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BARRIERS TO HEALTH CARE BY WOMEN INFECTED WITH TUBERCULOSIS IN KIBERA SLUMS, NAIROBI 7

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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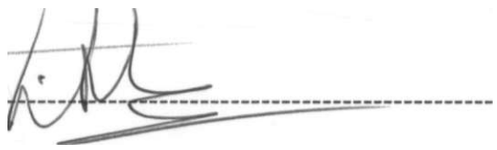
This thesis has been submitted for examination with my approval as the University Supervisor

Prof. Simiyu Wandibba  

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DEDICATION

This work is dedicated to all the women who struggle with poverty, ignorance and disease.

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ABSTRACT

This thesis presents the findings of a study on the barriers to health care by women infected with tuberculosis in Kibera slums. Kibera slums are located in Kibera division of Nairobi province. The main objective of the study was to identify the barriers to Tuberculosis health care by women infected with the disease in these slums.

The study was carried out among residents of Kibera slums. These included men and women as well as female TB patients in the area. This was done during the month of January 2006.

Data was collected by use of both qualitative and quantitative methods. Case studies and key informant interviews were used to collect qualitative data while questionnaires were used to collect quantitative data. Information from questionnaires was subjected to quantitative analysis using descriptive statistics. The Statistical Package for Social Sciences (SPSS) was used for analysis. Quotes were extracted from the case studies and key informant interviews and incorporated in the findings.

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Findings from the study show that most female TB patients either delay or fail to seek for health care whenever they are infected with the disease because of ignorance of the disease, poverty, stigma and inadequate time to visit health care facilities.

The study recommends that Kibera community members be sensitized about the disease, the available treatment and the importance of early detection, treatment and compliance.

CHAPTER ONE: BACKGROUND TO THE STUDY

1.1 Introduction

Tuberculosis, commonly known as TB, is a disease that usually attacks the lungs but can affect almost any part of the body apart from the nails and hair. A person infected with TB does not necessarily feel sick, such cases being known as silent or "latent" infections. When the lung disease becomes "active", the symptoms include a cough that lasts for more than two or three weeks, weight loss, loss of appetite, fever, night sweats and coughing up blood (WHO, 2004). Whenever a person infected with active TB sneezes, coughs, breathes or laughs, a bacterium called *Mycobacterium tuberculosis* that causes the disease is released into the air where the liquid surrounding the bacterium evaporates and leaves it hanging in the air for up to six hours. When an uninfected person breathes in this air, the rod-shaped bacteria, or bacilli, travel down into the lungs, where they lodge in the alveoli of the lungs that contain air. Therefore, the bacterium enters the body through the lungs but can cause disease in any part of the body. Lung TB is, however, the most common type of TB and the only transmittable type among humans (WHO, 2003a).

Tuberculosis kills two million people every year, and about one third of the world's population is currently infected with TB. There are an estimated 8.8 million new cases of TB each year of which 3.9 million are infectious. According to the South African Humanitarian Information Network for coordinated disaster response, TB incidence rates continue to rise at an alarming rate in African countries with high HIV prevalence (Sahims, 2004).

Tuberculosis, which many believed would disappear in their lifetime, has staged a frightening comeback. It is re-emerging after 40 years of decline and, despite medical progress in fighting it, TB remains a major health problem, especially in developing countries that are being ravaged by the AIDS scourge (Sahims, 2004). The World Health Organization has identified tuberculosis as one of the most important emerging global health threats, with an estimated one-third of the world population infected with the causative agent. Nevertheless, TB is not specific to national borders whose impact is being felt in every community across the globe, from the poorer developing states to the wealthy industrial economies (WHO, 2003a).

HIV infection and the AIDS pandemic complicate the TB epidemiology and control. TB is the most significant and life-threatening opportunistic infection for HIV. It is also the leading cause of death among HIV positive people. This is because TB is dangerous, especially for people with compromised immune systems as is the case with people infected with HIV. An estimated one-third of the 40 million people living with HIV/AIDS worldwide are co-infected with TB. Furthermore, without proper treatment, approximately 90% of those living with HIV die within months of contracting TB. The majority of the people co-infected with both diseases live in sub-Saharan Africa (WHO, 2004). In India, Myanmar, Nepal and Thailand, between 56% and 80% of people with AIDS also have TB (WHO, 2003b).

According to the World Health Organization, more men die from TB than women. Women, however, bear a disproportionate burden of poverty, ill-health, malnutrition and

disease. TB causes more deaths among women than all causes of maternal mortality combined, and more than 900 million women are infected with TB worldwide. According to WHO (2003b), 1 million women would have died in 2005 and 2.5 million, mainly between the ages of 15 and 44, would have become sick from the disease. The impact of gender on health has been largely ignored and in TB research and control efforts, gender was not just missing, it was considered unnecessary (Uplekar et al. 1999).

In their everyday lives, women face many barriers including access to health care. The main barriers of female TB patients' access to health care revolve around their triple roles, which are reproductive, productive and community roles (Kabeer, 2001). This paradigm was first coined by Carol Moser (1989). The productive roles refer to income earning activities while reproductive roles refer to children/domestic labour. Community roles, on the other hand, refer to the collective aspect of production at the community level. Unlike men who are generally involved in only productive roles, women are engaged in all the three roles. This is attributable to socio-cultural factors which assign roles to men and women in society. These factors include gender and the stigma attached to certain diseases in a community. This study addressed these socio-cultural barriers: religion, knowledge of TB and lack of time for women to attend to their health needs. The socio-economic barriers that the study addressed were women's level of education and their income levels.

1.2 Statement of the problem

Access to health care by women is a socio-cultural as well as a socio-economic problem. In most of the world, more men than women are diagnosed with TB and die from it. It is,

however, a leading infectious cause of death among women. This could be linked to the socially constructed nature of men and women's identities, otherwise known as 'gender'. Gender configures both the material and symbolic positions that men and women occupy in the social hierarchy, and shapes the experiences that condition their lives. What people know or perceive of TB and how they classify it determines how they manage it. It is therefore an important determinant of their health seeking behaviour (Auer et al., 2000). People's perceptions are usually based on their social and cultural backgrounds.

Access to health care is, therefore, also a gender issue because women are more affected due to their productive, reproductive and community roles in society (Kabeer, 2001). Women's reproductive work involves biological reproduction as well as care and maintenance of the household, which includes taking care of children, food preparation, water and fuel collection and general family health care, for instance, home based care for persons living with HIV/AIDS. Women's reproductive roles are often manual, labour intensive and rarely employ modern technology. This in turn leaves them with very little time to access health care when sick. In the case of TB, women spend most of their time in their dwellings where contraction of the disease is most likely. This is especially in cases where there are some TB patients residing in the dwelling, and since part of their duty is to take care of the sick, they are at a higher risk of contracting the disease as compared to the men who spend most of their time outside the dwelling.

Productive work, however, is done by both men and women for cash payment or payment in kind. It involves production of goods and services for subsistence and cash payment like jua kali and peasant farming (Kabeer, 2001). When women combine both the

productive and reproductive roles at the household, they become too overburdened to even consider their own health.

The current approach to the control of TB relies on passive case finding and thus entirely depends on whether and when people decide to present themselves to a health centre for help (Cambanis et al., 2005). Delays in the diagnosis of TB exacerbate the disease in affected individuals, increase their risk of death and prolong the period of time they can spread the disease.

Due to the socio-economic status of women who live in the slum areas, there is a cycle in health care issues in the sense that these women are poorly educated, remain poor and live under poor conditions that expose them to disease-carrying pathogens. When they fall sick, they are more unlikely than others to benefit from some form of effective health care. In a situation where both the man and woman get infected with TB and require health care, popular rules state that the man should get treatment before the woman since he is the pillar of the household (Thorson and Johansson, 2004). This is further reinforced in cases where women are not economically empowered and, therefore, have to depend on their partners financially. In such cases, if the partners are not willing to cater for the cost of health care, they will fail to access the treatment.

Illiteracy is also a barrier to women's access to health care. This is because, these women lack vital information on TB, and so they might not know that they are infected with the disease and what intervention to undertake. In addition, although TB treatment is given free in government health facilities, lack of knowledge may prevent patients from low-

income areas (like the slums) from either accessing this free treatment or finishing the required dose. This in turn leads to lack of treatment or multi-drug resistant TB which is more expensive to treat.

In Kibera slums, just like in most slum areas in the country, there are high levels of TB patients, yet TB treatment is given free in both government and non-governmental health facilities in the area. This implies that there is a gap between the availability of the health facility services and access and utilization of these services (IMC, 2006).

The study therefore aimed to answer this basic question: What are the barriers to health care by women infected with tuberculosis in Kibera slums?

1.3 Objectives of the study

1.3.1 Overall objective

The overall objective of the study was to investigate barriers to TB health care by women in Kibera slums.

1.3.2 Specific objectives "

The specific objectives of the study were:

1. To investigate the extent to which low levels of education among women in Kibera slums affect their access to health care.
2. To examine the extent to which poverty among women in Kibera slums affects access to health care by those suffering from TB.

3. To determine whether multiplicity of roles is a hindrance to the access of health care by women from Kibera slums.

1.4 Justification of the study

The infection of TB is a cause of concern for the health and well being of large numbers of people, especially women. Women are an invaluable asset to any community, especially in non-western societies. Besides their pivotal role in the national economy, they are building blocks of food production and household management. However, their role in any society is greatly weakened if their health is neglected.

With more women falling sick and dying from TB than all causes of maternal deaths combined, Kenya requires studies which are aimed at establishing the obstacles to women's access to health care so that these factors can be used in formulating appropriate policies and programmes to improve access to TB health care by women from slum areas. This is necessary if a substantial reduction in morbidity and mortality arising out of TB infection is to be achieved.

This study is therefore important because its findings and recommendations will be used by policy planners, development workers, medical providers and community health workers to develop strategies to address issues of women's access to health care during TB infection. Information from this study will therefore be useful to different groups already working in the area of health care in Kibera slum, other slum areas and Kenya in general.

1.5 Scope and limitations of the study

Several barriers can be said to be a hindrance to women's access to health care. These include socio-cultural, economic, geographical and health system barriers (WHO, 2005a). The socio-cultural factors include gender, religion and stigma arising from TB infection. On the other hand, the socio-economic factors include pre-existing financial constraints and low levels of education. On their part, geographical barriers include distance froip services providing TB diagnosis and treatment while health system barriers comprise lack of health system responsiveness and potential consequences of decentralization. This study, however, confined itself to: knowledge of TB, the female TB patients' level of education, the income levels of households in Kibera and the gender roles that leave women with little or no time to attend to their health needs.

However, TB is a very sensitive issue and there is stigma attached to it. This sensitivity and the stigma might have influenced the quality and quantity of the information collected, thereby limiting the value of this research since respondents were not very open in giving responses to the research questions. Some even declined to participate in the study. "

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

TB infection is currently spreading at the rate of one person per second. It kills more young people and adults than any other infectious disease and is the world's biggest killer of women (WHO, 2003b). Socio-economic and cultural factors, among other barriers, are the major stumbling blocks to women's access to health care whenever they become infected with TB. In this section, I review literature on the barriers to health care in case of TB infection and how they are addressed, but first literature on the status of TB globally, regionally (sub-Saharan Africa) and the Kenyan situation is highlighted.

2.2 The current status of tuberculosis epidemic

2.2.1 The global situation

According to the World Health Organization's (2004) community documents on malaria and tuberculosis in Africa, there were 8.8 million new cases of TB in 2002, of which 3.9 million had sputum smear-positive pulmonary TB (the most infectious type of TB). Between 1995 and 2002 the global incidence rate of TB (per capita) was growing at approximately 1.1% per year, and the number of cases at 2.4% per year. The growth notifications have been faster in African countries with high HIV prevalence.

Estimated TB incidences and mortalities in various regions of the world in 2002 are given in Table 2.1 below:

Table 2.1: Estimated TB incidence and mortality in different parts of the world in 2002

	Number of cases (thousands)		*Cases per 100,000 population*		**Deaths from TB**	
WHO region	**Ail forms** (%)	**Smear-positive**	**All forms**	**Smear-positive**	**Number (thousands)**	**Per 100,000 populations**
Africa	2354 (26)	1000	350	149	556	83
The Americas	370(4)	165	43	19	53	6
Eastern Mediterranean	622 (7)	279	124	55	143	28
Europe	472 (5)	211	54	24	73	8
South-East Asia	2890 (33)	1294	182	81	625	39
Western Pacific	2090 (24)	939	122	55	373	22
Global	8797 (100)	3887	141	63	1823	29

Source: WHO, 2004

2.2.2 Sub-Saharan Africa

Findings published by the World Health Organization in 2004 indicated that in the previous 10-15years, TB cases had increased by 300-400% in high prevalent countries of Africa like Nigeria, DR Congo, South Africa, Ethiopia, Uganda, Tanzania, Sudan, Botswana and Kenya. The findings also revealed that the highest mortality rate per capita in the African countries was quite alarming, with 350 cases per 100,000 population (WHO, 2004).

2.2.3 Tuberculosis situation in Kenya

Life expectancy in Kenya has plummeted to 46 years with only 50% of the population reaching 40 years of age. Diseases of poverty, including malaria and tuberculosis, as well as preventable early childhood illnesses are on the rise. The country's failing health care system is further reflected in such statistics as:

- Tuberculosis cases have increased annually by 20% over the last five years;
- 35% of Kenyans have no access to health services (IMC, 2006).

Kenya has a large and rising-tuberculosis disease burden and is ranked 12th among the world's 22 countries with a high tuberculosis burden. According to the World Health Organization's Global Tuberculosis Control (WHO, 2004), in 2002 Kenya had more than 170,000 TB cases and an incidence rate of 223 new sputum smear positive (SS+) cases per 100,000 people, which was a dramatic increase from 51 cases in 1987.

The WHO estimates that the number of TB cases notified each year continues to climb steadily with no signs of slowing down. Figure 2.1 below shows the rates of TB increase between 1997 and 2002.

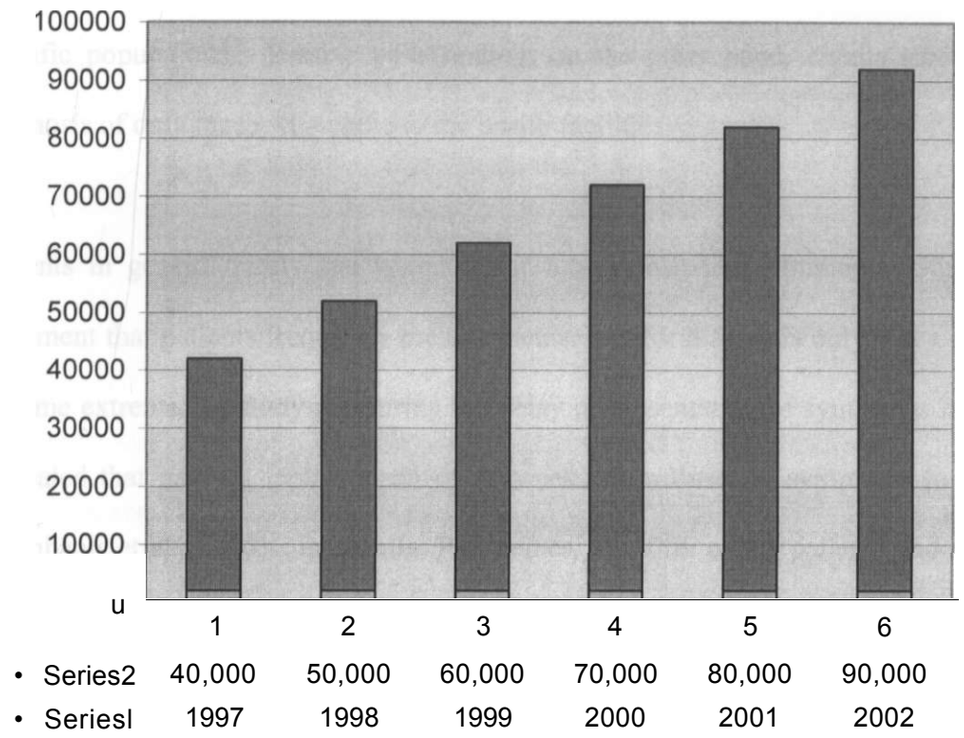

Figure 2.1: TB trends in Kenya from 1997 to 2002.

Source: NLTP, 2003.

There has been an average annual increase of 16% in the number of TB cases notified to the Kenya National Leprosy and Tuberculosis Control Programme (NLTP) over the last 10 years. It is also estimated that approximately one-half of the Kenyan population carries a latent tuberculosis infection. In the past decade, the HIV/AIDS epidemic has helped to triple the number of new adult tuberculosis cases in Kenya. A survey conducted in the country indicates that the Kenyan situation is more alarming with more

than 50% of the public hospital beds occupied by patients with TB related complications (Obonyo and Owino, 1997).

Currently, TB diagnosis is referred to as case finding which may either be active or passive. Active case finding entails attempts to screen populations at large or to target specific populations. Passive case finding, on the other hand, entails screening and diagnosis of only those who come to the health facilities.

Patients in general rarely see a doctor for tuberculosis-like symptoms. Studies done document that patients frequently present themselves for diagnosis only when symptoms become extreme. A study measuring the delay of presentation of symptoms in Ethiopia indicated that patients took a mean of 10 weeks from onset of symptoms to diagnosis (Cambanis et al., 2005). In Manila, Philippines, one fifth of the patients had symptoms for at least three months before they approached a health facility (Auer et al., 2000). One contributing factor to this delay could be lack of knowledge of TB and its symptoms, which may therefore translate into patients not presenting themselves for diagnosis and treatment because of this ignorance.

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2.3 TB treatment

Directly observed treatment short-course (DOTS) is a 6-8 months course of treatment administered to patients infected by TB. With DOTS treatment, a patient can be treated in the clinics, hospitals and at home. In the recent "WHO Global TB Control report 2004", WHO hails its treatment strategy of the disease a success. The direct observation of treatments (DOTS) scheme has been in place for 10 years and is used in 180 countries

worldwide to fight tuberculosis. According to WHO (2004), the number of patients diagnosed and treated under DOTS, the internationally recommended strategy for TB control, was rising much faster than at any time since DOTS expansion began in 1995. The report also indicated that DOTS programmes were treating three million TB patients every year, an increase of more than one million patients compared to just the previous two years. However, the current approach to the control of TB relies on passive case findings and thus entirely depends on whether and when people decide to present themselves to a health facility for help (Cambanis et al., 2005).

Kenya's National Leprosy and Tuberculosis Control Programme (NLTP) began to implement the WHO-recommended DOTS strategy in 1993 and had reported 100 percent DOTS coverage by 2001(Chakaya et al., 2005). However, the large TB disease burden in Kenya is making it difficult for the public health sector to continue delivering quality DOTS services.

Women generally have reduced access to health care services and this also applies to access to TB control services. The Stop TB initiative estimates that in the world, among women sick with TB at any given time, at least a third die because they are undiagnosed or receive poor treatment. This is because there are some barriers that they have to overcome before they can access health care. For example, they have dual responsibilities both at home and at work and this leaves them with very little time to reach diagnostic and curative services.

2.4 Social networks and health care systems

Social networks or therapy management groups refer to the relationships or links that exist between people. The strength of the bond determines the flow of information and how fast it does. It also determines whether or not someone will act on information from a social actor and how fast this will happen. The influence people have on others depends on the bonds that exist between them. According to the social network theory, social networks work by placing social pressure on individuals hence one will act depending on what the actors in the social network believe in. In health care regarding TB, the patients will either seek health care or not and this will be dependent on the views of the social actors. Their influence will also determine whether TB patients will come out in the open and declare their condition for if it is stigmatising to be infected, the patients will not only be isolated but may also not be able to seek proper health care for fear of being stigmatised. (Helman, 1990)

Health care systems encompass ideas, values, expectations in the way of doing things within health, sickness and healing. There are three types of health care systems which include the popular sector, thS folk sector and the professional sector. The health care systems help organise society so that it can address issues related to health, sickness and healing (Helman, 1990). These include beliefs about particular illnesses, values, expectations like what constitutes the sick and relationships such as the doctor-patient, the sick-family as well as the relationship between the family and the health care provider. These relationships influence health care provision in the sense that the family relationships influence the decisions made when a family member falls sick, in

attempting to restore the health of those close to them. In every family there are decision makers and what they decide is what is done. The family can therefore be said to make decisions on behalf of the sick and also pay for the services of the health care provider. The patient's relationship with his or her family can therefore be said to be a social network.

Different health care systems have their own explanatory models regarding particular illnesses. Health care systems are systems that are used to construct certain realities about a health problem, that is, the cause of the illness, its cause and the intervention for the condition. The explanatory models are constructed by different cultural systems and this affects what is done in search of therapeutic interventions. The different explanatory models place the cause of sickness differently hence bringing about a difference in the therapeutic interventions sought.

2.5 Theoretical framework

2.5.1 Structuration theory

Structuration theory, as proposed by Anthony Giddens is composed of analytical concepts. The theory refers to an exceedingly wide range of topics and areas of interest: the nature of day-to-day interaction, the development of the nation-state and citizenship rights, class analysis, evolutionary theories of society, time-geography, the nature of modernity, surveillance and war, among others (Layder, 1994).

The main assertion of this theory is that social structures are the medium of human activities. The theory can be seen to be composed of analytical and logical concepts of human behaviour or action. It is a formal social theory, and can be seen as an answer to the classic actor/structure dualism.

One of the core assumptions of the theory is that behaviour and structure are intertwined; people go through a socialization process and become dependent on existing social structures, but at the same time alter those structures with their activities. This means that social structures are the medium of human activities as well as the result of those activities. Social structures not only restrict behaviour but also create possibilities for human behaviour. The point is, it is not all about the restrictions people encounter in unrolling their behaviour in space and time, but people also contribute to the creation of a certain time-space-structure (Giddens, 1984).

Structuration theory is based on the premise that the classic actor/structure dualism has to be reconceptualised as a duality - the duality of structure. The structural properties of social systems exist only in se far as forms of social conduct are reproduced chronically across time and space. The structuration of institutions can be understood in terms of how social activities become 'stretched' across wide spans of time-space.

In this theory, 'structure' is regarded as rules and resources recursively implicated in social reproduction; institutionalised features of social systems have structural properties in the sense that relationships are stabilized across time and space. 'Structure' can be

conceptualised as two aspects of rules which are written and unwritten. Resources are also of two kinds: authoritative resources, which derive from the co-ordination of the activity of human agents, and allocative resources, which stem from control of material products or of aspects of the material world (Giddens, 1984).

2.5.2 Relevance of the theory to the study

A synthesis of the central assumptions and beliefs of structuration theory gave the necessary guidelines to this study. The theory posits structuration as a two-way process where individuals are shaped by society and at the same time people are intrinsically involved in society in the sense that they can change or structure it. What people do during sickness is therefore related to their structure, to the way they have been socialised and thus to their surrounding. The barriers to the health care of women infected with TB in Kibera slums have a lot to do with the structure which shapes the women's day to day lives.

The structure, which refers to the rules and resources that agents draw upon as they produce and reproduce society and can either be written or unwritten, enables social actors to go on in their social situations. Such resources as education, knowledge of TB and household income, which affects how residents of Kibera react in situations of sickness and health. Because of low education levels, limited knowledge of TB and low income levels at the households, women infected with TB in Kibera either delay health seeking or fail to seek it.

Structure does not have a tangible existence; rather it can only be seen as a consequence of the behaviours of those behind the actions. Individual behaviour is instantaneous to structure, that is, structure is inbuilt in activity. The Kenyan society, for example, is a highly engendered society. This translates into access to health care by women infected with TB as a gender issue since it configures both the material and symbolic positions that both men and women occupy in the social hierarchy. Women delay or sometimes fail to address their health needs because of their triple roles, that is, productive, reproductive and community, both at the household and in the community.

The man is also seen to occupy a superior position to the woman's at the household level. In resource constraint societies, the effect of this is that the man is given a priority in accessing these resources. In a case of illness in general and TB infection in particular, when both the man and woman fall sick and need medical attention, it is a natural fact and expectation that the man will access health care first. On the other hand, the woman is expected to be strong so as to ensure the daily activities at both the household and in the community are not paralysed. She, therefore, treats her health needs as secondary to her roles as a woman, a wife and a mother. The result of this is delayed or lack of health care seeking when infected with such a highly contagious and killer disease as TB.

Social structures do not exist independently but in connection with individuals. On one side, we have the situated actors (in the structures) and on the other side, the rules and resources that these actors draw from in their day-to-day activities (in their actions). This mutually dependent duality however creates time, space distanciation, routinization and system integration. Because of the gender issues in Kenyan societies, and therefore

among Kibera residents, access to health care by the female TB patients becomes stretched over time and space. Structuration can therefore be seen as a barrier to health care by female TB patients in Kibera slums.

2.6 Hypotheses

In light of the literature reviewed and the theoretical framework stated, the following hypotheses were advanced for the proposed study:

1. Low levels of education among women in Kibera slums is likely to significantly affect their access to health care during TB infection;
2. Poverty among women in Kibera slums is likely to affect their access to health care by those suffering from TB;
3. Multiplicity of roles is a likely hindrance to the access to health care by women suffering from TB in Kibera slums;

2.7 Definition of terms

Some of the terms used in this study may have varied meanings and, so, by defining them, the investigator seeks to clear any confusion that may arise

Gender: this is the socially constructed nature of men and women's identities that configures both the material and symbolic positions that they occupy in the social hierarchy, and shapes the experiences that condition their lives.

Gender roles: the different male and female roles assigned respectively to men and women in a particular society as part of the socialization process.

Economic status: economic level or well-being of a family unit as denoted by the educational level and the skills possessed by parents which determines the employment status and level of earnings.

Level of education: Number of years one has spent in acquiring formal knowledge. In this study, educational status was categorised into five levels, including no formal education, primary, secondary, post-secondary (college or university) and vocational or craft making.

Socio-cultural factors: these are beliefs, perceptions, assumptions, cultural norms and values which influence the access of TB health care services by women in Kibera slums.

Socio-economic factors: this relates to a person's social status and economic position. This variable refers to the monetary resources accessible to the household to expand their various needs. It was measured by occupational and household monthly income.

Stigma: this refers to both individual and societal beliefs of shame, disgrace and dishonour related to the TB disease. These beliefs and feelings form social barriers to the effective management of the disease in that they may lead to forms of denial and

concealment of the disease which can have important implications for case-findings, disease transmission and compliance with treatment.

Poverty: this refers to the state of lack, scarcity or deficiency regarding basic needs for instance shelter, food and clothing. In this study, poverty was used to refer to the inability of the Kibera residents to afford adequate basic necessities.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter presents the study area and population, that is, the physical location, characteristics of the slum area, the size, and the total number of people. It also gives the villages in the slum area. The design that guided the study is also described, emphasizing on the methods of data collection used, sampling design, and the methods used to analyse the findings. The problems experienced and the ethical considerations during the study have also been presented.

3.2 Study area and population

According to the Government of Kenya (2001), Nairobi city has an area of 648 square kilometres and a population of 2,143,254. While the average population growth is estimated to be 10%, the upper and middle income area is growing at 5-7% per year.

Nairobi is a vast city (Map 3.1) having the features of any modern city, on the one hand, and pockets of extreme poverty and destitution, on the other. Infrastructure and development has been modest in the middle and upper income areas and inadequate in low-income areas.

The acute shortage of housing against a background of rapid population growth in these low economic areas has led to the development of large unplanned slum areas. According to the Government of Kenya (2001), in urban areas, 76% of the poor and 80% of the non-poor rent their dwellings. It is estimated that over 47% of the Kenyan urban dwellers seek shelter in informal settlements, which are poorly constructed and are in

areas of high unemployment, high crime rate and increasing cases of HIV/AIDS. These informal settlements are characterised by degradation of the environment and they, in most cases, develop outside the formal urban plan. Life in most informal settlements depicts abject poverty.

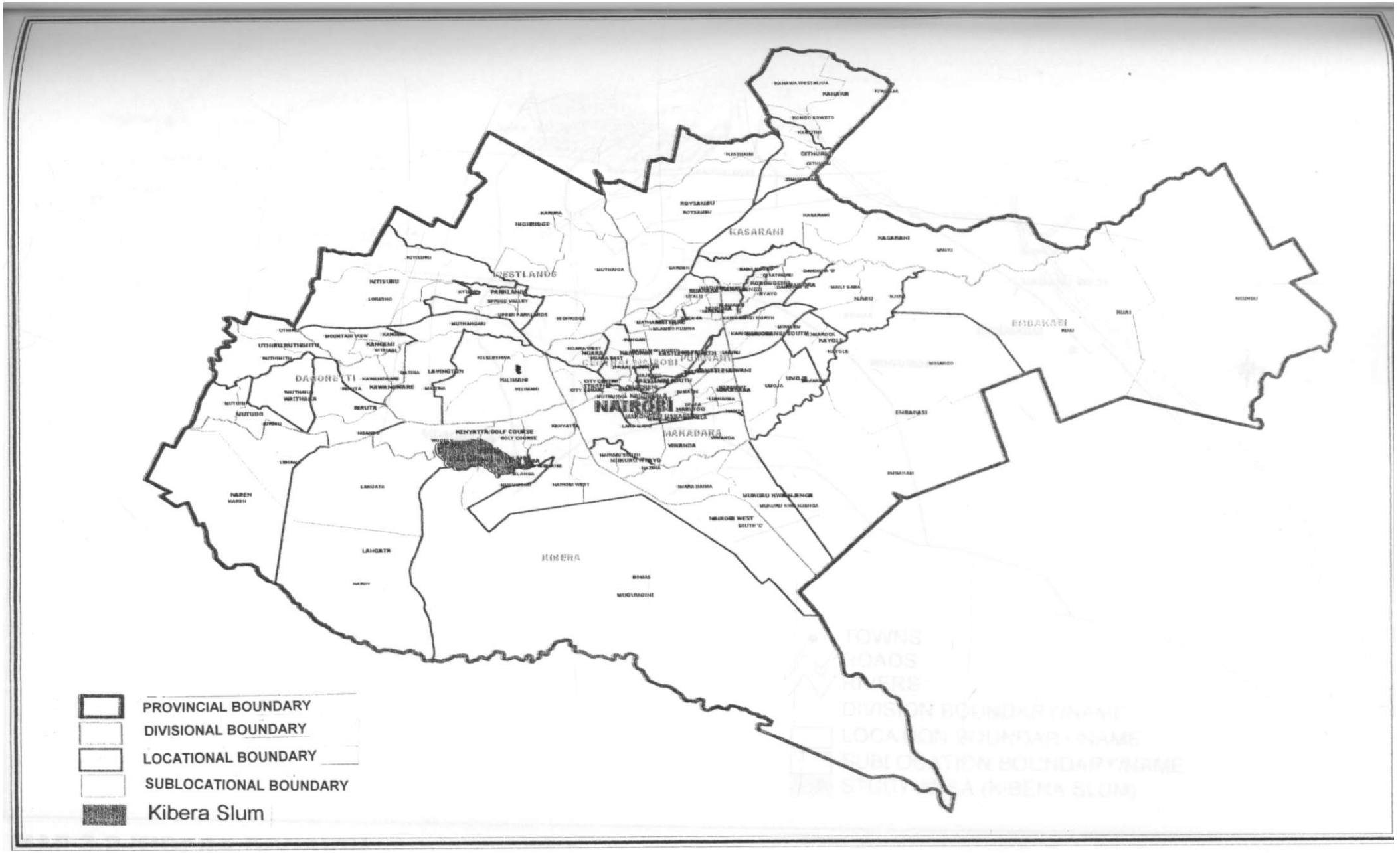
Kibera slum (Map 3.2) is the oldest informal settlement in Nairobi and is currently the largest. It is situated 10 kilometres from the city centre and located between Ngong Road, Mbagathi Road and Jamhuri Park forest. The slum has an area of approximately 225 hectares and a population of 394,000 with a density of 11,000 persons per hectare, making it one of the most densely populated areas in the country. It is composed of nine villages, namely, Makina, Laini Saba, Lindi, Soweto, Silanga, Kianda, Gatwekero, Kisumu Ndogo and Kisumu Ngong. Laini Saba is the most densely populated (GoK, 2001). Most Kibera residents are employed in the informal sector, that is, in petty business and manufacture of petty items by artisans.

On average, 16.4% of the slum houses are permanent structures. The structures are crowded and are mostly made^of wood, which makes them prone to infections while 80% of the households share single rooms (GoK, 2001). The households are mushroomed in a relatively chaotic manner at the expense of latrine and road passages.

3.3 Study design

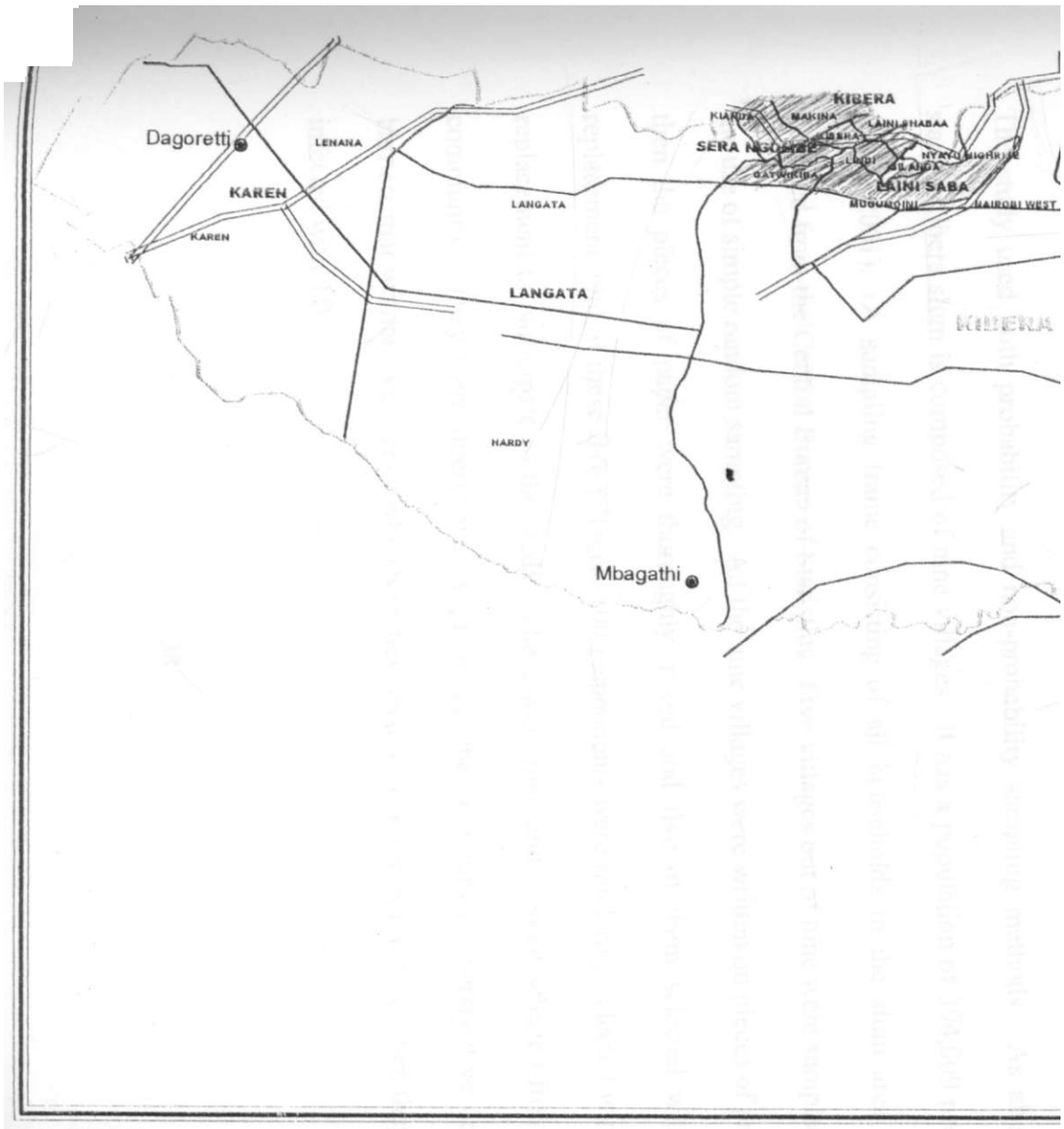
This study was descriptive since the aim was to describe women's health care during TB infection in Kibera slums. Data was collected both at the quantitative and qualitative

levels. Quantitative data was collected using questionnaires, while qualitative data was collected using key informant interviews and case studies. The questionnaire was administered to Kibera residents at the household level. The household is an important decision making unit and greatly influences access to health care. Key informant interviews were administered to opinion leaders like community leaders as well as leaders of women organizations in the study area. Case studies were made of female TB patients in order to get an indepth understanding of their experiences in accessing health care.



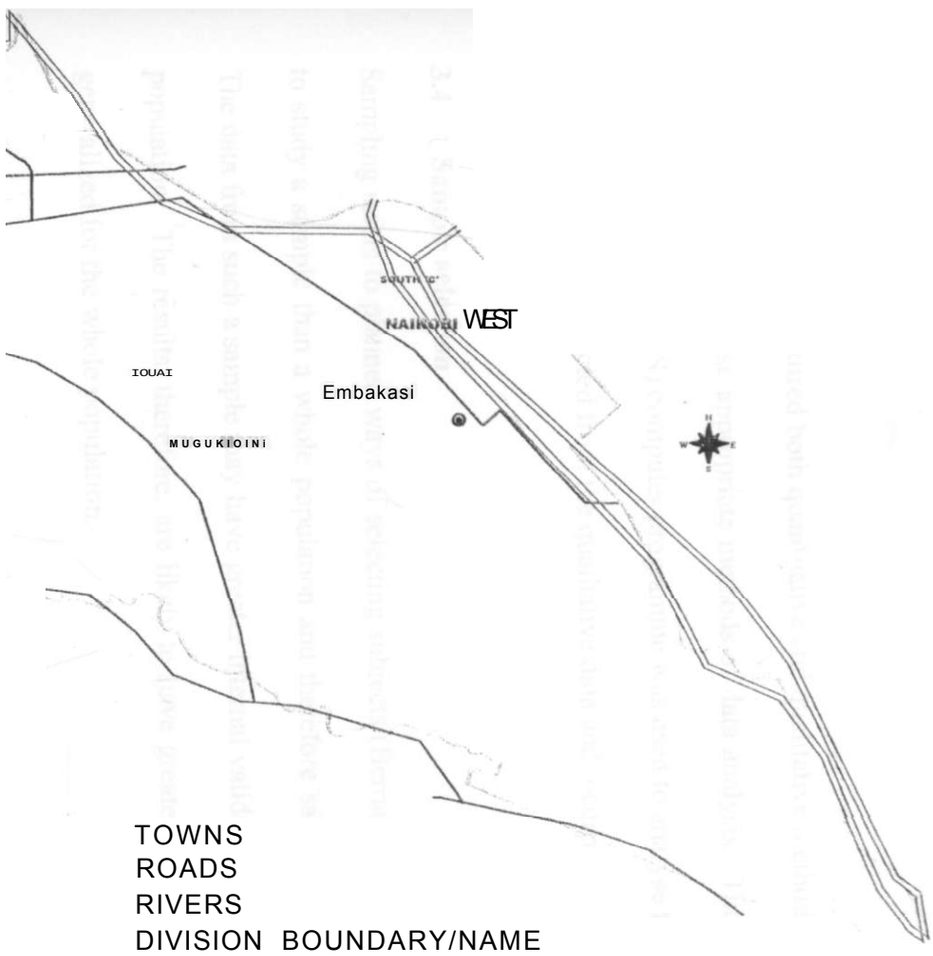
MAP 3.1 NAIROBI PROVINCE

SOURCE CENTRAL BEREAU OF STATISTICS 2007



MAP 3.2 KIBERA DIVISION

SOURCE CENTRAL BEREAU OF STATISTICS 2007



TOWNS
ROADS
RIVERS
DIVISION BOUNDARY/NAME
|___| LOCATION BOUNDARY/NAME
[—1 SUBLOCATION BOUNDARY/NAME
^JGG STUDY AREA (KIBERA SLUM)

Since the researcher required both quantitative and qualitative methods of data collection, there was the need to use appropriate methods of data analysis. The statistical package for social sciences (SPSS) computer programme was used to analyse the quantitative data while quotes were extracted from the qualitative data and incorporated in the thesis.

3.4 Sample selection

Sampling refers to planned ways of selecting subjects (Bernard, 1994). It takes less time to study a sample than a whole population and therefore saves on costs (Baker, 1999). The data from such a sample may have greater internal validity than data from the whole population. The results, therefore, are likely to have greater similarity and thus can be generalized for the whole population.

The study used both probability and non-probability sampling methods. As already stated, Kibera slum is composed of nine villages. It has a population of 394,000 people (GoK, 2001). A sampling frame consisting of all households in the slum area was obtained from the Central Bureau of Statistics. Five villages out of nine were sampled by the use of simple random sampling. All the nine villages were written on pieces of paper, then the pieces of paper were thoroughly mixed and five of them selected without replacement. Out of these five villages, 100 respondents were randomly selected without replacement to participate in the study. These were men and women selected from the community. They were interviewed so as to get the community's perspective on the barriers that women experience whenever they need to seek for health care when they are infected with TB.

The unit of analysis therefore was the household and the respondent was the person responsible at the time of study. These were either adult men or women (those above 18 years of age) who were found in the household.

3.5 Methods of data collection

3.5.1 Primary methods

3.5.1.1 Structured Interviews

In structured interviews, people are asked to respond to nearly identical sets of questions or stimuli (Bernard, 2000). Men and women selected from the community were asked to answer a set of questions asked in the same order using a standardised questionnaire. The questionnaire had both open-ended and closed-ended questions (Appendix I). This tool was used to elicit information about barriers to women's access to health care whenever they are infected with tuberculosis from the community perspective.

3.5.1.2 Case studies

These are short specialized interviews that attempt to make sense out of an individual's life experiences up to the present (Nkwi et al,, 2001). Women suffering from TB or those who have ever suffered from TB were selected using the purposive method of sampling. In this method, the informants are selected to meet the study's needs. At health facilities in the slum, 5 female TB patients were selected purposively and then case studies conducted on them. These women who have ever suffered or who are suffering from TB were interviewed in order to get to know of any barriers they encountered when they wanted to seek health care. By administering case studies, the researcher was interested

in in-depth narrative accounts of their TB status. What happened when the women fell sick with TB and what they did is the information that was sought from them (Appendix **II).**

3.5.1.3 Key informant interviews

These consist of interviewing a number of strategically selected, knowledgeable individuals, representing different perspectives and categories (groups, positions, functions with respect to project activities) which may provide the needed information on a given issue or subject (Bernard, 2000). Respondents to key informant interviews are also known as opinion leaders. Five opinion leaders from Kibera were selected haphazardly and interviewed using a key informant interview guide (Appendix **III).** These were selected in order to administer key informant interviews on them. These included chiefs, village elders as well as leaders of organizations addressing health issues affecting community members.

The information collected was important in understanding barriers to TB healthcare as well the general health care among Kibera residents.

3.5.2 Secondary methods

At the formulation stage, documentary materials such as journals, books and articles were used. Relevant literature on TB was reviewed to provide background information for the study. The researcher continued to use relevant journals, books and articles in the course of the study.

3.6 Data analysis

Bernard (1988) defines data analysis as the search for patterns in data and explanations for the existence of such patterns. Data analysis procedures largely depend on methods of data collection. In my study, both qualitative and quantitative methods of data collection and analysis were utilised. Information from questionnaires was subjected to quantitative analysis using descriptive statistics. The Statistical Package for Social Sciences (SPSS) computer software was used for analysis. Percentages and frequencies were used to show the distribution. The data was categorised, arranged, summarised and presented using tabulations, pie-charts comparative bar graphs and histograms.

Data collected through case studies and key informant interviews was subjected to qualitative analysis. Quotes were extracted from this information and incorporated in the main findings of the study.

3.7 Problems experienced and their solutions

Since TB infection is in itself stigmatising, I had anticipated to encounter problems in getting the respondents to agree to participate in the research. To solve this problem, I used a contact person on the ground who is a community worker and therefore already acceptable to the community. This made my work easy and therefore I faced very little resistance from the community members.

3.8 Ethical considerations

The study of human subjects raises many and complex ethical issues. In order to avoid abuse of the research participants I undertook to do several things. First, I obtained permission from the relevant government authorities, that is, the Ministry of Education, Science and Technology (MoEST). Any other relevant government offices were also asked for permission to conduct research in their area of administration, for example, the Provincial Administration.

I only interviewed those who were willing to participate once I had explained the research purpose to them. I also informed them that just in case any of them felt like withdrawing from the interview, they were free to do so. Finally, confidentiality was maintained by not using the real names of the study subjects. The respondents were assured of this before commencing the interviews and that the information will only be used for the intended purpose, that is, education.

CHAPTER FOUR

BARRIERS TO TB HEALTH CARE IN KIBERA SLUMS

4.0 Introduction

This chapter presents the research findings. The chapter is divided into two sections. The first section presents the socio-economic characteristics of the study population in relation to the concept of TB healthcare among women in Kibera. These characteristics include sex, marital status, level of education, religion and occupation. The second section presents findings of the main research objective which was to find out the barriers to health care by women infected with tuberculosis in Kibera slums. In order to verify this objective, a number of questions concerned with conceptualization of TB, the major signs and symptoms of the disease, how TB can be passed from one person to another, the available cure for TB, and the obstacles that prevent TB patients in Kibera from accessing medication were asked.

4.1 Socio-economic characteristics of the respondents

4.1.1 Sex, marital status and access to TB health care

The questionnaire was administered to both men and women in Kibera slums. As shown in Table 4.1, out of the 100 respondents interviewed, 71 (71%) were women. This is because the study involved interviewing people from their households and two scenarios were observed. One, most of the households were headed by women and, two, since the study was carried out during the day, in the households where there were men, most of them had gone out to work. This includes going out to seek casual work as well as carrying out small income generating activities some of which are own-businesses. In

such households, after making three visits, replacements were done with the next households. Out of the 33 (33%) respondents that were single, 23 (70%) were women (Table 4.2). This large number of women heading households could have been a contributing factor to the large number of women interviewed during the study. However, more than a half of the women interviewed, that is, 41 out of 71 (58%) were married. Four other women (4%) had been separated while only three (3%) were widowed. A majority of the men interviewed were married. These were 18 (62%) while only one had been separated, with the rest, that is, 10 (10%) being single.

Table 4.1: Sex of respondents

Sex of respondents	**Frequency**	**Percentage**
Male	29	29.0
Female	71	71.0
Total	**100**	**100.0**

Table 4.2: Marital status versus sex of respondent

Sex of respondent	**Marital status**				**Total**
	Single	Married	Separated	Widowed	
Male	10	18	1	0	**29**
Female	23	41	4	3	**71**
Total	**33**	**59**	**5**	**3**	**100**

In this study, case studies were done with women who were suffering or had ever suffered from TB. The age ranges of the respondents in the case studies were between 25 and 40 years. This age range is within a woman's most productive years, both economically and reproductively. It is also during this age that most women have children who still need their care. Of the five women case studies done, all the women had children. This ranged from between one and 18 years. Apart from the one 18 year old daughter to one of the female TB patients who had left home to get married, all the rest of the children lived with their mothers at the time of the study.

4.1.2 Education levels

Slightly less than half of the respondents, that is 45 (45%), had attained primary level education while only 6 respondents (6%) had attained college or university level education. Just over a third, 37 (37%), had attained secondary level education and only one respondent had acquired vocational training skills. He was a carpenter. The results from the qualitative data indicate that only one respondent in the case studies had attained secondary level of education. The other four had not completed primary level of education.

Table 4.3: Respondents' education levels

Education level	Frequency	Per cent
None	11	11.0
Primary	45	45.0
Secondary	37	37.0

College or University	6	6.0
Vocational	1	1.0
Total	**100**	**100.0**

4.1.3 Respondents' religious affiliation

Figure 4.1 below summarises the religious affiliations of the respondents in this study.

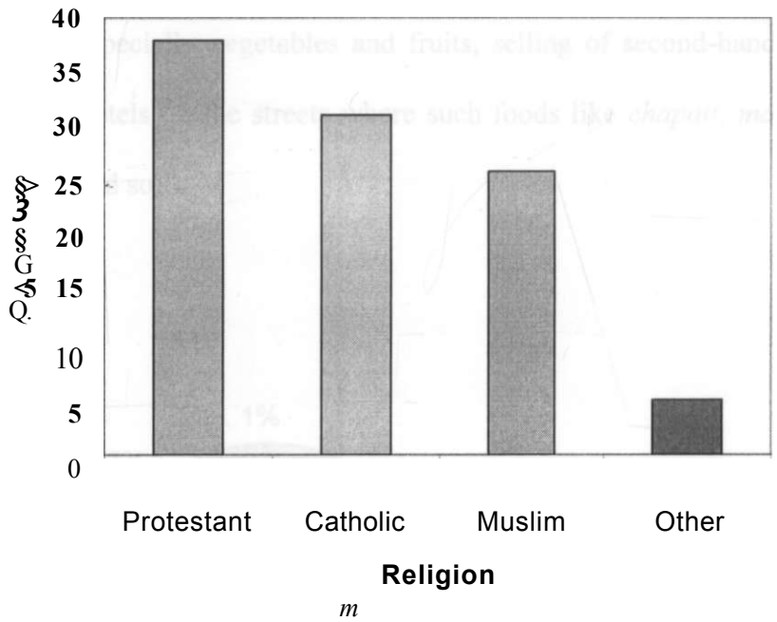


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Figure 4.1: Respondents' religious affiliation

From the bar graph above, it can be seen that one third of the respondents (38%) were protestants followed by 31% who were Catholics. The least number of the respondents (5%) belonged to other religions including the traditional African ones like *Dini ya Musambwa.* The researcher analysed religion as one of the cultural beliefs that affect access to health care. It however turned out that most respondents are not committed to their religion and might not necessarily adhere to their religious beliefs.

4.1.4 Occupation of the respondents

Figure 4.2 below gives a breakdown of the percentages of the respondents and their occupations. The figure indicates that 45 respondents (45%) were jobless, a majority of whom were women. Similarly, the figure shows that some of the respondents were in business (20%), seven were teachers while only one was a landlord. A further 20% of the respondents were engaged in casual labour. This included working as cleaners, guards, drivers and salespeople on a temporary basis whereby their remuneration was on a daily or weekly basis. The businesses that most of these respondents engaged in were vending of food, especially vegetables and fruits, selling of second-hand clothes and operating informal hotels on the streets where such foods like *chapati, mandazi* and *samosas* are prepared and sold.

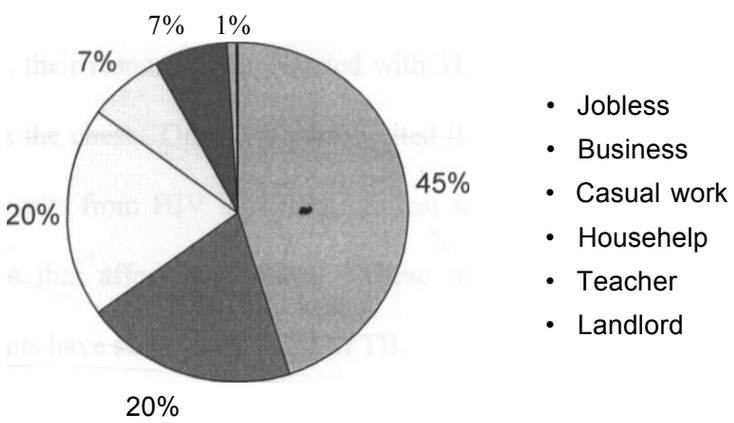

Figure 4.2: Respondents' occupation

4.2 Education and TB health care

As already stated, 45% of the respondents had completed primary level of education, while 37% had completed secondary level of education. Only six (6%) respondents had attained college or university education. This data suggests that educational attainment could be closely related to TB health care. With a majority of the respondents having only attained primary education, there is a high possibility that they do not understand what the TB disease is. This includes understanding the symptoms of the disease and the treatment available for those infected with the disease.

4.3 Understanding of TB

Attempts were made in this study to investigate what Kibera residents understood by the term tuberculosis. According to the analysis, most of the respondents gave varied responses implying that they understand what the disease is. When asked what TB is, slightly less than a third of the respondents correctly answered this. From Figure 4.3 below, their responses were varied with 31 (31%) of them saying that it is a disease that affects the chest. Only one person cited it as a viral disease, and one other as a disease that results from HIV infection; the rest said that it was either an airbone disease or a disease that affects the lungs. These responses indicate that a majority of Kibera residents have some knowledge of TB.

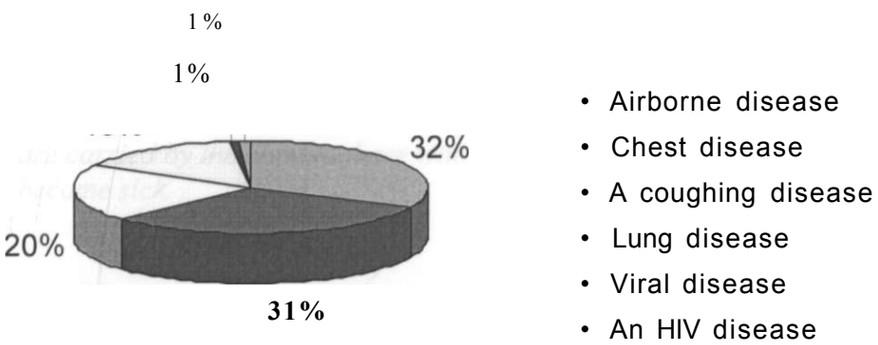

Figure 4.3: Respondent's understanding of tuberculosis

Table 4.4: Whether TB can be passed from one person to another

	Frequency	**Percent**
Yes	95	95.0
No	5	5.0
Total	**100**	**100.0**

At the same time, most of the respondents (95%) understand that TB is a highly contagious disease and that it can be passed on from one person to another. This is highlighted in Table 4.4 above. Further asked how this can happen, 71% of the respondents said that it would be through the air, 45 (45%) said that it would be spread by sharing of things like utensils and clothes, while contact with spittle was sighted by 10

respondents. While only one respondent cited inheritance, 3 (3%) others said that TB could be spread through sex. This is highlighted in Figure 4.4 below. One 25 year old female TB patient had this to say:

> *TB is a coughing disease that people can pass on to others if they cough in the air because the germs stay in the air and are carried by the wind to those who are not infected, so they become sick.*

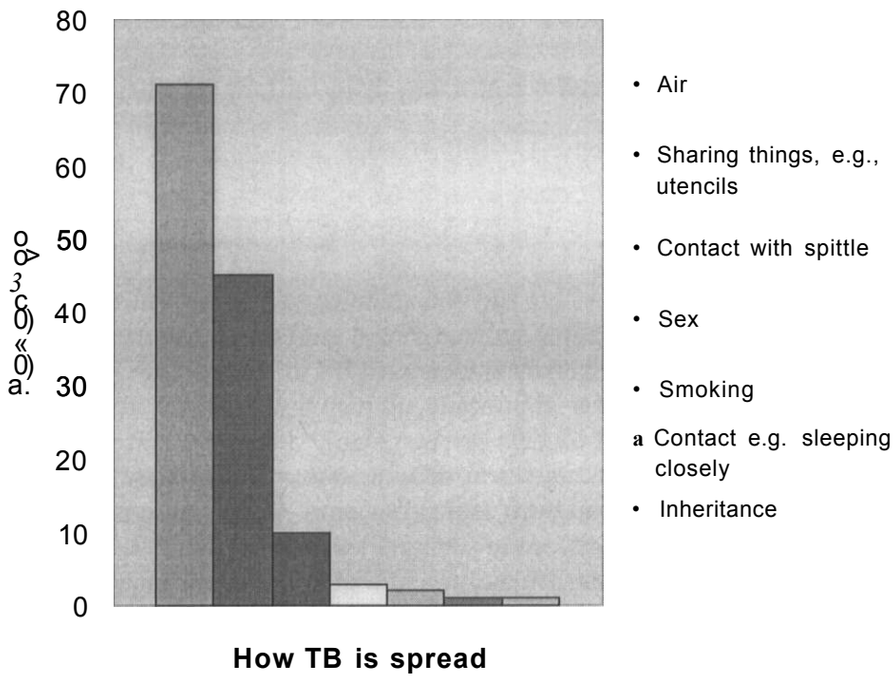

Figure 4.4: Ways through wHtch TB can be spread

This data indicates that although the respondents were not highly educated, many of them were nonetheless literate on the spread of TB. A majority, however, did not understand the cause of the disease, in this case, a bacterial disease. From Figure 4.4, only five (5%) respondents correctly cited this. The result of this is that Kibera residents might not know the treatment to access when infected with the disease. With one (1%) respondent

citing that TB is a viral disease, a few people might think that it is an incurable disease, and so fail to go for the available treatment. One other respondent reported that TB is a disease related to HIV/AIDS. While this may be true, it is however a disease that can be cured. Without this knowledge, Kibera residents are less likely to access TB treatment whenever they are infected. The result of this is prolonged suffering due to the disease and sometimes death. This lack of information leading to prolonged suffering by those who contract TB is strongly manifested in the following narration by a health care provider at Mbagathi District hospital which is a referral point for most patients of TB from Kibera slum:

> *In this facility we receive so many patients suffering from TB and who have stayed for so long before coming to the facility for treatment. One thing for sure is that TB treatment is given free of charge in all government facilities, but then the question is, why people take so long accessing this treatment. Some patients who visit this hospital even die while undergoing treatment. Our investigations into this matter reveal that most people, especially those from the surrounding slum areas, do not understand the symptoms of the disease and that they more often than not are not able to differentiate the symptoms of tuberculosis from those of the common cold or flu. It is only when they have ailed for such a long period and on the verge of dying that their relatives bring them to the facility. Because of this ignorance, we have realised that there is a need to educate people on the disease by putting up such IEC materials you can see on the hospital walls.*

When asked whether TB can be cured, 93% of the respondents answered in the affirmative while only one person did not know the answer to this question. This means that education level might not be the barrier to TB healthcare when one is infected with the disease. In spite of the fact that a sizeable number of the respondents (45%) had only attained primary education level, most Kibera residents understood what the disease is,

that is, the symptoms as well as how one can contract it and also that it is a curable disease.

The respondents were then asked to cite the major signs and symptoms of the disease. As shown in Figure 4.5 below, coughing was a major sign and symptom according to 76 (76%) of the respondents while coughing of blood was cited by only 14 (14%) respondents. Weight loss was cited by 34% of the respondents, fever by 22%, night sweats by 13 (13%) respondents and loss of appetite by only 10 (10%) respondents.

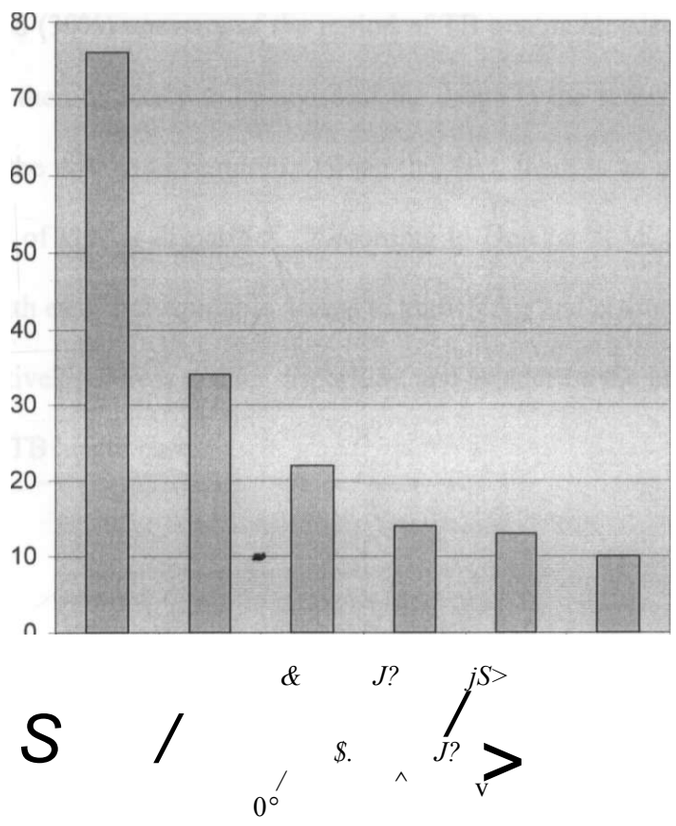

Figure 4.5: Signs and symptoms of TB

One 40 year old female TB patient had this to say about the symptoms of TB:

> *There is a continued cough like for my case , I coughed for one and a half years. One also experiences a blocked chest and pain when breathing as well as weight loss and weakness of the body.*

According to Figure 4.6 below, slightly less than a half of the respondents correctly mentioned between 6 and 8 months as the period which a TB patient is supposed to undertake treatment. These comprised 44 (44%) respondents while 30 (30%) others did not know for how long someone should take the treatment. With about a third of those interviewed (30%) unaware of the period of TB treatment, access and compliance of the treatment, there is likely to be abuse of the drugs in the sense that the patients may not complete the dosage as required. Given this fact, there is an urgent need to address the root cause of gender disparities. According to Uplekar et al. (1999), empowering poor women with easy and equitable access to knowledge and resources on a sustainable basis may effectively address gender disparities, and so address the barriers that women face in accessing TB health care.

Figure 4.6: The duration for TB treatment

To identify the barriers faced in accessing services that provide TB diagnosis and treatment, it was necessary to consider all the steps that have to be taken by women infected with the disease in Kibera slums. In the qualitative data collected, the patients were asked to narrate their experiences from when symptoms developed to diagnosis, treatment and cure. These steps make up a pathway that is often represented, for simplicity, as a straight line (Fig 4.7). In reality, the steps are rarely followed in a linear sequence; people look for a range of remedies from a variety of different providers at all stages of their illnesses (WHO, 2005a).

Poverty affects people's ability to access services at all stages of care-seeking

Symptoms	Help Seeking	Health services	Diagnosis	Treatment adherence	Positive outcome

Figure 4.7: Pathway to accessing TB services

Source: WHO (2005a).

The steps taken by female TB patients in Kibera slums in the quest for health care were associated with barriers that they had to overcome before getting the treatment. When one of the female TB patients was asked to cite some of the reasons for the delay or lack of access to TB care when sick, this is what she had to say:

> *Many people in this area, and women included, do not understand what the symptoms for TB are. Yes, there is a cough included but many of us just assume it is a cold until it lasts for very long and we become really sick, then people advise us to go to hospital.*

From the above quote, it is clear that since TB often starts gradually, the symptoms are more often than not ignored. This, coupled with a lack of knowledge about TB, may lead patients to dismiss symptoms as unimportant or to attribute them to other conditions such as a chronic cough or prolonged influenza. Illiteracy and low levels of education among the urban poor contribute further to lack of awareness on the importance of early detection and treatment of TB.

One key informant also cited ignorance of the symptoms as a major hindrance to TB care. He said:

> *Many of these people never know that it is TB they are suffering*

from. This is why they take so long to come to hospital, some take as long as two years from the onset of the symptoms.

Health Care Provider, MSF Kibera.

A volunteer in a self help-group in Kibera also reported that lack of knowledge of the symptoms of TB was a major contributing factor to delay or even failure to access TB health care in good time. She said:

Many people wait until it is too late before they can go to be tested if they have TB. Most of them never even realise that they are suffering from this disease. By the time they are tested, the disease is very serious, some of them just die. But here, we try so much to help each other cope with this disease and others also, like HIV/AIDS.

Volunteer, Kibera women self help group.

However, one other reason for the delay to seek health care during TB infection is the fear to know one's HIV status. All the participants in the case studies cited this as a major contributing factor to the fear of one going to the hospital for a TB test. This, they said, is because most Kibera residents understand TB to be an opportunistic infection resulting from one's immune system becoming immnosuppressed due to the HIV virus. In fact, most of them had both JHIV and TB at the same time. Due to this knowledge, therefore, whenever one coughs for a long time, one fears that one could be having the virus, and this is enough to keep one from visiting a health care facility for fear of being diagnosed with the virus.

Poor women with TB and/or HIV/AIDS tend to suffer from fear of being rejected by the family and the community. It has been shown that the fear of both diseases has been

more pronounced among women than men. While men usually worry about the loss of wages and capacity for work, women worry most about social rejection, that is, from husbands, in-laws and the community in general.

According to a health care provider with the International Medical Corps:

> *Whenever a patient comes to this clinic with a cough that has lasted for more than three weeks, we usually perfom a sputum test to determine whether he/she has TB. It is also mandatory for us to determine their HIV status at the same time, so we usually carry out the two tests so that the patient can be given the necessary treatment. Most people therefore shy away from coming to the facility whenever they suspect themselves of having TB since they know that they could also be suffering from HIV/AIDS. Most people here in Kibera still fear to know their HIV status.*

Gender-related factors and especially stigma can therefore be said to be one of the barriers inhibiting women's access to TB health care, disgnosis and complete treatment of the disease in Kibera slums. In the slum, however, there are support groups whose membership consists of both those infected and uninfected with HIV/AIDS and TB. In these groups, sick members get psycho-social support whenever stigma sets in and this helps them cope with the conditions. »

Asked how long a person can undergo TB treatment, 43% of the respondents correctly cited it as between 6 and 8 months. Only about 30 (30%) of them did not know the duration of TB treatment. In all the five case studies conducted, the respondents answered this question correctly. One reason for this could be because all of them had accessed TB care so they had this knowledge already. However, lack of compliance was

cited as a major problem during the treatment of the disease. Most patients never observe the dosage of the medication to the end. The result of this is multi-drug resistant TB which, according to the World Health Organization, is more expensive to treat and also takes longer. One TB patient cited the long period required to take the drugs as one major contributing factor to non-compliance.

> *The problem with the treatment is that one takes it for such a long period of time and this makes one get bored and stop. When I was tested and found to be having the disease, I got the medicine required to treat the disease. I swallowed the tablets for about two months but then they became a bother and I stopped taking them. Actually I was feeling fine already, so I thought that I was healed.*
>
> Female, 32 yrs.

Furthermore, once one starts to take the medication, one starts to feel better and so one stops taking the medication.

> *Usually, one feels fine after some time and then they think that they are cured of the disease, so they stop taking their drugs. After some tima, it recurs and they come back here for treatment. With such patients, we have no choice but to give them the jab which is more powerful. This is because many of them become resistant to the drugs. We also have to monitor how they take these drugs. Sometimes I have to visit them in their households when they fail to come for their drugs. I actually know where most of the patients live.*
>
> Health Care Provider, IMC

In Kibera, there are self help groups that help to monitor how these patients comply with the treatment. Those who are sick with TB are encouraged to join the groups so that they

can feel motivated to take their medication. These patients are usually encouraged to attend meetings organised by the group so as to share their experiences. Whenever one misses to attend these meetings, other members have to go and look for him or her at home. Usually, some of them are sick and so are not able to attend the meetings.

4.4 Poverty among women in Kibera and TB health care

> *My husband died last year and his family rejected me saying that they did not recognise me as their son's wife. My husband's family comes from Western Kenya but I come from Uganda. They rejected me and my children claiming that since I was the second wife, I was the one who killed their son. They refused to take care of me yet even at the time ,Iwas sick. They came to the house and took all household property forcing me to struggle and fend for myself and the children. But when my condition worsened, my daughter had to stop going to school to take care of me.*

The above narrative which came from a 32 year old female TB patient, a widow and a caretaker of her five children, describes a typical situation female TB patients within the study area face and which in turn becomes a hindrance when it comes to access to TB treatment, compliance and completion of the treatment. In this study, since the barriers to healthcare by female TB patients were investigated, certain questions were asked about the barriers that these women have experienced. According to the above narrative, the patient faced several problems in her condition. Apart from being an HIV/AIDS widow, the husband's family had rejected her and since she is a Ugandan, her family was just too far to give any assistance. With five children who were of school going age, she had to fend for them. But when the disease took its toll on her and she became bedridden, her eldest daughter, aged 11 years, was forced to stay home and take care of her and her siblings since the mother was just too ill to fend for the family. There is also stigma

associated with TB, especially when the patient is suffering from HIV/AIDS at the same time. The patient then just suffers in loneliness since even the neighbours fear to visit.

As a result of this dual infection, support groups are in place and they try to help these women cope with the disease. The members take it upon themselves to visit the other sick members and this gives them moral support during their periods of suffering. The importance of these support groups in the study area is highlighted in the narrative below:

> *The situation with TB and HIV/AIDS patients in Kibera is better now. This is because of the support they receive from groups that have come together specifically for the sake of helping those who are sick cope with the situation. Some members in the group are sick with these diseases while others are not sick but just belong to these groups.*

All the other four female TB patients that were interviewed during the study were single mothers, which meant that they were taking care of their families single handedly. This makes the sick situation worse for the patients because every patient needs support, both psychologically and materially, in order to hasten their recovery.

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As stated earlier, out of the 100 respondents, 45 (45%) of them were jobless. Out of those who were jobless, 32 (71.1%) were housewives. As housewives, their sole responsibility was to take care of the household, that is, facilitating their reproductive roles. However, many were still involved in business which included hairdressing, selling household goods and food vending. This implies that most Kibera residents are of low socio-economic status and their lives just involve a struggle.

According to Watkins and Plant (2004), one of the reasons for delayed TB treatment in Bali, Indonesia is poverty. Worldwide, the greater burden of ill-health is attributable to diseases of poverty, of which infectious diseases are a major part. In Kibera slum, poverty was found to be a major barrier to health care by women infected with the disease. This includes the women's earning abilities, means of livelihood and the economic activities that Kibera people were involved in.

Occupation of Kibera people can, therefore, be said to have a negative effect on TB care during times of infection. This is because whenever such people are affected by a particular disease, they are too preoccupied with their state of poverty to even notice that they are unwell and therefore seek for health care. Because they are also in less contact with communication avenues, they are more often than not uninformed and so, they will not know where to seek for health care or even that TB treatment is free in some facilities in the slum. This ignorance and 'isolation' is most likely to be a hindrance to TB health care among these community members. For those who operate these small businesses, they hardly have time to access any form of health care. To them, there is very little time to do this. All they concentrate on is their businesses so that they can provide for their families at the end of the day. This is so especially if the women are single parents. This came out in the case studies when a 38 year old patient gave this narration in a case study:

> *Because of the small businesses that most of us are engaged in here in Kibera, a woman cannot just afford to be sick. Who will take care of your family? You see , because of my illness, my young children have to fend for themselves and me. My daughter is currently out of school*

so that she can take care of me and the other children. I am not able to work because I am sick. For a long time, I did not go to hospital because I had to go to the market to do my business. When I finally went to see the doctor, my condition had become worse, which means that I have to work extra hard in order to get well so that my children do not suffer more than they already have.

The above quote clearly outlines the barriers that women in the slum area have to overcome before they cannot only access health care but also comply with the treatment up to completion so as to recover from the disease. This is because TB is a curable disease but if the medication is not taken as prescribed by the health care providers, then resistance arises which is not only more expensive to treat, but it takes the patient a longer period of time to complete the required dosage of the TB drugs. Women's sickness with TB in Kibera brings out another issue. More often than not, whenever a mother is sick, girls are taken out of school so that they can assume the responsibilities of daily household activities. Their education is therefore compromised because in some situations these women are suffering from both TB and HIV/AIDS and due to poverty, poor feeding and the overcrowded conditions in the slum area, some of them never recover. The girl then becomes the head of the household compromising her education

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and her childhood.

With many women being housewives, this suggests that most of their time is spent doing household chores. With no income of their own, they are left with no resources to access TB care. Most of those who were housewives depended on their husbands for their upkeep. They are not empowered economically and therefore are also not able to make a decision independent of their husbands. One 32 year old patient reported that she had

stayed for one year since the time she started coughing because her husband did not have any money to pay for health services in hospital. She said:

> *I stayed for one year before going to hospital. At first, I dismissed it just as a mere cough, but when it persisted, I wanted to go to hospital but my husband did not have enough money to feed the family and also to give me so that I can pay the hospital to help me. So I just used to take cough syrup until it became very serious to the point of almost dying. When I finally went to the Medicens Sans Frontiers clinic, they did not ask me for any money, and that is the time they referred me to Mbagathi District Hospital where I was treated and given drugs free of charge.*

This finding indicates that there is very little information on TB among Kibera residents. Despite the fact that TB treatment is free and it is a much publicised issue, still some people do not understand that they can access the treatment without being charged. Lack of economic empowerment therefore becomes a barrier to TB health care among women in Kibera slums.

With lack of or scarcity of food by residents in the study area, especially those suffering from the disease, compliance to the treatment becomes a tricky issue. Without proper diet, a sick person is not able to take her medication effectively. The side effects of the TB drugs also often make the patient weak.

The study site was a slum and therefore most of the people in the area are of very low socio-economic status. Most of the houses are makeshift structures. According to the UN HABITAT, a slum area has such characteristics as non-permanency in the households which results from the fact that slum dwellers build their houses on pieces of

land that do not belong to them. In Kibera, most of the households are one-roomed, and are in very close proximity to each other. Since TB spreads through the air, the study area has all the conditions necessary for fuelling the spread of the disease. The housing structures also do not do much in aiding the recovery of the sick people. This is because of lack of warmth, especially during the cold seasons. Most houses in Kibera are built of iron sheets for both the walls and the roofs, some are made of timber while others are built of mud. Since the disease affects the chest, these women's sick period is likely to be prolonged due to the lack of warmth.

High levels of poverty in the households studied, therefore, and generally the socio-economic status of the residents in the study area, did not put the residents in a position to prevent the spread of the disease and prolonged suffering to those infected. Lack of money was found to be an inhibiting factor in the ability of the households to carry out preventive mechanisms such as proper feeding, seclusion of the sick person and maintaining a reasonable hygiene standard. Being a slum area which has a characteristic of overcrowding and lack adequate sanitary facilities, this was an obvious contributing factor to the spread of the disease. This is because the TB causing bacterium stays in the air.

4.5 Multiplicity of women's roles and TB health care

Because of the low socio-economic status among Kibera residents, people spend most of their time fending for their families. For the housewives, even though they may not engage in any economic activities, they spend most of their time doing household chores

such that going to hospital when sick becomes a challenge. Most of these women have children who still need their care. Because the residents of the study area are of low socio-economic status, most of them are unable to afford hiring the services of a househelp. The situation is worsened when the infected women are single parents.

Generally, women in many countries have to overcome several barriers before they can access health care. When they undertake multiple roles in reproduction, production and community activities, they are left with less time to reach diagnostic and curative services than men. Women from Kibera slums are not an exception to this.

It is only in nine households out of the 100 visited that there were women who had recently suffered from TB. Out of these, 5 had stayed for more that two months before accessing health care. The reasons that were advanced for this delay in care seeking were that for one of the women, she did not have time to access health care while the other four did not know that they were suffering from TB. From the case studies, all the five respondents had taken long before accessing health care. One of the reasons advanced by a 32 year old female patient is captured in the following quote:

> *Whenever I am sick even with just malaria, it is not easy to go to the hospital. Where can I get time when I have four children to look after? I wake up in the morning and I work practically the whole day. So when I got sick with TB, I couldn Y even go to the hospital because I am occupied the whole day. This made me take 6 months before going to the hospital. This is despite the fact there are so many places to go for treatment here in Kibera. When I finally went to the Medicens San Frontiers clinic, I realised that the disease I was suffering from was very serious.*

4.6 TB treatment

According to the data from both the respondents and the health care providers, many women are unable to fully comply with the treatment to completion. Out of the five case studies done, one had had recurrent TB due to no-compliance with the treatment given to her, while three others had also not been able to complete their dosage of the treatment. Only one more was still in the initial stages of the treatment. According to a health care provider at the IMC, as a result of patients absconding treatment, the health care providers are forced to make follow-ups of all the TB patients that they treat. Being a non-governmental facility but working with the Ministry of Health in Kibera, the treatment of TB was given free at the time of study. For all those who failed to comply with the treatment instructions by the health care providers, additional treatment had to be given to them. This, according to the IMC health care provider, ensured that resistant TB is treated. The mode of treatment also changes from administration of tablets, to giving of injections.

> *We usually make follow-ups of all our patients. This includes visiting them at home in order to monitor the treatment given to them. For those who have failed to comply with the treatment and stopped mid-way, we have to give them jabs so as to ensure that the TB treatment is completed.*
>
> Health Care Provider, IMC

Successful chemotherapy of tuberculosis has two basic requirements: a combination of anti-tuberculosis drugs must be used and the treatment has to be prolonged. The treatment takes between 6 and 8 months. This prolonged period of time discourages patients from continuing with the treatment.

CHAPTER FIVE

DISCUSSION AND CONCLUSIONS

5.1 Introduction

These discussions are based on the research objectives outlined in chapter one. These were: to investigate the extent to which low levels of education among women in Kibera slums affect their access to health care; to examine the extent to which poverty among women in Kibera slums affects access to health care by those suffering from TB; and to determine whether multiplicity of roles is a hindrance to the access of health care by women from Kibera slums. The findings of the study specifically addressed the position that while there are free tuberculosis health care services offered by government facilities and other private sector facilities in Kibera slums, there are barriers that prohibit women from accessing these services whenever they are infected with the disease. In this study, an attempt has been made to locate the main factors responsible for this gap with the objective of mapping out strategies to curb them.

5.2 Discussion

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5.2.1 Education and TB health care

The first objective of this study was to determine the extent to which low levels of education among women in Kibera slums is likely to affect their access to health care during TB infection. The findings of the study suggest that educational attainment is closely related to accessing TB health care among women in Kibera slums. This is because about a half of the respondents (45%) in the study had attained primary level education while only a few had attained tertiary level education (6%). Most respondents,

however, had a good understanding of what TB is. For instance, a majority of the respondents were conversant with what TB is, with 32%, 31%, 20% and 15% correctly citing TB to be an airborne disease, a chest disease, a coughing disease and a lung disease, respectively. Most of the respondents (95%) knew that TB could be passed from one person to another. A majority of them knew how the TB disease could be spread but very few knew the cause of the disease. Slightly less than two thirds of the respondents (69%) cited HIV as the cause of TB. Only five (5%) respondents correctly mentioned bacteria as the cause.of the disease. This implies that this lack of knowledge is obviously a hindrance to accessing TB treatment. This is because despite some respondents mentioning HIV to be the cause of TB, there are those who reported that it is an HIV disease.

Despite the fact that a good number of the respondents in the study were quite knowledgeable about what TB is, its transmission as well as its signs and symptoms, from the results, a majority did not know the cause of the disease. This means that whenever such people contract the disease, they will not seek proper health care because they more or less understand the disease to be incurable.

This also brings about stigma because those suspected of having the disease are shunned by society. Due to this stigma, no one is willing to announce that they have the disease or that they are taking medication for TB which lasts for between 6 and 8 months. This is therefore likely to lead to non-compliance, and in turn multi-drug resistant TB that takes longer and is also more expensive to treat. The negative attitude towards TB as revealed

in this study that eventually leads to the stigma is due to both lack of awareness and social stigmatization towards HIV/AIDS. Stigma, though not one of the objectives of the study, can be termed as a barrier to TB health care by women suffering from the disease in Kibera slums.

Some of the TB patients reported that the reason they delayed to go to hospital when they started feeling sick was lack of money to pay at the health facilities. In three out of the five case studies done, this was the main reason given. Out of the 100 households visited during the study, it was only in nine households that there had been a woman suffering from TB. Slightly less than half of these (44%) delayed to seek health care for more than two months from the onset of symptoms and the reason given for this delay was lack of money to go to hospital. These respondents obviously did not have the information that TB treatment was free in all government facilities and even in some non-governmental facilities in the slum area.

The findings of this study therefore suggest that, to a large extent, low levels of education among women in Kibera slums significantly affects their access to health care during TB infection.

5.2.2 Poverty among women and health care

This study revealed that a majority of Kibera residents are of low socio-economic status. The findings of the study show that slightly less than half of the respondents (45%) in the study were jobless, and more than half of these were women who reported that they were

housewives. Others were involved in small-scale businesses as a means of livelihood. Some of the businesses they involved in include hairdressing, operating hair cutting salons, selling second hand clothes and food vending which entails cooking food and selling it to the residents. This is basically done on the streets since most of them cannot afford fees for renting space to put up a small eating place. A fifth of other respondents (20%) earned their livelihood by engaging in casual work which was very unpredictable, so most of the time they were out of work.

Some of the TB patients interviewed reported that they delayed to seek treatment when they were sick because they did not have money to pay for hospital fees. Those who reported to be housewives had to rely on their husbands to give them money. As long as this was not forthcoming, the women did not access health care whenever they fell sick. This situation, coupled with lack of knowledge about the disease, was found to be a major hindrance to health care seeking by the women who contracted the disease in the slum area.

Therefore, poverty among wonaen can be said to be a hindrance to health care seeking by these women. It becomes even more serious in the case of TB which is a deadly disease that causes high morbidity and mortality in the slum area. These findings confirm that poverty among women in Kibera slums largely affects their access to health care by those suffering from TB.

5.2.3 Multiplicity of roles by women and TB health care

The third objective of this study was to investigate whether multiplicity of roles by women in the slum area was a contributing factor to delay in health care seeking when infected with TB. The findings of the study suggest that lack of time for women in Kibera was a major hindrance to accessing health care during TB infection. Some of the women who are housewives spend the whole day carrying out household chores and so seldom get time to attend to their health needs. Of those women who had delayed for more than two months without seeking health care despite the onset of the symptoms of TB, 11% cited lack of time to visit a health care facility as the main reason for this delay.

There were those who engaged in some form of economic activities, for instance, business activities. This means that aside from taking care of the children and the household, they spent more time out of their households trying to get some income for their families' livelihood. Some of these were single parents and therefore the heads of households. With children to take care of, their health needs become secondary. Of the five case studies conducted from women who had either ever suffered from the disease or were suffering from it at the time of the study, two of them had delayed to visit a health care facility for treatment because they could not get time away from their household chores and business activities.

There are still some obligations for the community that women in Kibera are expected to fulfil. These include attending the chiefs *baraza* to discuss matters affecting the community. Many women from the slum area also involve themselves in voluntary work

in the community, for instance, they belong to support groups and other community based organizations that carry out social work in the area. This has to be factored into these women's programmes and eats into their time, so their own health needs become secondary.

This multiplicity of roles by women in Kibera can therefore be confirmed to be a barrier to TB health care by women whenever they are infected with the disease.

5.3 Conclusion

In the course of the reflections and arguments advanced in this study, certain conclusions have been arrived at concerning the barriers to TB health care by women infected with the disease in Kibera slum.

The study set out to investigate the extent to which low levels of education among women in Kibera slum, their poverty level and their multiple roles of reproduction, production and community hinder their access to TB health care whenever they are infected with the disease. The study has found that despite the fact that TB is a curable disease whose treatment is given free of charge in all government health facilities and in some private facilities in Kibera, there is still high mobility and mortality arising from failure or delay of women to access treatment when infected with TB.

Firstly, it has clearly come out that most of, if not all Kibera residents, are not very well informed about tuberculosis, especially on the causes and course of the disease. This

lack of awareness seems to be rooted in the low levels of education among the residents, especially women. This lack of proper understanding has led to those women falling sick with the disease failing or delaying to seek the necessary treatment. Some who do seek the treatment fail to fully comply with it, making the disease worse.

Also following from our analysis, poverty among women in Kibera slum was found to be a barrier in accessing health care during TB sickness. This is because with no money to access medical facilities as well as the slum environment which is predominantly overcrowded, patients with TB could not access treatment or fully comply with it even after accessing it. Lack of time on the women's part due to their multiplicity roles of reproduction, production and community was also found to be a stumbling block in accessing TB services by these women. Furthermore, from our analysis, stigma was also found to be a hindrance to TB health care by women in Kibera slums.

Our analysis has consequently established that there exists a notable gap between the free TB services offered in all government health facilities and some private ones in the area and access to these services by female TB patients in Kibera slum.

5.4 Recommendations

- Based on the findings of this study, massive educational campaigns need to be established to inform women in Kibera slums of facts about TB. Tuberculosis projects should focus on educating women and the whole community at large about the disease, showing the importance of early detection of TB, treatment and

compliance. Of even more importance, there is need to educate Kibera community members on where to get TB health care services.

- A gender approach to health should be adopted in order to address gender related health problems that affect women and increase morbidity and mortality arising from TB infection. This can be undertaken by both private and public health projects in the country. Involvement of men in the community is important because they will be able to understand the importance of supporting women in accessing TB health care services.

5.5 Areas for further research

- To provide more comprehensive information on barriers to TB health care among women, similar studies should be undertaken in various parts of the country where similar groups of people exist.

- Indepth studies also need to be carried out on other barriers such as stigma as another socio-cultural barrier, distance from services providing TB diagnosis and treatment as a geographical barrier, and traditional practices and systems that prevent the seeking of modern treatment.

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APPENDIX I: STRUCTURED QUESTIONNAIRE

Introduction

Hello, my name is Hilda. I am a Master of Arts student in Anthropology at the University of Nairobi. I am conducting research on the barriers to TB health care by women in Kibera slums. This is part of the requirements for my Masters degree. You are one of the respondents selected for the study. I will be very grateful if you provided responses to these questions. No names will appear on this questionnaire and the information you give me will be treated with utmost confidentiality. However, you are free to withdraw from the interview in case you feel uncomfortable. If you agree to participate in the interview, we may begin.

1. Sex of the respondent
   a) Male b) Female
2. Marital status
   a) Single b) Married c) Separated d) Divorced e) Widowed
3. Level of education
   a) None b) Primary c) Secondary d) College/ University
   b) Vocational/ Craft making
4. Religion
   a) Protestant b) Catholic c) Muslim d) Traditional
   b) Other (Specify)
5. Main occupation
6. What is Tuberculosis?
   a)
   b)
7. What is the cause of TB?
8. What are the major signs and symptoms of TB?
   a)
   b)
   c)
9. If a person is infected with TB, can he/she pass it to someone else?

a) Yes b) No

10. If yes, how can this happen?

11. Is TB curable?

a) Yes b) No

12. For how long does a person undergo tuberculosis treatment?

a) 1 - 3 Weeks b) 1 - 5 Months c) 6 - 8 Months

d) 9 months - 1 year e) Don't know

13. Has there been a woman in this household who has been infected with TB?

a) Yes c) No

14. If yes, when was she infected with TB?

a) Less than one month ago b) Two to three months ago

c)Three to six months ago d) More than six months ago

15. Did she get TB treatment?

a) Yes b) No **(If No, go to 20)**

16. Where did she get treatment?

a) Health centre b) Mbagathi District Hospital

c) Kenyatta National Hospital d) Private doctor e) Herbal medicine

f)Traditional healer g) Faith healer h) Self treated

e) Other (Specify)

17. What was the period between the onset of symptoms and access to treatment?

a) Less than one month

b) Between one month and two months

c) More than two months

18. If the period was more than two months, what were the reasons for this delay?

a) Health care facility not available

b) Health care facility too far

c) Was not aware that was suffering from TB

d) Did not have consultation fees

e) Did not have time to go to a health care facility

f) Husband had not given permission

g) Other (Specify)

19. How did this woman address the above factors?

a)

b)

c)

d)

20. If the women infected with TB did not seek health care, what was the reason this?

a) Health care facility not available

b) Health care facility too far

c) Was not aware that was suffering from TB

d) Did not have consultation fees

e) Did not have money to finance own trip to the health facility

f) Did not have time to go to a health care facility

g) Husband did not agree

h) Other (Specify)

APPENDIX II: CASE STUDY GUIDE

Introduction

Hello, my name is Hilda. I am a Master of Arts student in Anthropology at the University of Nairobi. I am conducting research on the barriers to TB health care by women in Kibera slums. This is part of the requirements for my Masters degree. You are one of the respondents selected for the study and the selection was on the basis of being or having been infected with TB. I will be very grateful if you provided responses to these questions. No names will appear on this questionnaire and the information you give me will be treated with utmost confidentiality. However, you are free to withdraw from the interview if you feel uncomfortable. If you agree to participate in the interview, we may begin.

1. Marital status
2. Level of education
3. Religion
4. Main occupation
5. What is tuberculosis?
6. What are the major signs and symptoms of TB? Is TB curable?
7. For how long does a person undergo tuberculosis treatment?
8. Did you get treatment for your infection when you fell ill?
9. Where did you get the treatment?
10. What was the period between the onset of symptoms and access to treatment?
11. If the period is more than two months, what were the reasons for this delay?
12. If no, why did you not get treatment?
13. How did the above reasons affect your access to treatment?
14. What would you recommend to be done in order to address the issue of barriers to TB health care by women?

APPENDIX III: KEY INFORMANT INTERVIEW GUIDE

Introduction

Hello, my name is Hilda. I am a Master of Arts student in Anthropology at the University of Nairobi. I am conducting research on the barriers to TB health care by women in Kibera slums. This is part of the requirements for my Masters degree. You are one of the respondents selected for the study and the selection was on the basis of being an opinion leader in this community. I will be very grateful if you provided responses to these questions. No names will appear on this questionnaire and the information you give me will be treated with utmost confidentiality. However, you are free to withdraw from the interview if you feel uncomfortable. If you agree to participate in the interview, we may begin.

1. What are some of the signs and symptoms of TB that residents of Kibera understand?

2. In your opinion, which is the most affected age group or group of people?

3. When people in this area fall sick with TB, what do they do to address the condition?

4. What are some of the barriers to TB health care for female patients in Kibera slums?

5. How do these women address these barriers?

6. In your opinion, what can be done in order to address barriers to TB health care for women in Kibera slums?