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Community Perceptions of Tuberculosis and People Diagnosed with Tuberculosis in a Rural Community in Malawi

By

Simon Edingtone Sikwese

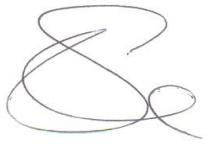
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A research report submitted to the Faculty of Health Sciences, School of Public Health, University of the Witwatersrand, Johannesburg, in Partial fulfillment of the requirement for Masters Degree in Public Health – Social and Behaviour Change Communication

November 2012

DECLARATION

I, Simon Edingtone Sikwese declare that this research report is my own work. It is being submitted for the degree of Master of Public Health at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.



S.E Sikwese (Mr) Signature:……..

23rd November 2012

Dedication

I dedicate this report to my dear father Edingtone, a clinician by profession who dedicated his life to serve people's lives and committed his life to educating his children.

To my wife Fiskani, and sons, Kayakangu "My Home" and Twapalisha "Thank You" for your never ending support and encouragement.

Abstract

The aim of the study was to qualitatively explore and compare the beliefs and perceptions of adult men and women towards Tuberculosis (TB) and TB outpatients in a rural community in Ntcheu district in Malawi January 2011.

Method:

This qualitative research study was conducted in January 2012 and used focus groups discussions and individual in-depth interviews to collect data. A total of eight FGDs and 16 In Depth Interviews (IDI) were conducted in Ntcheu district in Malawi. Data were collected among adult males and females aged between 18-49 who had ever had and those who had never had TB. Discussions were audio taped, translated and transcribed verbatim into English and analysed using MAXQDA software for qualitative analysis.

Results: The local word for TB is "Big Cough". There were different levels of knowledge about TB between people who have never had and those who had ever had TB. People who had ever had TB could explain different types of TB and discussed multiple symptoms of TB as compared to those that had never had TB. There were positive attitudes towards early diagnosis, treatment and adherence among most respondents. Most respondents believed that TB is curable and that they would go for diagnosis if they had symptoms suggestive of TB. However, they expressed some apprehension based on their belief about the contagiousness of TB and the social consequences of being diagnosed. This apprehension did affect participants' responses about seeking diagnosis and treatment. Issues of misdiagnosis were also reported where people with symptoms suggestive of TB would travel to the healthy facility repeatedly without being diagnosed with TB. This was another potential barrier to early diagnosis.

Conclusion: Early diagnosis of TB among this rural community is affected by several factors. While respondents demonstrated intentions to go for early diagnosis through their belief in the curability of TB, these intentions were obstructed by people's perception of the severity of the consequences of being found with TB as well as low knowledge on contagiousness of TB. A combination of mass media and interactive communication campaigns covering TB symptoms, contagiousness, addressing issues of stigma related to TB as well as distinguishing TB from HIV can help address the barriers to early diagnosis seeking behaviour.

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Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
DOTS	Directly Observable Treatment Short-Course
FGD	Focus Group Discussion
HIV	Human Immune-Deficiency Syndrome
HSA	Health Surveillance Assistant
IDI	Individual in-Depth Interview
MDG	Millennium Development Goals
NTP	National Tuberculosis Programme
RA	Research Assistant
TA	Traditional Authority
TB	Tuberculosis
WHO	World Health organisation

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Chapter One: Introduction and Background

This chapter introduces TB as a global health issue and the extent to which TB has become a global public health problem that require urgent attention. It also presents aims and objectives of the study and a literature review that I conducted for this study.

1.0 Introduction

Tuberculosis (TB) which is caused by Mycobacterium Tuberculosis, a tubercle bacilli [1] is a major public health problem globally. There has been a global increase in the number of cases. One of the reasons could include delay in diagnosis, case detection and treatment seeking [2-4]. World Health Organization (WHO) has set targets to reduce by half the burden of TB by 2050 with the 2015 target falling within the context of the Millennium Development Goals (MDGs) [5]. The 2015 target is to halve TB prevalence and death rates globally. According to the report (WHO, 2010), Directly Observed Treatment short course (DOTS) is the foundation for the stop TB campaign and it emphasizes early case detection as the central pillar of global TB control [2, 6-7].

While implementation of DOTS saw a global decline in TB in several countries, the approach did not achieve the much anticipated success as the incident rate did not fall as rapidly as was expected to achieve the MDG target [8-9]. There have been reported delays in seeking diagnosis, treatment and poor treatment adherence which has negatively affected morbidity and mortality and potentiated the spread of TB to other people. This has in part been attributed to overreliance on biomedical interventions without considering the social, cultural and economic environment of the infected people and the community at large [7-13]. Effective TB control strategy which

includes early case detection is dependent on early recognition of signs, care and early treatment seeking [2, 11, 14-15].

To achieve this it is important to understand people's knowledge, attitudes and perceptions of TB as these can benefit planning and development of effective health promotion programs which could potentially contribute to the success of the TB control programmes in many countries [16]. This should further be informed by a broader theoretical understanding of people's health beliefs and concerns emanating from their perceived severity and expectations towards the disease [17]. These beliefs are influenced by factors such as knowledge about TB, the availability of social support, access to diagnosis and treatment facilities, which together may influence their perceptions about TB [17].

1.1 Problem Statement

Tuberculosis is still on the increase due to continued transmission through undiagnosed cases in communities. The delay in diagnosis is partly due to the lack of knowledge about the cause, mode of transmission and symptoms as well as perceptions and beliefs that communities hold about TB and people diagnosed with TB [18-21]. The high HIV infection rates in countries in the sub-Saharan region have resulted in a resurgence of TB diagnosis in the past two decades and Malawi is no exception. In Malawi, the National TB Control Programme (NTP) has been recognized internationally for its effective approach to TB control but the gains made have been affected by the HIV and AIDS pandemic which has led to increased cases of TB as well as stigma about TB due to HIV and AIDS [22]. With an HIV prevalence rate of 12% among the adult population, Malawi has been faced with increasing numbers of patients with Acquired Immune Deficiency Syndrome (AIDS) and TB [23]. As of the 1970s, Malawi was reporting approximately 4,000 cases yearly with 90% of the cases being successfully treated. This trend

surged to about 20,000 cases yearly while mortality rate rose from five percent in 1995 to 22 percent in 1998 with figures showing that Malawi registered 28,200 cases of TB in 2003 due to HIV and AIDS [24]. The linking of TB to HIV gradually created attitudes and perceptions that have become a source of stigma associated with being found with TB as well as fears of being infected with TB and has been cited in several studies as one of the reasons for delays in diagnosis [25-27]. A study in Zambia demonstrated a strong link between HIV and TB stigma in relation to people's perceptions of the disease as well as how visible TB symptoms trigger stigma and discrimination largely based on assumptions that people diagnosed with TB have also AIDS [27]. While it has been acknowledged that DOTS is the most effective strategy based on the bio-medical model [1, 28], most TB control programmes have not considered patient's perspective of the disease which is influenced partly by socioeconomic and cultural factors as well as people's beliefs and how these affect patient's care seeking behaviour [1, 28]. Effective health seeking and case finding is influenced by a combination of health system, community, family and other personal issues including how people experience their symptoms and illness as well as their perceptions of the causes and experience with the health system [9, 18]. Our limited understanding of community perceptions towards TB and factors that influence perceptions may be affecting the success of DOTS [6]. The placing of little or no value on cultural and traditional perspectives towards TB by most National TB Programmes (NTPs) has and will lead to poor understanding of local beliefs and perceptions towards TB which can result in more undetected cases due to delayed diagnosis [2, 9-11, 29] resulting in increasing TB incidence. There is limited data on the social aspects of TB as most studies have mostly focused on clinical and operational research [23]. Understanding community perceptions, beliefs and knowledge about

TB can therefore provide a pathway to understanding people's health seeking behaviours and factors affecting early diagnosis seeking.

1.2 Justification of the study

In Malawi, TB is one of the major public health issues with an estimated 29,000 to 30,000 cases and 8,000 deaths every year [30]. TB situation has been made worse by the co-infection of TB and HIV. Delay in diagnosis and case detection is an issue. To improve early diagnosis and case detection, we need to understand community perceptions of TB and the social issues that influence their perceptions and the related gender differences. This in turn may make us understand why people delay to seek treatment [7]. Individual health seeking behaviour is determined by a series of factors which include perceived severity, consequences and expectation towards TB and TB treatment [17]. Little is known of community perceptions of TB in rural Malawi. An understanding of these beliefs and perceptions can benefit planning and implementation of TB control programs to correct erroneous beliefs, attitudes and perceptions that can in turn improve early diagnosis seeking behaviours [1, 17]. This study will help inform the development of a health education model for the prevention of TB in a community in Ntcheu district in Malawi being implemented in a larger project.

1.3 Aim and objectives of the study

1.3.1 Main Aim

The main aim of this study was to qualitatively explore and compare knowledge beliefs and perceptions of adult men and women towards TB and people infected with TB in a rural community of Ntcheu district in Malawi in January 2012.

1.3.2 Specific objectives

The specific objectives of the study were:

- To explore knowledge, beliefs and perceptions of male and female adults and TB in a rural community in Ntcheu district during the period of the study.

- To explore perceptions of adult males and females towards people infected with TB in a rural community in Ntcheu district during the period of the study

- To explore beliefs, perceptions and experiences of adult males and females towards TB care seeking and treatment in a rural community in Ntcheu district during the period of the study.

- To compare knowledge, beliefs and perceptions towards TB between those who have ever had, and those who have never had TB, during the period of the study.

1.4 Literature Review

1.4.1 Global landscape of TB Incidence and Prevalence

Tuberculosis (TB) remains one of the major public health problems globally with an estimated 9.4 million incident cases in 2009 which is equivalent to 137 cases per 100,000 population [5]. The majority of these cases occurred in Asia (55%) and Africa (30%). The WHO report (2010) estimates that in 2009 there were 1.3 million deaths among HIV-negative cases of TB and 0.4 million deaths among incident TB cases that were HIV-positive resulting in a total of 1.7 million deaths. Southern Africa, home to 25% of the sub-Saharan African population accounts for 50% of the TB cases reported in sub-Saharan Africa and the number of cases continue to rise [31-32]. TB Cases in this region have been increasing by approximately 10% every year from 1990 [32]. This has been attributed to the human immunodeficiency virus (HIV) which increases the risk of reactivation of latent TB infection and is highly endemic in this region [4, 32-33]. HIV has been associated with an increase in the burden of TB especially in sub-Saharan Africa with an

estimated 70% of the people co-infected with TB and HIV living in this region [28, 34-36]. There have also been differences in gender perceptions towards TB as well as people diagnosed with TB. Recent studies have shown that women are less likely to be diagnosed with TB, yet women's social, economic and cultural status differ significantly with that of men making them suffer more consequences than men. Men have more exposure factors through their large numbers of social contacts which would increase transmission risk [7, 10, 37-38].

1.4.2 Tuberculosis Prevalence in Malawi

In Malawi, the actual prevalence of TB is not well known as no prevalence surveys have been conducted nor studies to understand factors contributing to low case detection [39-40]. Nyirenda (2006) further states that since 1985, TB cases have been on the increase with an increase of 45% of notified cases between 1994 and 2003. In 2009, case detection rate averaged 42% which is below the WHO target of 70%. It was still suspected that there were many unreported cases of TB with 72% of the cases being HIV positive as of 2007 [41].

1.4.3 Individual and social factors underlying TB

Some of the major factors leading to increased cases of TB are delay in diagnosis, case detection and treatment seeking [2-4]. These factors are influenced by the individual's perceptions of TB as incurable, associated with AIDS stigma and death, a dirty disease, and other social consequences of TB. These are further influenced by, for example, gender related factors which include women's inability to get married due to TB infection [10-11, 14, 29]. TB is influenced by multiple factors [29] which include socio-cultural and socio-economic factors. Together, these results in forms of thinking that correspond to the individual's immediate environment which in turn can influence an individual's motivation to seek health care at the onset of

symptoms suggestive of TB [7-8, 10, 12, 37]. In the Eastern Cape, South Africa 95% of people said they hid their TB status for fear of what others might say, while 63% delayed to go to the clinic for fear of being told they have HIV [4]. The findings indicate that people's perceptions of the consequences of TB influenced their intention to seek medical attention leading to delays in diagnosis and treatment. Such a situation provides a fertile ground for transmission of TB to other community members thereby exerting financial strain on the patient, their family and the health system [10].

While this is the case, current National TB Control Program (NTPs) objectives have focused on biomedical interventions such as treatment supported by DOTS with little attention given to the experiences of people living with TB in the communities [9, 14, 29]. Recent studies however have shown evidence of the effects of cultural beliefs, attitudes and perceptions towards TB. Lay perceptions may explain reasons why people delay in seeking treatment [4, 17]. Even though people's knowledge of TB may be high, their perceptions of stigma play a significant role in influencing health seeking [1-2, 29, 42]. For example, in Vietnam, negative views that people hold towards TB made people hide their symptoms and avoid seeking medical care earlier enough for fear of social isolation [3].

Chapter Two: Study design and Methodology

This chapter explains the methodology used in this study. It outlines the study design, study location and how data was collected. In addition it explains how data was managed and analyzed.

2.0 Study design

The study was a formative phenomenological study. Qualitative methods were used to explore and compare knowledge beliefs and perceptions of adult men and women towards TB and people infected with TB in a rural community of Ntcheu district in Malawi in January 2012. Phenomenological research focuses on identifying the essence of human experience about a phenomenon as described by participants and focuses on the lived experiences of the participants [43]. As such the study described as accurately as possible the community's experiences and perceptions of TB without using any preconceived framework [44]

2.1 Study setting

The study was conducted in the Traditional Authority (TA) of Makwangwala in the rural district of Ntcheu in Malawi. Ntcheu is located in the southern region of Malawi and has an approximate total area of 3,424 square kilometres and an approximate population of 474,464 [45]. Most of the community in Ntcheu is classified as rural and has a population of people aged 18 years and above of about 192,183 [45]. The district has nine TAs and the dominant tribe is Ngoni. It has two hospitals, 19 health centres and four dispensaries. TA Makwangwala is 681 square kilometres in size, has four group village headmen and 66 villages with a population of 48,388. It has six health centres. Ntcheu was selected because it is one of the districts with high TB prevalence rates, estimated at 57/100,000 [30].

2.2 Study Population

The study population comprised of adult males and females aged 18-49 years living in the villages that fall under TA Makwangwala in Ntcheu district. Participants were recruited among males and females aged 18–49 who had never been diagnosed with TB as well as adult male and female who had ever been diagnosed with TB. The age 18-49 were selected because TB is said to affect the most productive ages in poor countries like Malawi [46].

2.2 Sampling

Three villages in TA Makwangwala were selected based on feasibility including ease of transport and related costs. The villages were Kambuku, Majiri and Mwadzangati. Participants for the study were purposively selected for sex, age, and TB diagnosis to ensure the provision of substantial contributions and sufficiently rich data of their perceptions towards TB and people infected with TB. Study participants were distributed across the age groups to ensure maximum variation. Male and female participants were interviewed separately so that their participation is not affected by male domination but also to enable appropriate comparison of male and female views.

Table One below provides a breakdown of the number of focus groups and individual interviews that were conducted. A total of 16 IDIs were conducted. 12 IDIs were conducted among adult males (6) and females (6) who had never been diagnosed with TB. Four IDIs were conducted among adult males (2) and females (2) who had ever been diagnosed with TB. A total of 8 FGDs comprising 8–10 people each were conducted. Six FGDs were conducted among adult males (3) and females (3) who have never been diagnosed with TB while two were conducted among adult male (1) and female (1) participants who have ever been diagnosed with TB. Two FGDs, one for males and one for females were conducted in each of the three villages.

Table 1: Sampling breakdown: (8-10 participants per FGD)

Data gathering method	**Age category Never had TB**		**Age category Never had TB**		**Age category Never had TB**		**Diagnosed with TB**		**Total**
	18 – 24		**25 – 35**		**36 – 49**				
	Male	Female	Male	Female	Male	Female	Male	Female	
	Kambuku Village		Majiri Village		Mwadzaangati Village		Pooled from the 3 Villages		
IDIs	2	2	2	2	2	2	2	2	16
FGDS	1	1	1	1	1	1	1	1	8

2.3 Data Collection

Potential participants who had never had TB were recruited with the assistance of one of the chief's councillors or a person designated by the chief. For those that had ever been diagnosed with TB, hospital staff especially Health Surveillance Assistants (HSA) were consulted and helped to identify participants through their hospital records and ask them to be part of the study. The who had ever had TB approached to participate were a combination of people who were current TB patients on treatment and those who had had TB and were treated. HSAs sent word to participants who were on TB treatment and those that had been on TB treatment inviting them to come to the clinic and take part in the focus group discussion. HSAs are community health care workers who among other duties are also involved in following up on people diagnosed with TB to ensure treatment adherence. The HSAs approached these potential participants before any researcher engaged with them to get their consent to avoid breach of confidentiality. Information regarding the study was then provided again by the researcher and written consent was obtained.

IDIs were conducted at a place convenient to the participants and this was mostly at their houses. Four IDIs, two for male and two for females were conducted from each village among those that had never had TB while four (2 male and 2 female) were conducted from participants pooled from the three villages. FGDs were conducted at designated places and these were usually in a classroom with permission from relevant authorities or at a chief's court which was usually under a tree.

Participants who had ever had TB were asked to travel to the nearest health center for the FGD and transport refund was provided after the interview for those that travelled from far.

2.3.1 Data collection instruments

Four discussion guides were used. Two were for FGDs (never diagnosed and ever diagnosed with TB) while two were for IDIs. The discussion guides were based on the study objectives to ensure that data collected provided in-depth information as per the research question. The key areas for discussion included: what participants to the study knew about the disease and its causes and transmission, what their views were regarding TB and TB patients and why they held such views, what they thought about being diagnosed with TB, what the local names and signs and symptoms for TB were. For people previously diagnosed with TB, we also explored views about how they felt community, friends and family perceived and treated them. The discussion guides were translated into Chichewa by the Principle Investigator (PI) and were given to an independent person to edit to ensure consistency in the meaning of Chichewa words used.

Four Digital recorders were provided to the research assistants to record all discussions. Note books and pens were also provided for recording observations they made that could add value to the data. All interviews were conducted in the local language Chichewa. Interviews took a maximum of 60 minutes. Each team conducted one FGD per day (afternoon) and two IDS per

day. Respondents preferred to be interviewed during the afternoon because most people work in the gardens during morning hours . Research Assistants (RAs) were assigned interviews by sex so that males interviewed males while females interviewed females to ensure free flow of information that may be created due to the use of interviewers of the different sex.

2.4 Training of data collectors

Prior to data collection, RAs were trained for two days on the purpose of the study and the methods being used. The RAs were also taken through the data collection instruments to ensure that they had the same understanding of the discussion guides and any potential probes to use in the interviews. The training also involved use of the digital recorders and how to save data to avoid over writing and mis-recording. RAs were also trained in transcriptions and translations because they were assigned to transcribe and translate the data since they had prior experience in transcriptions and translation.

2.5 Pre-testing

Training was followed by pre-testing of the discussion guide. The purpose of pre-testing was to explore whether the questions were understandable to the participants. The pre-testing process also aimed at assessing the interviewing skills of the RAs. Participants for the pre-test were recruited from a rural community of Blantyre, a different from the study site. Blantyre is in the southern regional of Malawi and the selected participants were of the same age and sexes. One FGD for males and one for females and one IDI for male and female were conducted. The PI was also involved in data collection during the pre-testing. The findings from the pre-test informed the revision of the discussion guides to make it more understandable. Pre-test findings were presented to the research team and discussed to inform the actual data collection.

2.6 Data Management and Analysis

Audio recorded data was transferred into a computer and saved as audio data as back up immediately after an interview. Each interview was identified by an audio recorded voice indicating the type of interview, age range, sex and whether it were for those that had ever had or those that had never had TB. Audio recorded data were transcribed and translated verbatim in Chichewa by the RAs immediately after the interviews. Translation and typing into English was done immediately after all interviews were transcribed. Typed English transcripts were saved in word format. The process of transcription and translation took approximately 14 days.

MAXQDA software for qualitative data analysis was used. Prior to importing data into the software, data was read specifically to check for spelling mistakes and grammatical errors that could have been done during transcription and translation. Where necessary, the PI had to go back to the recorded data to verify that any corrections made would not change the meaning as per the raw data.

Data was read and re-read and text segments were coded. Data was analyzed by predominantly using inductive codes. This involved breaking the data into text segments and then assigning codes to identify recurring patterns and themes relating to people's experiences with TB and TB patients. Once all the interviews had been coded, themes were identified. The identified themes were used to develop a model that explains perceptions and beliefs that adult males and females held in the community and how these may affect care seeking and treatment adherence behaviours. Themes emerging from interviews and focus groups were compared and contrasted among men and women participants who had never had and those who had ever had TB.

2.7 Ethical Consideration

The protocol was approved by the Wits Ethics committee under approval number M110956. This study was part of a larger study taking place in Ntcheu district investigating effectiveness of a heath education and awareness model on early diagnosis and treatment which was also approved by the Health Sciences Research Committee in Malawi. Participation in the study was voluntary. Written consent was obtained from participants prior to data collection and they were informed that interviews would be kept confidential and only the research team would have access to the data. For those that had ever had TB, HSAs approached the patients before RAs met them for interviews. Focus group participants were informed that confidentiality could not be guaranteed as other participants could have share information from the group. All interviews were de-identified after transcriptions. Consent for audio recording was also obtained.

CHAPTER THREE: Findings

This chapter provides a description of findings of the study.

3.0 Findings

Participants to the study expressed different views regarding TB. The depth of knowledge about TB varied between those that had ever had and those that have never had TB. For example, some TB symptoms were known by most participants while some were mostly known among people who had ever had TB. Perceptions of TB also varied between those that had ever had and those that had never had TB.

3.1 Knowledge about TB

Knowledge about TB was relatively high among most study participants. Some knowledge about TB symptoms were prominent across all the groups while some were only prominent among participants who had ever had TB.

3.1.1 Symptoms of TB

Respondents were asked how they know if a person could have TB before being diagnosed. The aim was to find out their knowledge about TB symptoms. Findings show that participants' knowledge about TB was high but there were some variations noted among respondents who had ever had and those who had never had TB. For example, respondents who had ever had TB reported on symptoms that they had experienced while those that had never had TB reported on what they saw from their relatives of friends who had ever had TB or what they had heard about TB symptoms from different sources.

Coughing was the commonest sign mentioned by most respondents and among respondents who had never had TB. Referred to as, "The Big Cough" (Chifuwa chachikulu) in the local language, participants across all groups expressed that people with TB coughs continuously for weeks or months. Related to this was **difficulty in breathing.** Participants across all groups expressed that people with TB experience difficulties when breathing.

> *I was coughing but I was not producing sputum and after I coughed up to 3 weeks I went to Ntcheu where I was diagnosed with shortage of blood in my body* ***Male FGD EHTB***

> *Others coughs a lot, others it comes through the bones but it is difficult to discover it unless the patient is coughing, when someone is coughing for several weeks.* ***Female FGD NHTB (18-24)***

While respondents who had ever had TB also mentioned coughing and difficulty in breathing, they mentioned **night sweats** and **production of sputum** as some of the symptoms of TB which was not mentioned by respondents who had never had TB.

> *I was producing more sweat at night and I was failing to sleep using one side for a long time.* ***Male IDI EHTB***

> *I was coughing but I was not producing sputum and after I coughed up to 3 weeks I went to Ntcheu where I was diagnosed with shortage of blood in my body* ***Male FGD EHTB***

3.1.2 TB is curable

Respondents across all groups spontaneously expressed the view that TB is curable. Respondents, especially those that had ever had TB, believed that if someone went to the hospital for early diagnosis and treatment they would get cured. They also consistently said that TB is curable if a person follows the doctor's advice.

If one follows the doctor's advice it is easy to get cured from TB. It is a good drug, one just have to choose time to take the drugs every day. You can choose to drink it in the evening or morning or even afternoon. You don't have to take the drugs any where you go. ***Male FGD EHTB***

3.1.3 Drugs are available

Availability of TB drugs was another theme that most participants mentioned consistently throughout the interviews. While respondents expressed the knowledge and belief that TB is curable, curability of TB was reported based on their belief and knowledge that TB drugs were available and that if a person is diagnosed with TB, he or she would be provided with the drugs at the hospital. Respondents described the drugs as "strong" and that if a person who has TB takes them according to the doctor's advice, they can be healed. They, especially females consistently mentioned the need to go for TB diagnosis mostly if you have a persistent cough that last for over three weeks. Some respondents who had ever had TB testified that they experienced significant improvements in their health soon after they started TB treatment as compared to the time they were just manifesting the symptoms of TB and before onset of treatment.

When you see that you have a continuous cough, you have to go to the hospital and give out sputum for TB screening, and when you have been found with TB, you can start taking the drugs and you will be healed. ***Female IDI NHTB (18-24)***

…but when I started taking the drugs, I have seen great improvements because am now eating just as I used to , I failed to cook but now I can cook, I used to fail picking tins but now am able to, and I believe the TB drugs are very strong and have cured me ***Female FGD EHTB***

3.1.4 How TB is spread

Study findings show that across all groups, respondents expressed high knowledge regarding how TB is spread. While views on the spread of TB varied, there was a noticeable inability to distinguish risk factors and causes of TB. Respondents mentioned breathing contaminated air, smoking, sex and alcohol as some of the ways in which TB is spread.

3.1.4.1 Through air

Most respondents both males and females and those who had and those who had never had TB reported that TB is transmitted through the air. Respondents explained that one can get TB by sleeping in the same room with a person who is infected with TB. They explained that an infected person releases the germs in the air and that one can get infected by breathing that air.

> *It gets spread through the air. When a person who has TB coughs, TB germs are released in the air and anyone who breaths that air get the disease. The only difference is that people start to get sick at different times.* ***Male FGD NHTB 25-35***

> *But others can get it by sleeping together with infected people especially when they have not started taking drugs, sleeping in one house with infected people, but also caring for a TB patient one can get it.* ***Female FGD NHTB***

3.1.5 Misperceptions of how TB is transmitted

While respondents demonstrated knowledge about how TB is spread using the germ theory that explains the transmission of TB bacterium through air, there were misconceptions about how TB is spread which consequently emanated from respondents' lack of knowledge regarding causes of TB and risk factors.

3.1.5.1 Smoking

Some respondents mentioned smoking as one of the ways in which TB is spread. They explained that when one is smoking, the smoke damages the lungs leading to TB. Related to smoking was alcohol. Some respondents said that both smoking and alcohols causes TB because they damage the lungs. Alcohol was also mentioned by some respondents as a cause for TB.

> *Smoking. When the person is smoking, the smoke damages his lungs and once the lungs are damaged he develops TB.* ***Male FGD NHTB 25-35***

> *It's because of smoking and when one smokes a lot, he/she coughs a lot and that causes TB* ***Male IDI NHTB 18-24***

3.1.5.2 Sexual intercourse

Both male and female respondents who had never had TB mentioned sexual intercourse as another way in which TB is spread. The expression of sex as a means of spreading TB was related to types of TB in which some participants mentioned that there is a type of TB which is spread through sex and is associated with HIV and the normal TB which one gets through breathing contaminated air. This finding relates to respondents association of TB to HIV which may emanate from their knowledge that HIV is transmitted through unprotected sexual intercourse as a result they link TB to HIV. The expressions that TB came along time ago but that now it can also be transmitted through promiscuity as well as then natural way shows how respondents associated TB to HIV.

> *TB came long time ago but now it comes in different ways, one can get TB through promiscuity (CHIWEREWERE) and through the natural way (YACHILENGEDWE).*
> ***Female FGD NHTB 18-24***

There are few people who contract TB through the natural way but through sex they are a lot of people who contract the disease, so when one has TB through sex, then automatically he must know that he has two kind of diseases that is TB and HIV ***Female FGD***

3.1.6 Types of TB

Respondents were asked the types of TB that they know. Respondents especially those who had ever had TB were able to distinguish between pulmonary TB from other types such as Orthopaedic TB, which in literal terms they called "*TB of the bones".* Some mentioned the different types of TB because they had suffered from *TB of the bones* while some knew it through their interaction with relatives or friends who had the disease and medical personel during the diagnosis process. *TB of the bones* was reported to be more dangerous than Pulmonary TB because it did not manifest the same symptoms. According to the findings, some participants who had ever had "*TB of the bones"* reported that it is not easy to diagnose and that patients are put on trial and error tests and sometimes doctors prescribe TB medicines on suspicion that the person could have TB. All through this time, the patient undergoes a lot of suffering due to the symptoms.

.....more especially the TB which attacks the bones, it takes more than 3 times to discover the disease being x-rayed, by the time they discover the disease, it is at its on advanced stage. ***Male IDI EHTB***

For example there was a boy in this village who had TB that affects the bones but he did not know that what he was suffering from was TB of the bones, he went to Bilila health centre but they did not discover the disease up to Ntcheu District Hospital but they did

not discover the disease as well then he went to Queen Elizabeth Central Hospital for x-rays for so many times but they too did not discover the disease then the doctor said that he was suspecting that the boy was suffering from TB of the bones and they put him on TB drugs and eventually he was well again and as I am talking to you now the boy is ok, so I think there are different types of TB, one is not difficult to find and the other one is difficult to discover it. ***Female FGD NHTB (18-24)***

Participants who had never had TB did not regularly mention different types of TB and tended to describe symptoms such as coughing which is typical of pulmonary TB.

3.2 Perceptions of TB

Study findings show that respondents held varying perceptions towards TB. Respondents across all groups perceived TB as being a dangerous disease while some associated TB with HIV. Findings also show that perception of risk was relatively high across all groups as respondents expressed that anyone can contract TB because of the way in which it is spread.

3.2.1 TB is Dangerous

Across all groups, a prominent theme was that most people in these communities look at TB as a dangerous disease while recognizing that it could infect anyone. TB was described to be dangerous because of a number of reasons which included the severity of the disease in terms of the pain they undergo due to the manifested signs and the difficulties they go through during the diagnosis process. The diagnosis process was reported that it takes long because sometimes the hospital takes time to diagnosis the TB and meanwhile the person continue suffering because they are not put on treatment. Some respondents mentioned that TB is dangerous more especially if they delay to diagnose it.

3.2.2 Severity of TB

Both respondents who had never had and those who had ever had TB described it as being a dangerous disease because of the suffering a person goes through prior to being diagnosed with the disease. Respondents reported the various ordeals that people undergo before being diagnosed which included problems with breathing, uncontrollable coughing, difficult to sleep and inability to work. Inability to work or be functional was mentioned in most of the groups and this may be because most people in the area are subsistence farmers and realise that once they have TB, they will not be able for farm and feed their families.

TB is a very dangerous disease, and a person who is suffering from TB cannot work properly and he/she have difficulties when breathing Female ***FGD NHTB (36-49)***

What I have heard is that TB is a very difficult disease and one cough uncontrollably. Male ***FGD NHTB (36-49)***

People who had ever had TB reported based on the experience they had with symptoms and how severe these were. They also reported how dangerous TB was before being diagnosed in terms of transmitting it to other people as well as the effects of late diagnosis.

> *TB is a dangerous disease more especially when one is not yet diagnosed with the disease but he/she is only showing signs and symptoms of the disease.* ***Male IDI EHTB***
>
> *This disease becomes very dangerous "if a person has delayed in taking its treatment or if you have started taking its treatment while it has reached at an advanced stage".* ***Male IDI EHTB***

Both male and female respondents acknowledged that TB patients experience a lot of physical pain. Coughing in particular was identified as a source of pain. This assertion was also shared by

people who have ever had TB. Both males and females explained that they suffered a lot prior to being diagnosed with TB because of the symptoms that they had, as well as the process it took for them to be diagnosed and be put on treatment.

> *E-e-eh; the person also feels pain in side of the libs more especially when breathing and sleeping aside. Male FGD 25-34*

> *..... and a person who is suffering from TB cannot work properly and he/she have difficulties when breathing.* ***Female FGD NHTB***

3.2.2.1 TB makes you weak

TB was perceived to be servere because of the body wekeness it cause to someone who has the disease. When respondents described people with TB, they stated that the person looks thin, pale, weak and others described that their bodies do not look healthy which is similar to how some people with AIDS look. Some respondents said that TB patients look like they have AIDS because they become weak and pale. Some respondents mostly those who had never had TB used metaphorical language to describe some of the signs for TB. For example some respondents said that people with TB looked thin and pale while some referred to them as looking like AIDS patients or people who had cholera. The links that participants made between TB and other diseases could contribute to stigma.

> *When one is suffering from TB, he / she looks like someone who has AIDS. The body becomes pale, the person is not flexible enough, his body is not flexible as well, he / she doesn't have strength, because the body is weak and the person is not happy.* ***Female IDI NHTB 35 – 49***

Laughs … The body looks like he/ she is suffering from cholera, like he is dehydrated (It fades) ***Female IDI NHTB (18-24)***

3.2.2.2 Inability to work

Most respondents especially female respondents expressed that TB is severe in the context of believing that TB may affect their ability to work effectively again. Most women in the rural Malawian society like elsewhere in Africa are involved in subsistence farming and in most cases they do most of the household chores as well as making sure that the home has food. This feeling could have been expressed bearing in mind the consequences of being incapacitated and what would happen in terms of managing the home. Some males who had ever had TB also expressed the same fear as one of them said for him to eat, he must work and yet when one has TB he or she is not supposed to do hard work.

….Because the person will never work properly again. The body becomes weak. ***Female FGD NHTB****.*

TB is a very dangerous disease, and a person who is suffering from TB cannot work properly and he/she have difficulties when breathing. ***Female FGD NHTB (36-49)***

3.2.2.3 TB affects sexual lives

Most men who had ever had TB expressed fear about an interruption to their sexual lives. They expressed concern regarding the medical advice they received which indicated that they should not have sex for up to six months when they start treatment and not to have sex regularly thereafter until they finish treatment. Some men described how some women (wives/spouses) reacted when a man is diagnosed with TB. Some said that their wives deserted them for fear of being infected with TB and only returned upon hearing that they were cured.

*The problem was that, women do not want to have sex with her husband for fear of being transmitted with the disease. After seeing that the drugs are working it's when they will be back again, otherwise other women run away because of fear of being infected with the disease. (**Male FGD EHTB).***

3.2.3 They think it is HIV

Many of the participants, especially women who had ever had TB, held the view that if a person is diagnosed with TB, they are automatically thought to be HIV positive. This view was reinforced by respondents who had never had TB. Most respondents reported that they look at TB as being closely related to HIV, and that nowadays it is rare to find someone with TB without having AIDS. The association of TB to HIV relates to respondents' knowledge about the spread of TB where promiscuity was mentioned as one of the ways in which TB is spread. This was expressed in the context that TB came a long time ago and that then it was spread in the natural way (through air) but that now it is spread through sexual intercourse the primary transmission mode for HIV. Further, the similarity in the physical signs of HIV and TB could also have made respondents associate TB to HIV.

*TB came long time ago before HIV so nowadays it is very rare to be found with TB only as a result when one is suffering from TB automatically he has HIV. **Female FGD NHTB 18-24***

*They spoke negatively about us. Most of them were saying we have AIDS and especially because we became thin and weak they took that for AIDS. **Female FGD EHTB***

3.3 Delays associated with TB diagnosis

The process it takes to diagnose TB was expressed to be lengthy leaving the person in pain due to the signs as well as the travelling to and from the hospital. Findings show that while people had TB symptoms, the hospitals took a long time to diagnose the disease. This made them to travel to and from the hospital several times while being referred to different hospitals. In an isolated case of delayed diagnosis, one respondent explained the time and trouble it took for him to be diagnosed with TB after visiting a rural clinic and later referred to Ntcheu district hospital and subsequently the referral Central Hospital in the major city of Blantyre. The respondent was referred to several hospitals without being diagnosed with TB. He first visited his rural clinic where they did not trace the TB. He later went to the district hospital where they did not diagnose him with TB too. During this time, he was undergoing pain due to the undiagnosed TB.

> *I suffered a lot, I went to different hospitals like Bilila Health Centre and then I was told to go to Ntcheu District Hospital for further screening, I was feeling back pains, pain in the joints, sweating a lot during the night, fever the whole body, those were the signs but when I went to Ntcheu District Hospital I was only given the tablets instead of X-ray because that was what I was told at Bilila Health Centre.* ***Male IDI EHTB***

Having not being diagnosed with TB, he was prescribed drugs to take while being observed on in case his condition would improve after that treatment. After five days, his health did not improve and he went back for an X-ray but they did not diagnose him with TB. All the while, he said he was in pain and he asked the doctors what the next step would be. He was answered that there was nothing they could do except from prescribing him medicine to reduce the pain he was undergoing. He had to buy the medicine on his own.

So I asked the doctors what next and they told me that there was nothing they could do except to prescribe me with the medicine to reduce the pain which I was feeling that time and I was told to buy the medicine at Chirani Pharmancy. ***Male IDI EHTB***

As the pain persisted and he remained undiagnosed, with the help of his parents, he went to one of the referral hospitals in the major city of Blantyre. Once there, he had five X-rays and TB was not diagnosed. He was later tested for HIV but was found to be negative and the doctors decided to put him on TB treatment and observe him for 21 days to see if there would be any improvement. According to the respondent a few days after the treatment his condition improved and the doctors recommended that he finished the TB treatment. At the time of the interview, the respondent was still on treatment and was looking healthy but in his account of his experiences, he looked really ill prior to being put on TB medication.

Women who had ever had TB also described experiences of delays in the process of health service providers trying to diagnose TB which delayed the initiation of treatment. Women who shared these experiences also described pain and stress of managing the symptoms of TB. These views were shared by most of the respondents who have ever had TB.

"….. I am talking from experience because I was strongly troubled by this disease. I was admitted three times while being given several drips, bottles for sputum and until the third time when I was taken for x-raying then they found it. I stayed there but was heavily affected by the TB. I was so weak because I could not eat as each time I ate I was vomiting. I was frequently found with fever and had no piece but when I started taking the drugs, I have seen great improvements because am now eating just as I used to , I failed to cook but now I can cook, I used to fail picking tins but now am able to, and I believe the TB drugs are very strong and have cured me". ***Female FGD EHTB***

Worth noting is the finding that a type of TB referred to as '*TB of the bones'* was frequently mentioned as the one which was difficult to diagnose. Where participants reported to have suffered from *TB of the bones,* they said that diagnosis for this type of TB was difficult because it did not manifest some of the common signs such as persistent coughing. Some of the symptoms they experienced included general body weakness and pain in the joints which was not the case with pulmonary TB. A similar situation was reported by one female participant about a boy who had *TB of the bones* and how difficult it was to diagnose it.

> *For example there was a boy in this village who had TB that affects the bones (TB of the bones) but he did not know that what he was suffering from was TB of the bones, he went to Bilila health centre but they did not discover the disease up to Ntcheu District Hospital but they did not discover the disease as well then he went to Queen Elizabeth Central Hospital for x-rays for so many times but they too did not discover the disease then the doctor said that he was suspecting that the boy was suffering from TB of the bones and they put him on TB drugs and eventually he was well again and as I am talking to you now the boy is ok, so I think there are different types of TB, one is not difficult to find and the other one is difficult to discover it.* ***Female FGD NHTB (18-24)***

3.4 TB Risk perception

Respondents were asked who they thought was at risk of contracting TB. Most respondents expressed the view that everyone is at risk of contracting TB. This belief was reported in the context of TB being an airborne disease meaning that everyone can be infected with the disease if and when they are breathing air that could have been contaminated by someone who has TB.

Respondents mentioned that staying in close proximity with infected people exposes them to infection because they will be breathing contaminated air. There was no mention regarding risk factors such as smoking, HIV that can facilitate the onset of TB infection.

> *Because it transmits through the air, so we all breathe the air, so it is likely to get it if you are staying close to the person suffering from TB.* ***Female FGD 18-24***
>
> *In my view, I cannot say that there is specific group of people which is entitled to suffer from TB. Every person can suffer from this disease because it gets spread through the air.* ***Male IDI EHTB***

3.5 Views on being diagnosed with TB

Respondents were asked to express their views regarding how they would feel and react if they were diagnosed with TB and what they think about people who have been diagnosed with TB in order to establish their perceptions of being infected with TB. Respondents had a variety of responses. Some respondents said that they would not be worried about it. These views came from both males and females and across all age groups that were interviewed.

3.5.1 TB is treatable

Respondents said they would not be worried because TB is treatable. Most respondents said that TB is just like any other disease and that anyone can be infected by TB, it would be beneficial for them to know that they have TB so that they can be treated and healed.

> *"I cannot be worried because treatment or rather drugs for TB is always there and if taken according to doctor's advice one is able to get cured.* ***Male FGD NHTB (35-49)***

This view was strongly supported by respondents who had ever had TB, some of whom were still on treatment at the time of the study. Respondents who had ever had TB reported that TB is curable and they based this on their experiences. Most of them reported that they had been very sick prior to being diagnosed and put on treatment. Soon after they were put on treatment, their health improved and most of them acknowledged that they are now better and some are even able to function normally and have been certified as completely cured from TB by the doctors.

> *"….but when I started taking the drugs, I saw great improvements because am now eating just as I used to , I was failing to cook now I can cook, I used to fail picking tins but now am able to, and I believe the TB drugs are very strong and have cured me."* ***Female FGD EHTB***

3.5.2 Early diagnosis is important

Respondents explained that early diagnosis as well as following doctor's advice makes it easier for a person to be healed. Both male and female respondents who had ever had TB reported that they had TB but got cured after they received treatment. Respondents who had finished treatment reported that they were able to work again and that their lives returned to normal. Respondents who were still on treatment reported improvement of their health some days after they had started treatment and also that they returned to normal duties to fend for their families.

> *But when I started getting drugs, I noticed great change even my children could not believe because everybody thought I would die at the hospital. I always thank my friends for giving me money and supporting my daughter during my illness. Am now fully cured and am able to cultivate and find food for my children which I could not do in the past three years I have been down* ***Female FGD EDTB***

3.5.3 Cannot be disappointed

Some male and female respondents reported that they cannot be disappointed after being diagnosed with TB but would be happy and proceed to seek medical help to get treated. They said they would accept it because the disease is already in their body and that all they need is to follow the doctor's advice. Respondents consistently mentioned treatment availability and adherence to doctor's advice as critical if they were to be diagnosed with TB.

> *I cannot be disappointed because the disease is already in my body but rather I will just accept it and follow the doctor's advice and instructions.* ***Female FGD NHTB (25 – 34)***
>
> *My first reaction will be to get the treatment so that I may live again. I can be very happy to be told that I have the disease because I will receive the treatment.* ***Male IDI NHTB (36-49***

3.6 Apprehension

While some respondents said that they would not be worried if diagnosed with TB, some expressed feelings of apprehension and various reasons were given for these feelings. Most respondents said that they would be worried because of **what their friends would say** upon knowing that they have been diagnosed with TB such as being labelled as having HIV. Some said they would be worried because of **the severity of the disease, especially some of the symptoms such as persistent coughing, inability to work as well as the fear that they spouse may ran away from them. S**ome respondents said they feared they would die while some said they would be worried because **they will think it is AIDS**.

It is Aids, because it comes exactly like the way TB is, one can start coughing and be thinking that it is TB but he/she only end up being diagnosed with Aids. ***Male FGD NHTB (36-49)***

Because you will know that the body will become weak and you will not have strength as it used to be before and even when you are eating you will thinking about the same things and thinking on how the disease will end. ***Female FGD NHTB (25-34)***

3.7 Views about people infected with TB

Participants expressed mixed feelings about people infected with TB. On the one hand, there were feelings of sympathy and on the other hand people with TB were viewed as vessels of disease that threaten the community. Some respondents expressed the feeling that such people needed support and encourage to seek medical help.

3.7.1 They feel sorry for them

Most respondents especially females reported that they felt sorry for a person who has been diagnosed with TB. This view was expressed in the context of believing that someone who has TB automatically has AIDS, and that he or she will not look healthy and will not be able to work properly and that such a person requires help from anybody and must seek medical attention.

I feel sorry for that person because when one is suffering from TB, he/she doesn't look healthy, he/she is not flexible enough to work and what that person needs is help from everybody. So you can help him/her by taking the person to go to the hospital. ***Male IDI NHTB 36-49***

Some respondents, both male and female who had never had TB reported that they feel sorry about people who have been diagnosed with TB because they perceive TB as ***a disease one would not want to suffer from*****, *a difficult disease*** and that it is not good for one's health. These

feelings may have emanated from the perceptions people had about TB which is associated with HIV as well as the severe consequences suffered by people diagnosed with TB.

I just feel sorry for them because it's the type of disease that one can never wish to have. ***Male NHTB 18-24***

It is a dangerous disease and a difficult one for that matter and when we hear that one of us in this community has been found with the disease we feel sorry for him/her. ***Female FGD NHTB***

3.7.2 Support to seek medical help

There was a general spirit of providing support to those affected. The view of both women and men was that people with symptoms of TB must be encouraged to go to the hospital because that is the only place where they could get help. One male respondent reported that such persons must seek medical help quickly because if they don't, they would continue spreading the disease.

If one is having a continuous cough he or she is supposed to rush to the hospital to get the treatment and to go for TB screening because if you don't go to the hospital you will be spreading the disease, and if not careful, it will produce some bumbles inside one's body. ***Male FGD NHTB 36-49***

3.8 Discrimination against people who have TB

Findings from this study show that discrimination was experienced by those who have ever had TB. Supporting this finding, community members who had never experienced TB expressed views that are stigmatizing and could result in discrimination. While this was the case, women expressed more supportive views than men.

3.8.1 Discriminatory views among community who have never had TB

Most discriminatory views were expressed in the context of fear of being infected by people diagnosed with TB such as labelling them as *"wa TB" (a TB person) or " don't eat with the.,"* for fear that he can infect you. People with TB were viewed as containers of disease that threatens those who breathe the same air, as a result some people expressed that they must be avoided. Findings show that more men than women expressed these discriminatory views while some women expressed supportive and non-discriminatory views towards people diagnosed with TB.

> *They are stigmatized. People who have TB are discriminated against, the reason is to avoid getting the disease from them, they think they will get the disease when they are close to them.* ***Male FGD NHTB (25 – 34)***

> *We stay away from them because of how they breathe. We are told that the disease can be transmitted to another person so we are afraid of getting the disease from them.* ***Male IDI (18-24***

Views from women were also passionate about the potential harm of discriminating against a person diagnosed with TB. Most women suggested that avoiding people who have TB and not sharing meals and food with them can affect the healing process of the patient.

> *We must not discriminate them. We must not feel like she / he is going to transmit the disease to us, sometimes they are given the food separately for fear of being transmitted with the disease which is not a good thing to do.* ***Female FGD NHTB (35-49)***

If you discriminate the TB patient, the patient feels bad inside him and sometimes he may die because of that treatment. The B.P is raised through that treatment. ***Female FGD NHTB (35-49)***

3.8.2 Experiences of Discrimination: Ever Had TB

Both male and female respondents who had ever had TB reported that they were discriminated against. They understood that people without TB feared that they would be infected by them. Respondents explained the various forms of discrimination that they had experienced. Some said they were isolated and given a separate room to sleep in, while some said they were given separate utensils to use. As one respondent explained that the time he had TB was the most painful time because he experienced the worst form of discrimination in his life.

I took TB treatment for six months starting from October 2010 to March 2011 but "it was my sour time in the history of my life because I saw different kinds of Stigma and Discrimination". ***Male IDI EHTB***

Views from this respondent shows that he suffered discrimination from both relatives and friends. He also explained the ordeal of social isolation, of being given separate utensils and plates to use, a separate room to sleep in, as well as his personal observation that most people were not happy with him.

"E-e-eh my brother it was a painful time just imagine I was stopped eating together with my relatives and friends from the same plate, I was also using my own plates and cup which were not used by anyone in the family and even sleeping in one room with them was prohibited". Many people were not happy with me at all and they stopped chatting with me. ***Male IDI EHTB***

I knew that they were thinking that if they eat, sleep in one room and chat with me they will contact the disease. ***Male IDI EHTB***

Some respondents who had ever had TB expressed different views over how relatives and friends reacted to their TB status. Findings show that discriminatory practices were more pronounced from friends than relatives. Some relatives were also supportive. In a particular case, a woman narrated that her husband's relatives encouraged him to leave the woman because they suspected she had AIDS. She was taken care of by her relatives until she got cured. Seeing that she is fine, the husband apologized and now they have twins.

For some of us we had no problem from the relatives but other people. For example in my case my husband relatives were saying I had AIDS and encouraged my marriage to end. I was with my relatives at the hospital and now am ok and my husband has apologized and we are back as marriage. He has been with me but he has never had any signs of TB and we are happy as a family. ***Female FGD EHTB***

3.9 Supportive role of women

Findings show that gender roles influenced the reactions and responses of women and men. Women played a care giving role to their husbands while men did not speak about caring for their wives. Some men, while acknowledging the support they got from relatives, singled out their wives as being the people who took care of them from when they were very sick to when they got healed. Much as women got support from friends and relatives, they reported that female relatives are the ones who offered support, for example, granddaughter.

I was taken care of by my wife, there are times when people discriminate someone who has TB but my wife was able to wash the bottles which I was using, she was able to escort

me to the toilet because I was failing to walk I was weak, even my relatives were there for me, I was not discriminated. ***Male FGD EHTB***

Like for me when I fell sick my granddaughter looked well after me until I got all the medication. My relatives and friends supported me and nobody discriminated against me. We were sleeping in one house. ***F FGD EHTB***

Females expressed more supportive views than males. More female respondents than males who had never had TB reported that people who have TB must not be discriminated against. They said they must be treated as human beings and that it was not their fault to be infected with TB. They also expressed the need to provide **emotional support** to people with TB by showing love to them and encouraging them to take their drugs.

We must not discriminate them rather we should or must take care of them and take them as our fellow human beings. ***Female IDI NHTB (18-24)***

When someone is sick, he / she sees everything. He must worry about his sickness but not the way we are treating them, we must show some love and take care of them, for him / her to feel good. ***Female IDI NHTB (35-49)***

Another form of support that women expressed was **material support**. They expressed that TB patients must be supported by providing or encouraging them to eat food. They made this assertion because they said some people with TB do not have appetite as such they need to be encouraged to it. There was also an emotional attachment to it because they also said a person with TB cannot manage to prepare food on their own.

There are others who do not have appetite to eat but the best way is to encourage them to eat so that the drugs should work properly in their body. ***Female FGD NHTB (18-24)***

3.10 Why people delay going for diagnosis

Respondents mentioned lack of knowledge of TB symptoms, fear of restrictions and being diagnosed HIV-positive as some of the reasons why people delay to go for diagnosis. Respondents also mentioned that cost of transport to the hospital and use of traditional healers makes people delay to go for early diagnosis.

3.10.1 Lack of knowledge about TB symptoms

Some males who had ever had TB and females who had never had TB perceived that **lack of knowledge** about TB symptoms was one of the reasons why people do not go for early diagnosis. This is interesting in the context of the findings of this study where it was evident that community knowledge of the symptoms of TB are pretty well-developed.

The other reason why people don't go for TB screening is that they don't know the signs and symptoms of TB. Had it been that they have the knowledge of TB or there is a campaign for TB, they would have gone for TB screening. ***Male FGD EHTB***

They don't have the knowledge of the disease, they just hear it from their friends and then become afraid of the syringes, injections and some people doesn't like pills. ***Female FGD NHTB (25-34)***

3.10.2 Fear of being found with HIV

Some respondents, both males and females who had ever had TB mentioned that people delay to go for diagnosis for fear of being found with HIV. Study findings show that some respondents held the belief that when one had TB, he or she automatically had HIV. This finding links to the

respondents' perception where TB is associated with HIV. Since HIV is highly stigmatised, the association of it to any disease may also lead to similar fears.

> *Others it's because of fear of being found with AIDS or the virus that causes AIDS. They think that if they go for TB screening then automatically they will be found with the virus* ***Male FGD, EHTB***
>
> *What I heard from people is that, they are afraid to go for TB screening because they say that or think that if one is found with TB then automatically he /she has the virus that causes AIDS.* ***Male FGD EHTB***

3.10.3 Fear of restrictions

Respondents who had ever had TB reported that when one is diagnosed with TB, he is told to change some behaviour such as refraining from alcoholic drinks, smoking as well as reduction in the frequency of sexual intercourse. Respondents expressed that because of such restrictions, people are afraid of going for diagnosis for fear of being diagnosed with TB which will result in them being told to stop some of these behaviours.

> *There are a lot of reasons why people don't go to the hospital for treatment. There are other people who heard that when one is on TB treatment he/she is not supposed to do this and that so they don't want to be told to stop some of the things which to them make them happy. They are shy to face the doctors and be told to stop some of the things which they do and they know that they cannot stop doing them even if they are told to stop by the doctors.* ***Male IDI EHTB***

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> *I was told not to drink alcohol, not to smoke, not to have sex with my wife up to 6 months (up to the end of the treatment)* ***Male FGD EHTB***

3.10.4 Lack of transport

The cost of travelling to and from the hospital was expressed as a factor leading to delayed diagnosis by some respondents. They reported that lack of transport due to frequent visits to the hospital made them unable to go for treatment because they feared that they would waste time travelling to and from the hospital instead of working. This may have been expressed in the context of situations where some patients reported having been sent to and from a hospital then referred to different hospital before being diagnosed with TB.

> *Others they think that they will be busy going to and from the hospital for TB treatment instead of being at home working.* ***Male IDI NHTB (25-34)***

Some respondents, who had ever had TB and on treatment reported **a general lack of money** for transport which makes them unable to travel to the hospital to collect the drugs. This assertion shows that lack of transport money which may be due to poverty not only affects people's ability to go for early diagnosis, it may also affect adherence to treatment.

An example is myself, I was supposed to go today but I don't have transport money to go to the hospital to take the drugs, you can check on my papers I have them with me. I was diagnosed on 20th November. I was given the drugs for TB for two months and after screening for TB, it was found out that the TB was gone. The other paper is with the volunteer you can check, I don't hide them. ***Male FGD EHTB***

3.10.5 Use of traditional healers

Use of traditional healers was another reason mentioned as to why people delay in getting diagnosis. Respondents expressed different reasons why some people got to traditional healers. Some mentioned the belief in religious teaching that prohibits use of modern medication, the

belief that they have been bewitched and lack of knowledge of what they are suffering from. While respondents said this, some respondents, both male and female were quick to mention that it is only at the hospital where one can be diagnosed and get cured of TB. None of the respondents who 'ever had TB' mentioned going to a traditional healer for treatment.

> *….some people who rush to the traditional doctors to seek medicine for TB thinking that someone has bewitched them instead of going to the hospital for treatment.* ***Female IDI, NHTB 25-35***
>
> *Of course some they do access from Traditional healers but three quarters they access TB services from the Hospitals.* ***Male IDI NHB 36-49***

CHAPTER FOUR: DISCUSSION

This chapter presents a discussion of the findings and what the study findings mean for TB control.

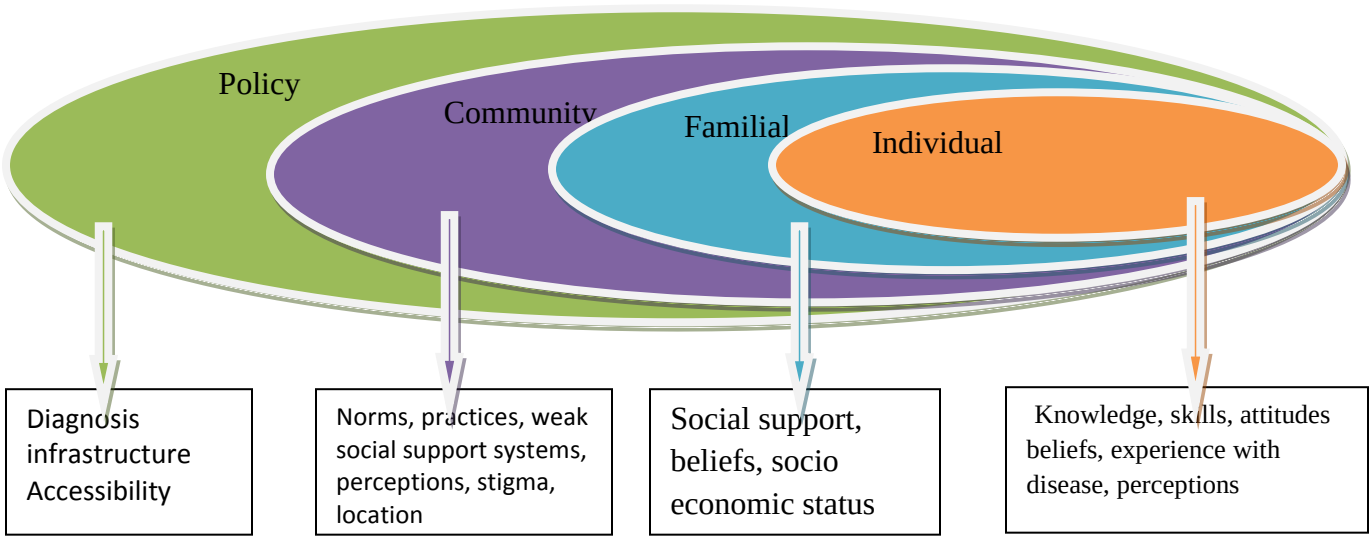
4.0 Overview

This study has provided insights into community members' and people infected with TB's perceptions of TB and how this affects health seeking behaviours, which has implications for the early diagnosis of TB. The study highlighted that knowledge and perceptions differed among those participants who had been diagnosed and treated for TB and the other community participants who had not been diagnosed with TB. The experiences of participants who had been diagnosed with TB highlight some of the health systems issues that impact on the diagnosis and treatment of TB. In particular, participants shared narratives of misdiagnosis which resulted in delayed treatment initiation, as well as costs related to travel several times to and from the hospital. They also shared their experiences of stigma and discrimination within the community which is primarily due to the association of TB and HIV. These narratives highlight the interplay of factors at an individual, household and community levels and how they affect TB-related health seeking behaviour, diagnosis and treatment. The multi-level framework is a model based on the premise that behaviour is influenced by the individual's interaction with the social and physical environment which include culture, family, society and peer influence [47-48] as presented in figure one below.

Using a multi-level framework for understanding and responding to the different influences on behaviour has been applied in different ways. The social-ecological model is an example of a multi-level framework to understand behaviour and design interventions which acknowledges that individuals are embedded in a complex multilevel environment [49]. Individuals are

constantly interacting with the family, friends, work environments, health systems and policies that influence their behaviours. At the individual level, factors such as age, education and knowledge may influence the individual's likelihood of behaving in a certain way. At family and interpersonal level, people who are closest to the individual such as family members and friends can influence the individual's behaviour through peer influence, social support and based on their beliefs. The community forms norms and perceptions that the individual may want to identify with and may also influence his or her behaviour. Finally the society provides an environment that will enable or disable an individual to act in a different way based on the availability, enforcement and even proximity of either services or laws that can facilitate adoption of the desired behaviours.

Figure 1: The Social Ecological Model

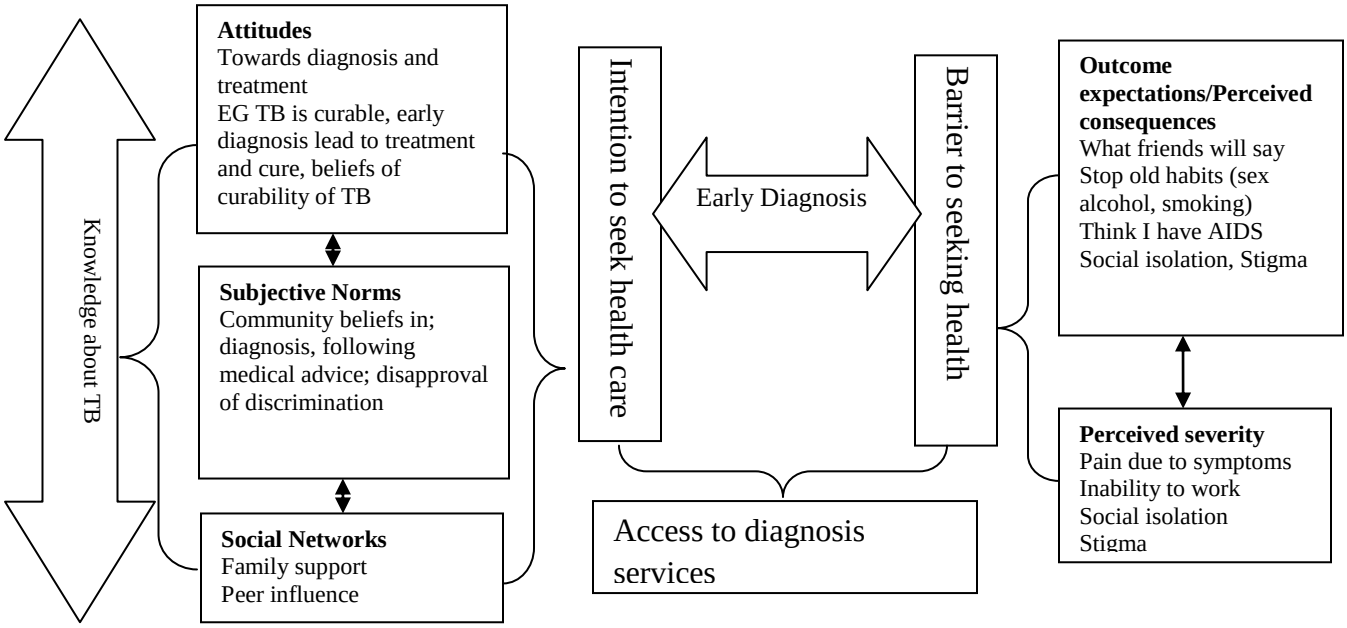


4.1 The Role of context and other influences on early diagnosis of TB

Findings from this study show how the interplay of different factors at various levels of the social ecological model affect people's ability to go for early diagnosis as will be described

below. **Figure Two** below is a model that is explaining early diagnosis seeking behaviour showing how individuals' intentions to seek services and decision making is affected by their knowledge levels, perceived consequences as well as perceived severity of TB.

Figure 2: Model of early diagnosis seeking behaviour



4.2 Individual level factors

Individual level factors deals with issues of knowledge, beliefs, attitudes and skills that a person has to reduce risk and improve health. In this study, gaps in knowledge on the symptoms of TB and how it is spread were identified such as inability of people who have never had TB to mention night sweating as a symptom and smoking, alcohols and sexual intercourse as ways in which TB is spread. Knowledge, defined as factual and interpretive information leads to the understanding of taking informed action but does not directly lead to action. In a qualitative study conducted in Zomba, a semi-urban District in Malawi, lack of knowledge about TB, accessibility and negligence were the main reasons causing patients' delay to seek early

diagnosis [22]. According to Langenhoven (1991), promotion of healthy behaviours, has principally involved knowledge dissemination which impacts on and influences attitudes and beliefs. According to Van Zundert (2009), the Social Cognitive Theory (SCT) states that cognitive factors such as outcome expectations, self efficacy and intentions are also important determinants of behaviour [50]. In the context of TB, therefore factor such as individual knowledge about TB may make an individual develop expectations of, for example, consequences of being diagnosed with TB. The knowledge that TB is curable can be a factor that can influence a person towards going for early diagnosis. Other factors such as social support from peers can increase an individual's intentions to go for early diagnosis. For a person to perform certain behaviours, he or she must know the issues and what the behaviour is and how to perform it making knowledge a precursor to behaviour [51-52]. In figure 2 above, knowledge cuts across the model because the depth of knowledge that a person has can have an influence on his ability to act differently as will be discussed below.

4.2.1 Knowledge about TB

Knowledge about TB was varied and there were some misconceptions among people who had never had TB. Nearly all knew some of the critical signs and symptoms suggestive of TB such as coughing that continue over a period of time and difficulty when breathing. Comprehensive knowledge of other signs and symptoms of TB, such as night sweating, fever was high among people who had ever had TB largely due to the experience that they had of having TB and the interaction they may have had with health service providers who may have provided health related information regarding TB. Recognizing other signs and symptoms, such as fever, were not as widespread among the general community.

4.2.1.1 Knowledge about how TB is spread

Misconceptions about the spread of TB seem to exist. While some respondents mentioned that TB is spread through air, misconceptions were common with some respondents especially men mentioning smoking, alcohol and sex as some of the ways in which TB is spread. These findings are similar to other findings in the region where misconceptions about causes of TB abound [19]. This further shows a general lack of knowledge and the distinction between risk or exposure factors and causes of TB.

Unlike other studies where knowledge about the germ theory is very low with people attributing TB to witchcraft or God [53-54], some respondents in this study both those who had ever and those who had never had TB demonstrated knowledge of the germ theory by reporting that a person with TB releases the germ in the air and that one can get infected by breathing the contaminated air.

4.2.1.2 Knowledge of infectiousness of TB

Transmission of TB is controlled through early detection of cases and putting them on anti-tuberculosis chemotherapy [55]. Knowledge of infectiousness of TB before and after case detection is therefore essential to prevent new infections. The ability for individuals and communities to identify TB in people who show signs and symptoms suggestive of TB can significantly contribute to early diagnosis seeking behaviours which can subsequently lead to early treatment and reduced risk of infection within communities [56]. There was general lack of knowledge among people who have never had TB regarding infectiousness of TB before and after a person is diagnosed and put on treatment. Respondents who had ever had TB had the knowledge that once on treatment, a person is no longer infectious but this was not common

among those that had never had TB. TB becomes non-infectious two weeks after a person has been on treatment. Lack of knowledge of this fact brings exaggerated fear of being in close contact and proximity with the TB patient yet he or she is not infectious [27] leading to social and physical isolation. It is feasible to conclude that most people do not realise the potential risk of TB infection from people manifesting TB signs but not yet diagnosed unlike those infected and on treatment.

4.2.1.3 Knowledge about TB signs and symptoms and early diagnosis

Findings from this study show that TB knowledge levels were specific to some symptoms for example, coughing and difficulty in breathing which were mentioned by more respondents than the other signs. The Chichewa word for TB is directly translated as "*the big cough*". It makes sense therefore that these are the symptoms that first come to mind. Other signs of TB such as night sweats, fever, general body weaknesses, production of sputum, and coughing blood were mostly mentioned by respondents who had ever had TB. It was therefore not common for respondents who had never had TB to mention multiple signs and symptoms of TB. This finding is similar to a qualitative study in Tanzania where coughing was a symptom most often mentioned characteristic of TB. Few patients are reported to have mentioned symptoms such as general body weakness, weight loss and fever [54].

Knowledge of the importance of early diagnosis and treatment, which has the potential to reduce further transmission of TB, appeared to be high. However, the ability to act or go for early diagnosis seem to have been partly affected by people's low knowledge of most of the symptoms of TB as well as fear of the perceived consequences of being found with TB such as social isolation and being suspected to have AIDS. For example, in this study, some respondents who

had ever had TB reported that they did not know that they had TB until they went for diagnosis. During such time, the symptoms they were experiencing got worse leading to severe suffering as well as possible transmission of the disease to others. This therefore shows people's inability to suspect early symptoms suggestive of TB as well as their infectiousness confirming inaccuracies in the levels of knowledge regarding TB signs and symptoms. Increasing people's knowledge of and the ability to suspect TB within themselves and among people with signs and symptoms suggestive of TB can potentially influence their intention to go for early diagnosis.

4.2.2 Risk perceptions

TB was generally perceived as a dangerous disease with severe consequences and that everyone is vulnerable. The severe consequences that were mentioned included the painful symptoms. Other dimensions that made it a difficult disease included delays in diagnosis and time spent travelling to and from the health facility as well as it being an airborne disease that can affect anyone as long as you are exposed and breathe contaminated air.

By virtue of being an airborne disease, respondents believed and put themselves at high risk of infection as evidenced by their view that everyone is at risk of TB infection. Most models of behaviour change states that *risk perception* is a prerequisite for behaviour change [57]. The fact that most people believe themselves to be at risk of TB infections may present an opportunity for a campaign that can focus on how people can reduce the risk of infection through early diagnosis and treatment which can significantly reduce the further spread of TB. It is estimated that each untreatable case can lead to 20 more infections in a year [39].

The findings therefore presents varied levels of awareness of the signs and spread of TB among individuals calling for expanded health education campaigns in order to minimize the gap in

knowledge and increase their perception of risk and health seeking behaviours which is crucial for a successful TB programme. This can consequently improve the knowledge base and result in early diagnosis, and treatment [10].

4.2.3 TB Treatment

Despite respondents' fears of infection and the perceived consequences of having the disease they universally understood that TB is treatable. Many mentioned that if TB is diagnosed early, it can be curable. The intention to go for early diagnosis if a respondent thought that he/she had TB was expressed through the respondents' spontaneous views that people with TB related symptoms must go for early diagnosis. Many mentioned that treatment is available and that TB is curable. This existing view could be reinforced to motivate for early diagnosis seeking.

The belief that TB is curable was widely held and may be suggestive of effects of health education campaigns that people may have been exposed to in Malawi [39], or it could be that community members have witnessed people with TB being cured. People who had ever had TB shared their experiences of being cured after being on treatment. The belief among most respondents that TB is treatable and that drugs are available is an opportunity and entry point for a campaign to promote early diagnosis seeking which can lead to early treatment and reduced burden of the severity of TB. However the paradox remains that while respondents strongly held the belief that TB is treatable, most of them expressed fear of going for diagnosis as will be discussed below.

4.2.4 Fear of being diagnosed with TB

Respondents in this study expressed the fear of being found with TB. This fear was based on what friends would say if they were diagnosed with TB, and fear of being thought to have AIDS,

and as a consequence, being isolated. Respondent's fears of being diagnosed with TB were associated with HIV because some of the physical symptoms of TB such as physical frailty and extreme weight loss are similar to that of TB. Respondents' expression of this fear was made regardless of whether that person had been on treatment for a period of time.

Another fear was based on being unable to work properly again. Respondents held the belief that when a person has TB, his or her body becomes weak making him or her unable to work. Some respondents held a further belief that even after a person has been treated from TB, their health does not return to normal and that they are no longer as strong as they used to be.

These findings are similar to studies in other parts of the world. In Tanzania and Ghana for example [54, 58], TB symptoms such as physical frailty and extreme weight loss have made some people link HIV to TB leading to fear of infection which is prolonged even after the person has been on treatment and is no longer infectious. The fear of infection has been acknowledged in other studies elsewhere and show similar trends in this study where the fear of infection and discriminatory tendencies tend to be prolonged until treatment completion [58]. This exaggerated fear may be as a result of lack of knowledge of the infectiousness of TB prior to and after the onset of treatment.

Fear of infection was also evident through the tendency to socially isolate peoples diagnosed with TB by providing them special utensils for use. In other cases it was reported that family level pressure was used to force spouses to temporarily be on divorce for fear of being infected. While in other studies this situation led to permanent loss of marriage and inability to marry if the person was single [10, 53], findings in this study show that this was temporal. Spouses would go back to their partners after realizing that they had been cured of TB. This is another

manifestation of people's belief of the curability of TB which is an added opportunity to influencing diagnosis and addressing the stigma associated with TB. The linking of TB with HIV and AIDS contributed to people's perception that TB was dangerous as presented in figure 2 above. Because of these perceptions, most people expressed the fear of being infected with TB which could affect people's intention to go for diagnosis.

4.2.5 Fear of recommendations of health care providers

Findings show that people who go for TB diagnosis and are found to be infected are told to refrain from drinking beer, smoking and having frequent sex. Avoidance of sex was a concern among most male respondents as was the case in Zambia [27] The lack of proper explanation and information about these restrictions may also affect people's desire to go for diagnosis. A quantitative study conducted in several district hospitals in Malawi found that 94% of TB patients said they could not have sex at the initial phase of TB treatment while 58% said they could have sex during the continuation phase [59]. According to Salaniponi (2000), reasons given for not having sex included body weakness due to TB, sex would lead to recurrence to TB and sex would inhibit effectiveness of anti-TB drugs. From a public health point of view abstinence from sex intercourse which entail avoidance of close contact during the initial phase of treatment may be a good measure especially among patients who may remain infectious for several weeks [59]. This finding brings in the importance of medical personnel to talk about sexual issues with TB patients in order to clarify issues that they may take for granted or misinterpret.

4.3 Interpersonal/Familial Level Factors: Role of relatives and friends

At interpersonal level, family members, friends and other close social-circle peers form informal social networks that could provide immediate social support [49]. One of the critical aspects of

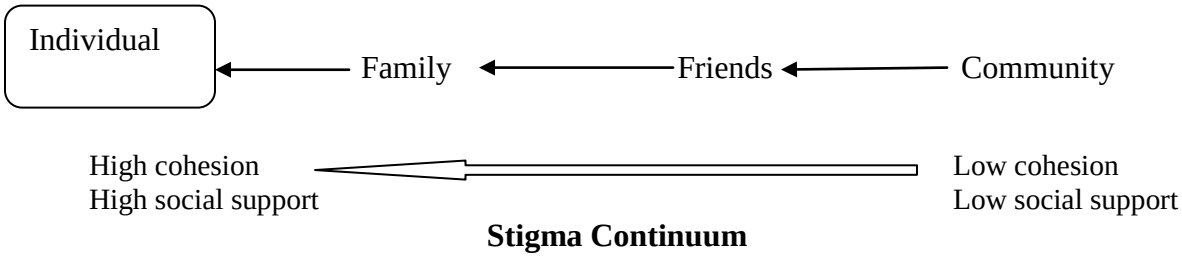
having TB is the ability of the infected person to access health services in order to be diagnosed. This is dependent in part on a number of factors, one of which is social support. Feelings of helplessness, depression and quality of social support as well as the social consequences of having TB such as stigma and community perceptions of people with TB can have negative impact on people's adherence to treatment [60]. Social support in this study is generating from close family relatives especially women (wives and daughters) than men and friends and other community members.

4.3.1 Social Support

While there were reports of stigma and discrimination resulting in social isolation at community level, family members seem to have been closely connected to the TB patient providing all forms of support including ensuring that they take the TB drugs at the right time.

The fear of associating with people infected with TB was uncommon among family members followed by friends making the TB infected person more at ease and free from the social isolation he or she could have suffered from other community members. This finding is similar to a qualitative study conducted in Nicaragua where family members had the most homogenous and supportive feelings and behaviours while the community developed more fears, isolation and mistrust while friends were described to be in between [61]. In Ghana, a quantitative study found that lack of social support especially from close family members was a significant determinant for defaulting treatment [62]. The findings therefore shows that close family members are the closest persons that a person diagnosed with TB can get support from calling for health education campaign that must promote social support from not only family members but the entire community as well.

Figure 3: Stigma continuum



As presented in figure 3 above, the strong family social cohesion, where the family is seen to have an intervening effect on the relationship between the negative social factors that may affect diagnosis, treatment adherence and social stigma and related health outcomes provides a supportive environment to the patient and reduces effects of social isolation. A study in Uganda demonstrated similar trends where people infected with TB are reported to have chosen to keep their diagnosis a secret within the family because family members reacted well and offered care to the patients [63]. Findings also show that the strength of social support was dependent on the closeness of the relationship. Social support was stronger among family members, friends and very weak among community members.

4.3.2 Effects on marriage

Findings show that family members of a partner whose spouse was diagnosed with TB exerted negative pressure in terms of promoting stigma where family members were protective of their relative if his or her partner was diagnosed with TB. Findings show that there had been pressure from relatives of a spouse to abandon the infected partner for fear of being infected. Studies in other countries show that people infected with TB find problems with marriage and this mostly affect women and these were in most cases permanent[10]. While this is the case, findings from this study show that such arrangements are temporal in that spouses came back after the partner

had been healed. This may be as a result of the strong belief that TB is curable but also the lack of knowledge that TB infectiousness stops few weeks after a person has been put on treatment.

4.3.3 Gender Roles

Traditionally, women have been ascribed the role of taking care of the health of the family as well as the community [64-65]. From a tender age girls are socialized to be care givers by, for example, nursing and caring for children and sick people. Girls grow up bearing the burden of ensuring the health of the family [65]. . Findings from this study show the role that women play as care givers and this is due to the gendered roles ascribed to men and women from the tender age. While the family was found to provide social support to family members who had TB, most of this support was provided by women. Male respondents who had ever had TB acknowledged being closely supported by their wives from the onset of the TB-related signs, to seeking diagnosis and treatment. Support included providing them with food washing their utensils as well as cleaning cups for throwing sputum. On the other hand, females who had ever had TB reported to have received support from their daughters. The care giving role of women was clearly demonstrated through women's expression of empathy and the need to provide emotional and materials support to people infected with TB. This finding shows that trust, norms and social relationships are a valuable resource and that such social structures have the ability to influence certain actions. Thus the family as a source of social support and a potential determinant of health is seen providing health related information, reinforcement of psychological resources, self esteem, providing emotional and material support, encouraging engagement in health norms and behaviours as well supporting access to health care and reminding the TB patient to take drugs according to the advice of the medical doctor [53, 60, 66-68]. A qualitative study conducted in another rural district of Malawi found that people who had been diagnosed with TB

disclosed their status but mostly to people closer to them such as family members for fear of being stigmatised due to the link between TB and AIDS [23].

4.4 Community Level factors

At community level, an individual interact with different environments including groups of people which has a normative influence on their life.

4.4.1 TB and HIV related Stigma and discrimination

Findings from this study show strong community perceptions that link TB to HIV, making TB a stigmatized disease. While some respondents, especially females expressed sympathy towards people who have been infected with TB, stigma and discrimination were evident. The physical frailty shared between AIDS and TB patients made people to suspect HIV. Further, the use of figurative language to explain TB signs is in itself stigmatizing as TB infected people are referred to as "*like a person suffering from cholera*." This may fuel community perceptions of behaviour towards TB patients and may determine how community society should respond to the threat of TB. All this was taking place in an environment where expressions related to care giving and support were high such as *"these people need our help",* or "*they must seek medical help quickly".* The feeling that if found with TB one will face stigma and discrimination could possibly deter people from seeking diagnosis and hide the symptoms.

The strong perception and belief that when one is found with TB means they automatically have HIV provides a potential avenue for hiding signs thereby delaying diagnosis. TB associated stigma appeared to have been manifested in the respondents reaction to how they perceive people infected with TB and how they would react if they were diagnosed with TB. There was a contradiction on views regarding how to interact with a person who has TB and the reported

discriminatory practices that community show to people with TB. While they reported that TB infected people must not be discriminated against, most respondents reported that TB infected people are discriminated against. One of the reasons given for this is that most people are afraid of being infected with TB. As described in **figure 3** above, proximity to a person with TB determines the level of stigma that an individual suffers. The community being distant from the TB patient develops more mistrust and fear of people with TB thereby discriminating and stigmatizing them.

These findings are similar to studies done elsewhere [21, 27, 52, 54, 63, 69] where community members' fear of being infected led to stigma and discrimination. Even though community members expressed mixed feeling and attitudes towards TB treatment, most respondents expressed fear of being infected with TB as well as being thought to have AIDS. The attribution of TB signs and symptoms to HIV is a challenging task to addressing TB which has brought fear among people who have never had TB. The fear attached to TB has been documented in many studies [27, 53-54, 58, 63]. As presented in Figure 2 above, on the one hand, knowledge about TB is relative while beliefs and attitude towards TB treatment and need for seeking early diagnosis are high. On the other, there is fear of contagion because of the social consequences of being diagnosed with TB which consequently affects people's intention to seek health care.

4.4.2 Health Care System: Misdiagnosis

Findings from this study show that the health care system plays a role in determining community attitude towards diagnosis seeking. Accounts from respondents show that the inability of community level health facilities to diagnose TB and provide referrals in good time is a potential barrier to diagnosis seeking. This should be looked at in the context of other factors such as time and cost of travel as well as the other social consequences of being found with TB. Malawi, like

other countries in the region has high levels of poverty which not only affects vulnerability to TB but also access to services. The diagnosis of TB is complex requiring repeated trips to health facilities amidst lack of transportation to transport sputum to a diagnostic facility affecting communication of results [40]. In Malawi diagnosis of TB is centralized except treatment which is decentralized to the rural community. Delays in diagnosis therefore affect people's confidence to go for diagnosis.

4.5 Societal policy level factors

While delays in diagnosis have been partly influenced by individual level factors, findings show that service delivery has considerably contributed to delays to diagnosis [49, 70]. Most respondents who had ever had TB experienced delays in diagnosis due to misdiagnosis. This shows that there are critical issues such as access to diagnostic services, misdiagnosis and time it takes to get the results and start treatment that need to be addressed in the health sector. Misdiagnosis results in a patient having to travel to and from one health facility to another for diagnosis. This entails having to provide sputum and go back to wait for the results. In the mean time, as has been presented above, the person may be a breadwinner and his time is being lost. He is suffering the severe effects of the symptoms because he or she is not yet on treatment and has to spend money to travel to and from the hospital. This may explain why some people present at health care facilities after their symptoms have gotten worse. There is therefore need for more investigation and direction in terms of provision of improved laboratory equipment for example to improve diagnostic services at community health facility level. Issues of referrals as well as diagnosis delays due to provider delays must also be looked into in order to speed up diagnosis. The inability of government to provide equitable access to diagnostic equipment to designated hospital becomes a barrier to access diagnosis. While this is the case, there was no

mention of being dissatisfied with health care provision. No direct question was asked about the quality of health care and there was no mention of any problems related to it.

5.0 Limitations

The study was conducted at a time when Malawi was facing acute fuel shortage as a result we were limited in terms of travelling to be able to recruit discussants from across the villages where we collected our data from. Travel into the interior of the villages was dependent on the amount of fuel that the study team had. Participants were therefore not selected based on a cross section of people from the three villages rather they were selected based on their availability and willingness to participate. Participant recruitment was arranged through the local community head who may have selected his close allies. It should however be noted that while this was the case findings from this study is still comparable with studies done elsewhere.

Social desirability was another limitation. Discussants sometimes hid information such as whether they were discriminated against or not or whether they suffered marital problems or not. There were cases where respondents divulged more information regarding stigmatizing incidences after the discussion.

This study was conducted in three villages of one rural community making it difficult to transfer the findings to the entire district. The study does however provide an insight into community perceptions towards TB and treatment seeking behaviour that may call for a lager qualitative and quantitative study to establish the extent of these perceptions.

Chapter Five: Conclusion

This chapter summarises the main findings of the study.

6.0 Conclusion

The study findings show that there is a link between low levels of knowledge about TB and misconceptions about how TB is spread. There are also positive attitudes and beliefs towards TB diagnosis and its curability and subjective norms that encourage diagnosis and need to go for treatment, follow medical advice as well as condemn discriminatory practices. Together with the support provided at family level which can be promoted to also operate at community level, there are strong intentions among community members to go for early diagnosis in order for them to get treatment and be cured.

On the contrary, barriers abound that strongly affects community members' intention to act positively. Community members' fear of the outcome of a diagnosis and the perceived consequences of being found with TB such as fear of what friends will say, fear of HIV or AIDS, effects on sexual life and refraining from old habits seem to outweigh their intentions to seek early diagnosis. This is also affected by their perception of the severe consequences of TB that included pain due to symptoms, inability to work, and issues related to misdiagnosis. This becomes a potential barrier to seeking early diagnosis and can potentially affect the success of DOTS because of few cases presenting for diagnosis thereby fuelling more infection from undiagnosed cases.

As highlighted above, the knowledge that most people have on TB does not provide a full package of information that would make a person be able to suspect symptoms suggestive of TB nor encourage people with such symptoms to go for diagnosis. The strong belief that TB is curable and knowledge that TB drugs are available is an opportunity to demystify fears that people may have and promote early diagnosis. This knowledge is however obstructed by the stigma associated with being diagnosed with TB especially the fear of being infected and the

social consequences that follow. The suspected shortfall of health education campaigns and any information dissemination attempts to emphasise on the infectiousness of TB before and after being put on treatment is a missed opportunity to reduce stigma and social isolation which results from fear of infection.

A strong advocacy campaign regarding management of diagnosis and referrals need to be considered to reduce cases of misdiagnosis which contributes to delayed diagnosis. Most rural health facilities may not have state of the art equipment to diagnose TB but could have health personnel who can assess the signs and provide referral information before the person suffers the consequences of the symptoms as well as costs of travel to different health facilities for referral.

This study has attempted to give an insight into some community level understanding of TB which shows that there are issues that need to be looked into using a multilevel approach in order to improve early diagnosis seeking behaviours. This can in turn compliment the success of the DOTS strategy whose success is affected by issues of delayed diagnosis which in turn is affected by behavioural factors than can only be addressed using non-biomedical interventions.

6.1 Recommendations

In line with the findings of this study, there is a strong need to reduce the stigma associated with TB which is closely linked with HIV and AIDS. The level of importance that the stigma campaign must take should be aligned to the importance that has been attached to the AIDS related stigma campaign because the two have been viewed as one. Distinction between TB and HIV and AIDS also need to be made clear to the population. It is important for people to know that TB could be an opportunistic infection due to HIV infection as well as just being a disease not associated with HIV. Further the following need to be considered:

6.1.1 Health Education Campaign

There is need for a health education campaign that must build on the existing knowledge about TB for people to have comprehensive knowledge of all symptoms suggestive of TB. Knowledge of contagiousness of TB is low. People must be made aware that people who are not on treatment are highly contagious unlike those on treatment. Importance of early diagnosis must be emphasized in terms of preventing further transmission of TB and adverse consequences as a result of late diagnosis. This can in turn build the ability of people to suspect TB if they or their friends have similar signs and symptoms. Further people must be able to distinguish causes of TB and exposure factors to deal with misconception on the causes of TB. Knowledge of the contagiousness of TB must also be emphasised to reduced prolonged periods of social isolation.

Further, the finding offers another opportunity to strengthen behaviour change campaigns to influence health seeking behaviours through strengthening of social networks such as the family and other social groups, for example targeting male involvement in care and support. Ntcheu like other tribal districts in Malawi has extended family relationships and strengthening these can potentially impact on individuals' ability to seek early diagnosis and adhere to treatment due to the support they know they will get from family members. This support must however be promoted to the entire community as this has the potential to reduce stigma associated with TB.

6.1.2 Social systems

As stated above, the poor social network systems at community level need to be strengthened to compliment the support giving role the family is playing. Greater involvement of other social networks, for example involving men in care and support giving can provide support to people diagnosed with TB thereby reducing stigma and discrimination and encouraging others to go for

early diagnosis. The gendered roles that make women as health care givers at family and community level must be shifted by addressing issues of gender inequalities and promote male involvement.

6.1.3 Health Systems

There is need for review of management of diagnosis of TB at facility level to reduce delays caused by misdiagnosis as well as late referrals. The constant referrals of people for TB diagnosis need to be looked into in terms of use of reliable equipment or explaining to suspected patients of possibilities of misdiagnosis. The centralisation of TB diagnosis needs to be revisited. District hospitals must not be the only facilities providing diagnosis. Some facilities at community level should be considered for upgrading to provide diagnostic services.

6.1.4 Analysis of barriers and opportunities

This study has unveiled opportunities for early diagnosis seeking change behaviours through, for example respondents, knowledge of the curability of TB, willingness to offer support and empathy as well as reported expressions that they cannot be worried if diagnosed with TB. It has also unveiled barriers that have the potential to impact on people's ability to seek early diagnosis.

Table Two below presents an analysis of barriers and opportunities to addressing TB as presented in this study.

Table Two: Analysis of barriers and opportunities to diagnosis seeking

LEVEL OF INFLUENCE	BARRIERS TO CHANGE: What people do not know about TB or negative things they do	OPPORTUNITIES TO CHANGE: What people know about TB or positive behaviours being practice d	What must change
Individual	**Knowledge** • Knowledge about TB signs & symptoms is limited • Low knowledge about the contagiousness of TB that a person is not contagious when on treatment • Fear of being isolated if diagnosed with TB	**Knowledge** • High awareness that TB is curable • High awareness that drugs are available • There is strong social support from family	• People must be able to suspect signs suggestive of TB • People must know that a person on treatment is no contagious
Family	• Most families may not have money for transport to take relatives for diagnosis	Social support • Families are providing support to relatives who have TB	• Strengthen the family support system
Community	• Knowledge of contagiousness of TB • Fear of being infected • Stigma and discrimination • Perceived consequences of TB • Perceived severity of TB	• Intention to provide support • Knowledge of curability of TB • Risk perception • Evidence of people who have been treated from TB	Health education campaign Community mobilisation Modelling – involvement of people healed from TB
Policy	Lack of diagnostic equipment Misdiagnosis	• International and national commitment to reducing the burden of TB	Policy review Advocacy for increased access to facilities that can offer diagnosis.

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Appendix A: Participant Information Sheet: Focus Group Discussion

Note: This information sheet will be translated into Chichewa

Study title: A study on community perceptions of Tuberculosis and people diagnosed with tuberculosis.

Introduction:

Hello and welcome. I sincerely thank you for giving me your time. My name is …….. I am a student at the University of Witwatersrand. I am conducting research to explore the perceptions of TB and people diagnosed with TB in this community as this influences people's health seeking behaviour and further spread of the disease.

Invitation to participate:

I would like to invite you to volunteer to participate in the research study which will be conducted in this village of ……..TA Phambala in this district of Ntcheu. You should agree to participate in the study only if you fully understand what will be asked and are completely happy with the procedures that will be involved. If you do not understand the information or have any questions, please feel free to ask me or the interviewer.

What is involved in the study:

This study will require you to participate in a group discussion that will last between one to one and half hours. There will be between 8-10 people in the group. Participants for this study will include people with and without TB. With your consent, an interviewer will ask you few questions about TB to which you will be requested to verbally explain your views. No answer to these questions is neither right or wrong as these will be your personal views and experiences. The discussion will be recorded on tape for purposes of capturing as much information as possible. No one will listen to the recorded tapes apart from the research team. We will write down word by word all what will be discussed in order for us to write a report. No names will be written to indicate who said what. We will conduct 8 focus group discussions four of which will comprise of males while the other four will comprise of females. All these people will be aged between 18 – 49.

Risks:

The discussion will be conducted in a private room/class room or any safe place within your community. The only potential risk you may face from participating in this study are:

You may feel uncomfortable answering some questions that may be addressing some sensitive and personal issues

The other participants in the groups will hear what you say about TB and may speak to others outside the group. This will make the group discussion not confidential.

You will have to spare at least an hour and a half to participate hence may lose time for doing your routine household chores.

You are however informed that you are free not to answer questions that make you uncomfortable.

Benefits:

You will not get direct benefits from this study. The information collected in this study will be helpful in supporting government efforts to reduce the further spread of TB in our community and Malawi as a nation, by coming up with health education campaign that will make people understand and look at TB positively so as to improve early health seeking behaviour.

Participation is voluntary:

Participation in this research is voluntary. There will be no penalty or any repercussions if you refuse to participate. You will be free to discontinue participation at any time that you feel uncomfortable.

Reimbursements:

We will provide refreshment and snacks at the end of the discussion. Participants will be given MK200.00 each for travel to the data collection place.

Confidentiality:

All the information collected in this study will be strictly confidential. Absolute confidentiality cannot be guaranteed. Personal information may be disclosed if required by law. Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the Research Ethics Committee and the Medicines Control Council (where appropriate). If you volunteer, your will sign consent forms but these will not be linked to the responses that you will give.

Contact details of researcher/s:

In the event that you want further information regarding your rights as a researcher or complaints regarding this research, you may contact the Chairperson of the University of Witwatersrand, Human Ethics Committee at this number (+27) 11 717 2230/1, the chairperson of the Malawi Health Sciences Research Committee on this number……..

Information and contact person:

If you have any questions regarding this study, you can contact:

Simon Sikwese

Pakachere Institute of Health and Development Communication

Delamere House, 4th Floor, South Wing

P.O Box 30248, Chichiri, Blantyre 3

Cell phone: 09 99 963 305

Telephone: 01 831 661

Fax: 01 831 771

Appendix B: Informed Consent: Focus Group Discussion

I hereby confirm that the person seeking my informed consent to participate in this study has given me information to the best of my satisfaction. He explained to me the purpose of the study and procedures that will be followed to collect data. He has also explained to me the risks and benefits and my rights as a participant of the study.

I have received the information for the study in Chichewa and have had enough time to read it on my own and ask any questions where I was not clear. I feel that I am comfortable to take part in this study having all the questions I had answered to my satisfaction.

I have been informed that the information that will be gathered from this study and from all participating people will be processed with confidentiality into a research report that may further be published. I am aware that this report and any publications from it will be shared with other academics and Ministry of Health officials for use in TB efforts to address TB.

I am aware that it is my right to withdraw my consent from the study without any prejudice. I hereby freely and voluntarily give my consent to participate in the study.

Participant's name_____

Participant's signature_____Date_____

Researcher's name_____

Researcher's signature_____Date_____

Witness name_____

Witness signature_____Date_____

Appendix C: Informed Consent Audio-recording Focus Group Discussion

I hereby confirm that the person seeking my informed consent to participate in this study has given me information to my satisfaction. He/she explained to me the purpose of the study and procedures involved, risks, benefits and my rights as a participants in the study.

I am aware that my voice will be recorded alongside the other participants in the group discussion. I have been informed that only the research team and unless otherwise required the Human Ethics Committee and other human rights organisations will access the tapes and hear my recorded voice. I have been informed that the recorded voices will be destroyed at the end of the project.

I am aware that it is my right to withdraw my consent in this study without any prejudice. I hereby freely and voluntarily give my consent to be audio-recorded in this study.

Participant's name_____

Participant's signature_____Date_____

Researcher's name_____

Researcher's signature_____Date_____

Witness name_____

Witness signature_____Date_____

Appendix D: Participant Information Sheet: Individual In-depth Interviews

Note: This information sheet will be translated into Chichewa

Study title: A study on community perceptions of Tuberculosis and people diagnosed with tuberculosis.

Introduction:

Hello and welcome. I sincerely thank you for giving me your time. My name is …….. I am a student at the University of Witwatersrand. I am conducting research to explore the perceptions of TB and people diagnosed with TB in this community as this has an influence on people's health seeking behaviour and the further spread of TB.

Invitation to participate:

I would like to invite you to volunteer to participate in the research study which will be conducted in the village of ……..TA Phambala in this district of Ntcheu. You should agree to participate in the study only if you fully understand what will be asked and are completely happy with the procedures that will be involved. If you do not understand the information or have any questions, please feel free to ask the interviewer.

What is involved in the study:

This study will require you to participate in an individual in-depth interview that will last between one to one and half hours. You will be alone with an interviewer who will be asking the questions. Participants for this study will include people with and without TB. With your consent, the interviewer will ask you few questions about TB to which you will be requested to verbally explain your views. No answer to these questions is neither right or wrong as these will be your personal views and experiences. The interview will be recorded on tape for purposes of capturing as much information as possible. No one will listen to the recorded tapes apart from the research team. From what will be recorded, we will write down word by word all what will be discussed in order for us to write a report. Your name will not be written so that no one will know who said what. We will interview 16 people individually eight of which will be male and eight will be female. All these people will be aged between 18 - 49

Risks:

The discussion will be conducted in a private room/class room or any safe place within your community. The only potential risk you may face from participating in this study are:

You may feel uncomfortable answering some questions that may be addressing some sensitive and personal issues

You will have to spare at least an hour and a half to participate hence may lose time for doing your routine household chores.

You are however informed that you are free not to answer questions that make you uncomfortable.

Benefits:

You will not get direct benefits from this study. The information collected in this study will be helpful in supporting government efforts to reduce the further spread of TB in our community and Malawi as a nation by coming up with health education campaigns that will address real experiences that people have regarding TB.

Participation is voluntary:

Participation in this research is voluntary. Refusal to participate will involve no penalty. You will be free to discontinue participation at any time that you free uncomfortable.

Reimbursements:

We will provide refreshments and snacks at the end of the discussion. Participants will be given MK200.00 each for travel to the data collection place.

Confidentiality:

All the information collected in this study will be strictly confidential. Personal information may be disclosed if required by law. Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the Research Ethics Committee and the Medicines Control Council (where appropriate). The consent forms that you will sign will not be linked to the responses that you will give.

Contact details of researcher/s:

In the event that you want further information regarding your rights as a researcher or complaints regarding this research, you may contact the Chairperson of the University of Witwatersrand,

Human Ethics Committee at this number (+27) 11 717 2230/1. Or you can contact the Health Sciences Research Committee in Malawi on this number……..

Information and contact person:

If you have any questions regarding this study, you can contact:

Simon Sikwese

Pakachere Institute of Health and Development Communication

Delamere House, 4th Floor, South Wing

P.O Box 30248, Chichiri, Blantyre 3

Cell phone: 09 99 963 305

Telephone: 01 831 661

Fax: 01 831 771

Appendix E: Informed Consent: Individual In-depth Interview

I hereby confirm that the person seeking my informed consent to participate in this study has given me information to the best of m satisfaction. He explained to me the purpose of the study and procedures that will be followed to collect data. He has also explained to me the risks and benefits and my rights as a participant of the study.

I have received the information for the study in Chichewa and have had enough time to read it on my own and ask any questions where I was not clear. I feel that I am comfortable to take part in this study having all the questions I had answered to my satisfaction.

I have been informed that the information that will be gathered from this study and from all participating people will be processed with confidentiality into a research report that may further be published. I am aware that this report and any publications from it will be shared with other academics and Ministry of Health officials for use in TB efforts to address TB.

I am aware that it is my right to withdraw my consent from the study without any prejudice. I hereby freely and voluntarily give my consent to participate in the study.

Participant's name_____

Participant's signature_____Date_____

Researcher's name_____

Researcher's signature_____Date_____

Witness name_____

Witness signature_____Date_____

Appendix F: Informed Consent Audio-recording Individual In-depth Interview

I hereby confirm that the person seeking my informed consent to participate in this study has given me information to my satisfaction. He/she explained to me the purpose of the study and procedures involved, risks, benefits and my rights as a participants in the study.

I am aware that my voice will be recorded. I have been informed that only the research team and unless otherwise required the Human Ethics Committee and other human rights organisations will access the tapes and hear my recorded voice. I have been informed that the recorded voices will be destroyed at the end of the project.

I am aware that it is my right to withdraw my consent in this study without any prejudice. I hereby freely and voluntarily give my consent to be audio-recorded in this study.

Participant's name_____

Participant's signature_____Date_____

Researcher's name_____

Researcher's signature_____Date_____

Witness name_____

Witness signature_____Date_____

Appendix G: Focus Group Discussion Guide: Never had TB

'Welcome ladies / gentlemen to our discussions. My name is _____. I am a researcher and I am here to discuss with you about TB. I will ask you to participate freely and note that each one's views are very essential in these discussions. There is neither a right nor a wrong answer to the questions in the discussion. Also be mindful that whatever we will get here is for research purposes only and the information will not be used by any other person apart from this research. The discussion is open and therefore confidentiality cannot be guaranteed. However your names will not be mentioned or be attached to anything that you say. During these discussions I will record the discussion on tape so that we do not miss any valuable information that we will share here. I therefore ask your permission to use the recorder. [When permitted]. Please let us speak clearly and one at a time so that our discussions should be recorded clearly. Once again feel free to participate. All views must be respected even though they differ from yours."

What are your views about TB? What do you know about the disease?

What are your views regarding people who have TB?

How do you perceive to be your reaction if you were diagnosed with TB?

What should people who have TB related signs do when they notice the signs?

What are your views regarding TB treatment?

What are your views regarding people who are on TB treatment?

What do you think about TB and TB cure?

What are the local names for TB?

Appendix H: Focus Group Discussion Guide: Ever had TB

'Welcome ladies / gentlemen to our discussions. My name is _____. I am a researcher and I am here to discuss with you about TB. I will ask you to participate freely and note that each one's views are very essential in these discussions. There is neither a right nor a wrong answer to the questions in the discussion. Also be mindful that whatever we will get here is for research purposes only and the information will not be used by any other person apart from this research. The discussion is open and therefore confidentiality cannot be guaranteed. However your names will not be mentioned or be attached to anything that you say. During these discussions I will record the discussion on tape so that we do not miss any valuable information that we will share here. I therefore ask your permission to use the recorder. [When permitted]. Please let us speak clearly and one at a time so that our discussions should be recorded clearly. Once again feel free to participate. All views must be respected even though they differ from yours."

What are your views regarding TB? Why do you say so?

How did you know that you have TB? What signs did you have?

When did you know that you have TB?

Having being on treatment, what are your views regarding TB treatment?

How do you think you got TB? Why?

What do you think about the treatment outcome?

What do you think of TB and getting cured?

What are the local names for TB?

Appendix I: Individual In-depth interview Discussion Guide: Never had TB

'Welcome sir/madam to our discussion. My name is _____. I am a researcher and I am here to discuss with you about TB. I will ask you to participate freely and note your views are very essential in this discussion. There is neither a right nor a wrong answer to the questions in the discussion. Also be mindful that whatever we will get here is for research purposes only and the information will not be used by any other person apart from this research. The discussion is strictly confidential this means that your name will not be mentioned or be attached to anything that you say. During these discussions I will record the discussion on tape so that we do not miss any valuable information that we will share here. I therefore ask your permission to use the recorder. [When permitted]. Please speak clearly so that our discussions should be recorded clearly. Once again feel free."

What are your views regarding TB? Why do you say so?

How do you know if someone has TB?

What do you think about people who are diagnosed with TB?

How must people with TB be treated? Why?

What do you think about TB treatment?

How should you relate with people who are on TB treatment? Why?

Appendix J: Individual In-depth Interview Discussion Guide: Ever had TB

'Welcome ladies / gentlemen to our discussions. My name is _____. I am a researcher and I am here to discuss with you about TB. I will ask you to participate freely and note that each one's views are very essential in these discussions. There is neither a right nor a wrong answer to the questions in the discussion. Also be mindful that whatever we will get here is for research purposes only and the information will not be used by any other person apart from this research. The discussion is strictly confidential this means that your names will not be mentioned or be attached to anything that you say. During these discussions I will record the discussion on tape so that we do not miss any valuable information that we will share here. I therefore ask your permission to use the recorder. [When permitted]. Please let us speak clearly and one at a time so that our discussions should be recorded clearly. Once again feel free to participate. All views must be respected even though they differ from yours."

What are your views about TB? Why do you say so?

How did you know that you have TB?

When this problem started, where did you go initially to seek help? Why?

(If they sought medical attention later) What made you seek medical attention?

What was your reaction when you were diagnosed with TB? Why?

What do you think about TB treatment?

How did you relate with people when you were on TB treatment?

How do you think you got TB? Why?

What do you believe are the reasons why people diagnosed or with TB signs delay to seek treatment?

Appendix K: National Health Sciences Research Committee Approval

Telephone: + 265 789 400
Facsimile: + 265 789 431

All Communications should be addressed to:
The Secretary for Health and Population



In reply please quote No. MED/4/36c
MINISTRY OF HEALTH AND
POPULATION
P.O. BOX 30377
LILONGWE 3
MALAWI

24th August 2011

Dr Peter Nyasulu
University of Witwatersrand

Dear Sir/Madam,

Re: Protocol # 862: Effectiveness of health education and awareness model on early TB diagnosis in resource-limited settings: A cluster randomized controlled trial in Ntcheu district, Malawi

We write to let you know that during its June sitting the committee approved your application to conduct the above titled study.

As per National Health Sciences Research Committee (NHSRC) general guidelines you are supposed to pay 10% fee for NHSRC capacity building prior to commencement of the research study.

Kind regards from the Secretariat.

Rage Majamanda
FOR: CHAIRMAN, NATIONAL HEALTH SCIENCES RESEARCH COMMITEEE

Appendix L: Clearance Certificate: Human Rights Ethics Committee

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Mr Simon Edington Sikwese

CLEARANCE CERTIFICATE	M110956
PROJECT	Community Perceptions of Tuberculosis and People Diagnosed with Tubercuosis in a Rural Community in Malwai
INVESTIGATORS	Mr Simon Edington Sikwese.
DEPARTMENT	School of Public Health
DATE CONSIDERED	30/09/2011
M1109560DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 16/01/2012 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Ms N Christofides

DECLARATION OF INVESTIGATOR(S)
To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...