries (3.3%) blamed the distance and poor roads to the general hospital. They visit the general hospital for only tests to ascertain whether they have TB or not. TB medicine is offered free in the government dispensaries

therefore, after tests in the district general hospital, they collect medicine from the dispensaries, which are nearer and therefore cheap in terms of transportation costs.

The 3.3% who reported to prefer the private hospitals claimed that with free medication in government institution, there has been congestion and therefore poor services. These informants reported that there is always quick attention and quality services where money is paid. Despite the high cost of treatment in private hospital, the informants reported that they valued good health and life more than money, so they would rather pay for their medical services and receive the best than go for free medication, which might be ineffective.

This shows that as much as free TB treatment has attracted many people to the government health institutions, it has sent some away especially those who are financially stable and those who stick to their cultural beliefs. This brings us to another group of people who constitute mostly old people. These people have a different opinion concerning free TB treatment in government health centres. They believe that payment for any medicine to work is very important and part of their culture. They claim that for any treatment "something" at least has to be paid to those who prepare and administer the medicine. They usually call this payment, *eya rosana*, and that it is meant to appease the gods who are responsible for a given medicine. Traditionally, the herbalists among the Gusii people believed that the art of healing is given by the gods or ancestors. It is these same supernatural beings that direct them to a specific herb for specific disease. It is a requirement for the money to be paid to those who prepare and administer the medicine. When these people were informed that TB treatment is offered free of charge in the government health institutions, they became suspicious and doubted the effectiveness of the medicine. One key informant elaborated thus;

> Free treatment means no cure, our beliefs are that for any medicine to work, one has to pay some money be it little, *eya rosana*, for blessing and for the medicine to be effective. Free medicine means no recovery...(female, 72 years)

After paying for the medicine, these people would believe that they would recover and indeed as many reported they do recover. Therefore, payment for medicine gives people

some psychological comfort, which contributes to their healing, so claimed some of the older people. The younger people do not hold beliefs in payments for effective healing. To them, free treatment is a big relief to many people who are not in a position to pay for TB treatment, which is expensive. Some referred the general hospital as "ours" in the sense that it is their only choice having that private hospitals are rather too expensive for them.

In conclusion, therefore, the cost of treatment influences people's treatment seeking behaviour in one way or the other. Those who can afford visiting private hospitals do so due to congestion in public hospitals; those who cannot afford to pay for health services choose the government health institutions to benefit from free services and those who do not believe in free medication go for alternative medicine where they can pay "something small". This group, which comprises of mostly old people, is unable to visit private hospitals because they are too expensive for them. It is apparent that the free TB treatment scheme in government hospitals has also led to quicker action in the event of TB. Before the scheme, people tended to delay taking action to first mobilize the resources to meet the cost of treatment.

5.2.2.5 Distance

In studying the health-seeking behaviour of people, distance to the nearest health care provider cannot be ignored. It influences this behaviour in that, in most cases people visit providers, which are easily accessible. This is because some people are unlikely to afford the cost of transportation to the health centres, which are situated, too far from the users. Sometimes a patient may be in serious condition, which needs urgent attention. Therefore, people will be inclined to utilize the health services, which are nearer. 13% of the respondents reported that, distance to the health care provider affects their treatment-seeking behaviour. In Kiogoro division where the study was conducted, there were only few private clinics and government dispensaries. Unfortunately, all these had no facilities to carry out TB tests. That means patients had to travel all the way to the district general hospital for tests and treatment. To some people the district hospital was out of reach. People could travel for more than 10km to reach the district hospital (see Table 5.2). This was a problem having that the roads in the division are very poor and therefore,

transportation is almost impossible especially during rainy seasons. Because of transportation problems, People sometimes get their way to the local healers in the event of TB. They do not see any reason of traveling all the way to general hospital for the services they could easily get from these local practitioners. However, those near the district hospital (up to 5km) prefer the hospital for their treatment because to them, it is easily accessible.

Table 5.2 Distance to the District Government Hospital

Distance	N
Less than 5km	36
5km-10km	46
More than 10km	18
Total	**100**

Source: Field Data, 2006

5.2.2.6 Cultural beliefs

Culture is very important in any given society. It unites a given people and dictates what should be done and what should not be done in the society. It includes people's norms, worldviews, beliefs, practices and all that people hold as their own. Culture is usually passed from generation to generation. This study found that culture plays an important role in the health-seeking behaviour of people. It dictates when and from whom to get help in the event of any illness. The older generation tends to be more conservative than younger people when it comes to matters of their culture. In this study, it was revealed that these older people prefer traditional mode of healing which they consider "ours". One of the key informants reported this on traditional healing.

> ... Traditional cure, *emete*, is ours and we have been using it to treat any disease including TB, *esese*. Hospital medicine is not our discovery, it was discovered by "white people" and should therefore be utilized by white people. In addition, our hospital doctors do not have manners; they handle people whom culturally, they are not supposed to handle. Take for example, a young man attending to a woman who is giving birth. This is abominable in our culture... (Female aged 81, no formal schooling)

This shows that older people have negative attitudes toward the modern medicine/modern healing system. These people are so embedded in their culture in that whatever is considered foreign is not easily accepted. However, the younger generations are

flexible and are more likely to utilize the hospital medicine. Some of the younger people reported that culture is dynamic and people should not stick to traditional healing which is ineffective and "dirty." They claimed that when it comes to a dangerous disease like TB, people should seek treatment from modern health care providers for proper and effective treatment. Therefore, according to the findings, cultural beliefs that people hold tend to push them to a specific health care provider in the event of an illness. Older people prefer traditional mode of healing which they claim take their cultural practices or beliefs into consideration unlike modern hospital healing processes, which seem to violate some of the cultural beliefs of the people.

5.2.2.7 HIV/AIDS

TB is a disease that is highly associated with HIV/AIDS. It is one of the leading opportunistic infections among HIV/AIDS patients. It is estimated that about 50 – 60% of all TB patients in Kenya are HIV infected (MOH, 2005). The researcher undertook to asses the knowledge of people regarding the relationship between HIV/AIDS and TB. The study revealed that most people are aware of these facts. The majority of the informants (68%) reported that there is a strong relationship between HIV/AIDS and TB. 27% reported that the diseases are not related in any way (they are different entities) whereas 5% were not real sure whether the two diseases are related.

Table 5.3 Knowledge of HIV/AIDS and TB co-infection

Any relationship between HIV/AIDS and TB?	N	%
Yes	68	68
No	27	27
Don't know	5	5
Total	100	100

Source: Field Data, 2006

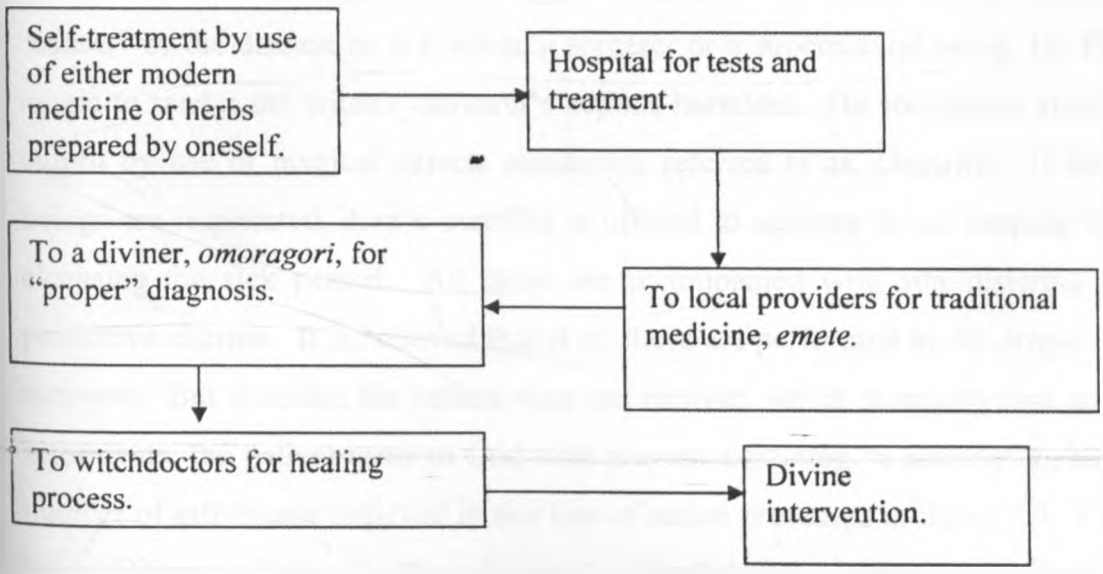
TB patients are in most cases considered HIV positive. There is usually stigma associated with HIV/AIDS. Most HIV positive victims are stigmatized and discriminated against. Because of the stigma, many people tend not to disclose their TB status because people will mistake them to be HIV positive. As it was revealed, some TB patients fear to

visit modern health centres because of tests, which are carried out. More often, TB patients are screened for HIV/AIDS for proper medication should the patient be found with both diseases. All the three focus groups reported that many people do not want to know their HIV/AIDS status. This makes them prefer traditional mode of healing where no tests are carried out to reveal whether one has only TB or both TB and HIV/AIDS. This means, the fear of AIDS can affect the treatment-seeking behaviour of TB patients.

5.3 Course of action

The study revealed that people have different views regarding the course of action in the event of an illness. As it has been mentioned earlier, 86% of the respondents reported self-treatment as their first action and the remaining 12% reported to visit a modern health facility to ascertain the exact problem. There is always a switch between the available health care providers should the first fail to help. The study unveiled three courses of action as reported by the respondents. These are presented in figures 5.2, 5.3 and 5.4 as treatment pathways 1,2 and 3 respectively.

Figure 5.2: Treatment pathway 1

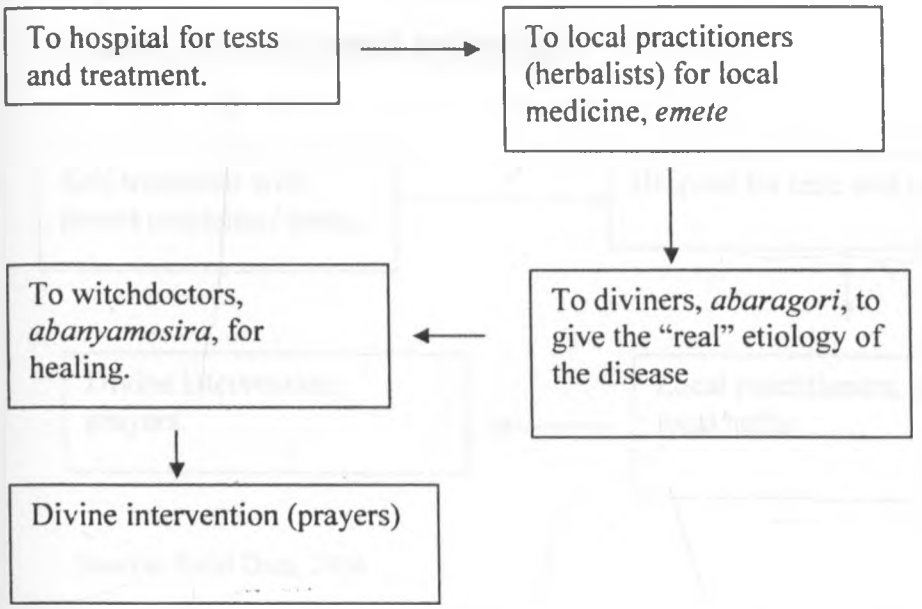


Source: Field Data, 2006

Figure 5.2 shows the course of action taken by patients depending on the success or failure of the preceding action. As shown in the figure, the first action is to try to treat oneself by use of modern medicine (over- the-counter medicine) or herbs that a patient prepares himself or herself. Should this fail to bring about recovery; the patient goes to hospital for tests and subsequent treatment. The respondents reported that sometimes hospital treatment may fail and if this happens, the patients take refuge in local or traditional medicine, which is prepared and administered by special providers (herbalists) commonly called *abanyamete* (sing. *Omonyamete).* The traditional medicine is considered or perceived by this group to be better than the modern medicine. Therefore, in case this medicine fails to help a patient, a different interpretation regarding the disease's aetiology is given. This makes the patients to seek explanation from a local diviner, *Omoragori (Pl. Abaragori).* At this stage, the disease is considered or explained to be the result of witchcraft or sorcery or sometimes, supernatural beings.

Depending on the explanation of *Omoragori,* the patient proceeds to a witchdoctor, *Omonyamosira, (pl. Abanyamosira*) whose specialization is to deal with diseases caused by sorcerers/witches or supernatural beings. The main aim of the witchdoctor is to target the "causer" of the disease be it a witch, a sorcerer or a supernatural being. He Performs some magic to render the witch's /sorcerer's actions harmless. He sometimes aims at killing the culprit by use of magical objects commonly referred to as, *Omosira.* If the supernatural beings are implicated, then a sacrifice is offered to appease them, keeping them at bay or cleansing the sick person. All these are accompanied with administering medicine and protective charms. It is believed that if all these are performed in the proper way, a patient recovers. But if incase the patient does not recover, which is usually rare according to the informants, the patient turns to God with prayers expecting "a miracle" to happen. A good number of informants believed in this line of action presented in figure 5.2. However, some have different views. To them, going to hospital for diagnosis before any medicine is administered is crucial. This group constituted 12% of all the respondents. Their treatment pathway is presented in figure 5.3.

Figure. 5.3: Treatment pathway 2



Source: Field Data, 2006

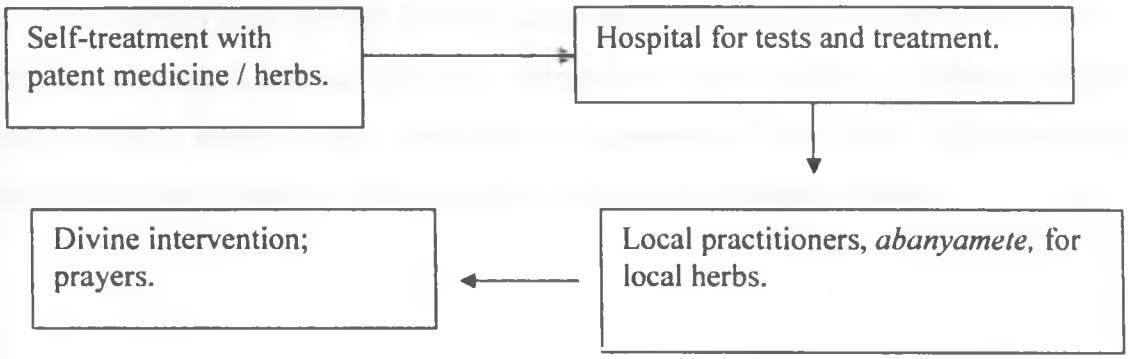
Figure 5.3 presents a line of action by some people as reported by respondents. These respondents, 12% (N=98) reported that in the event of any illness (TB included) they simply go to hospital for tests and treatment. They do not attempt self-treatment for they do not know the exact disease or the intensity of the problem so, they rather inquire from the health care providers first. One key informant had this to say,

> ... you cannot treat something you do not know, you might be treating a different disease while the real disease in you worsens, so it is good to go for tests first for proper diagnosis, treatment and quick recovery...(male aged 48 years, literate)

Just like figure 5.2, figure 5.3 shows that should the hospital medicine fail to help, patients switch to traditional healing: Herbalists, *abanyamete*; diviners, *abaragori*; witchdoctors, *abanyamosira* and finally divine intervention. This was a trend among many informants. The claim was that, if a treatment fails to bring desired results, you do not sit and wait to die, you try the other providers available. However, there was a group of

respondents who did not believe in diviners and witchdoctors. Their line of action is presented in figure 5.4.

Figure 5.4: Treatment pathway 3



Source: Field Data, 2006

Figure 5.4 presents the course of action taken by mostly those people who claim to be "born again" and some other Christians. They do not believe in offering sacrifices to the gods or demons for healing. They consider the diviners, *abaragori* and witchdoctors, *abanyamosira* as representatives of the devil. It is worthy noting that the work of these witchdoctors involves magical acts, *omosira,* which in most cases end up killing the perceived causer of a given disease, witch or sorcerer. This might be one of the reasons why some people are against the actions of witchdoctors. But the research revealed that many respondents, "born again" Christians included, sought help from local herbalists commonly called *abanyamete,* should the hospital treatment fail to help. Others believe that even if one takes the hospital medicine, local herbs were necessary for "complete" recovery. That, treatment is never finalized until some local medicine is administered. This means that even if the modern/hospital medicine clears the disease, some patients proceed to local herbalists for their local medicine to complete the healing process.

From the ensuing discussion, it can be concluded that most people consider TB disease a dangerous one, which needs quick and proper medication from what is perceived effective health provider. There are always different stages in decision making apparent in the health behavior of people in Kiogoro division. People switch between therapies not only because of income level but also because of the actor's worldview, perceived effectiveness of a given therapy among other factors, some which, are beyond the actor's control. The TB, which is considered normal by many respondents, can be given a different interpretation should it fail to resolve, thus, witchcraft or supernatural forces are implicated and help is sought from local "experts" and not within the modern healing system.

CHAPTER SIX

ADHERENCE TO THERAPY

This chapter tackles the third and last objective of the study. The objective was to investigate factors that influence TB treatment compliance. To achieve the objective, data was gathered from people who had suffered or were still suffering from the disease. Also data from medical officers, traditional healers and case histories were used to enrich that collected through the survey.

6.1 Cases of TB in the study area.

Out of the 100 respondents, 23% had either suffered from TB or had a close relative in the household who had either suffered from the disease, or had died of the disease. The rest, 77% had not suffered from the disease or there was nobody in the household with TB.

Table 6.1 Cases of TB (N =100)

Suffered from TB or close relative with TB?	**N**	**%**
Yes	23	23
No	77	77
Total	**100**	**100**

Source: Field Data, 2006

Out of 23 TB cases that were found, 21.7% had died, 21.7% were still under medication at the time of the study. 13 (or 56.5%) reported to have recovered fully. The recovered cases reported to have either received treatment from modern health care providers or from local herbalists. On further probing, some of these respondents reported that they had abused the drugs and had to restart the treatment all over again. Therefore, the study revealed that some patients do not comply with treatment a behavior that can endanger their lives and of those around them. The researcher undertook to investigate why some patients tend to abuse their drugs or do not comply with TB treatment even though they are equipped thoroughly with relevant instructions on how to use their medicine. Various factors that influence TB treatment compliance were revealed.

6.2 Factors that influence treatment compliance

6.2.1 Long regimens

TB treatment regimens are too long; patients are required to adhere to treatment for up to 8 months. Due to long regimens, some patients withdraw before recovery or they simply skip some days before resuming treatment. As the research revealed, the patients "get tired" on the way and decide to take a break. Some even complain that a lot of medicine weaken their bodies and make them even sicker. The research also found that most people are not aware that the disease can resist the available medicine – if medicine is not taken properly as required, some germs tend to become resistant to that medicine. According to the findings also, due to long TB regimens, some patients switch to traditional healing. They think that hospital medicine is ineffective that is why it has to be taken for a long time to finish the disease. They mix both medicine (modern and local) or simply abandon the modern medicine in favour of local therapy, which they reported, is taken for only a short period and one recovers. An informant, an old man aged 72 years had this to say concerning the long TB regimens:

> Hospital medicine is taken for long time but "ours" (traditional medicine), you only take for two or three weeks and you get well. Furthermore, our traditional medicine, you take one type and every disease in you is cured but hospital medicine is meant for only a specific disease...(male, 72 years)

All the informants who reported to prefer traditional medicine for TB treatment agreed that they only need to take local herbs for few weeks and the disease is cured unlike the modern/hospital medicine where one is required to take medicine for long periods.

6.2.2 Lack of knowledge

Many patients who reported to have abused drugs or who withdrew before recovery claimed that they thought they had recovered. After taking medicine for a time, patients feel better; they withdraw from taking medicine thinking that their disease is completely cured. One of the informants who gave their life histories reported that after taking medicine for six months, she felt perfectly well so she stopped taking more medicine. But after four months she got re-infected.

> I took medicine for six months but stopped thinking that I had recovered fully. After few months I started coughing again and this forced me to go to hospital again. The doctor told me I had to start medicine all over again....(female, 34 years)

The patients seem to lose the information given to them or simply ignore it and abuse the medicine. This is mostly found among the old people who are also illiterate. Some of these people claim that they have no sufficient knowledge regarding the risks associated with non-compliance to therapy and that there is nobody around to remind them to take their medicine. Others believe that the doctor is wrong to instruct them to take medicine for 8 months when they feel cured after only few months. These patients think that if they have felt better it means they have recovered. If a patient regains his/her energy to be able to work, then he/she sees no reason to continue taking the medicine until it is all over. To this person, if he/she can work, that means the disease is all gone.

The study also discovered that due to lack of proper knowledge, some patients tend to combine both modern and traditional medicine. The argument was that by so doing, the period of medicine taking could be reduced. This means, the patients are likely to abuse the modern medicine. Following this, there is a need to educate people on the risks of non-compliance especially those without formal education. The study revealed that this is the group that is more likely to abuse drugs if there is nobody to monitor them as they take their medicine. There is also a need for directly observed therapy (DOT) when dealing with these old people who also lack formal schooling because if they abuse drug it means great problem not only to themselves but also to their family members and the community at large. Therefore, to improve on drug adherence, community based observation through caregivers and the community volunteers has to be done. In addition, appropriate community mobilization/ sensitization must be used through mass media campaigns, public meeting, group therapies and house-to-house campaigns in most affected parts, for example, slum areas that are highly populated and under served.

6.2.3 Alcoholism and cigarette smoking

People's lifestyles may influence compliance to treatment. The study found that alcoholism and cigarette smoking had negative influence on compliance to TB treatment.

Patients who are under medication are usually warned against alcohol and cigarette smoking. Because of this, some patients are likely to withdraw from medication so as to take their stuff- alcohol and cigarettes. When the researcher inquired more on this behaviour, some informants reported that the urge to smoke or drink is so great that some can even be forced to either withdraw from medication and quench their urge or simply ignore the doctor's precautions and smoke while taking their medicine. It was reported that some patients had died of TB in the study area because "... they ignored the doctor's precaution and indulged in alcohol drinking and cigarette smoking and therefore forgetting their medicine." As per the respondents, the patients who have the habits of smoking and drinking alcohol are likely to abuse the drug in that, sometimes they get too drunk and forget to take their drugs as required. This usually happens when there is no caretaker to monitor them. Smoking is dangerous to already ailing lungs and if the patients continue smoking while sick they are likely to endanger their lives.

6.2.4 Medicine sharing

The informants reported the habit of sharing medicine. Some reported to have shared TB medication (pills) with either friends or family members. This is because these people showed signs and symptoms just like the patient's meaning same problem and hence same medicine. Even with full knowledge that TB medicine was given free in public health institutions these people still share their medicine with others "... to help them before going to hospital which is too far and due to lack of money for transport..." Others claimed that the pills were rather too many for only one patient. So to ensure that they get finished faster, one could share with a family member who experience similar problems.

In other instances, medicine is stored for future use after the patients "recover". This means that should anybody in the family experience the same problem or show similar symptoms like those of the "recovered" person, he/she is given the drugs in store without any consultations to ascertain the real problem. This of cause, is a health risk because first; the real problem is not known to the family – wrong diagnosis and secondary, the manner in which this medicine is stored. Poor storage can lead to destruction of medicine or the

medicine can even become poisonous. Many informants do not see anything wrong with sharing medicine with those with a problem exactly like theirs- this was mostly reported by informants without formal education. This also calls for not only giving them proper instructions, but also somebody to monitor them to ensure proper adherence. This is because as it was revealed, even with proper instructions and knowledge, still people abuse their medicine.

6.2.5 HIV/AIDS

As it has been discussed in Chapter 5, most informants associated TB with HIV/AIDS. When the knowledge of TB and HIV/AIDS co-infections was assessed, it was indeed revealed that many informants associated TB with HIV/AIDS and some even strongly hold that TB is a sign that one has HIV/AIDS. The majority (68%) of the respondents believed that TB is related to HIV/AIDS (see Table 5.4). These people assume that any TB patient must also be having HIV/AIDS. One informant confessed that he nearly made mistake because of his strong belief that a person with TB also has HIV/AIDS. His son had suffered from TB and he was under medication. They did not care to go for more medicine for the patient because they thought it was a waste of time and money to travel all the way to the hospital for more medicine because after all he was bound to die. It was reported that even TB patients themselves believe they have both diseases and that even if they comply with medication as required, they will die anyway because AIDS has no cure. These patients lose hope after taking medicine for a while. Some informants who were suffering from TB also reported the idea of stigma. One of the informants had this to say,

> If people realize that I take medicine every day, they may think that I am under anti-retroviral pills and discriminate against me. I do not want this to happen to me. So it is good to abandon the medicine after feeling well…(male, 46 years)

However, some informants (27%) believed HIV/AIDS and TB are not related; they are different entities. As one old female informant reported,

> *Egekuba egeku*, TB has been with us for long and can be treated unlike the new disease, *Enyamoreo*, AIDS that is a recent one and has no cure. So these two are real different…(female, 68 years)

These findings may partly explain why some patients may withdraw from medication or why they do not comply with TB treatment as required. Stigma that is associated with HIV/AIDS plays a role in this behaviour. People want to conceal their HIV status or even TB status. They do not want to be seen taking medicine because people may mistake them for HIV/AIDS patients under anti-retroviral. This calls for counseling among TB patients and educating the public informing them that having TB does not mean one has HIV/AIDS and even if that is the case, TB is curable if patients comply with the treatment. These TB patients who are co-infected with HIV/AIDS should also be informed that if TB is treated effectively, they might live longer.

6.2.6 Distance

In the previous Chapter, I explained that people in Kiogoro division travel for long distances (up to 10km) to reach the health centres. It was also discussed that, this affects the treatment–seeking behaviour of people. It was found that distance also affects treatment compliance. Informants reported that due to long distances and poor transport networks [poor road, lack of vehicles in remote areas], some patients are unlikely to go for more medicine. In most cases, patients are required to collect medicine on weekly or monthly basis from hospitals or dispensing centres near them. But, as it was established, some of these health institutions are not easily accessible by some patients. Some are just " too far" for patients. One informant reported that she did not go for more medicine because it was far and she had nobody to send. She was too weak to walk all the way to the health centre to collect the medicine (the patient had to walk for approximately 7km to reach the nearest public health centre which served as dispensing centre). An interview with some medical officers revealed that some patients could just "disappear" for months and when they "resurface", they have lots of explanations to give one of them being the transportation problem. Some reported that they did not have money to board vehicles to health centres.

Therefore, long distances to health centres may contribute to non-compliance to TB treatment. According to the informants, this is beyond their control and the government should come in for their assistance. Some health officers had an opinion that patients should

be warded until they finish their medicine. But this could also be a problem to many since free TB treatment in the government health centres does not include free accommodation in the wards. Patients have to meet cost of staying in wards. Therefore, free TB treatment needs to be redefined to include free accommodation in wards. Alternatively, the distance covered by people to reach health care facilities must be reduced to improve access to services – these services should be moved closer to the people.

6.2.7 Lack of follow-ups

Making follow–ups to ensure proper adherence to TB therapy is important due to long TB regimens and problems associated with non-compliance. The study discovered that follow-ups are not done in the study area. The health institutions are understaffed. The few officers are required to serve large populations. This means, there are no enough health officers who could make these follow-ups. Health officers reported that they attend to many patients from both near and far. It is hard to attend to many patients who visit the health institutions and at the same time make follow-ups to ensure they comply with treatment. This can only be done if patients are confined in wards, which as well is difficult because to some patients, it is too expensive to stay in wards. In one of the dispensaries visited, there was only one clinical officer and one nurse. This dispensary served more than three sub-locations that means; the patients were always too many for the two officers. There were long queues at the dispensary when the researcher visited the institution. The clinical officer reported that serving the visiting patients alone was tedious leave alone making follow-ups. Nevertheless, the officers usually give full information on how the medicine should be taken. They also inform the patients on the risks associated with non- compliance. A clinical officer in one of the dispensaries visited reported thus,

> We have a lot of work here, the patients are too many and we are few surely, we cannot make follow-ups unless the government employs community health officers to carry out this exercise. However, we give the best information required, we instruct them on how to use their medicine. Their caretakers, if any, are also informed accordingly. But still we have many defaulters. Some disappear and never to be seen for more medicine. We do not know whether they die or switch to alternative medicine. There is nothing we can do beyond giving proper instructions...(male medical officer, 46 years)

Following the illiterate and ignorant populations that are likely to abuse drugs, follow-ups are very important to ensure adherence. If possible, directly observed therapy (DOT) should be used when dealing with this group of people (illiterate and ignorant). The government and other bodies should consider follow-ups, one of the ways to ensure proper treatment.

Other factors that were reported to influence compliance to TB treatment include vomiting of the pills as soon as they are swallowed and a new disease emerging. One informant reported that she vomited TB pills in more than four occasions but unfortunately, never reported to the health officers. Patients should be informed to report any cases of tablets vomiting for replacement. Another group of informants reported that in some cases, during medication, another disease may crop in. They specifically mentioned malaria. Because of this, a patient may suspend TB drugs to tackle the "new" disease first. They only resume TB treatment after they have recovered from the "new" disease.

From the discussion, it can be concluded that indeed some people do not comply with TB treatment. There are several factors that influence the TB treatment compliance; some of them, are beyond patients' control, and some are within their control. The health centres are not easily accessible by patients. Due to this some patients do not go for more medicine, which they are supposed to collect after every one week, two weeks or even a month. Besides being "too far" from patients these same institutions are poorly equipped and are understaffed that even the issue of making follow-ups does not raise. Other factors that were revealed included; long TB regimens, HIV/AIDS, emergence of another disease, and lack of knowledge. Following this, it is essential that clinic attendance by TB patients should be observed, counsel patients against treatment default and preparing default lists. Family or close associate of patients who have defaulted from treatment should be contacted to bring them back for treatment. Through community health workers, patients and their facilitators should be supported throughout the TB treatment, monitoring and evaluations made and recording the treatment outcomes of the patients.

CHAPTER SEVEN

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

In this chapter, a summary of what has already been discussed in the previous Chapters is given, conclusions are drawn and finally recommendations are made. The main objective of this study was to explore people's knowledge of TB, their treatment-seeking behaviour in the event of TB and adherence to therapy.

7.1 Summary

Tuberculosis remains an important cause of adult and childhood morbidity and mortality in the world today. Every year, many new infectious cases of TB occur. The continuous spread of the disease can be partly attributed to lack of knowledge of the disease among the lay people. Even though many people are conversant with the causes, symptoms and the transmission of TB, some do misinterpret all these which often lead to delayed action, improper medication and non-compliance to TB treatment.

People have different beliefs and varying levels of knowledge with regards to the interpretation of the disease. The way people interpret the symptoms and causes of a given ill health, affects their treatment-seeking behaviour. To take a given action one must first be able to recognize the symptoms and understand what the causes are. The recognition of symptoms is the starting point of any action. Therefore, for any action to be taken, one must first recognize the symptoms and be able to interpret them. This research reveals that people recognize various symptoms of TB, which are classified as serious, less serious, or insignificant. For example, coughing is not considered a disease; it is a normal phenomenon, which is not taken to health care providers. As many say, *Ikuba India mioro*, meaning, the cough is of the nose, it comes and goes. Somebody coughing considers himself or herself in good health. However, if the coughing persists, a person tries to treat himself/herself using over–the–counter medicine or herbal medicine prepared by oneself or family members. This shows that, coughing which is one of the TB symptoms can be mistaken to be a "normal" common cold and people would try to treat themselves hence delayed appropriate action.

Unlike coughing, chest pains are considered serious symptoms. The health-seeking behaviour of a person with chest pains is not the same as that of a person who is just

coughing. Whereas coughing is considered a "normal" phenomenon, chest pains are taken seriously and there is always quicker action. As people reported, chest pains make one weak and unable to do heavy work making one to abandon his/her daily activities. These findings support the ones by Zola (1966) among the Anglo-Saxon Americans, which revealed that these people visited a doctor when the symptoms of a given disease were considered to be interfering with their work or physical activity.

This shows that people handle each TB symptom differently. People react to serious symptoms faster than they do with what they consider less serious or insignificant. In addition, when a symptom is considered serious (for example blood in sputum), treatment is sought from what is perceived to be the best health care provider. In other words, if people perceive that a given symptom is serious and their lives are at risk, they tend to visit health care providers that will lead to expected outcome (recovery) – well equipped and with experienced staff.

On the cause, first people place TB aetiology in the natural world but later give a different interpretation when it fails to resolve. That means, first TB is considered "normal" with normal causes and if it does not heal quickly, it is considered "abnormal" and its cause can either be placed in the social world or supernatural world, thus: sorcery or witchcraft, spirits/ancestral shades, or gods are blamed for this "abnormal" form of TB. When witchcraft or sorcery is blamed for the disease, help is sought from local "experts" who include: diviners, *Abaragori,* to tell who is responsible for the disease; exorcists, *Abariori,* to identify where the magical objects are buried and witchdoctors, *Abanyamosira*, to counter witches and sorcerers, *abarogi.* Any disease believed to be caused by witchcraft or sorcery in Kiogoro division is never taken to hospital. This is a belief that is common in most African societies. The findings of this study concur with Osero's (1990) among the people of Ukwala who believed that a disease caused by the acts of witchcraft or sorcery is only curable using local therapies. The point of argument here is that the hospital medicine is inadequate when dealing with diseases caused by sorcery or witchcraft. This is because the disease will always come back if the witch or sorcerer's powers remain intact. Therefore, an

"expert" is needed to render these powers ineffective and/or killing the culprit should a need arise.

Those who place the cause of TB in the individual world think that people's "bad" habits such as cigarette smoking and alcoholism cause the disease. There are mixed reactions on this: while some believe that smoking cigarettes and drinking alcohol cause TB, others have views that these only fuel the disease. Nevertheless, the general agreement is that changing one's lifestyle – avoiding cigarette smoking and alcohol consumption, will help in the treatment process. When TB patients are under medication, they are usually warned against cigarette smoking and bitter foods, alcohol included. This can explain why most people believe that TB is caused by cigarette smoking and alcohol drinking and that avoiding them means avoiding TB. This means should a person be infected, he/she only needs to stop smoking or alcoholism and he/she is healed. This leads to delayed appropriate action and the continuous spread of the disease. Besides lay people's beliefs on the causes and symptoms as determinants of health-seeking behaviour, other factors that influence this behaviour include cost of treatment, distance to the nearest health care provider and HIV/AIDS.

On therapeutic options, the findings show that there is a wide range of therapeutic options available to people in Kiogoro division. Each of these options is used at one time or another, hence all the therapeutic options were found to be valued at different times. But, the majority (86%) reported self-treatment as the first action to try to bring about good health. It is therefore only when this fails to avert symptoms of a disease that people now find it necessary to engage in more elaborate therapeutic processes ranging from consultation with modern medical doctors to prayers for faith healing. That means, preference for modern medicine is not always the last resort, some cases that are taken to hospital can be forced to resort to alternative systems. Therefore, should the first alternative fail to bring about the expected results or if the results are not satisfactory, people switch to other providers.

There is one agreement among most people in the Gusii community that if the modern medicine does not bring about recovery, it is appropriate to seek help from local providers who include: diviners, *abaragori*; witchdoctors, *abanyamosira;* seers, *abariori*

and many others who are believed to posses special ability to treat both natural and supernatural illnesses. This behaviour was found to exist in both literate and illiterate groups. This is a trend in most African societies. Most people hold beliefs that the local medicine starts where the modern medicine stops.

The habit of non-compliance to therapy was revealed. TB fails to respond to treatment when people fail to adhere to therapy as required. Factors that influence treatment compliance as per the findings include: long regimens, lack of knowledge, alcoholism, cigarette smoking, sharing of medicine, HIV/AIDS, distance and lack of follow-ups. All these have been discussed in chapter six but I will give a brief summary. Patients do not like taking medicine for long periods. It makes them weak therefore; they abandon it when they feel better. Despite the instructions by physicians, these patients, especially the older ones, see no point of continuing with the medicine even after "recovering." It is obvious that when medicine is taken, some patients may feel perfectly well. This may make them to withdraw thinking that they have fully recovered. Most of these defaulters lack knowledge as to how they are supposed to take medicine. Even though the health personnel give them sufficient instructions, these people tend to forget easily especially those without formal education and if they are not monitored. It is evident that these people either skip some days before resuming their treatment or withdraw completely believing that they have been cured. On this note, O'Brien and Munn (2004) are right to call for new TB drugs to improve on the current treatment by shortening the total duration of treatment and/or by providing for more widely spaced intermittent treatment. This will help those patients who may withdraw due to long regimens or those who may forget to take their medicine regularly as required.

In most parts of the developing countries, medical institutions are few, poorly equipped and understaffed. These same facilities are mostly located in the urban centres making it difficult for rural majority to access them. Besides this, the infrastructure is poor and most of the roads are impassable during rainy seasons. All these have negatively influenced the people's behaviour regarding therapy choices and even compliance to treatment. Patients who visit the health centre for the first time often do not revisit them for more medicine or for check-ups. Furthermore, there are no follow-ups to ensure the patients

adhere to their treatment. The majority of the health personnel interviewed admitted that it is difficult to make follow-ups because there is no enough staff. In other words, the health institutions are poorly staffed and there is always congestion in the health centres. Serving the reporting patients itself is difficult that there is hardly time to visit the patients. At the time of study, there were no even community health workers in Kiogoro division who could conduct case finding or make follow-ups. Some patients need to be monitored or to be followed-up to ensure they correctly take their medicine. This would help to ensure that there are no defaulters and that all patients comply as required.

To address the issue of non-compliance, it is suggested that TB patients should be confined in wards until they recover, services brought closer to people; this will include building more health centres, equipping the existing health centres and dispensaries with necessary testing kits for easy diagnosis; community workers to be hired to monitor treatment and report any cases of default, resistant or side effects –this is because some patients report severe side effect as the reason for withdrawal before recovery. People should also be equipped thoroughly with knowledge and all information vital for proper treatment.

7.2 Conclusion

From the study it is concluded that the majority of the people are conversant with TB disease: its causes, symptoms and transmission. This information is acquired through the public media, books, from friends or family members, encounters with TB patients, past experience and in schools. However, some few people lack this vital TB knowledge. As it was indicated in the assumption that people sometimes misinterpret the clinical causes and symptoms of TB, indeed the research reveals that this is the case. Some people associate TB with witchcraft/sorcery, others blame the supernatural beings and still others think the disease is hereditary. On the other hand, some TB symptoms are considered serious whereas others are regarded as insignificant.

The second assumption of the study – people's beliefs (beliefs about the causes, symptoms and also cultural beliefs) affect the choices they make regarding TB therapy, was also confirmed. It was found that, the interpretation of the symptoms and causes influence

the health-seeking behaviour of the people. When the disease's aetiology is placed in natural world, help is sought from modern medical facilities, but if the disease does not resolve (more especially if the patients abuse the drugs), then it is given a different interpretation and its aetiology is place in the social or supernatural world. In this case, help is sought from a chain of local "experts" ranging from diviners to witchdoctors.

The third and final assumption – "patients, especially the illiterate ones are likely to withdraw from medication before recovery" was also proven to be true. Indeed, as per the research findings, despite proper instructions that patients receive from providers, they go ahead and abuse TB drugs, which as discussed early, has severe economic and social consequences: resistant form of TB, destructions of lungs, continuous spread of the disease hence rising TB cases and even death. The abuse of drugs was found rampant among the old people without formal education whereas the younger people had high degree of compliance. Also, the economically disadvantaged groups living in medically under-served areas were reported to abuse drugs most because the services were not accessible and sometimes unaffordable (transport costs).

7.3 Recommendations

1. Since the perceptions of the causes and symptoms of the diseases are vital in the treatment-seeking behaviour and adherence to therapy, it is recommended that people should be educated on the clinical causes and symptoms of TB to correct misconceptions. This can be done through public seminars in the village to reach more people and especially the illiterate groups. Other important channels of passing information are public media and schools. Schools should be used to pass this TB knowledge to students/pupils, who will in turn pass it to their parents,

2 There is a growing need to include members of the community in TB control programmes. The community will assist in case finding and monitoring those who are under medication to ensure they adhere to therapy. In Bangladesh, Haiti and Peru community based TB programmes successfully contributed to effective TB control (WHO). This means, if the same strategy is applied in Sub-Saharan Africa and specifically in Kenya, it will work.

Community involvement in TB will not only help in prevention and control of TB, but it is also a cost effective intervention. This is because the government will spend less when the members of the community take charge in case finding and monitoring the patients as they take their medicine,

3 People should be educated, on the importance of modern medicine and adherence to it in fighting TB. They should be assured that the modern medicine is effective if taken correctly as prescribed by the physicians. This will ensure that people seek treatment from modern providers and that they do not turn to local medicine before even completing the prescribed dose (or, combining both therapies).

4. Due to rampant cases of default despite sufficient information, the study recommends that the free TB treatment program should include cost of accommodation in the wards. This will enable many patients to stay in wards for easy monitoring to ensure compliance to treatment,

5. Gender-related barriers to TB knowledge may vary greatly in diverse settings. Therefore, this research proposes that future studies should look into the magnitude and nature of gender disparities with regard to TB knowledge. These studies should also investigate whether matters of TB and HIV/AIDS are discussed in the family.

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Appendix 1. Questionnaire

Introduction

SECTION A. Demographic information.

Location .....

Sub location .....

Name (Optional)

Age: ☐ 18 - 25

☐ 26 – 35

☐ 36 – 45

☐ 46 – 65

☐ Over 65 (Please tick one)

Sex: ☐ Male ☐ Female

Education;

☐ Never went to school

☐ Up to standard 8

☐ Finished high school

☐ College/ University

☐ Others (Please Specify)

What is your religious affiliation? (Sect)

☐ Catholic

☐ S.D.A

☐ Muslim

☐ Traditionalist

☐ None

☐ Other (Please specify)

Occupation----------

SECTION B. TB perceptions (causes, symptoms, and transmission)

1. Do you know a disease called TB?

   ☐ Yes

   ☐ No

2. What are the causes of TB?

   .....

   .....

   .....

   .....

3. What are the symptoms of TB?

   .....

   .....

   .....

   .....

4. Of these, which symptoms are considered serious? .....

   .....

   .....

5. a) Can TB be transmitted from one person to another?

   ☐ Yes

   ☐ No

   b) If yes, please explain how.....

   .....

   .....

   .....

   .....

   c) If No, explain

   .....

   .....

   .....

6. a) Is there anything one can do to stop the spread?

☐ Yes

☐ No

b) If yes, explain.

.....

c) If No, explain. .....

.....

7. From which source did you acquire knowledge regarding the causes, symptoms and transmission of TB?

.....

.....

.....

SECTION C. <u>Treatment – seeking behaviour</u>

8. What can TB do to a person who has it and is not under medication?

.....

.....

9 a) Can TB be treated?

☐ Yes

☐ No

b) If yes, explain how.....

.....

c) If No, explain why .....

.....

10 What are some of the health care providers in this area where TB treatment can be received?

.....

.....

.....

.....

11.a) Of the above health care providers, which is your choice in the event of TB?

.....

.....

b) Give reasons for your choice. (Factors that influence therapy choice)

.....

.....

.....

.....

c) How far is the general hospital from this area?

☐ Less than 5km

☐ 5km-10km

☐ More than 10km

12. a) What is your first action when symptoms that reveal TB appear?

☐ Self-treatment using patent medicine/herbs.

☐ Go to hospital for tests.

☐ Visit traditional healer.

☐ Do not seek treatment at all.

☐ Other (please specify).

b) Explain your action.

.....

.....

.....

SECTION D. <u>Knowledge of HIV/AIDS and TB co-infection and how patients are handled</u>

13 a) Is there any relationship between HIV/AIDS and TB?

☐ Yes

☐ No

b) Please explain.

.....

.....

14 a) When you realize that one has TB, do you stay away from him/her?

☐ Yes

☐ No

b) Explain your action.

.....

.....

15 a) Do you think TB patients are stigmatized in the community?

☐ Yes

☐ No

b) Explain why.

.....

.....

16 a) Do you think fighting TB will help in the fight against HIV/AIDS or vice versa?

☐ Yes

☐ No

b) Explain.

.....

.....

SECTION E. Adherence to therapy

17. Have you or any member of this household, ever suffered from TB?

☐ Yes

☐ No

18. If yes, how did you know it was TB?

.....

.....

19. a) What action did you take?

.....

.....

b) Explain why you took the above action.

.....

.....

20. a) Were you given medicine?

☐ Yes

☐ No

b) Explain.

.....

21. a) Did you or he/she adhere to therapy as required?

☐ Yes

☐ No

b) If yes please explain

.....

c) If No, please explain why. .....

.....

.....

.....

.....

22. a) Did you go or take the patient for check-ups upon medicine completion?

☐ Yes

☐ No

b) If yes, explain.

.....

c) If No, explain. .....

.....

.....

23. a) Did you or the patient recover fully?

☐ Yes

☐ No

b) If yes, please explain.

.....

c) If No, explain. .....

.....

.....

24. Why do you think some patients do not comply with TB treatment as required? (Factors that influence treatment compliance)

.....

.....

.....

25. What do you think should be done to ensure people adhere to TB therapy as required?

.....

.....

.....

.....

26. Give your recommendations on what should be done to ensure effective fight against TB.

.....

.....

.....

.....

Appendix 2. FOCUS GROUP DISCUSSIONS AND INTERVIEW GUIDES.

1. Causes of TB.
2. Symptoms of TB.
3. Places where people go for treatment in case of TB.
4. Effects of cultural practices on therapy choices.
5. Factors that influence compliance to TB treatment.
6. People's attitude towards TB patients.
7. HIV/AIDS and TB co-infection
8. Attitude towards long TB regimens and recommendations.