# TUBERCULOSIS TREATMENT INTERRUPTION

by

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# **DECLARATION**

I declare that TUBERCULOSIS TREATMENT INTERRUPTION is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

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### TUBERCULOSIS TREATMENT INTERRUPTION

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# **ABSTRACT**

This quantitative, descriptive study investigated factors that contributed to TB patients registered in four Tembisa clinics in 2001, defaulting treatment. An interview schedule with closed and open-ended questions was used for 30 patients who could be traced who had interrupted treatment.

The reasons for treatment interruption were related to socio-economic, TB policy-related and health care worker-related factors. The findings illustrate that TB management requires a multi-sectoral approach and joint efforts to tackle the disease that continues to kill people even though it is curable.

#### **KEY CONCEPTS**

DOTS; interruption; multi-drug resistant tuberculosis; perception; re-treatment; treatment; tuberculosis.

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# **Dedication**

To my late parents, my family, friends and colleagues, and nurses everywhere

# Chapter 1

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# List of abbreviations

TB Tuberculosis

HIV Human Immuno-deficiency Virus

AIDS Acquired Immuno-deficiency Syndrome

MDR Multi-drug Resistant

WHO World Health Organization

DOTS Directed Observed Treatment Short Course

PHC Primary Health Care

SANTA South African Tuberculosis Association

TADSA TB Alliance DOTS Support Association

INH Isoniazid

NTCP National Tuberculosis Control Programme

ETR Electronic TB Register

NGOs Non-governmental Organisations

RDP Reconstruction and Development Programme

PWT People living with TB

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### **CHAPTER 1**

# Orientation to the study

#### 1.1 INTRODUCTION

Tuberculosis (TB) is an infectious but curable disease. In terms of health policy in South Africa, TB treatment is available free of charge at clinic level. Health care workers are trained to manage and administer TB cases according to standardised protocols and to provide relevant health education. In spite of free TB treatment and the provision of health education about TB at clinics, one out of five patients does not complete treatment. TB is curable, but the morbidity rate worldwide is on the rise due to the impact of the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) (Department of Health 2000a:7).

The problem of people with TB not complying fully with the treatment prompted the researcher to investigate how TB patients perceive the disease and its treatment and what other factors impact on TB and its treatment. The value of obtaining such information directly impacts on TB patients because they may develop multi-drug resistant (MDR) TB if treatment is interrupted. MDR-TB is very expensive to treat and can be fatal (*Saturday Star* 2003:6)

#### 1.2 BACKGROUND TO THE PROBLEM

TB has been a problem in the world since the eighteenth century (Pallangyo 2001:488). According to Jaramillo (1999:39), TB is still one of the leading causes of death. Tuberculosis kills an estimated 1,5 million people every year worldwide, and every 20 seconds, a person dies of TB (<a href="http://www.who.int/tb/publications/global">http://www.who.int/tb/publications/global</a> report/2008/keypoints/en/index.html).

In the 1980s, the incidence of TB declined in developed countries. With the outbreak of AIDS, however, the incidence of TB increased and interest in research on TB revived (Bateman 1994:381). An epidemic of HIV-associated TB is now affecting Africa and

threatening parts of Asia. HIV infection gives rise to an estimated 10,0% of global TB cases and 70,0% of cases in Sub-Sahara Africa (WHO 2004:36).

TB is getting out of control in many regions of the world, about 8,8 million new cases of TB are notified worldwide, of which more than half are in Asia. An estimated three quarters of all TB cases are concentrated in the economically productive age group (between 15 and 59) of the world's population (Department of Health 2004:7). In 2006, the World Health Organization (WHO) ranked Bangladesh, sixth among the world's 22 high-burdened TB countries (WHO 2006:1).

In 1994, war in Rwanda and elsewhere forced refugees to flee to neighbouring countries. Among the diseases that affected the refugees was TB. Tribal and civil unrest in Burundi also led to the displacement of thousands of refugees into neighbouring Tanzania. Between January 1995 and December 1999, 546 patients were notified with confirmed smear-positive TB in refugee camps in Tanzania (Rutta, Kipingili, Lukonge, Assefa, Mitsilale & Rwechungura 2001:628).

South Africa is rated among the countries with the highest incidence of TB. South Africa reports more than 100 000 TB cases yearly (Department of Health 2004:7). Edginton (1997a:7) notes that not all TB patients put on treatment complete their treatment. Moreover, TB treatment interruption leads to the increase of MDR-TB.

In the UK, in 1992, 45,0% of homeless people and 10,0% of adults interrupted their treatment (Morse 1996:720). Ruck (1997:23) points out that although TB is well known to lay people as well as professionals and is curable, the disease is still not under control. Ruck (1997:23) emphasises that treatment programmes alone are not enough to control the problem; environmental factors need to be taken into consideration when dealing with a TB epidemic. For example, poverty has an influence on the level of immunity and nutritional status, which predisposes the person to TB. Hence a twin approach of treatment and environmental and human factors should be adopted (Ruck 1997:23).

Africa is struggling to get TB under control because of poverty and instability. Wars and unstable political conditions in many African countries cause TB control programmes to fail. The rendering of proper health services in socially and politically unstable conditions is not possible and many patients flee from their countries without having completed treatment. Effective arrangements for the transfer of these patients to health services in the host countries to continue with treatment are not feasible. Many of these refugees are homeless in their new countries for lengthy periods and are not known to health workers as people with TB. This augments the problem because they then not only discontinue their treatment but also develop resistance to TB drugs. In addition, refugees are often without proper nutrition and live in unsatisfactory conditions (Rutta et al 2001:628).

HIV and AIDS and MDR-TB further complicate the management of TB. TB is the leading cause of death of 50,0% of patients with HIV and AIDS. The WHO states that there were an estimated 0,5 million cases of MDR-TB in 2006 (<a href="http://www.allafrica.com/stories/200802270523.html">http://www.allafrica.com/stories/200802270523.html</a>).

In 1993, the WHO declared TB a global emergency. In 1996, Nkosazana Dlamini-Zuma, then Minister of Health, declared TB a major health issue in South Africa. The control of TB and its treatment were to be a priority on the Government's health agenda (Department of Health 1997:9). Recognising TB as a major health concern resulted in improved rendering of health services to TB patients, including

- a regular supply of TB drugs to clinics
- sputum results turnaround times between clinics and laboratory services improved to between 48 and 72 hours
- regular TB training for health personnel in the sub-district

However, these measures did not ensure patients' compliance with treatment. Some patients still do not complete their treatment (Department of Health 2000a:9).

Tembisa is a big township situated in the north of Ekurhuleni Metropolitan Municipality. Ekurhuleni means "place of peace" and was established in 2000. Formerly called the East Rand, Ekurhuleni consists of 190 147 hectares of land and has a population of approximately 3 million people. There are more than 8 000 industries and the

Johannesburg International Airport (now called the OR Tambo International Airport) in the area. Ekurhuleni is responsible for 23,0% of the gross geographical product of the Gauteng Province and is also the most economically powerful region in Sub-Saharan Africa (Ekurhuleni District Annual Report 2006-2007:4).

Tembisa was established in 1956. Tembisa is about 183 km² with a population of 1 million people. It is surrounded by the industries of Kempton Park, Spartan, Isando, Modderfontein, Edenvale, Elandsfontein and Olifantsfontein. According to the 2001 census, of the population 40,0% were unemployed; 45,0% were males, and 55,0% were females. Many people live in informal settlements and hostels where poor socioeconomic conditions exist. The income distribution was as follows (Ekurhuleni Metropolitan Municipality Annual Report 2002-2003:4):

Less than R800 - 42,0%
R800 - R1 500 - 12,0%
R1 500 - R3 500 - 17,0%
Above R3 500 - 29,0%

The population of Tembisa is highly mobile/migrant, especially in the informal settlements and among those who live in backyards. This situation makes it difficult for the clinics to manage TB effectively.

Tembisa has four clinics operational for eight hours per day for five days a week and a TB nurse conducting a "fast lane" for TB patients in each clinic (Ekurhuleni District Annual Report 2005-2006:14). It is important that all forms of TB are treated effectively according to the national TB control guidelines (Department of Health 2001:14). Pulmonary TB spreads through droplet infection so smear-positive TB patients must be treated promptly and effectively (Arnadottir 2001:564).

For the purpose of this study, only smear-positive TB patients were considered. TB treatment for patients diagnosed with pulmonary TB for the first time lasts for six months, while patients diagnosed with TB more than once are treated for eight months. Taking treatment for such long periods is not easy; some TB patients stop as soon as they feel better (Edginton 1997a:7).

During 2006, only 286 out of 395 registered smear-positive patients completed their treatment in the four clinics in Tembisa, which means that 24 (6,0%) interrupted their

treatment (Ekurhuleni District Annual Report 2005-2006:14).

Areas like Hillbrow in Johannesburg and Bophelong in the Vaal area also had an interruption rate of over 20,0%, which was far above the 5,0% set by the national and provincial health departments (*Saturday Star* 2003:6).

#### 1.3 RATIONALE FOR THE STUDY

The researcher wished to investigate why TB patients in the Tembisa area do not comply with the TB treatment and how they perceive TB as a disease.

#### 1.4 SIGNIFICANCE OF THE STUDY

The findings of this study could increase the body of knowledge to promote compliance with TB treatment and prevent TB patients defaulting. Patients who interrupted treatment in the Tembisa area were considered the most suitable respondents in a study of this nature. The findings can be used to identify problems contributing to interruption of TB treatment.

#### 1.5 STATEMENT OF THE PROBLEM

Tuberculosis treatment outcome reports in Tembisa indicated that 16,0% of the TB patients interrupted treatment. This leads to the spread of TB as well as an increase of MDR-TB. MDR-TB is caused by strains of Mycobacterium TB resistant to both Rifampicin and Isoniazid, with or without resistance to other drugs (Department of Health 2000a:40).

The following questions were derived from the problem statement:

- What is Tembisa TB patients' level of knowledge of TB as a disease?
- What are their opinions on, perceptions of and attitudes towards TB as a disease?
- How do TB patients in Tembisa perceive the health services they receive at the clinics?
- What factors contribute to TB patients in Tembisa interrupting treatment?
- What recommendations will be made to decrease TB treatment interruption in

#### Tembisa?

#### 1.6 AIM OF THE STUDY

The aim of the study was to investigate factors that could influence the interruption of TB treatment in the Tembisa area.

#### 1.7 OBJECTIVES

The specific objectives of this study were to

- determine the level of knowledge of TB patients in Tembisa about TB as a disease and the treatment of TB
- determine the patients' opinions, perceptions of and attitudes towards TB
- determine what factors contribute to the interruption of treatment at Tembisa clinics
- determine the patients' perceptions of health services at the clinics in Tembisa
- make recommendations to decrease interruption of TB treatment in Tembisa, and for further research

The World Health Organization (WHO) designed the Direct Observed Treatment Short course (DOTS) strategy to improve TB patients' compliance and to prevent the development of MDR-TB (Walley 1997:21). The DOTS strategy entails patients on treatment taking their medication under the direct observation of the DOTS supporter to ensure that the prescribed treatment is taken exactly as prescribed. The DOTS strategy has improved compliance with TB treatment in many countries (Walley 1997:21). According to Morse (1996:72), DOTS originated in the late 1940s when British researchers used it in chemotherapy trials in Africa, Asia and London.

The DOTS strategy is an organisational framework that consists of five key elements (Department of Health 2000a:9):

- Government commitment to the national TB programme
- Case detection through smear microscopy
- Standardised treatment of TB cases via the DOTS strategy

- Regular, uninterrupted drug supply
- A system of monitoring and evaluation

DOTS is a community-driven strategy in which members of the community participate voluntarily as DOTS supporters. They are trained by health care workers on how to effectively supervise TB patients when taking their treatment in the community. Over and above the issue of taking the correct dosage, the DOTS supporter should remind and encourage people on TB treatment to continue until the final dosage of the treatment regime.

Community-based DOTS is not yet well established in Tembisa. For patients who live far from the clinics, however, arrangements are made to receive their TB treatment from the general practitioners who practise near their homes. Doctors' receptionists often voluntarily act as DOTS supporters for the patients.

Although TB patients are educated on the treatment of TB and the importance of completing the treatment when they attend the clinics, there are still patients who do not complete their treatment. The interruption rate is highest in the clinics that serve hostel dwellers and informal settlements. One out of every five patients tends to interrupt treatment (Weyer, Coggin & Lancaster 1999:1).

The non-compliance of patients on TB treatment was of major concern for the researcher, who decided to investigate possible factors that could contribute to TB treatment interruption, by exploring patients' perceptions of TB as a disease and its treatment.

#### 1.8 DEFINITION OF TERMS

For the purposes of this study, the following terms are used as defined below.

#### **♦** Tuberculosis

The Oxford Advanced Learners Dictionary (1992:1375) defines TB as "an infectious disease in which growths appear on body tissues, especially the lungs". Bailliere's Nurses Dictionary (1974:245) defines TB as "a specific infectious disease produced by Mycobacterium Tuberculosis discovered by Kock".

In this study, tuberculosis refers to TB that has been confirmed by a positive sputum smear in patients who live in Tembisa.

#### Patient

The Oxford Advanced Learners Dictionary (1992:906) defines a patient as "a person who is receiving medical treatment especially in a hospital".

In this study, a patient is a person who has been diagnosed with TB on a positive sputum smear and who comes for TB treatment at the Tembisa clinics or at the general practitioners' surgeries once a day from Monday to Friday for six or eight months.

#### Treatment

The Oxford Advanced Learners Dictionary (1992:1336) defines treatment as "an action taken to relieve or cure an illness or defect". Bailliere's Nurses Dictionary (1972:342) defines treatment as "a mode of dealing with a patient or disease".

For the purpose of this study, treatment means the management of patients attending TB clinics in Tembisa. Treatment includes registration as a TB patient, provision of health education, home visits, and providing and administering TB medication.

#### ♦ Retreatment

A retreatment patient is a TB patient who was treated for TB for more than 9 months in the previous episode (Department of Health 2000a:18).

For the purpose of this study, a retreatment patient is a patient who was previously treated for TB.

#### Interruption

The Oxford Advanced Learners Dictionary (1992:657) defines interruption as "a break in the continuity of something".

According to the National Tuberculosis Control Programme (Department of Health 2000b:27), interruption is "stopping of taking TB medication for more than 10 days in the first two months of treatment or more than one month during a four to six months duration of treatment".

In this study, interruption means an act by TB patients of not taking treatment for more than 10 days in the first two months of treatment or more than one month during a four to six months duration of treatment (Department of Health 2000b:27).

#### Perception

The Oxford Advanced Learners Dictionary (1992:917) defines perception as "a way of seeing or understanding something".

In this study, perception means the opinions, feelings and attitudes of TB patients in Tembisa regarding TB as a disease and its treatment.

#### 1.9 ASSUMPTIONS

According to Polit and Hungler (1995:10), assumptions are "basic principles that are assumed to be true without proof of verification".

This study was based on the following assumptions:

- TB patients are responsible for their own health and are therefore committed to take and complete their treatment.
- Regardless of the efforts directed towards the care of TB patients, a percentage of patients will interrupt treatment.
- Specific factors experienced by TB patients as well as health care workers may contribute to TB treatment interruption by TB patients.

#### 1.10 RESEARCH APPROACH

According to Polit and Hungler (1995:11), the research approach refers to the researcher's overall plan for obtaining answers to the researcher's questions and for testing the research hypothesis. The research design directs the strategies that the research adopts to develop information that is accurate, objective and interpretable.

In this study, the researcher adopted a quantitative research approach because factors that may contribute to the non-compliance of patients on TB treatment, such as health personnel's attitude, social or economic issues, personal perceptions, and environmental factors, could be quantified.

#### 1.11 RESEARCH DESIGN

The research design was descriptive. Descriptive statistics were used to present the findings.

#### 1.11.1 Population

According to Polit and Hungler (1995:35), the study population refers to "the aggregate or totality of all the objects, subjects or members that conform to a set of specifications". In this study, the population consisted of all the patients who were diagnosed with TB on a positive sputum smear who came for TB treatment at the Tembisa clinics, namely Tembisa Health Care Centre, Tembisa Main Clinic, Erin Clinic and Winnie Mandela Clinic from January 2001 to December 2001 (see table 1.1).

#### Table 1.1 Total number of patients diagnosed with smear-positive TB

NAME OF CLINIC	NUMBER OF CLIENTS WITH POSITIVE SMEARS	NUMBER OF DEFAULTERS	PERCENTAGE DEFAULTERS
Tembisa Health Care Centre	163	48	29,4
Tembisa Main Clinic	155	11	7,1
Erin Clinic	69	5	7,2
Winnie Mandela Clinic	34	5	14,7
TOTAL	421	69	16,3

#### 1.11.2 Sample and sampling

Sampling is the process of selecting a representative portion of the population, as it is not always possible to study the entire population (Polit & Hungler 1995:278). In this study, the researcher used non-probability, purposive sampling. Purposive sampling is based on the belief that a researcher's knowledge about the population can be used to hand pick the cases to be included in the sample (Babbie & Mouton 2001:266). The criteria for selecting the research sample as well as the sample and sampling method will be discussed in more detail in chapter 3.

#### 1.12 DATA COLLECTION

Data was collected by means of a structured approach, using an interview schedule. The researcher asked the questions during face-to-face interviews with the respondents. The structured approach was chosen because it yields data that is easy to analyse and does not require much effort from the respondents (Polit & Hungler 1995:310). The researcher answered respondents' queries and clarified any words they did not understand.

#### 1.13 DATA-COLLECTION INSTRUMENT

The research instrument is a tool that the researcher chooses to use in collecting data (Polit and Hungler 1995:310). In this study, the researcher compiled an interview schedule to collect data during interviews with TB patients attending one of the four clinics in Tembisa and who interrupted treatment. The questionnaire was based on Louw's (1995:1-15) structured interview schedule. The researcher obtained written permission from Dr Louw to access the questionnaire and adapt it for use in this study (see annexure D). The questionnaire was adapted in consultation with the researcher's

supervisors (see annexure F).

#### 1.14 DATA ANALYSIS

According to Brink (1996:179), data analysis entails categorising, ordering, manufacturing and summarising the data and describing them in meaningful terms. The study was quantitative therefore descriptive, statistical methods, including graphs, tables, percentages and averages, were used. A statistician from Unisa analysed the data.

#### 1.15 RELIABILITY AND VALIDITY OF THE RESEARCH INSTRUMENT

Reliability is concerned with the consistency, stability and repeatability of the informants' accounts as well as the investigator's ability to collect and record information accurately (Brink 1996:124). If the same questionnaire is administered to the same individual at different times, the expectation exists that the same responses will be obtained. If responses differ, there is a chance that the instrument is not reliable.

Reliability of an instrument is the degree of consistency with which the instrument measures the attribute. An instrument can be said to be reliable if it accurately reflects the true measures of the attribute under investigation (Polit & Hungler 1995:277).

Validity is the degree to which an instrument measures what it is intended to measure. Internal validity refers to the extent to which it is possible to make an inference that the independent variable truly influences the dependent variable and the relationship is not false, while external validity is achieved when results can be generalised to situations outside the specific research setting (Polit & Hungler 1995:277).

To ensure the reliability and validity of this study, the researcher took the following specific steps:

- The interview schedule was pretested and questions not interpreted correctly by peer reviewers were adapted.
- The questions in the interview schedule were clearly worded, as verified by peer reviewers.

- In situations where the respondents did not understand the meaning of specific words, the researcher explained them in more detail.
- Only the researcher conducted the interviews, which ensured consistency of the interview and the interpretation of responses.

The validity of the study and the research instrument was ensured by means of the following:

- The study was based on an in-depth literature review as well as previously tested questions based on Louw's study.
- Loose standing constructs were organised into a framework.
- Operational definitions were used to clearly describe the variables of the study.
- The sample size was large enough to be representative of the phenomenon being studied.
- Congruence was ensured between research questions, objectives, investigation, findings and recommendations (Polit & Hungler 1995:246).

#### 1.16 ETHICAL CONSIDERATIONS

Ethics is a system of moral values that is concerned with the degree to which research procedures adhere to a profession as legal and social obligations to the study participants (Polit & Hungler 1995:701). Chapter 3 discusses the ethical considerations fully.

#### 1.17 LIMITATIONS OF THE STUDY

The findings are limited to clients who attended the four clinics in Tembisa only and the recommendations based on the findings may not be relevant to other areas in South Africa. The findings might also differ from research using a different paradigm such as a qualitative approach.

#### 1.18 OUTLINE OF THE STUDY

Chapter 1 briefly describes the problem, the purpose of and approach to the study, and the research design and methodology.

Chapter 2 discusses the literature review undertaken for the study.

Chapter 3 describes the research design and methodology.

Chapter 4 discusses the data analysis and interpretation.

Chapter 5 concludes the study, briefly discusses its limitations, and makes recommendations for practice and further research.

#### 1.19 CONCLUSION

Tuberculosis is an infectious but curable disease, if effectively treated. Interruption of treatment by TB patients, however, remains a problem. This chapter outlined the background to the problem, the purpose and significance of the study as well as the research design and methodology, and defined key terms used in the study.

Chapter 2 discusses the literature review conducted for the study.

## **CHAPTER 2**

#### Literature review

#### 2.1 INTRODUCTION

This chapter discusses the literature review conducted by the researcher on treatment interruption by TB patients in South Africa and elsewhere.

The purpose of the literature review was to

- familiarise the researcher with the scope of the study field
- identify trends and developments in the research field
- examine existing research on compliance with TB treatment

#### 2.2 HEALTH SYSTEMS IN SOUTH AFRICA IN RELATION TO TB

#### 2.2.1 Health facilities

National and provincial departments, districts, health authorities and municipalities work together to deliver adequate and comprehensive health services to communities. The Department of Health is responsible for defining the type of available health services, and organising such services, operating schedules and procedures for access to the service (ANC 1994:44). In South Africa, health services are rendered in different kinds of facilities that are classified according to services rendered and hours of operation. National, provincial and local government manage the facilities, as in the Ekurhuleni Metropolitan Municipality and Tembisa area (Ekurhuleni Metropolitan Municipality Annual Report 2002-2003:11).

Facilities are classified as follows (Ekurhuleni Metropolitan Municipality Annual Report 2002-2003:12; WHO 1998:23):

- Community health centres provide the full core service package of preventive, promotive, curative and rehabilitative services, including obstetric services.
- Fixed clinics provide essential services as first contact care.
- Satellite clinics usually provide the full range of core services provided by "mother" clinics and only operate on certain days of the week.
- Mobile clinics provide outreach services and consist of light duty vehicle or buses and provide health care to communities where there is no fixed facility.
- Specialised TB or chest disease clinics that treat severe cases of complicated TB, including MDR-TB.

In South Africa, public health functions are decentralised from national and provincial to district levels. The planning, administration and implementation of health functions are carried out at district level. The WHO (2003:9) states that decentralisation enhances community participation and reduces the administrative costs associated with hierarchical systems. TB control depends not only on diagnostic and treatment services, but also on the community's active participation. TB services are integrated with primary health care (PHC), resulting in an increase in the overall number of health workers whose mandate includes TB control. The integration of TB care with PHC provides further motivation for programmes to move from hospitalising patients during the intensive phase of treatment to a system of ambulatory DOTS (WHO 2003:12).

South Africa has one of the highest TB rates in the world and the performance of the National Tuberculosis Programme has been disappointing (Edginton1997a:4). In Cape Town, TB care has been incorporated into PHC services for many years but the treatment outcomes have been low with cure rates of 50,0%. After the introduction of community DOTS by community health workers in Gugulethu, Cape Town, cure rates improved to 76,0% in 2006 (<a href="http://www.capetown.gov.29/press/newpress.asp?itemcode">http://www.capetown.gov.29/press/newpress.asp?itemcode</a> =2558).

In Tembisa clinics, specific TB registered nurses are used to provide TB services in "fast lanes", to prevent long waiting hours for TB patients and, in turn, prevent the spread of the disease (Ekurhuleni District Annual Report 2006-2007:4). Tembisa has four clinics, namely Tembisa Health Care Centre, Tembisa Main Clinic, Erin Clinic and Winnie Mandela Clinic, which are not far from the communities' residential areas. Each clinic has its catchment areas, which are defined by the geographical boundaries, and

patients are encouraged to attend the clinics nearest to their places of residence, to avoid travelling long distances and prevent interruption of treatment, and to promote community participation (ANC 1994:45).

In KwaHlabisa in KwaZulu-Natal, health facilities are far from where people live, which is a problem especially in TB management (Edginton1997a:10).

#### 2.2.2 Health personnel

Health personnel are the most important component in the management of TB. Dedication to the national TB control programme and a positive attitude towards TB patients contribute to the decrease and effective management of TB (Escott, Nsutebu, Walley & Khan 2001:12).

In Nicaragua, Arnadottir (2001:564) found that the progress in the control of TB in 1981 was due to health workers' hard work in spite of challenges like distances between the clinics and the communities, staff shortages and lack of resources.

In South Africa, Edginton (1997a:1) found that, in some instances, the negative attitude of health workers towards TB patients contributed to the spread of TB. TB patients were given large numbers of tablets with little or no explanation of the disease and the treatment. Health workers did not listen to or empathise with TB patients and gave them no time to ask questions, yet wondered why the patients failed to complete treatment (Edginton 1997a:1).

#### 2.2.3 Training of health personnel

The WHO (1998:91) emphasises that training must be offered to everyone, from programme managers to communities. Training methods and material used must suit the category of personnel trained at a given time, and training must be monitored in quality and quantity (WHO 1998:99).

On-the-job training and mentoring during supervisory visits are among the means offered to expand and maintain training in TB control. The WHO TB training manual

ensures that pre-service training reflects the changing terms of reference of health staff and that technically sound training in TB control is included (WHO 2003:36).

In South Africa, health personnel training and regular in-service training in TB management is conducted. TB as a communicable disease was included in the curriculum for doctors and nurses. Other categories of health personnel like health promoters, DOTS supporters and volunteers, including traditional healers, were also trained by organisations like the South African National Tuberculosis Association (SANTA) and TB Alliance DOTS Support Association (TADSA) (Matsha 1997-1998:30). Treatment outcomes improved significantly at Tintswalo, in Limpopo province after training clinic staff in TB management (Edginton 1997b:4).

#### 2.2.4 Staff shortages

According to the WHO (2003:35), policy on human resources states that sufficient staff capacity exists to detect and diagnose patients, administer treatment, maintain recording and reporting forms, provide health education to patients and communities, oversee TB treatment supporters, trace patients who default from treatment, monitor drugs and coordinate activities with partners.

In Malaysia, Jaramillo (1999:370) found that TB treatment interruption was caused, among other factors, by an inability to trace defaulters because of staff shortages. In KwaHlabisa in KwaZulu-Natal, the staff admitted that staff shortages and lack of transport to do home visits were among the factors that contributed to treatment interruption (Edginton 1997a:4). Edginton (1997a:4) found that the constraints of inappropriate management and provision of staff, vehicles and drugs were not unique to Tintswalo in the Limpopo Province. Staff shortages were also reported in the Northern Province and Northern Cape as one of the causes of treatment interruption (Matsha 1997-1998:21).

In the Tembisa area, the clinic staff complained of staff shortages although management denied this, stating that according to the patient-nurse ratio there was no staff shortage. At the same time, there was no policy that clearly stipulated how many patients one nurse should see per day. When health care moved towards PHC, the number of patients increased in all clinics but the staff establishment remained the same (Edginton1997a:11).

## 2.2.5 Supplies and equipment

It is important that TB patients are treated in a national TB programme. Government commitment to a national TB programme ensures that equipment is available from the prevention of TB, diagnosis to the outcome of treatment (WHO 2003:12). The following equipment should be available:

- Literature, in the form of posters and pamphlets, to raise awareness on TB
- Protocols and TB management guidelines
- Accredited laboratory services with laboratory technicians who are trained to ensure quality services
- Stationery, including suspect registers, TB registers, patients' records
- Uninterrupted TB drugs supply
- Computers and cars

The DOTS strategy dictates the necessity of the above supplies and equipment (Department of Health 2000b:9). Provision of supplies and equipment is also informed by the five key elements of DOTS (see chapter 1) that were reinforced in 1997 after the Minister of Health declared TB a priority in South Africa (Mkele 1998:164).

#### 2.2.6 Drug supplies

To ensure a standardised technically appropriate and high-quality drug supply, anti-TB drug tendering and procurement are centralised. Decentralised levels may specify the quantities of drugs needed and transfer payment for them, but control procurement monitors specifications, quantities and distribution plans (WHO 2003:38). The WHO (2003:40) emphasises the need to ensure standardised drug regimens and drug combinations.

### 2.2.7 Legal issues and principles

TB was declared a notifiable disease in the 1880s in the UK and the USA because it is communicable. A communicable disease refers to one resulting from an infection due to pathogenic agents or toxins generated by the infection, following the direct or indirect transmission of the agents from the source to the host (Dormandy 1999:209).

The following legislation regulates TB management in South Africa:

- Health Professions Act, 56 of 1974, as amended
- Nursing Act, 50 of 1978, as amended
- Pharmacy Act, 53 of 1974, as amended
- Medicines and Related Substances Control Act, 101 of 1965, as amended
- Information Act, 2 of 2000, as amended
- National Health Act, 61 of 2003

#### 2.2.8 Patients' Rights Charter

In terms of the Patients' Rights Charter (Department of Health 1999:2), all patients have the right to:

- Healthy and safe environment
- Participation in decision-making
- Access to health care
- Knowledge of one's health insurance scheme
- Choice of health services
- Be treated by a named health care provider
- Confidentiality and privacy
- Informed consent
- Refusal of treatment
- Be referred for a second opinion
- Continuity of care
- Complain about health services

#### 2.2.9 Batho Pele principles

The *Batho Pele* (Sotho meaning "people first") principles safeguard (<a href="http://www.en.wikipedia.org/wiki/Bath">http://www.en.wikipedia.org/wiki/Bath</a> pele):

- Consultation
- Service standards
- Access
- Courtesy
- Information
- Openness and transparency
- Redress
- Value for money

Every health professional must observe all the above principles for the success of health delivery, including TB programmes.

#### 2.3 MANAGEMENT AND CONTROL OF TB

TB services are part of PHC services, where TB patients are identified and treated. However, not all health professionals screen every patient who has had a cough for more than two weeks, and patients with TB are identified at the later stage when TB had progressed and had been spread before the initiation of the treatment (Jaramillo 1999:399). In South Africa, TB services are also integrated in the PHC services and its management is also included in the standard treatment guidelines and essential drug list for South Africa (Department of Health 2000b:217).

## 2.3.1 Morbidity patterns

TB is a global problem and concern estimated to cause about 8,8 million new cases and about 1,5 million deaths each year, more than half of which are in Asia. Fifty percent of the world's TB cases were found in the Philippines and Bangladesh alone. An estimated three quarters of all TB cases and deaths in the developing countries are concentrated in the economically productive age group of the population, between 15 and 59 years (<a href="http://www.who.int/tb/publications/global\_report/2008/keypoints/en/index.html">http://www.who.int/tb/publications/global\_report/2008/keypoints/en/index.html</a>.

In 1997, the Western Cape in South Africa had the highest incidence of TB in the world. Overcrowding, lack of employment, malnutrition and alcohol abuse were cited as the main causes of the high incidence (Ruck 1997:23).

South Africa has one of the highest recorded incidence rates of TB in the world. The National Department of Health reported smear-positive rates of 163 per 100 000 of the total population (Department of Health 2000b:19). It is estimated that one person dies from TB every 40 minutes in South Africa (Schneider, Oskowitz & Hlatshwayo 1997:6). The main factors counteracting the control of TB are drug resistance, HIV and AIDS, poverty, and marginalisation. In parts of Europe and the former Soviet Union, MDR-TB is the chief force (Arnadottir 2001:32).

Demographic factors also played a major role in the global re-emergence of TB. In 1998, the WHO (1998:4) pointed out that many adolescents and adults were infected with TB bacilli during childhood, so there is a pool of infected population that could develop active TB, thus increasing the global TB incidence to around 100 000 cases every year in the twenty first century.

#### 2.3.2 TB and co-infection with HIV and AIDS

TB and HIV are sweeping across Africa. It is estimated that about 23 million people in Africa are infected with HIV and a third of these are also infected with TB (Escott et al 2001:12).

HIV and AIDS compromise the body's immune system thereby making it easy for TB, one of the commonest opportunistic infections, to flare up. Malawi reported deaths of up to 25,0% among sputum-positive patients co-infected with HIV and AIDS. TB is nevertheless curable even if it co-exists with HIV, but the presence of HIV contributes to the reactivation of dormant TB and death (Escott et al 2001:12).

Pinto, Haddad and Silva-Telles (2001:94) found significant co-infection with TB and HIV in Sao Paulo, Brazil together with drug resistance among patients at an AIDS reference centre. TB was recorded in 33,0% of adult patients with AIDS.

According to Nunn (2001:330), in Sub-Saharan Africa alone, nearly 1,6 million cases of active TB occur every year, with HIV infection being the leading cause for the increased cases. In 1996, 45,0% of Black females admitted to Somerset Hospital with TB were also diagnosed with HIV infection. In 1997, over 60,0% of TB patients admitted to the Sizwe Tropical Disease Hospital, in Gauteng, were also infected with HIV (Blumberg & Constantinou 1997:102).

In KwaZulu-Natal HIV is estimated to account for 50,0% of the TB cases, while in the Northern Province the HIV prevalence was relatively low, compared to other rural areas in South Africa (Barker, Millard & Nthangeni 2002:291).

In TB/HIV collaboration all patients who are diagnosed with TB must be screened for HIV, and patients who are HIV positive should be screened for TB for early detection of TB and initiation of prophylaxis. HIV-positive patients are screened for TB by sending two specimens of sputum for a smear and one specimen for culture. When the TB results are negative, the Montoux skin test is done on adults who are HIV positive to establish the extent of TB infection. If the Mantoux is 5 mm or above positive, then the patient is given Isoniasid (INH) 5 mg per kilogram as prophylaxis for six months. It is very important to exclude active TB before starting the INH prophylaxis to prevent MDR-TB (Department of Health 2000a:39).

The association of HIV and TB has made it crucial to deal with both conditions. The management and control of TB revolve around five key elements (Department of Health 2000a:9):

- Government commitment to sustained TB control activities.
- Sputum smear microscopy to detect infectious cases among the people attending health care facilities with symptoms of TB, most importantly a cough of two weeks duration or more.
- Standardised short course anti-TB treatment for at least all confirmed sputum smear-positive pulmonary TB cases, with direct observation of treatment for at least the initial two months.
- A regular, uninterrupted supply of all essential anti-TB drugs.
- A standardised recording and reporting system, which allows assessment of treatment results and overall programme performance.

TB management in South Africa is measured against the following National Tuberculosis Control Programme indicators (WHO 2001:7):

Case detection - 70,0%
 Cure rates - 85,0%
 Smear conversions - 85,0%
 DOTS coverage - 100,0%
 Defaulter rate - 5,0%

The Department of Health in South Africa determines, compiles and issues policies and protocols informed by the National TB Control Programme, which was launched in 1995 (Barker et al 2002:29). All clinics must have regular TB drugs supply. Sputum results must be made available to the facilities within 48 hours to ensure that TB patients are treated promptly to prevent the spread of TB (Department of Health 1997:9).

TB is part of PHC therefore, according to Section 38A of the Nursing Act, 1978, all registered nurses can examine, diagnose and treat TB patients (South Africa 1978:5). Registered nurses can prescribe medicines from schedule 1 to schedule 4. TB drugs are classified under schedule 4. The National Tuberculosis Control Programme, informed by the National Drug Policy, provides guidelines on the treatment of TB including essential drug lists with medicines that can be accessed at all public clinics and hospitals free of charge. In Tembisa, registered nurses not trained in PHC were sent on a course and all nurses follow the protocols in the treatment of TB patients.

According to the Department of Health (2000b:217), the objectives for the management of TB are to

- prevent and cure the disease
- prevent the spread of infection from infected adults to children
- prevent the progression of TB infection and TB disease in children
- prevent MDR-TB
- promote DOTS

In spite of TB being preventable and curable, its control is failing. TB patients are not always diagnosed and put on treatment early enough, and not all patients who are put on treatment, complete their treatment. There is a rise of MDR-TB and the DOTS strategy is not taking off the ground because of lack of incentives for community care workers (Edginton 1997a:20). Cure rates remain below 85,0%. At the time of the study the cure rate in Tembisa was 56,0% and the interruption rate was 17,0% (Ekurhuleni District Annual Report 2005-2006:28).

The clinics order TB drugs from the district hospitals where the pharmacists are based. The clinics order the drugs at monthly intervals, and are required to order enough stock to prevent drug shortages. The doctors, pharmacists, assistant pharmacists and registered nurses manage the medication according to the following:

- Medicines and Related Substances Control Act, 101 of 1965, as amended
- National Drug Policy
- Standard Treatment Guidelines and Essential Drug List.

## 2.3.3 Identification of people with TB

All patients who present with the following symptoms are screened for TB (Department of Health 2000a:12):

- Persistent cough for two weeks or more
- Sputum production which may be blood stained
- Shortness of breath and chest pain

Loss of appetite and loss of weight

Fatigue

Night sweats and fever

2.3.4 Diagnosing and categorising TB patients

South Africa follows the WHO guidelines for diagnosing and treating TB patients. At

least two sputum specimens are collected from a TB suspect. The first specimen is

collected on the spot at the first interview with the patient and the second is collected

early in the morning the following day. The patient's personal particulars, together with

the date and time of dispatch of the specimens to the laboratory, are entered in a TB

suspect register, which must be kept by all clinics and hospitals. To prevent and

decrease the spread of TB, results should be made available within 48 hours and

treatment initiated as soon as positive results are reported.

There are three main categories of TB patients. The categories determine the

treatment prescribed (Department of Health 2000a:28):

Category I: A patient who has never had treatment for TB or who has taken TB

treatment for less than four weeks.

Category II: A patient who was previously treated for TB.

Category III: A TB patient who is eight years old or younger.

2.3.5 Prescribing drugs

In South Africa, TB drugs recommended by the WHO are prescribed according to

patients' regimen, category, age and weight. There are three regimens, which include

the combination of TB drugs, classified as follows (Department of Health 2000a:28):

Regimen I is for new patients.

Regimen II is for retreatment of adult patients.

Regimen III is for children under eight years old.

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## 2.3.6 Registering the patients

Every country should have a register for TB patients. In South Africa, at the time of the study, an electronic TB register (ETR) had not been implemented. All clinics and hospitals that register patients with confirmed diagnosis of TB must enter the data in the TB register. The person responsible for TB services in that clinic or hospital transfers the information from the TB patient's file to the TB register. The National TB Control Programme (Department of Health 2001:21) requires the TB register. The data stored in the register facilitates monitoring the progress of the patient from the time the patient is registered to the end of the treatment, which is called the outcome. According to the register, TB patients have one of the following outcomes (Department of Health 2000a:20):

- Cured. Patient was TB smear positive at the beginning of treatment and has proof of a TB smear-negative result at the end of treatment.
- Treatment completed. Patient has completed treatment but without proof of a TB negative smear at the end of treatment.
- Treatment failure. Patient remains or becomes smear positive again at five months or later during treatment.
- Died. Patient dies (for any reason) during the course of TB treatment.
- Treatment interrupted. Patient's treatment was interrupted for two months or more.
- Transferred out. Patient has been transferred to another district and the treatment outcome is not known.

# 2.3.7 Retrieving and managing patients who interrupt treatment

TB patients who interrupt treatment spread the disease, may develop MDR-TB or may even die unnecessarily from a curable disease. It is easier to notice that a patient is defaulting treatment if the patient is on DOTS. The DOTS supporter, if in the community, notifies the health personnel immediately the patient misses a dose of treatment. Patients on clinic DOTS can also be identified easily if they miss their treatment, and where workplace DOTS is used it is not easy to lose the patient.

Patients should be traced before they miss more than ten doses because after missing ten doses they are registered as retreatment patients when they are recovered. These patients' treatment takes eight months and includes the injection of streptomycin amounting to twenty doses. If defaulters miss less than ten doses of treatment, they continue treatment and the missed doses are added at the end of treatment (Department of Health 2000a:27). Patients who interrupt treatment may develop MDR-TB (Department of Health 2000a:27).

## 2.3.8 Multi-drug resistant TB (MDR-TB)

MDR-TB is a specific form of TB that is resistant to at least two most powerful anti-TB drugs: Isoniazid and Rifampicin. All TB patients with MDR-TB should be observed with the DOTS-Plus strategy when taking their treatment (Department of Health 2000a:40).

- Persons who are immuno-compromised and exposed to MDR-TB patients.
- Patients who were under-treated by medical staff.
- Previously treated TB patients who experience recurrence.
- Persons from other countries and areas with a high incidence of MDR-TB.

MDR-TB spreads from person to person through the air, just as "normal" TB. MDR-TB spreads well in hot areas all over the globe, from Brazil to China, India to Russia and could spread to the Western world through international flights (*City Press* 2004:31).

The WHO (1995a:22) expressed concern over the rise in treatment interruption by TB patients and the emergence of MDR-TB. MDR-TB was declared the third epidemic, following the first and second epidemics of HIV co-infection and resurgent TB. In 1997, an estimated 1,0% of new cases and 4,0% of retreatment cases in South Africa were MDR. MDR-TB exacerbates already rising morbidity and mortality rates (Blumberg & Constantinou 1997:103). According to Walley (1997:22), if TB treatment interruption is not tackled seriously, MDR-TB will be out of control. MDR-TB is expensive. To treat a patient with "normal" TB costs R200 for the 6 months treatment, while the cost for a patient with MDR-TB is at least 100 times more (*Daily Sun* 2004:11).

In South Africa, MDR-TB patients are treated in isolation in designated hospitals, one of which is the Sizwe Hospital in Gauteng. Infection control is rigorously practised. Smear-positive patients are treated separately from patients whose sputum tested negative.

After two consecutive negative sputum-smear results MDR-TB patients are discharged and treated as outpatients. MDR-TB is treated over a period of 18 to 24 months, during which the patients are reviewed at monthly intervals. All people who are in contact with MDR-TB patients or TB patients who interrupted treatment are screened for MDR-TB to prevent the spread. After being cured, the patient is monitored for five years, with sputum collected for culture every six months (Multi-drug Resistant Tuberculosis Fact Sheet 2003).

# 2.3.9 Direct Observed Treatment Short course (DOTS)

DOTS involves watching TB patients swallow their drugs (Walley 1997:21). TB patients are admitted to hospital during the intensive phase during which nurses give patients tablets to swallow but do not always watch the patients swallow them. The WHO insists that all smear-positive TB patients should be on DOTS throughout the treatment.

In Malawi, prior to 1991, the cure rate for TB was 24,0% among smear-positive patients. After DOTS was implemented, the cure rate increased to 68,0% (Kelly 2001:111).

In Malaysia, Naing, D'Este, Isa, Salleh, Bakar and Mahmod (2001:375) found that TB patients not on DOTS had three times significantly higher chances of being non-compliant. Jaramillo (1999:394) emphasises that DOTS is the most effective strategy, is becoming the backbone of TB control programmes in developing countries, and is cost-effective. Walley (1997:21) points out that DOTS implementation is not easy. Ruck (1997:24) maintains that DOTS alone is not the answer in the management of TB when so many factors militate against treatment adherence.

DOTS should be community driven but patients are given an option to choose a DOTS supporter they prefer. NGOs, volunteers and community leaders can be DOTS supporters, but if a patient prefers to go to the clinic for DOTS that must be granted. According to Khan et al (2000:4), DOTS can be impersonal. Health care workers in busy clinics commonly provide less personal care, whilst community health workers are

more personal in the way they deal with TB patients. Health care workers explain, educate and counsel patients about their diagnosis and treatment.

#### 2.3.10 Health education

According to the Patients' Rights Charter (Department of Health 1999:2), all patients have a right to health information that includes the availability of health services and how best to use such services and such information shall be in a language understood by the patients.

Health personnel give health education on TB and its treatment to patients and members of their families to strengthen prevention of TB and improve compliance with the treatment. Health education is further given to communities through the radio, TV and newspapers. However, not everybody can read or has access to the media. TB campaigns are also strategies used to educate communities on TB. In KwaZulu-Natal, DOTS volunteers educated the community through drama on TB (Matsha 1997-1998:18). In Tembisa clinics, health promoters gave health education for the patients at the waiting areas; however, there were not enough health promoters to cover all the clinics, as they had to give their attention to other programmes too. Where video machines were available to educate the patients, the shortage of health promoters and other health personnel prevented their use.

According to Arnadottir (2001:563), in Nicaragua progress was made in the control of TB in 1981 when there was political commitment for improving health education of the population. The impact of failure of educating TB patients was explored in the area of Soweto in Gauteng where up to three quarters of TB patients failed to complete the treatment (Blumberg & Constantinou 1997:107).

According to Jaramillo (1999:395), poor health education on TB was the cause of treatment interruption by TB patients. Health personnel are often too busy to give health education to patients. In Pakistan, Khan et al. (2000:247-254) found that the majority of the respondents and their families were not aware of the causes and symptoms of TB, treatment, duration of treatment, dangers of defaulting or precautions to minimise the risk of infection, due to lack of health education. Only four respondents acknowledged any knowledge of TB prior to their first diagnosis (Khan et al. 2000:250). The health

care workers admitted that they did not have time to give enough information to patients due to high patient loads and shortage of staff.

In a study conducted at Chris Hani Baragwanath Hospital, Badenhorst et al (1997:106) found that only 24,0% of the respondents completed their treatment because of poor or no health education on discharge, which resulted in unacceptably high interruption rates of treatment.

#### 2.3.11 Home visits

TB treatment lasts from six to eight months, which is a relatively long period. Nunn (2001:331) describes TB as an infectious disease of which that treatment lasts at least half a year. Patients who fail to come for treatment are supposed to be followed-up as soon as it comes to the health workers' attention that treatment has been defaulted. Patient follow-up is difficult in areas like informal settlements, where there are no streets and formal addresses (Matsha 1997-1998:17).

In a study conducted in Malaysia in 1999 among 167 non-compliant patients, 26 patients could not be traced during home visits because the addresses given were wrong (Naing et al 2001:369). In Pakistan, it was also found during follow-up of TB patients that addresses on the patients' records were either wrong or inadequate (Khan et al 2000:249).

In the Tembisa area at the time of the study, the TB nurses of each clinic did home visits once a week because the driver and the vehicle were only available then. TB nurses who had driver's licenses could not easily do home visits alone fearing car hijacking and the reason that it was not easy to drive and check the house numbers which were not all properly displayed. Another constraint that affected home visits was the lack of community health workers and NGOs in the community because there were no funded NGOs and it was difficult to keep volunteers without incentives.

In the Eastern Cape, volunteers who did home visits were unemployed and received no incentives except for food parcels for also helping with RDP projects, so patients could get treatment at any time they worked and defaulters could easily be traced (Matsha 1997-1998:13).

## 2.3.12 Monitoring and evaluation

The DOTS strategy provides indicators for monitoring health systems performance in general. DOTS strategy is an effective tool for patient monitoring, drug planning and national trend observation. The TB National Control Programme (Department of Health 2001:12) recommends the following:

- TB indicators should be included among the care indicators for monitoring health system performance.
- Adoption of the National Standardised TB case recording and reporting forms.
- Inclusion of TB control indicators in the integrated supervisory activities.
- Monitoring and supervision that is specific to TB control programmes.

In the Eastern Cape in 1998 dedicated TB district coordinators were also involved in other activities which made it difficult to adequately support TB activities in districts. There was less time to check TB registers, complete quarterly reports, encourage tracing of defaulters and evaluate outcomes. Furthermore, 41,0% of patients was lost during transfer from the hospital to clinics (Matsha 1997-1998:15).

In Gauteng province during supervisory and support visits by TB coordinators the staff reported that the register was complicated and time consuming and that rotation of movement of staff prevented staff from coming to grips with the implementation of DOTS (Matsha 1997-1998:18).

The purpose of monitoring and evaluation is to recognise success and solve problems. The process should be ongoing whereby deviations from the expected are corrected as soon as supervisors observe them. All clinics and hospitals are expected to report on the progress of TB management on quarterly basis. Each facility is required to strive towards meeting the TB management objectives and indicators mentioned above. The report also includes drug supplies, laboratory services and DOTS coverage. The reports are compiled per district then forwarded to provincial level. The reports are further consolidated and forwarded to national authorities until they reach the WHO (WHO 1998:175). It is very important that any deviation from the expected is investigated thoroughly to find out its cause in order to solve the problem. Poorly performing districts are encouraged to learn from best performing districts.

## 2.4 FACTORS CONTRIBUTING TO TREATMENT INTERRUPTION

Studies on treatment interruption by TB patients in South Africa, Tanzania, Malaysia, Malawi, Peru, Uganda, Ghana, Scandinavia and Asia found that factors like poverty, unemployment and homelessness contributed to TB patients not completing treatment (Ministry of Health 1996-1999:370).

It has, however, been found that control of TB is both possible and affordable even for developing countries. Each country needs to identify its problems and plan according to what suits it, and what the country can afford (Mario, Raviglione, Pixie, Shider & Kochi 1995:1). Table 2.1 indicates the treatment interruption rate in South Africa in 1999.

Table 2.1 Treatment interruption rate, 2005

PROVINCE	TREATMENT INTERRUPTION RATE
Eastern Cape	9,0%
Free State	5,9%
Gauteng	6,9%
KwaZulu-Natal	14,7%
Mpumalanga	10,8%
Northern Cape	13,1%
Limpopo Province	7,4%
North-West	9,5%
Western Cape	11,1%
South Africa	9,9%

(http://www.doh.gov.za/aids/newsletter/2002/0815/html)

According to Hackman (1999:1), countries that review their strategies, correct the mistakes of the past, and plan TB programmes to suit their country's unique needs, succeed in controlling TB. Arnadottir (2001:563) emphasises that the global burden of TB is enormous. Jaramillo (1999:393) found that the factors that contribute to interruption of treatment are interrelated and overlapping. These factors are

- poverty
- unemployment
- homelessness
- alcoholism

- migration policy
- non-prioritisation of TB
- cultural beliefs/attitudes

## 2.4.1 Factors influencing treatment interruption by TB patients

The factors that influence treatment interruption by TB patients are poverty, unemployment, overcrowding and homelessness, alcoholism, migration, non-prioritisation of TB, and cultural beliefs/attitudes.

## 2.4.1.1 Poverty

Poverty is the leading factor that leads to TB patients' interruption of treatment. TB is a disease of poverty that throws communities into a vicious cycle, particularly if the patient is a breadwinner (WHO 2003:5). In 1991 a dual approach was adopted to fight poverty and TB at the same time (Hackman 1999:1). Since 1994 health care services in South Africa have been free at public hospitals and clinics and TB treatment is available free of charge, yet TB treatment interruption continues (Weyer et al 1999:1).

Poverty alleviation is the greatest challenge in South Africa where unemployment is escalating, and strategies and projects to alleviate poverty are on the government agenda (*Sowetan* 2003a:10). The problem of poverty was also addressed at the World Summit on Sustainable Development held in Johannesburg in August 2002 (Imbizo 2002:3).

In KwaHlabisa, KwaZulu-Natal, TB patients reported that TB treatment increased their appetite, but they did not have food, so they stopped taking the TB treatment. Patients also complained of the long distances that they travelled to clinics because they could not afford the taxi fare and had to seek work away from their homes (Edginton 1997b:4).

Badenhorst et al (1997:104) found that many patients could not afford transport to go to Chris Hani Baragwanath Hospital to collect their treatment, so they stopped taking TB treatment.

# 2.4.1.2 Unemployment

Unemployment is a critical problem in many countries. Unemployment increases the chances of interruption of treatment in countries where TB treatment is not free of charge (Khan et al 2000:251). In India, TB patients who were unemployed could not afford transport to the clinics and defaulted treatment. Jaramillo (1999:393-404) stresses that in less developed countries, it is not enough to have efficient health care services for people living with TB to benefit from the biomedical-based TB control programmes.

In KwaZulu-Natal, patients are encouraged to join the community development projects in the valley to help them escape the disease poverty cycle (Matsha 1997-1998:18). The household economy of people living with TB is a prime predictor of the success of those programmes. Unemployed people usually suffer from malnutrition, which increases their chances of TB infection. The *Sowetan* (2002b:4) points out that TB is a socio-economic condition that forces people to spend what little money is available on food rather than for travelling to clinics to seek medical help and treatment. In South Africa, patients in rural areas travel long distances to get TB treatment, especially where community DOTS is not in place (Edginton 1997a:1). In Malaysia, however, Chuah (1991:262) found that the distance between the place of residence and Taipeng District General Hospital had no significant effect on treatment interruption behaviours.

## 2.4.1.3 Overcrowding and homelessness

Homeless people usually stay in unhealthy conditions in shelters, one-roomed houses and hostels. TB is rife in overcrowded places, including prisons (WHO 1998:7). In a study of 27 TB patients in Kumasi, Ghana, Lawn, Frimborg, Al-Shusein, Acheompeng, Uttley, Butcher and Griffin (2001:94) found that 13 of the patients had one to six people sleeping in the same room. The patients were receiving TB treatment from the hospital, but 10 (37,0%) of the patients defaulted treatment because they could not be found on follow-up as they had moved.

There is a high incidence of TB treatment interruption among patients with no fixed place of residence (Khan et al 2000:249; Pinto et al 2001:95; Driver, Matus, Bayuga, Winters & Munsiff 2005:362).

#### 2.4.1.4 Alcoholism

Alcoholism is a social problem that predisposes people to malnutrition, which increases the chances of getting TB. TB patients who have a problem with alcoholism often do not collect their treatment regularly and have a high possibility of defaulting treatment (Ruck 1997:23).

Naing et al (2001:379) found a 40,0% rate of TB treatment interruption among homeless alcoholics. In South Africa, alcoholism, especially among men, contributes to increased defaulter rate (Barker et al 2002:294).

According to Jaramillo (1999:396), malnutrition, unsafe sex and alcoholism are the main risk factors for breakdown in people with TB. At Kota Bharu in Malaysia, Naing et al (2001:379) found that intravenous drug users were more compliant, but the fact that they were on DOTS should be taken into consideration.

## **2.4.1.5** *Migration*

Wherever border control is not effective, refugees without valid permits escape and cross to other countries. Refugees from less developed countries often bring diseases of poverty like malaria, HIV and TB with them (Imbizo 2002:3). For example, some illegal refugees in South Africa had not completed their TB treatment in their countries, did not bring transfer letters and were afraid to present themselves to health facilities until they were sick again (Matsha 1997-1998:17).

War and political unrest in African countries, such as Ghana, contributes to the spread of TB (Lawn et al 2001:92). In a study among Rwandan and Burundian refugees in Tanzania, Rutta et al (2001:628) found that although TB patients died, 7,1% of the patients defaulted their treatment because of poor communication among health facilities in the camps and neighbouring countries.

Internal migration also occurs in most countries (eg, Nicaragua, Sweden, Denmark, Norway and South Africa) (Nunn 2001:630). People move from rural to urban areas, which makes TB control extremely difficult. In Sebokeng, South Africa, Louw (1995:15) found that patients defaulted treatment because they had left the area temporarily. Moreover, immigrants who are put on TB treatment in South Africa, interrupt their

treatment again when they are deported back to their countries if they do not have permits (WHO 2001:114).

# 2.4.1.6 Non-prioritisation of TB

According to Jaramillo (1999:394), since the discovery of a cure for TB in the early 1940s and 1950s governments concentrated more on TB drugs and less on prevention. Prevention encompasses improving people's socio-economic status, such as provision of food and housing. Less effort was directed at discovering an effective vaccine against TB, especially in adults.

Blumberg and Constantinou (1997:102) maintain that although TB is curable, without legislation to make it compulsory for TB patients to complete their treatment, its control will not succeed. In this regard the rights of citizens seem to be overlooked and TB patients who interrupt their treatment seem less responsible.

## 2.4.1.7 Stigmatisation of TB

The stigma associated with TB is centuries old. The disease was associated with the poor, the malnourished and the disadvantaged. In the 1920s, in the USA, a doctor would rather lie about a patient's smear result than disgrace a wealthy family (Dormandy 1999:209). The disease was believed to be hereditary and an indication of bad character. Furthermore, the notification of TB patients exacerbated the problems they faced instead of improving the treatment and management of the disease (Dormandy 1999:209).

In Asia, young female TB patients in particular interrupted the treatment because they feared that they would not get men to marry them if they were known to have TB (Khan et al 2000:248). According to Jaramillo (1998:396), the stigma attached to TB and the social discrimination it entailed, contributed to poor compliance with TB treatment. Health care workers also discriminated against TB patients.

According to Escott et al (2001:21), mineworkers diagnosed with TB were retrenched right to the 1980s. According to Louw (1995:12), the stigma and rejection (denial) of the diagnosis are among the factors that contribute to treatment interruption. Health care

workers and the communities did not discuss TB openly, which led to the patients being ashamed of TB and defaulting treatment.

In a study in KwaZulu-Natal, Van der Walt, Wilkinson, Wilkinson, Nthuli and Coleman (1997:5) found that surviving HIV-positive TB patients were three times more likely to fail to complete their treatment than their HIV-negative counterparts because of the stigma attached to HIV and AIDS. At the same time, in Ghana, however, Lawn et al (2001:94) found that all patients with co-infection were fully compliant.

HIV infection has made the stigma worse. For example, in KwaHlabisa, KwaZulu-Natal where it was practice to test TB patients for HIV infection, most patients lost hope and interrupted treatment because they were told there was no cure for HIV. They felt isolated and lonely, found it difficult to disclose their HIV status, and did not get the required support (Edginton 1997a:5).

According to Ruck (1999:23), TB is a universally "sensitive" disease because it is associated with poverty, dirt and social ostracism, in reality and in peoples' minds. People are consequently often ashamed to present symptoms even though they recognise them.

## 2.4.2 Cultural beliefs/attitudes

In Pakistan, TB patients are not motivated enough to take treatment because they believe TB is a punishment from God (Khan et al 2000:25). In Tintswalo, Limpopo province, Edginton (1997b:4) found that some patients believe that TB is a punishment for breaking sexual rules like abstinence or sleeping with a widow. Health workers find it difficult to convince patients to take their treatment as required because their beliefs make them interrupt treatment.

According to Escott et al (2001:12), to improve treatment compliance among TB patients, educational messages should reflect the local context and address local beliefs and attitudes about TB and its treatment.

## 2.5 CONCLUSION

This chapter discussed the literature reviewed on factors that contribute to TB treatment interruption by TB patients. The literature indicated that certain factors were common to all TB patients. Factors like unemployment, poverty, wars and HIV and AIDS undermine the control of TB as well as MDR-TB. Well-developed countries have more resources.

Chapter 3 covers the research design and methodology.

# **CHAPTER 3**

# Research design and methodology

#### 3.1 INTRODUCTION

This chapter describes the research design and methodology, including the population, sample, and data collection and analysis.

#### 3.2 DELIMITATION OF THE STUDY

The study focused on factors that could influence compliance with TB treatment in four clinics in Tembisa, namely the Tembisa Health Care Centre, Tembisa Main Clinic, Erin Clinic and Winnie Mandela Clinic.

#### 3.3 RESEARCH APPROACH

Polit and Hungler (1995:11) describe the research approach as "the researcher's overall plan for obtaining answers to the research questions and for testing the research hypothesis. The research design directs the strategies that the researcher adopts to develop information that is accurate, objective and interpretable."

The researcher undertook a quantitative, descriptive study of smear-positive TB patients registered in four Tembisa clinics, who did not complete treatment.

#### 3.3.1 Quantitative

Quantitative research is "the investigation of phenomena that lend themselves to precise measurement and quantification, often involving a rigorous and controlled design" (Polit & Hungler 1999:712).

A quantitative research approach is one of the scientific methods of obtaining information (Brink 1996:5). It involves the systematic collection of numerical

information, often under conditions of considerable control, and the analysis of that information using statistical procedures (Polit & Hungler 1999:24). The researcher considered this approach, which includes structural procedures, a formal instrument to collect data, and the procedures followed to analyse the data, ideal for this study. The study had the following characteristics (Polit & Hungler 1999:193):

- The study began with preconceived ideas obtained from the literature and the researcher's experience of how the concepts were interrelated.
- The researcher used structured procedures and a formal instrument, namely an interview guide, to collect information.
- The researcher collected information under conditions of control using a copy of the same instrument for each respondent during the interviews.
- The researcher did not participate in the events under investigation but had to clarify the questions for the respondents and translate the questions into their home language where necessary (Polit & Hungler 1999:24).
- The interview schedule consisted of closed and open-ended questions and a statistician ensured objectivity in the data analysis.
- Statistical procedures were used to analyse the numerical information obtained from the interviews. The researcher categorised, then analysed and discussed the open-ended questions.

## 3.3.2 Descriptive

Descriptive research aims to obtain information in an accurate manner from subjects in their natural environment. It helps in discovering new meaning, determining what exists and how often a phenomenon occurs, and categorising information (Burns & Grove 1993:251).

A descriptive design has the following advantages (Polit & Hungler 1995:44; Brink & Wood 1998:108):

- The researcher can collect a large amount of data about the problem area and it tends to be high in realism.
- The results of a descriptive study will provide detailed information on the variables under study.

#### 3.4 STUDY POPULATION

Polit and Hungler (1995:35) define a "study population" as the aggregate or totality of all the objects, subjects or members that conform to a set of specifications. The study population for this research was all positively diagnosed TB patients who were registered in any of the four clinics in the Tembisa area, namely Tembisa Health Care Centre, Tembisa Main Clinic, Erin Clinic and Winnie Mandela Clinic in one year and who did not complete their treatment.

Table 3.1 Number of patients diagnosed with smear-positive TB

NAME OF CLINIC	NUMBER OF CLIENTS WITH POSITIVE SMEARS	NUMBER OF DEFAULTERS	PERCENTAGE DEFAULTERS
Tembisa Health Care Centre	163	48	29,4
Tembisa Main Clinic	155	11	7,1
Erin Clinic	69	5	7,2
Winnie Mandela Clinic	34	5	14,7
TOTAL	421	69	16,3

#### 3.5 SAMPLING

Sampling is the "process of selecting a portion of the population to represent the entire population" (Polit & Hungler 1995:278). This study used non-probability, purposive sampling because it was not possible to locate all the clients who interrupted their TB treatment.

According to Brink (1996:125), in non-probability sampling the researcher objectively judges a likely starting point and decides on the direction the sampling will take as the study progresses.

Non-probability sampling has the potential to obtain high quality data. According to Brink and Wood (1998:131), convenience, non-probability sampling may or may not accurately represent the population. The researcher chose non-probability sampling because it is economical and is applicable in cases when it is not practical or feasible to reach the entire study population.

The disadvantages of non-probability sampling are that it is not possible to generalise findings to the entire population; the extent of sampling error cannot be estimated, and bias may be present (Brink 1996:135).

In purposive sampling, also called judgemental or theoretical sampling, a researcher judges whether subjects are typical or representative of the phenomenon being studied (Brink 1996:141). Purposive sampling was therefore seen as suitable for this research.

Brink (1996:133) describes a sample as "a part or fraction of a whole, or a subject of a larger set selected by the researcher to participate in a research project". The researcher should ensure that the sample is representative of the population. According to Burns and Grove (1998:295), representative means that the sample must be like the population in as many ways as possible.

This study used purposive sample because only TB patients who could be traced were interviewed if they agreed to participate in the study. The names and addresses of the TB patients who interrupted treatment were obtained from the TB registers of the four Tembisa clinics. Those who were reported to still be living at the same address were revisited if not found the first time.

## **3.5.1 Sample**

The total number of smear-positive patients who interrupted TB treatment from the clinics under study was 69 (see table 3.2).

Table 3.2 Defaulters from the clinics in Tembisa

NAME OF CLINIC	STUDY POPULATION	ACTUAL SAMPLE
Tembisa Health Care Centre	48	18
Tembisa Main Clinic	11	6
Erin Clinic	5	3
Winnie Mandela Clinic	5	3
TOTAL	69	30

Five patients from Erin Clinic interrupted treatment, and three patients could be traced because the clinic serves a more stable community with no informal settlements. Five patients defaulted treatment at Winnie Mandela Clinic though it was an area with informal settlements and mobile/migrant communities, but the researcher traced three of the patients. Tembisa Health Care Centre serves an area with informal settlements and Tembisa Main Clinic serves an area with informal settlements and two hostels.

## 3.5.2 Sample size

The sample consisted of the defaulters who could be traced. The mobility and migration of the defaulters meant that the researcher had great difficulty in tracing all the patients who interrupted treatment. Purposive sampling was used to the advantage of this study because other patients were not found at the given addresses (Polit & Hungler 1995:278).

# 3.5.3 Inclusion criteria

To be included in the study, the respondents had to be TB patients:

- registered in one of the four clinics in Tembisa
- who interrupted their treatment and could be traced
- who were willing to take part in the research voluntarily

#### 3.6 DATA COLLECTION

A structured data-collection approach was adopted, using an interview schedule or questionnaire (see annexure F). The researcher held face-to-face interviews with the respondents at their homes. The structured approach was chosen because it yields data that is easy to analyse and does not require much effort from the respondents (Polit & Hungler 1995:310). During the interviews the researcher assisted respondents who did not understand the language and the meaning of certain words.

#### 3.6.1 Interview schedule

The interview schedule was considered a suitable tool for the following reasons (Polit & Hungler 1995:205):

- The response rate tends to be high in face-to-face interviews.
- Interviews are feasible with most people.
- Interviews are less prone to misinterpretation by the respondents because the interviewer is present to determine whether questions have been misunderstood.

The interview schedule consisted mainly of closed questions. Closed questions have the following advantages (Polit & Hungler 1995:205):

- They are easy to administer and analyse.
- They yield a high degree of consistency for comparative purposes.
- The same information is collected for all respondents.

According to Burns and Grove (1998:358), open-ended questions are not advised when data is obtained from a large sample. To enhance data analysis, the questionnaire contained only a few open-ended questions (annexure F).

The interview schedule covered the following aspects:

# (1) Demographic information

This section covered the respondents' age, gender, marital status, employment, educational level, type of housing, number of people living in the house, and whether they used liquor regularly or smoked.

## (2) TB history

The respondents' TB history covered the onset of TB treatment, how long treatment was taken, treatment for TB before this episode, if any, and how the treatment was administered.

# (3) Reasons for interrupting treatment

This section covered factors that could have contributed to the respondents interrupting treatment, for example, accessibility to clinics, side effects or amount of tablets. The issue of patients consulting traditional healers was also covered in this section.

# (4) Health education given by TB nurses

The respondents' level of general knowledge of TB gave an indication of the health education they received. Here the questions covered the duration of taking treatment; signs and symptoms of TB they experienced; knowledge about the importance of taking treatment regularly, and whether people who are HIV positive can be successfully treated for TB. Possible reasons for defaulting were also explored.

## (5) Clinic services

In this section, the respondents were asked how they perceived the health services they received at the clinics.

#### 3.6.2 Interviews

The researcher conducted face-to-face interviews with the respondents, using the interview schedule. Informed consent was obtained from the respondents before the interviews (see annexure E). Confidentiality was maintained by not using the respondents' names (Brink 1996:37).

The interviews were conducted at the respondents' homes. Polit and Hungler (1995:205) state that data collection can occur in a variety of settings. For example, in studies done in the field, data can be collected in the natural settings in which the subjects work and live.

The researcher personally conducted the interviews for the following reasons (Polit & Hungler 1995:205; Babbie & Mouton 2001:258; Brink 1996:153):

- Interviews yield high response rates.
- In face-to-face interviews respondents are less reluctant to refuse to participate,
   while it is easy to ignore a mailed questionnaire.
- Respondents are less prone to misinterpret questions.
- Respondents do not have to be literate and researchers can explain and clarify questions for respondents.

#### 3.7 DATA ANALYSIS

Polit and Hungler (1995:39) emphasise that data must be processed and analysed in an orderly, coherent fashion so that patterns and relationships can be discerned. Researchers must first determine whether the findings answer the research question or preconceived ideas. The limitations of the study should also be considered in the data analysis (Polit & Hungler 1995:40). If this is not done, there will be no satisfactory answers to the research questions. As this was a quantitative study, descriptive statistical methods consisting of graphs, tables and diagrams were used (Brink 1996:179). Graphic displays should be accurate, simple and clear. A statistician at Unisa performed the data analysis, using the Statistical Analysis System Version 9.1 for Windows.

## 3.8 RELIABILITY AND VALIDITY

#### 3.8.1 Reliability of the research instrument

Reliability is concerned with consistency, stability and repeatability of the informants' accounts as well as the investigator's ability to collect and record information accurately (Brink 1996:124). If the same questionnaire is administered at different times, the same responses should be obtained. If the responses differ, however, there is a chance that the instrument is not reliable.

To ensure reliability, the researcher developed the questionnaire in consultation with the supervisor and the joint supervisor. Questions regarded as not clear by them were then corrected accordingly.

Babbie and Mouton (2001:250) points out that it is better to ask people to complete the questionnaire than to read through it looking for errors. Consequently, the researcher pre-tested the interview schedule in a pilot study with nurses rendering TB services in the four clinics in the Tembisa area together with the TB co-coordinator in Tembisa. These nurses were not part of the main study.

# 3.8.2 Validity of the research instrument

Validity is the degree to which an instrument measures what it is intended to measure. Internal validity refers to the extent to which it is possible to establish that the independent variable truly influences the dependent variable and the relationship is not false, while external validity is achieved when results can be generalised to situations outside the specific research setting (Polit & Hungler 1995:277).

The questionnaire was considered valid for the following reasons:

- The researcher referred to Doctor Riana Louw's interview schedule to investigate interruption of treatment by TB patients in the Sebokeng area, and adapted it in consultation with her supervisors.
- Content and face validity was ensured because the questionnaire was given to the supervisor and co-supervisor to review and corrections and recommendations were followed.
- The questionnaire was constructed according to the objectives of the study and organised according to the literature review.

# 3.8.3 Validity and reliability of the study

According to Burns and Grove (1998:28), study validity is a measure of the truth or accuracy of a claim and is an important concern throughout the research process. Validity provides a major basis for making decisions about which findings are useful.

The researcher ensured the validity and reliability of the study by means of the following (Polit & Hungler 1995:31, 246):

- Undertaking an extensive literature study.
- Organising loose standing constructs into a framework.
- Giving operational definitions of concepts, which are specifications of the operations that the researcher must perform to collect the required information (see chapter 1).
- Ensuring congruence between the research questions, objectives, investigation, findings and recommendations.
- Validity and reliability of the data.

#### 3.9 ETHICAL CONSIDERATIONS

Ethics is "a system of moral values that is concerned with the degree to which research procedures adhere to professional, legal and social obligations to the research subjects" (Polit & Hungler 1995:435). Accordingly, the researcher obtained permission to conduct the study from the authorities concerned and informed consent from the respondents. Furthermore, the researcher observed the rights of the respondents to self-determination, privacy, confidentiality and anonymity, and fair treatment.

## 3.9.1 Permission to conduct the study

Permission was obtained from the Director of Health Services of Ekurhuleni City to conduct the study in the Tembisa area (see annexure A). The researcher also obtained permission from the facility managers to have access to patients' TB records and registers in the four clinics under study (see annexure C).

### 3.9.2 Informed consent

The researcher obtained informed written consent from the respondents (annexure E). The researcher explained the purpose and nature of the study to the respondents and informed them that participation was voluntary and that they were free to withdraw from the study at any time. The respondents were not coerced to participate in the study and no harm was done to them (Burns & Grove 1998:343). The respondents were assured that they would be treated confidentially, because no names would be written on the questionnaires and the researcher would not divulge any information or names to anyone.

# 3.9.2 Human rights

Human rights are claims and demands that have been justified in the eyes of an individual or by the consensus of a group of individuals (Burns & Grove 1998:340). Therefore, the researcher explained to the respondents why it was important to conduct the study and that TB patients would benefit from the findings because recommendations would be implemented to improve TB services. Respecting the rights of others is necessary for an individual's self-respect, dignity and health.

The following rights of the respondents were respected and observed in this study:

#### Self-determination

The right to self-determination is based on the principle of respect for persons, which states that humans are capable of self-determination or controlling their own destiny (Burns & Grove 1998:340). In this study, the respondents were treated as autonomous agents who had the freedom to conduct their lives as they choose without external control from the researcher.

The respondents were informed about the study and allowed to voluntarily choose to participate or not to participate. The respondents were free to terminate their participation in the study at any time without penalty. No treatment or nursing care was withheld from those who elected not to participate. No respondents were coerced to participate. No deception took place in this study, as the respondents were fully informed in the language of their choice.

## Privacy

Privacy is the individual's freedom to determine the time, extent and general circumstances under which private information will be shared with or withheld from others (Burns & Grove 1993:342). In this study the interviews were conducted in privacy at the respondents' homes.

## Confidentiality and anonymity

Based on the right to privacy, respondents have the right to anonymity and the right to assume the data collected will be kept confidential (Burns & Grove 1993:343). Anonymity exists if even the researcher cannot link a respondent's identity with his or her individual responses.

The interview schedule was designed to achieve respondent anonymity. No names were mentioned. Codes were allocated to enable data analysis and interpretation and discussion of the findings (Babbie 2002:523).

### Fair treatment

A research project should benefit the participating individuals and society in general. This indicates that members of the society should take an active role in preventing discomfort and harm and promoting good in the world around them (Burns & Grove 1998:175). In this study, the respondents were treated with respect and dignity. Moreover, the researcher ensured that the findings were in no way manipulated to suit her wishes or views (Brink 1996:37-47).

#### 3.10 CONCLUSION

This chapter dealt with the research design and methodology, including the population, sample, research instrument, data collection and ethical considerations. The respondents were TB patients diagnosed with TB on positive sputum and interrupted their treatment. TB patients' names and addresses were taken from TB registers from the Tembisa Health Care Centre, Tembisa Main Clinic, Erin Clinic and Winnie Mandela Clinic.

Chapter 4 discusses the data analysis and interpretation.

# **CHAPTER 4**

# Data analysis and interpretation

#### 4.1 INTRODUCTION

This chapter 4 discusses the data analysis and interpretation.

The study wished to establish:

- The respondents' level of knowledge of TB as a disease.
- Their perceptions of and attitudes towards TB as a disease.
- Their perceptions of the health services they received at the clinics
- What factors contributed to the interruption of treatment by TB patients in Tembisa.
- What recommendations will be made to decrease TB treatment interruption in Tembisa.

The questionnaire was arranged into the following subsections and data was analysed in the same order:

Section 1: Demographic information

Section 2: Information about the patient's habits

Section 3: TB history

Section 4: Discontinuation of TB treatment

Section 5: Health education given by TB nurses

Section 6: Knowledge of TB and its treatment

Section 7: Clinic services

## 4.2 SECTION 1: RESPONDENTS' DEMOGRAPHIC DETAILS

# 4.2.1 Item 1: Age (n=30)

The respondents' ages ranged from 17 to 54 years. Figure 4.1 represents the respondents 'ages.

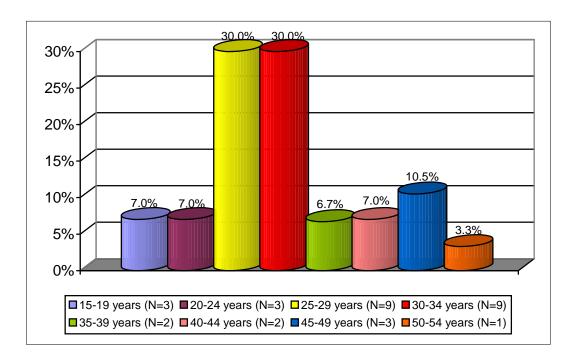


Figure 4.1
Respondents' age (n=30)

Figure 4.1 shows that 30,0% (n=9) of the respondents were aged between 25 to 29 years and 30 to 34 years. According to Khan et al (2000:248), three quarters of all TB cases and deaths in developing countries are concentrated in the economically productive age group. The present study could not conclude whether most of the respondents were in the economically productive age group, because a purposive sample was used.

## 4.2.2 Item 2: Gender (n=30)

Of the respondents who interrupted treatment, 73,3% (n=22) were males, while 26,7% (n=8) were females. Barker et al (2002:292) found that more men than females

defaulted treatment, but gave no particular reasons for the results. According to Khan et al (2000:247), in Pakistan, women are restricted from moving about, while men are compelled to move away from their homes seeking for work, which results in more males defaulting treatment.

# 4.2.3 Item 3: Educational level (n=30)

Figure 4.2 depicts the respondents' educational level.

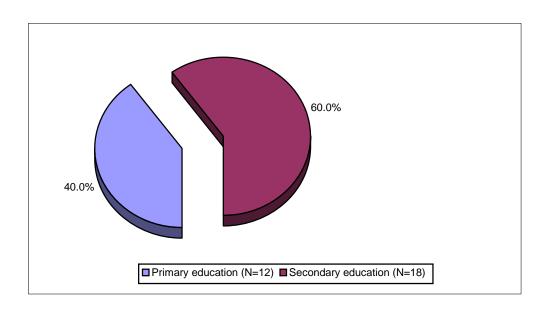


Figure 4.2
Respondents' educational level (n=30)

Of the respondents, 40% (n=12) had primary education while 60,0% (n=18) had secondary education hence the majority were literate. None of the respondents had tertiary education. The level of education, however, had no influence on compliance with treatment.

According to Naing et al (2001:379), age, gender, income, occupational status and education were not consistent predictors of non-adherence.

## 4.2.4 Item 4: Marital status (n=30)

Of the respondents, 60% (n=18) were single and 40,0% (n=12) were married. None of the respondents were divorced or widowed. The respondents' marital status had no

significance in this study, however, as they were not asked if they lived together with their partners for support during treatment or not. According to Barker et al (2002:292), supervision by a family member was usually the last option.

# 4.2.5 Item 5: Employment status (n=30)

Of the respondents, 66,6% (n=20) were unemployed, while 33,03% (n=10) were employed. This finding is similar to those of Khan et al (2000:252) and Naing et al (2001:379) in Pakistan, Kota-Bharu, Kelantan and Malysia. The difference between South Africa and these countries is that TB treatment is free of charge in South Africa.

According to Louw (1995:14), the high rate of unemployment reflects the relationship of TB with lower socio-economic conditions and may indicate that unemployed patients tend to interrupt treatment more often.

## 4.2.6 Item 6: Income (n=30)

Of the respondents, only ten were employed and of these, 10,0% (n=1) earned below R1 000,00 per month; 50,0% (n=5) earned between R1 000,00 and R3 000,00 per month, and the remaining 40,0% (n=4) earned above R3 000,00 per month. However, the study found no evidence that income influenced compliance with treatment.

# 4.2.7 Item 7: Dependants on respondents' income (n=30)

Of the respondents, the majority (60,0%; n=18) did not answer this question. Of the 12 respondents who did, 30,0%% (n=9) reported between 1 and 5 dependants, while 10,0% (n=3) reported 6 to 9 dependants. Most of the respondents were unemployed (see item 5) and only 4 of the 10 who were employed earned above R3 000,00 per month (see item 6). The study, however, did not establish how the employed respondents spent their income.

According to Jaramillo (1999:400), nutrition plays a pivotal role in the control of TB at individual and population level. Louw (1995:2) found that feeling dizzy and nauseous after taking the tablets on an empty stomach was one of the reasons given for

abandoning the treatment. In KwaZulu-Natal, Van der Walt et al (1997:5) found that one of the factors that contributed to interruption of treatment was hunger.

# 4.2.8 Item 8: Type of housing (n=30)

Of the respondents, 76,7% (n=23) lived in brick houses, 3,3% (n=1) lived in an informal settlement structure, while 20,0% (n=6) stayed in an informal dwelling in a backyard. Since the respondents constituted a purposive, convenience sample, many clients living in informal settlements may have been excluded due to inaccessibility of clinics or other factors. Table 4.1 indicates the respondents' housing.

Table 4.1 Respondents' type of housing (n=30)

TYPE OF HOUSE	PERCENT (%)	FREQUENCY (n)
Brick	77,0	23
Informal settlement	3,0	1
Informal, in backyard	20,0	6
Back room	0,0	0
Other	0,0	0
TOTAL	100,0	30

## 4.2.9 Item 9: Number of people living in the house (n=30)

The respondents indicated the occupants in one house as ranging between 26,7% (n=8) and 3,3% (n=1). The issue of overcrowding was not established, for the respondents who lived in brick houses were not asked about the number of occupants and the number of rooms. The remaining 60,0% of the respondents reported that the number of occupants in their names varied from time to time.

# 4.2.10 Item 10: Duration of stay in the house (n=30)

Of the respondents, 83,3% (n=25) had lived in the same house for 12 months or more and 16,7% (n=5) had lived in the house for 1 to 11 months, while no respondent had stayed in the house for less than 1 month. The community of Tembisa is highly mobile, with some staying in hostels and informal settlements. Yet even the respondents who lived in houses permanently, interrupted treatment. The period of stay in the same area is therefore a poor predictor of compliance, but it could be that respondents in hostels and informal settlements were excluded from this study.

# 4.3 SECTION 2: RESPONDENTS' PERSONAL HABITS

# 4.3.1 Item 11: Smoking (n=30)

Figure 4.3 indicates the respondents' smoking habits.

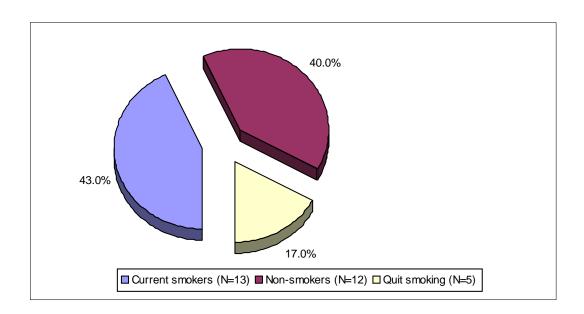


Figure 4.3
Smoking habits (n=30)

Of the respondents, 43,0% (n=13) were current smokers, 40,0% (n=12) were non-smokers, while 16,7% (n=5) had quitted smoking.

# 4.3.2 Item 12: What does/did the patient smoke? (n=30)

Of the respondents, 40,0% (n=12) did not answer the question. Of the remainder, 53,3% (n=16) smoked cigarettes and 6,7% (n=2) smoked dagga. Smoking damages the lungs, making people susceptible to TB. There was no proof that the 6,7% (n=2) respondents who smoked dagga defaulted treatment because of the effects of dagga.

#### 4.3.3 Item 13: Frequency of liquor use (n=30)

Of the respondents, 50,0% (n=15) took liquor over weekends only; 13,3% (n=4) did not take liquor; 16,7% (n=5) drank liquor on social occasions only, and 10,0% (n=3) drank liquor on a daily basis; 10,0% (n=3) did not respond to the question. According to Louw (1995:15), alcoholism contributes to treatment interruption. In this study only 10,0% (n=3) drank liquor on a daily basis. The respondents' TB treatment was taken during the week so alcoholism did not significantly contribute to treatment interruption.

In Barcelona, Naing et al (2001:379) found high rates of treatment interruption among homeless alcoholics.

## 4.3.4 Item 14: Type of liquor (n=30)

Of the respondents, 66,7% (n=20) drank beer; 10,0% (n=3) drank home made beer; 3,3% (n=1) drank wine, and 10,0% (n=3) did not answer the question.

The issue of life-style is usually a sensitive issue, so it did not surprise the researcher that 10,0% (n=3) of the respondents chose not to respond to the question. Jaramilla (1999:397) found alcoholism a high risk factor for breakdown in people with TB. In the Western Cape, Ruck (1997:23) found alcohol abuse a factor in TB, but it did not contribute to interruption of treatment.

### 4.4 SECTION 3: RESPONDENTS' TB HISTORY

## 4.4.1 Item 15: Duration of treatment during last cycle (n=30)

Of the respondents, 70,0% (n=21) had taken treatment for 3 to 4 months, 13,0% (n=4) took treatment between 1 and 2 months, while 10,0% (n=3) stopped taking treatment after 4 months. The remaining 6,7% (n=2) took treatment for less than 1 month.

In Sebokeng, Louw (1995:10) found patients' feeling better was one of the reasons for interrupting treatment.

#### 4.4.2 Item 16: Prior treatment (n=30)

Of the respondents, 80% (n=24) reported they were new patients on TB treatment, while 20,0% (n=6) were re-treatment patients.

### 4.4.3 Item 17: Time of treatment (n=30)

Of the respondents, 80,0% (n=24) did not answer the question; 3,3% (n=1) took treatment less than 6 months ago; 3,3% (n=1) took treatment over 6 to 12 months ago, and 13,3% (n=4) took treatment more than 13 months ago. Furthermore, 6,7% (n=2) reported back at the clinic within a year after defaulting and 13,0% (n=4) after a year of defaulting. However, it was not established how long the respondents took their treatment during the last episode (see item 15).

# 4.4.4 Item 18: If the answer to question 16 is yes, did the patient complete treatment then? (n=6)

Of the respondents, 20,0% (n=6) were treated for TB prior to the last cycle of treatment; 3,3% (n=1) did not answer the question; 6,7% (n=2) had completed treatment in the last cycle, and 10% (n=3) had defaulted in the last cycle of treatment.

It was not easy to determine whether the respondents were new or retreatment patients, unless they were known to the clinic or had brought previous records of treatment. The study was conducted among smear-positive patients who, if not treated properly, spread TB.

Louw (1995:11) maintains that there is a risk of previous treatment interrupters doing so again whereas Khan et al (2000:252) state that a history of previous default does not appear to be associated with increased risk of default from the current treatment episode. The findings of this study concur with Khan et al (2000).

#### 4.5 SECTION 4: DISCONTINUATION OF TB TREATMENT

### 4.5.1 Item 19: Reasons for discontinuing treatment (n=30)

#### 4.5.1.1 Item 19.1: The large number of tablets (n=30)

Of the respondents, 90,0% (n=27) did not interrupt treatment because of the large number of tablets; 3,3% (n=1) did discontinue for this reason, and 6,7% (n=2) did not answer the question. Over the years the number of tablets taken by TB patients has decreased due to the introduction of a combination of drugs compared to single doses. It therefore appears that the large number of tablets does not impact on the interruption of treatment.

#### 4.5.1.2 Item 19.2: Side effects of treatment (n=30)

Of the respondents, 7% (n=2) did not answer the question; 13,3% (n=4) reported that the side effects made them stop, but 80,0% (n=24) indicated that they had not interrupted treatment because of the side effects.

According to Badenhorst et al (1997:104), health personnel often overlook educating TB patients about the side effects. Van der Walt et al (1999:6) found the severity of the side effects given as a reason for non-adherence.

In this study side effects were not seen as a major reason for default.

#### 4.5.1.3 Item 19.3: Distance from the treatment centre (n=30)

Most of the respondents (93,3%; n=28) agreed with the accessibility of the treatment centre, while 6,7% (N=2) did not answer the question.

This study therefore excluded accessibility of the treatment centre as a factor contributing to the interruption of TB treatment. Khan et al (2000:252) and Naing et al (2001:373), however, found the distance to the treatment centre contributed to interruption of treatment.

#### 4.5.1.4 Item 19.4: Other (n=30)

Of the respondents, 33% (n=10) did not answer the question. Of those who answered, 10% (n=3) stopped taking treatment because they had left the area temporarily; 10,0% (n=3) defaulted because they were sick; 10,0% (n=3) stopped because they felt better; 7,0% (n=2) stopped after testing positive for HIV; 7,0% (n=2) were arrested and treatment was not continued in prison; 10% (n=3) stopped because they found a job; 3% (n=1) found the injection too sore; 3% (n=1) had vaginal bleeding, and 7,0% (n=2) stopped taking treatment for no reason.

Jaramillo (1999:395) maintains that biological, behavioural and socio-economic forces must be taken into consideration when dealing with TB, because relying exclusively on the current biomedical model is an inadequate approach to the lasting control of TB.

In this study, the respondents indicated several factors that made them default treatment. For example, 10% (n=3) left the area temporarily. The community of the Tembisa area is highly mobile. TB nurses often report after home visits that some patients have gone to visit relatives or families. Louw (1995:15) reported similar findings in Sebokeng, where 19,6% of the defaulters had left the area temporarily. In Mzuzu, Malawi, Kelly (2001:114) found that reinforcing the TB control programme and training health personnel improved the cure rates though the patients remained mobile.

In this study 10,0% (n=3) remained sick and did not see any improvement, while another 10,0% (n=3) stopped treatment because they felt better. At the World TB Day at Mpumalanga, Doctor Neil Cameron said that once symptoms subside, patients stop taking treatment (Edginton1997a:7). According to Sbarbaro (1990:325), knowledge about an illness, its origins, its dangers or its treatment does not necessarily lead to improved compliance.

#### 4.5.2 Item 20: Place of treatment during the last treatment cycle (n=30)

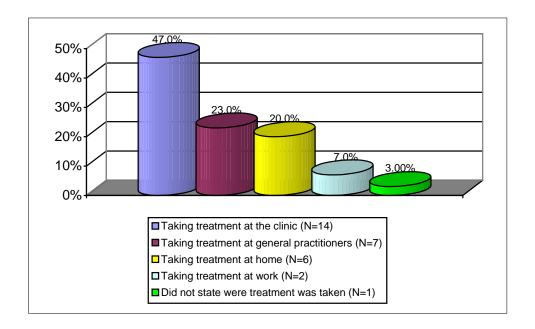


Figure 4.4

Place of treatment during the last treatment cycle (n=30)

Of the respondents, 47.0% (n=14) took treatment at the clinic; 23.0% (n=7) took treatment from general practitioners; 20% (n=6) took treatment at home; 7% (n=2) took treatment at work, and 3.0% (n=1) did not state where treatment was taken.

Many respondents took treatment at the clinic, which could result in patients waiting longer for treatment, because the TB nurse also has to attend to new registrations and update all TB records. Community-based DOTS should be strengthened to keep the patients in the community. However, 80,0% (n=24) of the respondents were on DOTS but still interrupted treatment.

According to Glatthaar (1997:11), treating patients in the community takes a lot of the workload off clinic nurses, which means that nurses can spend more time with the TB patients who come to them.

In a South African randomised controlled trial, Kelly (2001:111) found no significant increase in the cure rates among patients receiving DOTS. Kelly (2001:111) expressed doubts whether DOTS alone was the answer in TB control and advocated a more holistic approach.

### 4.5.3 Item 21: Side effects experienced (n=30)

Regarding side effects, most of the respondents experienced one or more. Of the respondents, 63,3% (n=19) experienced nausea and vomiting and only a few experienced other side effects. The study established that the respondents were not sure what side effects are, because in item 19.2 only 13,0% (n=4) indicated interrupting treatment because of side effects. Table 4.2 depicts the respondents' side effects.

Table 4.2 Side effects experienced (n=30)

ITEM	SIDE EFFECTS	Υ	ES	NO	
		N	%	n	%
21.1	Nausea and vomiting	19	63,3	11	36,7
21.2	Severe skin rash	8	26,7	22	73,3
21.3	Joint pains	4	13,3	26	86,7
21.4	Needle-like sensations under feet	4	13,3	26	86,7
21.5	Blurred vision	1	3,3	29	96,7
21.6	Yellow discolouration of the eyes	1	3,3	29	96,7

# 4.5.4 Item 22: Was the respondent on DOTS with the last cycle of TB treatment? (n=30)

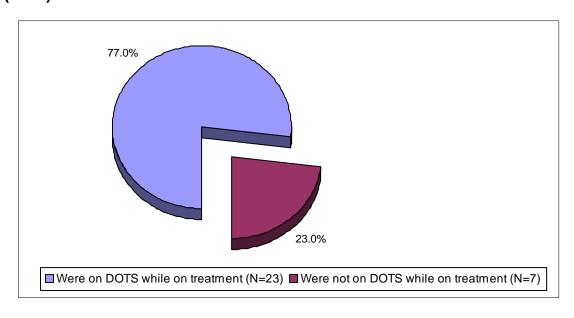


Figure 4.5
Respondents on DOTS with the last cycle of TB treatment (n=30)

Of the respondents, 76,7% (n=23) were on DOTS while on treatment, and 23,3% (n=7) were not.

As indicated in chapter 1, community-based DOTS is not well-established in Tembisa, but TB patients are encouraged to be observed while on treatment. Patients staying far from the clinics are referred to nearby general practitioners (GPs) participating in DOTS, but flexibility is exercised, when necessary. Family members are accepted as DOTS supporters as a last resort. Barker et al (2001:291) report similar findings.

Tembisa had a 56,0% cure rate at the time of the study (Ekurhuleni Metropolitan Municipality Annual Report 2002-2003:20). According to the WHO, a well-functioning TB control programme must achieve 85% cure rates among new smear-positive cases (Department of Health 2000b:5).

# 4.5.5 Item 23: If the answer to item 22 is "yes", who was the DOTS supporter? (n=30)

Of the respondents, 46,7% (n=14) were supervised by the nurse at the clinic; 23,3% (n=7) were supervised by a GP; 20% (n=6) were supervised by others; 6,7% (n=2) were supervised at work, and 3,3% (n=1) did not answer the question.

According to the responses, only 3,3% (n=1) did not answer the question, and 76,7% (n-23) were on DOTS. It was of concern that not all the TB patients on DOTS completed the treatment.

According to Walley (1997:21), DOTS is necessary because "it has been shown to work, though an open-mind is needed because we do not know for sure that direct observation itself is essential in all settings, perhaps good quality TB care, health education, microscopy, drugs and follow-up can be made effective, without direct observation".

#### 4.5.6 Item 24: DOTS contribution to take TB treatment regularly (n=30)

Of the respondents, 50,0% (n=15) stated that DOTS helps patients to take treatment regularly; 6,7% (n=2) said that DOTS does not help, and 43,3% (n=13) were not sure whether DOTS does help patients take treatment regularly. However, the respondents were not probed further about their responses.

#### 4.5.7 Item 25: Difficulty in reaching the treatment point (n=30)

Of the respondents, 86,7% (n=26) stated that they had no difficulty in getting to the treatment point, while 13,3% (n=4) had difficulty doing so (see figure 4.6). Most of the respondents did not complete their treatment even though they had no difficulty in getting to the clinic.

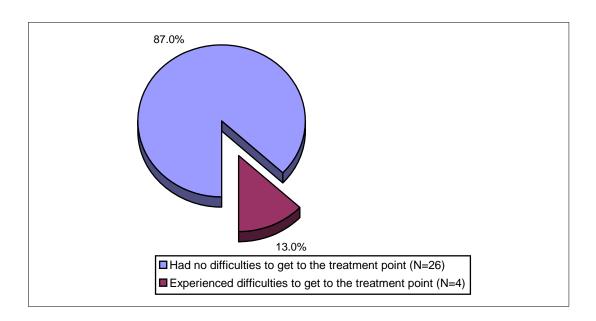


Figure 4.6
Difficulty (n=4) and no difficulty (n=26) in reaching the treatment point

According to Edginton (1997b:4), patients' beliefs, perceptions and problems should be understood. Scolding patients who present themselves late for TB treatment and the defaulters will not promote adherence.

#### 4.5.8 Item 26: If the answer to item 25 was "yes", state the reason (n=4)

Of the 30 respondents, 13,3% (n=4) stated that they had difficulty getting to the treatment point for the following reasons: 50,0% (n=2) had to attend training; 25,0% (n=1) found a part-time job, and 25,0% (n=1) indicated the clinic hours were unsuitable for them.

There is a need, upon the first encounter with the patients, for TB nurses to explain all available alternatives where patients can access treatment. At the time of the study, most of the general practitioners closed at 19:00, but if flexibility is exercised, though DOTS is important, all patients need to be given responsibility to take treatment regularly whether on DOTS or not.

## 4.5.9 Item 27: Transport to the clinic (n=30)

Of the respondents, 56,7% (n=17) walked to the clinic, while 43,3% (n=13) travelled to the clinic by taxi. Although the respondents were observed by nearby general practitioners for their treatment, they had to attend the clinic for their reviews.

Badenhorst et al (1997:104) found that TB patients who defaulted treatment reported that taxi fares were an issue. They were unemployed, stayed far from the hospital and could not afford to pay for the transport to the hospital to collect their treatment.

## 4.5.10 Item 28: Report back to the clinic after stopping treatment (n=30)

Of the respondents, 93,3% (n=28) did not report back to the clinic after they stopped the treatment and 6,7% (n=2) did report to the clinic after defaulting.

TB patients who do not complete the treatment may develop MDR-TB and continue to spread TB, and may even die from the disease which is curable. Health personnel should not have a negative attitude towards TB patients, so that the patients may have the confidence to discuss their problems with them. There should be a system in place that makes it easy to identify defaulters in time and bring them back for treatment. DOTS, if well established, can minimise the number of patients lost to treatment, because DOTS supporters can report early that the patient missed treatment.

## 4.5.11 Item 29: Reasons for not reporting back to the clinic after default (n=30)

#### 4.5.11.1 Item 29.1: Difficult to get to the clinic (n=30)

Of the respondents, 80,0% (n=24) indicated that they did not have difficulty to get to the clinic, while 10,0% (n=3) did, and 10,0% (n=3) did not answer the question.

#### 4.5.11.2 Item 29.2: Felt better (n=30)

Of the respondents, 40,0% (n=12) indicated that they stopped taking treatment because they felt better; 43,3% (n=13) did not stop treatment for that reason, and 16,7% (n=5) did not answer the question. Louw (1995:2) found that 44,6% defaulted treatment because they felt better.

The duration of six to eight months of TB treatment is a problem. Jaramillo (1999:395) found that personal and family income could be badly affected by case holding and the length of treatment. These factors are an economic burden on people with TB.

In South Africa, TB treatment is offered free of charge at public clinics and hospitals, but for the poor and unemployed, it is still a problem because they default treatment while looking for employment.

According to the *Sowetan* (2002b:4), families would rather spend their money on food than on seeking medical help.

#### 4.5.11.3 Item 29.3: Afraid of health personnel (n=17)

Only 17 of the 30 respondents answered this question. Of the respondents, 58,8% (n=10) indicated that they were not afraid of health personnel; 23,5% (n=4) was afraid of health personnel, and 17,7% (n=3) did not answer the question.

According to Badenhorst et al (1997:104), there is a tendency to hold the TB patients primarily responsible for completion of treatment, but occasionally it is the unhelpful attitudes of health workers that contribute to unsuccessful treatment outcomes. In

Pakistan, 6 out of 36 respondents who defaulted treatment complained of the unsympathetic attitude of the health personnel (Khan et al 2000:251).

Accessibility to the health facilities is often thought of in terms of distance, but in many instances facilities are inaccessible because of unacceptable staff attitudes. In Sebokeng, the majority of defaulters did not report back to the clinic because of negative staff attitudes (Louw 1995:11).

#### 4.5.11.4 Item 29.4: Other (n=30)

The respondents were asked to specify other reasons for not reporting to the clinic after stopping treatment. Of the respondents, 6,7% (n=2) did not answer the question; 66,7% (n=20) had no other reason; 3,3% (n=1) stated that nobody did anything for her vaginal bleeding; 10,0% (n=3) had left the area temporarily; 3,3% (n=1) did not want to be hospitalised, and 10,0% (n=3) only came to the clinic when they became more ill.

The factors cited by the respondents should be examined closely in order to reach 85,0% cure rates. Every TB smear-positive patient is very important for the TB programme in the prevention of the spread of TB and decreasing interruption rates to below 5,0%. TB nurses should treat TB patients holistically and have empathy towards them so as to be able to handle their problems. A good relationship should be established with each visit by the patients to the clinic so as to build patients' confidence and cooperation.

According to Walley (1997:24), socio-economic processes are not incidental to the TB epidemic and health professionals need to tackle them seriously.

# 4.5.12 Item 30: Consulting other service delivery centres after discontinuing the TB treatment (n=30)

Of the respondents, 73,3% (n=22) stated that they did not consult another health services after discontinuing the treatment, while 26,7% (n=8) did consult another health service.

It is of concern that 26,7% (n=8) of the respondents did consult another health service. To avoid losing them, registered nurses should be trained comprehensively in order to deal with other conditions that may affect TB patients while they are on treatment. Health education is also essential to TB patients before and during their treatment to inform them that they can be referred to other services, including social services, without discontinuing TB treatment.

# 4.5.13 Item 31: If the answer is "yes" to question 30, why did the patient consult another health service? (n=8)

Of the respondents who consulted another health service, 12,5% (n=1) did not state why; 37,5% (n=3) stated that they had other illnesses; 25,0% (n=2) stated that they did not feel better; 12,5% (n=1) was advised by someone else, and 12,5% (n=1) consulted another health service because of being bewitched. TB is an opportunistic infection and 40,0% of TB patients are HIV positive (Department of Health 2000b:39). Since the present study did not include HIV status, however, the factor of not improving while on TB treatment needs further investigation.

Khan et al (2000:252) found that some patients stopped treatment because they could not see any improvement. Naing et al (2001:374) found that HIV-positive patients had three times statistically significant higher odds of being non-compliant.

## 4.5.14 Item 32: Other reasons for stopping TB treatment (n=23)

Of the respondents, 23,3% (n=7) did not answer the question; 78,3% (n=18) gave no other reason; 8,7% (n=2) were using "imbiza" (a herbal mixture usually given by traditional healers) because they were bewitched; 4,3% (n=1) had requested a weekend

off from the TB hospital and did not go back, while 8,7% (n=2) did not believe they would be cured because they had AIDS.

Van der Walt et al (1997:5) maintain that HIV testing could be considered once the patient's TB treatment was completed.

It is very important to take the patient's beliefs into consideration whenever treatment is involved. In some cultures, it is vital to consult a traditional healer at some point. For example, Louw (1995:15) and Peltzer, Onya, Seoka, Tladi and Malema (2000:59) found that some defaulters visited traditional healers.

#### 4.6 SECTION 5: HEALTH EDUCATION GIVEN BY TB NURSES

## 4.6.1 Item 33: Respondents' level of knowledge (n=30)

Most of the respondents had a good knowledge of TB, which might imply that the health education given by nurses was reasonably good. Knowledge of side effects could improve, however, as 33,3% (n=10) said the nurse did not tell them about the side effects and 63,7% (n=11) said they were not told what to do about the side effects.

Table 4.3 indicates the respondents' answers regarding their level of knowledge of TB.

Table 4.3 Respondents' level of knowledge (n=30)

ITEM	HEALTH EDUCATION	Y	'ES	NO	
I I E IVI		n	%	n	%
33.1	What TB is	30	100,0	0	0,0
33.2	Duration of treatment	29	96,7	1	3,3
33.3	Side effects	20	66,7	10	33,3
33.4	What to do when side effects are experienced	19	63,3	11	36,7
33.5	What happens if TB treatment is not taken regularly	29	96,7	1	3,3
33.6	Reasons for DOTS	30	100,0	0	0,0
33.7	TB is an infectious disease	30	100,0	0	0,0
33.8	Treatment according to prescription	29	96,7	1	3,3
33.9	When to visit the clinic for follow-up	30	100,0	0	0,0

When health education is given to the patients about the importance of adherence to the treatment, side effects are often overlooked or not discussed. TB medication consists of a combination of different drugs, which may result in patients' experiencing side effects. This, in turn, could lead to patients abandoning the treatment. This possibility can be overcome by informing the patients prior to the commencement of the treatment of what to expect while on treatment and which are the minor or severe side effects to expect. For example, urine discolouration is a minor side effect, but very worrying to any person who was not informed that the medication would cause that discolouration. Badenhorst et al (1997:104) found that health workers often minimised or ignored the side effects of the treatment.

According to Van der Walt et al (1997:6), the severity of the side effects was often mentioned as a reason for non-adherence. In addition, in Pakistan some patients stopped their treatment because they felt worse (probably due to the side effects of the drugs) (Khan et al 2000:252).

#### 4.6.2 Item 34: Respondents' perceptions/knowledge of causes of TB (n=30)

It is of concern that most of the respondents (83,3%; n=25) thought TB is caused by poison. This could imply that the word "poison" means something else to them, as 96,7% (n=29) indicated that ancestors do not cause TB. Table 4.4 indicates the respondents' replies to the guestion of the causes of TB.

Table 4.4 Causes of TB (n=30)

ITEM	CAUSES OF TB	\	'ES	NO	
		n	%	n	%
34.1	Poison	25	83,3	5	16,7
34.2	Food	30	100,0	0	0,0
34.3	Ancestors	29	96,7	1	3,3
34.4	Germ	25	83,3	5	16,7
34.5	Other	6	20,0	0	0,0

In the Tintswalo district, Edginton (1997:4) found that many patients and others believed that TB was a punishment from the ancestors if a person had sex with a woman who had had a miscarriage, and that the traditional healers play a vital role in that situation.

Khan et al (2000:247) found that some patients believed that TB was a God-given disease and they had to accept it positively.

In this study, 83,3% (n=25) of the respondents knew that a germ causes TB. If patients do not know the causative organism, it is not easy to comply with treatment. Of the respondents, 17,0% (n=5) stated that they were not sure what caused TB, and 3,0% (n=1) thought "jam" caused TB, which may have meant "germ".

It is essential not to take for granted that patients understand the language that health workers use. Sometimes when health workers try to simplify terms for the patients, they are often misinterpreted. It is advisable to explain in locally used terms in the patients' own language. Health care workers should take it upon themselves to find out the common terms used in the communities, or ask their co-workers who understand the local languages better.

## 4.7 SECTION 6: KNOWLEDGE OF TB AND ITS TREATMENT

## 4.7.1 Item 35: Signs of TB (n=30)

All the respondents (100,0%; n=30) knew what the signs of TB are (see table 4.5).

Table 4.5 Signs of TB (n=30)

ITEM	SIGNS OF TB	Y	'ES	NO	
I I E IVI		n	%	n	%
35.1	Cough for more than two weeks	30	100,0	0	0,0
35.2	Poor appetite	30	100,0	0	0,0
35.3	Night sweats	30	100,0	0	0,0
35.4	Chest pain	30	100,0	0	0,0
35.5	Loss of weight	30	100,0	0	0,0
35.6	Coughing up blood	30	100,0	0	0,0

## 4.7.2 Item 36: Spreading TB (n=30)

The respondents had a good knowledge about the spreading of TB (see table 4.6). Overcrowding was the only aspect that 40,0% (n=12) of the respondents did not know enough about.

Table 4.6 Spreading TB (n=30)

ITEM	SPREADING OF TB	•	YES	NO	
I I E IVI	SPREADING OF TB	n	%	n	%
36.1	The patient with TB who is not on treatment	29	96,7	1	3,3
36.2	Overcrowding	18	60,0	12	40,0
36.3	The client with TB not covering mouth when coughing	26	86,7	4	13,3
36.4	Touching the patient with TB	29	96,7	1	3,3
36.5	The patient who does not complete TB treatment	27	90,0	3	10,0

## 4.7.3 Item 37: Will all people infected with TB bacteria become ill? (n=30)

Of the respondents, 53% (n=16) stated that all people infected with TB bacteria would become ill, while 46,7% (n=14) said "no".

There is a need to educate patients and communities about TB being an infectious disease to reduce its spread. The information should include messages on the prevention of TB, but health personnel should give themselves time to explain that infection does not necessarily mean disease and that TB is an opportunistic disease that only flares up when one's immune system is depleted. Health education in communities may help health care workers to create the necessary awareness to improve the efficiency of TB control programmes. When the public is educated on TB, they may understand, challenge and follow medical advice and participate in political debates where the sustainability of TB control programmes could be discussed and ensured (Jaramillo 1999:400).

#### 4.7.4 Item 38: Cure for TB (n=30)

Of the respondents, 93,3% (n=28) stated that TB could be cured, while 6,7% (n=2) disagreed.

Tuberculosis is curable, even if it co-exists with other conditions like HIV and AIDS. It is important to report at the clinic during the early stages of the signs and symptoms for early diagnosis and treatment. This does not concern the patients only. Health care workers and health institutions should also adhere to the practices ensuring early diagnosis and case holding (Jaramillo 1999:399).

## 4.7.5 Item 39: Body parts infected by TB (n=30)

All the respondents, 100,0% (n=30) correctly stated that lungs can be infected with TB; 100,0% (n=30) did not no know that other body parts could also be infected. Table 4.7 indicates the respondents' answers.

Table 4.7 Body parts infected by TB (n=30)

ITEM	BODY PARTS INFECTED BY TB	Y	ES	NO	
		n	%	n	%
39.1	Lungs	30	100,0	0	0,0
39.2	Intestines	0	0,0	30	100,0
39.3	Kidneys	0	0,0	30	100,0
39.4	Eyes	0	0,0	30	100,0
39.5	Knee	0	0,0	30	100,0

## 4.7.6 Item 40: The correct period for TB treatment (n=30)

It was encouraging that 100,0% (n=30) of the respondents correctly stated that TB treatment should be taken for 6 months or more. The duration of TB treatment is long. It is important for patients to be informed from the onset of the treatment to obtain their cooperation and increase the chances of compliance with treatment because they can adjust their activities to accommodate days on which to report to the clinic.

Khan et al (2000:251) found that patients were informed about the duration of treatment, although none said they were told why such a long regime was necessary, nor the danger of defaulting.

## 4.7.7 Item 41: Consequences of not completing TB treatment (n=30)

The majority of the respondents had a good knowledge about the consequences of not completing TB treatment. However, 33,3% (n=10) of the respondents were of the opinion that they would not contract TB again if they did not complete their treatment, which is a disturbing finding. It also contradicted by 86,7% (n=26) of the respondents who had knowledge of MDR-TB. Table 4.8 illustrates the respondents' answers to the consequences of not completing TB treatment.

Table 4.8 Consequences of not completing TB treatment (n=30)

ITEM	CONSEQUENCES OF NOT	YES		NO	
I I E IVI	COMPLETING TB TREATMENT	N	%	n	%
41.1	Spread the disease	30	100,0	0	0,0
41.2	Develop multi-drug resistant TB	26	86,7	4	13,3
41.3	May die	29	97,0	1	3,0
41.4	Will not contract TB again	10	33,0	20	66,7

# 4.7.8 Item 42: Can people who are HIV positive be successfully treated for TB? (n=30)

Of the respondents, 93,3% (n=28) agreed that people with HIV could be treated successfully for TB and 6,7% (n=2) disagreed. This corresponds with the findings in item 38.

## 4.7.9 Item 43: Reasons for continuing treatment even if they feel better (n=30)

The respondents were generally knowledgeable about the reasons for continuing treatment even if they felt better. However, only 30,0% (n=9) said they had to continue treatment even if they felt better so that they would never suffer from TB again, which contradicts the 100,0% (n=30) response that continuing treatment even if they felt better

is to make sure that they are cured. Some of the respondents may possibly not have clearly understood this question.

Table 4.9 indicates the respondents' reasons for continuing treatment even if they felt better.

Table 4.9 Reasons for continuing treatment even if they feel better (n=30)

	REASONS FOR CONTINUING	YES		NO	
ITEM	TREATMENT EVEN IF FEEL BET- TER	n	%	N	%
43.1	To prevent multi-drug resistant TB	27	90,0	3	10,0
43.2	To make sure that the patients are cured	30	100,0	0	0,0
43.3	Never to suffer from TB again	9	30,0	21	70,0
43.4	To prevent the spread of TB	29	96,7	1	3,3

According to Jaramillo (1999:396), the worldwide stigma attached to TB, with some social discrimination, contributes to some extent to poor adherence. Health education should include facts that stress that TB can affect anyone whose immunity system is compromised whether they have had TB or not. Communities with a low socioeconomic background should be encouraged to have small vegetable gardens around their homes to boost their families' nutritional status.

In KwaHlabisa community, where volunteers were responsible for the patients' supervision, the money "saved" was used to set up a community-based feeding scheme for impoverished TB patients given the immense health risks of non-compliance and reinfection (Edginton1997a:5).

At the time of the present study, the Tembisa clinics had limited budgets. There was a limited and irregular supply of food parcels, which were given only to TB patients who had no other means of an income.

#### 4.7.10 Item 44: Source of knowledge of TB (n=30)

To the question about the source of knowledge of TB, respondents answered as indicated in table 4.10.

Table 4.10 Source of knowledge of TB (n=30)

ITEM	SOURCE OF KNOWLEDGE OF TB	YES		NO	
I I E IVI		n	%	n	%
44.1	The clinic health care workers	30	100,0	0	0,0
44.2	TB literature	12	40,0	18	60,0
44.3	A friend or relative	2	6,7	28	93,3
44.4	The hospital staff	15	50,0	15	50,0
44.5	Other	0	0,0	30	100,0

#### 4.7.10.1 Item 44.1: Clinic health care workers (n=30)

All the respondents (100,0%; n=30) stated that they got knowledge on TB from the clinic health care workers. The fact that the clinic health care workers were giving health education to the TB patients was encouraging. The interruption of treatment could be an indication of the gaps in the information given to the patients. Improvement in this area can be achieved if all clinic health care workers regularly receive training on TB.

Khan et al (2000:251) found that none of the respondents reported being informed about the causes of TB; some were advised not to eat sour food and to avoid "cool" food, and only a few respondents were advised to eat nutritious food.

### 4.7.10.2 Item 44.2: TB literature (n=30)

Of the respondents, 40,0% (n=12) stated that they got TB knowledge from TB literature, while 60,0% (n=18) indicated that they did not gain their knowledge from TB literature. Literature plays an important role in educating patients and communities therefore the literature should be published in different languages to enable everyone to understand it. Posters printed in locally spoken languages should be displayed on clinic walls.

#### 4.7.10.3 Item 44.3: A friend or relative (n=30)

Of the respondents, 7,0% (n=2) reported that they received their knowledge from a friend or relative, while 93,0% (n=28) stated that they did not receive knowledge of TB from a friend or relative. The researcher is of the opinion that everyone should talk more openly about TB. TB is not just a health problem, but affects almost all societies. Health education should not be directed solely to TB sufferers, but also to their families. The social stigma attached to the disease makes society avoid talking about TB.

In Pakistan, Khan et al (2000:251) found that most patients reported that they were instructed by TB facility staff to avoid meeting or having close contact with other people, essentially recommending voluntary social isolation. This suggests that health workers shared the same cultural beliefs about TB as the rest of Pakistan society. Badenhorst et al (1995:106) found that patients at Diepmeadow clinics also referred to the social stigma.

### 4.7.10.4 Item 44.4: Hospital staff (n=30)

Of the respondents, 5,0% (n=15) stated that they received knowledge on TB from the hospital staff, while 50,0% (n=15) did not.

Badenhorst et al (1997:106) found that most patients identified the ward doctors as their source of knowledge and none identified the ward nurses as a source of information. Khan et al (2000:251) reported that most medical and paramedical staff admitted that they did not have time to give information to the patients due to heavy workloads and staff shortages.

The present study found it encouraging that 50,0% (n=15) of the respondents gained their knowledge of TB from the hospital staff.

## 4.7.10.5 Item 44.5: Other (n=30)

All the respondents (100,0%; n=30) gave no other source of knowledge of TB.

The WHO prioritised TB in 1993 and it should, in fact, be treated as a global emergency. Given the findings of this study, however, it is clear that more needs to be done to educate communities on TB.

## 4.8 SECTION 7: CLINIC SERVICES

## 4.8.1 Item 45: Clinic staff's attitude (n=30)

The majority of the respondents (83,3%; n=25) indicated that the clinic staff was friendly, while only 13,3% (n=4) reported that the clinic staff was rude (see table 4.11). Louw (1995:2) found that the minority of patients reported that they stopped treatment because the staff were rude.

Table 4.11 Attitude of clinic staff (n=30)

ITEM	ATTITUDE OF CLINIC STAFF	YES		NO	
IIEIVI		n	%	n	%
45.1	Friendly	25	83,3	5	16,7
45.2	Helpful	26	86,7	4	13,3
45.3	Rude	4	13,3	26	86,7
45.4	Important	18	60,0	12	40,0
45.5	Always in a hurry	24	80,0	6	20,0
45.5	Always available	12	40,0	18	60,0

Item 29.3 underlines the importance of nurses' attitudes towards TB sufferers, where 23,5% (n=4) of the respondents stated that they did not report back to the clinic after interrupting treatment because they were afraid of the health personnel.

According to Edginton (1997a:1), health workers have a tendency to label TB patients as "difficult". Little is explained when treatment is given to them. Nurses seldom have the inclination or the time to ask, listen to and empathise with TB patients, yet wonder why patients fail to complete treatment. Khan et al (2000:251) found the unsympathetic attitudes of the staff contributed to patients' interruption of treatment.

#### 4.8.1.1 Item 45.6: Always available

Of the respondents, 40,0% (n=12) stated that the clinic staff were always available, while 60,0% (n=18) said they were not always unavailable. At the time of the study, a TB nurse was allocated to each clinic to do fast lane for TB patients. The aim was to alleviate long waiting times for the patients before they were attended. However, this created a problem in other areas where staff members distanced themselves from the TB services, even if the allocated TB nurse was not available. The practice further stigmatised TB and clearly demonstrated the negative attitude staff had towards the TB patients. This further led to mismanagement of the TB programme (eg, incomplete record keeping and loss of patients to treatment).

## 4.8.2 Item 46: Willingness of clinic staff to answer questions (n=30)

Of the respondents, 70,0% (n=21) stated that the clinic nurses were sometimes willing to answer the patients' questions, and 30,0% (n=9) said they were always willing. This situation is an obstacle to the management of TB because it means that most of the nurses are not always willing to answer the patients' questions, thereby denying the majority of them information on TB, which could lead to their not completing the treatment.

## 4.8.3 Item 47: Conditions at the clinic (n=30)

All the respondents (100,0%; n=30) indicated that the clinic was clean and not dark. At the same time, all the respondents (100,0%; n=30) indicated that the clinic was overcrowded and 73,3% (n=22) indicated that the clinic was cold (see table 4.12).

Table 4.12 Conditions at the clinic (n=30)

ITEM	CONDITIONS AT THE CLINIC	YES		NO	
		n	%	n	%
47.1	Clean	30	100,0	0	0,0
47.2	Overcrowded	30	100,0	0	0,0
47.3	Hot	1	3,3	29	96,7
47.4	Cold	22	73,3	8	26,7
47.5	Dark	0	0,0	30	100,0

The environment in which TB patients are managed needs to be conducive to care. A clean clinic sets a good example because the patients are always educated to stay in clean well-ventilated houses. The overcrowding, coldness and darkness of the clinics could have a negative impact on compliance with treatment. The clinics at which the study was conducted had fast lanes for TB services, but the waiting areas were shared with patients who came for other services. It is important to strengthen community-based DOTS so as to reduce the number of patients coming to the clinics for their daily medication.

#### 4.9 CONCLUSION

Chapter 4 discussed the data analysis and interpretation. The statistical data analysis revealed that:

- There will always be a link between the way patients perceive TB and compliance with TB treatment.
- No matter how minor the reasons for not completing TB treatment seem to nurses and researchers, they do contribute to the interruption of treatment.
- There is a need for TB patients to be given relevant and adequate information on TB for them to adhere to the treatment.
- There is a need to improve TB services and staff attitudes because what TB
  patients perceive about our services has a direct impact on treatment outcomes.

Chapter 5 discusses the findings and limitations of the study and makes recommendations for practice and further research.

### **CHAPTER 5**

## Findings, limitations and recommendations

#### 5.1 INTRODUCTION

This chapter summarises the study, presents the findings, discusses the limitations of the study and makes recommendations for practice and further research.

#### 5.2 SUMMARY OF THE STUDY

The aim of the study was to investigate factors that contributed to patients' interrupting TB treatment in the Tembisa area which is situated in the Northern part of Ekurhuleni district, Gauteng, South Africa.

The researcher conducted an extensive literature review to gain insight into the factors that contributed to TB treatment interruption nationally and internationally.

The objectives of the study were to

- determine the level of knowledge of TB patients in Tembisa about TB as a disease and the treatment of TB
- determine the patients' opinions, perceptions of and attitudes towards TB
- determine what factors contribute to the interruption of treatment at Tembisa clinics
- determine the patients' perceptions of health services at the clinics in Tembisa
- make recommendations to decrease interruption of TB treatment in Tembisa, and for further research

Data were electronically captured in a dedicated Excel for Windows spreadsheet and analysed using the Statistical Analysis System (SAS) for Windows Version 9.1.

#### 5.3 FINDINGS

The findings are discussed according to the four objectives of the study.

# 5.3.1 Determine the level of knowledge of TB patients in Tembisa about TB as a disease and treatment of TB

The findings revealed that the respondents had knowledge of TB as a disease, however, there were gaps identified in their knowledge.

All the respondents, namely 100,0% knew the signs of TB and that it is an infectious disease. Forty percent of the respondents did not know that TB spreads easily in overcrowded places and 13,3% of the respondents did not know that TB patients do not cover their mouths when coughing, spread TB. It was a worrying factor that 73,3% of the respondents stated that the clinics were overcrowded, and therefore could contribute to the spread of TB. Hundred percent of the respondents knew that the lungs can be infected with TB but all the respondents did not know that TB can affect any part of the body.

All the respondents knew that TB treatment should be taken for six months or longer, but 13,0% did not know that patients who do not complete treatment could develop MDR-TB. The WHO (1995a:22) expressed concerns over the rise in treatment interruption and the emergence of MDR-TB. Ninety-three percent of the respondents agreed that TB is curable even if a patient was HIV positive, while 7,0% of the respondents disagreed.

All the respondents obtained their knowledge on TB from the clinic staff, however, there were gaps in the information that called for a need to develop key messages in the health education on TB, and the use of locally spoken languages by patients.

The study found that the clinics were overcrowded and there was staff shortage. Even though the health personnel tried to give health education to patients, it was often hurried and sometimes vital information omitted. According to Jaramillo (1999:395) poor health education on TB was the cause of treatment interruption by TB patients.

## 5.3.2 Determine the patients' opinions, perceptions of and attitudes towards TB

Of the respondents, 8,7% defaulted treatment because of the belief that they were bewitched and had to use "Imbiza", a mixture usually given by traditional healers to their patients; or that they had "Isidliso", a sickness caused by intentional poisoning and they had to visit the traditional healer.

Another 8,7% of the respondents defaulted treatment because of the fact that they were HIV positive. They perceived themselves as having AIDS and did not believe they could be cured.

The respondents' opinions, perceptions and attitudes regarding TB as a disease had no significant impact on treatment defaulting. Furthermore, the study found no evidence that TB, as a disease, was stigmatised.

The majority of the respondents, namely 83,3% reported that the clinic staff were friendly, helpful and not rude, although 13,3% found the staff to be unfriendly, unhelpful and rude.

Forty percent of the respondents found that the staff was always available for them, though 80,0% found them always in a hurry, they could hardly stop to listen. The respondents, when asked for the reasons of not returning to the clinic after interrupting treatment, 24,0% reported that they were scared of the clinic staff. In South Africa, Edginton (1997a:1) found that in some instances, the negative attitude of health workers towards TB patients contributed to the spread of TB.

# 5.3.3 Determine what factors contribute to the interruption of treatment at Tembisa clinics

Eighty percent of the respondents did not stop the treatment because of the side effects of the medication, even though 63,0% of the patients experienced nausea and vomiting.

Forty percent of the respondents interrupted treatment because they felt better, while another 10,0% of the respondents abandoned treatment because they felt worse while on treatment.

Other reasons for interruption of treatment included leaving the area temporarily (10,0%), and another 10,0% of the respondents interrupted treatment because they found a job. Several factors contributed to the respondents' interruption of treatment, including unemployment, lack of permanent residential place and socio-economic factors. In 1991 a dual approach was adopted to fight poverty and TB at the same time (Hackman 1999:1). Sixty-six percent of the patients who interrupted treatment were unemployed and 73,0% of the non-adherent patients were males.

# 5.3.4 Recommendations to decrease the interruption of TB treatment in the Tembisa area and for further research

The findings call for a plan of action by all the stakeholders to improve TB services in the clinics and decrease TB treatment interruption.

#### 5.4 LIMITATIONS OF THE RESEARCH

The study was restricted to the Tembisa area in Ekurhuleni, in Gauteng and a small sample was used, therefore the findings cannot be generalised to other areas. However, similar findings are likely to prevail in other parts of the African countries burdened by TB. The presence of the researcher during the face-to-face interview schedule might have influenced the responses by the respondents.

#### 5.5 PRACTICAL SIGNIFICANCE OF THE STUDY

The findings will be presented to the Directorate of the Communicable Disease Control Division in Ekurhuleni district. The findings will also be made available to Tembisa clinics from which the study was conducted.

The findings should influence the policies and training implications for health personnel in the management of TB and customer care services in Ekurhuleni district and Gauteng Province.

#### 5.6 RECOMMENDATIONS FOR FURTHER STUDY

The researcher recommends that further research be conducted into the

- reasons for males interrupting treatment more than females
- impact of HIV and AIDS in the management of TB

#### 5.7 RECOMMENDATIONS TO DECREASE THE TB INTERRUPTION RATES

Based on the findings, the researcher makes the following recommendations:

- Health education should be strengthened and locally spoken languages used. A
  checklist must be used to ensure that no vital information is omitted; for example,
  the duration of the treatment, how to recognise and handle the side effects, and
  the importance of compliance with the treatment.
- Staff shortages should be addressed to allow nurses to spend more time with patients.
- The referral system between the clinics and the prisons should be strengthened.
- The follow-up system should be improved by making the necessary resources available, like vehicles.
- Government must give incentives to DOTS supporters in order to sustain them.
- Suggestion boxes should be made available at the clinics for communities to identify well-performing, dedicated health personnel as well as the staff with negative attitudes to enable and facilitate correctional steps and action plans.
- Staff to be trained in customer care and the "Batho Pele" principles.
- Dedicated coordinators should be appointed to the TB programme.

#### 5.8 CONCLUSION

The study found that various factors contributed to the interruption of treatment in Tembisa. The situation requires the combined efforts of all the stakeholders, namely the government, health care workers, patients and the community to tackle the problem. The researcher is of the opinion that this study will contribute significantly to alleviating the scourge of TB and decrease the TB treatment interruption.

#### **BIBLIOGRAPHY**

ANC - see African National Congress.

African National Congress. 1994. *The reconstruction and development programme*. Johannesburg: Umanyano.

Arnadottir, T. 2001. Tuberculosis: trends and the twenty-first century. *Scandinavian. Journal of Infectious Diseases* 33(8):563-567.

Babbie, E. 2002. *The practice of social research*. 4<sup>th</sup> edition. Wadsworth: Brooks/Cole.

Babbie, E & Mouton, J. 2001. *The practice of social research.* Cape Town: Oxford University Press.

Badenhorst, WT, Ward, C & Edginton, ME. 1997. Tuberculosis at Chris Hani Baragwanath Hospital: patients' knowledge, attitudes and referral outcome. *The South African Journal of Epidemiology and Infection* 12(4):104-107.

Baillière's Nurses' Dictionary. 1974. 18th edition. New York: MacMillan.

Barker, RD, Millard, FJC & Nthangeni, ME. 2002. Unpaid community volunteers: effective providers of Directly Observed Therapy (DOT) in rural South Africa. *South African Medical Journal* 92:291-294.

Bateman, ED. 1994. What is new in tuberculosis? *Continuing Medical Education* 15:381-387.

Bless, C & Smith, CH. 1995. Fundamentals of social research methods: an African perspective. 2<sup>nd</sup> edition. Kenwyn: Juta.

Blumberg, L & Constantinou, D. 1997. Tuberculosis: a century of discovery, an epoch of disaster. *South African Journal of Epidemiology and Infections* 12(4):102-103.

Brink, HI. 1996. Fundamentals of research methodology for health care professionals. Cape Town: Juta.

Brink, PJ & Wood, MJ. 1998. *Basic steps in planning nursing research: from question to proposal.* 4<sup>th</sup> edition. Philadelphia: Lippincott.

Brouwer, JA, Boerre, MJ, Kager, P, Varkevisser, CM & Haries, AD. 1998. Traditional healers and pulmonary tuberculosis in Malawi. *International Journal of Tuberculosis and Lung Disease* 2:231-234.

Burns, N & Grove, SK. 1993. *The practice of nursing research, conduct, critique and utilization.* Philadelphia: Saunders.

Burns, N & Grove, SK. 1998. *The practice of nursing research, conduct, critique and utilization*. 4<sup>th</sup> edition. Philadelphia: Saunders.

Chuah, WY. 1991. Factors associated with poor patient compliance with antituberculosis therapy in North-west Perak, Malaysia. *Tubercle* 72:261-264.

City Press. 2004. The white plague that keeps killing across the world. 28 March 2004:31.

Daily Sun. 2004. Where are the TB campaigns? 25 March 2004:11.

Davey, S. 2001. New global plan to halve TB. *Bulletin of the World Health Organization* 79(12):1172-1173.

Department of Health. 1997. TB training manual. Pretoria: Government Printer.

Department of Health. 1999. Patients' Rights Charter. Pretoria: Government Printer.

Department of Health. 2000a. White Paper on the delivery of primary health care services through a district health system. Pretoria: Government Printer.

Department of Health 2000b. *The South African tuberculosis control programme: practical guidelines.* Pretoria: Government Printer.

Department of Health. 2001. *National TB control programme*. Pretoria: Government Printer.

Department of Health. 2003. *Standard treatment guidelines and essential drug list*. Pretoria: Government Printer.

Department of Health 2004. *The South African tuberculosis control programme:* practical guidelines. Pretoria: Government Printer.

De Vos, AS. 1998. Research at grassroots. Pretoria: Van Schaik.

Dormandy, T. 1999. The white death: a history of tuberculosis. *Nature* 198:209-210.

Driver, CR, Matus, SP, Bayuga, S, Winters, AI & Munsiff, SS. 2005. Factors associated with tuberculosis treatment interruption in New York City. *Journal of Public Health Management Practice* 11(4):361-368.

Edginton, ME. 1997a. Tuberculosis: our problem. *Health Systems Trust Update* 23:1-23.

Edginton, ME. 1997b. Improving tuberculosis treatment outcomes in a rural district. *Health Systems Trust Update* 23:1-23.

Escott, S, Nsutebu, E, Walley, J & Khan, A. 2001. Management of TB in countries with high HIV prevalence. *Africa Health* 22(3):12-15.

Ekurhuleni District Annual Report. 2005-2006. *Ten years of democracy*. Germiston: Communications and Marketing Directorate.

Ekurhuleni District Annual Report. 2006-2007. *A partnership that works*. Germiston: Communications and Marketing Directorate.

Ekurhuleni Metropolitan Municipality Annual Report. 2002-2003. *Ten years of democracy*. Germiston: Communications and Marketing Directorate.

Fourie, BP. 2000. The burden of tuberculosis in South Africa. Online www.healthnet.org.za.

George, JB. 1995. *Nursing theories: the basis for professional nursing practice*. 4<sup>th</sup> edition. Englewood Cliffs, NJ: Prentice Hall.

Glatthaar, E & Berends, LJA. 1995. The community and TB control: a success story. *The Community and TB Control* 6:179-186.

Glatthaar, E. 1997. *Tuberculosis: a guide for the primary health care worker*. Unpublished master's dissertation. Pretoria: University of Pretoria.

Hackman, RN. 1999. Tuberculosis control in middle-income countries. TB News.

Hanson, C. 2003. Expanding DOTS in the context of a changing health system. Geneva: WHO.

Harries, D & Maher, D. 1996. TB/HIV: a clinical manual. Geneva: WHO.

http://www.allafrica.com/ stories/200802270523.html.

http://www.doh.gov.za/aids/newsletter/2002/0815/html.

http://www.en.wikipedia.org/wiki/Bath pele. Meaning of Batho Pele.

http://www.ebscohost.com/ehost/detail?vid=lb&sid=9c2daa45-9638-9638-42d6-9c2 ...

http://www.capetown.gov.29/press/newpress.asp?itemcode=2558

http://www.nih.go.jp/JJID/58/152.html

http://www.who.int/tb/publications/global report/2008/keypoints/en/index.html

Imbizo. 2002. Lend a hand, speak out. Government Communications and Information.

Jaramillo, E. 1999. Encompassing treatment with prevention: the path for a lasting control of tuberculosis. *Social Science and Medicine* 49(3):393-404.

Kelly, PM. 2001. Local problems, local solutions: improving tuberculosis at the district level in Malawi. *Bulletin of the World Health Organization* 27(2):111-117.

Kempton Express. 2002. Take part in a fun walk for TB. 21 March 2002:9.

Khan, A, Walley, J, Newell, J & Imdad, M. 2000. Tuberculosis in Pakistan: sociocultural constraints and opportunities in treatment. *Social Science and Medicine* 50:247-254. Lawn, SD, Frimborg, EH, Al-Shusein, H, Acheompeng, JW, Uttley, AHC, Butcher, PD & Griffin, GE. 2001. Pulmonary tuberculosis in Kumasi, Ghana: drug resistance, molecular epidemiology and outcome of treatment. *World African Journal of Medicine* 20(2):92-97.

Louw, MC. 1995. TB treatment adherence. Unpublished master's dissertation. Johannesburg: University of Witwatersrand.

Matsha, N. 1997-1998. Strides and struggles in TB control. Annual Report. Cape and Transvaal Printers.

Mario, C, Raviglione, MD, Pixie, E, Shider, JR & Kochi, A. 1995. Global epidemiology of tuberculosis. *Special Communication* 273(3):220-226.

Ministry of Health. 1998-1999. *Annual Report. Kota Bharu General Hospital, Kelantan.* Malaysia: Ministry of Health.

Mkele, GC. 1998. TB: the people's plague. South African Pharmaceutical Journal:164-166.

Morse, I. 1996. Directly observed therapy for tuberculosis. *Medical British Journal* 312:720.

Multi-drug Resistant Tuberculosis Fact Sheet. 2003. On line <a href="https://www.lungusa.org">www.lungusa.org</a>.

Naing, NM, D'Este, C, Isa, AR, Salleh, R, Bakar, N & Mahmod, MR. 2001. Factors contributing to poor compliance with anti-TB treatment among tuberculosis patients. *Southern Asian Journal for Tropical Medical Public Health* 32(2):368-383.

Nunn, P. 2001. The global control of tuberculosis. *Scandinavian Journal of Infectious Diseases* 33(5):329-332.

Oxford Advanced Learners Dictionary. 1992. 7<sup>th</sup> edition. London: Oxford University Press.

Pallangyo, KJ. 2001. Clinical features of tuberculosis among adults in the sub-Saharan Africa in the 21<sup>st</sup> century. *Scandinavian Journal of Infectious Diseases* 33:488-493.

Peltzer, K, Onya, H, Seoka, P, Tladi, FM & Malima, RM. 2000. Factors at first diagnosis of tuberculosis associated with compliance with the Directly Observed Therapy (DOT) in the Limpopo province, South Africa. *Curationis* 25(3):55-65.

Pinto, WP, Haddad, DJ, & Silva-Telles, MA. 2001. Tuberculosis and drug resistance among patients seen at an AIDS reference centre, Sao Paulo, Brazil. *International Journal of Infectious Diseases* 5(2):93-100.

Polit, DF & Hungler, BP. 1995. *Nursing research: principles and methods*. Philadelphia: Lippincott.

Polit, DF & Hungler, BP. 1999. *Nursing research: principles and methods*. 6<sup>th</sup> edition. Philadelphia: Lippincott.

Porter, JDH, Keith, PWJ & Adam, MC. 1994. *Tuberculosis: back to the future*. New York: Wiley.

Ruck, N. 1997. Human factors in the TB epidemic. African Health 19(1):23-24.

Rutta, E, Kipingili, R, Lukonge, H, Assefa, S, Matsilale, E & Rwechungura, S. 2001. Treatment outcome among Rwandan and Burundian refugees with sputum smear-positive tuberculosis in Ngara, Tanzania. *International Journal for Tuberculosis and Lung Diseases* 5(7):628-632.

Saturday Star. 2003. Doctors are losing fight against TB. 5 April 2003: 6.

Sbarbaro, JA. 1990. The patient-physician relationship: compliance revisited. *Annals of Allergy* 64:325-331.

Schneider, H, Oskowitz, B & Hlatshwayo, Z. 1997. Tuberculosis: our problem. *Update* 23:1-24.

Siringi, S. 2003. Africa seeks new tuberculosis control methods. *The Lancet* 361:2135.

South Africa. 1965. *Medicines and Related Substances Control Act, 101 of 1965, as amended.* Pretoria: Government Printer.

South Africa. 1974a. *Health Professions Act, 56 of 1974, as amended.* Pretoria: Government Printer.

South Africa. 1974b. *Pharmacy Act, 53 of 1974, as amended.* Pretoria: Government Printer.

South Africa. 1978. *Nursing Act, 50 of 1978, as amended.* Pretoria: Government Printer.

Sowetan. 2002a. TB or not TB? Let test answer question. 21 March 2002:7.

Sowetan. 2002b. Drug company builds clinics. 23 April 2002:4.

Sowetan. 2002c. Patients left to die. 16 May 2002:2.

Sowetan. 2003a. Little hope of ending poverty. 13 June 2003:19.

Sowetan. 2003b. Refugees put pressure on local resources. 23 June 2003:15.

Sunday Sun. 2004. TB set to double due to HIV. 28 March 2004:10.

The Star. 2006. TB on the rise due to HIV. 25 March 2006:11.

Van der Walt, H, Wilkinson, D, Wilkinson, N, Nthuli, N & Coleman, R. 1997. Tuberculosis: our problem. *Update* 23:1-24.

Walley, J. 1997. DOTS for TB: it's not easy. African Health 19(1):20-25.

Weyer, K, Coggin, I & Lancaster, J. 1999. *Transfer and treatment interruption patterns of tuberculosis patients in demonstration and training districts in South Africa*. Report of the Department of Health. Pretoria: Department of Health.

WHO - see World Health Organization.

Wilkinson, D & Davies, GR. 1997. Coping with Africa's increasing tuberculosis burden: are community supervisors an essential component of the DOT strategy? *Tropical Medicine and International Health* 2:700-704.

World Health Organization. 1995a. Global epidemiology of tuberculosis. *Special Communication* 272(2):220-226.

World Health Organization. 1995b. Stop TB. Annual Report. Geneva: WHO.

World Health Organization. 1998. TB handbook. Geneva: WHO.

World Health Organization. 2001. New global plan to halt TB. Geneva: WHO.

World Health Organization. 2003. Community contribution to TB care: practice and policy. Geneva: WHO.

World Health Organization. 2004. TB/HIV: a clinical manual. Geneva: WHO.

World Health Organization. 2006. Global tuberculosis control. Geneva: WHO.