# UNIVERSITY OF MALAWI. KAMUZU COLLEGE OF NURSING.

Contributing Factors to Recurrent Cases of Smear Positive Tuberculosis.

Ву

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Bachelor of Science in Nursing.

Supervised by

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#### **DECLARATION.**

I declare that this research study is the result of my own work and has not been submitted for any degree. It does not contain any material previously submitted by another except where there is reference in the text.

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#### **DEDICATION.**

This work is dedicated to my parents for their support and encouragement. To my sisters and brothers for enduring my long absence from home and to Vincent for your love and support.

I also dedicate this research to all the patients with Tuberculosis. God be with you.

#### ACKNOWLEDGEMENT.

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#### GLOSSARY OF TERMS AND OPERATIONAL DEFINITIONS.

WHO: World Health Organization.

NTP: National Tuberculosis Control Programme.

DOTS: Directly Observed Treatment Short course.

#### SMEAR POSITIVE PULMONARY TUBERCULOSIS:

Either: A patient with at least two sputum specimens positive for acid-fast bacilli by microscopy.

OR: A patient with at least one-sputum specimen for acid-fast bacilli microscopy and radiography abnormalities consistent with pulmonary Tuberculosis.

OR: A patient with at least one sputum specimen positive for acid fast bacilli by microscopy which is culture positive for mycobacterium Tuberculosis.

#### CASE CATEGORY.

Patients are not only classified according to site of disease but also according to whether they had previous treatment.

NEW: Patient who has never taken ant TB drugs for more than a month.

RELAPSE: Patient who has previously been treated and completed treatment and has now developed active TB with smear positive.

FAILURE: A newly diagnosed TB patient who is sputum positive 5 months or more after the start of chemotherapy.

RECURRENT TUBERCULOSIS: Reappearance and encompasses everything; whether relapse, failure or default.

RETURN AFTER DEFAULT: Patient who interrupted treatment for more than 2 months after at least one month of chemotherapy and subsequently found to have smear positive TB.

### DIRECTLY OBSERVED TREATMENT SHORT COURSE.

This is the most effective strategy available for controlling TB. It is one element in the WHO recommended policy package for TB control. In this strategy, a supervisor watches the patient swallowing the drugs to ensure that TB patients take the drugs, in the right doses at the right interval in order to promote patients compliance/ adherence to the treatment.

EFFECTIVE TB TREATMENT: Depends on the following factors; use of appropriate combination of at least 2 drugs given in the correct dosages, taken regularly and for the required length of time.

#### ABSTRACT.

Tuberculosis is a leading cause of death among adults in Malawi and the single type that is giving many problems is smear positive Tuberculosis. This type of Tuberculosis needs adequate treatment with ant TB drugs for the required period. Many patients are readmitted into the hospital with recurrent smear positive Tuberculosis and this gives problems to the health care system as it calls for retreatment.

The purpose of this study was to assess and evaluate the contributing factors to recurrent cases of smear positive Tuberculosis. The study specifically aimed at exploring how supervision of patients is done at hospital, health center and guardian level, identifying problems that hinder effective treatment of smear positive Tuberculosis and exploring suggestions from health workers patients and guardians on how to improve treatment and supervision of patients with smear positive Tuberculosis.

A descriptive research design was used and the study involved 30 subjects who consisted of health workers, patients and guardians. The study was conducted at Bottom hospital and area 25-health center. An interview guide was used to collect data from patients and health workers and a question guide was used for focus group discussions to collect data from guardians. Data was analyzed manually to determine frequency distributions and responses from focus group discussions were categorized and subjected to descriptive statistics of content analysis.

The study findings indicated lack of adequate knowledge by patients and guardians on TB disease and principles of treatment as one of the main contributing factor to recurrent cases of smear positive TB. The results also indicated lack of adequate supervision and adequate follow up of defaulters due to lack of human and material resources as other contributing factors. Poor social

economic status of the patients and guardians, poor relationship between clients and health workers and long period of treatment featured as the other major contributing factors to recurrent cases of smear Positive Tuberculosis. If health planers and health workers do not address these areas, the hospitals will continue registering increased numbers of Smear Positive Tuberculosis.

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#### **CHAPTER 1**

#### 1.0 INTRODUCTION

#### 1.1 Background Information.

Tuberculosis is a communicable systemic disease caused by the tubercle bacillus (mycobacterium Tuberculosis). Most infections are caused by inhalation of droplet nuclei containing virulent human strains of the Tubercle bacillus. Tuberculosis continues to be the major cause of morbidity and mortality in our community and this is more regrettable since the disease can be diagnosed following standard procedures and can be cured even in the presence of Human Immunodeficiency virus infection (NTP, 1999). If an individual is diagnosed, given treatment and the treatment is taken in the right way and course finished, recovery has to take place.

The National Tuberculosis Control Programme has been employing different measures to eliminate Tuberculosis as the major public health problem. Previously, patients were treated for two months at the hospital and then they were sent home on treatment for six months. In all the regimens used previously, the treatment contained both oral and injectable medications like streptomycin. Problems that arose with this system of treatment were congestion and the service providers were overworking. Recently the National Tuberculosis Control Programme has introduced decentralized treatment that it claims to be a patient friendly approach. This approach was introduced in order to reduce congestion, overworking and costing. The other reasons for introducing this system was to allow nurses to have ample time to care for patients, to make services close to the patients and avoid exposing patients to an environment with many droplet nuclei. Using this approach, only oral drugs are used except in re-treatment phase where streptomycin is also used. Patients are admitted and receive treatment daily for 14 days. At the end of two weeks, all patients automatically change to intermittent

treatment for the remaining 6 weeks (18 doses) either in hospital, under health center supervision or guardian supervision. Each patient is supposed to receive no less than 32 doses in the intensive phase. Under health center and guardian supervision, Directly Observed Treatment (DOT system) is used. During the treatment, sputum examination is done at two, five and seven months. Despite all the efforts made by the National Tuberculosis Control Program (new drug regimens, decentralization of treatment and patient supervision), hospitals continue to register a lot of recurrent cases from smear positive Tuberculosis.

# 1.2 Statement of the problem.

Tuberculosis is curable with proper management and that is if an individual is diagnosed, treatment is given and course is finished at the right time. However, numbers of recurrent cases from smear positive TB continues to be high in the hospitals. Are these cases coming about because instructions are not properly followed or given? Are the guardians not assisting? Is it because patients stop taking drugs once symptoms subside? Is it that supervision at hospital and health center level is not done properly?

# 1.3 Significance of the study.

Tuberculosis is the single biggest cause of adult illness and death from a communicable disease in Malawi. The high death rates threaten credibility and inappropriate treatment fuels the development of resistance to drugs. Tuberculosis control is expensive and heavily dependent on donor support for drugs, reagents, training and supervision. If the control and treatment of tuberculosis is tackled effectively, there is a possibility of saving the generated funds and revenue, which is currently being directed at the Ministry of Health.

Tuberculosis is a curable disease; therefore it is believed that with proper efforts put in place to control and treat it effectively, the hospital could have been registering reduced numbers of recurrent cases or none. It is possible that patients do not take drugs either at hospital or at home because they are not supervised effectively. It might also be that guardians are not assisting the patients, the patients themselves stop taking the drugs once the symptoms subside. On the other hand, drugs may not be available sometimes at the hospitals and this makes the patients to miss the doses during the treatment.

The results of this study will help to identify the areas that are missed when treating patients with smear positive Tuberculosis and therefore it will be possible to tackle the problem effectively. The results will help to identify the relationship between the independent variables that are the contributing factors and the dependent variable, which are recurrent cases and the major upset in controlling the disease. The results will also help the health planners and health personnel to plan on how to give instructions effectively, educate patients and supervise patients to reduce the numbers of recurrent cases.

## 1.4 OBJECTIVES OF THE STUDY.

# 1.41 General Objective.

The purpose of the study is to assess and evaluate the factors that contribute to recurrent cases of smear positive Tuberculosis.

# 1.42 Specific Objectives.

- 1- To explore how supervision of patients is done at health center, hospital and guardian level.
- 2- To identify problems or factors that hinder effective treatment of smear positive Tuberculosis.
- 3- To find out suggestions of health workers, guardians and patients on how to effectively supervise patients on TB treatment.

#### **CHAPTER 2.**

#### 2.0 LITERATURE REVIEW.

### 2.1 Tuberculosis: A global epidemic.

Tuberculosis is the leading cause of death among adults in less developed countries. It kills more youths and adults than any other infectious disease in the world today. Seventy five percent (75 %) of tuberculosis in developing countries is among the people that are in there most economically productive year's i.e. 15 –45 years (Maher & Mikulencak, 1997). Scot, Ratzan, Garry, Filerman and Lesar (2000), indicated that worldwide, 8 million people were infected with tuberculosis in 1998. Jansens, Suetes, Witjen, & Muynk (2001) stated that a staggering one third of global population is currently infected and nearly 6,000 people die from it each day. Every year there are almost 2 million deaths from tuberculosis and 8 million new cases of disease, 95% of which are in the developing world.

According to global TB control (GTC), WHO report (1999), the total number of new smear positive cases notified by 173 countries in 19996 was 1,286,299. In 1997 the number increased to 3,388,879 the majority of which occurred in the sub-Saharan region. Harries (1997), indicated that in sub-Saharan Africa there has been an upsurge in the number of patients with smear positive TB in the past 10 years. In South Africa, 160,000 people are getting sick with TB every year. It is describe as 'people's plague' and it kills more adults annually than any other infectious disease. About 10,000 die every year with TB.

In order to deal with the high rate of TB, more especially smear positive tuberculosis, the World Health Organization declared tuberculosis epidemic a global emergency in April 1993. The WHO then developed new treatment regimens, introduced a modern strategy of Tuberculosis

treatment called DOTS (Directly Observed Treatment Chemotherapy-Short Course). It also recommended ambulatory programs for treating patients (Pio & Chaulet, 1998).

Tuberculosis is fully 100 % curable and 100 % preventable and can be cured if patients take an appropriate combination of drugs in the right dosages and for a sufficient period (Health Link, 1999). The new treatment regimens for smear positive Tuberculosis consists of drugs like Rifampicin, Isoniazid, Pyrazinamide and Ethambutol. These drugs are taken for a period of 8 months with 2 months initial intensive phase and the last 6 months continuous phase. (WHO, 1999).

The DOTS strategy was introduced and it is used as an answer to problems of poor compliance and drug resistance (Jansens et al 2001). This strategy provides the patient with all the necessary requirements for cure and the emphasis is on placing the patient at the center of TB control activities (Maher & Harries, 1997). However, Jansens et al explains that DOTS remains difficult to be applied in many countries due to lack of human resources because it requires regular observation of ingestion of tablets by qualified personnel. DOTS also require correct prescription of treatment and handling without errors because sometimes there may be lack of qualification or high workload of health staff which may lead to poor distribution of correct medication to patients. DOTS need careful planning and follow up. Failure to have trained supervisors, reliable TB drug supplies may lead to failure of TB program. None availability of drugs at the peripheral areas also lead to difficulties with applying the DOTS strategy.

The implementation of ambulatory services was aimed at making patients part of TB control program and that they should lead a socially active life.

Despite the implementation of new treatment regimens, use of DOTS strategy and introduction of ambulatory services, many countries continue

to register recurrent cases from smear positive pulmonary tuberculosis (Jansens et al, 2002).

WHO Geneva (1999) conducted a study on treatment results after using new treatment regimens and DOTS strategy. The results indicated that out of a global total of 495,092 smear positive cases that were notified, 72 % got cured and there was 58% failure cases with 1.3% default cases. Out of 794,207 notified cases of smear positive TB in countries that do not use DOTS, 17% were cured, and 4.6% were failure cases and 2.4% default cases. According to the results, there is not a big difference between failure and default cases in countries that use DOTS and those that do not use DOTS. This shows that there are other factors that contribute to increased rates of recurrent cases (default, failure and relapse) from smear positive Tuberculosis.

Maher and Mikulencak (1997) stated that the problem with TB has not been lack of ways to detect and cure TB but lack of organization of services. Reich man (1996) explains that Health personnel love to blame patients for none compliance in taking drugs. However, their failure to deal with TB clearly and documentedly rests with a lack of compliance on several levels. TB will never be eliminated until this lack of compliance at all levels is addressed and corrected.

#### 2.2 Tuberculosis in Malawi.

Tuberculosis remains a killer disease in Malawi. In 1998, there were 22,674 notification cases of TB, 8,768 (36%) of which were smear positive cases. TB kills 8,000 people annually with 22 deaths and 70 admissions for treatment per day. (Salaniponi, 2001). Salaniponi continues to explain that in December 2000, 8,654 TB cases were recorded as opposed to 5,000 cases a decade ago. In addition, the worst hit areas being Blantyre, Lilongwe and Mzuzu. The highest percentage i.e.62% was smear positive tuberculosis. In 1992 there were 15,183 TB cases with 149 patients per

100,000 people and in 1999, the number increased to 19,155 with 172 patients per 100,000 people. In 1997, the total number of TB cases was 20,676 with 7,587 (37%) smear positive and 507 (2%) relapse cases. (Kruyt et al, 1999).

Malawi has always placed high priority on the prevention, control and treatment of Tuberculosis. Inorder to deal with the increasing rate of smear positive TB in Malawi, the National Tuberculosis Control Program (NTP) has been struggling to bring about high cure rates. The NTP has the goal of controlling TB through active case finding, treatment and prevention. The goal, purpose and objective of NTP is to eliminate Tuberculosis as a major public health problem. (NTP, 1999).

In 1984, Malawi adopted the new DOTS strategy of TB treatment. It was one of the first countries in the world to implement DOTS. With the assistance from the International Union against TB and Lung Disease, Malawi adopted DOTS and initiated a country wide standardized reporting and evaluation system. (Kruyt et al, 1999). NTP tried its best in 1998 to improve case finding, especially positive cases by supporting health center training and health center supervision by TB officer.

# 2.3 Diagnosis, registration and treatment of Tuberculosis In Malawi.

The NTP uses a system of passive case finding. TB suspects are screened either at the central hospital or at the health center. Previously, patients were screened on out patient setting or were admitted to hospital for investigation. (NTP, 1999). Currently, the NTP is attempting to decentralize treatment therefore; suspects are screened at the nearest health center or hospital. Admission is allowed only if the condition is critical. Sputum is submitted for microscopy and patients with sputum smear positive for Acid and Alcohol fast Bacteria are classified as smear

positive. The District TB officer keeps records and the records include date of diagnosis, name, age, address and type of TB.

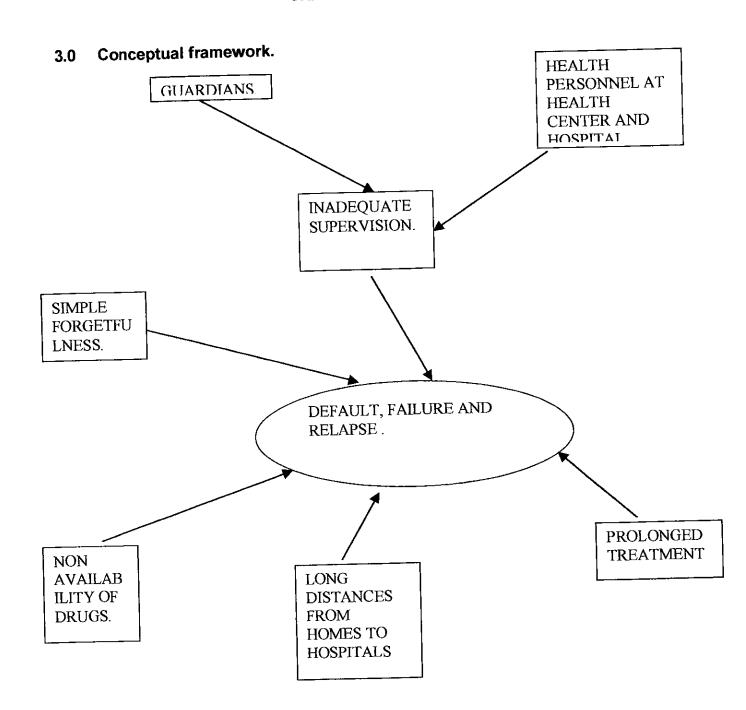
Treatment of smear positive TB consist of a combination of drugs like Rifampicin, Isoniazid, Ethambutol and Pyrazinamide. The regimen for smear positive TB consists of two months initial intensive phase and 6 months continuation phase. Patients are admitted for 2 weeks only for observation of treatment and then they are discharged to continue with the intermittent phase under either health center or guardian supervision and the new DOTS strategy is used.

Malawi is still registering recurrent cases from smear positive Tuberculosis despite the implemented use of new drug regimens, use of the famous DOTS strategy and the decentralization of services. Results of treatment of new smear positive patients treated with short course chemotherapy in a study done by WHO in 1996, indicated that out of 6,702 enrolled patients, 47 were still positive after treatment, 1,390 died (21%) and 387 (6%) absconded. In 1997, 3523 patients enrolled, 31 were still positive after treatment. 749 died and 152 (4%) absconded.

NTP, in March 1998, conducted a study on results of treatment of new smear positive patients after short course chemotherapy. The results showed that out of 623 patients enrolled in the north; there were 9 failure cases and 22 default cases (4%). In the central region, 1918 enrolled and 35 (1%) were failure cases and 74 (9%) were default cases. In the southern region, 6702 enrolled, 47 (1%) were failure cases and 387 (6%) were default cases. The numbers of failure and default cases might have increased by now. (NTP, 1999). Study done by Kryut et al (1999), in Blantyre on default cases indicated that 20 % of the enrolled patients were defaulters.

From the figures, it shows that there are some factors that are overlooked that contribute to the recurrence of smear positive TB, which include failure, relapse and default cases. NTP also indicated that default and failure cases contribute to about 10 % of treatment outcomes, which can be either recurrence or recover. From the reviewed literature, no specific study was found that specifically looked at the factors that contribute to recurrent cases of smear positive TB.

#### **CHAPTER 3.**



Factors that may contribute to increased numbers of failure, default and relapse cases there by leading to recurrence of smear Positive Tuberculosis.

# 3.1 Application of the Conceptual model to the study.

From the above model, non availability of drugs, simple forgetfulness, prolonged treatment, long distances from the homes to the hospitals and health centers and inadequate supervision either at the hospital, health center or by the guardians may affect the outcome of treatment. These factors may contribute to the occurrence of default, failure and relapse cases that may lead to recurrence of smear positive Tuberculosis.

Many patients commit themselves to taking the drugs when they have symptoms which affect their health. Once the symptoms subside, they simply forget taking the drugs. Later on the symptoms come back and this leads to treatment failure, default and relapse cases. Beeson, Walsh & James (1975), explain that many patients simply forget to take the drugs due to the illusion of the symptoms.

Treatment regimens for Tuberculosis last for about 6 to 8 months. Many patients fail to cope with this long period of treatment. Pio & Pierre (1998), state that experience has shown that one third or more of patients prescribed this regimen will fail to take their drugs regulary or will discontinue treatment altogether, and this leads to failure, default and relapse cases. There is always reluctance of all persons to subject themselves to any disciplines for prolonged periods.

Patients on TB treatment need to take drugs daily or on alternate days depending on the phase of treatment and TB treatment requires several drugs taken in the right combination and appropriate duration. If drugs are not available especially at the peripheral areas, patients may miss their doses and this creates a gap in the treatment. This may lead to failure of treatment and default cases.

Long distances from the homes to the hospitals and health centers for a resupply or taking of drugs may make patients reluctant to go for their treatment and this may lead to missing of doses. Janseens et al (2001),

state that many times patients face many problems to complete their teratment correctly and have to make a considerable effort to reach a health center or hospital due to long distances.

Patients supervised by the guardians can easily miss the drug doses. If the guardian is not strong enough to convince the patient to take the drugs, the patient can easily stop taking the drugs and this can lead to default, relapse and failure cases. At the same time patients need to be reminded to take the drugs always. There is also need for the guardian to continuously observe the patient while taking the drugs and make sure the drugs have really been taken.

The patients supervised by the hospital or at health center level sometimes have to queue for long hours and accept the absence of suport from Staff. This usually demolarise the patients. Due to inadequate number of health personnel supervision is not effective. Patients easilly stop taking the drugs or throw the drugs away cheating that they have taken them. Further more staff may fail to contact and trace patients when they have failed to keep their appointments with health workers. All these may lead to inappropriate taking of TB drugs which contribute to failure of treatment, relapse and default cases ther by leading to recurrence of TB.

#### CHAPTER 4.

#### 4.0 METHODOLOGY.

#### 4.1 Research design.

This research project used a descriptive research design. The purpose of descriptive studies is to observe, describe and explore aspects of a situation (Polit & Hungler,1989). The design helps to describe inorder to know, analyse characteristics and examine the frequency with which an event is associated with another event (Seaman & Verhnick 1982). This design was chosen to explore the contributing factors to recurrent cases of smear positive Tuberculosis and it helped the researcher to assemble and analyse information on these contributing factors.

## 4.2 Sample and setting.

A sample of 30 participants was selected using a convenience sampling technique. There were ten patients, fifteen guardians and five health workers. The study was conducted at Bottom hospital and Area 25 health center.

The ten patients were the ones that were supervised either by the hospital, health center or guardian. From these ten patients, six were females and four were males. According to the study findings, there was one patient in the age category of 10 - 24 years representing 10 %, six patients in the age category of 25 - 34 years representing 60 % and three patients in the age category of 35 - 44 years representing 30 %. The majority, 70% of the patients were married while the minority, 30% were single.

The health workers came from Bottom hospital and Area 25 health center. Out of these five health workers, two were nurses who were nursing the patients at the hospital. The other three health workers were TB officers i.e. two from Bottom hospital and one from Area 25 health center. These TB officers supply drugs and supervise patients taking these drugs.

Guardians who were supervising their patients taking medications at home also participated in the study. In this study, only 15 guardians were included i.e. three males and twelve females.

Only 30 participants were included in this study because this was a qualitative study and a lot of information was generated. Therefore a sample of 30 was enough to help avoid clouding the issues and overcomplicating the complex analysis process.

#### 4.3 Data collection.

An interview guide was used to interview health workers and patients. A question guide was used for focus group discussions to collect information from the guardians. Interviews elicit high response rate and have an added advantage in their ability to produce additional data through observation and probes. (Parahoo, 1992). The exercise of collecting data took two weeks. Both qualitative and quantitative data was collected.

## 4.4 Data analysis.

Data was analysed inorder to summarise, organise, evaluate, interprete, and numerically communicate the collected information. Qualitative data from both open ended and closed questions was analyzed manually and responses from focus group discussions were categorised and subjected to descriptive statistics of content anlysis.

#### 4.5 Ethical considerations.

Inorder to protect the rights of the participants, permission was sought from the relevant authorities such as: The Ministry of Health, the Senior Matron of Bottom Hospital and the incharge of Area 25 health center. Before participation in the study, informed consent was obtained from each participant. Each subject was given an explaination about the nature and purpose of study. The subjects were assured about their anonymity and were allowed to pull out of the study at any time they wished to do so.

Code numbers were used instead of real names inorder to guarantee the participants anonymity.

# 4.6 Limitations of the study.

The sample size was relatively small i.e only 10 patients, 15 guardians and 5 health workers were interviewed. This was due to financial constraints to meet transport and material costs for the research study if it had included more participants. The sample was un representative and therefore could not be generalised to all patients, guadians and health workers. However the results give a true reflection of what patients, guardians and health workers experience and gives a basis for health planners at different levels in addressing the problems.

Time factor also affected the research process in the data collection tool as it was not pretested and modification of some of the questions was not done and this might have affected the quality of the results interms of validity.

#### CHAPTER FIVE.

#### 5.0 FINDINGS.

In the study, the main focus was on demographic data, knowledge on disease condition and treatment regimen and problems experienced during the period of treatment. The study also looked at attitude and feelings towards TB treatment, education to patients and guardians, supervision and suggestions that can help to improve delivery of services to patients with smear positive tuberculosis.

# 5.1 Level of education of patients.

From the ten patients interviewed, the majority (70 %) indicated that they had gone as far as secondary school while 10 % had gone as far as primary school. 20 % of the participants had done one or more years of college.

Table 1: Level of education of patients.

|        | Primary |   | Secondary |   | College |   |
|--------|---------|---|-----------|---|---------|---|
| Male   | 0       |   | 2         |   | 2       |   |
| Female | 1       |   | 5         |   | 0       |   |
| Total  | 10%     | 1 | 70%       | 7 | 20%     | 2 |

The majority of the patients (70%) explained that they are not employed currently due to lack of jobs related to their level of education.

#### 5.2 Knowledge.

#### 5.21 Disease condition.

The findings of the study indicated that almost all the patients demonstrated knowledge on the disease they were suffering from. They explained that they learnt about the disease from the health workers and the radio. However they differed on the symptoms that they knew to be associated with smear positive Tuberculosis.

Table 2: Symptoms associated with TB as perceived by patients.

| SYMPTOM           | FREQUENCY |   |
|-------------------|-----------|---|
| Fever             | 60%       | 6 |
| Chest pains       | 20%       | 2 |
| Coughing sputum   | 30%       | 3 |
| Fatigue           | 30%       | 3 |
| Loss of appetite  | 40%       | 4 |
| Vomiting          | 30%       | 3 |
| Sweating at night | 10%       | 1 |
| General malaise   | 40%       | 4 |
| Weight Loss       | 10%       | 1 |

Note: percentages could not add up to 100 % because the respondents mentioned more than one symptom.

During focus group discussions the guardians demonstrated knowledge on the disease their patients suffered from. However, they indicated diarrhea and shortness of breath as other symptoms associated with TB in addition to the ones mentioned by the patients. See appendix B.

### 5.22 Information given on the disease.

The findings of the study indicated that the majority of the patients (80 %) were partially educated by the health workers on the disease they suffered from. The patients explained that they were only told that they had TB and started on treatment. Only 20 % explained that they were educated fully on the disease that is issues like mode of transmission, signs, symptoms, and preventive measures were tackled.

The guardians during focus group discussions explained that they were not fully educated on the disease their relatives suffered from during the first diagnosis.

#### 5.23 Education on treatment regimen.

The study also aimed at finding out if the patients and guardians were given information on the treatment regimen and the principles of treatment. The study findings revealed that the majority of the patients (80 %) were educated by the health workers on the treatment they were supposed to take. However, they reported that the information given was not detailed for somebody to follow easily. They explained that health workers only told them about the drugs, for how long they were supposed to be on treatment and how to identify the drugs using colours but it was not easy to follow and therefore easy to forget. There was no explanation on the side effects of drugs and how to deal with them.

Table 3: Education on disease and treatment regimen.

| RESPONSE     | FREQUENCY |   |
|--------------|-----------|---|
| Yes          | 20%       | 2 |
| Not detailed | 80%       | 8 |
| No education |           | 0 |

The majority of the guardians during focus group discussions explained that they were not given detailed information on the drugs their patients were taking when they were on treatment first time.

#### 5.24 Identification of drugs.

The research findings indicated that the majority of the patients (90 %) identified the drugs by colour and not by names. They indicated red, white, yellow and pink as the colours they used to identify the TB drugs. They said they had problems in differentiating the drugs when they were given other drugs to take apart from ant TB drugs. Only 10 % of the participants said that they knew the drugs by names thus Rifina, Pyrazinamide, Ethambutol and Isonazide. The guardians during focus group discussions

explained that they had problems in identifying drugs using colours because sometimes their patients were given other drugs, which had the same colors with ant TB drugs, and yet they did not know the name of the drugs. See appendix B.

#### 5.25 Schedule for treatment.

From the study findings, all the patients said they knew the schedule for the treatment they were supposed to take. However, these patients differed on responses on how the schedule was like.

Out of the ten patients, only 10 % gave the correct schedule for the treatment regimen of smear positive tuberculosis that is daily in hospital for two weeks then three times a week for six weeks. Lastly, daily for a period of six months at home.

Table 4: Schedule for treatment of smear positive Tuberculosis as perceived by Patients.

- Three times a week for 3 months then daily for five months.
- Daily in hospital for two weeks, three times a week for 6 weeks then daily for 6 months.
- Three times a week for 5 months then daily for 3 months.
- Daily for 2 months then daily for 6 months.
- Once daily for 11 months then injection for 60 days.
- Daily for 14 days then three times a week for 5 months.
- Three times a week for 2 months then daily for 2 months.
- Three times a week (don't know for how long) then daily for 8 months.
- Three times a week for 2 months then daily for 5 months.

The majority of the respondents (70 %) however explained that they finished taking the medication as prescribed by the health worker. This

indicates that these patients, who said they finished taking medication, did not because they used a wrong schedule for treatment. Thirty percent of the participants said they did not finish taking the medication. The guardians during focus group discussions explained that it was difficult for them to follow the schedule because they did not have adequate knowledge and therefore could easily get confused.

#### 5.3 Problems experienced.

The patients were also asked about the problems that they experienced when they were on treatment first time. They were asked on the concerns that they had when they were told that they had TB and the specific problems they encountered. The patients explained that they experienced different problems when they were on treatment first time. All the patients explained that they had problems with side effects of drugs. The majority (60 %) said they experienced side effects such as vomiting, body rush and red eyes after taking medication. Others explained that they experienced swelling of legs and mental illness.

Table 6: Side effects of drugs as experienced by patients.

| SIDE EFFECTS     | FREQUENCY |   |
|------------------|-----------|---|
| Rush             | 60%       | 6 |
| Red eyes         | 60%       | 6 |
| Hunger           | 50 %      | 5 |
| Loss of appetite | 30%       | 3 |
| Swelling of legs | 10%       | 1 |
| Continuous fever | 10%       | 2 |
| Mental illness   | 10%       | 1 |
| Vomiting         | 60%       | 6 |

Note: Percentages could not add up to 100% because some patients Mentioned more than one side effect experienced. Results after focus group discussions revealed that the guardians saw their patients experiencing the above problems. See appendix B.

The findings of the study indicated that the patients met other problems apart from side effects of drugs. The majority, (80 %) of the patients that the drugs they were supposed to take were many, some big and difficult to swallow at the same time. Because the drugs were many and difficult to swallow, sometimes they could vomit the drugs and have fewer amounts of drugs to take them to the end of the week.

Research findings also revealed that seventy percent (70 %) of the patients had problems with the long treatment regimen because it is very long for them to manage and comply with easily.

Others patients said that there were long distance from their homes to the hospitals and health centers. This brought problems when they were supposed to go for a re-supply of drugs.

Some patients explained that sometimes the drugs were not available at the hospitals or health centers such that they were told to go back the next day. Because they were not employed and it was difficult for them to find money, going back the next day was a threat to them and their guardians. They also said that sometimes they were supplied with less medication than the required amount. Other patients said that they experienced a problem of social stigma from either their relatives or neighbours.

Almost 40 % of the participants said that sometimes the relationship with the health workers was not good that the health workers shouted at them. This they said was more evident when the patients failed to follow instructions and instead of reminding them, the health workers had to shout at them. However, the health workers during interviews said that patients do not want to follow instructions most of the times. They said some patients refuse to take drugs at the right time while others pretend to vomit the drugs and due to this they sometimes lose patience.

Table 7: Other problems experienced by the patients.

- . Long distances from homes to hospitals.
- . Treatment regimen very long.
- . Poor relationship with the health workers.
- . Drugs many and difficult to swallow.
- . Lack of knowledge on the treatment regimen and disease condition.
- . Relatives' failure to accept patients' condition and related symptoms.
- . Non-availability of drugs at health centers and hospitals.
- . Supply of fewer drugs than the required amount.
- . Social stigma.

The guardians during focus group discussions said that they experienced the above problems when they escorted their patients for a resupply of drugs.

However, some guardians explained that sometimes their patients refused to take drugs once symptoms subsided while others refused to stop smoking and drinking alcohol during treatment. See appendix B.

#### 5.4 Concerns.

The majority of the patients (70 %) were afraid of lack of adequate knowledge on the disease condition and treatment regimen since they were not educated adequately. Other patients, (60 %) explained that they were afraid that they would not be able to comply with the long period of treatment regimen.

Others explained that they were afraid of transmitting the disease to relatives. In addition, others were afraid of the reaction from the partner. Only 20 % of the participants said they had no fears because they thought having treatment would be the end of the problem (Table 5).

#### Table 5: Concerns.

- Afraid that will not be able to comply.
- Afraid of death.
- · Afraid of reaction from relatives and partner.
- Afraid of lack of knowledge on disease condition and treatment regimen.
- Afraid of hospital admission.
- No fears and concerns.
- · Afraid of transmitting disease to relatives.

The guardians during focus group discussions explained that their patients had these concerns when they were on treatment first time. The guardians themselves said they were afraid of being infected by their patients. See Appendix B.

#### 5.5 Attitude.

The study also looked at the attitude and practices that the patients have in relation to education, treatment and supervision of patients when they are on treatment for smear positive TB.

# 5.51 Attitude and practices of patients towards education, treatment and Supervision.

The findings of the study indicated that the majority of the patients (70 %) said that the treatment is good, very effective and the symptoms subside after a short period. On the contrally, they said that the treatment regimen is very long and this discouraged the patients to finish the course.

Other participants explained that the drugs have many side effects, are many, big and difficult to swallow. The minority (10 %) said that the tablets on their own are not effective unless an injection is added.

Almost 70 % of the participants said that there was no effective education on the disease condition and treatment regimen. At least 60 % of the

respondents said there was no education on specific side effects of drugs and how to manage them. Others said that no explanation was given on the mode of action of drugs and the names of the drugs. They were not told about the importance of compliance. The minority said that they got most of the information from their fellow patients. Because of these points, they felt that they did not have adequate information to help in guiding them when they were on treatment. Only 30 % of the participants explained that the health workers give effective and detailed education on disease condition and treatment regimen.

Most of the participants (60 %) said that there is no effective supervision of patients when they are taking drugs. They explained that at hospital level, the patients are just given medication and the health worker doesn't wait to see whether the patient has taken the drugs or not. Because of this the patients supervise each other. At guardian level, some guardians tell their patients to rest for a day or two without taking medications especially if side effects of the drugs are severe. These patients also said that some patients refuse to take drugs when supervised by a guardian. However, 10 % of the participants explained that there is effective supervision of patients.

# 5.6 Suggestions as perceived by patients on the improved delivery of services to patients with smear Positive Tuberculosis.

The study also aimed at soliciting information from the patients on how delivery of services can be improved. The suggested the following points that they said can help to improve delivery of services to patients with smear positive Tuberculosis so that recurrent cases can reduce:

The majority of the patients said that the health workers should try as much as possible to observe the patients swallowing the drugs.

Others explained that these health workers should also try to give an explanation on the disease condition, the associated symptoms, the

drugs, and mode of action, side effects and how to deal with these side effects. They said that all these should be explained to them when they are first diagnosed TB positive and not after it has recurred.

In addition to the above, they explained that health workers should give health education to patients and other people the way it is given to antenatal mothers. However on the same point of education and supervision, the health workers said that they fail to give detailed information when giving education because they have a lot of work to do and they are only few. They fail to meet the demands of all the patients.

Table 8: Suggestions from patients.

- Health worker should always see patient swallow drugs.
- Health workers should stop shouting at patients.
- More supervision should be health center based if not hospital based.
- Medication should always be in stock.
- Health workers should go home by home to supply drugs.
- Each patient should have a guardian at hospital level to help with supervision.
- Health workers should give full health education on disease condition,
   drugs, side effects and how to manage them.
- Health education should also be given on the symptoms associated with TB and the mode of action of drugs.
- Treatment regimen should be reduced.
- Patients should realize that it is their life and therefore learn to be responsible.

The guardians during focus group discussions said they should be educated on how they can protect themselves from being infected by their patients. They also explained that they should be told the kind of TB their patients suffer from when they are diagnosed positive.

#### CHAPTER SIX.

#### 6.0 DISCUSSION.

#### 6.01 Demographic data.

The results of the study revealed that a large number of recurrent cases from smear positive Tuberculosis was found in the age range of 15-45 years. Maher and Mikulencak (1999), in their study found out that 75% of TB cases in developing countries are among those in their most economically productive years of 15-45 years. This shows that their findings agree with the findings this study. In addition, Antonio & Pierre (1998), reported that TB kills more youths and adults than any other single infectious agent in the world. Further more, Brouwer et al (996), found that 80 % of TB cases involve persons in their productive years of life (15-59).

According to the results, it was noted that recurrent cases from smear positive TB are within the productive years of 15-45 years. This is because the people within this age range are mostly affected yet they do not have adequate knowledge on TB and its treatment. Due to this, it takes along time before they seek treatment and when they start treatment, they fail to comply. It was noted that these people do not comply due to lack of adequate knowledge, which can help them to follow instructions easily. These people lack knowledge on how to combine drugs, how to take drugs at the right time, in the right amount and for the required period. Because they are mostly affected and do not comply with treatment, they are the group affected with default, failure and relapse cases that lead to recurrences.

#### 6.02 Educational level and economic status.

The study findings revealed that most of the patients interviewed had gone as far as junior classes of secondary school. It was noted from the results that patients and guardians fail to acquire adequate information from health workers on TB, means of prevention and strategies of treatment because of break down in communication brought about by their low level of education.

Dick & Vandewart (1997), supports these results by indicating that patients' and guardians level of education is very detrimental to the level of understanding of conditions and treatment. He reported that low level of education of patients and guardians contributes to poor communication between patients and health workers.

The results of the study also showed that most of the patients and guardians are not presently employed due to their academic background whereby they do not qualify to be recruited in different jobs. Because the patients and guardians fail to secure a job, their financial status is affected and they face many problems when it comes to traveling to and from the hospitals or health centers for a resupply of drugs. When they do not have money it is difficult for them to travel and then they miss some doses other days. Missing treatment is a predisposing factor to relapses and drug resistance. When patients are on treatment, they need to take food to maintain their nutritional status and improve immunity. Lack of financial support makes patients unable to have the needed foods to help maintain their nutritional status.

WHO Global report (1998), and Scot et al (2000), concur with these results by indicating that most TB cases occur where patients, guardians and the government face a lot of financial constraints. They further agree with the results by explaining that it is difficult to supervise patients on TB

treatment properly in most of the developing countries due to lack of adequate funding and patients poor economic status.

The government of Malawi adopted the DOTS strategy to answer the problems of poor compliance and drug resistance. However, Jansens et al (2001) reported that directly observed treatment (DOTS) is difficult to implement due to lack of funding. DOTS need many trained personnel to properly supervise patients.

Therefore, according to the research findings, it was noted that low level of education of patients and guardians, poor economic status of both the patients and Government lead to problems with supervision of directly observed treatment. Patients and guardians who are poor and not educated, can easily be tempted to stop treatment because of failing to understanding the importance of compliance and failure to cope with daily traveling to go and get a resupply of drugs or observed treatment.

### 6.03 Knowledge of patients and guardians on Tuberculosis and treatment.

The findings of the study showed that all the patients and guardians demonstrated some knowledge on TB and the associated symptoms. These patients mentioned fever, loss of appetite, general malaise and coughing as the symptoms they associate with TB. They could not identify the real symptoms that feature high in TB because they did not have adequate knowledge. The results showed that they were not educated adequately on the disease and the real symptoms associated with TB. Attawel (1996), agree with these results by indicating that there has been little community education to tell people about TB as a disease, the associated symptoms and to encourage them to seek treatment as early as possible. She indicates further that patients are not told about symptoms of TB, what they are experiencing, how TB is transmitted and the preventive measures. She also explains that people may be unaware of TB and its symptoms, how it spreads and its seriousness.

The findings of the study also revealed that the patients and guardians were not given adequate knowledge on the way they were supposed to take medication. No detailed information was given on how to take drugs, for how long, the side effects of drugs, how to identify drugs and how to deal with the side effects. Most of them did not understand the principles of TB treatment and the schedule for the treatment they were supposed to take. However health workers explained that patients and guardians are supposed to receive detailed information on disease condition, the associated symptoms, the principles of treatment, and the side effects of drugs and how to deal with these side effects. They explained that they fail to give detailed information because there are many patients and they are only few to meet the demands of these patients.

Attawel (1996), in his study found out that most of the times patients and guardians are not given careful explanation on the principles of treatment of TB and how to manage the side effects of drugs. In many cases patients are not told in advance about the side effects that they may experience and how to manage them. Salaniponi (1998) and Kruyt et al (1999), also concur with the above results by indicating that health workers know what it means by cause and effect, microbes and tissue damage and the importance of compliance but they rarely see things from the side of the patient and therefore give full and detailed education. This clearly indicates that inadequate knowledge on treatment of TB and duration of drugs lead to non-compliance. Health Systems Trust (1997), also indicated that most of the patients start and stop treatment because health workers only know how to dole out pills in large numbers with little explanation on the disease and treatment. Health workers seldom have the time to ask, listen or empathize and then they wonder why patients fail to complete treatment.

However, Jansens et al (2001), in their study found out that in most developing countries there is lack of human resources especially health workers' dealing with TB as compared to the large number of patients. Maher & Mikulencak (1999), supports this by indicating that in many places access to full and detailed health education on TB and its treatment is difficult because there are no enough health workers.

Basing on the results, it is evident that lack of full and detailed health education to patients and guardians lead to non compliance because the patients and guardians have problems in following the principles of treatment. Due to non-compliance, there are a lot of relapses and recurrences. It is also evident that the health workers fail to give full and detailed health education to patients and guardians due to work over load. Because of this problem, patients and guardians do not have the access to full and detailed health education hence the failure to follow instructions easily.

It was therefore noted that it is important that patients and guardians should be educated fully, and given all the details on the principles of TB treatment and the importance of complying with the treatment. These patients must be encouraged to start treatment and complete it. More appropriate health education and advice would help patients and guardians to understand. A better understanding results in better compliance therefore this step should not be neglected by practitioners. Patients need to be assured that treatment will make them feel better as long as they take it for the full eight months. At the same time community supporters and health workers should be well trained.

No appropriate health education can be given to patients and guardians if there are only a few health workers. Therefore more health workers should also be trained to match the increasing number of patients with smear positive Tuberculosis.

## 6.04 Problems experienced by patients and guardians.

The results of the study showed that most of the patients were afraid that they would not be able to comply with the treatment regimen. They said they were afraid because the treatment is very long and the drugs are many and difficult to swallow. Beeson et al (1996) and Health systems trust (1997), concur with the results by reporting that most patients fail to complete TB treatment because it is difficult to subject oneself to treatment for prolonged periods and that some of the reasons for patients' non-adherence to treatment are difficulties of swallowing 20-25 tablets twice weekly and severity of side effects.

Kruyt et al (1999), support this by indicating that frequency and long duration of treatment are some of the possible reasons for relapse cases.

The results also revealed that sometimes there was poor relationship between patients, guardians and health workers and this demoralized patients. The patients explained that they would feel like not going back for treatment due to their poor relationship with the health workers. Reichman et al (1996), concur with the results by reporting that health personnel love to blame patients for non-compliance in taking medication and this demoralizes patients.

Health Link (1999), however recommends that there is need for good relationship between patients and health workers or other treatment observer to encourage patient return regularly for treatment and adhere to the treatment.

The findings of the study also revealed that other patients experienced social stigma and relatives' failure to accept patients' condition. This they

said affected them a lot because the relatives are the source of support when somebody sick.

TB patients need a lot of support from guardians during treatment. The guardians help in escorting the patient to the hospital and reminding the patient to take drugs. Anthony et al (2001) in their study found out that most TB patients are affected with social stigma attached to the disease so that they easily give up and stop treatment. It is evident basing on the results that the patient can easily stop taking the drugs if the guardians fail to accept the patients condition. Failure to complete treatment leads to recurrence and drug resistance.

The results also showed that sometimes patients were given fewer drugs than the required amount and sometimes there were no drugs at all at the hospital that they were told to go back the next day. Some patients may not afford to travel again the next day due lack of finances and this may lead to missing of doses especially if these patients are not followed up by health workers in time. Jansens et al (2001), explain that sometimes patients do not comply with TB treatment due to non-availability of drugs at the periphery.

It was noted from the results that there is need for good relationship between patients, guardians and health workers always so that patients are motivated to take drugs. Patients should be assured always that drugs if taken for the required period would help them to recover despite being many and difficult to swallow. Guardians need to be informed about importance of their support to patients when they are on treatment. This can be done through community health education and every time the patient and guardian come to take drugs.

# 6.05 Attitude and practices of patients and guardians towards TB treatment and supervision.

The results of the research indicated that a large number of patients and guardians had positive feelings towards TB treatment because they reported that the treatment is effective and that symptoms subside within a short period of time. They reported that they would work extra hard this time to complete treatment since TB is life threatening and they would not want it recur again. These findings are contrary to Brouwer et al (1996), who found out that most of the patients 33 out of 89 (37%) had positive attitude towards traditional medicine than western medicine to TB. In addition to this, a report by WHO (1998) indicated that most of the patients start and stop treatment several times because of their negative attitude towards TB treatment.

The findings of the study revealed that there is no effective supervision of patients when they are taking medication. The results showed that at hospital level, patients are just given drugs and the health workers do not observe whether patient has really taken drugs or not. At guardian level, the findings showed that some patients refuse to take drugs when supervised by a guardian while some guardians tell their patients to rest a day or two without taking drugs.

However the findings also revealed that some patients do not listen to health workers instructions; they refuse to take drugs and sometimes pretend to vomit. It was also found that it is time consuming for health workers to see each and every patient swallow drugs. Some patients do not come for a resupply of drugs and health workers fail to follow them up due to pressure of work and lack of transport to take them to patients' homes.

Jansens et al (2001), in agreement with the results report that health workers fail to effectively supervise patients take drugs due to high workload. There is lack of human resource in the health system while directly observed treatment requires daily and twice weekly observation of ingestion of tablets by qualified personnel. Directly observed treatment calls for daily patient contact staff and this is not feasible in a low-income country like Malawi. However, Attawell et al (1996), indicates that a supervised programme with directly observed therapy which means watching the patients take drugs is very important. Health worker need to observe each patient take each dose of drug and to give support and encouragement. She indicates further that health workers need to ensure that people with active PTB take all their drugs and complete their treatment and this can only be effective if these patients are observed taking the drugs.

Jansens et al (2001), reports that guardian based supervision is only effective if patient is supervised taking the treatment by a health worker at clinic or community based health worker during home visits. The health worker needs to visit regularly and to check that patient taking medication and patients that fail to keep their appointment with health worker should be immediately contacted and helped to resume treatment.

It was noted from the results that it is important that every patient is observed taking medication by a health worker whether at hospital, health center or home. Though there is guardian based supervision, there must be a coordinated programme which should do home visits to ensure that patients take medication. Home based care programmes should be promoted so that patients are observed right at home taking drugs with the help of guardian and health worker. This can only be effective if more health workers are trained as explained earlier on.

#### 6.1 Conclusion.

It has been noticed from the study findings, discussion as well as literature that the major contributing factors to recurrent cases of smear positive Tuberculosis include; lack of adequate knowledge by patients and guardians on TB disease and principles of treatment, lack of effective supervision and adequate follow up of defaulters due to lack of human and material resources, poor social economic status of the patients and guardians, poor relationship between clients and health workers and long period of treatment i.e. 6-8 months which patients fail to comply with.

From the above factors it is evident that if patients and guardians do not have adequate knowledge on TB disease, the strategy and principles of treatment, they cannot take the drugs according to the required schedule. If the schedule is not followed these patients cannot recover hence leading to relapses and recurrences. The patients would think that they have finished taking the treatment while they used a wrong schedule.

Lack of adequate supervision would lead to lack of support to the patient. Drugs for TB treatment are many and when tired, the patient can easily stop taking them. This will lead to non-compliance and non-compliance is a major contributing factor to recurrences. Supervision helps to ensure that a patient has taken drugs and this is the point where a patient needs to be encouraged to finish the treatment. Lack of follow up of defaulters also leads to non-compliance and hence recurrences. Defaulters need to be followed up so that they are started on treatment as soon as possible. Poor economic status of patients, guardians and the government lead to lack of adequate resources needed for continued support of patients and health workers in the course of treating TB. Failure to go for treatment and lack of human and material resource for the government lead to lack of compliance and in the long run recurrences occur.

Some patients stop going to the health facilities for treatment due to the poor relationship with health workers. Patients cannot feel comfortable to go back for drugs when they know that health workers will be shouting at them.

#### 6.2 Recommendations.

- ❖ The researcher recommends that that all nurses more especially the ones that work in TB wards should be trained frequently and given information on TB, the principles of treatment and strategies of treatment with emphasis on DOTS. The training should be at al levels that is at district, health center and central hospital level. This training can be done in collaboration with the National Tuberculosis Control Programme. Nurses are the ones that are always in contact with patients i.e. 24 hours and therefore can easily provide care and patient education. Nurses cannot provide proper health education if they do not have adequate knowledge themselves.
- ❖ The Government should try as much as possible to support hospitals and health centers with more resources such as motorcycles, bicycles and adequate drugs so that health workers can follow some of the patients in their homes especially those that live very far and defaulters. Patients that live very far would be relieved since health workers would be within reach. This would help to promote compliance and proper monitoring of TB treatment by the health workers.
- More health workers dealing with TB should be recruited so that workload is reduced and this would help to ensure provision of detailed health education to patients and effective supervision since the ratio of patient to health worker would be manageable.
- All youths and young adults should be given detailed health education on disease process, mode of transmission, means of prevention, principles of treatment and importance of compliance. Community health nurses deal with the youth and young adults at school level during home visits and

outreach clinics. Therefore these community health nurses should be fully involved because they play a big role in promoting health of the people at community, school cities and towns. They are close to the community and therefore can easily provide health education to the youths and young adults. They should therefore be properly oriented to new strategies of TB treatment training and workshops. These can work together with TB officers who are trained by NTP. Good collaboration can help TB officers get adequate support from trained community health nurses.

Guardians need to be educated fully also on TB and treatment strategy. These guardians can be a very good support to health workers if they are given detailed information on control and prevention of TB, how to handle drugs, combine and give them to their patient and how to take care of their patients at home. Support to guardians might help them to have positive attitude towards TB treatment. Frequent evaluation on how health workers are supporting guardians need to be done by district TB control programme officers.

#### 6.3 Issues for further research.

A study should be conducted at national level to determine the major contributing factors to recurrent cases of smear positive Tuberculosis.

A study should be done at national level to find out why some more people still present with recurrent TB even after finishing treatment if TB is curable even in the presence of HIV/AIDS.

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## APPENDIX A: QUESTION AND INTERVIEW GUIDE. INTERVIEW GUIDE FOR THE PATIENTS.

| SECTION A: | DEMOGR | RAPHIC | DATA |
|------------|--------|--------|------|
|------------|--------|--------|------|

| 1. How old are you? (tick)     | (a) 10 – 24 years [ ].                   |
|--------------------------------|--|
|                                | (b) 25 – 34 years [ ].                   |
|                                | (c) 35 – 44 years [ ].                   |
|                                | (d) 45 – 54 years [ ].                   |
|                                | (e) 55 – 64 years [ ].                   |
|                                | Others (specify)                         |
|                                | Others (specify)                         |
| 2. Marital status ( tick )     | (a) single [ ].                          |
|                                | (b) married [ ].                         |
|                                |  |
| 3. Educational level (tick)    | (a) None [ ].                            |
|                                | (b) Primary [ ].                         |
|                                | (c) Secondary [].                        |
|                                | (d)Other( specify )                      |
|                                |  |
| 4. Occupation                  |  |
|                                |  |
|                                |  |
| 5 Who supervised you when y    | ou were on treatment first time( tick ). |
| (a ) Hospital                  | []                                       |
| (b)Health ce                   | nter[].                                  |
| (c)Guardian                    |  |
| 6. Sources of information abou | ut your condition and treatment.         |
| (a) Guardians [                | ].                                       |
| (b) health worker              | rs [ ].                                  |
| Other (specify).               |  |
|                                |  |

#### SECTION B: KNOWLEDGE.

| D        | isease condition.  |  |  |  |  |  |  |  |
|----------|--|--|--|--|--|--|--|--|
| 1.       | What do you know about the disease you are suffering from?             |  |  |  |  |  |  |  |
|          |  |  |  |  |  |  |  |  |
|          |  |  |  |  |  |  |  |  |
| 2.       | Where did you learn about the disease?                                 |  |  |  |  |  |  |  |
|          | ***************************************                                |  |  |  |  |  |  |  |
|          |  |  |  |  |  |  |  |  |
| 3.       | Were you educated on the disease you are suffering from?               |  |  |  |  |  |  |  |
|          |  |  |  |  |  |  |  |  |
|          |  |  |  |  |  |  |  |  |
| <b>T</b> | rootmant ragiman   |  |  |  |  |  |  |  |
|          | reatment regimen.  |  |  |  |  |  |  |  |
| 1.       | What drugs were you taking when you were on treatment first time?      |  |  |  |  |  |  |  |
|          |  |  |  |  |  |  |  |  |
| 2.       | Did you know the schedule for the treatment you were supposed to take? |  |  |  |  |  |  |  |
|          | A) Yes B) No   |  |  |  |  |  |  |  |
| 3.       | If yes, what was the schedule like?                                    |  |  |  |  |  |  |  |
|          |  |  |  |  |  |  |  |  |
|          |  |  |  |  |  |  |  |  |
|          |  |  |  |  |  |  |  |  |
|          |  |  |  |  |  |  |  |  |
| 4.       | Did you know for how long you were supposed to take the drugs?         |  |  |  |  |  |  |  |
|          | a) Yes b) No   |  |  |  |  |  |  |  |
| 5.       | Which combination of drugs were you supposed to take?                  |  |  |  |  |  |  |  |
|          |  |  |  |  |  |  |  |  |
|          |  |  |  |  |  |  |  |  |

| 6.     | Who explained to you about the drugs and how you were supposed to take them?         |
|--------|--|
| 7.     | Were you educated on the treatment you were supposed to take?                        |
| 8.     | Did you finish taking the medication as prescribed for you by the health worker?     |
|        | CTION C: PROBLEMS EXPERIENCED.   |
| 1.     | What specific concerns and fears did you have when you were on treatment first time? |
|        |  |
| 2.<br> | What problems did you experience when you were on treatment first time?              |
|        | . Probe more on a. Long distances from homes to hospitals and health center          |
|        | b. Availability of drugs.  |
|        | ***************************************  |
|        | c. Relationship with health workers.   |
|        |  |
|        | d. Relationship with guardian supervisor.  |
|        |  |
|        | e. Length of treatment.  |
|        |  |
|        | f. Lack of knowledge on treatment regimen.   |
|        | g. Simple forgetfulness  |
|        | h. Guardians perception of the disease.  |

## SECTION D: ATTITUDE.

| 1. | What can you say about the treatment given to patients with smear positive Tuberculosis?                                |
|----|---|
|    |   |
| 2. | What are your feelings on education given to patients when they are on treatment for the first time?                    |
|    |   |
| 3. | What can you say on the way supervision of patients with smear positive Tuberculosis is done?                           |
|    |   |
|    | What sugestions do you have that can help to improve delivery of services to patients with smear positive Tuberculosis? |
|    |   |

## QUESTION GUIDE FOR FOCUS GROUP DISCUSSIONS WITH GUARDIANS.

- 1. How would you describe the type of illness your relative is suffering from?
- 2. What do you know about the drugs your relative was taking when he/ she was on treatment for the first time?
- 3. Did your relative finish taking the medication as prescribed?
  - . (If yes, probe on the problems encountered during the period of treatment).
  - . (If no, probe on the reasons for not finishing the treatment.)
- 4. What role did you play in caring for your relative?
- 5. What problems were you experiencing when supervising your relative taking medication?
- 6. What information were you given conserning the treatment your relative was receiving?

### QUESTION GUIDE FOR HEALTH WORKERS.

| What do you think are the advantages and disadvantages of supervisi patients taking medications? | ng  |
|--|-----|
| How is supervision of patients done at hospital, health center and guardial level?               | an  |
| 3. What problems do you experience when supervising the patients taking medication?              | ng  |
| 4. What are the advantages and disadvantages of supervising patients hospital level?             | at  |
| 5. What are the advantages and disadvantages of supervising patients at heal center level?       | lth |
| 6. What are the advantages and disadvantages of supervising patients guardian level?             | at  |
|  |     |

| 1. | vvnat into | ormation are                          | you su            | uppose                                  | a to g | give to pa | itients and                           | guar  | dians w | nen .    |
|----|------------|---------------------------------------|-------------------|---|--------|------------|---------------------------------------|-------|---------|----------|
|    | they are   | diagnosed                             | ТВ р              | ositive                                 | and    | starting   | treatment                             | for   | smear   | positive |
|    | Tuberculo  | osis?                                 |                   |   |        |            |                                       |       |         |          |
|    |            |                                       |                   | • |        |            |                                       |       |         |          |
|    |            |                                       |                   |   |        |            |                                       |       |         |          |
|    |            |                                       |                   |   |        |            |                                       |       |         |          |
|    |            |                                       |                   |   |        |            |                                       |       |         |          |
| 8. | What sug   | gestions do                           | you ha            | ave tha                                 | at can | help to    | ensure effe                           | ctive | treatm  | ent of   |
|    | Smear p    | ositive Tube                          | erculos           | is.                                     |        |            |                                       |       |         |          |
|    |            |                                       | • • • • • • • • • |   |        |            |                                       |       |         | • • •    |
|    |            | · · · · · · · · · · · · · · · · · · · |                   |   |        |            | · · · · · · · · · · · · · · · · · · · |       |         |          |

#### **APPENDIX: B**

#### FOCUS GROUP DISCUSSION REPORT.

The focus group discussion comprised twelve females and two males. All the members were adults and guardians to patients with recurrent smear positive Tuberculosis.

#### Description of illness.

Most of the respondents described the illness their relative are suffering from as recurrent smear positive Tuberculosis. They said the disease is characterized by symptoms such as coughing, diarrhea, chest pains, general body malaise, loss of appetite and vomiting. However they said they were not fully educated on the disease their relative suffered from during the first diagnosis.

#### Knowledge on drugs and treatment regimen.

Some of the members explained that drugs are very effective that the symptoms subside within a short period of time. Others said that with the drugs, the symptoms proceeded so that their patients got sicker than at first. The majority of the guardians said that they had no knowledge on the kind of drugs that their patients were taking when they were on treatment first time. They only knew how to combine the drugs using colours since they did not know them by names.

Most of them said that their relatives finished taking the medication although sometimes their patients could vomit the drugs. They explained that the patients were asking for the drugs themselves and they were taking them early in the morning before doing anything. They said that if their patients missed may be it was due to wrong combination of drugs or if the patient vomited and did not have other drugs to replace the lost once.

#### Role-played in caring for the patient.

The group members said that they tried as much as possible to give total loving care to their patients. They were taking care of their patients' daily needs and some said they made sure that the patient had a sputum bottle for disposal of sputum. The majority said they made sure that the patient had taken medication before doing anything. They also helped in escorting the patient to hospital or health center for resupply of drugs.

#### Information given on patients treatment.

The guardians explained that the health workers told them that their patients were suffering from TB and that they were going to start TB treatment. They were given the drugs and told how often the patient should take them. They said the health worker explained to them how the patient was supposed to take the drugs. They also told them that the patient should eat enough food, and take care of sputum so that he/ she does not infect others. They were also advised to make sure that the patients don't do a lot work to avoid shortness of breath, stop smoking and drinking alcohol. On drugs they were not told the side effects of drugs and how to manage them. The mode of action of the drugs and importance of compliance was not clearly explained.

#### Problems experienced.

The majority of the members explained that they experienced problems related to long distances from homes to hospitals and health centers, side effects of drugs and anger from health workers. Most of them said that they stayed far from hospitals or health center such that it was either difficult to walk on foot or they had problems in having transport money every week for resupply of drugs. However they said they tried as much as possible to escort their patients.

They further explained that their patients sometimes vomited the drugs and because of this they had no other drugs to replace the lost ones. They were

afraid of going back to the health workers to explain this because they had seen some health workers shouting at patients as if they vomit deliberately. Others said that instead of explaining issues or reminding the patient, the health workers shouted at them and this demoralized them. They sited an example of being given more drugs than the required amount where they said health workers shouted at them instead of listening to the patient's explanation. They were thinking that the patient did not finish the drugs supplied the previous week.

Long period of treatment is another problem they sited. They said that they had problems in convincing their patients to take drugs sometimes. Their patients could sometimes say they were tired of taking drugs. They also had a problem of fear of contracting the disease from their patients as they were taking care of them. Other guardians said that their patients refused to stop drinking and smoking while on treatment and this disturbed their taking of drugs.

#### Suggestions from guardians.

The guardians suggested that there should be full health education on the following areas when the diagnosis of their patient's condition is confirmed and when these patients start treatment.

- Education on how guardians should take care of themselves so that they are not infected as they take care of their relatives.
- Education on what kind of TB patient has.
- Explanations on side effects of drugs when drugs are given to patient and not after the patient meet the side effects.
- Explanation on the reasons for a lot of side effects after taking medication.

They also suggested the following:

- Guardians should be checked after patient finishes treatment to see if she/ he
  is TB positive or not.
- Health workers should visit patients in their homes to supply drugs or assess how the patient's condition is progressing.

#### APPENDIX: C

#### REPORT FROM INTERVIEWS WITH HEALTH WORKERS.

Interviews with health workers were done to elicit information on advantages and disadvantages of supervising patients at hospital, health center and guardian level. The health workers were also asked on how supervision of patients is done at health center, hospital and guardian level.

They were asked if they provide detailed information to patients on disease condition and treatment regimen, drugs and their side effects and what they do when a patient has missed medication or he/ she has not been showing up for respell of drugs. They also gave in suggestions that can help to ensure effective treatment of smear positive Tuberculosis.

#### Supervision of patients.

The health workers explained that supervision of patients helps to ensure that patients have taken drugs, helps to give confidence to patients, follow up on progress of patients' condition and identify problems that they experience as they take drugs. They said the disadvantages of supervising patients taking medication are that patients stand for a long time waiting to receive the drugs, some patients feel uncomfortable to be seen taking drugs and that it time consuming for the health workers to supervise each patient take drugs.

At hospital level, the health worker gives drugs to the patient and sees that he/she has taken them. At health center level, patients go to the health center three times a week that is on Monday, Wednesday and Friday and takes medication right there. At guardian level, the guardian gives drugs to the patient, controls them and sees the patient take drugs.

The health workers said that the advantages of supervising at hospital level is that they see the patient swallow drugs, health education is given to patients on prevention and their is quick recovery of patients because they are well taken care of.

The disadvantages of supervision at hospital level are that patients get used to nurses that they do not listen to their instructions and there is congestion of patients.

They said that it is advantageous to supervise the patients at health center level because the patients' sleep at home hence there is no congestion at the hospital. However the disadvantages are that the patients default and stop taking drugs before the right time and that they lack encouragement.

They also explained that the advantages of supervision at guardian level are that the patient is well cared for at home, hardships of going to the hospital are minimized and there are less movements. The disadvantages are that the guardians fail to convince the patient who are reluctant to take drugs and that some patients refuse to take drugs from guardian.

#### What information is provided to patients?

The health workers said that the patients and guardians are supposed to be given detailed information on disease condition, drugs, side effects, and importance of compliance, full treatment regimen and management of side effects of drugs. They said that they fail to provide detailed information to the patients and guardians because they have a lot of work to do since there are a lot of patients and they are only few to meet the demands of these patients. However they said they try their best to give the basic information needed to patients who are on treatment.

#### Problems experienced when supervising patients.

The health workers explained that they meet a lot of problems when supervising patients taking medication. They said that other patients refuse to take drugs because they are many, while others pretend to vomit the drugs. Other patients refuse to take drugs in the morning and want to find their own time for taking the drugs.

They further explained that it is time consuming for them to see each and every patient swallow drugs. Because of this they just distribute the drugs and do not see each and every patient swallow them. The other problem is that other patients miss the days for treatment and this disturbs the treatment regimen. When this happens they are supposed to follow up these patients but sometimes they fail due to pressure of work and lack of transportation to patients homes.

#### Suggestions from health workers.

The health workers suggested that there should be close monitoring and supervision of patients taking drugs and this can only be effective if more TB health personnel are trained so that the ratio of patient to them balances. Others suggested that effective and detailed health education should be given to people on preventive measures and importance of compliance. Effective health education should also be given on disease condition; drugs and symptoms so that patients follow easily, are not disturbed and finish taking medication according to the prescription.

#### APPENDIX D: CLEARANCE LETTERS.

Unversity of Malawi,
Kamuzu College of Nursing,
Private Bag 1,
Lilongwe

Lilongwe District Health Office, Area 25 Health Center, Po Box 40131, Kanengo,

Att: The In - Charge.

Dear Sir/ Madam,

Lilongwe 4.

## APPLICATION FOR PERMISSION TO CONDUCT A STUDY AT YOUR HEALTH CENTER.

lam a fourth year generic student pursuing a Bachelor of Science Degree in Nursing at the above mentioned college. As a partial fulfilment of the programme, lam required to do a research project in my area of interest.

I write to apply for permission to conduct the research study at your health center. The title of the study is: Contributing Factors to Recurrent Cases of Smear Positive Tuberculosis.

Your favourable consideration on this issue will be greatly appreciated.

Yours Faithfully,

Victoria Mayamingie Lwesha.

University of Malawi,
Kamuzu College of Nursing,
Private Bag 1,
Lilongwe.

The Secretary for Health,

Ministry of Health and Population,
Po Box 30377,

Lilongwe 3.

Att: Controller of Nursing Services.

Dear Sir /Madam,

#### PERMISSION TO CONDUCT RESEARCH AT BOTTOM HOSPITAL

I write to seek permision to conduct a study at the above mentioned institution during the months of february to march.

lam a student at Kamuzu College of Nursing pursuing a Bachelor of Science Degree in Nursing. Iam required to conduct a reseach study as a partial fulfilment to my academic award. The title of my study is: Contributing factors to recurrent cases of smear positive Tuberculosis.

Loking forward to your favourable consideration.

Yours Faithfully, Victoria Mayamingie Lwesha.

University of Malawi,
Kamuzu College of Nursing
Private Bag
Lilongwe.

The secretary for Health,

Ministry of Health and Population,

Po Box 30377,

Lilongwe 3.

Att: Research Coordinator.

Dear sir / Madam

#### PERMISSION FOR CLEARANCE.

lam a fourth year generic student pursuing a Bachellor of Science Degree in Nursing.As a partial fulfillment to my Degree award, Iam required to do reseach in my area of interest and write up a dissertation. The title of my study is: Contributing factors to recurrent cases of smear positive Tuberculosis.

The purpose of this letter is to request for National clearance to enable me to conduct the research study in Malawi at Bottom hospital and Area 25 health center.

Looking forward to your assistance and consideration.

Yours Faithfully,

Victoria Mayamingie Lwesha.

Universty of Malawi,
Kamuzu College of Nursing,
Private Bag 1.
Lilongwe.

The Director,
Lilongwe Central Hospital,
Po Box 149,
Lilongwe.

Att: The Senoir Matron (Old Wing).

#### PERMISSION TO USE BOTTOM HOSPITAL AS A RESEARCH SITE.

In partial fulfillment of the award of Bachellor of Science Degree in Nursing at Kamuzu College of Nursing, lam required to conduct a study on a topic of my interest. The title of my study is: Contributing factors to recurrent cases of smear positive Tuberculosis.

I propose to carry out the study in the month of february or march, 2002.

The purpose of this letter is to seek permission to conduct the study at Bottom Hospital.

Looking forward to your favourable consideration.

Yours Faithfully,

Victoria MayamingieLwesha.

APPENDIX E: CONSENT LETTER

University of Malawi, Kamuzu College of Nursing, Private Bag 1, Lilongwe.

Dear participant,

In partial fulfillment of the Bachellor of Science Degree in Nursing, lam required to conduct a study and the title of my study is: Contributing factors to recurrent cases of smear positive Tuberculosis. Findings of the study will help the health planners to identify the areas that are missed when treating patients with smear positive Tuberculosis and therefore the problems will be tackled more effectively. You have purposefully been selected to participate in the study. Interviews will be done using a question guide. Code numbers will be used instead of names to identify participants inorder to maintain confidentiality.

Feel free to ask any questions relating to the study. You are free to refuse, accept and withdraw from participating in the study. If you wish to participate in this research study, please sign the attached form.

Thank you for your cooperation and support.

Victoria Mayamingie Lwesha

#### CONSENT FORM.

| ١, | the    | undersign    | ned  | have  | read  | and  | understo   | od  | the  | information   | and    | conditions | of |
|----|--------|--------------|------|-------|-------|------|------------|-----|------|---------------|--------|------------|----|
| pa | artici | ipating in t | he : | above | resea | arch | study. I a | gre | e to | participate i | n this | s study.   |    |

| Participants signature | Date |
|------------------------|------|
| Researchers signature  | Date |

University of Malawi, Kamuzu College of Nursing, Private Bag 1, Lilongwe.

Kwa otenga mbali,

Kuvomereza kuchita nawo kafukufuku wa kupeza zomwe zimathandiza kuti matenda a chifuwa chachikulu cha TB ayambilenso.

Ndili pa maphunziro a unamwino ku Kamuzu College of Nursing komwe ndikuyenera kupanga kafukufuku. Cholinga cha kafukufukuyu ndi kufufuza zomwe zimathandiza kuti matenda achifuwa chachikulu cha TB ayambilenso. Zotsatira za kafukufuku ameneyu zizathandiza anthu ogwira ntchito ya za umoyo makamaka achipatala kuti alongosole njira zabwino zothandiza kuti odwala matenda a TB achire ndipo matendawa asayambilenso.Inuyo mwasankhidwa kuti mukhale nawo mgulu la anthu ochita nawo kafukufukuyu. Mukafukufuku ameneyu tidzagwiritsa ntchito mafunso omwe adzakutsogolereni kuti muthe kufotokoza zomwe mumakumana nazo panthawi yomwe munkadwala ndipo pomwe munkamwa mumankhwala. Maina anu sadzagwiritsidwa ntchito kuti wina asadzaziwe zomwe inu mwayankhula.

Khalani omasuka poyankha mafunso, ndinso kuvomera, kukana kapena kusiya mutayamba kale kuchita nawo kafukufukuyu. Ngati mwavomera kuyankha mafunso, musayine mmunsimu.

Zikomo kwambiri chifukwa chakuthandiza pakafukufukuyu.

Ndine Victoria Mayamingie Lwesha

Ine ndavomera ndiponso zonse zokhuzana ndi kafukufukuyu nadzimvetsa. Ndikuvomereza kuchita nawo kafukufukuyu.

| Sayinani apa               | Tsiku |
|----------------------------|-------|
| Posayina ochita kafukufuku | Tsiku |