

Socio-Cultural and Behavioral Factors affecting adherence to Tuberculosis treatment in Malawi

by

Ruth Munyu Lipato



Submitted as the dissertation component in partial fulfillment for the degree of Master of Medical Microbiology in the school of Health Sciences, University of KwaZulu-Natal, Durban

Supervisors

Vernon Solomon

Professor Fanuel Lampiao

February, 2021

**SOCIO-CULTURAL AND BEHAVIORAL FACTORS AFFECTING ADHERENCE TO
TUBERCULOSIS TREATMENT IN MALAWI**

FEBRUARY, 2021

RUTH MUNYU LIPATO

214583328

A dissertation submitted to the School of Health Sciences, College of Health Science, University of KwaZulu-Natal, West Ville Campus, for the degree of Master of Medical Microbiology

This is to certify that the content of this dissertation is the original research work of Miss Ruth Munyu Lipato.

As the candidate's supervisor, I have approved this thesis for submission.

Supervisor:

Signed:  Name: V.P. Solomon

Date: 18/02/2021

Signed:  Name: Professor Fanuel Lampiao

Date: 18/02/2021

Declaration

I **Ruth Munyu Lipato** declare that the content of this dissertation is the product of my own original research and that all sources used are cited and that the work has not already been accepted in substance for any degree, and is not being concurrently submitted for any degree. This dissertation does not contain other person's data, graphs or other information, unless specifically acknowledged as being sourced from other persons. This dissertation does not contain tables, graphics or text copied and pasted from the internet, unless specifically acknowledged in the dissertation and in the references section.

Signature:

A solid black rectangular box redacting the signature of the author.

Date:18/02/ 2021

DEDICATION

To the loving memory of my dear parents Willie and Rosaria, for always encouraging me to reach my greatest potential in life and for always believing in me. This achievement should make you proud.

ACKNOWLEDGEMENTS

My sincere thanks and gratitude are due to my supervisors Vernon Solomon and Professor Fanuel Lampiao for their support and guidance in shaping up this work.

I also would like to extend my appreciation to Janine Upton for her help with the data analysis.

The tireless effort and constructive criticism by Professor Christine Varga is not taken for granted.

I appreciate the assistance of the NORHED project for funding this study and my previous employer Mulanje Mission Hospital for allowing me to pursue this study.

I also would like to appreciate the support of management of Bwaila hospital for allowing me to use their facility to recruit participants for the study. Special thanks are due to all staff of Bwaila who helped me with the data collection process.

I would like to express gratitude to the study participants who shared their experiences and time with me.

I am grateful to my family and friends for their moral support and encouragement as I undertook my study.

Finally, I remain ever grateful to the Almighty God for seeing me through my academic journey this far.

TABLE OF CONTENTS

| | |
|---|-----|
| DEDICATION..... | iii |
| ACKNOWLEDGEMENTS | iv |
| TABLE OF CONTENTS..... | v |
| LIST OF FIGURES | ix |
| LIST OF TABLES..... | x |
| LIST OF ACRONYMS | xi |
| ABSTRACT..... | xii |
| CHAPTER ONE. INTRODUCTION AND LITERATURE REVIEW | 1 |
| 1.1 INTRODUCTION..... | 1 |
| 1.2 LITERATURE REVIEW..... | 3 |
| 1.3 PROBLEM STATEMENT | 9 |
| 1.4 AIMS AND OBJECTIVES..... | 10 |
| 3. To identify practices among TB patients with the potential to affect TB treatment adherence through the use of a questionnaire | 10 |
| 1.5. RESEARCH QUESTIONS | 10 |
| 1.6. LAYOUT OF THE THESIS..... | 10 |
| CHAPTER 2. RESEARCH DESIGN AND METHODOLOGY | 11 |
| 2.1 STUDY SETTING | 11 |
| 2.2. RESEARCH METHODOLOGY | 11 |
| 2.3 RESEARCH DESIGN | 12 |

| | |
|---|----|
| 2.4. TARGET POPULATION..... | 12 |
| 2.5 RESPONDENTS..... | 12 |
| 2.6. SAMPLING STRATEGY | 12 |
| 2.6.1. Sample frame and Sample Size..... | 12 |
| 2.7. DATA COLLECTION TOOLS..... | 12 |
| 2.8 DATA COLLECTION PROCESS | 13 |
| 2.9 PILOTING AND VALIDATION..... | 13 |
| 2.10 DATA ANALYSIS..... | 14 |
| 2.11. ETHICAL CONSIDERATIONS | 14 |
| CHAPTER 3. RESULTS | 14 |
| 3.1. Introduction | 14 |
| 3.2. Social demographic characteristics of the respondents..... | 14 |
| 3.2.1. Age..... | 14 |
| 3.2.2. Sex and Marital status..... | 15 |
| 3.2.3 Educational status. | 16 |
| 3.2.4. Current Occupation..... | 16 |
| 3.3 Participants' knowledge about TB and its treatment. | 17 |
| 3.4. Practices among TB patients with the potential to affect TB treatment Adherence. | 21 |
| 3.4.1. Do you take your TB medication according to guidelines? | 21 |
| 3.4.2. What are some of the challenges/barriers that prevent you from adhering to your medication? | 21 |

| | |
|---|----|
| 3.5. Socio-cultural attitudes with the potential to influence adherence to TB treatment among TB patients | 22 |
| 3.5.1. Did you disclose your TB status to others? | 22 |
| 3.5.2. Why didn't you disclose your TB status?..... | 23 |
| 3.5.3. Is it shameful to have TB? | 23 |
| 3.5.4. Why is it shameful to have TB?..... | 23 |
| 3.5.5. What other treatment options have you sought apart from taking Anti-TB drugs?.... | 24 |
| 3.5.6. Is it a common practice to combine TB medication with other treatment options? ... | 24 |
| 3.6. Support needed by TB patients from relatives and the community | 25 |
| 3.7. Ways of promoting adherence to TB treatment | 25 |
| 3.7.1. What do you think the government can do to promote adherence to TB treatment?..... | 25 |
| 3.8. Themes emerging from the Focus Group Discussions | 26 |
| 3.8.1. Adherence to TB treatment and its challenges | 26 |
| 3.8.2. Disclosure of TB status..... | 27 |
| 3.8.3. Perception of TB as a disease | 27 |
| 3.8.4. Use of other treatment options apart from anti-TB drugs..... | 27 |
| 3.8.5. Support needed by TB patients from relatives, healthy workers and the community | 28 |
| 3.8.6. Ways of promoting adherence to TB treatment..... | 28 |
| CHAPTER 4: DISCUSSION..... | 29 |
| 4.2 <i>Implications of the themes from the Focus Group Discussions</i> | 30 |
| 4.2.1. <i>Adherence to TB treatment and its challenges</i> | 30 |

| | |
|--|----|
| 4.2.2. Disclosure of TB status and perception of TB as a disease | 30 |
| 4.2.3. Use of other treatment options apart from anti-TB drugs | 31 |
| 4.2.4. Support needed by TB patients from relatives, healthy workers and the community . | 31 |
| 4.2.5. Ways of promoting adherence to TB treatment | 31 |
| CHAPTER 5. CONCLUSION AND RECOMMENDATIONS | 33 |
| 5.1. INTRODUCTION..... | 33 |
| 5.2. SUMMARY OF FINDINGS FROM THE STUDY | 33 |
| 5.2.1 To describe socio-cultural attitudes with the potential to influence adherence to TB treatment among TB patients through the use of focus group discussions (FGDs)..... | 33 |
| 5.2.2 To determine TB patients' knowledge of TB and its treatment through the use of a structured questionnaire | 33 |
| 5.2.3. To identify practices among TB patients with the potential to affect TB treatment adherence through the use of a questionnaire | 33 |
| 5.3. CONCLUSION | 34 |
| 5.4. RECOMMENDATIONS | 35 |
| 6.0 REFERENCES | 36 |

LIST OF FIGURES

| | |
|--|----|
| Figure 3. 1 Sex of the respondents..... | 15 |
| Figure 3. 2 Respondents' current occupation..... | 16 |
| Figure 3. 3 Ever heard of TB before this treatment?..... | 17 |
| Figure 3. 4 Gender against taking medication according to guidelines | 20 |
| Figure 3. 5 Disclose of TB Status | 22 |
| Figure 3. 6 Is it shameful to have TB?..... | 23 |
| Figure 3. 7 Other treatment option apart from Anti-TB drugs..... | 24 |

LIST OF TABLES

| | |
|--|----|
| Table 3. 1 Age distribution of the respondents | 15 |
| Table 3. 2 Marital status of the respondents | 15 |
| Table 3. 3 Respondent's level of education..... | 16 |
| Table 3. 4 Source of information on TB | 17 |
| Table 3. 5 Symptoms of TB | 18 |
| Table 3. 6 Is TB Contagious?..... | 18 |
| Table 3. 7 TB transmission | 19 |
| Table 3. 8 Individuals Knowledge about TB and Adherence to TB treatment | 19 |
| Table 3. 9 Chi-Square test..... | 20 |
| Table 3. 10 TB Medication According to Guidelines | 21 |
| Table 3. 11 Barriers to medication adherence..... | 21 |
| Table 3. 12 Regression Analysis..... | 22 |
| Table 3. 13 Why TB Patients do not disclose their status..... | 23 |
| Table 3. 14 Respondents views on TB..... | 23 |
| Table 3. 15 Practice of Combining TB Treatment and other Treatment options | 24 |
| Table 3. 16 Support needed by TB patients | 25 |
| Table 3. 17 promotion of TB treatment adherence by government | 26 |

LIST OF ACRONYMS

| | |
|--------|---|
| AIDS | Acquired Immune Deficiency Syndrome |
| ART | Anti-Retro Viral Therapy |
| CBCT | Cognitive based Behavior Change Technique |
| COMREC | College of Medicine Research and Ethics Committee |
| DOTS | Directly Observed Therapy Strategy |
| EID | Early Infant Diagnosis |
| FDC | Fixed Dose Combination |
| FGD | Focus Group Discussion |
| HIV | Human Immunodeficiency Virus |
| KMC | Kangaroo Mother Care |
| LTFU | Loss to Follow Up |
| MOH | Ministry of Health |
| SPSS | Statistical Package for Social Sciences |
| TB | Tuberculosis |
| VMMC | Voluntary Medical Male Circumcision |
| WHO | World Health Organization |

ABSTRACT

Background: Non-adherence to TB treatment poses a major challenge to Tuberculosis (TB) control programs because it increases the risk of treatment failure, relapse and the emergence of drug resistant tuberculosis.

Aim: The study aimed to describe socio-cultural and behavioral factors affecting adherence to TB treatment in Malawi.

Methods: A cross-sectional and mixed methods study design was used. A simple random sample of 200 participants who were on TB treatment at the time of the study and were getting their TB drugs from Bwaila hospital, in Lilongwe District, Malawi was selected. A pretested and structured questionnaire and Focus Group Discussions were used to collect data. Data were entered and analyzed using Microsoft excel. Focus Group Discussions data were subjected to a thematic content analysis.

Results: The majority of the respondents had ever heard about TB before being diagnosed with the disease (77.5%) and the most frequent source of information about TB was from friends, relatives and workmates (45.5%). 95.5% of the respondents disclosed their TB status to others and 90.0% of the respondents did not perceive having TB as shameful. 88.5% of the respondents reported taking their TB medication according to guidelines. While 88.5% of respondents reported that there were no barriers that prevent TB patients from adhering to their TB medication, the following barriers were reported by other respondents: travelled without medication (3.5%), forgetfulness (2.5%), long travel distance to health facility (2.5%), didn't understand dose instructions (1.5%).

Conclusions: This study found that TB patients who have the correct knowledge and information about TB and its treatment are more likely to adhere to treatment than those who have no knowledge about TB, and that having TB is not self-stigmatized and shameful. Despite the fact that most of the respondents reported facing no barriers preventing them from adhering to TB treatment, there were some reported barriers that prevent TB patients from adhering to treatment. There is a need therefore to address these barriers through support from the government and the community at large.

CHAPTER ONE. INTRODUCTION AND LITERATURE REVIEW

1.1 INTRODUCTION

Tuberculosis is an ancient disease, affecting humans throughout history. Robert Koch discovered its causative agent in 1882 and in 1944, the first anti-TB drug, Streptomycin, was discovered (1). Tuberculosis is an airborne disease caused by the bacterium *Mycobacterium tuberculosis* (*M. tuberculosis*). *M. tuberculosis* organisms are also called tubercle bacilli. The disease is spread via infectious droplet nuclei (1-5 microns in diameter) which are generated when persons who have pulmonary TB disease cough, sneeze, shout or sing. Depending on the environment, these tiny particles can remain suspended in the air for several hours. Transmission occurs when a person inhales droplet nuclei containing *M. tuberculosis* (2). It is estimated by the World Health Organization (WHO) that in 2018, 10.0 million people fell ill with TB globally with an estimated 1.2million TB deaths among HIV-negative people and an additional 251,000 deaths among HIV-positive people (3).

Malawi is one of the developing countries in Sub-Saharan Africa faced with many Tuberculosis (TB) health-related challenges. TB is considered a major public health problem accounting for one of the top ten killer diseases in the country and in 2007 Malawi declared TB as a national emergency in order to raise awareness and improve TB case detection (4) . In 2013, 20,335 new and relapse cases and 1,400 TB deaths were reported in Malawi (5). The national TB prevalence survey completed in 2014 showed a higher TB prevalence of 1014/100,000 compared to the previous estimated prevalence of 373/100,000 by the World Health Organization (6).

According to statistics in Malawi, TB treatment success rate was at 82% in 2016. Since then the number has steadily increased to 88% in 2018 (5) .

Adherence is defined by WHO as “the extent to which a person’s behavior- taking medication, following a diet, and or executing lifestyle changes, corresponds with agreed recommendations from a health care provider” (8). The use of the concept of adherence is important in that it conveys a partnership between patient and physician. It also allows for a more comprehensive assessment of factors related to adherence such as characteristics of the regimen, attitudes of the providers, socio-economic, cultural and environmental factors (8).

It is important to note the difference between the concepts adherence and compliance. In compliance, the guidelines given by physicians are assumed to be accurate and patient responses to treatment are measured according to these guidelines (9). Compliance contains a value statement and a bias for blame

in the event of suboptimal treatment responses. As the article explains, the term also exaggerates patient agency, as it suggests that all patients possess the ability to comply- or refuse to comply with anti-TB treatment, which it explains is far from true. According to the article “the poor are victims of structural violence, which includes factors such as poverty, racism and gender inequality which affects them from the time of exposure to the disease all the way up to their access to health care” (9). Therefore while addressing adherence we should not only address factors directly related to the patient but also the aforementioned factors related to structural violence, since as the article notes: “although adopting a patient-centered approach is important, it is nevertheless insufficient”. The challenge to researchers is to acknowledge that adherence is influenced by a complex array of factors, many of which are beyond the patient’s control, and to begin identifying and describing these factors. Adherence to long term therapy for chronic illnesses in developed countries averages 50%, with rates possibly being lower in developing countries (9).

Despite the magnitude and potential gravity of suboptimal medication adherence, a gold standard intervention remains elusive; a recent Cochrane review highlighted the paucity of effective interventions in current practice (10). Evidence suggests that complex, multifaceted interventions tailored to meet individual needs are most likely to be efficacious. Which is understandable given the complex, multistage process that is taking medication.

Having looked at the difference between compliance and adherence, it is important to note that in our study we were focusing on adherence and not compliance because adherence is not only influenced by patient related factors but by a number of other factors some of which are cultural and social so this study is hoping to contribute to determining those factors and coming up with interventions.

Non-adherent behavior is traditionally categorized into unintentional and intentional. Unintentional non-adherence includes behaviours arising from forgetfulness, misunderstanding and confusion. Intentional non-adherence describes patient choice that deviates from the prescribed medication regimen (10). Unintentional and intentional non-adherence are not mutually exclusive; thus an amalgam of these behaviours often exist in any one patient. An understanding of patient behavior and its underpinning psychology plus the wealth of factors, both internal and external that may influence medication taking is crucial to understand how to change patient behavior and thus improve medication adherence (10).

Historically, adherence interventions have encompassed behavior change techniques such as simplifying dosage regimens and providing adherence aids or education to address the practical issues of adherence in terms of knowing how and being able to take the medication as prescribed. Pooled data for such studies have demonstrated marginal effects, yet such interventions continue to form the cornerstone of routine

healthcare provision. These interventions may have particularly poor efficacy in cases of intentional non-adherence as the provision of persuasive advice may evoke further resistance to change (10). Thus, there has been a paradigm shift from the former adherence interventions premised on behaviour change to a novel approach premised on cognitive behaviour change techniques (CBCT).

Through an understanding of the challenges faced in changing behaviors and the motivation necessary to achieve change, novel cognitive based behavior change techniques (CBCT) have emerged. These interventions aim to change a patient's behavior by altering thoughts, feelings, confidence or motivation to adhere. CBCT interventions can vary widely in content such as incorporating techniques to enhance patient sense of self-efficacy, problem solving and increase motivation to adhere (10).

Treatment adherence is a process which needs to be fully understood in order to establish its determining factors (11). In order to control TB, effective treatment, as well as a clear understanding of the complex factors that undermine adherence is required. Most TB treatment regimens are long and patients fail to adhere to such long treatment regimens. The risk of treatment failure and the emergence of drug resistant TB are exacerbated by non-adherence to tuberculosis treatment. This poses as a challenge in the global fight against TB (12).

The impacts of non-adherence are many, including poor treatment outcomes and increased health-related costs. Additional consequences, of public health importance, occur with infectious diseases such as TB. Non-adherence to TB treatment might lead to an increased risk of drug resistance and a prolonged infectiousness, in addition to relapse and death. This in turn will have implications not only for the patient but also for the community at large.

1.2 LITERATURE REVIEW

Tuberculosis is an ancient disease, affecting humans throughout history. Robert Koch discovered its causative agent in 1882 and in 1944, the first anti-TB drug, Streptomycin, was discovered (1). Tuberculosis is an airborne disease caused by the bacterium *Mycobacterium tuberculosis* (*M. tuberculosis*). *M. tuberculosis* organisms are also called tubercle bacilli. The disease is spread via infectious droplet nuclei (1-5 microns in diameter) which are generated when persons who have pulmonary TB disease cough, sneeze, shout or sing. Depending on the environment, these tiny particles can remain suspended in the air for several hours. Transmission occurs when a person inhales droplet nuclei containing *M. tuberculosis* (2).

Adherence is defined by WHO as "the extent to which a person's behavior; taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" (8).

Poor adherence to treatment of chronic diseases including TB is a worldwide problem of striking magnitude. However, patients with TB are expected to have adherence levels greater than 90% in order to ensure cure. Failure of cure increases the risk of development of drug-resistant strains and spread of TB in the community, and this in turn increases morbidity and mortality (8).

In Southern Africa, tuberculosis remains a major public health concern with a huge economic impact in the region. Despite the global progress made in tackling TB, the burden is still unacceptably high in Southern Africa. The region has the highest per capita burden of TB; with countries such as Lesotho and Mozambique bearing the brunt of the disease, with one of the world's highest TB incidence at 665/100,000 and 551/100,000 population respectively (13). Indications by the World Health Organization shows that in 2017 alone 49,000 and 78,000 TB deaths occurred in Mozambique and South Africa respectively. The high burden of disease in the region is compounded by the high HIV/AIDS burden and intra-regional movement of people for labour and other economic activities facilitating cross-border movement of the disease (13).

One study that was conducted in 2018 in Jayapura Papua province in Indonesia on factors associated with non-adherence during tuberculosis treatment among patients treated with directly observed therapy strategy (DOTS) identified several factors related to non-adherence to TB treatment which included younger age, a family history of TB treatment, difficulties in accessing health care (i.e. distance/cost) and a history of moving residence in the past year which were all independent risk factors for non-adherence during TB treatment (14) In addition, treatment experience including the use of loose drugs versus fixed dose combination (FDC), having received any education from TB nurses and TB knowledge (cause of TB, how TB is transmitted and the consequence of incomplete TB treatment) were also significant risk factors associated with poor adherence or loss to follow up (LTFU) (14)

Similarly, another study that was conducted in southern Ethiopia on assessment of Anti-TB drug non adherence and associated factors among TB patients attending TB clinics in Arba Minch governmental health institutions also found out that one of the factors that contributes to non-adherence to anti-TB drugs among TB patients is distance to the health facility. The further away the health facility is; the less likely TB patients are to adhere to their treatment. Other factors that were identified in this study as having an effect on anti-TB drug non-adherence were side effects of the drugs and waiting time at the health facility with longer waiting time being a contributing factor for treatment non-adherence (15).

A study on non-adherence of new pulmonary tuberculosis patients to anti-tuberculosis treatment found out that one of the risk factors for non-adherence is lack of knowledge of importance of regular anti-tuberculosis treatment. Adherence to anti-tuberculosis treatment is improved by correct knowledge about TB and its treatment and this includes the ability to recognize symptoms, identify causes and transmission

routes and familiarity with the availability of cure (16). This study is in line with findings from another study which also depicted lack of or poor knowledge about TB as one of the contributing factors to treatment non adherence (17). Non-adherent patients are found to have less or no knowledge about TB and its treatment. Knowledge and health awareness and treatment seeking behavior of an individual are increased by education overall. Individuals who are literate are more likely to complete the treatment. Underutilization of TB services, delay in seeking diagnosis and poor treatment adherence are caused by lack of knowledge about the disease and stigmatization. Non adherence to treatment often results from inadequate knowledge or understanding of the disease and its treatment (18).

The study further found that another risk factor associated with treatment non-completion was poor awareness especially about symptoms and treatment results and consequence (18). Similarly, in China a study among internal migrants with pulmonary Tuberculosis revealed that lack of knowledge about TB treatment among TB patients was one of the most significant factors predicting non-adherence (17). As Muture B.N et al in their article note that an individual's health seeking behavior and adherence to treatment is influenced by a number of factors including knowledge attitudes and perceptions. The article further explains that one of the risk factors that determine default from treatment is poor knowledge about TB treatment (19). On knowledge and attitudes, all the articles are in line with their findings that knowledge about TB and its treatment plays a very big role in adherence with poor knowledge resulting in poor adherence. There have been no such reviews or studies done in Malawi and that served as a basis for conducting the study.

A 2008 literature review assessing the impact of medication regimen on adherence to chronic treatment, gave the following findings, although the authors underline the fact that it was difficult to obtain quality studies for the review (20). The authors mention that several factors have been identified as correlates of adherence to long term medication regimens and include patient factors such as depression, health literacy, and substance use disorders, environmental or contextual factors such as social support and socioeconomic status, clinician factors such as clear communication and the time spent explaining the disease and treatment, patient clinician relationship factors like trust, disease factors such as chronicity, symptom prominence, response to treatment, health care delivery factors such as waiting time, pharmacy and clinic convenience, and treatment regimen factors such as pill burden, regimen complexity, side effects, duration of needed treatment and dosing schedule (20) In addition, the review showed that in most areas of chronic illness study, there is some evidence that greater dosing frequency is associated with poorer adherence. In some areas such as diabetes, hypertension, HIV/AIDS, strong and consistent evidence exists that dose frequency and regimen complexity are related to poorer adherence. The authors recommend that regimens as simple as possible requiring the fewest doses per day would help improve adherence (20).

Understanding of the factors that prevent people from adhering to treatment and those factors that help in treatment completion is one of the key factors that will help in improving treatment outcomes and designing effective interventions (21). In Sub-Saharan Africa there are some patient-related factors that influence default from treatment such as; older age, the male sex, inadequate knowledge, ignorance on need for treatment compliance and stigma (21). Tuberculosis is a disease which can be cured if patients strictly adhere to treatment but despite this fact, a lot of patients fail to complete their treatment because of the side effects that are associated with the anti-TB drugs (14).

In most cases of non-adherence to TB medication therapy it has been found that there are several factors that contribute to non-adherence some of which are factors related to the patients such as discontinuation of medication after feeling better, forgetfulness and side effects. There are other factors like fear of stigma, long travel distance to the nearest health facility that have also been reported to contribute to non-adherence to TB medication therapy (11). Structural factors which include poverty and gender discrimination, social context factors, health service factors and personal factors which include attitudes towards treatment and illness are some of the factors that were identified to have an influence on adherence to TB treatment (20). Patients' knowledge about TB and its treatment alone is not enough to improve adherence to TB treatment and ensure that patients complete their treatment but efforts should rather be focused on supporting the patients and enabling them to overcome treatment barriers (21).

A systematic review conducted in Ethiopia on prevalence and determinants of anti-tuberculosis treatment non-adherence linked forgetfulness, fear of side effects of the drug, long waiting time in health institutions and long distance to health institution as significant factors predicting non-adherence (22). These findings are in agreement with another study conducted in Northwest Ethiopia in which they also found that drug side effects, forgetting to get medication among other factors were the main reasons for non-adherence in anti-TB treatment (23).

Many factors may lead to poor completion rates. On the surface, it appears that treatment outcomes for TB patients are an indication of the quality of care they receive. However, various authors have acknowledged that the complex interactions of a wide range of personal, socio-economic and infrastructural factors determine patient behavior. In fact, TB may not be cured and may recur in patients who do not take their medications for the full treatment period. These patients may also become resistant to the drugs, and drug-resistant TB may then be transmitted to other persons (9). Drug-resistant TB is difficult and expensive to treat. Thus, the most important step to prevent drug-resistant disease is to ensure that patients are cured at the first attempt. This threat of TB has provided a major momentum into the study of factors that determine patients' treatment adherence. For perhaps the first time, the world is faced with a health threat against which the only effective barrier is not only medical, but also behavioral

(9). According to the WHO report on adherence to long term therapies, adherence is influenced by several factors simultaneously. The ability of patients to follow treatment plans in an optimal manner is frequently compromised by more than one barrier. Adherence is a dynamic process that needs to be followed up. Improving adherence requires a continuous and dynamic process. Adherence requires a multidisciplinary approach which means that emphasis should not only be put on the patient but on the health workers, the family and the community as well if adherence is to be improved (9).

Over the years a number of strategies have been introduced to improve treatment adherence. These include Directly observed therapy (DOT), which until recently was endorsed by the WHO, the provision of free TB diagnostic and treatment services, the packaging of TB medicines in blister packs in individualized boxes and more recently the use of mHealth and wisepill boxes. Direct observation and supervision of patients is assumed to be more effective than self-administration to ensure that patients successfully complete the recommended six-to-nine-month chemotherapy (28). Weekly distribution of medicines is intended to be a more effective method than monthly distribution to induce adherence. The provision of free diagnosis and medicines aims to eliminate costs that deter patients from seeking care and completing treatment. Packaging medicines in blisters and storing them in individualized boxes aims to facilitate correct intake and adherence. Recent studies seem to support the rationale behind those decisions. For example, treatment completion rates are higher among patients with direct supervision rather than among those with no supervision (9).

Several ongoing national and global initiatives that are part of TB control programs also aim to address behavioral challenges. Programs that offer enablers such as transportation and food subsidies for patients assume that by minimizing costs the numbers of patients seeking diagnosis and care would increase. Similarly, incentive programs also assume that modifying the behaviors of health providers is necessary to increase treatment rates, for example, through offering monetary retributions for each patient who completes treatment (9).

From a TB control point of view, informed and motivated frontline health workers may contribute to positive treatment outcomes (9). Conversely, de-motivated and ill-informed health workers may contribute to interruptions of patients and the resulting transmission of TB in affected communities. This study has revealed some important dysfunctional aspects of attitudes of health care providers to TB patients (9). According to the study, non-compliance may result from differing interests or expectations of the patient and health care provider. Misperceptions or dissatisfaction with the patient-health care provider relationship may also be a cause of non-compliance. Indeed, the health provider-patient relationship has for a long time been regarded as important variable in compliance (9).

As Mekonnen explains that, adherence to long course tuberculosis treatment is complex, dynamic phenomenon with wide range of factors impacting on treatment taking behaviors (24)

Different control strategies have been adopted to fight against TB and to meet the above-mentioned targets. One such strategy is the Directly Observed Treatment, Short Course (DOTS) strategy, launched by WHO in 1994. After further subsequent expansion and clarification, the framework has been implemented in 182 countries (25). Major progress in TB control has been achieved with the expansion of DOTS which has also helped national TB programs, although the targets for TB control have not yet been met in every corner of the world. The five major components of this Strategy are: political commitment with increased and sustained financing, case detection through quality assured bacteriology standardized treatment with supervision and patient support, effective drug supply and management system, monitoring and evaluation system and impact measurement (25).

One of the most important components of the DOTS strategy is the direct observation of treatment (DOT), which implies that the patient should be supervised while taking treatment, most often by a health worker. DOT's purpose is to ensure that patients take the correct treatment regularly (to achieve cure and prevent development of drug resistance); to find out quickly when a dose has been missed by a patient, in order to find out why that happened and to try and solve it; and to monitor any disease or treatment associated problem e.g. side effects (25). It is necessary to ensure that supervision is done in a patient sensitive and contextualized manner and that it is aimed to enhance adherence among both patients and providers. In addition, identifying physical, financial, social and cultural barriers to TB treatment is very important to ensure proper patient support (25). The HIV epidemic has challenged DOTS as the sole strategy for TB control in Africa, because of the rising incidence of TB related to high HIV prevalence (25).

In Sub Saharan Africa, TB cases have markedly increased as a consequence of the HIV epidemic (26). According to a review of compliance to anti tuberculosis treatment and risk factors for defaulting treatment in Sub Saharan Africa, it was found that distance from the hospital, not being on the first course of TB medication, lack of repeated smears, unit transfer after the intensive phase, experiencing side effects, having no family support, poor knowledge about TB treatment, being more than 25 years old and use of public transport were some of the risk factors for defaulting treatment (26).

Most of the studies that have been conducted on determinants of TB treatment adherence have cited lack of or poor knowledge about TB treatment, experiencing drug side effects and long travel distance to health facility as risk factors for poor treatment adherence.

One of the main reasons for treatment default is knowledge. Studies in India, Swaziland, Thailand and Zambia (9) indicate that poor knowledge about the length of treatment predicts default behavior. Most defaulting patients interrupt treatment soon after they feel better and/or around two months after initiating chemotherapy. For example, findings from India suggest that patients' misconception of well-being with cure leads to default. Also, patients who did not know about potential side effects of medicines were more likely to default (9).

External constraints are also predictors of adherence. A study in Ethiopia (9) found that default is higher among patients who need longer travel distances to health center and pay for consultation (9). In Thailand, findings suggest that patients who cannot cope with the economic costs associated with treatment adherence (e.g. paying for transportation to go to clinics) are more likely to default. Besides poor knowledge, poverty largely accounts for default in Zambia: patients lack means to travel to the hospital and pay for consultation coupled with lost income for clinic attendance (9).

It is evident from the literature review that adherence to anti-Tuberculosis treatment is influenced by a number of factors some of which are patient related for example lack of or poor knowledge about TB and its treatment, experiencing side effects and forgetting to take medication while others maybe be socio-economical, infrastructural and cultural. This study hopes to determine such factors among TB patients in Malawi and also demonstrate how they influence adherence to TB treatment.

1.3 PROBLEM STATEMENT

Internationally, adherence to treatment for tuberculosis is recognized as a key principle of the TB elimination framework within low incidence countries, yet little is known of the personal, social and cultural factors that drive non-adherence across different groups in these settings. Poor adherence is cited as the primary reason for suboptimal clinical benefit and leads to poorer clinical outcomes, the development of drug resistance, increased duration of infectivity and consequent onward transmission of infection (27)

According to statistics in Malawi, TB treatment success rate was at 82% in 2016. Since then the number has steadily increased to 88% in 2018. On the other hand, the incidence is at 131/100,000 population (7). Poor adherence to treatment of chronic diseases including TB is a worldwide problem of striking magnitude. However, patients with TB are expected to have adherence levels greater than 90% in order to facilitate cure. Failure of cure increases the risk of development of drug-resistant strains and spread of TB in the community, and this in turn increases morbidity and mortality (15)

However, very little is known about social-cultural and behavioral factors that have the potential to influence treatment adherence practices among Malawians infected with TB. Yet in accordance with the

cognitive based behavior change techniques, if full adherence is to be achieved the focus must be on changing the patient's behaviour by altering thoughts, feelings, confidence or motivation to adhere.

The interventions can vary widely in content such as incorporating techniques to enhance patient sense of self-efficacy, problem solving and increase motivation to adhere, taking into account attendant social and cultural factors. This study therefore intends to explore the socio, cultural and behavioral factors that contribute and affect adherence to TB treatment among TB patients in Malawi and come up with recommendations on how to improve TB treatment success rates in Malawi.

TB treatment success rate is at 88% as of 2018, the remaining 12% is high and maybe attributed to non-adherence to treatment among other factors. As such it is critical for Malawi to interrogate the factors for non-adherence in order to inform holistic measures and strategies for addressing the problem of non-adherence and in turn increase the TB treatment success rate.

1.4 AIMS AND OBJECTIVES

The study aimed at describing socio-cultural and behavioral factors affecting adherence to TB treatment in Malawi.

The study had the following objectives:

1. To describe socio-cultural attitudes with the potential to influence adherence to TB treatment among TB patients through the use of focus group discussions (FGDs)
2. To determine TB patients' knowledge of TB and its treatment through the use of a structured questionnaire
3. To identify practices among TB patients with the potential to affect TB treatment adherence through the use of a questionnaire

1.5. RESEARCH QUESTIONS

1. What socio-cultural attitudes have the potential to influence adherence to TB treatment among TB patients in Malawi?
2. What is the TB patients' knowledge of TB and its treatment in Malawi?
3. What practices among TB patients have the potential to affect TB treatment adherence in Malawi?

1.6. LAYOUT OF THE THESIS

Format of the study comprises five chapters.

Chapter one offers a preamble to the study and is entitled Introduction and literature Review. It discusses the introduction to the study, background of the study, literature review, problem statement, aim of the Study, research objectives, research questions and layout of the thesis. This chapter one serves an important role in conveying information about the research.

Chapter Two discusses study area, research design, methodology and sample and sampling procedures, data collection, ethical consideration and all elements associated with design and methodology of the research.

Chapter Three presents the major findings from the questionnaires, which is mainly presented in graphs and tables.

Chapter Four analyses the major findings from the questionnaires and FGDs.

Chapter five provides a summary of what the study has established, this leads to the conclusion and recommendations made on the basis of the findings and analysis of the research study.

CHAPTER 2. RESEARCH DESIGN AND METHODOLOGY

2.1 STUDY SETTING

The study was conducted at Bwaila hospital which is situated in Lilongwe District, the capital city of Malawi. It is a 255 bed facility which serves a catchment population of 164,856 people within Lilongwe city. The population that it serves includes the urban, semi-urban and rural population. Apart from serving as a referral hospital for all facilities in Lilongwe, it also serves as a referral hospital to other populations outside the Lilongwe catchment area. The hospital provides the following services to both inpatients and outpatients: family planning; antenatal and postnatal care; maternity; Kangaroo Mother Care (KMC); HIV testing and counseling; Early Infant Diagnosis (EID); Anti-Retro Viral Therapy (ART); Tuberculosis screening; Voluntary Medical Male Circumcision (VMMC) and Laboratory services.

This facility was selected based upon the broader population that it serves which provided the study with the possibility of sampling people from a diversity of back grounds in terms of the social, cultural and economic factors thereby allowing the study to generate much more rich data and also because it is centrally located in the city of Lilongwe which makes it easily accessible.

2.2. RESEARCH METHODOLOGY

Methodology refers to the theory of how research should be undertaken. This study used mixed method. The mixed method was used in order to allow for triangulation of findings generated through one method

with another and also to allow for a much more in-depth analysis of the study findings, so as to inform deeper reflective conclusions and pragmatic recommendations.

2.3 RESEARCH DESIGN

There are a number of research designs that a research may be able to employ. For the purpose of this research a cross-sectional design aimed at describing socio-cultural and behavioral factors affecting adherence to TB treatment in Malawi was used.

2.4. TARGET POPULATION

The target population was TB patients accessing their TB drugs from Bwaila hospital.

2.5 RESPONDENTS

Respondents were selected from the Bwaila Laboratory (Lab) TB register which was used as the sampling frame. The register contains the following information: Lab serial number, date of sputum collection, receipt and examination, full patient's name, sex, age, complete address, name of referring facility, reason for sputum smear microscopy examination, results of sputum smear microscopy examination, TB registration number and remarks.

The selection of respondents was based on these inclusion criteria. The participant was an active TB patient on treatment and was above 18 years of age. Participants that were resident in Malawi for less than six months were excluded from the study.

2.6. SAMPLING STRATEGY

2.6.1. Sample frame and Sample Size

Through simple random sampling with replacement, 200 participants were selected from the Bwaila Laboratory TB register.

2.7. DATA COLLECTION TOOLS

Development of data collection tools (structured questionnaire and focus group discussions) was guided by objectives of the study and available literature. The data collection tools were aimed at responding to each objective in detail. Based on an extensive literature review, a 22-item interviewer administered questionnaire was developed and it was used to elicit information from respondents. The first section addressed demographic data of participants. Second section assessed participant's knowledge about TB and its treatment. Third section explored practices and attitudes among TB patients with the potential to affect TB treatment adherence. The last section explored ways of promoting adherence to TB treatment. The questionnaire was administered in English for those participants who were able to converse in

English (Appendix 1) and for those participants who were unable to converse in English it was administered in the local language of Chichewa (Appendix 4). The Chichewa responses were then translated back to English for data analysis.

While the questionnaires explored individual knowledge and attitudes about TB, the focus group discussions were aimed at capturing broader social and cultural influences and elucidated on the socio behavioral practices that affect adherence to TB treatment at community level (Appendix 2).

The FGDs were also conducted in Chichewa for those participants who were unable to converse in English (Appendix 5). A total of 3 FGDs were conducted and each group comprised of 6 participants and the sample was stratified based on age and gender.

These tools related to each other in the sense that the demographic data from the questionnaires informed us which age groups and gender were more likely not to adhere to TB treatment. At the same time, they also informed on the level of knowledge about TB and its treatment across different age groups and between males and females. The focus group discussions informed on people's beliefs, cultural norms and practices concerning TB and its treatment at society level.

2.8 DATA COLLECTION PROCESS

Eligible participants who were identified from the Laboratory TB register were contacted by telephone and they were informed about the study. Verbal consent was sought and after agreeing to participate in the study they were traced and followed to their respective homes where written consent was sought and secured. Following on obtaining consent from participants a questionnaire was administered in an isolated room to maintain privacy and to avoid disturbance from other family members. The duration of the questioning varied from 25 to 30 minutes. For focus group discussions (FGDs), they were conducted in three different areas in Lilongwe namely: Mtsiliza, Kandikole and Kaondo villages with TB patients accessing their TB drugs from Bwaila hospital. They were informed about the study and asked for consent to participate. After consenting they were put in groups comprising six to ten people and the sample was stratified based on age and gender. Three FGDs were conducted. The discussions run for approximately 45 minutes and there was a note taker who was taking notes of what was being discussed. The principal investigator guided the discussions.

2.9 PILOTING AND VALIDATION

Once the data collection tools were developed, they were piloted with five voluntary non-participants in order to validate if the tools were able to capture all the needed information. It also provided the opportunity to get conversant with the tools.

2.10 DATA ANALYSIS

Data was analyzed using Microsoft excel and presented through the use of tables, graphs and verbal descriptions.

Qualitative data was subjected to a thematic content analysis. The analysis was done manually using general purpose software. Microsoft word was used for this process.

2.11. ETHICAL CONSIDERATIONS

The study protocol was submitted to College of Medicine research and ethics committee (COMREC) and BREC for ethical review and it was approved. To ensure privacy, participant's responses to the questionnaire and FGDs were kept in a locked cabinet and later the data was entered in a password protected computer. Only the investigator, research assistant and research supervisor had access to the data. To ensure confidentiality, participants were only identified by code numbers throughout the study.

A number of ethical considerations guided the study. This included: obtaining informed written consent from the participants whereby the purpose of the study was explained to all participants sampled to get their consent; explaining to the participants about their rights; and respecting the privacy of the participants. The respondents were assured that their participation was voluntary hence they had the right not to participate. An information sheet and a consent form were used to inform the participants about the background, the intention and confidentiality of the research. The consent form had two versions, the English version and the Chichewa version and was administered depending on what language the participant was comfortable with. (Appendix 3) The interviews were also carried out in private.

CHAPTER 3. RESULTS

3.1. Introduction

Following collection of data from respondents, it was analysed using Microsoft excel and presented through the use of tables, graphs, and verbal descriptions. The results of the research are discussed below.

3.2. Social demographic characteristics of the respondents.

3.2.1. Age

From table 3.1 below, the research has established that the majority of the participants were those aged 39 years and above, 73 (36.5 %). While the lowest number of respondents were those aged between 18 -22 years and they were 17 (8.5%) of the total respondents.

Table 3. 1 Age distribution of the respondents

| | | Frequency | Percent |
|--|----------|-----------|---------|
| | 18-22 | 17 | 8.5 |
| | 23-27 | 27 | 13.5 |
| | 28-33 | 42 | 21.0 |
| | 34-38 | 41 | 20.5 |
| | 39 above | 73 | 36.5 |
| | Total | 200 | 100.0 |

3.2.2. Sex and Marital status.

As shown in figure 3.1 below, the majority of participants were men 61 % (122). On marital status distribution, 56% (112) of the participants were married; while 44 (22%) were single; 22 (11%) were divorced, 14 (7%) were separated and 8 (4%) were widowed. (Refer to Table 3.2).

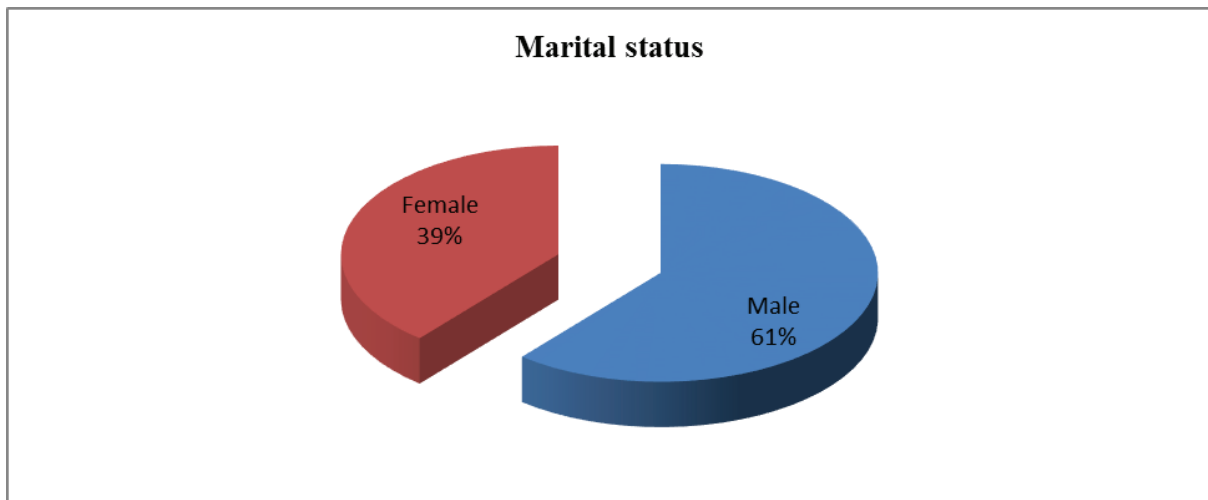


Figure 3. 1 Sex of the respondents.

Table 3. 2 Marital status of the respondents

| | | Frequency | Percent |
|--|-----------|-----------|---------|
| | Single | 44 | 22.0 |
| | Married | 112 | 56.0 |
| | widowed | 8 | 4.0 |
| | divorced | 22 | 11.0 |
| | separated | 14 | 7.0 |

| | | | |
|--|-------|-----|-------|
| | Total | 200 | 100.0 |
|--|-------|-----|-------|

3.2.3 Educational status.

On the participants' level of education, 88 participants (44%) had attended at least primary education; 86 (43%), secondary; while only 10 (5%) had done their tertiary education (Refer Table 3.3 Below).

Table 3. 3 Respondent's level of education

| | | Frequency | Percent |
|--|-----------|-----------|---------|
| | None | 16 | 8.0 |
| | primary | 88 | 44.0 |
| | secondary | 86 | 43.0 |
| | tertiary | 10 | 5.0 |
| | Total | 200 | 100.0 |

3.2.4. Current Occupation

A larger population of the respondents were employed 36 %(72) (Refer to figure 3.2)

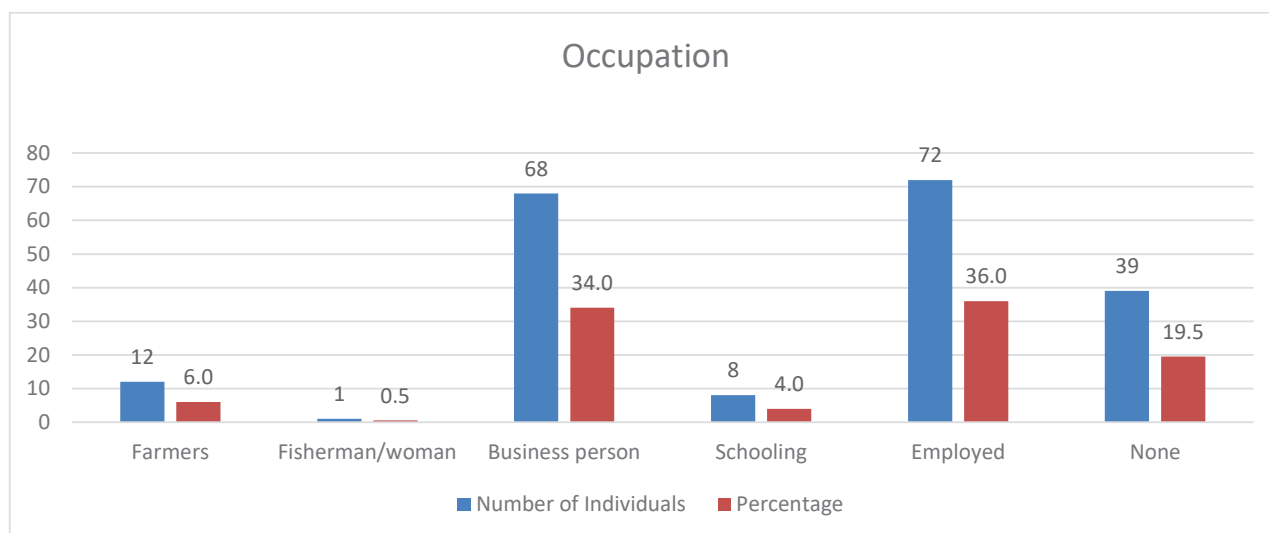


Figure 3. 2 Respondents' current occupation.

3.3 Participants' knowledge about TB and its treatment.

The majority of respondents (77.5%) had ever heard about TB before being diagnosed with the disease and the most frequent source of information about TB was from friends, relatives, and workmates representing 45.5%. 22.5% of the respondents had never heard about TB. Only 6% of the respondents heard from school. (Refer to figure 3.3 & and table 3.5 below)

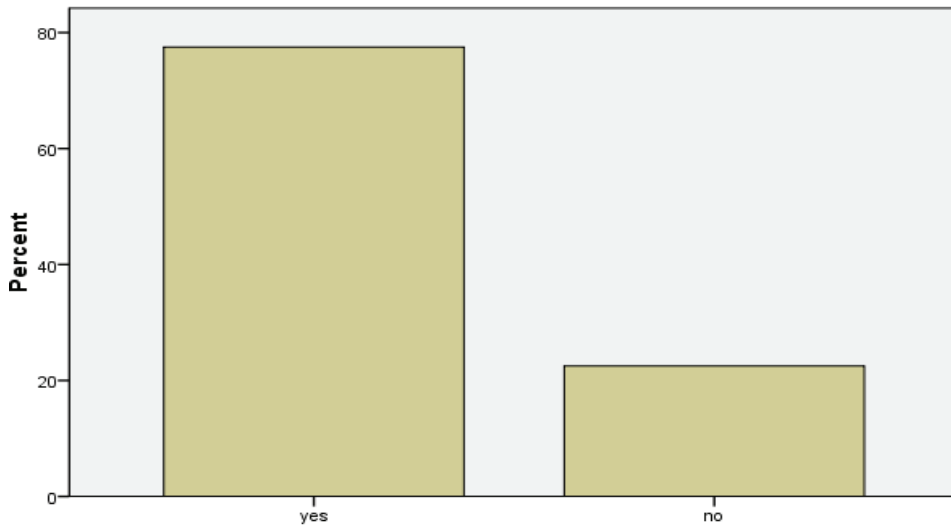


Figure 3. 3 Ever heard of TB before this treatment?

Table 3. 4 Source of information on TB

| Source of information on TB Crosstabulation | | | | |
|---|-------------------------------|------------------|----|------------|
| Count | | | | |
| | | Ever heard of TB | | Percentage |
| | | Yes | no | |
| Source of information on TB | friends, relatives, workmates | 91 | 0 | 45.5 |
| | healthy workers | 20 | 0 | 10 |
| | newspapers | 1 | 0 | 0.5 |
| | Radio | 24 | 0 | 12 |
| | television | 1 | 0 | 0.5 |
| | Booklet | 5 | 0 | 2.5 |
| | School | 12 | 0 | 6 |
| | None | 0 | 45 | 22.5 |
| | Others | 1 | 0 | 0.5 |
| Total | | 155 | 45 | 100 |

3.3.1 What symptoms can show that a person has TB?

The findings show that on symptoms of TB, “coughing for over 3 weeks”, was the most frequently mentioned symptom representing 50% followed by “coughing with sputum” which represented 18.5%. 11% of the respondents claimed not knowing any symptom of TB. The results on symptoms of TB have been summarized in Table 3.5 below.

Table 3. 5 Symptoms of TB

| Symptom | Frequency | Percent |
|---|-----------|---------|
| coughing with sputum | 37 | 18.5 |
| coughing for over 3 weeks | 100 | 50.0 |
| periodic increase of temperature for over 3 weeks | 11 | 5.5 |
| blood in sputum | 2 | 1.0 |
| loss of appetite | 4 | 2.0 |
| night sweating | 10 | 5.0 |
| pain in the chest | 11 | 5.5 |
| total weakness | 1 | .5 |
| weight loss | 2 | 1.0 |
| Don't know | 22 | 11.0 |
| Total | 200 | 100.0 |

Respondents were asked whether TB was contagious, 181 respondents answered yes representing 90.5% while 4% answered no and 5.5% claimed they did not know whether TB was contagious or not. (Refer to Table 3.7 below)

Table 3. 6 Is TB Contagious?

| | Frequency | Percent |
|------------|-----------|---------|
| yes | 181 | 90.5 |
| no | 8 | 4.0 |
| don't know | 11 | 5.5 |
| Total | 200 | 100.0 |

Furthermore, results indicate that majority of the respondents (79%) responded that TB is transmitted through the air when coughing, and on the other hand 11.5% did not indicate on what they know. One respondent said TB is transmitted through blood.

Table 3. 7 TB transmission

| | Frequency | Percent |
|--------------------------------------|-----------|---------|
| Through the air when coughing | 158 | 79.0 |
| Through blood | 1 | .5 |
| sharing food with an infected person | 5 | 2.5 |
| you're born with it | 9 | 4.5 |
| Don't know | 4 | 2.0 |
| Others | 23 | 11.5 |
| Total | 200 | 100.0 |

Table 3. 8 Individuals Knowledge about TB and Adherence to TB treatment

| Ever heard of TB * Do you take your TB medication according to guidelines * How is TB transmitted Cross tabulation | | | | | |
|---|------------------|-----|--|----|-------|
| How is TB transmitted | | | Do you take your TB medication according to guidelines | | Total |
| | | | yes | no | |
| Through the air when coughing | Ever heard of TB | yes | 119 | 12 | 131 |
| | | no | 25 | 2 | 27 |
| | Total | | 144 | 14 | 158 |
| Through blood | Ever heard of TB | no | 1 | | 1 |
| | Total | | 1 | | 1 |
| sharing food with an infected person | Ever heard of TB | yes | 2 | | 2 |
| | | no | 3 | | 3 |
| | Total | | 5 | | 5 |
| you're born with it | Ever heard of TB | yes | 4 | 2 | 6 |
| | | no | 2 | 1 | 3 |
| | Total | | 6 | 3 | 9 |
| Don't know | Ever heard of TB | yes | 2 | 0 | 2 |
| | | no | 0 | 2 | 2 |
| | Total | | 2 | 2 | 4 |
| Others | Ever heard of TB | yes | 11 | 3 | 14 |
| | | no | 8 | 1 | 9 |
| | Total | | 19 | 4 | 23 |
| Total | Ever heard of TB | yes | 138 | 17 | 155 |
| | | no | 39 | 6 | 45 |
| | Total | | 177 | 23 | 200 |

Results indicate that all the respondents said that TB was curable representing 100%. From table 3.8 above, and using the parameters set, it has been established that there were a total of 131 respondents who indicated that they have heard about TB and that TB is spread through the air when coughing. Out of these 131 respondents, 12(9.2%) indicated that they don't take their drugs according to the guidelines and 119(90.8%) indicated that they take their medication according to the guidelines.

The study further tested if gender had an effect on the knowledge on whether patients take TB medication according to guidelines or not. Figure 3.4 presents a visual indication on whether the association exist or not. The chi-square test table confirms that there was no association between gender and patients taking medication according to guidelines ($\chi^2(2) \geq 1.822$, $p=0.177$).

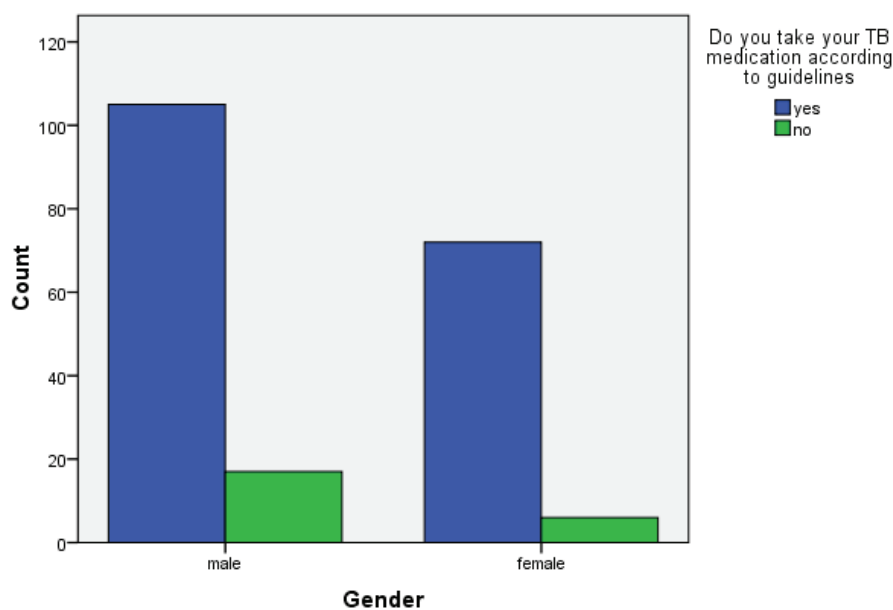


Figure 3. 4 Gender against taking medication according to guidelines

Table 3. 9 Chi-Square test

| | Value | df | Asymp. Sig. (2-sided) | Exact Sig. (2-sided) | Exact Sig. (1-sided) |
|------------------------------------|--------------------|----|-----------------------|----------------------|----------------------|
| Pearson Chi-Square | 1.822 ^a | 1 | .177 | | |
| Continuity Correction ^b | 1.260 | 1 | .262 | | |
| Likelihood Ratio | 1.911 | 1 | .167 | | |
| Fisher's Exact Test | | | | .256 | .130 |
| Linear-by-Linear Association | 1.812 | 1 | .178 | | |
| N of Valid Cases ^b | 200 | | | | |

| | | | |
|---|--|--|--|
| a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 8.97. | | | |
| b. Computed only for a 2x2 table | | | |

3.4. Practices among TB patients with the potential to affect TB treatment Adherence.

3.4.1. Do you take your TB medication according to guidelines?

The majority of the respondents, 177 (88.5) said that they take their TB medication according to guidelines.

Table 3. 10 TB Medication According to Guidelines

| | | Frequency | Percent |
|--|-------|-----------|---------|
| | yes | 177 | 88.5 |
| | no | 23 | 11.5 |
| | Total | 200 | 100.0 |

3.4.2. What are some of the challenges/barriers that prevent you from adhering to your medication?

On challenges or barriers that prevent TB patients from adhering to their TB medication, the majority of the respondents, 177 (88.5%) said that there were none, while 3.5% said they travelled without medication and 2.5% cited forgetfulness.

Table 3. 11 Barriers to medication adherence

| | | Frequency | Percent |
|--|--|-----------|---------|
| | Forgetfulness | 5 | 2.5 |
| | travelled without medication | 7 | 3.5 |
| | long travel distance to healthy facility | 4 | 2.0 |
| | thought that they were cured | 1 | .5 |
| | too weak to travel to healthy facility for drug refill | 2 | 1.0 |
| | None | 177 | 88.5 |
| | didn't understand dose instructions | 3 | 1.5 |
| | Others | 1 | .5 |
| | Total | 200 | 100.0 |

3.5. Socio-cultural attitudes with the potential to influence adherence to TB treatment among TB patients

3.5.1. Did you disclose your TB status to others?

The Pie chart below shows that on TB status disclosure, 95.5% of the respondents said they disclosed their TB status to others while 5.0% did not disclose. A logistic regression was performed to ascertain the effects of education, marital status and gender on the likelihood that the results influenced participant's disclosure of TB status. The results from the logistic regression shows that the variables were not statistically significant as the p values were greater than 0.05.

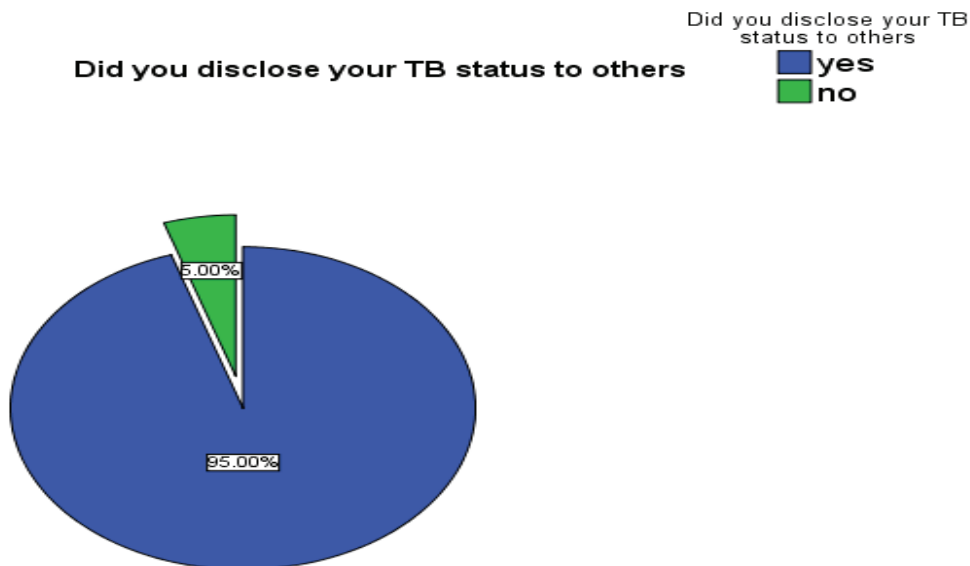


Figure 3. 5 Disclose of TB Status

Table 3. 12 Regression Analysis

| Variables not in the Equation | | | | | |
|-------------------------------|--------------------|----------------|-------|----|------|
| | | | Score | df | Sig. |
| Step 0 | Variables | Education | 3.735 | 1 | .053 |
| | | Marital status | .519 | 1 | .471 |
| | | Gender | 4.252 | 1 | .039 |
| | Overall Statistics | | 8.730 | 3 | .033 |

3.5.2. Why didn't you disclose your TB status?

Asked why they did not disclose their TB status to others, 95.0% of the respondents said there was no reason while 4.0% said people will avoid them and 1.0% said they will lose their friends.

Table 3. 13 Why TB Patients do not disclose their status

| | | Frequency | Percent |
|--|------------------------|-----------|---------|
| | I will lose my friends | 2 | 1.0 |
| | People will avoid me | 8 | 4.0 |
| | none | 190 | 95.0 |
| | Total | 200 | 100.0 |

3.5.3. Is it shameful to have TB?

Asked whether it was shameful to have TB, 95.0% of the respondents said no while 5.0% said yes.

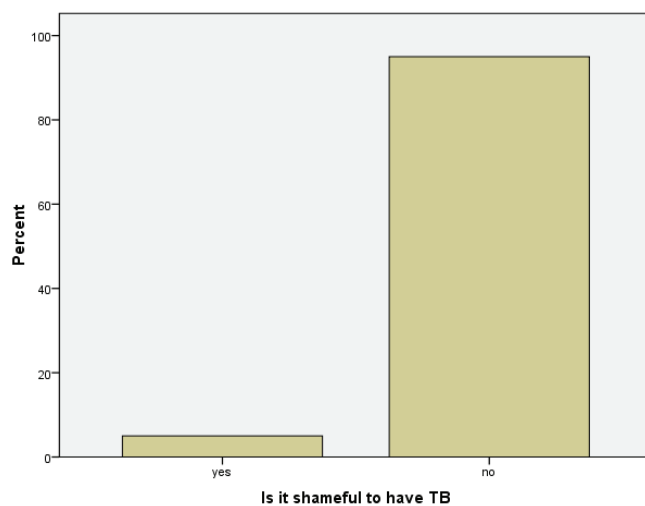


Figure 3. 6 Is it shameful to have TB?

3.5.4. Why is it shameful to have TB?

Asked why it was shameful to have TB, 94.5% of the respondents cited no reason while 2.5% said because people associate it with HIV, 2.5 % of the respondents cited fear of stigma.

Table 3. 14 Respondents views on TB

| | | Frequency | Percent |
|--|--------------------------------------|-----------|---------|
| | because people associate it with HIV | 5 | 2.5 |

| | | | |
|--|----------------|-----|-------|
| | fear of stigma | 5 | 2.5 |
| | None | 189 | 94.5 |
| | Others | 1 | .5 |
| | Total | 200 | 100.0 |

3.5.5. What other treatment options have you sought apart from taking Anti-TB drugs?

Findings presented on Figure 3.7 shows that 10.5% of the respondents said apart from taking anti-TB drugs they had also taken herbal medicine while 89.5% had not sought any other TB treatment option.

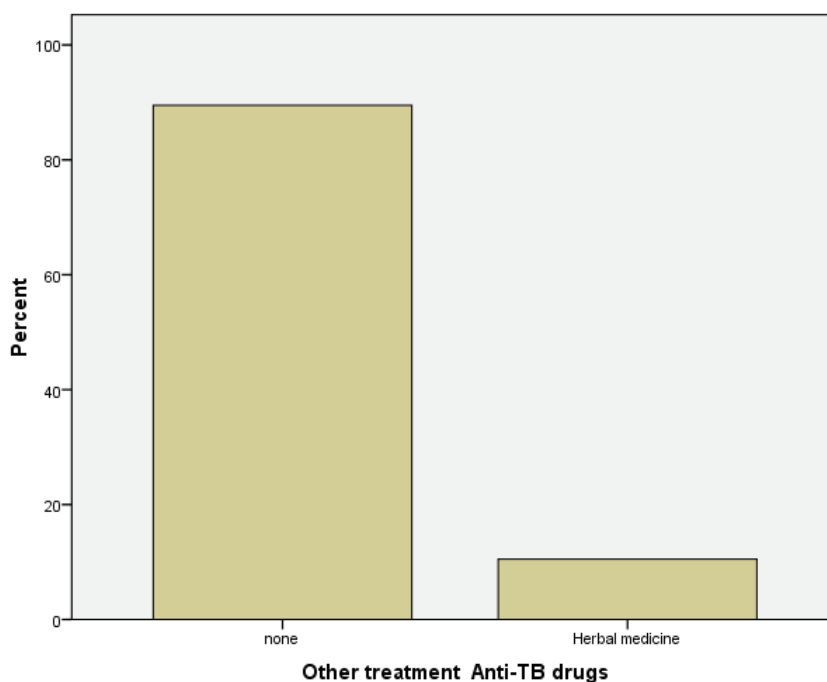


Figure 3. 7 Other treatment option apart from Anti-TB drugs

3.5.6. Is it a common practice to combine TB medication with other treatment options?

Asked whether it was common to combine TB medication with other treatment options, 26.5% of respondents said yes while 73.0% said no and only 0.5% said they did not know.

Table 3. 15 Practice of Combining TB Treatment and other Treatment options

| | | Frequency | Percent |
|--|------------|-----------|---------|
| | yes | 53 | 26.5 |
| | no | 146 | 73.0 |
| | don't know | 1 | .5 |

| | | |
|-------|-----|-------|
| Total | 200 | 100.0 |
|-------|-----|-------|

3.6. Support needed by TB patients from relatives and the community

On support needed by TB patients from relatives and the community, the majority of the respondents, 49.5% mentioned daily reminder to take TB medication, while 25.0% mentioned provision of food and only 0.5% mentioned financial support.

Table 3. 16 Support needed by TB patients

| | Frequency | Percent |
|--|-----------|---------|
| Daily reminder to take TB medication | 99 | 49.5 |
| provision of food | 50 | 25.0 |
| help with household chores | 5 | 2.5 |
| collection of TB drugs from healthy facility | 12 | 6.0 |
| None | 13 | 6.5 |
| not sure | 7 | 3.5 |
| moral support | 13 | 6.5 |
| financial support | 1 | .5 |
| Total | 200 | 100.0 |

3.7. Ways of promoting adherence to TB treatment

3.7.1. What do you think the government can do to promote adherence to TB treatment?

Asked on ways of promoting adherence to TB treatment, 24.0% of the respondents said conducting TB awareness campaigns while another 24.0% said provision of food supplements like soya, chiponde, milk and cooking oil, 12.5% mentioned supportive home visits, 9.5% mentioned availability of TB drugs in all health facilities across the country, 11.5% were not sure and 12.5% said none. (Refer to Table below)

Table 3. 17 promotion of TB treatment adherence by government

| | Frequency | Percent |
|--|-----------|---------|
| conducting TB awareness campaigns | 48 | 24.0 |
| provision of food supplements e.g. soya, chiponde, milk, cooking oil | 48 | 24.0 |
| financial support | 4 | 2.0 |
| physical pill count by healthy personnel | 6 | 3.0 |
| supportive home visits | 25 | 12.5 |
| availability of TB drugs in all heathy facilities across the country | 19 | 9.5 |
| not sure | 23 | 11.5 |
| None | 25 | 12.5 |
| Others | 2 | 1.0 |
| Total | 200 | 100.0 |

3.8. Themes emerging from the Focus Group Discussions

This section covers the findings of the Focus Group Discussions (FGDs) that were conducted in the areas of T/A Njewa at Mtsiliza village, T/A Tsabango at Kandikole and Kaondo villages. In summary the FGDs were conducted in two T/As and covering three villages. The following themes were identified from the FGDs:

- Adherence to TB treatment and its challenges
- Disclosure of TB status
- Perception of TB as a disease
- Use of other treatment options apart from anti-TB drugs
- Support needed by TB patients from relatives, healthy workers and the community
- Ways of promoting adherence to TB treatment

3.8.1. Adherence to TB treatment and its challenges

The research established that in the area of T/A Tsabango at both Kandikole and Kaondo villages, TB patients don't take their drugs according to the guidelines. It was indicated that some TB patients in the said villages throw their drugs in the toilets while others miss taking their drugs because of drinking beer. For example, at Kandikole village one member was captured as saying, “*Anthu ena amapezeka kuti aledzera mowa ndiye amaiwala kumwa mankhwala chifukwa choledzera*” Meaning some TB patients are

observed taking beer and as a result they forget to take their medication due to the influence of alcohol. Secondly, at Kaondo village, one member was captured as saying that, *anthu ena amadumphitsa kumwa mankhwala, ena amataya mankhwalaku toilet.*'' ''*Zimadabwitsa kuti anthu ena amadwala chifuwa cha TB mobwelezabweleza chomwe chili chitsimikizo kuti samamaliza mankhwala awo*'' Meaning that some TB patients do not take their medication according to the guidelines and others throw the drugs in the toilet. It is surprising to see some people suffering from TB repeatedly, a situation which demonstrates that some TB patients don't finish their dosage.

The FGDs also established that TB drugs have adverse side effects, such as feeling very weak, dizziness and feeling hungry. These side effects were cited as some of the reasons that deter others from finishing their dosage. Additionally, others also indicated that the TB pills are huge in size and therefore difficult to swallow. The other point was that the health wellbeing of some patients improves greatly before finishing the dosage and as such they don't see the need for finishing their dosage.

3.8.2. Disclosure of TB status

The disclosure of TB status was established to be a minor challenge. It was established that TB patients are able to disclose their status to their relatives and other members of the community. They felt that TB is just like any other disease because it can attack anyone regardless of one's social-economic status. However, at Kandikole village, under T/A Tsabango one member indicated that he did not disclose his status because he was afraid of stigma and discrimination which would have been levelled against him due to his status. The respondent was captured as saying, ''*ndimawopa kuti ndikauza anthu ayamba kundisala komanso ikhala ngati nkhani yonditozera*''

3.8.3. Perception of TB as a disease

In all the three villages covered, the FGDs established that it was not shameful to have TB. People in these areas perceived TB as any other disease and they did not feel ashamed that they were diagnosed with TB.

3.8.4. Use of other treatment options apart from anti-TB drugs

The FGDs revealed that some TB patients sought other treatment options apart from taking anti- TB drugs. A case in point is at Mtsiliza Village, under T/A Njewa where one member was captured as saying, ''*Anthu ena amakhulupirira kwambiri mankhwala a zitsamba kuposa a chipatala pa chifukwa chimenechi, anthu amatha kumaphatikiza mankhwalawa.*'' Meaning that some people believe in traditional medicine more than the conventional medicine and as such they combine the two. Secondly, at Kandikole village, under T/A Tsabango, it was also established that some TB patients combine the Anti-TB drugs with herbal medicine called Teras. The respondent was captured as saying, ''*Ndidayesapo mankhwala ama Chinese otchedwa Teras- mankhwala amenewa ndi a zitsamba.*'' The message from the

two scenarios is clear that TB patients apart from taking their anti- TB drugs also take traditional medicine as a supplement.

3.8.5. Support needed by TB patients from relatives, healthy workers and the community

Most members indicated that they expect their relatives to remind them consistently about the dates which they need to go to hospital for drug refill and also the time of taking drugs. Additionally, they also stated they expect their relatives to supply them with adequate food and also encourage them to eat adequate food since the anti- TB drugs make them feel hungry and weak. One respondent from Kandikole and another one from Mtsiliza stated that they expect the healthy workers to give them advice on TB and also to encourage them to take their TB medication according to guidelines. They also expect to be received with courtesy at the hospital.

3.8.6. Ways of promoting adherence to TB treatment

Most of the participants under this theme indicated that Government should provide them with food related items such as ‘soya flour’, maize flour and cooking oil. For example, at Kaondo Village, under T/A Tsabango, one member stated as follows, ‘*Boma likuyenera kumagawa zakudya monga chimanga kwa anthu omwe akumwa mankhwala a TB chifukwa timakhala ofooka ndipo sitingathe kugwira ntchito kuti tidzipezere chakudya.*’ Meaning that government should consider providing free food support to TB patients because in most cases they are weak and cannot afford to work and find food to feed themselves.

Secondly, participants also indicated that government should intensify public awareness campaign messages about TB screening, and taking TB medication according to guidelines. Another respondent stated that government should make sure that there is availability of anti-TB drugs in all healthy facilities across the country because some TB patients travel long distances to collect anti-TB drugs only to be told that the drugs are not available.

CHAPTER 4: DISCUSSION

4.1. INTRODUCTION

The objective of this study was to describe the socio-cultural and behavioral factors that affect adherence to TB treatment in Malawi. The use of both qualitative and quantitative methods has enabled us to understand the factors that prevent TB patients from adhering to treatment. This chapter will discuss those factors in detail and ways of promoting adherence to TB treatment. Five themes emerged from the focus group discussions which will also be discussed in detail.

TB patients who have the correct knowledge about TB and its treatment are more likely to adhere to treatment than those who have no knowledge about TB. This is actually in line with findings from other studies in which lack of knowledge about TB and its treatment was identified as a contributing factor to non-adherence (16) (18) (17). Poor knowledge about TB treatment is one of the risk factors that determine default from treatment (19). From our study, 77.5% of the respondents had knowledge about TB and 50.0% of them were able to mention at least one correct symptom of TB (coughing for over 3 weeks). This display of knowledge can be attributed to the fact that almost half of the respondents had attended secondary education (43.0%).

Majority of the respondents from our study (95.0%) felt that having TB is not a shameful thing. They felt that TB is just like any other disease and it can attack anyone regardless of one's social-economic status. This can further be evidenced by the number of respondents who were able to disclose their TB status to others (95.0%). It is actually in quite contrast with findings from one study in which having TB was found to be a contributing factor to treatment non-adherence mainly because of fear of stigma from the community. Majority of the respondents in that study indicated that they would feel embarrassed and ashamed if they learned they had TB (18)

4.2 Implications of the themes from the Focus Group Discussions

4.2.1. Adherence to TB treatment and its challenges

Alcohol abuse was perceived as a major barrier to TB treatment adherence. It was indicated among the respondents that some TB patients miss taking their TB drugs because of recurring use of alcohol. Some TB patients are often seen taking beer and as a result they forget to take their medication due to the influence of alcohol. This is in line with findings from one study in which the recurring use of alcohol was found to be a factor which leads to treatment non-adherence (24).

Further to this, inadequate supply of food was found to be another possible factor for non-adherence to TB treatment. Anti-TB drugs usually makes TB patients feel hungrier and crave more food as such inadequate food supply may pose a challenge to treatment adherence (18).

The study also established that side effects of the TB drugs such as feeling weak, dizziness and feeling hungry could be another possible factor for non-adherence to TB treatment. These side effects were cited as some of the reasons that deter other patients from finishing their course of treatment (23) (24) (26).

Additionally, other respondents indicated that the TB pills are huge in size which makes it difficult to swallow as such most TB patients prefer to skip taking the pills which eventually leads to treatment non-adherence.

Another possible factor cited by the respondents that prevents TB patients from adhering to treatment was the feeling of improvement after starting treatment. The health of some TB patients greatly improve after the first few weeks of treatment and as such they stop taking the medication all together thinking that they are cured. A number of studies have reported feeling cured as the main reason for treatment non-adherence and eventual default from treatment (16,18).

4.2.2. Disclosure of TB status and perception of TB as a disease

The disclosure of TB status was established to be a minor challenge in our study. The majority of the respondents indicated that they are able to disclose their TB status to their relatives and other members of the community. Additionally, in all the three villages covered, the FGDs established that people felt that it was not shameful to have TB. People in these areas perceived TB just like any other disease. This is contrary to findings from another study in which having TB was perceived as embarrassing and shameful (16).

4.2.3. Use of other treatment options apart from anti-TB drugs

The study established that some TB patients apart from taking the conventional anti-TB drugs sought other treatment options. These other treatment options mainly include the use of herbal medication and one particular herbal medication commonly used is “TERAS”. As such some patients opt to use the herbal medication instead of the conventional anti-TB drugs. This poses as a challenge to TB treatment adherence. These findings are similar to other findings from another study in which the use of herbal medication was reported as a risk factor for treatment default (18).

4.2.4. Support needed by TB patients from relatives, healthy workers and the community

Since forgetfulness was cited as one of the barriers that prevents TB patients from adhering to treatment, most of the respondents indicated that they expect their relatives/family to remind them consistently about the dates for drug refill at the healthy facility and also a daily reminder to take their medication.

Due to the feeling of increased hunger experienced by TB patients on treatment, it was indicated that not only do TB patients expect to be supplied with adequate amounts of food by their relatives but also expect encouragement to actually take the food.

Healthy workers are expected to give advice on TB and also encourage the TB patients to stick to the guidelines for taking their TB medication. Further it was indicated that TB patients expect to be received with courtesy at the healthy facility.

4.2.5. Ways of promoting adherence to TB treatment

Since the feeling of increased hunger experienced by TB patients was reported as a factor that prevents TB patients from adhering to treatment, the provision of food supplements by the government such as: Soya, maize flour and cooking oil was cited as one of the major ways of promoting adherence to TB treatment. If one has adequate supply of food, they can easily take their TB medication knowing that once they feel hungry there will be enough food readily available for them. Further to this, the fact that side effects of the anti-TB drugs, one of which includes feeling weak was indicated in our study as one of the challenges to TB treatment adherence, it justifies the provision of food supplements by the government since in most cases TB patients who are weak cannot afford to work and provide for their families. So these patients could really benefit from the provision of these food supplements.

Another way of promoting adherence to TB treatment that was identified was for government to intensify public awareness campaign messages about TB and its treatment. This will in turn ensure that people have the correct knowledge about TB and its treatment which is key to TB treatment adherence as this study and other previous studies have revealed.

Availability of anti-TB drugs in all healthy facilities across the country was also identified in our study to be one of the ways of promoting adherence to TB treatment. Shortage of anti-TB drugs in some healthy facilities is another factor that prevents TB patients from adhering to treatment. Some TB patients travel long distances to a healthy facility to collect anti-TB drugs only to be told that the drugs are not available. This discourages them and in the long run leads to treatment non-adherence. It is therefore government's responsibility to ensure that anti-TB drugs are available in all healthy facilities.

CHAPTER 5. CONCLUSION AND RECOMMENDATIONS

5.1. INTRODUCTION

The chapter aims at drawing conclusions from the discussions and analysis of the research findings on which basis some recommendations are being advanced. The study aimed to describe socio-cultural and behavioral factors affecting adherence to TB treatment in Malawi. The conclusions are made in the frame work of the following objectives stated in Chapter One:

5.2. SUMMARY OF FINDINGS FROM THE STUDY

5.2.1 To describe socio-cultural attitudes with the potential to influence adherence to TB treatment among TB patients through the use of focus group discussions (FGDs)

Alcohol abuse was perceived as a major barrier to TB treatment adherence. It was indicated among the respondents that some TB patients miss taking their TB drugs because of recurring use of alcohol. Some TB patients are often seen taking beer and as a result they forget to take their medication due to the influence of alcohol. This is in line with findings from one study in which the recurring use of alcohol was found to be a factor which leads to treatment non-adherence.

The study also established that side effects of the TB drugs such as feeling weak, dizziness and feeling hungry could be another possible factor for non-adherence to TB treatment. Another possible factor cited by the respondents that prevents TB patients from adhering to treatment was the feeling of improvement after starting treatment. The health of some TB patients greatly improve after the first few weeks of treatment and as such they stop taking the medication all together thinking that they are cured.

5.2.2 To determine TB patients' knowledge of TB and its treatment through the use of a structured questionnaire

From our study, 77.5% of the respondents had knowledge about TB and 50.0% of them were able to mention at least one correct symptom of TB (coughing for over 3 weeks). This display of knowledge can be attributed to the fact that almost half of the respondents had attended secondary education (43.0%).

5.2.3. To identify practices among TB patients with the potential to affect TB treatment adherence through the use of a questionnaire

Since forgetfulness was cited as one of the barriers that prevents TB patients from adhering to treatment, most of the respondents indicated that they expect their relatives/family to remind them consistently about the dates for drug refill at the healthy facility and also a daily reminder to take their medication.

Due to the feeling of increased hunger experienced by TB patients on treatment, it was indicated that not only do TB patients expect to be supplied with adequate amounts of food by their relatives but also expect encouragement to actually take the food.

5.3. CONCLUSION

The study has established that in general TB patients in Malawi have a good understanding of the disease which was demonstrated by their ability to cite symptoms such as “coughing for over 3 weeks”, mode of transmission “through the air when coughing” and that TB is contagious but at the same time it is curable. Again based on the study findings, it has been established that TB patients who have the correct knowledge and accurate information about the disease have low self-stigmatization and in general have a good adherence to treatment. However, the study also established that there are some practices among TB patients that have the potential to affect treatment adherence such as alcohol abuse and combining TB treatment with other treatment options (herbal medication).

Patients attitudes towards the disease such as side effects of the TB drugs and feeling of improvement after starting treatment were also found to be potential factors to treatment non-adherence.

It should be stated that TB can lead to devastating effects hence the need for TB patients to take their drugs in line with the given guidelines. The study results have clearly shown that though TB medical interventions were available but the affected patients were not following appropriate guidelines from the health personnel. In addition, other patients would combine the conventional TB treatment with other treatment options which posed as a risk factor for treatment non-adherence.

Tuberculosis is one of the and killer diseases worldwide and Malawi is no exception. Effective treatment and a clear understanding of the factors that undermine treatment is required in order to control TB.

It is therefore, important for TB patients to follow the prescribed medication and the given instructions for the same in order to prevent and control the spread of TB.

5.4. RECOMMENDATIONS

- There is need for government to provide food supplements such as: Soya, maize flour and cooking oil as one of the major ways of promoting adherence to TB treatment.
- There is need for government to intensify public awareness campaign messages about TB and its treatment. This will in turn ensure that people have the correct knowledge about TB and its treatment which is important to TB treatment adherence as this study and other previous studies have revealed.
- There is also need for the availability of anti-TB drugs in all healthy facilities across the country as it was identified in our study to be one of the ways of promoting adherence to TB treatment. Shortage of anti-TB drugs in some healthy facilities is another factor that prevents TB patients from adhering to treatment. Some TB patients travel long distances to a healthy facility to collect anti-TB drugs only to be told that the drugs are not available.
- There is also need for friends and families to remind and encourage the relatives suffering from TB to take their medication and also remind them when they are supposed to visit the healthy facility for drug refill.

6.0 REFERENCES

1. Thomas MD. The History of Tuberculosis. *Journal of Respiratory Medicine*. 2006; 100(11): p. 1862-1870.
2. CDC. <http://www.cdc.gov/tb/education/corecurr/pdf/capter2.pdf>. [Online].
3. WHO. *Global Tuberculosis Report*. Geneva; 2019.
4. Malawi National Tuberculosis Control Programme. 7th ed.; 2012.
5. <http://www.usaid.gov/malawi/global-health/tuberculosis>. [Online].
6. <http://www.usaid.gov/malawi/fact-sheets/malawi-tuberculosis-fact-sheet>. [Online].
7. CDC. Global HIV and TB available from <http://www.cdc.gov/globalhivtb/where-we-work/malawi/malawi.html>.
8. WHO. *TB/HIV, A Clinical Manual* available from; <http://www.who.int/martenal-child-adolescent/documents/9241546344/en/>. 2nd ed.; 2004.
9. WHO. *Adherence To Long Term Therapies; Evidence For Action*; 2003.
10. Claire E, Song F e. A meta-analysis of cognitive-based behaviour change techniques as interventions to improve medication adherence. *BMJ Open*. 2013.
11. Liegooghe R, Muynck AD ea. *The Dynamics of Tuberculosis Treatment Adherence*. *Journal of Pakistan Medical Association*. 2001.
12. Jossy vdB, Martin JB ea. The complexity of the adherence-response relationship in tuberculosis treatment: why are we still in the dark and how can we get out? *Journal of Tropical Medicine and International Health*. 2011 June; 16(6): p. 693-698.
13. NEPAD. <http://www.nepad.org/news/tb-and-health-systems-support-southern-africa>. [Online]; 2019.
14. Ruru Y, Matasik M ea. Factors associated with non-adherence during tuberculosis treatment among

- patients treated with DOTS strategy in Jayapura, Papua Province, Indonesia. *Global Health Action*. 2018.
15. Addisu AG, Megbaru D ea. Assessment of anti-TB drug non-adherence and associated factors among TB patients attending TB clinics in Arba Minch Governmental Health Institutions, Southern Ethiopia. *Tuberculosis Research and Treatment*. 2018.
 16. Kulkarni P, Arkate SV ea. Non-adherence of New Pulmonary Tuberculosis Patients to Anti-Tuberculosis Treatment. *Journal of Annals of Medical and Health Sciences Report*. 2013; 3(1): p. 67-74.
 17. Tang Y, Zhao M ea. non-Adherence to Anti-Tuberculosis Treatment among Internal Migrants with Pulmonary Tuberculosis in Shenzhen, China: a cross-sectional study. *BMC Public Health*. 2015.
 18. Tachfouti N, Slama K ea. The Impact of Knowledge and Attitudes on Adherence to Tuberculosis Treatment: A Case-Control Study in a Moroccan Region. *The Pan African Medical journal*. 2012 June 28; 12.
 19. Bernard N, MN Keraka ea. Factors associated with default from treatment among tuberculosis patients in Nairobi Province, Kenya: A case-control study. *BMC Public Health*. 2011; 11.
 20. Karen S, C J. The Impact of Medication Regimen on Adherence to Chronic Treatment: A review of Literature. *Journal of Behavioral Medicine*. 2008 June; 31(3): p. 213-224.
 21. Salla AM, Simon AL ea. Patient Adherence to Tuberculosis Treatment: A Systematic Review of Qualitative Research. *PLoS Medicine*. 2007.
 22. Akilew AA, Kefyalew Addis A ea. Non-Adherence to Tuberculosis Treatment and Determinant Factors among Patients with Tuberculosis in North West Ethiopia. *PLoS*. 2013.
 23. Abriham Z, Getnet D ea. Prevalence and determinants of anti-tuberculosis treatment non-adherence

- in Ethiopia: A systematic review and meta-analysis. PLoS ONE. 2019; 14(1).
24. Habtamu SM, Abere W A ea. Non-adherence to anti-tuberculosis treatment, reasons and associated factors among TB patients attending at Gondar town health centers, Northwest Ethiopia. BMC Res Notes. 2018.
25. WHO. The Stop TB Strategy, Building on and Enhancing DOTS to meet the TB related Millenium Development Goals. 2006. Geneva.
26. Castelnuovo B. A Review of Compliance to Anti-Tuberculosis Treatment and Risk Factors for defaulting Treatment in Sub-Saharan Africa. Journal of African Health Sciences. 2010 December; 10(4): p. 320-324.
27. Fatima BW, Vanessa C ea. Determinants of non-adherence to treatment for tuberculosis in high-income and middle-income settings: a systematic review protocol. BMJ Open. 2018.
28. Helen SR, Mary F, Antal M, Karina K, Pia AZ, Aaron KS, et al. All nonadherence is equal but is some more equal than others? Tuberculosis in the digital era. ERJ Open Res. 2020; 6(4).

APPENDIX 1

QUESTIONNAIRE (English version)

SOCIO-CULTURAL AND BEHAVIORAL FACTORS AFFECTING ADHERENCE TO TB TREATMENT IN MALAWI

1. ID.....

2. Age

3. Gender

a. Male

b. Female

4. Occupation

a. Farmer

b. Fisherman/woman

c. Business

d. Schooling

e. Others (Specify) _____

5. Education level.

a. None

b. Standard 1-4

c. Standard 5-8

d. Form 1-2

e. Form 3-4

f. Tertiary

6. Marital Status

a. Single

b. Married

c. Widowed

d. divorced

e. Separated

7. Before being diagnosed with TB, have you heard anything about the disease? YES...NO....

8. If yes, from which source?

- a. From friends/relatives/workmates
- b. From health workers
- c. Newspapers
- d. Radio
- e. TV
- f. Booklet
- g. Other (specify).....

9. What symptoms can show that a person has TB?

- a. Coughing with sputum
- b. Coughing for over 3 weeks
- c. Periodic increases of temperature for over 3 weeks
- d. Blood in sputum
- e. Loss of appetite
- f. Night sweating
- g. Pain in the chest
- h. Total weakness
- i. Weight loss
- j. Other (specify).....

10. Is TB contagious? YES.... NO..... DON' T KNOW.....

11. How is TB transmitted?

- a. Through the air when coughing
- b. Through blood
- c. Through handshake with an infected person
- d. Sexually transmitted
- e. Sharing food with an infected person
- f. You're born with it
- g. I don't know
- h. Other (specify).....

12. Is TB curable? YES..... NO..... DON' T KNOW.....

13. Do you take your TB medication according to guidelines? YES.... NO....

14. If no, what are some of the challenges/barriers that prevent you from adhering to your medication?

15. Have you disclosed or did you disclose your TB status to others? YES... NO....

16. If NO to question 15, why not?

- a. Because I will lose Job
- b. Because I will lose friends
- c. Because people will avoid me

d. Because no one will marry me

e. Other (specify).....

17. Do you think it is shameful to have TB? YES.... NO..... DON'T KNOW.....

18. If yes, why?

19. What other treatment options have you sought apart from taking Anti-TB drugs?

20. Is it a common practice to combine TB medication with other treatment options?

21. What support do you think TB patients need from health workers, relatives and the community?

22. What do you think government can do to promote adherence to TB treatment?

APPENDIX 2

FOCUS GROUP DISCUSSION (FGD) GUIDE (English version)

(Please record the following details for each FGD)

Name of Interviewer

Name of Recorder/Note taker

Date of Interview

Start Time Finish Time

District..... TA

GVH VG

Number of People Interviewed (Men)(Women).....

(Boys)(Girls).....

Estimated ages (ranging from ... to ...)

Estimated education levels (ranging from ... to ...)

INTRODUCTION

Hello everyone. My name is _____, and my colleague's name is _____. I am a student at the university of Kwazulu Natal in South Africa and I am conducting a research on socio-cultural and behavioral factors affecting adherence to TB treatment in Malawi. In this research I want to hear from you about TB treatment adherence issues. I would like to remind you that we want your honest explanation of how you see, feel about and understand the issues that we will be discussing. It is also imperative that you give us honest responses even if you feel that some people may not agree with them. We want everyone to feel free to say what he or she thinks even if others don't think the same way. Please speak up whenever you

are making your contribution. Also, I want to tell you that what you say here will be kept confidential. No one outside the group will know what you personally said. I will be guiding the discussions and would like to begin by asking some general questions. We will be writing down what is said although we won't write your names down. Everything you say will be anonymous. We will talk for about an hour.

QUESTIONS

1. Do people in this community take their TB medication according to guidelines?
2. If not, what are some of the challenges/barriers that prevent people from adhering to their medication?
3. Has anyone in the group disclosed or did anyone disclose their TB status to others?
4. If not, what are some of the reasons that prevent people from disclosing their TB status?
5. In this community do people view TB as a shameful disease?
6. Why do you think people might feel this way?
7. What other treatment options have people in this community sought apart from taking Anti-TB drugs?
8. Is it a common practice to combine TB medication with other treatment options?
9. In this community what support do people think TB patients need from health workers as far as TB treatment adherence is concerned?
10. What support do people think TB patients need from relatives and the community?
11. What do people think government can do to promote adherence to TB treatment

APPENDIX 3

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM (English version)

TITLE OF THE RESEARCH PROJECT: Socio-Cultural and Behavioral factors affecting adherence to TB treatment in Malawi by Ruth Lipato. Funded by University of Kwazulu Natal, Durban South Africa.

PRINCIPAL INVESTIGATOR: Ruth Lipato

ADDRESS: P.O. Box 45, Mulanje, Malawi

CONTACT NUMBER: 00 265 995 500 657

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is entirely voluntary and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by **the College of Medicine Research and Ethics Committee** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, Malawi Guidelines for Good Clinical Practice.

What is this research study all about?

This study will be conducted at Bwaila Hospital

This study is aimed at exploration of:

Socio-Cultural and Behavioral factors affecting adherence to TB treatment in Malawi.

No names of the participants will be recorded.

Why have you been invited to participate?

You have been asked to participate in this study because you were diagnosed with TB and currently you are on TB treatment.

What will your responsibilities be?

Your responsibility is to respond as honestly as possible to all the questions that will be administered to you through the questionnaire.

Will you benefit from taking part in this research?

You will not receive any payment for participating in this study. Participants will benefit from the information gathered in this Study because it will help identify ways that would maximize adherence levels to TB treatment hence reducing the development of drug resistance and the spread of TB in Malawi.

Are there any risks involved in your taking part in this research?

There are no risks involved in taking part in this research

If you do not agree to take part, what alternatives do you have?

You are free to decline not to take part in this study. Nothing will happen to you if you decide to decline.

Who will have access to the records of the data?

The data will be kept confidential. Only the investigators in this study will have access to the data. When the data is published, we will not use names or any other information that may lead to readers identifying you.

What will happen in the unlikely event of some form of injury occurring as a direct result of your taking part in this research study?

If due to your participation in this study you suffer any injury, we will refer you to a relevant/appropriate professional for assistance.

Will you be paid to take part in this study and are there any costs involved?

No you will not be paid to take part in the study. There will be no costs involved for you, if you do take part.

Is there anything else that you should know or do?

You can contact Ruth Lipato at cell: 0995 500 657 if you have any further queries or encounter any problems.

You can contact the Secretariat of College of Medicine Research and Ethics Committee at 0111871 911 EXT 334 if you have any concerns or complaints that have not been adequately addressed by the study staff.

You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled (Socio-Cultural and Behavioral factors affecting adherence to TB treatment in Malawi)

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been pressurized to take part.
- I may choose to leave the study at any time and will not be penalized or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (place) on (date) 2016.

Signature of participant

Signature of witness

.....

Finger print of participant

Finger print of witness

Declaration by investigator

I (name) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. *(If an interpreter is used then the interpreter must sign the declaration below.*

Signed at (place) on (date) 2016.

Signature of investigator

Signature of witness

APPENDIX 4

QUESTIONNAIRE (Chichewa version)

SOCIAL BEHAVIORAL FACTORS AFFECTING ADHERENCE TO TB TREATMENT IN MALAWI

1. ID.....

2. Age.....

3. Gender

a. Male

b. Female

4. Occupation

a. Farmer

b. Fisherman/woman

d. Business

d. Schooling

e. Others (Specify) _____

5. Education level.

a. None

b. Standard 1-4

c. Standard 5-8

d. Form 1-2

e. Form 3-4

f. Tertiary

6. Marital Status

a. Single

b. Married

c. Widowed

d. divorced

e. Separated

7. Musanapezeke ndi nthenda ya chifuwa chachikulu, mudayamba mwamvapo za nthenda imeneyi?

8. Ngati mudayamba mwamvapo, mudamva kuchokela kuti?

a. Kwa amzanga/abale/ogwila nawo ntchito

b. Kwa ogwila ntchito za umoyo

c. Mu nyuzipepala

d. Pa wailesi

e. Pa kanema

f. Mumabuku

- g. Other
9. Kodi ndi zizindikilo ziti zomwe zingawonetse kuti munthu ali ndi chifuwa chachikulu?
 - a. Kutsokomola makhololo
 - b. Kutsokomola kudutsa masabata atatu
 - c. Kutentha thupi kudutsa masabata atatu
 - d. Kutsokomola magari
 - e. Kusafuna chakudya
 - f. Kutuluka thukuta usiku
 - g. Kupweteka mu chifuwa
 - h. Kufooka
 - i. Kuchepa thupi
 - j. Other
 10. Kodi chifuwa chachikulu mutha kupatsilana?
 11. Kodi chifuwa chachikulu chimafalikila bwanji?
 - a. Kupyolera mumpweya potsokomola
 - b. Kupyolera magari
 - c. Popatsana moni wa padzanja ndi munthu yemwe ali ndi chifuwa chachikulu
 - d. Pogonana
 - e. Kudyela limodzi chakudya ndi munthu yemwe ali ndi chifuwa chachikulu
 - f. Umabadwa nayo
 - g. Sindikudziwa
 - h. Other
 12. Kodi chifuwa chachikulu ndichochizika?
 13. Kodi mumamwa mankhwala anu a chifuwa chachikulu motsatila ndondomeko?
 14. Ngati simutero, tiuzeni zina mwazokhoma zomwe zimakukanikitsani kumwa mankhwala anu motsata ndondomeko
 15. Kodi mudawulula kwa anthu kuti adakupezani ndi chifuwa chachikulu?
 16. Ngati simudawulule tiuzeni zina mwa zifukwa zomwe simudawululire
 - a. Kuwopa kuti andichotsa ntchito
 - b. Kuwopa kuti amzanga andithawa
 - c. Kuwopa kusalidwa ndi anthu
 - d. Kuwopa kuti ndingasowe banja
 - e. Other
 17. Kodi mukuganiza kuti ndizochititsa manyazi kupezeka ndi chifuwa chachikulu?
 18. Ngati mukuganiza choncho ndi chifukwa chani?

19. Kupatula mankhwala a kuchipatala omwe mukumwa, mwayesapo njila zina zothetsela chifuwa chachikulu?
20. Kodi ndizotchuka kuphatikiza mankhwala achifuwa chachikulu akuchipatala ndi njila zina zothetsa chifuwa chachikulu?
21. Kodi ndi thandizo lanji lomwe anthu odwala chifuwa chachikulu akulisowa kuchokela kwa ogwila ntchito za umoyo, achibale komanso anthu a mmudzi?
22. Kodi mukuganiza kuti boma likuyenela kupangapo chani pofuna kupititsa patsogolo kamwedwe koyenela ka mankhwala a chifuwa chachikulu?

APPENDIX 5

FGD GUIDE (Chichewa version)

(Please record the following details for each FGD)

Name of Interviewer

Name of Recorder/Note taker

Date of Interview

Start Time **Finish Time**

District..... **TA**

GVH **VG**

Number of People Interviewed (Men)(Women).....

(Boys)(Girls).....

Estimated ages (ranging from ... to ...)

Estimated education levels (ranging from ... to ...)

MALONJE

Moni nonse. Dzina langa ndi Ruth Lipato ndipo amzangawa dzina lawo ndi Ndine mmodzi mwa ophunzila pa sukulu ya za ukachenjede ku University of Kwazulu Natal ku South Africa. Ndikupanga kafukufuku yemwe tikuyang'ana zina mwazifukwa zimene zimapangitsa anthu odwala chifuwa chachikulu kuti asamatsatile ndondomeko yakamwedwe ka mankwala kuno kwathu ku Malawi. ndikufuna ndikukumbutseni kuti tifuna mayankho anu achilungamo pa mmene mukuwonela komanso kumvela pa nkhani imeneyi. Komanso nkofunika kuti mutipatse mayankho owona okhaokha ngakhale mukuwona kuti anzanu sakugwilizana nazo. Tikufuna aliyense akhale omasuka kunena zomwe akuganiza ngakhale ena asakuganiza chomwecho. Chonde lankhulani mokweza pamene mukupeleka mfundo zanu. Komanso ndikufuna ndikutsimikizileni kuti zones zomwe mulankhule pano zizasungidwa mwachinsinsi. Palibe wapambali yemwe akadziwe zomwe mwanena. Ndikhala ndikutsogolera zokambilana zathu ndipo ndikufuna ndiyambe ndikufunsa mafunso apo ndi apo. Tizilemba zokambilana zathu ngakhale pazolembapo sipalembedwa dzina la munthu. Titenga pafupifupi ola limodzi pazokambilana zathu.

MAFUNSO

1. Kodi anthu mdera lino amamwa mankhwala awo a chifuwa chachikulu motsatila ndondomeko?
2. Ngati sichoncho, zina mwazifukwa zomwe zimalepheletsa anthu kutsatila ndondomeko ya kamwedwe ka mankhwala ndi chani/
3. Kodi alipo mgulu mwathumu yemwe adawululapopo kwa ena kuti ali ndi chifuwa chachikulu?
4. Ngati sichoncho, zina mwazifukwa zomwe zimalepheletsa anthu kuwulula ndi ziti?
5. Kodi mdela lino anthu amachitenga chifuwa chachikulu ngati nthenda yochititsa manyazi?
6. Mukuwona ngati anthu amaganiza choncho chifukwa chani?
7. Kodi mdela lino ndi chithandizo chanji chomwe anthu amafunafuna pambali pomwa mankhwala a chifuwa chachikulu?
8. Kodi mchitidwe ophatikiza mankhwala a chifuwa chachikulu ndi zithandizo zina ndiwotchuka mdela lino?
9. Kodi mukuganiza kuti ndi chithandizo chanji chomwe anthu odwala chifuwa chachikulu amayembekeza kuchokela kwa anthu ogwila ntchito za umuyo pankhani yokhudza ndondomeko ya kamwedwe ka mankhwala?
10. Nanga mukuganiza kuti ndi chithandizo chanji chomwe anthu odwala chifuwa chachikulu amachisowa kuchokela kwa abale awo komanso anthu a mdela lawo?
11. Kodi mukuganiza kuti boma lingathe kuchitapo chani pofuna kupititsa patsogolo kutsatila ndondomeko ya kamwedwe ka mankhwala?