

**ACCESS TO TUBERCULOSIS INFORMATION AND ITS INFLUENCE ON
HEALTH-SEEKING BEHAVIOUR AMONG TUBERCULOSIS PATIENTS AT
ONE HEALTHCARE CENTRE IN NAIROBI, KENYA**

BY

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DECLARATION

Declaration by candidate

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DEDICATION

I dedicate this study to all the Tuberculosis patients in Kenya who have suffered stigma and discrimination due to lack of knowledge from the society around them.

ABSTRACT

Tuberculosis (TB) is a disease that has caused unprecedented suffering to millions of people, not to mention its impact on the country's economy. In spite of having a cure, numerous deaths continue to occur as a result of this virulent disease. The disease has outstripped HIV as the leading cause of death among infectious diseases. The main purpose of the study was to find out how public discourse on tuberculosis affects the self-disclosure and health-seeking behavior among TB patients. The study aimed to answer the following research questions: How do TB patients, TB survivors, TB patients' kin and TB healthcare workers access information on the disease? What kind of information do TB patients, TB survivors, TB patients' kin and healthcare workers have about the disease? How does public discourse on TB inhibit self-disclosure and health-seeking among TB patients. The study adopted a qualitative approach to generate and analyze data. Twenty five participants who included six TB patients, five TB survivors, eight TB patients' kin and six healthcare workers were selected to participate in the study using a purposive sampling technique. Data was generated using unstructured interviews. Thematic analysis was used to analyze the data, and some of the key emerging themes in this study were that having TB was seen as a death sentence and a sign of bad luck or witchcraft by most of the TB patients and TB survivors. Findings from this study indicate that despite the existence of multiple channels of communication, majority of the TB patients, TB survivors and TB patients' kin got their TB knowledge from the health care workers and friends. This study also established that despite the existence of multiple channels of communication, both correct and incorrect information on tuberculosis was evident in all the four different categories of respondents who were interviewed. The study further revealed that health-seeking behavior of TB patients is largely determined by the kind of information that they have about the disease. Majority of the survivors reported that they would have avoided delay in seeking healthcare if they had access to correct information about TB. Access to correct and timely information of TB is crucial for the control of this disease. The major recommendation from the study is that public awareness campaigns on tuberculosis need to be intensified all over the country so that more and more people are not only able to access information on tuberculosis, but also correct information about the disease.

ABBREVIATIONS AND ACRONYMS

CHS:	Community Health Services
DOTS:	Directly Observed Treatment System
GOK:	Government of Kenya
HCW:	Health Care Workers
HIV:	Human Immunodeficiency Virus
MDG:	Millennium Development Goals
MDR-TB:	Multidrug-resistant TB
MTB:	Mycobacterium Tuberculosis
SDG:	Sustainable Development Goals
TB:	Tuberculosis
WHO:	World Health Organization
WTBD:	World Tuberculosis Day

DEFINITION OF KEY TERMS

Health-seeking behavior: In this study, I adopt Mutsasa (2011) definition of health-seeking behaviour, as any action undertaken by individuals who perceive that they have a health problem for the purpose of finding an appropriate remedy.

Information access: In this study the term information access will mean ‘the ability and opportunity to obtain knowledge of classified information

(<http://www.thefreedictionary.com>)

Relapse: This study will use WHO (2013) definition of relapse to mean ‘previously treated for TB, were declared *cured* or *treatment completed* at the end of their most recent course of treatment, and are now diagnosed with recurrent episode of TB caused by re-infection (either a true relapse or a new episode of TB caused by re-infection).

Self-disclosure: This study will adopt Adler and Proctor (2014) definition of self-disclosure as a process of deliberating revealing information about oneself that is significant and would not normally be known by others.

Social stigma: This study borrows from Dhingra and Khan’s (2009) definition of ‘social stigma’ as ‘an undesirable or discrediting attribute that an individual possesses, thus reducing that individual’s status in the eyes of society’.

TABLE OF CONTENTS

DECLARATION.....	ii
DEDICATION.....	iii
ABSTRACT.....	iv
ABBREVIATIONS AND ACRONYMS.....	v
DEFINITION OF KEY TERMS.....	vi
CHAPTER ONE.....	1
INTRODUCTION.....	1
1.0 Chapter Overview.....	1
1.1 Background to the study.....	1
1.2 Communication interventions in tuberculosis management.....	4
1.3 The challenges in communication of tuberculosis.....	6
1.4 Stigmatization of tuberculosis.....	8
1.5 Statement of the problem.....	9
1.6 The purpose of the study.....	11
1.7 Research questions.....	11
1.8 Justification of the study.....	11
1.9 Significance of the study.....	12
1.10 The scope of the study.....	14
1.10.1 Content scope.....	14
1.10.2 Geographical scope.....	14
1.10.3 Methodological scope.....	15
1.11 Scope in terms of limitations.....	15
1.11.1 Content scope.....	15
1.11.2 Geographical scope.....	16

1.11.3	Methodological scope.....	16
1.12	Theoretical framework.....	17
1.13	Chapter summary.....	19
CHAPTER TWO.....		20
LITERATURE REVIEW.....		20
2.0	Chapter Overview.....	20
2.1	Global Trends in the spread of Tuberculosis.....	20
2.2	Communication and Health.....	23
2.3	Communication in the Management of Tuberculosis.....	26
2.4	Tuberculosis Stigma and Discrimination.....	30
2.5	Health-seeking Behavior among Tuberculosis Patients.....	37
2.6	Tuberculosis Knowledge.....	47
2.7	Self-Disclosure among TB patients.....	49
2.8	Public Discourse on TB and how it affects patients.....	52
2.9	Summary of literature review and emerging knowledge gaps.....	52
CHAPTER THREE.....		54
METHODOLOGY.....		54
3.1	Introduction.....	54
3.2	Research paradigm.....	54
3.3	Research Design.....	55
3.4	Research Approach.....	56
3.5	Research site.....	58
3.6	Study population.....	58
3.6.1	Study sample and sampling procedure.....	59
3.6.2	Purposive sampling.....	59
3.6.3	Sample size.....	60

3.7	Methods of data generation.....	61
3.7.1	Qualitative interviewing approaches.....	61
3.8	Methods of data analysis.....	62
3.9	Ethical considerations.....	64
3.9.1	Negotiating access.....	64
3.9.2	Confidentiality.....	65
3.9.3	Anonymity.....	65
3.9.4	Informed consent.....	67
3.9.5	Permits.....	67
3.10	Chapter Summary.....	67
	CHAPTER FOUR.....	69
	DATA PRESENTATION, ANALYSIS, INTERPRETATION AND DISCUSSION.....	69
4.0	Introduction.....	69
4.1	Social demographic characteristics of the respondents.....	69
4.2	Sources of information.....	74
4.3	Nature of information on TB that patients, survivors, kin and healthcare workers have on the disease.....	75
4.3.1	Correct Information.....	76
4.3.2	Incorrect information.....	76
4.3.3	Myths and beliefs about TB.....	77
4.3.4	Religious and cultural beliefs.....	78
4.4	Public discourse on HIV/Aids.....	79
4.4.1	Link with HIV.....	79
4.4.2	Public discourse on tuberculosis disease.....	81
4.4.3	Stigma and Discrimination.....	83
4.4.4	Death sentence.....	85
4.4.5	Bringing a coffin.....	86

4.5	Impact on self-disclosure.....	86
4.5.1	Fear of ostracization.....	86
4.5.2	Denialism.....	87
4.5.3	Signs of despair.....	88
4.5.4	Mis-interpretation of doctor’s actions.....	89
4.5.5	Attitude of healthcare workers and how it affects the health-seeking behaviour of TB patients.....	91
4.6	Discussion of findings.....	92
4.6.1	Information access.....	92
4.6.2	Nature of tuberculosis information.....	94
4.6.3	The determinants of health-seeking behaviour of TB patients.....	96
4.6.3.3	Structural factors.....	100
4.6.3.4	Stigma related factors.....	102
4.7	Impact of self-disclosure.....	102
4.7.1	Fear of ostracization.....	102
4.8	Public discourse on HIV/AIDS.....	103
4.8.1	Link with HIV.....	103
4.9	Public discourse on tuberculosis disease.....	104
4.9	Chapter summary.....	106
CHAPTER FIVE.....		107
SUMMARY OF KEY FINDINGS, CONCLUSION AND RECOMMENDATIONS.....		107
5.0	Introduction.....	107
5.1	The key findings of the study.....	107
5.1.1	Summary of the sources of information.....	107
5.1.2	Summary of the nature of information.....	108
5.1.3	Summary of the determinants of health-seeking behaviour.....	108
5.3	Public discourse on tuberculosis disease.....	108

5.4	Conclusion.....	109
5.3	Recommendations.....	110
5.4	Suggestions for further research.....	111
	REFERENCES.....	112
	APPENDICES.....	119
	APPENDIX I: INTRODUCTORY LETTER.....	119
	APPENDIX II: INTERVIEW GUIDE FOR TUBERCULOSIS PATIENTS.....	120
	APPENDIXIII: INTERVIEW GUIDE FOR TUBERCULOSIS SURVIVORS.....	124
	APPENDIXIV: INTERVIEW GUIDE FOR TUBERCULOSIS KIN.....	127
	APPENDIX V: INTERVIEW GUIDE FOR TUBERCULOSIS HEALTHCARE WORKER	129
	APPENDIX VI: LETER OF RESEARCH AUTHORITY.....	131

CHAPTER ONE

INTRODUCTION

1.0 Chapter Overview

The purpose of this chapter was to provide an overview of the entire chapter. I begin by giving a background to the study which looks at tuberculosis globally, in Africa and then Kenya. I then go on to discuss communication interventions that have been conducted to address the disease. This was followed by the challenges that have been observed in the communication of this disease. Stigma associated with the disease is also covered followed by the statement of the problem. Then next I revealed the key purpose of the study together with the list of research questions that this study sought to address. The justification and significance of the study follow in that order. Finally I present the scope of the study which clearly explains in detail the content, context and methodologies that were used for this study. I also explain the limitations that I faced. The chapter draws to an end with the theoretical framework that guided the study followed by the summation of the entire chapter.

1.1 Background to the study

Tuberculosis (TB) is an infectious disease caused by the bacillus *Mycobacterium tuberculosis*. It typically affects the lungs (pulmonary TB) but can affect other sites as well (extra-pulmonary TB). The disease is spread through the air when people who are sick with pulmonary TB expel bacteria, for example by coughing. Overall, a relatively small proportion (5-15%) of the estimated 2-3 billion people infected with *M. tuberculosis* will develop TB disease during their lifetime. However, the probability of

developing TB is much higher among people living with HIV (Global Tuberculosis report 2015).

The World Health Organization (WHO) declared Tuberculosis a global emergency in 1993 (WHO, 1998). Twenty two years later, considerable progress has been made in managing this infectious disease, but Tuberculosis remains a leading cause of premature death in young adults around the world. Roughly one third of the world's inhabitants are latently infected with *Mycobacterium tuberculosis*.

The year 2015 was a watershed moment in the battle against tuberculosis (TB). The Global tuberculosis report 2015 by the WHO marked the deadline for global TB targets set in context of the Millennium Development Goals (MDGs), and was a year of transitions that was from the MDGs to a new era of Sustainable Development Goals (SDGs) and from the Stop TB Strategy. The report established that advances are major meaning TB mortality has fallen to 47% since 1990, with nearly all of that improvement taking place since 2000 when the MDGs were set. The report further establishes that the MDG target to halt and reverse TB incidence has been achieved on a worldwide basis, in each of the six WHO regions and in 16 of the 22 high burden countries that collectively account for 80% of TB cases. TB incidence according to the report has fallen by an average of 15% per year since 2000 and is now 18% lower than the level of 2000.

According to the WHO fact sheet number 104 (WHO, 2015), TB occurs in every part of the world. In 2014, the largest number of new TB cases occurred in the South East Asia and Western Pacific regions, accounting for 58% of new cases globally. However, Africa

carried the most severe burden with 281 cases per 100,000 populations in 2014. Chaisson and Martinson (2008) explicate that Africa is facing the worst tuberculosis epidemic since the advent of the antibiotic era. Driven by a generalized human immunodeficiency virus (HIV) epidemic and compounded by weak health care systems, inadequate laboratories and conditions that promote transmission of infection, this devastating situation has steadily worsened, exacerbated by the emergence of drug-resistant strains of tuberculosis.

Tuberculosis is a disease that continues to kill thousands of people in Kenya despite the fact that it is preventable and treatment is offered free of charge in the country. According to the WHO latest rankings, Kenya has moved from position 13 in 2009 to position 15 out of the 22 countries with the highest TB burden, which collectively contribute to 80 percent of the global TB burden. In Africa, Kenya is fourth after South Africa, Nigeria and Ethiopia.

The Ministry of Health in Kenya has reported that the number of tuberculosis cases in the country has dropped by 40 percent though more still needs to be done to eradicate the disease. The report continues to state that in Kenya, the disease ranks as the fourth leading cause of death with over 81,000 cases and 10,000 deaths (27 deaths per day) reported last year. In Nairobi the slums are said to be the worst affected as they account for almost 30 percent of TB cases. The report further states that currently one in every three people has the TB bacteria lying dormant in their bodies, meaning they neither present the symptoms nor fall sick. The Ministry further reports that Nairobi county accounts for 15 percent of the country's TB burden and spends slightly over 200 million Kenya Shillings to diagnose and treat TB. Kenya spends nearly Kenya Shillings 11

billion annually in hospitalization costs, deaths and out of pocket expenditures for TB care and absenteeism from work (Merab, 2016).

There is a marked milestone in the nation's response to diseases like tuberculosis and leprosy. This National Strategic Plan (NSP) is based on epidemiological analysis of the burden of these diseases and information gleaned from the program review. The plan is aligned to the Kenya Health Sector Strategic and Investment Plan 2013-2017 and the global post – 2015 plan. The plan further promotes strategic interventions unique in each country, and which have the greatest impact for case notification, childhood tuberculosis, drug resistant tuberculosis, leprosy and lung diseases (The Kenya National Strategic plan on Tuberculosis, Leprosy and Lung diseases, 2015-2018).

The Government of Kenya (GOK) has a vision to reduce the burden of Lung disease in the country and aims at achieving a Kenya free of TB. In Kenya TB is a major cause of morbidity, with nearly 90,000 cases notified in 2013 and it happens to also be the 4th leading cause of death in the country. Kenya will remain a legacy in sub-Saharan Africa for being the first country to reach WHO targets for both TB case detection and treatment success.

1.2 Communication interventions in tuberculosis management

The Guidelines for TB and Leprosy Control (2009) indicates that within countries, and in the context of TB control, communication primarily seeks to create and improve knowledge among the general public about TB (e.g. symptoms and curability), TB control services (e.g. diagnosis and treatment) and improve interpersonal communication

between patients and service providers contributing to behavioral change or to meet a particular behavioral goal.

The Ministry of Health in Kenya started a National Communication Strategy for fighting TB in Kenya called 'Lights of Hope' (2006) for use in Kenya in the fight against tuberculosis (TB). The strategy is based on a study of health-seeking behaviour among Kenyans, strategy design workshops with stakeholders, and meetings with frontline TB workers. The goal is to present a strategy for reducing the impact of TB in Kenya through communication strategies aimed at behaviour change. This strategy is built upon three pillars which are Provoking enquiry, Demonstrating hope and options and empowering families to act. These pillars are the philosophical foundation on which the rest of the communication strategy is built. They are also derived from insights that emerged from research data and other evidence and are worded to provide broad guidance and emphasis for anyone developing a communication plan for TB in Kenya. Three TB infection stages which are Pre-diagnosis, Post-diagnosis and Treatment stages were identified. The main issue being addressed by this communication strategy is a family unit as an important primary audience for TB communication as its role spans all the three infection stages.

According to these communication strategies, the choice of media is based on the premise that persuasive information and individual and community endorsements are the most powerful tools for encouraging health-seeking behaviour to reduce the impact of TB. The communication strategy proposes deployment of interlinked mass media for example the use radio, print and television. They also propose to use mid-media for example closed circuit TV in hospitals, posters, pamphlets, booklets and testimonials. Last but not least

they also propose to use traditional media for example community theatre, puppets and song.

1.3 The challenges in communication of tuberculosis

According to Sarkar and Scalway (2005), there are several communication challenges relating to TB and one of them is how to increase case detection through public engagement moving beyond merely awareness raising. The closing of the time gap between the onset of TB symptoms and the seeking of treatment is another crucial challenge in combating this disease. The two scholars concur that it is of utmost importance to involve national and international partners in providing a link with broader health and development campaigns and movements. There is also a need in supporting the involvement of activities and TB patients in defining strategies for controlling TB and reducing stigma associated with the disease. Apart from these, support is also needed for the civil society in monitoring government responses to TB.

There are also other communication challenges relating to TB like the embracing of large numbers of private healthcare providers within a comprehensive TB response. There is also a need to address the issue of TB/HIV co-infection and capitalizing on successful HIV/AIDS communication interventions. Mobilization and advocacy for the strengthening of health systems has also proved to be another communication challenge relating to this disease.

The two scholars argue that if these challenges are addressed there will be a significantly enhanced response to TB hence public mobilization, political commitment and real

improvements in case detection and cure will be increased. They further argue that our failure to respond to TB is largely a communication failure. For example they claim that people suffering from TB symptoms often think they just have a cough rather than TB. On the other hand they claim that those affected and their care-givers, often do not know where to find help. They assert that less than half of all TB cases are currently detected and this presents a major challenge for communication. They further assert that even among the cases that are detected and treated there is often a very long delay between the onset of symptoms and diagnosis. In my opinion communication is supposed to start right from the onset of symptoms and diagnosis and possibly continue right to the end of treatment.

Communities need to be given simple information about TB that improves their knowledge, demystifies myths and misinformation and improves their health seeking behavior. People do not have to understand in-depth information about a disease but basic knowledge of the signs and symptoms, treatment options and care to avoid patient delay. With this kind of information apart from seeking health care they can also complete their treatment regime. Communication can play a big role in educating and mobilizing people to be aware of TB to avoid long delays between the onset of symptoms and diagnosis. The challenges in communication of TB can be dealt with by making people aware about TB beyond World TB Day. Awareness needs to be done more often so that people are always well informed about the disease (Hausler & Wills, 2007).

1.4 Stigmatization of tuberculosis

Tuberculosis (TB) remains a disease enshrouded by social stigma that affects the behaviour of patients, their kin and Health Care Workers. A high number of TB patients

including TB survivors suffer or have suffered from stigma associated with this disease. Due to very limited access to information on TB, many patients are likely to suffer from stigma, which in the long run affects their health-seeking behavior and adherence to treatment.

Wandwalo et al. (2000) conducted a study to determine patient's general knowledge of tuberculosis and the management of the disease. They found that a substantial number of patients interviewed in health facilities in the study period had an unsatisfactory knowledge of TB disease and its management. A similar study conducted by Hoa et al. (2004) found out that knowledge about TB and its treatment were generally high. Another similar study conducted by Tasnim et al. (2012) concluded that knowledge about cause and treatment of TB among TB patients was quite good, however, misconceptions also existed. The scholars concurred that mass media could be better utilized to remove misconceptions about the disease. Despite several studies having been conducted on this disease, it still remains a highly stigmatized disease.

Tuberculosis (TB) in Kenya is a huge public concern. The disease is characterized with public ignorance and high social stigma of TB-patients leading to increased number of TB positive cases. It has been estimated that Kenya could be failing to detect close to 20% (20,000 TB cases) of all persons with TB disease each year. There is therefore a need to intensify their efforts in case finding, treating and curing the missing TB cases among the Kenyan population and the need to accelerate the progress towards zero TB deaths, infections, suffering and stigma. It is for this reason that the Kenya government felt the need to conduct a TB prevalence survey 2015-2016. This survey was long

overdue bearing in mind that the last survey ever done in this country was in the year 1958-1959. This current nationwide survey is aimed at obtaining an accurate estimate of the country's TB burden. The survey not only aims to determine the existing challenges in accessing TB testing and treatment but it is also meant to identify presumptive TB cases that may not have been detected by the National TB control program.

1.5 Statement of the problem

Tuberculosis is a disease which has a cure yet many deaths have resulted from it due to lack of correct information. Many people seek healthcare when the disease has progressed to an advanced stage. Access to timely and correct information is crucial for the management of this disease. This disease is also highly stigmatized and many infected people end up spreading it because they would rather not disclose their status for fear of being ostracized. These views are in line with results of a recent study conducted in Ghana by Osei et al., (2015) which sought to assess the delays in diagnosing new TB patients and the factors associated with these delays in a municipality in Ghana. The findings of the study concluded that any delay in diagnosis and consequently treatment of TB patients not only increased the infectivity of the disease but also led to more advanced disease state, which was likely to result in more complications and further exposed the patients to higher risk of death.

In another similar study conducted by Courtwright and Turner (2010), which systematically reviewed literature on TB stigma to identify the causes and evaluate the impact of stigma on TB diagnosis and treatment, it was established that stigmatization is a social determinant of health. It also established that stigma occurs because of

community and institutional norms about undesirable or disvalued behaviors or characteristics. They further established that when diseases are stigmatized, the fear of the social and economic consequences following diagnosis can make individuals reluctant to seek and complete medical care.

The propensity of the patients to seek healthcare or for self disclosure is largely determined by the knowledge about and perceived risk of TB. There is also evidence that TB is highly stigmatized due to its relation to HIV/AIDS. Many medical studies have demonstrated a clear correlation between TB and HIV/AIDS which has threatened to sabotage the efforts to bring this disease under control. Kipp et al., (2011) who conducted a study in southern Thailand, who found out that incorrectly believing TB can increase the chance of getting AIDS was associated with higher stigma among patients. This they discovered was most likely due to the rate of TB/HIV co-infection and/or that patients with TB are routinely tested for HIV. In another similar study conducted in Western Kenya by Ayisi et al., (2011), reported that the association between HIV and TB could extend TB stigma. The study suggested that stigma related to HIV infection may reduce TB test uptake among TB suspects. It is against this background that this study sought to fill up the gaps of knowledge about the disease and understand the reasons why patients avoid self-disclosure. In particular, the study investigated the link between stigma, lack of knowledge and failure to seek healthcare.

1.6 The purpose of the study

The main purpose of the study was to find out how public discourse on tuberculosis affects the self-disclosure and health-seeking behavior among TB patients

1.7 Research questions

1. How do TB patients, survivors, kin and healthcare workers access information about the disease?
2. What kind of information do TB patients, survivors, kin and healthcare workers have about the disease?
3. How does public discourse on TB inhibit self-disclosure and health-seeking behavior among TB patients?

1.8 Justification of the study

The World Health Organization (WHO) has reported that tuberculosis (TB) remains a major global health problem. In 2014, 9.6 million people fell ill with TB and 1.5 million died from the disease. Over 95% of TB deaths occur in low and middle income countries, and is among the top 4 causes of death for women aged 15 to 44. The number of deaths is unacceptably large given that most are preventable. Despite advances in medicine and science, this disease has proved to be a challenge when it comes to its eradication. Access to correct and timely information can greatly reduce the number of deaths caused by this disease.

In a community-based cross-sectional study conducted in Gambella state of Ethiopia by Bati et al., (2013), whose objective was to assess the level of TB knowledge, attitudes and practices of rural communities of Gambella in Ethiopia, established that the majority of the study participants had no correct information about the causation agent of TB and the main symptom of pulmonary TB. There was also low level of overall knowledge, attitudes and practices about TB in female participants. The results of another study

conducted in Vanuatu by Viney et al., (2014), reported that the majority of the TB patients interviewed did not attribute TB to a bacterial cause. The findings show that people require better information about TB to correct commonly-held misperceptions about the disease. Recent studies like these shed new light on the need to understand how everyday conversations about tuberculosis affect the health-seeking behaviour of TB patients.

1.9 Significance of the study

Tuberculosis (TB) in Kenya is believed to create a state of discomfort and patients usually recourse to secrecy, dissimulation and disguise. Tuberculosis (TB) patients undergo ostracization from the society because this disease is seen as a contagion. There is an open fear of contagion from the society who opt to shun anyone suspected to suffer from the disease. Tuberculosis and HIV are also inexorably linked in the minds of many people which affects public discourse on the disease and self disclosure by the patients. A study designed to investigate psychosocial experiences of patients who had completed tuberculosis treatment in Brazil by Dias et al., (2013), found that TB still causes patients to suffer from fear of transmission, social prejudice and death. In addition to that, participants in the study revealed that friends and colleagues had distanced themselves from them for fear of contagion and/or prejudice due to ignorance about the disease and its transmission modes. The study concluded that people suffer from and are victims of prejudice due to continuing stigma and lack of knowledge about the disease on the part of patients themselves and society at large.

There have been challenges identified in implementing health policies and strategies to date. The new 'Kenya Health Policy 2012-2030' was developed in line with the

Constitution and the goals of 'Kenya Vision 2030'. The policy has therefore adopted a rights-based approach to health, and seeks to make the right to health for all Kenyans a reality. The objectives of the new health policy include the elimination of communicable diseases and reversing the rising burden of non communicable diseases amongst other policies (The Kenya Population Situation Analysis report, 2013).

This study may be beneficial to the National Tuberculosis Control program as it would highlight the current level of awareness of tuberculosis information amongst the TB patients, survivors, kin and healthcare workers. This study could also provide useful insights on the kind of information that is out there for patients and family including healthcare workers. The study hopes to support the government's plan into achieving the Sustainable Development Goals (SDG) number three, by aspiring to ensure health and well-being for all, including a bold commitment to end the epidemics of AIDS, Tuberculosis, Malaria and other communicable diseases by the year 2030. At a policy level, the Kenyan government is committed to giving its citizens the highest attainable standard of health, as enshrined in Article 43(1) of the Constitution. As part of this commitment, the country adopted the WHO's international standards of TB care and patients' charter for tuberculosis care, which endorses free TB treatment as a government responsibility. Furthermore this study would help understand the many misconceptions associated with this disease and apart from that, the study may bring to the forefront issues concerning public discourse and how it affects the health-seeking behaviour of TB patients. To the future researchers, this study may provide baseline information on recent status of TB knowledge in Kenya.

1.10 The scope of the study

1.10.1 Content scope

This study focused on how the everyday communication about TB influenced individual's willingness to seek healthcare. To achieve this, the study examined the sources and nature of information regarding TB and how the lack of correct information contributes to the stigma associated with the disease.

1.10.2 Geographical scope

For this study I adopted a single case study research design of one healthcare centre in Nairobi. I chose the case study because it is known to be a robust research design and it would be apt for the kind of investigation that I intended to undertake. This kind of research design is bound to produce very rich and in-depth information from the participants. One of the reasons why I chose the particular health facility was because of the accessibility and the availability of the research participants who were needed for the study.

1.10.3 Methodological scope

This study was guided by the relativist ontology and interpretivist epistemology. A single case research design was adopted for the study and a qualitative research approach was used. The study population that was selected for this study comprised of TB patients, TB survivors, TB healthcare workers and TB patients' kin. A purposive sampling procedure comprising of 6 TB patients who were on treatment, 5 TB survivors who had successfully completed treatment, 6 healthcare workers and 8 TB patients' kin were interviewed for this study. In total, 25 participants participated in the study. Unstructured interviews were

used to generate data which was analyzed using thematic analysis. Findings were presented in the form of a report.

1.11 Scope in terms of limitations

1.11.1 Content scope

There were gaps in literature for example there was a lot of focus on tuberculosis stigma and health-seeking behaviour of TB patients. There was also a lot of focus on information access on TB and communication in TB management and yet there was very little literature on drivers of health-seeking behaviour of TB patients and also the reason why stigma still exists despite several studies. Gaps in literature also appeared on the kind of information on TB together with very little studies on public discourse on TB and how it affects TB patient's self disclosure.

1.11.2 Geographical scope

There are many healthcare centers in Nairobi but this particular one was apt for this study in terms of accessibility and availability to the researcher as opposed to the other health-centers.

1.11.3 Methodological scope

One of the challenges that I encountered while conducting this study was the issue of participants backing out of the interview at the last minute. This was mainly due to the sensitive nature of the disease and the stigma that is attached to it. I did not take this rejection personally, but instead I took it with a lot of resilience and courage. I had to re-negotiate access to the participant and if they were still reluctant to continue with the

interviews, I went back to the TB healthcare workers to recommend to me another participant who was willing to participate in the study.

Another challenge that I encountered while conducting this study was the risks of exposure to the disease. Tuberculosis is a highly contagious disease especially in the initial stage of infection, so I had to first seek a lot of guidance from the healthcare workers on how I could safely conduct my interviews with the TB patients who were on treatment. For example if I wanted to interview a patient who was contagious in a room, I would first check whether the room had adequate ventilation and if the room was not well ventilated I would kindly request the TB patient to allow me to conduct the interview outside. I would use a lot of skill and tact so that the TB patient does not feel stigmatized by my decision. Once outside, I had been instructed by the healthcare workers to check the direction of the wind. This is because the TB patient should not sit in a position where the wind is blowing from them to my direction; it should be the other way round. The wind should blow from my direction towards them so that I do not get infected because TB can be transmitted through the air.

Generally, the interviews were mainly conducted in English language but a few respondents preferred that the interviews be conducted in Kiswahili. Translating some of the interviews from Kiswahili to English was a bit of a challenge, because it took more time to transcribe then translate, nevertheless the data collection was successful.

1.12 Theoretical framework

This study was guided by the Social Cognitive Theory (SCT). This is a theory that was developed as the Social Learning Theory (SLT) in the 1960s by a psychologist called

Albert Bandura. This theory is one of the Behavioral Change Theories which are used in health promotion activities and programs. Social Cognitive Theory (SCT) describes a dynamic, ongoing process in which personal factors, environment factors and human behaviour exert influence upon each other. The importance of having a theoretical framework for this study was crucial because it would provide a better understanding on the reasons why people adopt certain health-related behaviors depending on the environment where they are situated and how one can intervene under these circumstances. This theory helps us understand how the environment in this study can influence the behaviour of a patient. It also helps us understand how patients learn certain types of behavior regarding their health.

Glanze and Rimer (2005), suggested that theory “helps practitioners to interpret the findings of their research and make the leap from facts on a page to understanding the dynamic interactions between behavior and environmental context”. The two scholars suggest that according to SCT, three main factors affect the likelihood that a person will change a health behavior. The first factor is Self-efficacy, the second Goals and the third Outcome expectancies. This being the case, TB patients in this study would need to have a strong self-efficacy belief system that would enable them to promote a positive health-seeking behavior despite having barriers. These barriers could be issues like stigma and discrimination. Self-efficacy would also be used during communication between TB patients and the healthcare workers and the same would also be necessary during self-disclosure of diagnosis by the TB patients or TB kin.

According to the theory barriers could end up becoming impediments which can affect the health-related behavior of patients. The patients would want to know whether the action they take can result in a positive outcome. For example if a TB patient had knowledge on the benefits of taking and completing their TB medication and that this would result in them feeling better then automatically they would definitely take their medication without fail. The only problem that they were likely to face during this process would be the many obstacles that they would encounter towards their goal of changing their health-seeking behavior. Social Cognitive Theory evolved from research on Social Learning Theory (SLT), which asserts that people learn not only from their own experiences, but by observing the actions of others and the benefits of those actions (Glanz & Rimer, 2005). If we relate that to this study we find that TB survivors can act as role models for the TB patients who are seeking treatment. The fact that they got cured from TB is a motivational factor for those TB patients who need to change their health-seeking behavior so that they can also get well. The research further makes reference to the theory in the literature review and discussions of findings in the subsequent chapters of this thesis.

1.13 Chapter summary

In this chapter I have clearly outlined the various factors that conceptualized this study. From the introduction, I gave a background to this study and it is quite evident from my discussion that while some countries have witnessed a decline in new TB cases, the fight against this disease is still far from being won in Sub-Saharan Africa. I have demonstrated that more effort still needs to be put if this battle is to be won. The war is not only on the eradication of the disease, but it is on the obstacles which are along the

way in this fight. Obstacles like access to information on TB and also obstacles like stigma which have exacerbated the spread of this disease and have greatly affected the health-seeking behavior of those affected and infected. Drawing on these premises, this study agrees with previous studies that the ongoing TB pestilence has overwhelming evidence corroborating failure of the health systems in combating this disease. It is against this background that this study sought to understand how access to information on TB affects the health-seeking behavior of TB patients. The study used three research questions to guide the study. A justification of the study together with a significance to the study clearly explaining the contributions that the study will give to the National Tuberculosis Control Program. Limitations were clearly stated and the chapter summed up with a theoretical framework that guided the entire study.

CHAPTER TWO

LITERATURE REVIEW

2.0 Chapter Overview

After having built a background to this study in the previous chapter, this chapter reviews literature related to the present study. The first section reviews literature on the current global trends in tuberculosis spread. This is followed by an analysis of literature on the communication interventions that have been put in place with regards to health, knowledge and management for tuberculosis control. The next section reviews literature on stigma and discrimination and seeks to justify why this study focused on the two as possible determinants for the health-seeking behavior of TB patients. This is then followed by literature on tuberculosis knowledge and then literature on self-disclosure.

The chapter ends by highlighting the emerging knowledge gaps that constitute the focus of this study.

2.1 Global Trends in the spread of Tuberculosis

The year 2015 was a watershed moment in the battle against tuberculosis (TB). It marked the deadline for global targets set in the context of the Millennium Development Goals (MDGs) to a new era of Sustainable Development Goals (SDGs), and from the Stop TB Strategy to the End TB Strategy. The MDG target to halt and reverse TB incidence has been achieved on a worldwide basis in each of the six WHO regions and in 16 of the 22 high-burden countries that collectively account for 80% of TB cases. Globally TB incidence has fallen by an average of 15% per year since 2000 and is now 18% lower than the level of 2000. This year's report describes higher totals for new TB cases than in previous years, but these reflect increase in the spread of the disease.

Ending the TB epidemic by 2030 is among the health targets of the newly adopted Sustainable Development Goals. WHO has gone one step further and set a 2035 target of 95% reduction in deaths and a 90% decline in TB incidence similar to current levels in low TB incidence countries today. Despite these advances and despite the fact that nearly all cases can be cured, TB remains one of the world's biggest threats and it ranks alongside HIV as a leading cause of death worldwide (WHO report, 2015).

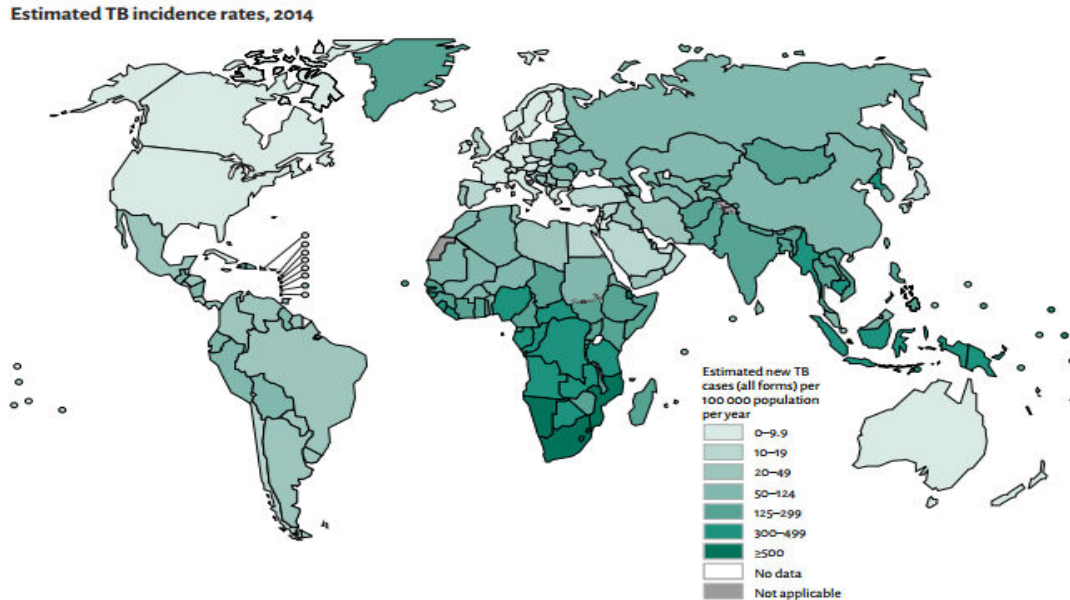


Figure 2.1 Estimated TB incidence rates 2014. Adapted from *Global Tuberculosis Report 2015*

Tuberculosis occurs in every part of the world. In 2014, the largest number of new TB cases occurred in the South-Eastern Asia and Western Pacific regions, accounting for 56% of new cases globally. However, Africa carried the greatest proportion of new cases per population with 281 cases per 100 000 population in 2014. During the same year about 80% of reported TB cases occurred in 22 countries. The 6 countries that stand out as having the largest number of incident cases in 2014 were India, Indonesia, Nigeria, Pakistan, People’s Republic of China and South Africa. Some countries are experiencing a major decline in cases, while in others the numbers are dropping very slowly (WHO report, 2015).

According to a report from the Ministry of Health Kenya by Odiwuor and Odhiambo (2015) the United States government in collaboration with the Ministry of Health in Kenya has launched a new drug intended to prevent tuberculosis (TB) among people

living with HIV and AIDS. This according to the report was pegged on the fact that there was a rise in the number of people infected with TB with figures reaching over 90,000 people aged between fifteen and forty four in the country in the year 2013. According to the report, the drug is supposed to prevent latent TB from progressing to active TB. The drug follows a six month dose that is given once in a lifetime to significantly reduce the risk of acquiring active TB and also mitigating its transmission to others.

Africa is facing the worst tuberculosis epidemic since the advent of the antibiotic era. Driven by a generalized human immunodeficiency virus (HIV) epidemic and compounded by weak health care systems, inadequate laboratories and conditions that promote transmission of infection, this devastating situation has steadily worsened, exacerbated by the emergence of drug-resistant strains of tuberculosis (Chaisson & Martinson, 2008).

Kenya has been reported to be one of the 22 high TB burden countries and is ranked 15th according to the WHO Global Tuberculosis Report 2015. The government of Kenya (GOK) is implementing all the six components of Stop TB strategy which have been further divided into 15 thematic areas in the 2011-2015 National Strategic plan. During the year 2010, a hundred and six thousand and eighty three patients were notified (all forms of tuberculosis) representing a 4% decrease compared to the 110,065 cases reported in 2009. In Nairobi alone, TB cases have increased from 1,048 in 1990 to 18,906 cases in 2007, which represents almost 18-fold increase in the last 17 years. The emergence of HIV prevalence among the general population in Nairobi is 9%. This is

higher than that for the country, which stands at 7.4%. With reference to the above, Kenya still has a long way to go in the eradication of Tuberculosis.

2.2 Communication and Health

Apart from facilitating dialogue and information-sharing, communication can also help people to understand and to influence positively their health-related behavior. Communication can also help health services to better understand the personal and social aspects of health problems to provide more adequate answers. Simple, clear and culturally appropriate messages are needed to inform and create awareness among the general public and people affected by TB. The messages are supposed to focus on the disease and available care with opportunities for people to become actively involved (WHO, 2008). These views are in line with those of the current study. Communication is about accessing information which can lead to behavioral change. The kind of communication can be between the healthcare worker and the tuberculosis patient or it can also be between the healthcare worker and the tuberculosis kin. This communication can lead to information sharing which can influence the health-seeking behavior of the TB patient. The kind of messages received by the patient apart from influencing behavior change can also encourage public discourse on TB leading to self disclosure. This study will seek to know whether the current messages out there on TB are easy to understand and whether they are appropriate.

Based on the above recommendations, communication is a vital element in any development activity. Communication apart from preparing people for change, provides information on key areas and helps in decision-making. The idea of getting individuals to

adopt new kinds of behavior has been the chief aim of the health sector for a number of decades. Good communication is the pillar for building a sense of cooperation with health care providers, beneficiaries and other stakeholders. This communication may range from something as simple as ensuring awareness regarding the disease, symptoms and treatment, to promoting the successful exchange of valuable technical information, through to the simple act of putting up messages in outdoor clinics (Agarwal & Chauhan, 2005). This study has demonstrated that communication leading to a positive change in the health-seeking behavior is one of its main goals.

The scope of health communication includes disease prevention, health promotion, healthcare policy and business of healthcare as well as enhancement of the individuals within the community. Health communication is an important part of a patient's ability to understand and act upon health information (Osoweni, 2014). Obregon and Waisbord (2012) reiterate that communication has played an important role in advocating for healthy policies and environments, mobilizing communities, creating trust between users and providers, promoting healthier behaviors or the adoption of new behaviors and raising awareness to rapidly and effectively respond to disease outbreaks. Obregon and Waisbord criticized how communication has become associated with information dissemination, materials, interventions (campaigns), target audiences and messages.

Campbell and Jovchelovitch (2000); Campbell and Macphail (2002), as cited by Obregon and Waisbord (2012) argue that several studies have shown how communication skills are central to the process by which people identify, understand, discuss and act upon health challenges. They state that the analytical focus of communication research should be

looking into how societies problematize health and disease, and lastly how they establish priorities for action. Dutta (2008) as cited by Obregon and Waisbord (2012) states that it is through communication that knowledge gets represented globally, and the values attached to it are circulated in the realms of developing interventions targeting global health problems. Dutta (2010) ,further states that since the process of representing knowledge is in itself a production of knowledge, the assumed product location of communication has changed from that of a message to be propagated among audiences, to one of engaging the very processes of producing knowledge about specific subjectivities and political configurations in the global landscape.

Communication expands both knowledge of and access to quality services and the products needed to practice health behaviors. Communication creates demand and helps patients understand the benefits of new behaviors. It can strengthen social networks and reflect norms that support healthy behavior. Communication also helps providers explain services and treatments to patients and encourage them to use those services consistently and effectively (Storey et al., 2014).

Communication in this case is seen as a tool which can help shape and implement policies that ensure the availability of resources and services required to change and maintain behavior. The scholars explore the vast diversity of communication processes across the continuum of care starting with prevention which they feel suggests a growing number of ways that biomedical and communication interventions can be deployed in a complementary fashion to improve and sustain outcomes and this they say can only be possible if they are willing to grab the opportunity.

Communication is important not only in the context of doctor-patient or family member's interaction, but also between healthcare professionals. The advantages to the patient are obvious as effective communication gives them better insight into their conditions and may aid compliance and quality of life. Poor communication with patients is thought to contribute to psychological morbidity, low personal achievement and emotional burnout (Khan, 2006). Raviglione (2010) argues that communication is concerned with informing and enhancing knowledge among the general public and people with TB and also empowering them to express their needs and take action.

2.3 Communication in the Management of Tuberculosis

Communication should be placed centrally on the tuberculosis (TB) agenda. Many logistical and medical components of the global response to TB are relatively robust yet the communication part is not. Cure rates are high, but the numbers of people with TB who require medical help are low. Better communication, which includes advocacy, social mobilization and program communication would provide much of the solution to this and a number of other problems within today's fight against TB (Sarkar & Scalway, 2005). All communication activities make use of some form of media or channel of communication for example mass media, community media or interpersonal communication. Communication practitioners stress that for communication to be effective, it should be understood as a two-way process with 'participation' and 'dialogue' as key elements (Deane & Parks, 2006).

The aim of communication is to increase awareness of the community regarding basic information about tuberculosis (Communication disease health education and training

(HEAT) module, 2015). This is the major aim of communication in this study. The module indicates that the availability of abundant information about this disease and raising levels of community awareness can enable one to influence what is socially normal and acceptable. The module further indicates that this has an impact on TB control and that it also changes behavior in both individuals and groups of people. This study agrees with these sentiments because if TB patients had information that if they take their medication faithfully, they would be cured, then they would not stop taking the medication at any given time just because they felt better. With abundance of information on the disease they would be well-informed which would lead to a change in their health-seeking behavior. Abundant information and communication awareness would help TB kin and healthcare workers reduce stigmatization of the patients. Communication which creates awareness in this case is bound to bring about this change.

The module suggests that the involvement of previously treated and cured TB patients appears to be a good idea because it helps improve with communication and counseling between people with TB, families and providers. TB survivors in this study can be seen as possible persons who can step in to improve with communication and counseling of those who are infected or affected with TB. In the theoretical framework discussed in the previous chapter, Social Cognitive Theory recognizes the fact that people learn not only from their own experience, but also by observing the actions of others and the benefits or outcomes of these actions. The healthcare workers can also use these TB survivors as examples of patients set goals and achieved them by adhering to the TB treatment regime.

The National Communication Strategy for fighting Tuberculosis in Kenya report (2006) states that for communication to be effective, it must occur during all the three stages at which an individual must act on his or her own behalf, that is, at the Pre-Diagnosis stage followed by the Post-Diagnosis stage and lastly at the Treatment stage. The report claims that wrong decisions at any of these stages can be fatal and that each phase carries its own communication requirements, audiences and risk profile.

Communication in TB management recognizes that just telling people what they should do does not necessarily mean that people will follow the prescribed message. The repeating of some information may also not encourage people to change their behavior. People from the onset should recognize the need to access services as soon as they develop a cough which persists for more than three weeks. The confidence in the health care system, that is (interpersonal communication between providers and patients) and also having information and confidence that good quality diagnosis and treatment facilities are available within the environs is very important for the patient (Agarwal and Chauhan, 2005). In context of this study, it is important to establish how confidence in the healthcare system enables or can disable disclosure and willingness of TB patients to seek treatment.

The healthcare workers in this study would be expected to use effective communication and education techniques like those outlined by 'The National Centre for HIV/AIDS, Viral Hepatitis, STD and TB prevention division of Tuberculosis (2014), when communicating with TB patients and kin. One of the techniques mentioned is the use of non medical terms. The kind of information that the four categories of participants should

have, should be easily understood. If these four categories of participants access the information on TB but they cannot understand it then it becomes irrelevant to them. The same applies to the technique of language level and the amount of information, meaning the target audience has to be considered. The technique of providing education materials, when related to this study, we have to consider that the information provided can either bring a positive or negative change in behavior. It can also encourage or discourage self disclosure by the patient or the kin. Feedback is very important during the communication process.

Communication is seen as having an important role in improving treatment adherence amongst TB patients. The aim towards a target goal of eighty five percent treatment success has been much more marked than that against case detection, although every effort must be made to maintain cure rates in many countries. Communication and social mobilization programs ensuring patient education, combined with broader community support and empowerment initiatives, are essential if cure rates are to improve and be sustained (Deane & Parks, 2006).

If existing baselines are established and the setting of specific measurable goals for achieving a critical level of awareness about TB among the population, is likely to go a long way towards developing communication interventions. The media in this case is seen to play a key role in this situation, going beyond newsroom reporting that draws on dry statistics and official press releases. TB communication must go beyond the usual flurry of media and communication around World TB Day (Sarkal & Scalway, 2005).

2.4 Tuberculosis Stigma and Discrimination

Tuberculosis is highly stigmatized, with considerable discrimination towards sufferers (Baral et al., 2007). The scholars cite Goffman's definition of stigma as being an 'attribute that is deeply discrediting' and that it reduces the bearer from a 'whole and usual person to a tainted, discounted one'. They further state that patients often cut themselves off from other people so as not to infect them and also to evade uneasy situations such as being shunned or becoming the subject of idle talk. They also claim that being either a patient or a former patient of tuberculosis is likely to affect employment and employment prospects.

TB patients experience psychological and social sufferings and their basic rights may be ignored (Goffman, 1963) as cited by (Dhingra and Khan 2009). Social stigma has been found to be one of the most common challenges met by TB patients. Dhingra and Khan (2009) define social stigma as 'an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society. The two scholars cite 'The Revised National Tuberculosis Control Program (RNTCP) status report of New Delhi (2005) which claims that India lags far behind developed countries in managing tuberculosis (TB) because of social stigma attached to it. The stigma attached to TB adds to the burden of disease for both men and women and even more so if they are of marriageable age. The report gives two scenarios where men have to deal with stigma at their places of work and when it comes to women, they have to face stigma at the community level. These women are ostracized within the household and in the immediate neighborhood. They are also inhibited in discussing their illness and participating in social functions due to fear of becoming outcasts in the community.

Among the various causes of TB stigma, the fear of being infected is identified as the most overwhelming (Dodor et al., (2008). TB stigma is not only limited to countries such as India but also south America and Africa. The unhealthy attitude and behavior of the community towards TB and towards those who suffer from it often leads to the patient hiding their diagnosis (Dodor and Kelly, 2009). This study discusses how lack of correct information and negative public discourse on TB inhibit self disclosure and health-seeking behavior among TB patients. For this study the views expressed by the above two scholars emphasize that unhealthy attitude and behavior of the community towards TB patients could inhibit self disclosure and health-seeking behavior of the patients.

Discrimination occurs in two forms, there is direct discrimination which occurs when a person is treated less favorably, on the grounds of their disease than others are or would be treated in the same or similar circumstances. The second type of discrimination is that of indirect discrimination which occurs when a requirement or condition is applied which, although applied equally to all persons, is such that a considerably smaller proportion of people with the disease can comply with it and it cannot be shown to be justifiable other than on health grounds. The point here is that, the perception of stigma by other people, or by the stigmatized person is what leads to discrimination. Stigma is of utmost importance because it is believed that it is the cause of discrimination. There is so much burden of stigma that is put on TB patients, yet there is little understanding of the precise nature of the causes of stigma and discrimination (Cremers et al., 2015).

Stigma and consequent discrimination have a double impact on TB control. TB patients do not want to be associated with the disease which eventually makes it very difficult for people suffering from a pro-longed cough and could be TB suspects to seek healthcare. This is because of the public nature of the disease's diagnostic process. These patients are likely to delay seeking care and in the long run there is a high chance of the disease progressing to a more advanced stage which is complicated to treat. The patients are also likely to continue infecting other people as they remain contagious. Stigma and discrimination for TB has made it quite a challenge for the patients to freely continue to seek care because of their fears of being suspected or associated with the disease. They also develop a fear of being identified as being or having been infected with the disease. This eventually blocks their access to services on a day to day basis (Baral et al., 2007). In the context of this study, access to information and the kind of information on this disease, by TB patients can either remove the fear that is making them not want to be associated with this disease or instill fear in them. If there is a lack of correct information and negative public discourse on TB then this can inhibit self disclosure which will affect their health-seeking behavior.

A lack of understanding about Tuberculosis has led to the disease being met with high levels of stigma and discrimination. It has also resulted in patients who are diagnosed with TB to be sent away from their communities. Patients in this situation, apart from being diagnosed early enough, continue spreading the disease when they delay seeking care for fear of stigma and discrimination. Treatment default is seen as being one of the biggest problems in the treatment of tuberculosis today. This is due to the long treatment regime which requires a patient to seek treatment several times a week for at least a

period not longer than six months. Despite this issue of treatment default, there is a bit of ignorance on the possible repercussions of treatment default and is common among TB patients in the developing countries. This situation is likely to make the issue worse which is reported to be the largest driver of drug resistance (Friends for International Tuberculosis Relief report, 2015).

On the other hand Newell et al., (2007), concur with other previous scholars that TB is a highly stigmatized disease. They claim that TB patients are despised and shunned by the public, much in the same way as people who are suffering from leprosy. The treatment schedule expected from a TB patient makes it very difficult for them to keep their status of the disease secret. The scholars further claim that the repercussions of being infected not only reduce the chances of one getting employment but also the chances of one getting married are also reduced drastically. A person's chance of standing in the society is also reduced and all these may lead to isolation and depression and majority of patients keep to themselves.

The stigma that accompanies tuberculosis can have a detrimental effect on the individual and family and may result in their withdrawal from society because of shame and fear. There appears to be widespread ignorance which requires education of both the individual, kin and the community. The aim of this education is to provide practical strategies to help people cope with tuberculosis. Confidentiality should be given priority during the provision of these management strategies. There are many beliefs about disease are culturally sensitive, therefore health education must also be culturally

sensitive and adapted to the focus on changing misconceptions about its cause and transmission, which could in turn reduce stigmatization (Tripathy, 2015).

Western countries such as Germany, claim that tuberculosis is a notifiable disease which means that physicians, microbiology laboratories and pathologists are required to report all diagnosed tuberculosis cases to the Health Department. This type of measure may not have been implemented in many developing countries. The legislation in the developed world makes sense, it may be a larger problem in developing countries where low levels of literacy are prevalent and a cure is not guaranteed for various reasons such as poor quality or inadequate supply of drugs, inappropriate treatments extra. Due to all these issues, patients end up having to face discrimination, ostracization and abandonment by the society and even their loved ones. This behavior by the society in general makes patients to further hide their status and in the process they continue transmitting the disease to many other people (Friends for international relief report, 2015).

Research has demonstrated that personal rejection occurs as a result of the strong stigma surrounding TB. The patient's perception about tuberculosis should be clearly understood. This is bound to enable a better design of a client oriented comprehensive program for tuberculosis. Other issues such as enacted stigma, whereby the patient develops a fear about the way other people treat them is also likely to occur. These patients end up developing a sense of inferiority due to the tuberculosis and the perceived stigma attached to it. Discrimination then sets in leading to social aversion. Patients under these circumstances avoid self disclosure due to this stigma and discrimination which eventually leads to a further delay in diagnosis and treatment. The chances of

transmission of the disease to a healthy community are greatly increased (Dhingra & Khan, 2009).

Prior research has suggested that stigma is perceived to increase TB diagnostic delay and treatment noncompliance. TB stigma is not new and that there's a well-documented literature which has shown why and how TB has been highly stigmatized throughout history. TB is seen as "a disease of the poor" and that of HIV/AIDS stigma which affects TB patients, particularly in communities where HIV/AIDS is common. Due to this two types of stigma, TB patients have to bear the burden of carrying both types of stigma (Waisbord, 2005).

Dhingra and Khan (2009) argue that enough needs to be done to change the mindset of the patients and the society in regards to stigma. There is a need to reduce stigma about TB which can help break the barrier of having undisclosed TB patients who keep on spreading the disease. There is a claim of fear of infection which has been seen as the main culprit for this problem called stigmatization attitudes and behavior of both health professionals and community members towards those with TB. Jaramillo (1999) as cited by Deane and Parks (2006) argues that stigma and discrimination associated with TB are among the greatest barriers to preventing further infections, providing adequate care, support and treatment. They further argue that stigma is harmful, both in itself, since it can lead to feelings of shame, guilt and isolation of people living with TB, and also because negative thoughts often lead individuals to do things, or omit to do things, that harm other or deny them services or entitlements that is discrimination. The families and communities may reject and ostracize those living, or believed to be living with TB. They

believe that such acts constitute discrimination based on presumed or actual TB-positive status.

According to Waisbord (2005) as cited by Deane and Parks (2006) claim that studies repeatedly demonstrate that stigma deters people from seeking care and diagnosis and that women bear the highest burden of stigmatizing behaviors. They proceed and claim that stigma and discrimination are triggered by many forces including lack of understanding of the disease, myths about how TB is transmitted, prejudice, lack of access to diagnosis and treatment, irresponsible media reporting, the link between HIV/AIDS and TB and fears relating to illness and death. They further proceed and state that lack of access to TB diagnosis and treatment is a key issue that enhances or advances TB-related stigma and discrimination in many countries. The perceived “un-treatability” of TB is a key factor contributing to the stigmatization of many of those affected. The two scholars argue that the challenge of reducing stigma and discrimination needs to be addressed within public and private health sectors and among health workers on the ground. Fear, lack of knowledge and misconceptions are deep-rooted. They further state that the ways of looking at patients in general and patients with contagious diseases like TB need to be radically changed. The services need to have a more patient-oriented approach.

2.5 Health-seeking Behavior among Tuberculosis Patients

The TB control community has recognized and addressed system components in which behavior is a key issue. Both diagnosis delay and non completion of treatment are two central behavioral challenges. There is a need for patients to seek care and complete treatment (Waisbord, 2005). According to Mackian (2003) as cited by Afolabi et al.,

(2013), health-seeking behavior has been defined as the activity undertaken by individuals who perceive themselves to have a health problem or to be ill for the purpose of finding an appropriate remedy.

Mutsatsa (2011) defines health-seeking behavior as any action undertaken by individuals who perceive that they have a health problem for the purpose of finding an appropriate remedy. A clear and detailed insight on how patients differ in how serious they consider different conditions to be is given, and this interacts with their perception of susceptibility. He gives an example of how a patient may be at low risk of developing bowel cancer, but since they perceive it as a very serious condition, they may feel motivated to see the doctor about persistent loose stools. He then gives another example of how another patient may consider a headache as something small and therefore possibly fail to have a serious condition diagnosed. He further claims that perception of seriousness can affect not only whether or not a patient presents to a healthcare service, but also where they present. He brings in the case of TB where a patient may feel that coughing up green phlegm is serious and this may lead them to consult a doctor, but if they consider it not important, they may decide to take the problem to a pharmacist.

Mutsatsa (2011) clarifies that this behavior starts with a decision-making process that is dependent on an individual's family, community values and expectations. It is also controlled by the characteristics and behavior of the health care provider. These factors work concurrently to yield a final choice of a health-seeking option that may typically involve recognition of symptoms and the perceived nature of the illness, followed by suitable care and observation.

Mutsatsa (2011, p.63) brings in the term self-efficacy which he defines as ‘the term used to describe how people view their own ability to carry out a particular action.’ Bandura (1991) as cited by McIntyre and Mooney (2007) define self-efficacy “as people’s beliefs about their capabilities to exercise control over events that affect their lives and their beliefs in their capabilities to mobilize the motivation, cognitive resources and courses of action needed to exercise control over task demands.” Self-efficacy attributions are concerned not with the skills one has but with the judgments of what one is able to do with whatever skills one possesses. These skills include a patient’s perception of how likely they are to change their health seeking behaviors.

The health seeking behavior of persons is influenced by their health and disease knowledge, beliefs, attitudes and perceptions. The reasons mentioned on behavior can influence prevention behaviors, the timing of diagnosis and treatment, patient understanding of the diagnosis and treatment initiation, treatment adherence and interactions with health care providers. The knowledge that people have or perceive about TB even when they are not yet affected is an important determinant of their future health seeking behavior (Auer et al., as cited by Yamira 2009).

There comes a situation when a patient has developed a perception about their health, there usually exists a trigger that turns this action to something called ‘cues to action’. This action analyzes this point from a communication perspective, where one can be seen as the nurse who will want to uncover what triggered a patient to seek health care. The possible triggers may be quite varied. They can either be the media, a relative, an overheard conversation or a reminder letter. A prompt like this, may increase a patient’s

perception of their susceptibility to a disease. This is likely to remind them of the increased advantages of seeking health care. The prompt in this case is likely to increase their motivation to change or persuade them that they may in fact be able to make any required changes themselves (Mutsatsa, 2011).

Concerns about how being identified as a person with TB can make it complicated for people with a cough of a long duration to seek care and this is because of the TB diagnostic process. These TB patients may choose to delay in seeking health care not knowing that by doing this they remain contagious for a longer period of time. The same patients are likely to infect other people with the disease during this period that they are contagious. Secondly, there are concerns about how stigma and discrimination towards TB patients make it more difficult for patients to continue with care. This is because they have fears of being identified as being, or having been infected with TB. This fear may stop the patients from seeking health services on a daily basis. This kind of behavior is likely to lead to serious symptoms and increased transmission (Cremers et al., 2015).

Deane and Parks (2006) reiterate what other scholars like Cremers et al., have said about stigma. The two scholars state that several studies have demonstrated that stigma deters people from seeking health care and diagnosis. They observed that most TB patients tend to postpone seeking care due to fears of people discovering their HIV status, and suffering stigmatization and social rejection as a consequence of their HIV and TB status being revealed. They further claim that from various studies it has been reported that women bear the highest burden of stigmatization behaviors. This stigma is suspected to be a contributing cause to why females are more likely to postpone diagnosis. Women

rarely go for sputum tests and they also feel more inhibited than men to discuss TB with their family. They further cite other studies which have documented that gender differences in health seeking behavior of TB patients explain delay differences between men and women. Despite the first studies which showed that women are more likely to delay in seeking care, other studies have shown that it is the men who are likely to postpone seeking care for a longer duration of time than women. They cite fear of individual costs of diagnosis and treatment as one of the reasons for delaying in seeking healthcare. They also claim that women are more likely than men to seek health care immediately after symptoms.

The stigma attached to many communicable diseases, such as Leprosy and TB, also determines the patient's health seeking behavior. There are interventions to improve accessibility to healthcare while preserving patient privacy which are important in promoting gender-equitable access to health services. The issue of improving physical accessibility by increasing numbers and strategic placement of community clinics is one of the many interventions that are seen to bring a change in health seeking behavior. The extending of opening hours and reducing costs of treatments are another set of basic interventions with huge potential which can have a positive impact. There is fear of social isolation owing to the stigma of infectious disease becoming another hindrance to health seeking behavior in women. Interventions that foster acceptance and support of those with communicable diseases therefore address a significant barrier to care (Murthy & Smith, 2010).

The International Standards for Tuberculosis Care (2006), indicates that quality of care accorded to patients and especially to TB patients determines the health-seeking behavior of these patients. Kenya's burden continues to increase because of TB transmission that is still going on and this is clearly manifested in new cases reported amongst children. The report emphasizes the point that there is a known delay in diagnosis of TB patients of up to eight weeks, which is both unacceptable and undesirable. According to the report, patients ought to be able to access services of the highest quality and standards at all times.

Cultural beliefs and religion were found to influence health-seeking behavior of patients. The understanding of traditionally held beliefs in causes and characteristics of TB is important for facilitating communication about the disease to the population and a good knowledge level among patients will positively influence treatment delay and also help reduce TB related stigma (Annan et al., 2013).

In another study conducted by Matebesi et al., (2005) in Free State, South Africa, whose primary aim was to investigate the health-seeking behavior among a sample of pulmonary TB patients. The findings pointed to significant factors that needed to be addressed in order to facilitate the early recourse to healthcare and to prevent the transmission and recurrence of TB. In this study, it was discovered that the majority of the patients in the study were not aware of TB before their own diagnosis. It was reported that low levels of knowledge and awareness of TB was likely to have two causes. The first cause was that TB health education and advocacy programs did not reach the community at large. The second cause was the fact that there was a general culture of

patients passively receiving instructions instead of being actively involved in their own treatment.

The study found that the results had several implications for public health policies. The first implication was that of long delay before patients seeking healthcare. They argued that this long delay contributed significantly to increased transmission of TB and that there was a need to minimize this long delay by means of improvements in the quality and coverage of the control program. The second issue was that of lack of awareness about TB which was closely linked to the delay in seeking care. The scholars argue that public education was paramount in raising people's awareness of TB from an early age. Lastly the study reported that it was important to identify remedies or alternative treatments that patients use before presenting themselves to healthcare providers because these therapies were believed to cause, complicate or exacerbate the problem.

In a similar study conducted by Abebe et al., (2010) in a rural community in South West Ethiopia found that less than fifty per cent of TB suspects did not seek help. A further less than thirty percent contacted a health facility, another less than thirty percent went to drug vendors, about six percent opted for self medication and a very tiny percent of about zero point four percent preferred going to traditional healers. Lack of money mainly for transportation was reported for about fifty six percent. The perception that TB will improve was reported from about forty seven percent of the community. A further eight point six percent considered the disease to be harmless yet a further one point four percent reported no health facility around as a reason for not seeking healthcare.

The study also reported that health seeking behavior was not associated with gender, literacy status, and marital status, knowledge about anti-TB treatment, stigma, age, occupation and knowing a TB patient. Traditional beliefs were found to contribute to the spread of TB as most people with such beliefs were not likely to visit health facilities. Mesfin et al., (2009) as cited by Abebe et al., (2010) in a study that was also conducted in Ethiopia showed that forty six percent of patients seeking care at health facilities did so after informal treatment failed. Moreover, patients' poor perception of the cause of TB such as "evil eye", were related to a prolonged delay to seek medical care.

Wang et al., (2008), as cited by Abebe et al., (2010) in a study reported that males were more likely to know the cause of TB compared with females. It was reported that the poor knowledge among women and non-educated individuals concerning the cause of TB will result in inappropriate health care seeking behavior. In the study conducted by Abebe et al., (2010) it was reported that health care seeking behavior of the study participants was poor. The majority of them did not seek help for their illness as a result of wrong perceptions and lack of financial resources mainly for transport. A significant number of them did nothing since they considered that their illness was not severe.

Raising awareness and educating community members about TB is key for changing behavior. The publication also claims that stigma is often a problem, especially in countries severely affected by HIV. The publication emphasizes that effective communication starts with personal communication between health workers and the people with TB, their families and local communities and this help build a supportive environment for people who feel ill and may have TB (WHO, 2008). On the other hand

Sarkal and Scalway (2005), argue that there are very few countries that have conducted surveys to assess awareness and knowledge levels about TB among their populations. The little that is known, either through surveys or anecdotal evidence, points to a fairly low level of public awareness-diagnostic or treatment services available.

Lack of adequate information is one of the reasons that affect health-seeking behavior of TB patients. The report explicates how TB patients in Kenya should be receiving basic information about TB from health facility providers. The report also claims that a large number of TB patients obtained information on TB signs and symptoms and were also educated on how TB is spread. Despite all the information obtained from the providers, there were still gaps in the provider's communication regarding TB treatment, screening of close contacts and counseling patients on HIV (The Kenya TB Care II report, 2013).

Health promotion programs worldwide have long been premised on the idea that providing knowledge about causes of ill health and choices available will go a long way towards promoting a change in individual behavior. There is already a growing recognition, in both developed and developing countries, that providing education and knowledge at the individual level is not sufficient in itself to promote a change in behavior. Health seeking behavior clearly varies for the same individuals or communities when faced with different illnesses. Several studies of health seeking behavior in relation to TB, repeatedly demonstrate that patients do not always choose a public health care facility. They delay diagnosis and often do not complete the lengthy course of treatment necessary. Health seeking behavior is not just a one off isolated event, it is part and parcel

of a person's family or a community's identity, which is the result of an evolving mix of social, personal, cultural and experiential factors (Mackian, 2003).

Ward et al., (1997) as cited by Afolabi et al., (2013) argue that information of health seeking behavior and health care utilization has important policy implications in health system development. They further argue that people are likely to seek help on health issues based on several reasons and the factors which influence the choice of treatment sources when symptoms occur include socio-cultural factors, social networks, gender and economic status. Access to healthcare facilities in terms of cost treatment and healthcare provider attitude are also determinants of health seeking behavior.

Qureshi et al., (2008) argue that there are many factors that contribute to patient and health system delay, which are different in other settings. These studies are meant to be carried out in each setting to determine the factors for delay which can guide proper intervention. They further argue that knowledge plays an important role in determining the behavior and practices of the individuals. They therefore claim that awareness regarding a certain type of disease is essential to mould the attitude or behavior of the patients towards the disease. The scholars bring in the issue of stigma and how it is related to TB. It was found that people do not disclose their disease and delay seeking health care for the fear of being stigmatized which was found to affect both genders. Vadlamudi (2012) argues that TB takes the greatest toll on the most productive age group of fifteen to forty four years. There appears to be inadequate information about TB and stigma associated with the infectious disease which has resulted in the high incidence rates which again has inhibited patients from seeking treatment.

McIntyre and Mooney (2007) argue that rather than blaming patients for their poor health seeking behavior, health professionals need, instead, to understand the beliefs and motivations of the public they seek to serve and to tailor service delivery to their perceptions and needs. They claim that particular attention must be paid to the circumstances of socially disadvantaged groups, given the influence of acceptability and trust access barriers over their health seeking behavior. Dixon and Le Grand (2006) as cited by McIntyre and Mooney (2007) argue that health care workers could be given the specific task of supporting patients in accessing health care by making available information on provider and treatment options, assisting to address specific transport or language needs, making appointments with providers and making available support for self-management.

Johnson and Winkvist (2002) as cited by McIntyre and Mooney (2007) argue that there is influence of family and friends over health care seeking behavior as well as patient disempowerment in relation to providers. There is a growing focus on enabling trusted local people or organizations to provide community education and informed support to community members. This is done in the initial stages of responding to ill health by patients for tuberculosis care.

It is a common occurrence for patients to be met by different options when choosing how to deal with their health concerns. The patients are likely to weigh up the potential barriers to health-seeking activity. The decision that the patients may decide to make and

the importance that they attach to individual benefits, disadvantages and barriers may differ markedly from person to person (Mutsatsa, 2011).

2.6 Tuberculosis Knowledge

Tuberculosis is transmitted not only by proximity, but also by ignorance. The lack of knowledge about having a cough for more than two weeks is a possible symptom of a fatal but curable disease which prevents millions of people from seeking treatment. Studies have repeatedly showed that if people have knowledge, they are far more likely to seek treatment as opposed to when they do not have any knowledge. In terms of traditional communication, the educating of people with the knowledge and persuading the people to seek treatment for TB ends up bringing challenges but is considered by many communication organizations to be a relatively straight forward process (Deane & Parks, 2006).

Several studies have been done on tuberculosis knowledge. A survey cited in 'A Media Guide' (2012) was conducted by the International Medical Foundation and Target Tuberculosis in 2011 in Lira, Makinye in Kampala and in Wobulenzi in the central region. The findings indicated that only 24% of the people interviewed were able to mention the correct cause of TB. The survey also found out that while a significant percentage of the interviewees were able to mention the commonest mode of transmission of pulmonary TB, an equally significant number named sharing of plates and food, which means there is still a gap of knowledge and understanding of issues related to TB.

A similar study conducted on TB knowledge by the community in south western Ethiopia, by Bati et al., (2013), revealed a low level of knowledge about the causative agent as well as about the main symptom of TB in the present study communities. The study also showed low level of overall knowledge, unfavorable attitude and poor practices towards TB especially in participants from one community. The study recommended that public health education on the cause, symptoms and mode of transmission of TB would be important towards the prevention.

TB stigma results in part from misinformation. Misinformation about what causes TB, how it is spread and whether it can be cured is linked to the stigmatization of this disease and of people with TB. The lack of knowledge or information has been greatly blamed for making people to be physically isolated, discriminated against and dismissed from their work places. Public education and awareness-raising programs designed to counteract myths and to encourage greater inclusion of people with TB are an essential element of any effort to combat stigma associated with TB. The core knowledge that people need to have to change their behavior is mainly knowledge on TB symptoms and how it is spread. Equally important is the knowledge on TB's curability and the knowledge that TB treatment is offered free of charge. People also need to have knowledge that potential TB cases should rigorously seek professional care and that active TB cases should adhere to a treatment regime (Deane & Parks, 2006).

According to 'A Human rights approach to TB: Stop TB Guidelines for Social Mobilization, WHO (2001) as cited by Deane and Parks (2006), stigma has its roots not only in lack of information but also in deep-seated social mores and structures. Stigma

particularly affects women because social pressures and status often make them especially vulnerable to marginalization and discrimination with the consequences of contracting TB sometimes leading to divorce, desertion and separation from children.

2.7 Self-Disclosure among TB patients

Zolowere et al., (2008) in a study conducted in rural southern Malawi which sought to explore the relationship of persons to whom TB patients disclose their diagnosis and secondly to identify the motivations for disclosures, found out that self-disclosure of diagnosis to others within the patients' social environment may be problematic because the diagnosis of TB may warrant unnecessary stigma largely derived from the association of this disease with HIV infection. The study also found out that the majority of patients reported having disclosed their status to their children. The most common way of disclosure was through personal discussion between the patient and their significant others.

In the study participants perceived that disclosure brought returns in terms of encouragement and empowerment. During the study it was found that some patients felt stigmatized or feared stigmatization following disclosure of their disease status and some patients on anti retroviral therapy for HIV felt stigmatized by fellow patients. The findings of this study suggest that TB patients in southern Malawi were interested in disclosing their TB diagnosis if they felt they would not be stigmatized or stood to gain as a result of self-disclosure. Disclosure of diagnosis was facilitated by trust, a feeling of safety and a sense of obligation to others. The perceived stigmatization of patients by other patients is a cause for concern.

A similar study on the analysis and implications for addressing TB related discrimination in Nepal found out that there is a mismatch between TB patients' fears of negative responses by friends to a disclosure of TB and the reality of the encouragement and support provided by friends towards patients who actually disclosed their infection. This mismatch provides a potential avenue for interventions to reduce discrimination associated with TB. The findings state that if more patients are made aware of the support that is being made available to other TB patients by friends and neighbors, they agree to open up about their disease, with two potential benefits. The benefits can come in the form of psychological support. The patients may gain from not having to keep their illness secret and materially, the patients may gain encouragement and support themselves (Baral, 2007).

The strategy being suggested has to first confirm the cause-effect mechanism involved. If the disclosure causes supportive behaviour from others, interventions to encourage disclosure may be useful; but if the mechanism is actually that having supportive friends and neighbors facilitates disclosure, then such interventions may prove harmful. Even if the former is the case, it would be wise to test such a strategy on a small scale before expansion, to ensure that unexpected consequences do not arise. This study concluded that patients' preference to hide their TB from other members of the community seems justified, since several community members reported that they did discriminate against people with TB.

Rajeshwari et al., (2005) as cited by Dhingra and Khan (2009) argue that the consequences of stigma can be seen affecting the health seeking behaviors, as patients have been known to hesitate or choose not to disclose their TB status to family or friends out of fear of being socially avoided. Stigma has also been shown to hinder adherence to treatment.

Stigma is a potential barrier to treatment because it makes patients reluctant to attend treatment in clinics located in their neighborhoods and leads to non-disclosure of illness. Disclosure can play a positive role because it can help the patient mobilize support thereby facilitating adherence, and is also important for public health reasons such as avoidance of further infection transmission. Health professionals should be aware of the negative impacts of self-disclosure in social environments where disease related stigma is widespread. If a scenario occurs where consequences of disclosure are not known, then it may require a patient not to disclose or to have very selective disclosure (Gebremariam et al., 2010).

2.8 Public Discourse on TB and how it affects patients

A study by Konradsen et al., (2014), explored how patients undergoing the medical examination for TB had to have a public diagnosis. These patients were suffering from an infectious, contagious and potentially life-threatening disease which put undue pressure on them to contact and provide the names of everyone with whom they had interacted with. The patients did not have a choice of keeping their diagnosis private towards family, friends or healthcare professionals. They had to disclose their status to everyone in public and explain to them about the disease and its treatment protocol. This involved

not only people with whom they had had a close relationship but also people with whom they had only had a very brief contact. At the end of it all, these same people would disclose this information to even more people. There was a constant demand for awareness and openness during the treatment period. This kind of public discourse eventually led to changes in the social interactions of these patients which became a huge concern to them.

2.9 Summary of literature review and emerging knowledge gaps

A review of literature has shown that there is a lot of focus on tuberculosis stigma, health-seeking behavior of TB patients and Information access on TB and communication in TB management and yet there are very limited discussions on drivers of health-seeking behavior of TB patients. Secondly, there are also very limited discussions on reasons why stigma still exists despite several studies having been done on the same. Thirdly there also very limited discussions on the kind of information on TB and public discourse on TB and how it affects TB patients self disclosure.

Studies have repeatedly showed that if people have knowledge, they are far more likely to seek treatment as opposed to when they do not have knowledge (Deane & Parks, 2006). The health-seeking behavior of persons is influenced by their health and disease knowledge, beliefs, attitudes and perceptions (Yamira, 2009). The kind of information on TB can determine whether a person will seek treatment or not. The literature reviewed in this chapter, has clearly shown that there is a gap of knowledge and understanding of issues related to this disease.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

The purpose of this chapter was to provide a snippet view of the type of research methods that were used to conduct the study in order to answer the research questions that were outlined in chapter one. The general objective of this study was to find out how TB patients, TB survivors, TB patients' kin and healthcare workers got information about the disease and the kind of information that was out there. It was also to find out how public discourse on tuberculosis affects self-disclosure and health-seeking behaviour among the four different categories of respondents. In this chapter, I discussed the overall methodology that was used, commencing with philosophical assumptions that guided this research. This was followed by the research design that was adopted to undertake the study. This was followed by an explanation of how data was generated up to how it was analyzed and discussed. Last but not least, I discussed how emerging ethical issues were handled throughout the research process.

3.2 Research paradigm

This study was guided by the interpretivist research paradigm. The purpose of this type of research is to understand and interpret the meanings in human behavior. I needed to understand and get meaning and different views on how TB patients, TB survivors, TB kin and healthcare workers get information on the disease and how the everyday discourse about TB shaped their actions. A paradigm is an overarching perspective that guides the research process. Qualitative research is multi-paradigmatic, with researchers

working from different worldviews such as post-positivist, interpretivism and critical orientations, which makes it a highly diverse field of inquiry (Leavy, 2014). Interpretive paradigm allows researchers to view the world through the perceptions and experiences of the participants. In seeking answers for research, the researcher who uses interpretive paradigm, uses those experiences to construct and interpret his understanding from gathered data.

According to Braun and Clarke (2013), qualitative research is underpinned by ontological assumptions and it is also underpinned by epistemological assumptions. Ulin et al., (2012) declare that research frameworks range from broad to very specific theoretical approaches that often contain their own vocabulary and logical assumptions. Broad theoretical frameworks also called paradigms provide researchers with a unified set of ideas, principles and roles which guide their research. There are more specific frameworks that can be found in substantive theories supported by research findings.

3.3 Research Design

This study used a single case study research design. I wanted to use this type of research design because it would give me data which was detailed and descriptive in nature. According to Cresswell (2007), case study research involves the study of an issue explored through one or more cases within a bounded system. Cottrell and Mckenzie (2011) affirm that case studies involve the in-depth study of one individual, program, community, setting, or event for a defined period of time. The choice of this type of research design was arrived at so that the researcher is able to understand the current situation in a more in-depth way. Cottrell and Mckenzie (2011) assert that case studies are

useful for learning more about a little-known or poorly understood situation and for investigating how programs of individuals change over time.

Baxter and Jack (2008), contend that qualitative case study is an approach to research that facilitates exploration of phenomenon within its context using a variety of data sources. He maintains that this ensures that the issue is not explored through only one lens, but rather a variety of lenses which allows for multiple facets of the phenomenon to be revealed and understood. For this study, there was a need to have a wider perspective of the phenomenon at hand and that is the reason why data was collected from four different categories of respondents.

3.4 Research Approach

This study adopted a qualitative research approach. This study was qualitative right from the problem, the research questions to the research paradigm that was adopted. All these determined the kind of approach that was to be used in this study. The sampling technique, sample and sample size were all qualitative. The mode of collecting data to the data analysis was all purely qualitative. In qualitative research, the sample size is usually small and the data collected provides depth and detail. It also simulates people's experiences. This study needed in-depth and detailed data from the participants. I needed to know the individual experiences that the participants had with TB. Qualitative research approach was going to help me understand why the participants behaved the way they did in relation to health-seeking behavior, negative public discourse and self-disclosure. I also needed to understand why they responded to questions the way they did.

Qualitative research approaches provide a valuable way of recognizing, understanding and sharing tacit knowledge. This type of research approach is person-centered, hence researchers consider the participants in the research as whole human beings and not as a collection of physical parts (Luton, 2010). On the other hand, Jwan and Ong'ondo (2011) explain meticulously that qualitative research can be seen as an approach to inquiry that accentuates a naturalistic search for relativity of meaning, multiplicity of interpretation, particularly detail and flexibility.

The reasons for particular types of behaviour can only be understood when it is observed and people are asked about it (Holloway, 2005). This approach suited this kind of study because as a researcher I was able to have a face to face interview session with each participant in order to have a better understanding and meaning of their health-seeking behavior. I was also able to find out how the four categories of participants accessed information on TB. In addition, I was able to find out the kind of information on TB that they had access to.

Qualitative design can lead us to underlying behaviors, attitudes and perceptions that determine health outcomes. Qualitative design is flexible, encouraging discovery and further investigation of the unexpected. Qualitative researchers know that they are always at least two key players and those are the participant who contributes the information and the researcher who, as a learner and co-interpreter, guides the process towards the understanding that both seek to articulate (Ulin et al., 2005).

3.5 Research site

This study was conducted in a certain healthcare centre in Nairobi. The healthcare centre is a public health facility run by the county government of Nairobi. I chose this health facility due to the locality which was convenient to me and I was familiar with the research area and negotiating access to the health facility was not a challenge. This type of public health facility would provided the kind of data that helped me answer the research questions.

3.6 Study population

The study population that was selected for this study comprised of TB patients, TB survivors, TB healthcare workers and TB kin. The research questions in this case determined the population that was to be used in the study. The TB patients were those who had been diagnosed in the health facility and were continuing with treatment. The TB survivors were those who had been diagnosed and treated at the health facility while the TB healthcare workers were those who had worked in the health facility for several years. The TB kin on the other hand were close family members and relatives of the TB patients and survivors.

According to Whitley and Kite (2013), the target population is the group of people to whom we want the results of our research to apply. The study population consists of those members of the target population. Gratton and Jones (2010) on the other hand refer to the population as everyone who shares those characteristics defined by the researcher as relevant to the investigation. Babbie (2015) defines a study population as that aggregation of elements from which the sample is actually selected.

3.6.1 Study sample and sampling procedure

For this study the non probability sampling category was the most appropriate because it was best suited for the particular population that the researcher was working with. Blankenship (2010) affirms that all random sampling techniques are based on a fairly equal probability that each individual group or organization has an equal chance of being selected to be part of the sample. The important point here is for the researcher to determine which technique is appropriate to the research question, the amount of time and money available for the study, and how accessible the population is to the researcher.

3.6.2 Purposive sampling

The type of non probability sampling technique that was used for this study was the purposive sampling. This study chose this type of sampling because of the particular characteristics of the participants and also the size of the sample. The participants either had TB or had had TB or had interacted with someone who had TB. This study used a qualitative research approach and was based on a case study research design, so whatever sampling technique chosen would have to be appropriate under these circumstances.

Qualitative research employs purposive sampling; this means that the one conducting the research intentionally selects participants who can contribute an in-depth, information-rich understanding of the phenomenon under investigation (Klenke, 2008). Babbie (2013) defines purposive sampling as a type of non probability sampling in which the units to be observed are selected on the basis of the researcher's judgment about which ones will be the most useful or representative.

3.6.3 Sample size

For this study, the sample size consisted of a total twenty five participants. These included 6 TB patients who were on treatment, 5 TB survivors who had successfully completed treatment, 6 Healthcare workers who were specifically trained to take care of TB patients and 8 TB patients' kin. The research approach which was qualitative determined the sample size. Sample sizes in qualitative research are usually smaller as compared to those in quantitative which are usually very large. This is due to the methods of data collection and the methods of data analysis which require a lot of time.

The reason for choosing this sample size was because of the nature of the population being studied which was generally homogeneous with regards to exposure to TB and TB patients, but if they were heterogeneous, then, a large sample size would be required. I also had to think of the time frame for undertaking the research. This is because of the nature of qualitative research which requires a lot of time to collect data and to analysis it. Leedy (2005) emphasizes this point on sample size by arguing that the size of an adequate sample depends on how homogeneous or heterogeneous the population is. He continues to emphasize that it is how alike or different its members are with respect to the characteristic of research interest.

Klenke (2008) argues that in qualitative research, sample size does not matter but does not take on the same importance as in quantitative research where large sample sizes are the drivers of many statistical analyses such as factor analysis or linear structural equation modeling techniques and are needed to generalize from the sample to the underlying population. Blankenship (2010) verifies the point on sample size in purposive

sampling as being influenced by the group being studied, that is if the group members are very similar, or homogeneous, then the number needed in the sample is smaller than if the group varies widely on the characteristics being studied.

3.7 Methods of data generation

This study used interviews as a method of data generation. According to Ritchie et al. (2005), define an interview as an interaction following a question-answer format (stimulus-response) or an interaction more akin to a conversation. They further clarify that the question-answer format (structured interview) is associated with a quantitative methodology which is not appropriate for this study. Ritchie et al. (2005), argue that the unstructured interview is more open and more conversation-like with no set questions, just a theme.

3.7.1 Qualitative interviewing approaches

For this study, unstructured interviews were used to generate data. This method of data generation allowed the tuberculosis patients, survivors, kin and healthcare workers to give more in-depth information about their inner self. The main aim for choosing this type of interviews was because there was a need to probe for deeper understanding and meaning of the situation. I interviewed a total of twenty five participants. I wanted to interview more people but due to the sensitive nature of the disease, many participants opted out of the interview at the last minute. The interviews mainly focused on how participants accessed information on TB and the kind of information that they accessed. The interviews also focused on how lack of correct information and negative public discourse on TB inhibited self-disclosure and health-seeking behavior among TB patients.

Unstructured interviews are wide-open, recorded conversations with no pre-determined set of questions. Unstructured interviews tend to be flexible and the questions can be adapted and changed depending on the answers given (Luton, 2010). According to Dantzker and Hunter (2012), the unstructured interviews are far less rigid than the structured interview.

3.8 Methods of data analysis

This study used thematic analysis to analyze the data. Thematic analysis provides a useful introduction to qualitative data and is a method that is particularly suited to the analysis of a range of qualitative data when the researcher seeks to allow key themes from the entire body of data to emerge. This type of analysis is one of the most commonly used methods that is not dependent on specific theory or approaches to data collection. It is for this reason that thematic analysis is suitable for most types of qualitative data. The overall aim of thematic analysis is that it identifies the key themes from the data and not superficial themes (Caulifield & Hill, 2014).

According to Jwan and Ong'ondo (2011), data analysis in qualitative research is basically a systematic process of transcribing , collating, editing, coding and reporting the data generated in a manner that makes it easier to understand and accessible to the reader and researcher for the purpose of interpretation and discussion. For this study, the tape recorded interviews were then replayed and transcribed slowly word for word. No word was omitted at this stage. For this study, respondents were free to be interviewed in whatever language that they felt comfortable with, so the transcriptions involved a few

translations from Kiswahili to English language, though majority were conducted in English and each lastly more than thirty minutes.

The next stage after transcription was to re-familiarize oneself with the data. I had to read and re-read the data to get a sense of what the data says as advised by Dempster and Hanna, (2015). Similarly, Jwan and Ong'ondo (2011) concede that re-familiarizing with the data involves the reading of each transcript for the purpose of forming a general idea of what the data is saying as well as the researcher's initial thoughts regarding the data.

The next stage after re-familiarizing with the data was to code the data. Coding simply meant that I had to categorize the data in such a way to facilitate the analysis. For this study, the transcriptions were divided into the four different categories, that is, firstly the category for TB patients alone, secondly the category for TB survivors, thirdly the category for TB kin and fourthly the category for healthcare workers. According to Jwan and Ong'ondo (2011), a code is simply a label or headline that is given to a particular chunk of data that is highlighted and grouped making a particular point relevant to the study. I used a colored highlighter to highlight the important data during the coding process. I then identified similar themes in the four different categories of data, followed by the emerging ones. At this point I had to pick out the themes bearing in mind the research questions by paraphrasing the statements of the respondents and in the process also picking out some of the quotations as spoken by the interviewee word for word.

3.9 Ethical considerations

The ethical imperative to ‘do good’ rather than simply ‘no harm’ in the context of qualitative inquiry significantly increases the obligations of the researcher to understand the ethical principles at stake in conducting research. These ethical imperatives are often safeguarded through principles and promises, such as confidentiality, anonymity, informed consent, avoidance of deception, respect, and privacy and do no harm (Jones et al., 2014).

3.9.1 Negotiating access

It was my duty to negotiate with the concerned authorities in the places that I hoped to conduct this research. According to Tracy (2012) it is the duty of the researcher to find people and places that will let them “in”, to study their lives, viewpoints and routines. She points out that the key part of qualitative research design is to find people who want to participate in the research and she gives this as one reason why qualitative researchers call the people involved “participants” rather than subjects. These participants have agency and free will meaning that they can be agreeable, helpful, cantankerous, secretive or a combination of all these. She sums up her statements by stating that qualitative researchers study participants, rather than conduct research on them. On the issue of rejection, the scholar states that if a researcher gets rejected, they should try not to take it personally. It is all about practicing to learn how to negotiate access, and failure is part of this learning process. Rejection she adds is just part of the game, and good qualitative researchers need to have ingenuity, courage and resilience to negotiate access. She counsels that if one gets obstacles in negotiating access, all they have to do is get up, dust themselves up, tweak their pitch and try again, using a different research destination.

Silverman and Patterson (2015) on the other hand asserts that the most important thing researchers should understand about gaining access to a research site is that this is not a static process. Researchers negotiate and re-negotiate access to a site throughout a research process. The two scholars feel that negotiating access is a repetitive process while conducting research and it tends to occur due to emergent themes that usually spring up during the course of the study.

3.9.2 Confidentiality

All the respondents who were interviewed had a right to confidentiality and it was my responsibility as a researcher to keep all that information that was been provided for by the patient private. Confidentiality refers to the treatment of information that an individual has knowingly disclosed in the research relationship or context with an expectation that this information will not be disclosed to unauthorized parties without consent (Jones et al., 2014). It is of outmost importance that the researcher is clear at the initial stage of the research as to what confidentiality means in the context of qualitative research. This is likely to make things clear with regards to the limits of confidentiality (Pope & Mays, 2013).

3.9.3 Anonymity

Due to the stigma attached to this disease, I had to conceal the identities of all the participants in all the materials that I used while conducting the research including the hospital where the study was conducted. As much as confidentiality and anonymity are often taken to mean the same thing in research, they are not the same. Though the ideas are similar, they have quite different meanings that are important in relation to qualitative

interviewing. Anonymity is the concealing of the identity of the participants in all documents resulting from the research, therefore actively keeping secret the identity of the research participants (King & Horrocks, 2010).

Anonymity suggests that if and when information is shared, no identifiable data will be disclosed (Jones et al., 2014). Yin (2011) brings a new dimension to anonymity by arguing that in nearly every study, participant anonymity, together with the use of pseudonyms, is the option of choice. Yin further argues that most studies tend to name their locations and in some cases the researcher may decline to name the location if it can readily lead to anyone identifying an otherwise anonymous participant. This study did not name the research site, but named the research town. This is because of the danger of the participants being easily identified.

Braun and Clarke (2013) feel justified to state that anonymity can be protective of participants, but it can remove their voice, and might conflict with social justice goals. The two scholars tend to agree with Yin (2011) on the use of pseudonyms, which they feel is the best practice for protecting participants' anonymity and confidentiality in participant information sheets, to discuss this with participants and to allow participants the possibility of choosing their own pseudonyms or (if appropriate) to be named recognizing that this can impact on other participants' anonymity. For this study, all the respondents chose pseudonyms to protect their identity except for one participant who insisted on using his real name.

3.9.4 Informed consent

There was an expectation to describe the research study to all potential participants and later they had the opportunity to decide whether they want to participate in the study or not. For this study, only willing respondents were invited to participate. According to Holloway (2005), for a one to undertake qualitative research, researchers in the health-care arena have to understand its principles and underlying epistemology.

All researchers should familiarize themselves with the relevant ethic codes that they work under. The core requirements for ethical practice include obtaining informed consent and avoiding deception, maintaining confidentiality and privacy, ensuring participants' right to withdraw (without explanation of negative impact) not subjecting participants to (unnecessary) risks and being honest and accurate in reporting research results (Braun & Clarke, 2013).

3.9.5 Permits

As a postgraduate student at Moi University, I obtained permission to undertake the study from the University's School of Human Resources and Development. I also applied for a research permit from the National Commission for Science, Technology and Innovation. Lastly I asked permission from all the participants in the study whether they were freely willing to participate in the study or not.

3.10 Chapter Summary

In this chapter, the research paradigm that guided this study together with the research design and approach are discussed followed by a description of the research site and the reason why it was chosen. The chapter then discussed the population and the sampling

technique that was used to select the sample with regards to the research approach that was adopted. The next step discussed how the sample size was chosen and justified. The method that was used to generate data followed by the technique that was used to analyze data was also discussed. Finally the chapter discussed the ethical considerations that the study conformed to. Chapter four focuses on the presentation, analysis and interpretation of the data that was generated.

CHAPTER FOUR

DATA PRESENTATION, ANALYSIS, INTERPRETATION AND DISCUSSION

4.0 Introduction

This chapter presents an analysis of the data generated using the tools discussed in chapter three. The first section discusses the background information of the respondents who participated in this study. The second section mainly deals with the respondents' sources of information, followed by the nature of information. In this section I discussed about correct and incorrect information that the respondents have on this disease. Thirdly, this chapter also discusses the public discourse on HIV/Aids and fourthly the impact on self-disclosure and health-seeking behavior. I conclude the chapter with a discussion of the findings analyzed in the chapter.

4.1 Social demographic characteristics of the respondents

For this study, a total of twenty five participants were interviewed, out of these, six were TB patients, five were TB survivors, eight were TB kin and six were TB healthcare workers. All the patients were receiving treatment at the healthcare facility. The first TB patient that I interviewed was a female university student who had been diagnosed with TB and had been put on treatment but after three months, stopped taking the medication because she felt she was now fine. This is a patient who had to be started all over again on treatment because of defaulting. The second patient I interviewed was a female high school student who travelled a long distance just to seek healthcare in the health facility because she feared stigmatization in the health facility near her home. The patient was in their third month of treatment. The third patient I interviewed was a male student from a

local university who had been on treatment also for three months. The fourth patient I interviewed was a male who was a relapse patient, meaning he had had TB before and he was being treated for the second time. The fifth was a female patient who had been on treatment for only two months. The last patient I interviewed was a female who had been on treatment for five months and was left with only one month to complete the treatment regime.

The second categories of participants that I interviewed were 5 TB survivors. The first TB survivor that I interviewed, was a married lady who was 32 years old. She told me she was living with her husband and two children. This particular lady did not know that she had TB when she developed a cough so she kept on buying over-the-counter drugs from the chemist. It took her three months to go and seek healthcare and that is when she was diagnosed with TB. The second TB survivor that I interviewed was a 19 year old female student who said she developed breathing difficulties while in a boarding school and immediately went to the school nurse who prescribed Malaria drugs. After taking these drugs, she felt worse because apart from the breathing difficulties, she started sweating so much and had to go home. The parents took her to a healthcare centre and that is when she was diagnosed with TB.

The third TB survivor that I interviewed was a 56 year old male primary school teacher who was diagnosed with TB for the second time. The first time he said he developed a persistent cough then sweating at night and after two weeks he started self-medication but when the cough persisted, that is when he went to seek healthcare. He confessed that getting TB was due to his carefree lifestyle and he was also an alcoholic. He eventually

went to seek healthcare and was diagnosed with TB and immediately put on treatment for 6 months and cautioned by the healthcare workers to stop taking alcohol. He resumed taking alcohol immediately after the six months were over and went back to his carefree lifestyle which exposed him to TB for the second time because some of his friends had TB and due to his lifestyle and interactions with them, he got re-infected with TB again. This time he went to seek healthcare immediately because he was already aware of the symptoms. He got treatment and was cured for the second time. The fourth TB survivor that I interviewed was a 47 year old male who was diagnosed with extra-pulmonary TB which had infected his neck. He was started on treatment which lasted for eight months. The last TB survivor that I interviewed was a 37 year old female who claimed that she was infected by TB by her late husband who she used to live with. She said her husband used to cough very often and it was only after he died that she went to seek healthcare because she had developed the same symptoms. It took her one month to realize the seriousness of her symptoms.

The third category of participants that I interviewed, were TB patients' kin. The first TB patients' kin that I interviewed was a 27 year old female who said that her family had lived with an aunt who was diagnosed with TB, put on treatment but unfortunately the patient died before completing the treatment schedule. They assumed that the patient died due to self-stigmatization. This patient started avoiding family members by keeping to herself in her bedroom. She never wanted to eat with the rest of the family and preferred to spend her entire day in her bedroom.

The second TB patients' kin that I interviewed was a 76 year old male who had lived with two relatives, an aunty and a cousin who had TB. One patient failed to seek healthcare and eventually died because she preferred to use herbal medicine. The second patient went to seek healthcare in hospital but was warned to refrain from taking alcohol and smoking during the treatment regime. The day he successfully completed treatment, he resumed heavy drinking and smoking and eventually he died.

The third TB patients' kin that I interviewed was a 58 year old male who had lived and taken care of a TB patient who was a family member. This particular family suffered stigma from neighbors because they assumed that if one has interacted with a TB patient then they are likely to be infected. The relative was taken to seek healthcare after about two months then he was diagnosed with TB and put on treatment until he completed successfully. The fourth TB patients' kin that I interviewed was a 50 year old female whose husband who was a smoker and alcoholic and had been diagnosed with TB and HIV. He eventually succumbed to the disease after being on treatment for about two and a half months. This was the second time that he was being diagnosed with TB. The fifth TB patients' kin was an 18 year old male secondary boarding school student who had a relative who was diagnosed with TB. The patient was diagnosed and put on treatment, so far now he has been on treatment for four months.

The sixth TB patients' kin that I interviewed was a 22 year old male student who lived with a relative who had been diagnosed with TB and was currently on treatment. The relative used to cough a lot and spit blood for several weeks before he went to seek

healthcare. The second last TB patients' kin that I interviewed was a 53 year old female whose school going child was diagnosed with TB. She observed a general weakness and a persistent cough. It took the mother four months to take the child to seek healthcare. The child took the drugs without fail for eight months and was declared TB free. The last TB patients' kin that I interviewed was a 26 year old male who had dropped out of school at class eight. He was living with his sister who had been diagnosed with TB. The sister had initially developed some rashes on her skin, lost appetite and was always weak and dizzy. She also complained of persistent coughs, headaches and weakness on her joints. It took five months before she went to seek healthcare and by then the symptoms had worsened. She was then put on treatment and is now in her last month of treatment.

The fourth category of participants that I interviewed, were TB healthcare workers. The first healthcare worker that I interviewed was a 45 year old female who had undergone training to specifically take care of TB patients and take them through the long treatment schedule. She had been working with TB patients for 10 years now. The second TB healthcare worker that I interviewed was a 44 year old female who had been working with TB patients for the last two years. The third TB healthcare worker that I interviewed was also a 44 year old female and she had been working with the TB patients for the last four years and had been trained specifically to take care of TB patients until completion of their treatment. The fourth healthcare worker was a 35 year old male clinical officer who had been working in a TB clinic for a few years. The fifth participant that I interviewed was a 47 year old female healthcare worker who had been working with TB patients for several years. The last participant that I interviewed was a 52 year old male

healthcare worker who had received training from several health organizations on how to take care of TB patients.

Regarding educational background, a few had gone past college level in all the four categories that I interviewed. In regards to occupation, some were healthcare workers, others were students, others were self employed and an insignificant number were dependant on family. The age range for the participants was from 19 years to 76 years. All the healthcare workers interviewed had some formal training on how to take care of a TB patient.

4.2 Sources of information

My study, found out that TB patients and TB kin got their information about the disease mainly from the healthcare workers. Healthcare workers were the number one source of information for most TB patients and their kin in form of health talks which were given when one visited the health centre. Healthcare workers, apart from being identified as the first source of knowledge for most TB patients and kin, had basic knowledge on TB disease and the current treatments that were available. Healthcare workers were also to give health talks to all the TB patients including their kin, majority of whom reported that they only concentrated on the patients. Generally the TB patients and survivors only sought information on TB after they were diagnosed with the disease. Most of them were not aware that they were suffering from TB until they were diagnosed.

One TB patient said:

I wasn't aware about it, even side effects of TB, I was really blank. I was depending on the healthcare worker to tell me everything about TB, like the

consequences of stopping the medication, and whether TB has a cure or not (Female TB patient aged 19 years).

Besides healthcare workers, this study highlighted the existence of multiple channels of communication. Interpersonal communication and mass media were the most frequently reported channels through which the TB patients and TB patients' kin obtained information on TB. The use of radio and television were commonly cited among the patients and kin. Another patient said that her source of TB information was usually through the internet because it was difficult for them to get TB information from the television and radio. This is what the patient said:

‘Normally I get TB information through research, maybe I can decide to research using the internet, I just Google. If I want to find out specific things or just information about TB because in local T.V and radio channels it is hard to get such information, you just don't get it’(Female TB patient aged 20 years)

4.3 Nature of information on TB that patients, survivors, kin and healthcare workers have on the disease.

The data yielded by this study on the nature of information that the respondents had on the disease demonstrates both correct and incorrect information. The incorrect information was frequent as compared to the correct information. All the five TB survivors only got to know about TB after they were diagnosed with the disease. They had not sought any information on this disease because they did not even know that they had TB until they decided to seek healthcare and were later diagnosed with the disease. Majority were taking over-the-counter drugs for cough to suppress the persistent coughs that they were experiencing. Majority of the TB patients did not suspect TB the first time they developed a cough, neither did their kin who were living with them.

4.3.1 Correct Information

Generally, out of the six healthcare workers that I interviewed five had correct information on TB. Only two out of the six TB patients that I interviewed had a clear understanding of what TB is. A TB patients' kin was also able to explain how TB is transmitted and when one was likely to get infected. Another TB kin that I interviewed said that TB has a cure, it is only that many people are not aware, they assume that TB is just like HIV which does not have a cure.

A TB kin said:

TB can be transmitted from one person to the other for instance if a person with it coughs near you and also when your immunity goes down like when one is HIV positive (TB Kin)

4.3.2 Incorrect information

Out of the eight TB patients' kin that I interviewed, three had incorrect information about TB. A TB patients' kin said that TB can be transmitted through sharing cups and water glasses with people who are infected. A second TB kin also reiterated the same sentiments that TB can be transmitted through sharing utensils. The other six TB patients' kin had correct information on TB. The six respondents were also aware of the symptoms, transmission, prevention of TB and how it is treated.

One TB kin said:

When people share utensils with someone who has TB, then that is how it is transmitted (TB patients' kin)

Out of the six TB patients that I interviewed, half of them had incorrect information about TB. One TB patient also reiterated the same sentiments expressed by two TB kin that TB can be transmitted by sharing utensils with TB patients. A second TB patient said that if

one had TB then it meant that they were HIV positive. A third TB patient also had incorrect information about TB. The TB patient believed that if one had TB, then it was a symptom for HIV, and he further justified his statement by claiming that people who have HIV have TB.

One TB patient said:

They assume that if you have TB, you have HIV (TB Patient)

The other half of the TB patients had correct information on TB. They were able to identify the symptoms, causes, the mode of transmission and the prevention of TB.

4.3.3 Myths and beliefs about TB

The most common myths about TB were that it was caused by witchcraft. One TB patients' kin said that people thought that when one gets TB, they have been bewitched. The aunty had been diagnosed with TB and was living with them in the same house. During several visits by relatives, most of them were debating on what this TB patient could be suffering from. Some thought that the TB patient was suffering from HIV, yet others concluded that the patient had been bewitched.

One TB patients' kin said:

Others think that it is witchcraft that made one to get the disease (TB Kin)

The above sentiments were reiterated by a TB patient who claimed that she had been bewitched by her grandmother. This is a patient who had complained of high body temperature and sometimes had terrible coughs. The patient later went to seek healthcare and after some tests were done, she was diagnosed with tuberculosis and started on treatment. Immediately after the diagnosis the spouse of this particular patient, deserted her and left her all alone with a young child. On the contrary, her neighbours even after

she disclosed her status to them, instead of stigmatizing her, encouraged her to be taking her medication without fail. The TB patient later on disclosed her status to her employer who was so infuriated by the news that she immediately sacked her from her job. Apart from the myths that TB was caused by witchcraft, they were those who believed that TB could be treated using herbal medicine.

One TB kin said:

Others think that it is witchcraft that made one to get the disease. (TB patients' kin)

A TB patient said:

She didn't know, she was saying that she has been bewitched. That she has been bewitched by her grandmother (TB patient)

Another TB patient said:

As a TB patient if your faith is not strong, you may not get cured (TB Patient)

4.3.4 Religious and cultural beliefs

Religious and cultural beliefs were common in this study and were found to influence the health-seeking behaviour of tuberculosis patients. These beliefs were common especially among some tuberculosis patients' kin and some tuberculosis patients. One TB patient who had been diagnosed with TB after complaining of high fever and persistent cough believed that it was only God who could heal him/her. This is a patient who believed that death was common and that living was just luck despite illness. The patient also believed that healing would only come by first trusting in God and praying that he would heal her.

A TB patient said:

Death is common and living is just luck. I trusted God and prayed that God will heal me (TB patient)

A TB patients' kin had lived in the same house with an aunty and a cousin who had TB said that most of their relatives and friends concluded that these two TB patients had TB due to bad luck.

A TB kin said:

I think people thought it was just bad luck because it was not a very common disease. People thought that this disease was brought by bad luck, now bad luck is very difficult to take action against (TB Kin)

4.4 Public discourse on HIV/Aids

4.4.1 Link with HIV

The TB/HIV connection has proved to be a major hindrance to the tuberculosis control programs. A significant number of the respondents in the four different categories believed that there was a link between tuberculosis and HIV/AIDS. Generally most of the respondents believed that if one was diagnosed with TB then it automatically meant that they were HIV positive. This statement has been mentioned above as falling under the incorrect information that the respondents have.

TB and HIV are inexorably linked in the minds of most of the patients and TB patients' kin.

Out of the six TB patients that I interviewed, three believed that if one was diagnosed with TB then automatically it meant that they were HIV positive. One patient said that all along she knew that most people who have HIV are known to have TB. It was only when she was diagnosed with TB and yet she had tested negative for HIV, that she came to realise that one can actually be HIV negative and still be diagnosed with TB.

One TB patient said:

I just know that most people who have HIV are known to have TB, or when someone knows that you have TB, they will assume you have HIV, so me personally I knew I do not have HIV, so when I was told I have TB, is when I realized that you can have TB on its own alone and not have HIV (TB patient)

A second TB patient said:

They assume that if you have TB, you have HIV (TB Patient)

A third TB patient said:

Mostly they say if you have TB it is a symbol of HIV (TB patient)

The other three TB patients that I interviewed believed that lack of correct information on TB is what makes people assume that if one has TB then they are HIV positive. The three TB patients who had correct information were all aware that some TB patients were HIV negative. One TB patients' kin also claimed that people always suspect HIV when one has been diagnosed with TB mainly because of the similarities of the symptoms of HIV and TB. A healthcare worker also recalled how a mother refused to take her drugs because people were saying that she was HIV positive which eventually led her to quit her job.

A TB kin said:

People always suspect HIV when one has TB because the symptoms are nearly the same. Yes they are the same, weight loss and loss of appetite. It's only coughing which is mainly for TB (TB Kin)

A TB healthcare worker said:

There was a mother who refused to take TB drugs because people were saying she is HIV positive so she even she quit her job (TB HCW)

4.4.2 Public discourse on tuberculosis disease

Generally most of the TB patients that I interviewed underwent many problems after being diagnosed with TB. A TB patient narrated to me the way her husband ran away from their house because she was diagnosed with TB. She was only left with her kid even her friends moved away from her for fear that she would infect them. She also lost her job when she disclosed to her employer that she was diagnosed with TB. Another TB Patient narrated to me the way her close friend at the university was very scared of her because she was diagnosed with TB. The friend was so scared that she would also get TB if she continued sharing a room with her in the university hostels. Most patients were in dire need of encouragement from family and healthcare workers. The patients were also yearning for knowledge about TB so that they could have some hope of getting better.

A TB patient said:

There are many deaths because there is no encouragement.... because when you are given the encouragement and knowledge you will be able to keep on taking the medication. If there is no one giving you information about TB, you wouldn't know why you are taking the medication. So like me the way I was given information by the healthcare worker and the doctor it really helped me to keep on taking the medication, but you know someone out there with TB and is not informed about TB it will be hard for you to even take this medication and then also the information should be accessible to everybody” (TB patient).

Another TB patient said:

Death is common and living is just luck. I just trusted God and prayed that God will heal me. (TB Patient)

A third patient said:

The one I was living with refused to come, in fact he ran away and has never come back. I was just left with the kid. There are those who moved away from me and there are a few who remained close. In fact I was laid off from my work place. (TB patient)

During the interviews, the TB survivors related their experiences, at the time of their diagnosis.

Generally they were all in a state of denial; they all seemed to express a lot of shock. They seemed more worried about how their family and friends would treat them once they got to know about the diagnosis. Generally most of them opted to keep their status secret for fear of stigmatization. Some cried and even refused to take the TB medication. They complained about the number of tablets that they had to swallow per day for six months. Others complained about the size of the tablets, they felt that these tablets were so big in size making them so hard to swallow. The healthcare workers had the task of encouraging the patients that they would be cured. When I asked some of these patients why they were in denial, this is what they said:

People were not aware of TB and were not well educated on TB and how it is contracted and how it affects human beings (TB Patients).

I was reluctant, I cried so much because I was like now what will people think about me and all that. They had to bring in doctors to talk to me but when I had been given my results, everything was negative. I told them everything is negative,” I don’t have anything that is even related to TB, why are you giving me these drugs”. I was so, so reluctant but it was the only way they could help me so I just had to take the TB medication (TB Survivor)

I could not believe. I went quiet for a moment but the doctor encouraged me that TB was not the end of life (TB Patient)

I was in denial but this person (HCW) encouraged me that she had seen people, with even worse cases so I wasn’t going to die. At that moment you find the whole world is against you (TB Patient)

People who go for treatment when TB has matured and are harassed like ‘where were you when other people were being tested?’ (TB Patient)

4.4.3 Stigma and Discrimination

The stigma and discrimination attached to tuberculosis disease can be truly profound. Majority of the tuberculosis survivors experienced stigma and discrimination during the period of their illness. Health care workers also reported several cases of tuberculosis patients who had experienced stigma and discrimination, on the other hand tuberculosis patients' kin also experienced stigma by virtue of them having a family member with the disease. A TB patient lost her job after informing her employer that she was diagnosed with TB. One survivor described how he was isolated and treated like an outcast by his family members and friends because he was infected with TB. This is what he said:

You are so isolated; they see you as an outcast so that is why we decided to keep the diagnosis to ourselves for fear of being treated in that manner (TB survivor)

A family whose child was diagnosed with TB, decided to keep the information to themselves because of fear of stigma. The family believed that if other people got to know that their child was diagnosed with TB, then people would also stigmatize them because those people would imagine that their child infected them. Stigma and discrimination has been seen as a contributing cause to why patients delay in seeking healthcare. A healthcare worker reported how a TB patient refused to take her drugs because people were saying that she was HIV positive. A TB survivor recalled how a TB patient was abandoned in a house by his family members because they suspected that he had been infected with TB. TB stigma was common among TB patients and survivors. One TB patient was stigmatized by her sister while she was undergoing treatment for TB. Another healthcare worker talked painfully of how a TB patient was locked up in a

cowshed by his family members so that he does not infect them with the disease. A healthcare worker also reported of a case where a TB patient was sent to go and live in the village because her family members feared that she would infect them with TB. The patient had a bad cough that sounded like a whooping cough and each time she coughed people would run away from her including her family members.

A healthcare worker recalled how some TB patients went to seek healthcare in very far off places just because of the fear of stigmatization, a second healthcare worker also recalled how a TB patient died because he was stigmatized by his family members. The healthcare worker said this patient died because the family members did not have any information on TB. A patient in this study also confessed to having gone to a very far off clinic to receive healthcare because of fear of stigmatization.

A TB survivor said:

There was a certain tuberculosis patient who was left in the house. I took him to hospital and I told the health care workers that he had been left alone. I helped him (TB Survivor)

A TB patient said:

I experienced stigma and discrimination from my sister because there was a time I was very sick and she came but she looked scared and did not stay in the house instead she left. I then thought that it was because I was coughing and I still think of that day to date. Yes she feared me (TB Survivor)

A TB survivor felt that it was lack of education that made people to stigmatize patients and families where there was a TB patient. A TB patients' kin spoke of how a family which had a TB patient was stigmatized by the society. That family was isolated from

other members of the community because the disease was feared and people feared visiting that home. This is what the TB kin had to say:

When I was growing up there was another family that was associated with TB. The family ended up being isolated from other members of the community because the disease was feared and people were not actually going to that house because the disease was feared. (TB patients' kin)

4.4.4 Death sentence

Majority of the healthcare workers who participated in this study reported that many TB patients lost hope when they were diagnosed with TB. Most confessed that having TB was a death sentence. Majority did not have that information that TB can be cured. They also did not know about what the treatment entailed and also did not know how TB is transmitted and how it can be prevented. According to the healthcare workers that I talked to, most patients after being diagnosed with TB, concluded that they were HIV positive and that they were just going to die, all they could see after diagnosis was a grave.

One healthcare worker said:

Perhaps people get stigmatized by just the thought of going for a check up, fearing that a diagnosis of this kind may mean death (TB HCW)

A TB kin said:

People don't have the information. They are told that when you get tuberculosis you die (TB patients' kin)

Another TB kin said:

It is because of stigma that they are fearing to be known because since this disease is associated with poor people, and if you get it you are likely to die, so they would prefer to get treatment somewhere they wouldn't be known and get drugs there and continue with it there (TB patients' kin)

4.4.5 Bringing a coffin

A healthcare worker reported a case where a TB patient was referred to as a 'coffin' by family members. The family had concluded that the patient was going to die anyway so they reprimanded a TB patients' kin who had come to take the patient for treatment. They had lost hope of her ever recovering, and they just knew she was going to die. When I probed further about this patient, I was told that the patient was started on TB treatment and once she completed, she was able to make a full recovery and she even went back to her old job.

4.5 Impact on self-disclosure

4.5.1 Fear of ostracization

A significant number of tuberculosis survivors, claimed to have experienced ostracization during the period of time that they were infected with TB. This fear of ostracization has led to delays in health-seeking behaviour which in some cases has resulted in deaths from this disease. Other patients have opted to keep their status secret also resulting in late diagnosis. There were also cases of married women who were diagnosed with TB but opted to keep their status secret from their spouses because of fear of stigmatization. A TB survivor said:

She removed all the TB drugs from the baskets because she did not want the husband to know she had TB and opted to hide the drugs in the flour for Ugali and while she was away a neighbour's house-help borrowed that flour with the drugs inside. When she found them she threw them away, later the owner of the drugs started a search for her TB drugs. When she couldn't find them she opted to keep quiet because of fear of stigmatization from her family and neighbours. She remained without her drugs for fourteen days which worsened her TB leading to her death in hospital. Her husband had been tested earlier for TB and had tested

negative but her test came out positive for TB due to lack of self-disclosure (TB Survivor).

A TB patient said:

I didn't want people to stay away from me because I have TB they will be scared because you know me I was scared when I knew I have the same reaction I had people will have with me people will not share the table with me. I was just praying that my friend doesn't tell anyone that I have TB (TB Patient)

4.5.2 Denialism

Denial in this study has appeared to be one of the major obstacles in the control of this disease. Many patients are usually in denial when they are diagnosed with TB and this has been cited as a major deterrent to health-seeking behaviour amongst most patients. The patients who are likely to be in denial are patients who are literate as opposed to those who dropped out of school. Most of the TB patients and survivors reported that they were in a state of denial when they were diagnosed with TB. According to one healthcare worker, this state of denial has resulted in the deaths of so many TB patients yet their lives could have been saved if only they got correct information about this disease.

A TB patient said:

I was in shock and state of denial because I have never had TB and I don't recall coming across anyone who had TB (TB Patient)

A TB survivor said:

I was in denial but this health care worker encouraged me that she had seen people with even worse cases so I wasn't going to die (TB Survivor)

A healthcare worker said:

Majority live in denial and most of them die because of that, and it becomes very expensive for a country such as ours which has few health care workers and I think that also calls for action. For the ones I have been with, apart from nutrition, the ones who die are as a result of denial (TB HCW)

4.5.3 Signs of despair

Signs of despair were alarmingly noted by health care workers during their interactions with tuberculosis patients. Signs of despair were common among patients who had to take a whole cocktail of TB medications for a long duration. Then there were those patients who were co-infected with HIV/Aids, the burden of taking both drugs for TB and HIV was too much for some patients and they got desperate. Due to this kind of desperation coupled with social economic issues led some patients to default during treatment. Some the patients complained about the size of the TB drugs and the number of tablets that one had to take on a daily basis. The situation was so bad amongst some patients that one even wanted to commit suicide because of the strict medication regime for TB. Others complained of lack of enough food when taking the medication as they had been warned by the healthcare workers not to take the drugs on an empty stomach.

A TB survivor said:

I was always keen and at times I felt lonely and needed to get well sooner (TB Survivor)

A TB survivor complained about the size of drugs that they had to take.

These drugs are very large in size, in fact that is why my husband quit and he eventually died after just after one week after starting treatment (TB Survivor)

A TB healthcare worker said:

Most patients I found had failed the first treatment and most of them told me that when they were put on TB drugs the doctor told them to eat and take the drugs and some missed food for three to four days and that is why they defaulted. Some

on the other hand are co-infected so they feel burdened by the drugs, for instance you find someone on ARVs and also on TB drugs (TB HCW)

Another healthcare worker said:

There is someone who wanted to commit suicide because of the medication and all those factors. We had to walk with that person all the way. But now he is okay (TB HCW)

4.5.4 Mis-interpretation of doctor's actions

The use of masks by health care workers as they handled tuberculosis patients brought a lot of mis-interpretation of the healthcare worker's actions because some patients felt stigmatized and did not understand why the HCWs wore these masks. Several TB patients complained that the HCWs scared them to the point that some lost hope, because they felt that if the HCWs could cover themselves so much like that, then it meant they were really suffering from something really deadly.

A healthcare worker reported that a patient who was being taken to hospital was so shocked with the way the healthcare workers who came for him at home wore protective clothes and they all had masks and gloves. The patient was so scared that he eventually died. Another healthcare worker revealed to me the way other healthcare workers scared another TB patient. The patient was very sick in the house and when the healthcare workers were alerted to go and help him, they also came dressed in protective clothing, wearing masks and gloves. The patient was very uncomfortable with this, because neighbours were wondering what was going on. The patient described it as such a humiliating moment.

A TB patient said:

I don't understand why the doctor is covering his mouth and nose. I think the doctor hates me (TB Patient)

A healthcare worker said:

So you can imagine you are getting into a hospital room and that health care worker is gowned in a face mask, has goggles, has head cap, it makes the environment so medical, it even scares the patient to open up (TB HCW)

A second healthcare worker said:

The patient feels as if you are discriminating against them when you wear a mask. It's even worse when you go to the households to visit a patient and you are wearing a mask, everyone in the neighbourhood will start peeping at a distance and wondering what patient could be suffering from that has made the health care workers cover themselves like that (TB HCW)

A third healthcare worker said:

I went to his house and he was very sick and I decided to call the other health care workers to help in taking him to the chest clinic, so when they came the patient was shocked because normally myself I do not wear any protective clothes, but those other colleagues of mine came wearing gloves and masks and they really scared the patient and eventually he died. Masks stigmatize some TB patients (TB HCW)

A fourth healthcare worker said:

Once you reach the patients house and you start putting on masks and people see you getting into the compound wearing masks and all that, it's very discriminative. It actually does more harm to the patient than good and people start asking why you are doing that. So for me masks, we would rather have another way that people can protect themselves from getting infected from the patient" (TB HCW)

4.5.5 Attitude of healthcare workers and how it affects the health-seeking

behaviour of TB patients

Several studies have reported that the health-seeking behaviour of TB patients can be determined by the attitude of the healthcare worker. In this study, a TB kin recalled how

her son who was diagnosed with TB was treated badly by the healthcare workers. The patient was kept waiting for several hours to get medication. The patient got tired and ran away without the medication. The TB patients' kin also complained about the harshness of the healthcare workers which she said made the patients to keep away from the healthcare centres.

A second healthcare worker said that some healthcare workers are known to intimidate patients from their actions and language when they are handling a patient. According to the healthcare worker, these are barriers which have resulted in TB patients absconding from treatment yet they are the ones who are supposed to improve the health-seeking behaviour of the patients. Another healthcare worker also recalled how TB patients after taking medication for a short duration of time suddenly stop the medication all because they feel they have become better. The healthcare worker blamed her colleagues for this kind of behaviour because they do not give the patients enough information on the importance of sticking to the treatment schedule. This has led to patients developing drug resistant strains of TB. Apart from TB patients complaining on how they were handled by the healthcare workers, healthcare workers too expressed the difficulties they had to undergo while handling TB patients. Majority of the healthcare workers cited various challenges while attending to TB patients, the major challenge being the fear of getting infected. The other challenges they expressed were lack of equipment in the healthcare facility and huge workload.

Working in a TB clinic is very difficult. You find that people fear getting infected. It is because TB is very infectious... so in a major health facility, there is that fear of somebody being infected and also there could be the issue of burnout. Burnout based on the number of clients that the facility has. And also lack of equipment

because at times when you want to handle somebody, you need to have all the equipment that you need in terms of things like gloves and other commodities that one would need to protect themselves. You know healthcare workers are also human beings (TB HCW)

4.6 Discussion of findings

The discussion in this chapter is based on the findings presented in the previous sections. Accordingly, the main points of discussion are on the following areas: Sources of information about tuberculosis disease for TB patients, TB survivors, TB healthcare workers and TB patients' kin. The second is the nature of information on tuberculosis for these four different categories of respondents and lastly public discourse on TB and how it inhibits self-disclosure and health-seeking behavior among TB patients. These are discussed systematically below.

4.6.1 Information access

The first objective of the study sought to determine the sources of information on TB that was available for TB patients, TB survivors, TB patients' kin and TB healthcare workers. Findings from this study indicate that despite the existence of multiple channels of communication, majority of the TB patients, TB survivors and TB patients' kin got their TB knowledge from the healthcare workers. An insignificant number of respondents reported that they did not get any information from the healthcare workers and hence they opted to go to the internet for a self-learning session. Findings further indicate that most of the respondents got TB information through interpersonal communication and mass media. There was also the use of radio and television which was commonly cited by the TB patients and their kin. However, this information was only gotten after they were diagnosed with the disease. The majority of the respondents accessed information on TB

from the hospitals in the form of health talks, leaflets, brochures and posters which were displayed on the walls of the health facility.

These findings are similar to a study conducted in India by Hemmavathy et al., (2014) which sought to identify the TB patients' key sources of general health related and TB related information. The study also sought to identify the TB patients' most trusted sources of information. In the study findings they cited that a significant number of the TB patients received their TB related information from interpersonal communication. In this study, interpersonal communication was viewed as an important medium through which a large portion of the TB patients received information.

The present study adds knowledge on the fact that healthcare workers play a very important role in disseminating TB information to TB patients, TB survivors and TB patients' kin through interpersonal communication. TB patients, TB survivors and TB patients' kin continue to suffer stigma and discrimination because of the limited sources of TB information. Majority of these respondents had no prior knowledge of TB. More channels of communication need to be used exhaustively to create awareness on TB disease.

4.6.2 Nature of tuberculosis information

The second objective of the study was to identify the nature of TB information that was available for the four different categories of respondents. The findings in this study found out the presence of both correct and incorrect information on TB. Incorrect information was domineering as opposed to correct information some of these incorrect information was on basic information on the causes, symptoms, prevention and treatment of TB.

Majority of the respondents could not explain the causes and symptoms of TB which eventually led to a delay in their health-seeking behaviour.

Due to incorrect information about TB, most respondents once diagnosed with TB viewed TB as a death sentence. They believed that the moment one was diagnosed with TB, it meant that they were just going to die. They did not know that TB has a cure. A TB patients' kin whose relative was diagnosed with TB, concluded that bringing the TB patient home was the same as bringing a coffin home. The findings in this study have established that most TB patients and TB patients' kin associate TB with death because of lack of correct information about the disease.

These findings concur with those of a study by Viney et al., (2014) which attempted to better understand the knowledge, attitudes and behaviors of a group of TB patients in Vanuatu. The patients in this study were generally not aware of the bacterial cause of TB and thought that TB could be caused by a range of factors including sharing food and eating utensils. These findings are consistent with studies from many African countries in which beliefs about TB causation include witchcraft and sharing eating utensils. The study justified that incorrect understanding of TB causation can not only influence TB patient's health-seeking behaviour, but also it can influence their adherence to a prescribed treatment regime and treatment outcome.

Further evidence supporting these findings may lie in the findings of Abebe et al., (2010), who conducted a study to investigate the knowledge, health-seeking behaviour and perceived stigma towards tuberculosis among tuberculosis suspects in a rural community

in southwest Ethiopia. The study found that perceived stigma and lack of awareness could contribute to the late presentation and low detection rate of tuberculosis. In their study they also found out that there was little knowledge about TB in the field research area where they conducted the study. They also observed inappropriate health-seeking behaviour and stigma towards TB. They identified gaps in knowledge about the cause of TB and traditional beliefs such as witchcraft which happened to be the commonest perceived causes of TB in their study.

In addition to revealing findings consistent with the previous studies mentioned above, the present study also explored the ways in which the respondents can get correct information about TB. The key finding is that there is very limited media coverage on correct information on TB. The public need to have correct information on TB and this information can be disseminated either through the mass media and the healthcare workers both in the public and private sector. Other media types for example posters with more visuals and billboards can be used to pass this correct information on TB. Branded materials, cartoons and drama can also be used to pass this correct information on TB. The study therefore revealed that TB healthcare workers have been the main sources of TB information. There is therefore a need to equip not only TB healthcare workers but also all healthcare workers in both public and private healthcare facilities. These findings reflected that there is a knowledge gap on TB information and there is therefore an urgent need to intensify public awareness on correct information about TB disease. This public awareness can be done through the media and the TB healthcare workers since they are usually the ones who have first contact with the TB patients and their kin.

4.6.3 The determinants of health-seeking behaviour of TB patients

The third objective of this study sought to find out the determinants of health-seeking behaviour of TB patients. In this study several of the TB patients delayed in seeking healthcare for several weeks despite the fact that early detection is critical to controlling the disease. The findings indicated various reasons which included personal factors, TB stigma, health service related factors which included the use of masks and gloves by healthcare workers, the intolerance to anti-TB drugs, the attitude of healthcare workers, lack of support from the healthcare workers and kin and lastly the structural factors.

4.6.3.1 Personal factors

The most compelling argument in this study was about the cause of TB. Most of the respondents argued that TB resulted from a curse, others argued that TB was caused by bad luck, yet another group of respondents argued that TB was caused by witchcraft. Surprisingly, another group argued that TB was a disease which was inherited from the family. The most prominent personal factor to emerge was the lack of knowledge about the disease and its treatment. A large number did not really believe that TB was curable and hence they saw TB as a death sentence. Others were of the opinion that TB can only be cured by the use of herbal medicine.

In a study conducted in Tanzania by Tarimo (2012), to determine the reason why TB patients delay in seeking healthcare, traditional beliefs such as witchcraft was perceived as one of the causes of tuberculosis. The study established that those TB patients who believed that they were bewitched opted to visit traditional healers or religious healers.

The study concluded that patients delayed seeking healthcare if they suspected that they had been bewitched.

4.6.3.2 Health service related factors

i. The use of masks and gloves by health care workers

There was a mis-interpretation of healthcare workers' actions. In this study, a respondent who was diagnosed with TB disease, thought that the doctor hated him because he was wearing gloves and a mask while attending to him. Another respondent felt discriminated against by the health care workers because of the masks and gloves. A third respondent also felt that the wearing of masks was very discriminative and felt that it actually did more harm than good to the TB patients. The wearing of these masks and gloves by the healthcare workers was because of the contagious nature of the disease. The healthcare workers did not explain to most of the TB patients the reason why they had to wear gloves and masks while attending to the patients.

In a recent study by Vaz et al., (2016) which sought to know the perceptions of stigma among medical and nursing students and tuberculosis and diabetes patients at a teaching hospital in southern India. The findings of the study noted that perceptions were high in regards to stigma. There was apparently an unreasonable fear of transmission of disease. These medical and nursing students had witnessed their seniors' use of gloves and masks, and their having seen the same seniors make requests for tests for only certain diseases. The study established that precautionary measures, such as wearing of gloves and masks, are often confused with discriminatory behaviour and stigma.

ii. Intolerance to Anti-TB drugs

For this study there were complaints on the duration of treatment, drugs not tasting nice, drugs been too strong especially for those who have tested positive for both TB and HIV. Other TB patients complained of irritating side effects of the drugs. The respondents also reported that the TB drugs were too big making them very difficult to swallow. Other complained about the side effects of the drugs especially when taken on an empty stomach.

A similar study conducted by Muture et al., (2011), established that TB patients who were co-infected with HIV found it a big challenge to undergo the TB treatment. The co-infected patients take anti-retroviral and TB drugs which means taking many tablets on a daily basis thus leading to many of these co-infected patients defaulting in treatment. TB patients in this study also found it very challenging to continue taking the drugs due to lack of adequate food. Signs of despair were evident amongst TB patients when they were being taken through the TB treatment regime. Apart from complaining about the number of drugs and the large tablets TB patients had to swallow, they also found the duration of treatment too long and tiresome. The side effects of the drugs also made some TB patients to stop treatment.

iii. Attitude of healthcare workers

For some TB patients and survivors, the bad attitude of the health care workers was a reason to interrupt treatment. Some TB patients talked of how they were spoken to harshly by the healthcare workers when they went to seek treatment. Others complained of being kept waiting for hours at the healthcare facilities despite arriving on time. A

female patient recalled her painful experience in the hands of healthcare workers. The patient complained of how the healthcare workers were stigmatizing her because of having being diagnosed with TB. The use of harsh words towards patients led to some patients withdrawing from treatment.

These findings concur with a study conducted in Nigeria by Ibrahim et al., (2011), who found out that TB patients' treatment protocol is affected by the attitude of the healthcare workers towards the TB patients. They argued that the relationship between the healthcare workers and the TB patients are critical elements in the success of TB treatment. They further argued that TB patients are expected to follow the instructions of the healthcare workers on their treatment; however, whether or not the patients follow the instructions depend on the attitudes of the healthcare workers adjudged to be negative or friendly by the patients. Negative attitudes will make TB patients lose confidence in the healthcare workers or they may feel threatened, not loved, or respected and they may choose not to continue with their treatment leading to interruption and eventually failure or defaulting from the treatment. They came to a consensus that negative attitude of the healthcare workers towards the TB patients were a key barrier to patients' adherence to treatment.

iv. Lack of support from the healthcare workers and kin

This study showed that some of the respondents complained of lack of support or encouragement from some of the healthcare workers and also from their own family members. Their family members appeared to be scared of the TB patients. They also complained of lack of support when seeking healthcare from the healthcare workers for

example one respondent was asked by a healthcare worker the reason for delaying in seeking healthcare.

A similar study by Lewis and Newell (2009) whose aim was to improve tuberculosis care in low income countries and to study patient support in Nepal established that most TB patients lacked encouragement from their family members. The majority of patients felt considerable isolation, both physical and mental, due respectively to precautions taken against disease spread and because of lack of understanding of TB. This isolation from close family members was stated as being the most difficult part of their treatment program to deal with on a day-to-day basis. The kind of isolation in their family home and a lack of anyone to whom they felt they could relate were the elements that had most affected their self-esteem.

4.6.3.3 Structural factors

Poverty among a significant number of the TB patients tended to determine whether they were likely to seek healthcare and eventually finish the treatment regime. A study by Essendi and Wandibba (2011) which sought to know the barriers to healthcare which affect women with tuberculosis in Kibera slums in Nairobi Kenya, cited poverty as one of the barriers to seeking healthcare. In the study, poverty specifically the lack of money was seen as the main reason for TB patients delaying to seek healthcare. This was despite TB testing and drugs being offered free of charge in government and some non-governmental facilities in the slums. The women required still required money to access transport to the health facilities.

Prior studies have suggested that men are usually the first to seek healthcare when infected by TB. In this present study it is the women who went to seek healthcare promptly. The male respondents confessed to delaying in seeking healthcare due to lack of knowledge and in some cases they were in denial. They reported cases where their male counterparts succumbed to the disease within the first two weeks of treatment due to late presentation. These findings are in line with a study conducted by Kaur et al., (2013) which sought to know the gender differences in healthcare seeking behaviour of tuberculosis patients in Chandigarh. In this study more delay in diagnosis occurred among men than in women. The reasons for the delay amongst the men was that men often did not share their illness with family until symptoms worsened when family members persuaded them to seek healthcare.

On ethnic issues, the respondents with low level of education were more prone to view TB as a curse, or as a disease caused by bad luck as opposed to the fairly well educated respondents who had an idea that tuberculosis was caused by a bacteria. Male respondents preferred accessing information on tuberculosis from mass and print media, whereas their female counterparts preferred receiving tuberculosis information from the broadcast media.

4.6.3.4 Stigma related factors

Despite several studies having done on TB stigma, stigma still exists and was established to be one of the determinants of health-seeking behaviour amongst TB patients. In this study, healthcare workers reported cases of TB patients experiencing stigma not only from friends and family but also from some healthcare workers. TB patients also experienced TB stigma by virtue of them having a family member infected with TB.

Jurcev-Savicevic (2010) conducted a cross-sectional study where he investigated the attitude towards tuberculosis and sources of tuberculosis-related information in Croatia. The findings of this study uncovered gaps in the knowledge about the disease etiology and transmission which could contribute to severe misconceptions which can lead to social stigma among TB patients and their families. The study then listed factors which are probably responsible for stigmatization of TB patients such as fear from casual transmission, willingness to interact with affected individuals and moral values of blame, responsibility, guilt, punishment and judgment.

4.7 Impact of self-disclosure

4.7.1 Fear of ostracization

The fear of ostracization has been considered as one of the factors that lead TB patients and TB survivors not to disclose that they are infected with TB. TB patients are scared of being ostracized after seeing the experiences of other TB patients and TB survivors. TB patients' kin also fear to disclose to people what their patient is suffering from for fear of apart from the TB patient, but also their family from being ostracized by their neighbors.

As cited in the literature review, a study by Zolowere et al., (2008) established that self-disclosure of diagnosis to others within the patients' social environment may be problematic because the diagnosis of TB may warrant unnecessary stigma largely derived from the association of this disease with HIV/AIDS. In the study, majority of the patients reported having disclosed their status to their children. In a similar study on disclosure by Gebremariam et al., (2010), disclosure can play a positive role because it can help the

parent mobilize support thereby facilitating adherence, and it is also important for public health reasons such as avoidance of further infection.

4.8 Public discourse on HIV/AIDS

4.8.1 Link with HIV

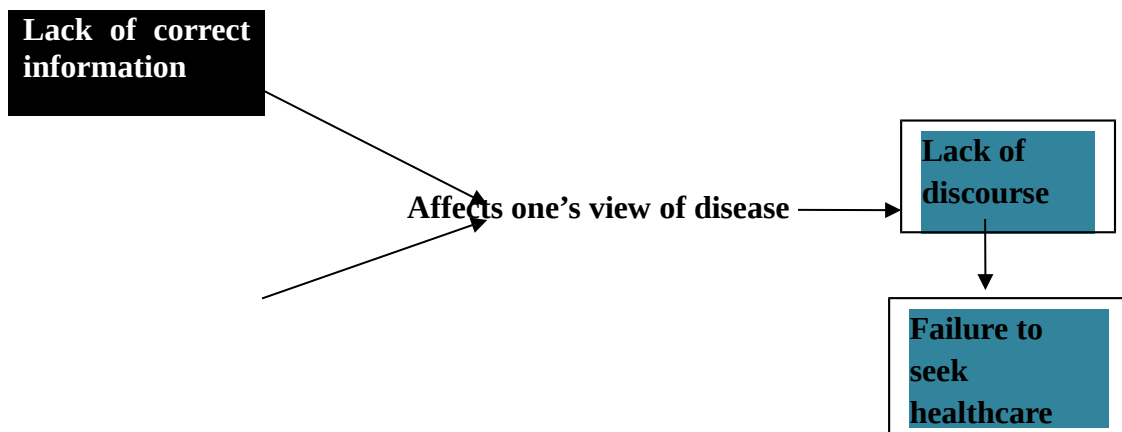
Generally most of the respondents believed that if one was diagnosed with TB then it automatically meant that they were HIV positive. This is one of the cases of patients believing in incorrect information about TB. In a similar study as cited in the literature review by Deane and Parks (2006), it was established that most TB patients tend to postpone seeking care due to fears of people discovering their HIV status and suffering stigmatization and social rejection. Stigma attached to many communicable diseases, such as Leprosy and TB, also determines the patient's health-seeking behavior. In another study on TB and HIV link, by Giri et al., (2013), stated that since the increase in HIV infection rate leads to increase in tuberculosis disease, there is need to re-examine the strategies for their effective control. The most important aspect of this control program is public awareness on how tuberculosis and HIV are transmitted.

4.9 Public discourse on tuberculosis disease

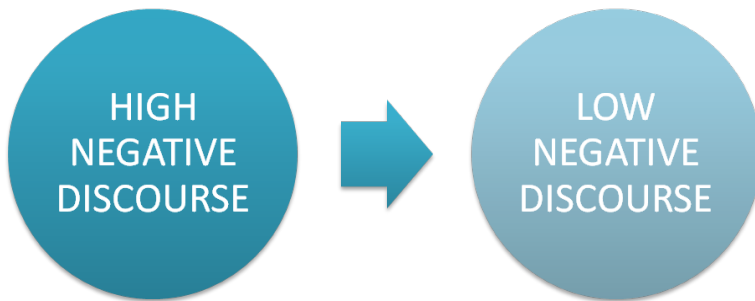
People generally fear tuberculosis disease because of its contagious nature. They believe that if one is infected with TB, then it means that they are just going to die. People generally stigmatize those who are diagnosed with TB and due to this kind of behavior many TB patients opt to keep their status secret for fear of being ostracized. The HIV link is another factor that makes TB patients to keep their status secret. There is really a great fear of tuberculosis that TB survivors despite completing their treatment regime and

being declared 'TB free', people still fear to associate with them. People say that there is no cure for TB and that is the reason why many of the TB patients and TB survivors confessed to being quite devastated when they were diagnosed with TB. There were signs of despair which were also evident amongst the patients.

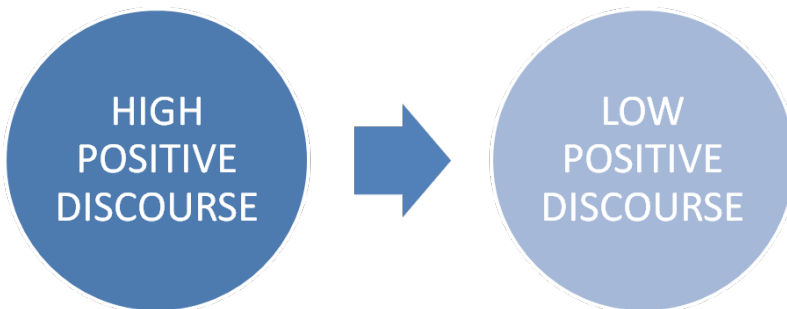
As cited in the literature review, a study by Konradsen et al., (2014) explored how patients undergoing the medical examination for TB had to have a public diagnosis. The patients did not have a choice of keeping their diagnosis private towards family, friends or healthcare workers. They had to disclose their status to everyone in public and explain to them about the disease and its treatment protocol. This kind of public discourse eventually led to changes in the social interactions of these patients which became a huge concern to them.



The above illustration shows how lack of correct information and negative public discourse on tuberculosis inhibit self-disclosure and health-seeking behaviour among TB patients.



The above illustration shows that high negative discourse often leads to low negative discourse whereas if there is high positive discourse, then there is low positive discourse as depicted in the illustration below.



4.9 Chapter summary

In this chapter, data has been presented, analyzed, interpreted and discussed based on the study objectives stated at the beginning of the study. In this section, the data generation and analysis procedure was discussed. Findings on the demographic characteristics of the respondents revealed that majority of them who participated in the study fall between the ages of 19 years and 76 years. Findings on the sources of information showed that TB

patients, TB survivors and TB patients' kin got their information from TB healthcare workers. Further findings on the nature of tuberculosis information revealed the presence of both correct and incorrect information about TB. This revelation was common in all the four categories of respondents. This chapter also presented data on public discourse and how it determines the health-seeking behavior of TB patients. Lastly I discuss the findings of the study. In the subsequent chapter, I present a summary of the key findings, conclusion and recommendations together with suggestions.

CHAPTER FIVE

SUMMARY OF KEY FINDINGS, CONCLUSION AND RECOMMENDATIONS

5.0 Introduction

In this section, I provide a summary of key findings of this study which will then lead to the key conclusions arrived at. I therefore suggest areas for further study. The purpose of this study was to investigate the accessibility of tuberculosis information. It also sought to determine the nature of tuberculosis information that was available for TB patients, TB survivors, TB healthcare workers and TB patients' kin. Public discourse on tuberculosis and the impact of self-disclosure and how it affects the health-seeking behavior of TB patients was also investigated. Twenty five participants who included six TB patients, five TB survivors, six TB healthcare workers and eight TB patients' kin participated in the study. The study used a single-case study research design and data was generated through interviews which were analyzed thematically. The key findings of the study are summarized in subsequent sections.

5.1 The key findings of the study

5.1.1 Summary of the sources of information

Findings from this study indicate that despite the existence of multiple channels of communication, majority of the TB patients, TB survivors and TB patients' kin got their TB knowledge from the health care workers and friends. Sources of TB information were limited for most of the respondents and majority disclosed that they did not have any access to TB information until they were either diagnosed or when a family member was diagnosed with the disease.

5.1.2 Summary of the nature of information

This study also established that despite the existence of multiple channels of communication, both correct and incorrect information on tuberculosis was evident in all the four different categories of respondents who were interviewed. The incorrect information on TB was more compared to the correct information. The respondents in this study appeared to believe more in the incorrect information as compared to believing the correct information about TB.

5.1.3 Summary of the determinants of health-seeking behaviour

This study also revealed that health-seeking behaviour of TB patients is largely determined by the kind of information that they have about the disease. Majority of the survivors reported that they would have avoided delay in seeking healthcare if they had access to correct information about TB and since majority of the respondents believed in incorrect information on TB, the delay to seek healthcare was rampant.

5.3 Public discourse on tuberculosis disease.

One of the challenges facing TB control programs is the public discourse surrounding the disease. The negative manner in which society talks about TB especially its relation to HIV and AIDS and its contagious nature makes patients hesitant to seek healthcare thus exacerbating the condition. Thus TB prevention communication should not only focus on raising the awareness of the disease but also dismantling the needs and negative discourse surrounding it if success has to be achieved in combating it.

5.4 Conclusion

This study established that despite there being many channels of communication, many still do not have information on tuberculosis. Information about Tuberculosis should not be limited only to interpersonal communication. The use of other communication channels for example print and mass media need to be intensified. Healthcare workers seemed to be the preferred source of information for TB especially for patients and survivors. The presence of incorrect information about this together with the many myths and beliefs related to TB, seems to be a major deterrence in the control of this disease. Another interesting finding that this study noted was that relapse TB patients defaulted because they did not have access to correct information about this disease. Stigma and the HIV correlation has been seen as another hindrance to TB control because it has led to lack of public discourse. This study revealed that health-seeking behaviour of TB patients is largely determined by the kind of information that they have about the disease. Majority of the survivors reported that they would have avoided delay in seeking healthcare if they had access to correct information about TB. Further findings of this study further point out that majority of TB patients are willing to complete their treatment

regime if they are encouraged by the healthcare workers and their kin and also if they are given correct information about TB. TB survivors were found to be very supportive to TB patients, presumptive patients and also to relapse patients.

Overall, the main contribution of this study is that it provides useful insights into the kind of knowledge that the public have about tuberculosis, and how this knowledge is contributing in exacerbating the challenge posed by the disease. The study may be beneficial to the National Tuberculosis Control program as it would highlight the current level of awareness of tuberculosis information amongst the TB patients, survivors, kin and healthcare workers. This study also hopes to support the government's plan into achieving the Sustainable Development Goals (SDG) number three, by aspiring to ensure health and well-being for all, including a bold commitment to end the epidemics of AIDS, Tuberculosis, Malaria and other communicable diseases by the year 2030

5.3 Recommendations

The Ministry of Health in Kenya needs to find ways of motivating healthcare worker because they seem to be the first source of TB information for many patients who are newly diagnosed. Majority of healthcare workers claim to work on voluntary basis yet the patients they have to handle are scattered all over their counties, without any remuneration, healthcare workers are not able to closely monitor the patients under their care leading to 'treatment after loss to follow-up patients (these are those patients who had been started on treatment but were declared lost because of lack of follow-up) numbers going up.

There is a lot funding allocated for the control of HIV/AIDS. There is an urgent need to allocate more funds for the control and possible eradication of tuberculosis disease. TB testing centers need to be increased just like the VCT centers for HIV testing. Public awareness campaigns need to be intensified all over the country so that more and more people are able to access correct information on TB. The government should also strive to conduct more regular surveys throughout the country to reach the many undetected cases of TB which are left untreated.

The Government of Kenya through its Ministry of Health should make it mandatory for all people living with HIV to go for a yearly TB test. TB is the number one killer of persons living with HIV virus, if they could go for a yearly TB test, many deaths resulting from this disease can be greatly prevented. TB patients need to be educated on the reason why healthcare workers have to wear masks and gloves while attending to them. The education should be made at the onset of treatment. TB patients do not seem to understand why healthcare workers wear these protective materials when attending to them. The patients also need to be educated on the reason why they in some situations they have to also wear these masks like the healthcare workers.

5.4 Suggestions for further research

In relation to the present study and in view of the findings, further research would be necessary in the following areas:

- 1) A study on public awareness materials like posters which are used to pass messages on TB. The study would reveal whether they are well understood or whether posters with more visuals which are eye-catching could be a better communication tool.

- 2) A study on why there is an increase of incorrect information on TB as compared to correct information.
- 3) More studies on public discourse on TB disease and how it inhibits health-seeking behaviour of TB patients.
- 4) A study on the reason why TB stigma and discrimination still exists despite several studies having been conducted by several scholars.

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APPENDICES

APPENDIX I: INTRODUCTORY LETTER

TO WHOM IT MAY CONCERN

Dear Sir/Madam,

RE: RESEARCH STUDY

I am a student pursuing a Master of Science degree in Communication Studies at the Moi University, Nairobi campus. In partial fulfillment of the requirements leading to the award of 'Master of Science degree in Communication Studies'. I am required to carry out a research on Information Access And Health Seeking Behavior Among Tuberculosis Patients, Survivors, Kin and Healthcare Workers.

I kindly request your assistance by availing your time to respond to the interview questions.

Yours faithfully,

Beatrice A. Koech

Moi University

APPENDIX II: INTERVIEW GUIDE FOR TUBERCULOSIS PATIENTS

Date:

Time:

Site:

Patient/ Other:

Interview No.:

1. How old are you?
2. What is your highest level of education?
3. What is your occupation?
4. Where do you live?
5. Gender
6. What do you know about tuberculosis?

Probe Questions

- Knowledge of tuberculosis
 - Ways of transmission
 - Ways of prevention
7. Where do you get information about tuberculosis?

Probe Questions

- Channels of communication
- Frequency of information, accessibility of information

- Usefulness of information

8. For how long have you had tuberculosis?

Probe Questions

- Tell me how you got to know that you had tuberculosis
- What was your reaction?
- Did you discuss it with anyone in the family? What were their reactions?

9. Tell me how you started getting treatment for tuberculosis?

Probe Questions

- What was your experience in getting treatment?
- Do you think tuberculosis is curable?
- Did you find the information useful?

10. How do people around you react to the fact that you have tuberculosis?

Probe Questions

- How do they treat you?
- What is their reaction?
- Are they afraid that you will infect them?

11. What information do you have about stigmatization and discrimination of some tuberculosis patients?

Probe Questions

- As a tuberculosis patient, have you ever experienced stigmatization and discrimination and if yes, from who?

- What do you think causes stigmatization and discrimination of tuberculosis patients?
- What happens when a tuberculosis patient suffers stigma?

12. What determines your health-seeking behaviour as a tuberculosis patient, is it the healthcare worker, or it your family members, or is it a tuberculosis survivor or is it you personal decision?

Probe Questions

- What is the role of information in terms of health-seeking behaviour?
- From your experience as a tuberculosis patient. Does the attitude of the healthcare worker determine a patient's health-seeking behaviour?

13. As a tuberculosis patient, would you disclose your status in public?

Probe Questions

- If yes, why?
- If no, why?

14. During the period that you have been ill with tuberculosis, what kind of information have you come across on tuberculosis?

Probe Questions

- Where did you get the information?
- Was it useful?
- Is it accessible to all?

15. What can you say about the information that you got from the healthcare worker?

Probe Questions

- Was it information that was useful to you?

- Was that information accessible, did it help you?

16. From your experience as a tuberculosis patient, are healthcare workers fully armed with knowledge on tuberculosis?

17. Did you have information that tuberculosis treatment is free of charge in all public health institutions?

Probe Questions

- If yes, where did you get that information?
- If no, how come you do not know?

APPENDIXIII: INTERVIEW GUIDE FOR TUBERCULOSIS SURVIVORS

Date:

Time:

Site:

Patient/ Other:

Interview No.:

1. How old are you?
2. What is your highest level of education?
3. What is your occupation?
4. Where do you live?
5. Gender
6. What do you know about TB?

Probe Questions

- Knowledge of tuberculosis
 - Ways of transmission
 - Ways of prevention
7. Where do you get information about tuberculosis?

Probe Questions

- Channels of communication
- Frequency of information
- Usefulness of the information

8. When did you come to learn that you had TB?

Probe Questions

- What was your experience?
- What was your reaction?

9. What made you seek healthcare?

Probe Questions

- What was your experience in getting treatment?
- Did you know whether TB has a cure or not?
- What information did the healthcare worker give you about tuberculosis?
- Did you find the information useful? (was it accessible?)

10. How did the people around you react to the fact that you had tuberculosis?

Probe Questions

- Did you disclose your status to anyone, and why?
- How did your family, friends, colleagues treat you?
- Were they afraid that you will infect them

11. What information do you have about stigmatization?

Probe Questions

- Having being a tuberculosis patient, did you at any point during your illness experience any form of stigmatization?
- What do you think causes stigmatization of tuberculosis patients?
- What happens when a tuberculosis patient suffers stigma?

12. What determines your health-seeking behaviour as a tuberculosis survivor?

Probe Questions

- Is it the healthcare worker, kin or personal decision
- What is the role of information in terms of health-seeking behaviour?

13. What can you say about the association of tuberculosis the disease and HIV/AIDS?

14. Being a tuberculosis survivor, what can you say about the association of tuberculosis the disease and HIV/AIDS?

Probe Questions

- What is the link and what is causing it?
 - Do you feel the association could be seen as a determinant of the health-seeking behaviour?
15. Being a tuberculosis survivor, if you were diagnosed with tuberculosis again, would you disclose your status in public?

Probe Questions

- If yes, why?
- If no, why?

16. Being a tuberculosis survivor, what can you say about information on tuberculosis?

Probe Question

- Is information readily accessible?
- Is the information adequate?
- What can be improved regarding information access?

APPENDIXIV: INTERVIEW GUIDE FOR TUBERCULOSIS KIN

Date:

Time:

Site:

Patient/ Other:

Interview No.:

1. How old are you?
2. What is your highest level of education?
3. What is your occupation?
4. Where do you live?
5. Gender
6. What do you know about TB?

Probe Questions

- Knowledge of tuberculosis
 - Ways of transmission
 - Ways of prevention
7. Where do you get information about tuberculosis?

Probe Questions

- Channels of communication
- Frequency of information
- Usefulness of the information

8. Do you know anyone in your family who has been diagnosed with TB?

Probe Questions

- How did you come to know that this family was suffering from TB?
- Did they know what they were suffering from?

9. What about his or her immediately family members, did they encourage the tuberculosis patient to seek healthcare?

Probe Questions

- When they eventually decided to seek healthcare this was after how long?
- Tell me the experience of this tuberculosis patient in seeking healthcare?

10. What information did this patient have on TB?

Probe Questions

- How much information did they have?
- What about you as family members, did you have any information on tuberculosis?
- Did the healthcare worker provide any information on TB, to the patient and to you as family members?
- Was this information easily accessible to you as a family and to the patient?

11. Did you as family members and the patient have information on whether tuberculosis has a cure or not?

12. What can you say about self-disclosure?

13. What about stigmatization of TB patients?

APPENDIX IV: INTERVIEW GUIDE FOR TUBERCULOSIS HEALTHCARE

WORKER

Date:

Time:

Site:

Patient/ Other:

Interview No.:

1. How old are you?
2. What is your highest level of education?
3. Where do you live?
4. Gender
5. When did you become a healthcare worker?
6. What information do you have about TB?
7. What knowledge about TB do you share with tuberculosis patients?

Probe Questions

- What do they know?
 - What don't they know?
 - Where are they supposed to get TB information from?
8. What kind of information is available for TB patients on the disease?

Probe Questions

- Is it useful to them?

- Do they understand it?
- What information materials do you give them?

9. What makes TB patients seek healthcare?

10. What has been your experience in handling TB patients?

11. As a healthcare worker, what do you think is the cause of TB patients defaulting in treatment?

12. What can you say about TB stigma?

13. What about self-disclosure?

14. What channels of communication can you use to reach would be TB patients and the general public?

APPENDIX VI: LETTER OF RESEARCH AUTHORITY



NATIONAL COMMISSION FOR SCIENCE, TECHNOLOGY AND INNOVATION

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Ref: No.

Date:
5th June, 2015

NACOSTI/P/15/8946/5878

Beatrice Achieng Koech
Moi University
P.O Box 3900-30100
ELDORET.

RE: RESEARCH AUTHORIZATION

Following your application for authority to carry out research on "*Access to Tuberculosis Information and its influence on health-seeking behavior among patients at one Health Center in Nairobi, Kenya,*" I am pleased to inform you that you have been authorized to undertake research in **Nairobi County** for a period ending **30th November, 2015.**

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

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


DR. M. K. RUGUTT, PhD, HSC.
DIRECTOR-GENERAL/CEO

Copy to

The County Commissioner
Nairobi County.

The County Director of Education
Nairobi County.