

**HEALTH CARE SEEKING BEHAVIOUR OF TUBERCULOSIS
PATIENTS IN OBUNGA SLUMS, KISUMU**

BY

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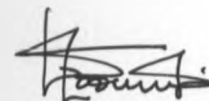
DECLARATION

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


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Lilian Akeyo Kawili

29/11/07
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Date

This thesis has been submitted with my approval as the University supervisor


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Dr. W. Onyango-Ouma

29.11.07
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Date

DEDICATION

This work is dedicated to my parents Veronica and Charles Kawili for their hard work and confidence in me

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LIST OF ABBREVIATIONS

- AIDS- Acquired Immuno Deficiency Syndrome
- CBS-Central Bureau of Statistics
- DOTS- Directly Observed Therapy Strategy
- DTC- Diagnostic Testing and Counseling
- EM-Explanatory Model
- FGD-Focus Group Discussion
- GNP-Gross National Product
- HIV-Human Immune Deficiency Virus
- MDR-TB- Multi Drug Resistant Tuberculosis
- NTBC- National Tuberculosis Centre
- NLTP-National Leprosy and Tuberculosis Control Programme
- SPSS- Statistical Package for Social sciences
- TB- Tuberculosis
- WHO-World Health Organization

ABSTRACT

This study was designed to investigate the health care seeking behaviour of TB patients in Obunga slums in Kisumu district. Field work for the study was conducted in the health care facilities located in Obunga slums and the surrounding area. The study sought to describe the perceptions of TB and their influence on health care seeking behaviour, document the health care options available to TB patients and examine factors that influence health care seeking behaviour of TB patients.

A total of 100 respondents were sampled using convenient sampling technique. Data collection methods that were used in the study included the survey, focus group discussions and key informant interviews. Three focus group discussions were conducted comprising of TB patients (2 groups) and TB ambassadors (1 group).

The findings indicated that all the patients had some idea about TB before being diagnosed but none thought that they could be suffering from TB. TB was identified by its symptoms mainly persistent cough and chest pains. The patients also associated their condition to other causal factors like cold, smoking, heredity and hard work. A few participants mentioned bacterial infection, indicating that they were not aware of the real causes of TB. Cultural beliefs about TB treatment were held by most patients.

The findings revealed that patients tended to use different therapeutic options for the same illness based on their perception of what they were suffering from. Most of the

patients preferred to self treat at home using both modern and herbal remedies with the hope that the illness would go away easily. With the persistence of the symptoms other therapeutic specialists were consulted, including herbalists, traditional healers, public and private clinics. The health facility was visited when everything else had failed to work, due to the pressure put on the patient by family members. After being diagnosed with TB at the health facility very few patients reported consulting other specialists for help.

Various factors were found to influence the patients therapeutic choice, including perceived seriousness of the illness, perceived causes of the illness, distance to the health facility, costs to be incurred, length of time taken, long queues at the health facilities, stigmatization of TB patients, and religious sects which restricted their adherents to spiritual healing.

It is recommended that members of the public should be sensitized to create awareness on the symptoms, mode of transmission and treatment of TB. This should be done using a medium that is accessible to all members of the public. The government should also fund diagnostic services offered to TB patients especially for chest x-ray so that patients who are smear negative can access this service at no cost. There is also need to equip health facilities with TB testing kits so that patients can get help easily and quickly, to prevent cases of misdiagnosis.

CHAPTER ONE

INTRODUCTION

1.1 Background information

Tuberculosis (TB) is a chronic bacterial infection that usually affects the lungs, although other organs are sometimes infected. Currently one-third of the world is infected with TB, most of who are found in resource poor countries and in the poor urban areas (slums) of the industrialized countries (WHO, 2002). TB is a contagious disease that kills approximately 2 million people every year and someone is newly infected every second (Strain, 2004).

TB is caused by the bacterium *Mycobacterium tuberculosis*, which is airborne. Evidence of the disease was first discovered by Sylvius in 1679, as tubercles, which were consistent and had a characteristic change in the lungs (National Tuberculosis Centre-NTBC, 1996). There are two forms of the disease, the pulmonary and the extra-pulmonary tuberculosis. Pulmonary tuberculosis is the most frequent of the disease and mostly affects the lungs; it is the form that is mostly contagious. Extra-pulmonary tuberculosis on the other hand, is the form that affects other parts of the body, which could be the pleura, lymph nodes, spine, joints, genito-urinary tract, nervous system or the abdomen (Enarson, 2000). Tuberculosis can affect any part of the body.

One can have active or inactive TB. People with active TB can pass the bacteria to whoever they come into close contact with. This means that the bacterium is active in the body and the immune system is unable to stop the bacteria from growing. Inactive/latent TB occurs where the body is able to fight off the bacteria and stop it from growing. People with inactive TB, thus, do not have any symptoms and cannot spread it. The bacterium may remain inactive for a lifetime and only become active if their immune system is weakened. Patients with pulmonary tuberculosis in whom the micro-organisms are so numerous as to be seen on the microscopic examination (smear positive) are the most infectious (Enarson, 2000). Those in whom the micro-organisms cannot be seen directly under the microscope (smear negative) are less infectious and the severity of the disease is usually less than that of smear positive cases. According to Enarson (2000),

among those who do become infected, most of them probably 80- 90% will never become ill with tuberculosis unless their immunity is seriously compromised (Enarson, 2000).

According to World Health Organization (2004), TB is the leading cause of death among HIV (Human Immune Deficiency Virus) positive people and it is estimated that it accounts for 13% of AIDS deaths worldwide. The two have been closely linked since the beginning of the HIV/AIDS pandemic back in the 1980s. The co-infection rate of TB-HIV is very high with HIV positive people being ten times more likely to contract TB than HIV negative people (De Cock, 1999; Ferrari, 2004). The HIV weakens the immune system and makes such individuals vulnerable to infections like TB. Eleven million people are currently estimated to be co-infected with TB and HIV (Ferrari, 2004). There is therefore need for vigorous screening for TB and active prophylactic treatment for all TB-HIV positive people to delay the onset of AIDS (Acquired Immune Deficiency Syndrome), reduce morbidity and mortality, and to prevent transmission.

TB can almost always be cured/treated with a combination of anti-biotics using the Directly Observed Therapy Strategy (DOTS), (WHO, 2004). This strategy was introduced in 1993, when the World Health Organization declared TB a global emergency. Under this strategy, a TB patient takes daily doses of pills during supervised treatment for 6–8 months. It is vital that the health system is able to offer infected people the simple anti-biotics needed under DOTS (WHO, 2004). Perlman et. al (2004) stressed the importance of putting TB patients on treatment after case finding as this minimizes the possibility of them spreading the bacterium further.

The Health care seeking behaviour of TB patients is a fundamental factor in the fight against TB. Health care seeking behaviour refers to what people do individually or collectively, to maintain and/or return to health (Liefoghe *et. al*, 1997). The therapeutic options that people have include taking bed rest or home remedy, asking advice from a friend or neighbour, consulting a priest, a traditional healer or a doctor (Kleinman, 1980) each of these approaches have their own ways of explaining and treating ill-health.

1.2 Statement of the problem

Tuberculosis is emerging as one of the world's biggest medical problems despite all the efforts put to control it (WHO, 2004). Of late, TB has shown great interrelationship with HIV and a number of those infected with HIV/AIDS have tested positive for TB (De Cock, 1999). According to National Leprosy and Tuberculosis Control Programme Report (NLTP, 2003), in Kenya alone there was an 18% increase of TB cases in the year 2003. Nyanza province has the highest TB notification rates in the country with an annual increase of 16% since the year 1999. Currently, TB services are offered in public health facilities at no cost. Services include treatment (drugs), diagnostic testing and counseling (DTC) and sputum testing during the treatment period. Ideally all people can access these services if they present TB signs and symptoms. And this in itself would lead to a significant reduction of the TB burden in the country. However, this has not been the case as NLTP (2004) reports show an upsurge in new TB infections and relapse cases, which has contributed to a high prevalence of TB in the country. The increase could be attributed to the infected continuing to spread the disease as they fail to seek for medical assistance for their illness or they could be using other alternative health care options with no experience of handling TB cases. The increase may also mean that people have a different perception of TB arising from their cultural beliefs and this could influence their health care seeking behaviour. This study therefore sought to investigate the health care seeking behaviour of TB patients in Obunga slum, by addressing the following research questions:-

- What are the patient's perceptions of TB and their influence on health care seeking behaviour?
- What are the health care options available for the treatment of TB in the slum?
- What are the factors that influence the health care seeking behaviour of TB patients in Obunga slum?

1.3.0 Objectives of the study

1.3.1 The overall objective

The overall objective of this study was to explore the health care seeking behaviour of TB patients in Obunga slum in Kisumu.

1.3.2 Specific objectives

- To examine patient's perceptions of TB and their influence on health care seeking behaviour.
- To document the health care options available for the treatment of TB in Obunga slum.
- To examine factors that influence the healthcare seeking behaviour of TB patients in Obunga slum.

1.4 Justification of the study

The rising rates of TB particularly in poor resource settings have been raising a lot of concern in the health care sector. There are fears that the battle in eliminating or at least controlling TB is being lost as TB statistics remain high. This study, therefore, aimed at addressing the disparity between the efforts aimed at controlling TB and the reality of the increase in TB cases particularly in Nyanza province as documented in the NLTP Report (2004). This study explored and described the health care seeking behaviour of TB patients among the residents of Obunga slum in Kisumu, and patient's perception of TB. The findings of the study provide necessary information to policy makers on the reasons behind the increase of TB case. The findings might also lead to a review of the strategies used to address the special medical needs of the slum residents in Kenya. Overall findings can be used to restructure, strengthen and improve existing national tuberculosis programmes and to bring the increasing cases of TB in Nyanza province and other parts of the country under control.

1.5 Scope and limitations

The study focused on the health care seeking behaviour of TB patients within Obunga slum in Kisumu, the available health care options and the perceptions of TB among the people of Obunga slum in Kisumu. The study was limited in the sense that only those living in Obunga slum in Kisumu were interviewed thus making generalization difficult.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

The chapter presents a review of existing literature on Tuberculosis, its incidence, the treatment options available to patients and determinants of health care seeking behaviour of TB patients.

2.2 The incidence of TB

According to WHO Report (2004), TB has become a major problem worldwide, with statistics indicating that out of the world's population of 6,219,011,000 the global TB cases have topped a total of 8,797,000 cases. The highest incidences are seen in countries of Africa, Asia and Latin America, which have the lowest Gross National Product (GNP). World Health Organization (2002) estimated that 95% of people infected with TB live in the third world countries. The Kenyan situation is not any different. According to NLTP Kenya Annual Report (2004) the number of TB reported cases has increased sevenfold from 11,625 cases in 1990 to 95,310 cases in the year 2004. The average annual increase over the past 10 years is 16% for all forms of TB.

The major reason for the increasing burden of TB in Kenya is the concurrent HIV epidemic (NLTP, 2004). HIV is known to be the most potent risk factor for the reactivation of latent TB and it also increases the risk of progression to disease of newly acquired TB infection. HIV infected TB patients are also at increased risk of recurrent relapses (NLTP, 2004).

2.3.0 Treatment options available for TB infected patients

The health seeking behaviour of patients is an issue often ignored by modern health workers. However, a better understanding of patient's motivation and actions is essential to understanding a disease like TB and its treatment. Such insights could possibly help to reduce delays in diagnosis, improve treatment compliance and supply suggestions for improvement of health education (Steen and Mazonde, 1999:164).

Society's health care system cannot be studied in isolation from other aspects of that society, especially its social, religious, political and economic organization. In most societies one form of health care, such as the scientific medicine is elevated above other forms, and its cultural and social aspects are up-held by law (Landy, 1977:44). Besides this official health care system, which includes the medical and nursing professions, there are usually smaller, alternative systems such as homeopathy, herbal and spiritual healing. Each has its own way of explaining and treating ill health, and the healers in each group may be organized into professional associations, with rules of entry, codes of conduct and ways of relating to patients (Kleinman, 1980: 82; Landy, 1977:44).

Liefooghe et al. (1997:810) stated that the relationship between culture, health-related beliefs and health behaviour is complex. Personal experiences, attitudes of the social network and health beliefs interact to influence health seeking behaviour.

According to Auer et al. (2000:648), most people with symptoms of TB first approach a private doctor. A process of multiple and varied health seeking that may be called shopping for diagnosis and treatment thereby begins. Typically poor patients end-up in public health services mainly because they cannot pay for prolonged care in the private sector.

Reasons that lead to shopping for diagnosis include:-

- The felt need of the patients to explore alternative providers especially when symptoms persist or reappear.
- Lack of trust in the public health services
- Sub optimal health services
- Financial constraints that require patients to shift from most expensive providers they see initially to others they can afford.

In a study done in Uasin Gishu, Liefooghe et al. (1997:814) found out that whenever a person felt any form of illness or discomfort, self treatment was initiated. This was done using herbs, drugs from the shops or left-over drugs from friends and relatives. They would also take drugs advertised in the media. The rural community would tend to start

self treatment with traditional medicine, and then move to self treatment with modern drugs before consulting modern health services.

Most TB patients went to modern hospitals once they experienced general discomfort and pain. Community members considered modern medicine for purposes of diagnosis, initiation of treatment, second opinion of diagnosis or for medical reviews. It was clearly stated, especially by the rural community, that modern health services at the rural level were not adequately equipped and lacked doctors to diagnose TB satisfactorily (Liefoghe et al. 1997:814; Hadley and Maher, 2000: 403). TB is perceived as a “sensitive” disease, thus hospitals are seen as the best place for diagnosis and specialized expert care.

In Botswana, Steen (1999:168), found out that 20% of the TB patients had visited a traditional doctor or a faith healer as their first step treatment. Thirty seven percent used alternative treatments after hospital TB treatment had been started. Most patients prefer to combine the hospital treatment and the use of traditional healers. A modern doctor can tell a TB patient that he/she has been exposed to the bacteria that cause TB, however the doctor cannot explain why he/she became afflicted and not somebody else in the household. A traditional healer seeing the same patient might tell him/ her that the real cause of the disease is that he/she has been bewitched by neighbours. Thus, unlike modern medicine, traditional medicine explains the meaning of the disease to the patient (Steen and Mazonde, 1999:164).

A modern health facility is used as the first step of action because of good coverage of highly subsidized health facilities (Grzybowski, 1987:34), a high awareness that prolonged coughing may be due to TB and finally that the patient may benefit from modern treatment. It is also reported that patients in Botswana, believe that western medicine works faster than traditional medicine (Steen and Mazonde, 1999:328). There is a tendency to use modern medicine as a “quick fix” solution, whereas traditional medicine is used to provide answers to questions that may be asked about the meaning of the misfortune, and to deal with the “real” causes of the illness. Preference for traditional

health care was highest among the elderly people with lower education and people of lower socio-economic status. (Staugaard, 1985:563).

In a study done by Xu *et al.* (2004:142) of the experiences of health care seeking of TB patients in China, they found out that financial difficulties influence their health seeking. Female and elderly patients were perceived to be more reluctant to seek for health care. They preferred to seek care for cough from village health stations rather than general hospitals. Many TB patients said they could not afford the cost of TB care, even where services were subsidized.

According to Auer *et al.* (2000:651), about two-thirds of TB patients had been told by someone to have a medical check-up for their symptoms. This advice came from a spouse, relative or neighbour. In a study they carried out in Manila, they found out that a private doctor was the first health provider approached for treatment, this was followed by a health centre and a few reported consulting a traditional healer (Auer *et al.* 2000:651). People prefer the use of private doctor first because people expect private doctors to be more effective, more easily accessible, more sympathetic and more likely to respect privacy than government health care providers. Auer *et al.* (2000:654) found that there is a lack of awareness that health centres provide TB services for free. Almost half of the patients who had used health centres for something else went there first where they sought for help for symptoms of TB. Prior use encouraged rather than discouraged further use.

According to Liefoghe *et al.* (1997:814), most rural women felt that the role of traditional healers should not be overlooked. They felt that there was nothing wrong with receiving treatment from traditional healers after getting diagnosis at the hospital. They saw traditional healers' medications as less cumbersome than modern treatment, and could be used side by side. The care of traditional healers was seen as a valid alternative when the modern health services had failed or when there was no improvement in the patient's condition. Traditional healers were considered easily accessible and had the added advantage that they are often paid after the patient has been cured (Liefoghe *et al.* 1997:815).

2.3.1 Delayed health seeking

According to Liefoghe, et al. (1997:814), most TB patients reported delay of several months, between onset of the symptoms and initiation of TB treatment. Appropriate treatment was delayed because most of the patients believed that they were suffering from something else other than TB. Prolonged self medication also delayed, patients felt the need to seek medical attention only after symptoms persisted for a period of time.

Reactions such as sadness fear of dying, guilt, embarrassment, and loss of self esteem increased health seeking delay (Auer, et al. 2000:652). Some mentioned that they were incorrectly diagnosed at their first place of consultation, which caused further delay (Liefoghe et al. 1997:814).

2.3.2 Decision to seek medical attention

The initial decision to seek medical attention came from various sources, the family was considered to be influential in the decision through finding the money for treatment and assisting in identifying suitable health facilities (Auer et al.2000:655). Others include friends, neighbours, community leaders, community members and health workers. Teachers also gave advice to their students to seek medical attention noticing signs as persistent coughs. Urban TB patients pointed out to the mass media influence through instructions such as “should symptoms persist, seek medical advice” (Liefoghe et al. 1997:815; Auer et al. 2000:655; Holm,1984:105).

2.4 Determinants of health care seeking behaviour

According to Liefoghe et al. (1997:812), pain and perceived seriousness of the disease determined the health care seeking behaviour of people suffering from TB. The symptoms that prompted them to seek for medical attention include prolonged cough with production of sputum, sharp chest pain, breathing difficulties, vomiting blood and loss of appetite. These symptoms had persisted for a long period of time, between 3 weeks and one month.

Kleinman (1980:88) did a study focusing on patients visiting hospitals and he found out that pain determined health seeking. Majority of the participants (60%) reported that pain was a trigger to take action.

The stigma that persists in relation to TB, that if you have TB you also have HIV/AIDS leads to individuals infected with TB hiding their illness. Late disclosure on the other hand means that the infection spreads to others, while this could be prevented. Social stigma also originates from doubts about its full curability and the perception that it is extremely contagious. Fear of isolation and segregation may have a negative effect on effective TB control, as it may lead to rejection of diagnosis and non-compliance of treatment (Auer et al. 2000:652; Liefooghe et al. 1997:818; Louw et al. 2000:14).

Lay people's knowledge and categorization of illness determines where they go to for treatment when ill. Perceived causes help to explain the meaning of a problem, whether it is considered a medical problem or a particular disease, and the implications based on cultural, familial, and personal background. According to Auer et al. (2000:650), the perceived causes of TB include drying sweat on the back, smoking, microbe, drinking alcohol, dirty environment, sleeping on cold floor, fatigue, poverty, inherited or being near a TB patient. The perceived causes determined where they sought for help when sick (Conner and Horman, 1996:102).

Liefooghe et al. (1997:812), found out that the local names given to TB reflect how people perceive the disease, e.g., the local name for TB among the Luo is "kahera" which means a disease that is in the chest and never disappears. Most local names describe TB as a chronic disease that affects the lungs, and often a reference to the fatal end is included. TB is seen as a wasting and debilitating disease. In most societies, TB together with leprosy and mental illness, are considered as very dangerous and the most shameful of diseases (Liefooghe et al. 1997:813). Because of this perception people shy away from seeking for treatment when they suspect that they have TB.

In other societies people classify illness along a continuum; there are those that are caused by natural agents and others by supernatural agents. Those that are caused by supernatural agents make people seek for supernatural intervention, while those caused

by natural agents are treated using natural intervention (Snow, 1993:112; Anderson, 1996:95). Supernatural agents include gods, spirits or ancestors; here illness is seen as a divine punishment and a cure involve the acknowledgement of sin and a vow to improve one's behaviour. Natural agents on the other hand, include climatic conditions such as excess cold, heat, wind, rain, dampness, e.t.c.

Anderson (1996:95), points that some illnesses are classified as being hot or cold. Hot illnesses are treated using cold remedies while cold illnesses are treated using hot remedies. Sputum is often an indication of a "cold" disease, while haemoptysis is a sign of excess "heat" thus TB may be classified as both hot and cold. This determines the patient's health seeking behaviour (Liefoghe et al. 1997:815).

The expenses that are incurred in health seeking are also a factor to consider, as fewer people will opt for an expensive treatment. In a study in Manila, Auer et al. (2000:654), found out that approximately half the monetary costs and majority of the time lost from work and other social costs are incurred before diagnosis. Most of the TB patients bought the prescribed anti-TB drugs when they go to the private doctors. Buying this medication rather than receiving it free at the health centre not only aggravates the financial hardships of the poor, but also often results in incomplete and irregular intake of drugs. They go to the private doctors because most of them are not aware that drugs are offered free of charge at the health centre. But according to Louw et al. (2003:12), the emergence of multi drug resistant TB and the impact of HIV on TB indicated that the epidemic was not under control. The government of South Africa thus had to make all TB treatment free of charge for all patients, using the DOTS strategy.

Transportation expenses can be a factor of distance. The further the patient is from the facility, the more they will incur during transportation in terms of money and time. If the patient is in an area with poor infrastructure the problem of access becomes more pronounced because you have to hire a vehicle or look for people to carry the patient. This multiplies the time one spends to access the facilities and makes people in remote areas to allocate more time in health seeking. With a new road the distance becomes

shorter; there is less wear and tear of the vehicle, more competition hence reduction in transportation costs (Alrey, 1999:583).

The initial clinical signs of TB are known but are often confused with other minor health problems, e.g., malaria (Liefoghe et al.1997: 813; Auer et al. 2000:651). This forms a sound base on which to build health education messages. TB treatment is perceived as exceedingly long, agonizing and cumbersome. Health education thus is necessary to inform the public without raising additional fears and should emphasize that TB is perfectly curable and that patients, once under treatment, become non – infectious within a few weeks. The positive side and the advantages of early diagnosis and correct treatment should be stressed. People should be made more aware of the early signs and symptoms of TB, especially those who recently had contact with known TB patients.

It should be stressed that health education will only be effective if health care providers understood cultural barriers to TB control and if they create the necessary supportive environment (Liefoghe et al. 1997:819; Steen and Mazonde, 1999:9).

However, health communication alone is insufficient for adequate control of TB. It cannot reduce the lag time to treatment unless health services are available, affordable and acceptable. Medicines must be readily available and efforts to promote the DOTS strategy must account for human aspect of clinical interactions (Auer et al. 2000:655)

From the existing literature it is clear that the facts that people know about TB symptoms, treatment and curability play a crucial role in their health seeking behaviour. It is also seen that culture and the people's belief about disease causation cannot be ignored, as they are what determines the kind of actions that patients will take when sick. When a patient believes that the illness is as a result of supernatural agents then the best mode of treatment at that time would be visiting a traditional healer. The hospital is seen as a second option for diagnosis when alternative modes of treatments have failed. Traditional healers on the other hand were preferred because they could offer explanations to the illness. And their treatment was seen as less cumbersome.

2.5 Theoretical Framework

This study was guided by the Explanatory Model (EM), which was suggested by Arthur Kleinman as a way of looking at the process by which illness is patterned, interpreted and treated (Kleinman, 1980). The Explanatory Model refers to the beliefs about an episode of illness and treatment that is employed by all those engaged in the clinical process. EM offers explanations of sickness and treatment, and guides people to make choices about available therapy options and helps patients to give meaning to the experience of illness. Explanatory models provide explanations for five aspects of illness; these include aetiology /cause, onset of symptoms, physiological changes, prognosis and treatment of the illness. They do not necessarily have all the components; some may only have the causes, prognosis and treatment.

The explanatory models are usually tied to a specific health system and will also vary from one culture to another or may at times overlap. According to Kleinman (1980) there are different sectors of health within the society these are the popular, folk and professional sectors, which do not exist independently but overlap. Individuals will always have an explanation of what they are going through and thus have their own explanatory model that is different from the health provider's EM. Explanatory models are used to explain, organize and manage illness. The seriousness of an illness depends on the explanation that people have for the origin of the illness, availability of a health provider and whether the patient can afford the costs to be incurred among other factors. The social and economic situation of the patient will also influence the types of treatment that patients can afford for their illness and whether this takes place in the popular, folk or professional sectors.

2.5.1 Relevance of the theory to the study

The Explanatory Model comes out as a theory of human behaviour that explains why people view illness the way they do and why they seek for health care where they do. The model suits this study because it helps to explain people's perception and behaviour in health care seeking. It helps to explain why a patient would visit a traditional healer and not a medical doctor or vice versa.

The most important aspect of EM is that it considers culture as a major determinant of human behaviour. Culture is a way of life and is shared by members of a community. It shapes the way people perceive illness and organize themselves for treatment. People's reaction toward illness is largely dependent on the meaning they attach to those illnesses, whether they are natural or influenced by supernatural forces. This perception determines the action to take, whether to see a doctor, a herbalist, spiritual healer or resort to self treatment. It is clear that the propositions of the EM are true and consistent with this study. Thus it is relevant in explaining and predicting the perception of TB and health care seeking behaviour of TB patient.

2.5.2 Assumptions

1. People suffering from TB perceive that the illness is caused by natural and supernatural factors.
2. When infected with TB, patients seek for health care from popular, folk and the professional (modern) sectors.
3. TB patients try out all options available in order to achieve better health as influenced by costs, availability of health care providers, beliefs, among others.

2.5.3 Definition of terms

Health care: - this involves organized behaviour and resources for maintenance of health, for prevention of physical illness or disability. Care involves more than medical treatment, and it occurs in many settings besides clinics or hospitals. In this case the study mainly focused on the medical treatment that is found at the hospital and other places visited before going to the hospital.

Sectors of health care: - these are the places where people go to seek for help when ill, this can either be in the hospital, traditional healer or self treatment.

Perceived seriousness: - refers to the beliefs a person holds concerning the effects a given disease or condition would have on his/her state of affairs. These effects can be

considered from the point of view of the difficulties that a disease/ illness would create, such as pain, discomfort, loss of work time, financial burdens, difficulties with family relationship.

Popular sector: - this is the lay, non- specialist domain of society, where ill health is first recognized and health care activities are initiated (Kleinman, 1980). These include self treatment or self medication, advice given by a friend or relative about treatment regimen to use or consultation with someone who has undergone the same experience.

Folk sector: - They are not part of the official medical system and include bone setters, midwives, tooth extractors, herbalists, spiritual healers and shamans. They deal with illnesses believed to be due to sorcery or divine punishment. In this case the researcher mainly focused on the role of herbalists, spiritual healers and medicine men in the treatment of TB.

Professional sector:- this comprises the organized, legally sanctioned healing professions such as western scientific medicine which comprises of paramedical professions like nurses, doctors, physiotherapists, etc. (Kleinman,1980).

Natural causes: - these are the natural agents presumed to cause ill health, they include, climatic conditions such as excess cold, heat, wind rain or dampness.

Supernatural causes: - these are the beliefs that people have about the agents that causes illness, they include gods, spirits, ghosts and ancestral spirit

CHAPTER THREE

METHODOLOGY

3.1.0 Introduction

This chapter provides a detailed description of the techniques that were employed during data collection, this includes the description of the study population, sampling techniques used, methods of data collection, data analysis and ethical consideration.

3.1.1 Research site

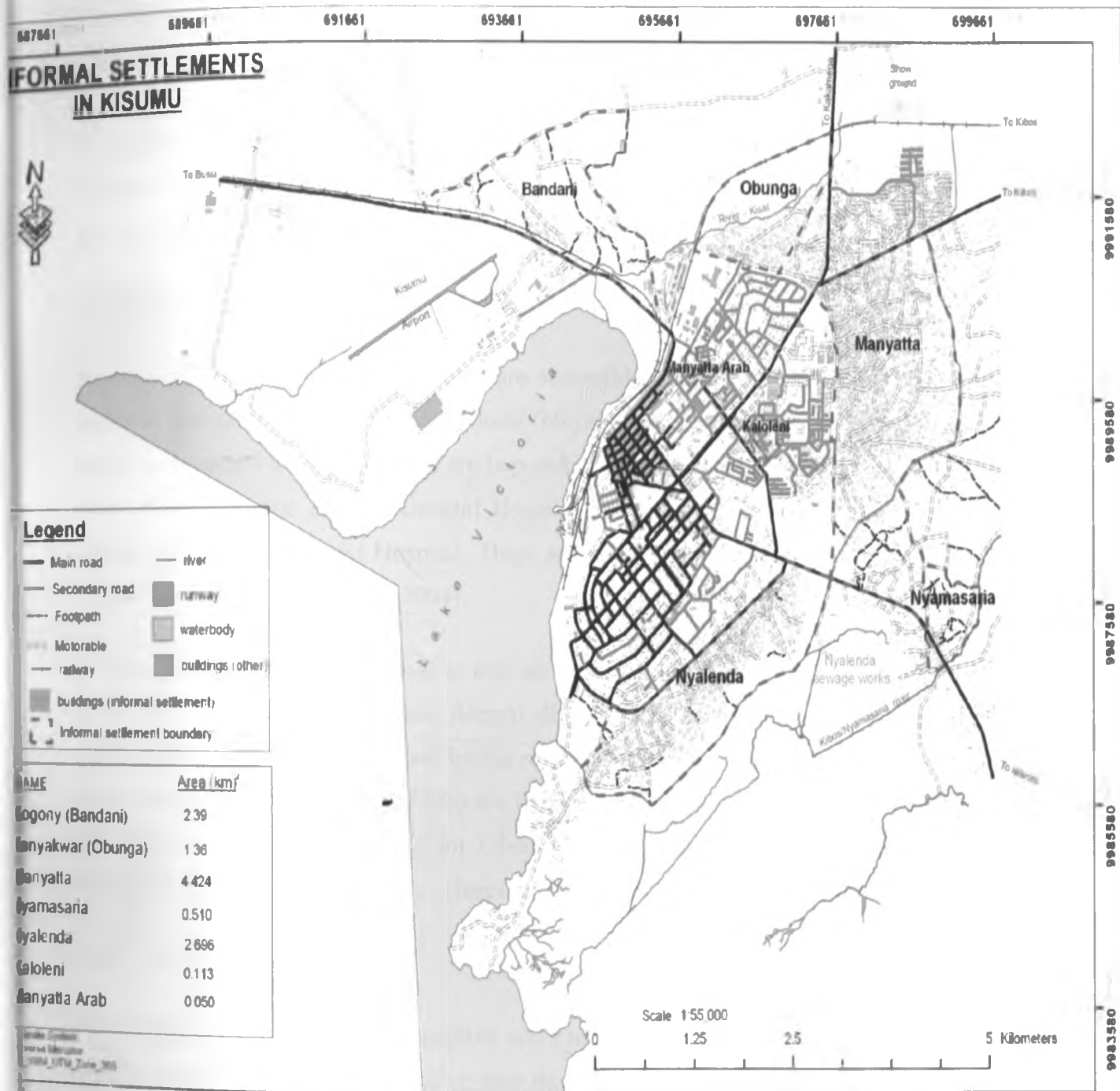
The study was carried out within Kisumu district. The district was established in 1967 following the split of the old Central Nyanza into Kisumu and Siaya districts. The total area is 2660 square kilometers of which 567 square meters are under water. Kisumu district is located between 0.30'S and 0.15'N latitude and 34.25' and 35.25' East longitude (CBS, 2005).

3.1.2 Location

The study was conducted within Obunga slums in Kisumu municipality (see figure 3.1). Kisumu municipality is the largest and most important urban centre west of Rift Valley. It is strategically located at the hub of communication network that serves most of the western Kenya. This has effectively facilitated its dominance as an administrative, industrial and commercial centre for this area.

The dominant tribe that occupies this region is the Luo, but since its an urban setting, there are also other people from different communities like the Luhya, Kisii among others

Figure 3.1: Map Showing Obunga Slums in Kisumu



Source: Demographical map – Kisumu Resource Center

3.1.3 Socio-economic activities

I observed that most people from Obunga engaged in brewing of *changaa* or *busaa* (traditional alcoholic drinks), these are the main sources of income especially for women. Other people engage in small-scale business opportunities like hawking vegetables, some are fishmongers or sell second hand clothes. Majority of the men engage in *bodaboda* (bicycle) taxi or work at the *jua kali* sector as mechanics. People who do not have the capital to startup a business, offer their services else where by working on people farms on the neighbouring village for money (*goyo otong'o*).

3.1.4 Infrastructure

Kisumu district has good roads, which are accessible, and user friendly. The dominant mode of transport is the use of *bodaboda* (bicycle taxis), which are cheap and can be easily accessed by everyone. There are two main public hospitals situated within the city centre these are New Nyanza General Hospital and the Old Nyanza General Hospital, which serves as the District Hospital. There are several privately owned, municipal and county council hospitals (CBS, 2004).

In Obunga there are two dispensaries that serve the people depending on how close one is to them; these are Mosque and Airport dispensaries. There is one privately owned clinic, which is not frequently used by the residents because of the high cost of services. There are also traditional doctors who are frequented because people trust them and they are easily accessible. Patients from Obunga also get services at the New Nyanza Provincial Hospital and the District Hospital both of which are located within the city.

3.2.0 Study design

The design of the study was descriptive and cross-sectional. This is because the study mainly aimed at collecting qualitative data though quantitative data was also collected. Both qualitative and quantitative data collection methods were used in the study, these included the use of survey method, focus group discussions (FGDs) and key informant interviews.

Fieldwork for the study was conducted for a period of 2 months in two phases. In the first phase, data was collected using a structured questionnaire, this involved conducting interviews at the health facilities used by the patients from Obunga. Data collected using this instrument included information on knowledge of TB, health care options available to TB patients and determinants of the patient's health care seeking behaviour.

The second phase involved the collection of qualitative data by conducting focus group discussions and key informant interviews. Key informant interviews were conducted with TB health providers, opinion leaders and TB ambassadors. FGDs were then conducted with patients and community opinion leaders. Pre-testing was done at a different location before the collection of the real data; this was done at Nyahera health centre.

3.2.1 Study population and unit of analysis

The study population comprised of people suffering from TB, health providers, TB ambassadors, community health workers and opinion leaders in Obunga slum. The unit of analysis was people infected with TB and are residing in Obunga slum. The population of people infected with TB was sampled and a sample size of 100 TB patients was obtained. This sample consisted of both men and women of ages 18 years and above and children who were under the care of their guardians. Key informants were also interviewed; they included the TB health providers, TB ambassadors and community leaders.

3.2.2 Sample and sampling procedure

The study employed non-probability methods of sampling mainly convenient sampling technique. Convenient sampling was used to locate TB patients at the health care facility.

Convenient sampling technique involves selecting cases or units as they become available. This study used this technique to locate TB patients at the health centre as they became available during treatment. The hospital register was scrutinized and personnel consulted to get a list of all the TB patients living in Obunga and had been on treatment

for 2 months and above. This was done because the patients became non- infectious after 2 months from the commencement of treatment. This reduced the risk of infection to the study team.

At this stage the patients were also likely to talk more freely because the frequency of coughing is reduced. A total of 100 TB patients were then picked as they became available to seek for healthcare at the health facilities.

3.3.0 Methods of data collection

Data was collected using both primary and secondary data collection methods. Primary data was collected using survey methods by using a semi-structured questionnaire. Key informant interviews, focused group discussion and direct observation were also used to collect primary data. Secondary data was collected using secondary sources of data, such as books, journals, statistical abstracts, development plans, theses, e.t.c. They were used to supplement the primary sources and for building data for the study.

3.3.1 Survey method

A standardized questionnaire, which comprised of both open-ended and closed-ended questions, was administered in a face-to-face interview. Open-ended questions gave the respondents the freedom to respond as they wished and to give their opinions and feelings. Closed-ended questions on the other hand were accompanied by a list of all possible alternatives from which the respondents selected the answer that was best for them (Mugenda and Mugenda, 1999).

The questionnaire was necessary to find out the health care options that were available to TB patients, the factors that influenced the people's health care seeking behaviour and their attitudes and perceptions of TB. The questionnaire was administered to 100 TB patients who were selected using convenient sampling. The questionnaire was formulated in English but translated into *Dholuo* and *Swahili*, languages the local people understood. The interviews were conducted at the health centres in a location that was well aired and had plenty of light, which makes the tubercle inactive. Each questionnaire took about 15-

20 minutes to complete depending on how fast a respondent was. This method was effective in getting information that was viewed as private and the demographic characteristics of the patients. For example, during an interview, a patient could easily tell you that they got TB because they had HIV but could not talk about this when conducting group sessions.

3.3.2 Focus group discussions

A focus group discussion (FGDs) is a group that brings together people from similar backgrounds to discuss a specific topic of interest to the researcher (Bernard, 1988). FGDs are used to yield information on the community's beliefs, values, understanding of health problems and permit rapid ethnographic assessment of barriers to health behaviour (Liefoghe et al., 1997).

One focus group comprised of 8 participants, a moderator and a note taker. A total of three focus group discussions were conducted. Patient participants were a sub sample of the 100 respondents who were interviewed. Their selection was based on how open a patient was during the interview, whether the cough was persistent or not and those who looked stronger and talked about issues more freely than the others. The participants for the third FGD were selected conveniently from the community. An audio cassette was used to record the discussions.

Focus group discussions allows for in-depth discussion of the topics and for more group synergy (Bernard, 1988). Questioning here is flexible and its easier to reveal the participants' real perception. These discussions were used to find out what the people knew about TB, their experiences and perceptions of TB and the factors that influenced their health care seeking behaviour. The problem with this method is that group leaders may monopolize and influence other people's opinions. This problem however was not encountered here as everyone was given equal chance of participating and airing their views. Funnel questioning approach was used whereby questioning began with broad questions and moved to narrower ones. The focus group discussions conducted, comprised of women only, the second of men only and the third one comprised of community leaders. Each FGD session lasted for about 30-45 minutes.

3.3.3 Key informant interviews

A key informant is a person who is knowledgeable in the topic of the researcher's interest. In this study, 8 key informants were selected conveniently, they were not drawn from the initial 100 patients. They included TB health care providers, TB ambassadors, church leaders and community village elders. The key informants were selected to give valuable information on the people's perception of TB and their health care seeking behaviour. In-depth interviews were used to gather information and this was tape recorded.

3.4 Methods of data analysis

Both qualitative and quantitative techniques of data analysis were used to analyze the data gathered from the field.

Qualitative data was analyzed using qualitative techniques mainly direct quotes and selected comments from the FGD and key informant interviews. Themes, categories and patterns were identified; these were then related to the study objectives.

Descriptive and inferential analysis was used to analyze quantitative data. The responses got were given codes and entered for computer analysis. This was analyzed using a computer package, SPSS (Statistical Package for Social Sciences). The results were then presented using descriptive statistics.

3.5 Problems encountered and their solutions

The major problem that was encountered was that of mistaken identity whereby most of the respondents on hearing that I was from Nairobi, felt that I could solve their problems. Respondents could explain to me all the problems that they have had with the drugs or other illnesses with the hope of getting some help from me. This was countered by making them understand that I was just carrying out a study that would benefit them later on. The other problem was that of demand for financial favours, this was mainly because the respondents were from the slum area and were undergoing a lot of hardships to make ends meet, so most of them expected to be given some money in exchange of the

information given. I was able to overcome this by explaining to them the purpose of the research and its long-term benefit to them. Some of the participants who had been selected to participate in the focus group discussions also failed to turn up and new ones had to be recruited, this led to the extension of the study by a few days.

3.6 Ethical consideration

I ensured that the respondents were informed of the research goals and objectives to minimize suspicion. The respondents were also assured of strict confidentiality during the period of study; this was done by ensuring that their names did not appear anywhere. This was also done to ensure anonymity because of the belief around the study area that people who had TB also had HIV, so the participants did not want to be stigmatized by other people. This was also done to de-link the respondents from the information that they had given so that whatever a respondent said could not be used to identify them. Informed consent was obtained from the respondents before including them in the study, only those who agreed participated those who refused were not forced into participating.

CHAPTER FOUR

PERCEPTIONS OF TUBERCULOSIS AMONG PATIENTS IN OBUNGA SLUM, KISUMU DISTRICT

4.1 Introduction

The findings of the study on the perceptions of TB among the residents of Obunga slum, as deduced from the qualitative and quantitative data are presented in this chapter. The chapter also discusses how patient's beliefs and attitude towards TB influence their health care seeking behaviour. The findings have been discussed and related to previous studies conducted on health care seeking behaviour among TB patients.

4.2 Knowledge of TB among the study population

A total of 100 patients were included in the study, of these 48% were males and 52% females. Out of the patients interviewed 25% were single, 64% married, 2% divorced and 9% widowed. The findings indicated that patients who were married sought for proper treatment sooner than those who were single. The spouses were found to have had an influence in pressurizing the patients to seek for help and so to the actions that they took to get back to good health.

The age distribution of the respondents ranged between 12 years and 65 years old with a median age of 24 years. These findings show that TB affects people of all ages though majority of those infected are aged between 26 and 30 years. Ninety eight (98) percent of the respondents were Christians, while the other 2% were Muslims. This could be attributed to the fact that few Muslims may be residing in the study area or that they may

be visiting other health facilities that were not included in the study. Under Christianity there were denominations like catholic, African independent churches and traditional churches like the *Legio maria*, *Roho* and *Dini ya msambwa*.

The main source of income in the study area came from small enterprises, which represented 26%. These included selling vegetables, fish, second hand clothes, shoes, and dealing in illicit brew. The other sources of income included casual work at 21%, automotive repair work/mechanic (10%), carpentry (4%) and teachers (3%). The other 12% of the respondents were unemployed.

The data contained in table 4.1 indicates that most patients (56%) had attained primary level of education, 39% secondary level with 5% having attained post secondary education. The participants' level of education could be part of the reason why most of them work in the informal sector.

Table 4.1 Participant's level of Education

Level of education	Frequency	Percentage
Primary level	56	56
Secondary level	39	39
Post secondary level	5	5
Total	100	100

Source: survey 2006

Data from the interviews and FGDs indicated that patient's knowledge about TB largely depended on the patient's level of education. The most educated (44%) patients were more aware of TB symptoms, its probable causes and acted faster when they fell ill. The

study also found out that patient's age was not a crucial factor determining patient's knowledge of TB. Less educated (56%) patients were mainly hampered by economic constraints and as such could not make quick decisions concerning their health.

Participant's knowledge of the signs and symptoms of TB was examined to find out whether patients had the capacity to identify the disease. The study revealed that all the respondents had some idea about TB symptoms prior to being infected. The information about TB was obtained from friends, relatives and neighbours who had been infected with TB, at one point. Some patients (8%) had also heard about the disease through the electronic media for example radio, while for others (92%), TB was considered to be a new disease that is infecting people currently.

In Obunga, majority of the people (96%) knew that TB only infects the lungs (Pulmonary TB), they do not, however, seem to know that there are other forms of TB including extra-pulmonary TB which some (2%) of them were suffering from. Ninety eight (98) percent of all the TB patients were pulmonary cases, with all of them indicating that they had persistent cough. This could explain why most patients associated TB with coughing. There were cases where a patient had pulmonary TB but did not cough and only experienced sharp pains and chest congestion. Two (2) percent had extra pulmonary TB mainly of the neck and the stomach. These patients had difficulty believing that they had TB because of the belief that TB only caused persistent coughs. A male participant in the study illustrated this:

I noticed that I had a small swelling on my neck which continued to increase as days went by, so I went to the hospital but I was just given some painkillers which

did not work and I had to go back to hospital. Various tests were carried out after this they told me I had TB. I did not believe it, in fact I even argued with the doctor that I was not coughing but he insisted and put me on anti-TB drugs.....(male TB patients FGD)

Majority of the respondents (98%) associated TB with persistent coughs especially at night. All the patients seemed to identify TB by its symptoms and not by its causal factors. Among the symptoms of TB mentioned included persistent cough (*aonda mak rum*), spitting blood (*ng'ogo remo*), chest pains and congestion (*kor mathung'*), loss of appetite (*dhok marach*), sweating at night (*golo luya*) and weight loss (*dhero*). Other symptoms mentioned included fever, feeling cold and general body pains. Similar symptoms were pointed out by Liefoghe et al. (1997), who noted that most of the participants in a study he carried out in Uasin Gishu recognized wheezing, chest pains, loss of appetite, weight loss and coughing blood, as definite signs of tuberculosis.

When asked to identify TB symptoms, most patients cited persistent coughs (98%), chest pains (83%), lack of energy (54%) and weight loss (40%). These ones seemed to be the major symptoms of TB the patients were aware of. There were other symptoms that were mentioned, these included blood in sputum (15%), loss of appetite (28%) and sweating at night (20%). Spitting blood and sweating at night were least mentioned, despite the fact that they were the main identifiers of TB (table 4.2).

Table 4.2 Patient's knowledge of TB symptoms (multiple responses possible) (N=100)

Symptom	Frequency	Percentage
Persistent cough	98	98
Loss of appetite	28	28
Lack of energy	54	54
Blood in sputum	15	15
Weight loss	40	40
Chest pains	83	83
Sweating at night	20	20

Source: survey 2006

Apart from the above mentioned symptoms, other patients (24%) tended to associate TB with HIV with patients infected with TB perceived to be HIV positive. This could be attributed to the fact that TB patients grew very thin and weak, and ended up looking like HIV patients. People around the study area also assumed that patients infected with TB had HIV/AIDS too. This finding confirm findings in a study that was done by Auer et al.(2000) in Manila where he reported that the stigma that persists that if a patient has TB he/she also has HIV/AIDS, leads to patients hiding their illness.

During my field work I observed that, other patients at the health facilities visited looked at TB patients with contempt. Some people even feared passing next to the TB patients waiting area. This is part of the stigmatization that TB patients suffered in this area. An opinion leader aged 42 years old had this to say:

People generally know that TB is a chest disease that makes people cough a lot, the situation is made worse by the belief around here that TB and HIV are

connected, such that a person who has TB will be seen to be suffering from HIV and not TB, there is still a lot of stigma on this (Key informant-TB ambassador)

When asked what they had to say about TB, patients gave various answers. The responses included, TB is a disease that make people grow thin (16%), TB causes persistent cough (30%), TB is *kahera* (3%)(a cough in the chest that is difficult to treat), TB is a chest disease (20%), TB comes due to bacterial infection (3%), TB is a communicable chest disease (10%), TB is a disease that makes people cough blood (7%), TB is a dangerous disease that kills quickly (7%), and patients with TB also have HIV (4%). (Table 4.3)

Table 4.3 Patient’s opinion about TB

Opinion	Frequency	%
Disease that makes people grow thin	16	16
Persistent cough	30	30
TB is <i>kahera</i>	3	3
Chest disease	20	20
Bacterial infection	3	3
Communicable chest disease	10	10
Disease that makes people cough blood	7	7
Dangerous disease that kills quickly	7	7
People with HIV also have TB	4	4
Total	100	100

Source: survey 2006

Information in table 4.3 was supported by data obtained from interviews conducted where majority (32%) of the participants felt that TB could kill very quickly when proper

treatment is not adhered to. Four percent (4%) of the participants believed that people infected with TB also had HIV. Only 3% mentioned that bacteria causes TB indicating that the patients were still ignorant of this fact yet they had been taught about the cause and mode of TB transmission at the TB clinic.

A majority of the respondents (68%) interviewed reported that before being diagnosed with TB, they knew that TB was a dangerous disease. Thus, people infected with it were supposed to be kept away from the public eye. TB patients were regarded as very contagious and community members were barred from interacting with them freely. A female participant aged 38 years old illustrated this:

I used to know that a person who has TB eats alone, sleeps alone and uses different utensils separate from the ones the other people use. They were regarded like "koko" (boogey man used to scare people whenever they did wrong). (female TB patients FGD)

The patient's attitude towards TB seemed to have changed after being infected with TB. The patients had consensus that TB is treatable and that it is airborne. The participants also came to accept the fact that TB is an opportunistic infection of HIV and mostly infects HIV patients due to their reduced immunity.

4.3 Patient's perceived causes of TB in Obunga slum

Patients were interviewed to find out what factors they attributed their illness to, and several factors were mentioned. However, most respondents (70%) were not aware of the real causal factor of TB (*Mycobacterium tuberculosis*). The patients tended to attribute

their infection to other causal factors like cold, smoking, alcohol, hard work, dust, heredity and pneumonia (table 4.4)

Table 4.4 Patient's perceived causes of TB

Cause	Frequency	%
Smoking	8	8
Bacteria	5	5
Cold	16	16
Exposed by an infected person	30	30
Alcohol	4	4
Heredity	27	27
Pneumonia	1	1
Low immunity	3	3
Hard work	2	2
Dust	2	2
Chest problems	2	2
Total	100	100

Source: Survey 2006

Table 4.4 shows that majority of the patients (30%) blamed their condition on exposure to an infected person. This was mentioned by patients who had been living with infected patients or had a sick neighbour. It was not that patients knew TB was airborne. They just assumed that their condition could have arisen from sharing the same living quarters with an infected person. Twenty seven percent (27%) of them blamed their condition on heredity; this was mostly put across by patients who believed that TB was passed on from one generation to the other. Liefoghe et al. (1997) also noted this and added that there was a common belief that inheritance and familial association constituted a

mechanism of transmitting TB. Low immunity (3%) was attached to patients being HIV positive.

The knowledge that people have about an illness informs and thus guides the action they take when sick. When people are aware of the symptoms and mode of transmission of a disease they are more likely to take proper action than when they are only speculating what they could be suffering from. Lack of knowledge about a disease is what leads to shopping for treatment. In the study setting, TB was considered as a disease of the poor as was illustrated by information from focus group discussions. The participants even wondered whether people from higher socio-economic backgrounds ever suffered from TB. This was mainly as a result of the fact that most patients at the TB clinic were from the slum areas of Kisumu like Jua kali, Bandani, Nyalenda, Manyatta and Obunga. A male participant aged 28 said thus:

Does this disease affect people from the rich estates too like Milimani or does it affect only those who do not have money (Jomo rem), here at the clinic it is like we are all from Obunga and Manyatta... (male TB patients FGD)

4.4 Obunga patients beliefs on TB

Societies have different cultural ways of defining and treating illnesses. Special attention is given to illnesses that do not heal easily even after utilizing available treatment options. The findings from this study revealed that TB was among some of the illnesses that residents of Obunga slums considered difficult to treat. Where other solutions had

failed, patients reviewed their cultural beliefs and traditions (*kitgi gi timbe gi*), to find out if they had gone against them. Patients did this to find alternative solutions for their illness. Of the respondents who were interviewed, 85% had some cultural beliefs attached to TB, 3% felt that it was inheritable while 12% did not know whether there were any traditional beliefs attached to TB. Seventy two percent (72%) reported that TB is *kahera* (a cough in the chest that is difficult to treat) 13% knew that TB is *chira* (a cultural illness among the Luo that afflicts people who break the taboos and cultural beliefs), 3% said that TB is inherited while 12% did not have any cultural beliefs associated with TB. The findings show how strongly patients uphold the belief that TB is *kahera* (a cough in the chest that is difficult to treat), as a result traditional remedies were considered the best for TB treatment.

Eighty eight percent (88%) of the respondents mentioned that they had cultural ways of treating TB, while the remaining 12% did not know of any traditional forms of treating TB. Majority of the patients (72%) mentioned using *yadh agulu and dwele* (a mixture of herbs that was boiled in a pot and given to a patient was to inhale the vapours by being covered with a blanket), 8% knew of *manyasi* (a mixture of herbs that was given to people who were believed to have broken cultural taboos), 4% knew that a patient was given drugs for taking and bathing, 4% knew that one was tied with roots to relieve chest pains while 12% had no idea whether there were any cultural remedies for TB. Majority of the patients (72%) believed that TB could only be treated using traditional means through *fundruok* (covering a patient under a pot of boiled herbs to sweat out the illness) using *yath agulu and dwele* (a mixture of herbs that are boiled in a pot and given to a patient to inhale by being covered in blanket) .

The study revealed that patient's cultural beliefs came into play right at the onset of symptoms. The Luo patients who had persistent coughs associated their condition to *kahera* (a cough in the chest that is difficult to treat). The local names given to TB reflect how people perceive the disease; most local TB names describe TB as a chronic disease with a fatal end (Liefhooghe et al. 1997). *Kahera* (a cough in the chest that is difficult to treat) was also thought to be a curse and a disease of the clan that could be passed on from one generation to the next. A male participant aged 26 years illustrated this:

When my cough became so persistent, my mother told me that I could be having kahera and I may have got it from the clan because my great grandmother also suffered from it. It did not just infect anyone (male TB patient FGD).

Participants from other ethnic regions also mentioned that they had local names for TB. TB was referred to as *olwera* among the Luhya and *kifua kikuu* among Swahili speakers, both terms translates to a disease that is in the chest. Among the Luhya, a patient was treated using herbal mixtures and were also isolated until they recovered. Participants concurred that traditional forms of treating TB cannot be used to treat the current strain of TB. The Gusii reported using herbal mixtures to treat the cough that was causing the chest pain.

4.5 Societal attitude towards TB patients

The findings indicated that most patients never disclosed their condition to their friends for fear of being rejected. Most of them revealed their condition only to their spouses and

parents. Information from the focus group discussions indicated that most patients who revealed their condition to their friends were later on isolated, neglected and treated with a lot of contempt. They reported being treated like people with some deadly plague. A male participant aged 26 years said:

People said a lot of things about me when they discovered I had TB. Most of my friends whom I used to drink with avoided me and even stopped coming to my house, instead they started spreading rumours that I had AIDS. I was seen and treated like someone who had a bad plague and even the neighbours stopped their children from coming to my house, I had to relocate from there to a place where no one knew me since I felt that the rejection, not the disease, could make me die quickly ... (male TB patients FGD)

Patients also recounted that they were seen as AIDS victims by their friends and neighbours, due to weight loss. Patients also seemed to be limping due to the side effects of anti-TB drugs, which caused some pricking on the soles of their feet. This made them look sicker than they were, some had to be carried to hospital, as they could no longer walk. Participants reported that when their condition improved after visiting the health facility, their relatives and friends accused them of using witchcraft to get better, a female participant aged 30 years said thus:

When my condition deteriorated, people said that I had AIDS while others said it was chira (cultural illness among the Luo that afflicts people who broke the taboos and cultural beliefs). They stayed away from my house nobody even wanted to be seen talking to me. I was taken to the hospital and now that I'm much stronger they are saying that I visited a witchdoctor who treated me ... (female TB patients FGD)

Members of the community did not readily welcome patients who had been diagnosed with TB. Patients were isolated and given separate beddings and utensils upon advise at the TB clinic during the intensive treatment phase because they were still contagious at this point. Though patients became non infectious after the first two months of taking anti-TB drugs, they were not allowed to interact with younger members of the family for fear that they could infect them. Similar findings were reported by Auer et al.(2000) and Liefoghe et al.(1997) who reported that children were instructed to avoid contact with TB patients, community members also avoided contact with TB patients and their family for the fear of being infected.

Patients mentioned that they experienced more rejection when they traveled to their rural homes. A female participant aged 24 put it thus:

When I travel back to the rural home where people do not know much about TB, I'm treated like an outcast because TB is considered a very dangerous disease and people feared coming near me. No one touches or uses the utensils that I have used and I sleep alone. I could hear them murmuring that I have been lucky to survive this time round ... I only get support from my parents there is one time that my brothers told me not to come home again until I'm sure that I'm completely healed... they felt that I could infect their children (female TB patients FGD)

Liefoghe et al. (1997) also noted that sometimes even relatives stopped their children from having contact with their parents who had TB. Utensils were kept separately and often it was suggested that patients take meals and live in separate quarters. A female participant reiterated that women suffered more rejection as they were abandoned by

their husbands as soon as they learnt of their condition. This happened to her, when she told her husband that she had TB, he simply packed his belongings and left. This was attributed to the belief that people with TB were also HIV positive thus the husbands took off to avoid being infected.

Ninety six percent (96%) of the respondents who were interviewed reported that they were accepted by their spouses and not the extended family in general after being diagnosed with TB. The findings further indicated that male participants preferred not to mention their condition to anyone; some never even told their spouses what they were suffering from. Two percent (2%) of the participants reported being blamed for the problem while the other 2% reported being isolated. All the participants who reported being isolated and being blamed for the problem were women. This is an indication that women are more likely to suffer rejection when sick and may not have anyone to care for them when sick. In most societies women took care of the sick members, when they also fell ill they were taken care of by the children (Hadley and Maher, 2000). Patients who did not have children were likely to suffer alone because as the findings show, people fear TB patients.

This chapter aimed at presenting the findings on patient's knowledge of TB in terms of symptoms and causation, patient's belief about TB and people's attitude towards TB patients. The study found out that the perception of patients about their ailment influenced their health care seeking behaviour.

The findings from the study also indicated that most patients knew some symptoms of TB though none mentioned all of them. Symptoms that were mainly mentioned included persistent cough and chest pains. It is important to note that the major symptoms of TB like blood in sputum and sweating at night were mentioned by very few patients, 15% and 20% respectively.

Patients tended to associate their illness to other causal factors mainly cold weather, dust, heredity, alcohol among other factors. Patients actions were found to be guided by the perceived causal factors of the illness such that if one thinks that it is as a result of the bacterium they would go to hospital first and not to a herbalist. TB was perceived to be dangerous chest disease that was difficult to treat and could kill very fast when proper treatment was not given in good time.

The study found out that TB was referred to locally as *kuhera* (a cough in the chest that is difficult to treat). Traditional remedies were believed to be the best for *Kahera*. *Kahera* (a cough in the chest that is difficult to treat) was believed to be a curse that was passed on from one generation to the next. People suspected to be infected by it were isolated from other members of the society. The study showed that some (4%) of the patients were rejected and isolated by friends and family members, though some (96%) were accepted and given the support they needed. The study found that TB is confused with *chira* (a cultural illness among the Luo that afflicts people who broke the cultural taboos and beliefs) due to its persistence and the way patients lost so much weight. There was further belief that *Chira* (a cultural illness among the Luo that afflicts people who broke

the cultural taboos and beliefs) could only to be treated through the use of traditional remedies.

Though most patients reported that their spouses and the nuclear family accepted them, they suffered rejection and isolation from their friends and relatives from the extended family. They were treated as outcasts, thus they preferred to only tell their spouses of their condition.

CHAPTER FIVE

HEALTH CARE OPTIONS AVAILABLE FOR THE TREATMENT OF TB IN OBUNGA

5.1 Introduction

Chapter four discussed findings on patient's knowledge, belief and attitude towards TB. this chapter presents findings of the study on health care specialists consulted by TB patients. The findings will mainly focus on services received from the three sectors of health (popular, folk and professional sectors) right from the onset of illness and actions taken to return to good health.

5.2 Therapeutic options utilized by TB patients in Obunga

The study revealed that availability of health care options to TB patients largely depended on patient's perception of what they were suffering from, their level of education, socio-economic status, cultural beliefs and the patient's gender. Patient's perception of the illness would determine whether they would go for folk, popular or professional sectors of health. The findings indicated that the most educated patients tended to use the professional sector sooner than the less educated patients. Economically empowered patients had control of their finances and took action faster when they fell sick than those who were dependant or lacked any source of income. A female participant aged 28 reiterated this:

The biggest problem that we have is lack of money especially for those of us who depend on our husbands for money so when I'm sick will I ask for money for food or for hospital, it is only good when one has a small business then I can help myself... (female TB patients FGD)

The findings indicated that TB patients had a variety of health care options to choose from right from the onset of symptoms. Among the health care options mentioned by the respondents include self treatment using both herbal and conventional drugs, seeking the services of herbalists or medicine men, or visiting public and private clinics and hospitals.

The treatment choices were used simultaneously or at different times. Failure of one option prompted patients to try other available options. Success rate of one treatment option determined the length of time taken by the patient before trying the next option.

5.3 Actions taken by TB patient's from the onset of illness

The findings indicated that at the onset of symptoms patients tried every means at their disposal to return to good health. Table 5.1 shows that at the onset of symptoms, majority (75%) self treated with drugs from the shop/pharmacy, 2% self treated with herbal medicine, 12% visited a medical doctor, 3% visited a private doctor, while the other 8% ignored the symptoms with the hope that they would go away on their own.

Table 5.1 Patient's first line of action at the onset of symptoms

Action taken	Frequency	Percentage
Self treated with drugs from the shop	75	75
Self treated with herbal drugs	2	2
Visited a medical doctor	12	12
Visited a private doctor	3	3
Ignored the symptoms	8	8
Total	100	100

Source: survey 2006

A majority (75%) of the respondents reported that they self treated with drugs from the shop at the onset of symptoms. Patients mostly used left over drugs from earlier illness episodes or bought over the counter drugs from the pharmacy/shop. Drugs bought over the counter included *Koo*, *Cofta*, *Breacol*, *Vicks kingo*, *Panadol*, *Hedex* and *Asprin*. These drugs were used as the first line of treatment from the onset of symptoms. When symptoms persisted, other anti-biotics (*Amoxyl* and *Seprin*) were used. Liefoghe et al. also (1997) observed that prolonged self treatment was one of the important reasons for delay of appropriate treatment.

Other patients (2%), reported that they self treated using herbal drugs which were bought from the streets or were found growing wildly. *Akwar* (a weed) was mostly used since patients believed that it had the ability to heal coughs and chest problems faster.

Twelve percent (12%) of the patients reported that at the onset of symptoms, they visited a public health facility, mostly a health centre or a dispensary. Patients explained that

they were given cough syrup, pain killers and anti biotics at the clinics. In other instances, patients were diagnosed with malaria and typhoid, thus were treated for these illnesses. Similar cases were reported by patients (3%) who visited private clinics at the onset of symptoms. This was because initial symptoms of TB were confused with symptoms of these other diseases.

None of the respondents mentioned going to the traditional healer or herbalist as the first option taken at the on set of symptoms. Other patients (8%) mentioned that they ignored the symptoms hoping the illness would go away. Self treatment was then initiated when the condition persisted; this action was mainly taken by male patients. A male participant aged 28 illustrated this:

At first I just ignored the cough and thought that it was the result of early morning cold. I used to take some warm water whenever I felt ill because I do not like taking drugs, but the cough continued to increase instead of subsiding so I decided to buy some drugs from the pharmacy ... (male TB patients FGD)

When patients realized that the first line of treatment was not working, they tried other health care options available and it was at this stage that shopping for health care solutions began. Table 5.2 shows other specialists that were consulted when initial medication failed to work, they included herbalists (32%), traditional healers (13%), medical doctors (21%), faith healers and friends (16%).

Table 5.2 Second line of treatment when symptoms persisted

Person consulted	Frequency	Percentage
Herbalist	32	32
Traditional healer	13	13
Medical doctor	21	21
Faith healer	18	18
Friends	16	16
Total	100	100

Source: survey 2006

A majority of the patients (32%) decided to consult a herbalist when self treatment failed to work. Patients reported that they consulted herbalists because they were easily accessible and affordable. From the observations I made during this fieldwork, I noticed that there was over supply of herbal medicine concoctions in Obunga slums and the surrounding areas. These have found their way into the country from the neighbouring countries of Uganda and Tanzania, and a few local ones. The herbalists claimed that herbal mixtures had the ability to cure all manner of illnesses including TB. It was as a result of these claims that most patients preferred to consult them than go for professional help in hospital. A male informant aged 36 reiterated this:

What has brought the biggest challenge in the fight against TB here, is the mushrooming of herbal mixtures that claim to have the ability to cure all illnesses even HIV. Most people thus prefer using them when they fall sick even after being put on hospital drugs you will still find patients combining them with hospital treatment. There are patients who even after being diagnosed with TB will still go back to buy the herbal concoctions... (Key informant-TB ambassador)

Some patients (13%) reported that they consulted traditional healers when symptoms failed to disappear after self treating. Traditional healers were consulted with the belief that they could offer satisfactory explanation to the causes of a patient's condition. It was at this point that the patient's cultural beliefs and traditions came into play. Patients relied on their cultural beliefs in their search for explanation of what they were suffering from; whether they had been bewitched or had broken one of the traditional taboos. A male participant aged 34 said thus:

When I was young I was brought up to know that a normal illness should go away once you treat it but when it fails to go then it means that there is more to it than meets the eye. I assumed that may be someone had looked at me with "bad eyes", or that I had been bewitched or broke one of the taboos, so have to decide to consult "ajuoga" (witchdoctor) to give me an explanation... for real when I went I was told that I slept with a woman whose husband had died and that was why my body was wasting away. So I needed cleansing to rid my body of the bad omen...(male TB patients FGD)

A majority (30%) of the older men and women aged between 40 and 65 years preferred to consult traditional healers first before initiating any modern treatment. This was done with the belief that not doing so could aggravate their condition in case they had *ndagla* (witchcraft) put on them. Steen and Mazonde (1999), also noted this and added that traditional medicine classifies disorders according to perceived cause whereby illness may be caused by God, spirits or ancestors. A traditional doctor may explain to the patient the real cause of the affliction and the person who caused it. In instances where patients went with persistent coughs to a traditional healer, they were diagnosed with

kahera (a cough in the chest that is difficult to treat). This was illustrated by a female participant aged 38:

Kahera was believed to be passed on from one generation to the next and patients infected by it had non stop coughs, so when I consulted a traditional healer with the problem he kept me away in seclusion where no one was allowed to come. I was treated using yath agulu. [The patient was to sweat out the disease]. Then I was given mor alenya (fat from skimmed milk) this was to heal the scar in my chest... (female TB patients FGD)

The findings indicated that there were other patients (18%) who consulted faith healers when their condition did not improve. They felt that people did not just fall ill by chance, but that illness was induced by something else beyond human powers and by evil people in society. These patients believed that ill health resulted from the work of witches and sorcerers, thus they needed miracles to rid them off the evil spells. Similar findings were also pointed in the past by Steen and Mazonde (1999) who noted that “faith healing churches” placed a lot of emphasis on healing by praying and using holy water to heal. Patients believed that prayers led to one getting a miracle and would then be healed by their faith (faith healing). Patients who consulted faith healers (*Jolemo*) were born again Christians and could not consult *ajuoga* (witchdoctor). In most instances the patient’s condition was associated with the work of *jonawi* (people who possess destructive charms used to harm others) Churches that were reported to offer faith healing included Legion *Maria*, *Roho* and *Dini ya Msambwa* and some Pentecostal churches. A male participant aged 26 reiterated this:

My condition was not improving even after being given drugs from the hospital so my mother took me to a church Joroho so that I would be prayed for. I went through "checking" to find out what my problem was. The person who prayed for me said that someone had put ndagla (witchcraft) on my chest and they had to remove it. One of them made some incision (saro) on my chest using a razor blade and sucked out something and spat it on the ground. Apparently this was the cause of my illness so I would get better...(male TB patients FGD)

These findings confirm the findings of Auer et al. (2000) and Liefoghe et al. (1997), who added that the care of traditional healers was seen as an alternative when the modern health services had failed or where there was no improvement in the patient's condition. Traditional healers were mainly consulted before proper diagnosis was made. From the findings it is clear that the effects of these modes of treatment did not last for long. Patients assumed that they were healed and so continued with their lives normally not knowing that they were still spreading the mycobacterium to the unsuspecting members of the public. The findings also showed that patient's condition deteriorated when the illness recurred.

Twenty one percent (21%) of the patients interviewed reported that they visited a medical doctor as a second line of treatment when self treatment failed to work. A majority of them (16%) visited private clinics while only 5% visited a public health facility. The public dispensaries visited by the patients lacked the facilities and equipments for conducting sputum tests. This resulted in misdiagnosis and most patients reported that they were diagnosed with pneumonia, chest congestion, typhoid or malaria.

A male key informant aged 32 reported that patients were misdiagnosed even at the private clinics where they ended up being given Septrin and painkillers. A female participant aged 26 said thus:

At first when I fell sick I bought drugs and I felt better but after sometime it came back so it was on and off. I went to a small private clinic nearby and they told me that I had bronchitis because my chest was congested, the drugs did not help me much. Then I decided to go to a government hospital though I do not like them because they do not have drugs and always give people Paracetamol. I went to Mosque dispensary and was diagnosed with malaria and typhoid but I do not remember being tested for these, so I was given Fansidar and Amoxyl. I got better but when I finished taking the drugs I just took three days and fell sick again so my friend took me to a herbalist... (female TB patients FGD)

When the symptoms continued to persist, 85% of the patients reported that they were advised by someone else to look for professional help while 15% decided on their own. Twenty nine percent (29%) were advised by their spouses, 40% by their family members, 10% by their friends while the other 6% were advised by their neighbours. Family members and friends came out to support the patient financially and out of concern that the patient's condition was getting worse.

The study revealed that the health facility was visited as the last resort when all the other options had failed. The hospitals visited by patients were Kisumu District Hospital, New Nyanza Provincial General Hospital and St. Monica's Mission Hospital. These were the diagnostic centres where TB sputum tests and chest x-ray were done. After diagnosis patients were referred to health facilities that were located near them for medication and registration. The health facilities within the reach of the study population were Mosque Dispensary and Airport Health Centre. Traders working within the city centre were allowed to utilize the facilities at New Nyanza Provincial Hospital. The patients who

visited New Nyanza Provincial Hospital as the first option were luckier because as a Provincial Hospital it had all the facilities and equipments.

After consulting a medical doctor and being diagnosed with TB, only 9% of the patients reported looking for help elsewhere. Reasons given for these actions were that the public facility was closed since it was a weekend (1%), chest problem persisted (3%), diarrhoea (2%), body was generally weak and tired (1%), while 2% said that the cough was still persistent.

The services that patients received when they consulted the services of other specialists included, being given an injection (1%), given herbal mixtures for drinking and to bathe with (4%), given *yath agulu* (1%) (a mixture of herbs that was boiled in a pot and given to patient to inhale the vapours by being covered with a blanket) while the other 3% were given a herbal mixture for drinking.

At the hospital, patients were required to give three samples of sputum that were tested for the mycobacterium. Sputum testing was offered at no cost at the hospital. Patients whose sputum tested negative for the mycobacterium had to be subjected to a chest x-ray to ascertain their status and were required to pay 150 shillings for the service. Patients who tested positive for the mycobacterium were put on anti-TB drugs immediately. Further, patients had to go through HIV testing; this was to help the health providers to establish whether a patient's condition was as a result of HIV.

HIV testing was made compulsory for all TB patients because as one health provider reported, there were patients who never revealed their status and some anti-retroviral

drugs were found to react negatively with anti-TB drugs. Where a patient's status is known much earlier they are given anti-retroviral drugs that do not react with anti-TB drugs.

Once diagnosed with TB, patients were put on anti-TB drugs for a period of eight months. The first two months are known as the intensive phase where patients are given a cocktail of drugs that are very strong. It is at this stage that patients also became non infectious. The other six months are the continuation phase where patients continue with medication that is not very strong. For children, treatment lasts for 6 months, 2 months intensive and 4 months continuation. Patients became stronger health wise after 4 months. It was at this time that most patients absconded treatment. This was mostly reported by patients who disclosed that they did not like taking drugs. Absconding treatment was found to be the main cause of TB relapse in Kisumu. A female health provider aged 45 said thus:

Most of our patients are relapse cases mainly coming as a result of absconding treatment after the intensive phase because they feel stronger and so believe that they are healed. There are patients who fear taking drugs so when they feel any slight changes in their health they disappear, most will come back after a few months sick again so we treat them using DOTS (Directly Observed Therapy) ... (Key informant-health provider)

A majority of the patients (38%) reported that they abandoned treatment because they were tired of taking drugs. These patients complained that the drugs were very big and choked them. A participant reported that "you have to put it inside a piece of 'ugali'" for

you to be able to swallow it because the smell can make you vomit". At the hospital the patients were given 2-4 capsules that were to be taken daily. The number of capsules depended on a patient's weight. Patients who weighed less were given fewer capsules and vice versa.

Other patients (12%) abandoned treatment after the intensive phase when the symptoms still persisted. Patients reported that they were advised by friends to use traditional herbs when anti-TB drugs were not working for them. A female health provider aged 38 explained thus:

We have other patients who run away after 2 months because they still believe that traditional drugs will work for them. Most of them do this when the symptoms do not improve after the intensive phase. We are forced to trace such patients and put them back on medication, problem came up when they did not give the right address... (Key informant-health provider)

TB relapse patients were retreated using Streptomycin injections together with anti-TB drugs. Patients were put on daily injection for a period of two months, then they continued taking anti TB drugs for 6 months under directly observed treatment. HIV was also attributed to the high number of relapse TB patients. Most patients who had HIV and TB tended to get relapses soon after the completion of the dose, because the virus reduced their immunity level. Such patients are retreated but when they get a relapse again, then their sputum is taken for culture and sensitivity test to examine whether they had developed resistance to anti TB drugs.

A health provider reported that a new TB strain had developed as a result of patient's resistance to anti TB drugs. This was the Multi Drug Resistant TB (MDR-TB), which was difficult and expensive to treat. In Nyanza alone they had 3 cases of MDR-TB (by 2006), patients infected with MDR were confined in wards to prevent them from spreading it. Complete treatment for one MDR-TB patient took half a year and cost 2 million shillings. It was for this reason that TB treatment defaulters and relapse patients were closely monitored and traced to ensure that they did not develop resistance to anti TB drugs.

The findings also indicated that all patients tried to adhere to the treatment regimen that they were given in hospital. Only 9% reported visiting other specialists but this was attributed to other small ailments like stomachache, diarrhoea and fatigue. Patients were advised against combining hospital drugs with herbal mixtures. Patients who reported doing this were counseled to stop and a family member was consulted to observe them when taking drugs.

All patients expressed hope that they would get better and they concurred that the hospital had a cure for TB. Though patients complained that anti TB drugs had so many side effects that made them spend so much money on food and especially milk, patients agreed that anti-TB drugs worked and would work for them too. All TB patients reported a delay time of going to the hospital of between 2 weeks and 4 months. Majority delayed for 2-4 months (43%), 54% delayed for 2 weeks -1 month, while only 3% went to the hospital immediately.

The duration of the delay was determined by various factors including prolonged self-medication (54%), misdiagnosis after the first visit (18%) and some believed that they were suffering from something else (28%). The duration of delay was also determined by a patient's perception of the illness, economic status and level of education. A male health provider aged 28 reiterated thus:

People who come from around the urban set-up come early to the clinic for diagnosis and treatment. It also depends on the economic and educational status of the patient, patients who have money and know about TB will come directly to the hospital. Those who are not well conversant with the treatment and mode of transmission of TB tend to take longer. On average most of them take 2-3 weeks before they come... (Key informant-health provider)

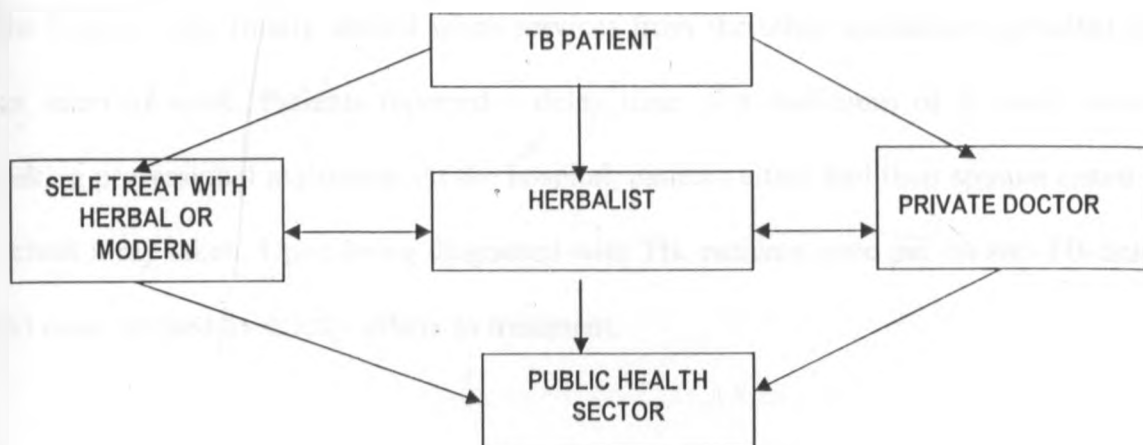
5.4 Health care seeking behaviour of TB patients

A health care seeking pattern can be deduced from the study findings on the health care options used by TB patients. At the on set of the symptoms the illness was ignored for sometime. Self treatment using both herbal and over the counter drugs was then initiated. When this did not work a specialist, either a herbalist, traditional healer, faith healer or private clinic was consulted. When the condition continued to deteriorate the patient was finally taken to a public health facility (figure 5.1).

This chapter presented findings on health care options available to TB patients. It was reported that TB patients consulted various specialists from the on set of symptoms to the stage where they got proper treatment. Treatment options used by TB patients included

self-treatment using both herbal and modern drugs, visiting traditional healers, herbalists, faith healers or medical doctors.

Figure 5.1: Health Care Seeking Behaviour of TB Patients



Treatment option used was mainly determined by a patient's perception of what they were ailing from. Patient's first self treated using over the counter drugs with the belief that the illness was minor and would heal. Shopping for treatment was initiated when self-treatment failed to work.

There were patients who decided to visit public and private clinics but were misdiagnosed so they opted for other treatment options. According to Steen and Mazonde (1999), modern medicine is seen as important for the diagnosis of the disease while traditional medicine is seen as a valuable alternative where modern medicine had failed. Other patients who thought that their illness was tied to cultural beliefs consulted traditional healers and herbalists who only offered short-term solutions to the illness. Patients, who believed that they had been bewitched, since their symptoms were

persistent, consulted faith healers. Liefoghe et al. (1997) reported similar findings and added that both modern and traditional medicines are consulted and there was no indication for a particular preference of either.

The hospital was finally visited when services from the other specialists consulted did not seem to work. Patients reported a delay time of a minimum of 2 weeks before seeking professional assistance. At the hospital, patients either had their sputum tested or a chest x-ray taken. Upon being diagnosed with TB, patients were put on anti TB drugs and were advised to strictly adhere to treatment.

These findings confirm the co-existence of several types of medicines offering a variety of treatments and causal explanations to the same illness. Each specialist consulted came up with his or her own explanations and modes of treatment to the same illness a patient had.

CHAPTER SIX

FACTORS THAT INFLUENCE HEALTH CARE SEEKING BEHAVIOUR OF TB PATIENTS IN OBUNGA

6.1 Introduction

In chapters four and five, I discussed findings on patient's knowledge and beliefs on TB, and actions they took to get back to good health when they fell ill with TB. In this chapter, I present findings on factors that determined therapeutic choice of TB patients. Among the factors discussed in this chapter include cost incurred, availability of health facility, time, distance, perceived causal factors, stigmatization among other factors.

6.2.1 Determinants of health care seeking behaviour of TB patients

Various factors were found to have influenced the action(s) taken by patients when deciding which therapeutic choice to use. Factors that were mentioned by the patients interviewed included too much pain 86%, fear of dying 3%, failure of medication from the first consultation 63%, distance 63%, cost 89%, stigma 20%, traditional beliefs 1%, religion 1%, time 1% while 1% mentioned long queues (table 6.1).

Too much pain and failure of medication from first consultation forced majority of the patients (89%) to go to hospital. According to Liefoghe et al. (1997), pain and perceived seriousness of the disease was a trigger for the patient to take action. Pain attributed to most patients (63%) having self treated with herbal and modern drugs without success. Other patients (3%) mentioned that they decided to go to the hospital because they feared they would die if they continued delaying.

Table 6.1 Factors that determined the health care seeking behaviour of TR patients (Multiple responses possible)

(N=100)

Factor	Frequency	Percentage
Too much pain	86	86
Fear of dying	3	3
Failure of medication from 1 st consultation	63	63
Distance	63	63
Cost	89	89
Stigma	20	20
Traditional beliefs	1	1
Religion	1	1
Time	1	1
Long queues	1	1
Just decided	8	8

Source: survey 2006

Most patients (63%) mentioned that the distance from their homes to the diagnostic centre was far and one had to part with 30 shillings for transport to get there.

The main means of transport for them was by the use of *bodaboda* taxis. After a patient had been referred to a diagnostic centre (District or Provincial General Hospital) from the dispensaries, most patients went back to their homes and waited for a number of days before they got money for transport. Majority of them being too weak to walk had to wait and raise money for transport. A male health provider aged 28 reiterated thus:

The distance to the hospital makes some patients not come straight away because they have other costs to consider like transportation costs and given that this is a district hospital some come from very far, the patients who are referred here end up taking even a month before they come...most patients think of coming to the

hospital when they are already too weak to walk on their own, those with money will be brought by the bodaboda riders or may get some good Samaritan who will use a wheel barrow... (key informant-health provider)

The other expenses mentioned had to do with costs that would be incurred when a patient went to hospital. Apart from transportation costs, patients reported that they had to pay a fee (shs.20) for registration cards at the general out patient clinic. Patients also had to buy prescribed drugs before being put on anti TB drugs which would cost about 200 shillings. According to Auer et al.(2000) buying these medication rather than receiving them free of charge aggravates the financial hardship of the poor and results in irregular intake of drugs. Patients whose sputum tested negative of TB had to part with 150 shillings to get a chest x-ray to ascertain whether they had TB. A health provider reported that the hospital had facilities that waived hospital fees for poor patients but that this mostly applied to patients who were in the wards. The general feeling by the patients was that people took so long before they went to the hospital because of lack of money to cover the expenses. A female participant aged 27 said thus:

... lack of money make most people not go to the hospital because they know that they will be asked to pay for the services they receive at the hospital. This is mainly because when we visit the dispensaries at times one is asked to buy even a syringe and needle for them to get an injection. Most people will assume that when you go with symptoms that are more serious you will have to pay more, they are not aware that the anti-TB drugs and TB treatment are offered for free of charge at the government clinics(female TB patient FGD)

Some patients (17%) complained that they spent a lot of time whenever they went to hospital; this in turn interfered with their other daily programmes. This finding confirms findings by Xu et al.(2004) and Grzybowski (1987) who reported that patients spent a lot of productive time off work looking for health care. Auer et al. (2000) also reported that most of the time lost from work and other social costs were incurred before diagnosis. Patients mentioned that there were long queues at the clinics thus they had to go there very early to be ahead in the queue. Health providers started offering services as from 9 am, by which time the waiting bay would be full with patients. Most patients reported to the clinic as early as 7 am and by the time they received the services they would have waited for two hours or more. Patients who reported later spent more time as the health providers also took time off to eat. By the end of the day, some patients, especially those going to the clinic for the first time and who are referred elsewhere for other services, ended up spending close to eight hours at the clinic.

Religious background of the patients determined what actions they took when they fell ill. The study found out that there were churches that preferred to pray for their sick members rather than have them go to hospital. These were churches that believed in faith healing. The belief was that patients could be healed miraculously through prayers. A woman aged 42, reported that when she fell sick, she was first taken to their church (*Roho*) for prayers and “checking” (to find out the real cause of the illness whether it was as a result of witchcraft and by whom). After prayers and consultation the church elder told her that God was saying that she should be prayed for first then go to the hospital and she would get healed. In other instances patients got instantaneous miracles and got

healed, her case was just unique and the church had to decide whether to let her go to the hospital or not.

Patient's knowledge and categorization of illness determined what actions they took when ill (Anderson 1996). This study found out that TB was classified along a continuum whereby causal factors were associated with either natural or supernatural agents. Most patients (66%) blamed their condition on natural agents, these included cold weather, dust, alcohol, smoking and bacteria. Patients mentioned that these were treated using natural remedies like keeping warm, behavioral change like abandoning smoking and alcohol consumption, and going to the hospital to treat bacterial infection. Supernatural agents that were blamed for patients condition included witchcraft and punishment for breaking cultural taboos. Patients believed that remedies for illnesses caused by supernatural agents could only be obtained from traditional healers. Thirty four percent (34%) of the participants fell in this category; they reported that they spent a lot of time moving from one traditional healer to the other with no success. They all ended up in hospital. These findings indicate that the perceived causal factors of the patient's illness were crucial in determining where they went to look for help.

Stigma that is attached to TB made patients shy away from looking for proper assistance (Auer et al. 2000; Liefoghe et al.1997). Patients infected with TB were isolated, looked down upon, considered very contagious and people tended to stay away from them. Patients feared going through this and did not therefore want their condition to be revealed by going to the hospital. In Obunga slums there was the belief that people infected with TB were also HIV positive, this made patients suffer from stigmatization.

This was attributed to the fact that people had not yet come to accept that HIV can infect anyone; thus, people suffering from HIV were shunned and ignored by all. Participants concurred that they feared going to the hospital as they could be found with the virus, a male health provider aged 28 reported thus:

People fear being tested for HIV, especially now that the government wants us to have a TB/HIV collaborative management, so we have to screen all the patients for HIV to be able to know how to help them when positive...most patients know this so they fear coming because there is still a lot of stigma about HIV (Key informant-health provider)

All TB patients were thus tested for HIV to know their status and to be able to put them on anti-retrovirals soon. Information is shared by people so when word gets out that patients have to be tested for HIV; they are likely to stay away from the hospital because of the stigma that is still attached to being HIV positive.

The aim of this chapter was to present findings on the factors that influenced patient's therapeutic choice. I found out that patient's actions were guided by various factors including the cost to be incurred to access treatment, distance to be covered while looking for treatment, cultural beliefs attached to the illness patients perceived to be suffering from, time spent while looking for treatment, long queues at public health facilities, religious background of the patient, and the perceived causes of the illness, homes, religion, cultural beliefs, time and pain. These findings clearly indicated that most patients were not aware that TB treatment was offered for free at the public health facilities. It was also evident that most patients were not aware of what they were ailing

from and the real causes of their illness. It is also clear that patients had cultural beliefs that were associated with TB, this coupled with the above mentioned factors worked together to influence a patient's decision on therapeutic choices.

The findings further revealed that most TB patients were relapse cases resulting from defaulting and HIV, these two factors were found to have also contributed to the high incidence of TB in Kisumu.

CHAPTER SEVEN

CONCLUSIONS AND RECOMMENDATIONS

7.1 Introduction

The general objective of this study was to explore the health care seeking behaviour of TB patients in Obunga slums in Kisumu district, and specifically to describe how perceptions of TB influence patient's health care seeking behaviour, document the health care options available for the treatment of TB and to examine factors that influence the health care seeking behaviour of TB patients. The findings from each objective have been summarized, conclusions drawn and recommendations for both policy and further research made.

7.2 Conclusion

The main conclusion drawn from the study is that the patient's perceptions of what they were suffering from played a crucial role in determining what action(s) they took to get back to good health. TB patients had some knowledge about the disease and had heard about it either from friends, relatives or the media. They believed that it was a chest disease, which could kill very fast if not treated properly. As opposed to the known causal factor of TB (*mycobacterium tuberculosis*), most patients demonstrated ignorance of this and majority of them attributed their illness to other factors including cold weather, smoking, dust, alcohol, heredity, low immunity, hard work and *chira* (cultural illness among the Luo that afflicts people who broke the cultural taboos and beliefs). TB was perceived to be *kahera* (a cough in the chest that is difficult to treat). Patients suffering from *kahera* (a cough in the chest that is difficult to treat) were isolated and

regarded as very contagious. A majority of those interviewed believed that *kahera* (a cough in the chest that is difficult to treat) could only be treated by traditional healers. This belief largely influenced the kind of treatment sought by TB patients.

The study found out that there were various health care options available to TB patients. These included self treatment, consulting herbalists, pastors, traditional healers and medical doctors. At the onset of symptoms all patients interviewed self treated with over the counter drugs and only consulted other specialists when this option failed. At this stage, patients used several treatment options either simultaneously or at different times before being put on anti TB drugs. The study found out that there was a delay time of three months before proper treatment was sought, during which time infectious TB patients continued to spread the bacterium unknowingly. Public health facilities were visited when all the other treatment options failed to yield acceptable results. This implies that lack of information about TB, its causes and treatment act as barriers to patients seeking for proper treatment and prevention. This also means that reduction of new TB infections may be achieved by informing patients and Obunga slum dwellers that TB treatment can only be obtained in hospital and not otherwise.

Several factors were attributed to the delay in getting proper treatment at public health facilities. Among the factors cited included cost to be incurred, distance from the facility, stigmatization, long queues at health facilities, time spent before being attended to, misdiagnosis and perceived causal factors of the illness. Distance from the slum to health facilities and perceived cost of treatment were found to be critical in determining the level of utilization of the facilities. Lack of TB diagnostic centre in the slum forced

patients to travel to the city for diagnosis. Majority of the patients were not aware that TB treatment was offered for free at public health facilities. Indeed, lack of information considerably contributed to most patients staying away from the health facilities under the false belief that they would be charged for the services. In addition, the perception of TB as *kahera* (a cough in the chest that is difficult to treat) by the slum dwellers and the belief that it could not be treated in the hospital hindered them from visiting hospital as the first option when sick.

Finally, the findings clearly demonstrate that the patient's perceptions of TB, the health options available to them and the factors they consider before deciding on which health care option to use collectively influenced the health care seeking behaviour of TB patients.

7.3 Recommendations

Based on the findings of the study the following is recommended to policy makers in helping to improve the health care seeking behaviour of TB patients: -

1. There is every need to train more TB ambassadors to help in tracing TB patients at the community level. The ambassadors' main objective would be to identify and refer suspected TB patients to health facilities for proper diagnosis. This will ensure early detection of TB in infected people and placement on treatment in good time. This will help in reducing the delay time when TB patients shop around for treatment thereby reducing TB transmission rate.

2. There is need to educate TB patients and Obunga slums dwellers in general about the biomedical causes of TB, its symptoms, transmission and treatment. Health education should be done in a way that is accessible to people from all walks of life. Greater emphasis should be placed on educating the least exposed members of society who are mostly found in slums, about TB and its management.

3. The government should consider further subsidies for TB x-ray charges or waive them altogether. This is because, as the study found out, the greatest impediment to utilization of public hospitals is the belief among most patients that they will be required to pay high costs in order to obtain appropriate diagnosis for TB. Indeed the amounts paid are as little as Kshs. 150 to 200. Though this may seem low to better endowed members of the society, slum dwellers, who were the subject of this study consider that cost as still very high. The reduction and/or waiver will most definitely encourage more patients to come forward for clinical TB diagnosis, thus ensure early detection and treatment of TB and in the long run help in reducing TB infection rates.

4. The government needs to create more awareness about the connection between TB and HIV to reduce stigmatization of TB patients. This study found out that there is high stigmatization of TB patients with the assumption that they are also HIV positive.

5. TB sputum tests should be offered immediately a patient visits hospital with complaints of cough and chest problems. This will help in minimizing cases of

misdiagnosis. This may be achieved by ensuring that all public health centres and dispensaries are equipped with testing and diagnostic kits. This will ensure easy access to health care for TB patients.

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APPENDIX I
INTERVIEW SCHEDULE

UNIVERSITY OF NAIROBI
INSTITUTE OF AFRICAN STUDIES

**HEALTHCARE SEEKING BEHAVIOUR OF TUBERCULOSIS PATIENTS IN
OBUNGA SLUMS IN KISUMU DISTRICT.**

Questionnaire Number

Name of Health Facility

Date of interview

Name of Interviewer

Time interview started

CONSENT FORM

Good morning/Afternoon. My name is LILIAN AKEYO KAWILI. I am a student at the University of Nairobi conducting a survey on the health care seeking behaviour of TB patients. I would like to discuss with you a few issues about TB to enable me establish what you know about TB. I would be grateful if you could spare a few minutes to answer the questions I would like to ask.

I would like to assure you that the information you provide will be treated with strict confidence and your name will not appear anywhere in the interview schedule. Do you agree, Yes No

Interviewer's Signature
If the respondent Agrees

Date

PART I: GENERAL QUESTIONS

(Please tick whichever is appropriate)

Age: _____

Gender:

- 1 Male
- 2 Female

Religion:

- 1 Christian 2 Muslim 3 Hindu 4 Other (specify)

Marital Status:

- 1 Married 2 Single 3 Divorced 4 Widowed 4 Other..... (specify)

Level of Education:

- 1 Primary Level and below
- 2 Secondary Level
- 3 'A' Level/Post Secondary Certificate
- 4 Graduate
- 5 Post Graduate

Residence:

Occupation

PART II: RESEARCH QUESTIONS

A. INFORMATION ABOUT THE HEALTH CARE OPTIONS

Q1. Is it this your first visit here?

- 1 Yes 2 No

Q2 (a) What medical assistance have you come for today?

- 1 Sputum test
- 2 Medication
- 3 Diagnosis
- 4 Others

(b) What have you been told you are suffering from?

.....

Q3. When did you first notice that you were suffering from the disease?
.....

Q4. Of the following known symptoms of TB, which ones are you aware of?

- 1 Persistent coughs
- 2 Loss of appetite
- 3 Lack of energy
- 4 Blood in sputum
- 5 Weight Loss
- 6 Chest Pains
- 7 Sweating at night

Q5..What did you do when you first noticed these symptoms?

- 1 Self – treated with drugs from the shop
- 2 Self – treated with herbal drugs
- 3 Visited a traditional healer
- 4 Visited a medical doctor
- 5 Visited a private doctor
- 6 Ignored and hoped the symptoms would go away

Q 6.(a) Did your condition improve after that visit?

- 1 Yes
- 2 No

(b) If No, what action did you take and why?

Q7. Who advised you to visit the hospital?

- 1 Wife
- 2 Husband
- 3 Friend
- 4 Family
- 5 Neighbour

Q8.What services did you get at the health facility?

- 1 Testing/ Diagnosis
- 2 Treatment
- 3 Medication
- 4 Told to come back

Q 9.How long were you told that you will be on medication?

Were you told to be collecting the drugs after ...

- 1 After every 2 weeks
- 2 Once a month
- 3 Don't know

Q 10. Do you expect to be cured by visiting the hospital?

1 Yes 2 No

If "no" why? _____

Q 12. a. Since you started visiting this health facility, have sought for help from someone else, e.g., a herbalist?

1 Yes 2 No

b. If yes, from whom and why. _____

Q 13.a. Do you pay for the services that you receive at this facility?

1 Yes 2 NO

b. If yes, how much do you pay per visit. _____

Q14.a. Have you ever heard of DOTS (Directly Observed Therapy)?

1 Yes 2 No , if no go to Q15

b. If yes, what does it mean? _____

c. Are you using it?

1 Yes 2 No

B. Information about the determinants of health seeking behaviour

Q15. In your opinion, what caused your condition?

1 Smoking 2 Bacteria 3 Cold 4 Exposed by an infected person
5 Punishment for sin

Q16. What persuaded you to visit the hospital the hospital after experiencing the symptoms?

1 Too much pain
2 Fear of dying
3 Medication from first consultation did not work
4 Just decided to come

Q 17. Apart from what you have mentioned above, what else did you consider before you sought for help?(probe to get more information).

1 Distance
2 Cost
3 Stigma
4 Traditional beliefs
5 Religion

- Q 18. How long did you take to seek for help from the on set of the symptoms?
1 Came immediately
2 After 2 weeks
3 After one month
4 Others (If immediately, go to Q20).
- Q 19. What made you stay for so long before seeking for help?
1 Prolonged self medication
2 Embarrassment
3 Guilt
4 Fear of dying
5 Misdiagnosis after first visit
6 Believed to be suffering from something else

D. Information on peoples perception of TB

- Q 20. Did you know about TB before you visited the hospital?
1 Yes 2 No

- Q 21. What do you know about this disease?

- Q 22. What do you think was the cause of your condition?

- Q 23. Are there any beliefs that are attached to this disease?
1 Yes 2 No
If yes, what are the beliefs about? _____

- Q 24. Does your community have any solutions or treatment for this disease?
1 Yes 2 No
If yes, how do you treat it ? _____

- Q25. What was the people's reaction on receiving the news of your condition?
1 Was accepted
2 Blamed for the problem
3 Was isolated

Thank you very much for taking your time to answer my questions.

Interview schedule:-

Completed _____ Not completed _____

Time interview ended _____

APPENDIX II

KEY INFORMANT INTERVIEW GUIDE (FOR OPINION LEADERS)

Introduction

Good morning/afternoon, my name is LILIAN KAWILI from the university of Nairobi, I am carrying out a study on the health care seeking behaviour of TB patients in Obunga slum in Kisumu. I would like to ask you a few questions about this topic, and would be grateful if you could spend a few minutes talking with me. Your participation is voluntary and every thing you saw will be strictly confidential.

Questions

1. What do you know about TB?
2. What is the level of TB infection in Obunga?
3. Do the people of Obunga know about TB?
4. What do they know about TB?
5. What do you think makes TB a problem in Obunga?
6. Where do the TB patients in Obunga go to seek for help when sick? Please explain.
7. What other health care options are available for them?
8. Which one among the ones you have mentioned do they frequent more and why?
9. Do TB patients in Obunga adhere to the treatment requirements that are given to them in hospitals?
10. How do the community members react towards those infected with TB? Why? If they are isolated ,what do you think can be done to correct this situation?
11. In your view, can one be cured of TB? If no give reasons.
12. Age sex occupation
13. Do you have any thing to add or questions?

APPENDIX III

KEY INFORMANT INTERVIEW GUIDE (FOR HEALTH PROVIDERS)

Introduction

Good morning/ afternoon, my name is LILIAN KAWILI from the University of Nairobi, I am conducting a study in Obunga on the health care seeking behaviour of TB patients. I would like to discuss some issues about this topic with you and I would be very grateful if you could spare a few minutes to talk with me. I assure you of strict confidentiality and whatever you say will not be used against you.

Questions

1. What is the prevalence rate of TB in Obunga slum?
2. Is it more prevalent in men or women?
3. What do you think is the reason for this?
4. What TB services do you offer at this facility (diagnosis, treatment or medication) ?
5. Do you charge any money for the services that you offer here ? If yes, how much and for what services.
6. From the experience that you have had with TB patients, what action do they take first when they notice the symptoms of TB?
7. Why do they do this?
8. If going to the hospital is not the first step they take, what are the other health care options available to the TB patients?
9. How does this impact on the treatment compliance and duration?
10. Once a person is diagnosed with TB, do they believe or do they have their own explanations to the illness that they have?
11. How do you deal with such cases?
12. For those who do not come for professional medical assistance immediately, how long do they take before they finally come for such help?

13. How long do they take before their condition improves?
14. Do the people's beliefs in Obunga affect the conventional treatment strategies? Please explain.
15. Do you have cases where a TB patient has been cured completely?
16. What happens in such cases?
17. What about cases that you get relapses, what causes this?
18. In your opinion what factors do you think influence the decision making process of TB patients on the health care option to take?
19. What do you think can be done to rectify this situation so that we reduce the TB prevalence rates in Obunga?
20. Age sex occupation

Thank you very much for time and participation.

APPENDIX IV

FOCUS GROUP DISCUSSION GUIDE

Introduction

- Greetings and the researcher introduces herself and the purpose of the discussion
- Seek consent from the participants
- Introduce the topic of discussion

Questions

1. Did you know about TB before you got infected?
2. .What did you know about TB then?
3. Has the experience you have had with TB given you more knowledge of TB? What do you know about TB now?
4. Would you share this information with other people?
5. What other names do people from your community have for TB?
6. What do these names translate to or what meanings do the names have?
7. How did you come to know that you were suffering from TB?
8. What was your reaction and your family's reaction when they heard that you had TB?
9. What do the people of Obunga think about TB (causes, treatment and how they relate to those who are infected) ?
10. In your opinion ,where should one seek for help first when he/she discovers that he/she has TB?
11. What do the people of Obunga do when they discover they have TB?
12. What other health options are available for those suffering from TB in Obunga?
13. In your view, do you think one can be cured of TB? Please explain.
14. Age Sex occupation marital status

Thank you for your giving me your time and for your participation.