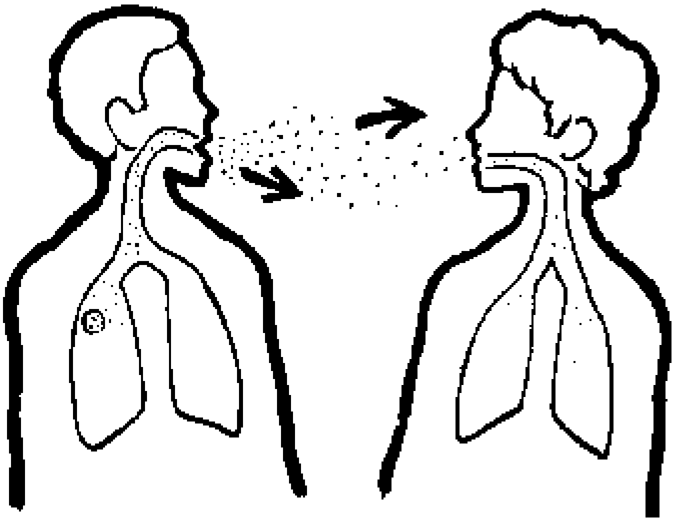

Living with TB: The ‘career’ of the tuberculosis patient in the Free State, South Africa

31 MAY 2004

Living with TB: The ‘career’ of the tuberculosis patient in the Free State, South Africa

by

Sethulego Zacheus Matebesi

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at the

University of the Free State

Promotor: Prof HCJ van Rensburg (UFS, Bloemfontein)

Co-promotor: Prof Herman Meulemans (UFSIA, Belgium)

31 May 2004

I declare that the thesis hereby submitted by me for the Doctor Societatis Scientiae degree at the University of the Free State is my own independent work and has not previously been submitted by me at another university/faculty. I furthermore cede copyright of the thesis in favour of the University of the Free State.

Sethulego Zacheus Matebesi

31 May 2004

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List of abbreviations

AIDS:	Acquired Immune Deficiency Syndrome
CBO:	Community Based Organisation
CHSR&D	Centre for Health Systems Research & Development
CDC:	Centre for Disease Control
COTS:	Community Orientated Tuberculosis Services
DoH:	Department of Health
DOTS:	Directly Observed Treatment Short-Course
DTDs:	Demonstration Training Districts
ed	Edition
Ed.	Editor
FDC:	Fixed-dose combination
FGD:	Focus group discussion
GP:	General Practitioner
HAART:	Highly active anti-retroviral drug therapy
HBM:	Health Belief Model
HIV:	Human Immuno-deficiency Virus
HST:	Health Systems Trust
IEC:	Information, education and communication
ISDS:	Initiative for Sub-district Support
IUATLD:	International Union Against Tuberculosis and Lung Diseases
MDR-TB:	Multi-drug resistance TB
MRC:	Medical Research Council
MTDP:	Medium Term Development Plan
NGO:	Non Governmental Organisation
NTCP:	National Tuberculosis Control Programme
OHS	October Household Survey
PHC:	Primary Health Care
PTB:	Pulmonary tuberculosis
RECAPP:	Resource Center for Adolescent Pregnancy Prevention
SADHS	South African Demographic and Health Survey
SANTA:	South African National Tuberculosis Association
SATCI:	Southern African Tuberculosis Control Initiative
SCC:	Short-course Chemotherapy
SCM:	Stages of Change Model
SDM:	Shared decision-making
SDT:	Self-Determination Theory
SPSS	Statistical Package for the Social Sciences
TADSA:	Tuberculosis Alliance DOTS Support Association
TB:	Tuberculosis

TBLRP: Tuberculosis Lead Research Programme
TBP: Theory of Planned Behaviour
UFS: University of the Free State
UN: United Nations
US: United States
USAID: United States Agency for International Development
WHO: World Health Organisation

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Abstract

This thesis has three main aims. The first aim is to profile the ‘career’ of tuberculosis patients. In this regard, the focus is broadly on the socio-economic and socio-cultural variables impinging on the health-seeking behaviour and adherence to treatment of pulmonary TB patients. Secondary to this aim, the intention is to provide all stakeholders with insight into the living circumstances and experiences of pulmonary TB patients. The third main aim is to propose criteria for innovative behavioural prevention strategies and health-seeking behaviour for TB patients.

The study was conducted at nine primary health care clinics in three geographic areas or health districts in the Free State province (South Africa). The areas were purposively selected to represent different regions in the Free State, including rural and urban areas. Together, the selected areas represent the broad spectrum of socio-economic and socio-cultural variables impinging on the illness ‘career’ of TB patients. The study was conducted using a combination of quantitative and qualitative research methods. Face-to-face interviews was conducted with 220 randomly selected pulmonary TB patients. In addition, nine focus group discussions (FGDs) were conducted with 85 PTB patients.

Fifty-five percent of interviewed patients were male and 45% female. The majority of patients were new patients (68%), while almost a third was re-treatment patients (32%). Of the re-treatment patients, just more than half were on re-treatment following previous cure (53%), while just more than a fifth (21%) was on re-treatment following treatment completion. A third (35%) of the patients was married. On average, the patients lived in families of 4.4 persons per household with an average of 2.1 persons per room.The majority of the patients indicated that they had access to electricity (80%), piped water (85%) and to refuse removal services at least once a week (77%). However, a third (35%) reported having no proper sanitation. While the average monthly per capita income of patients increased from R985.36 immediately prior to illness with TB to R1 113.16 afterwards, the mean cumulative monthly household income decreased from R1 214.50 before being diagnosed with TB to R946.85 afterwards.

It was shown that the illness ‘career’ of individuals with TB is characterised as a long-term experience in which the individuals had to rely families and friends to overcome daily challenges. In an attempt to provide a meaningful separation of events constituting the illness experience, the illness ‘career’ of the TB patient was divided into five different phases from experiencing symptoms, to assuming the sick role, to contacting a health care provider, to being a patient and, finally, relinquishing the sick role. The findings indicate that the patients in this study not only had to cope with physical disabilities and the side effects of treatment, but also with the psychological traumas of fear of recurrence of the disease and social stigma, and the disappointment of a

considerably reduced range of future possibilities for career and marriage. It was also indicated that few of the patients in this study were treated negatively by their spouses/partners, family members or their communities. Living with TB in “modern” society where stress, AIDS and an array other social and psychological factors are seen to threaten the individuals, is an enormous burden

In respect of determinants of treatment adherence, the quantitative evidence shows that stigma, the socio-economic circumstances of the patient, and migrancy play an important role in explaining non-adherence. In addition, patients whose tablet taking was supervised were more likely to adhere to treatment. Based on the qualitative evidence, some of the perceived factors affecting adherence included lack of knowledge about TB, non-sustainability of educational campaigns, side effects of drugs, hunger and lack of family support, stigma attached to TB, and the attitude of health care workers and the long delay in obtaining a diagnosis. Based on this evidence, recommendations are made regarding a number of provider-, patient- and community-centred interventions that can improve adherence.

SECTION ONE

Chapter 1:
Introduction

> "While one-fifth of the world's 5 billion people can now expect to live to see their 80th birthday, nearly half of the rest--about 1.6 billion people--suffer overwhelmingly the world's burden of unavoidable illness and premature death. Increasingly, citizens of developing countries are coming to believe that at the root of such inequity lies an attempt to apply "first world" solutions without sufficient adaptation to the realities of the third world" (Commission on Health Research for Development, 1990).

1.1 Background

According to the Southern Africa Tuberculosis Control Initiative (SATCI) (2000:2), "*tuberculosis (TB) hardly needs any introduction. At least, not in Africa.*" The debilitating bacteria of this curable, yet terminal disease, dictate the lives of thousands of people in Southern Africa." Globally, TB kills 5 000 people per day and more than 2.3 million a year (WHO, 2001). More than 8 million people become sick with TB each year and about 2 million TB cases per year occur in sub-Saharan Africa. This number is rising rapidly as a result of the HIV/AIDS epidemic. TB remains one of the major public health threats in South Africa despite the availability of effective treatment for over 50 years (Rubel & Garro, 1992:626; Thomson & Myrdal, 1986:263; *UN Chronicle,* 1998:73; Wilkinson, 1999:155) and the implementation of a National Tuberculosis Control Programme (NTCP). Due to incomplete coverage of health services and problems with the registration and notification systems, TB case notifications reflect only a proportion of the actual number of cases in South Africa (Department of Health, 2001a).

The TB epidemic in South Africa ranks among the worst in the world (SATCI, 2000:2). In 1999, the World Health Organisation (WHO) ranked South Africa third in the world in terms of reported TB incidence for 1999 and ninth among the 23 countries accounting for 80% of all new TB cases globally. A reported annual incidence[1] of 495 per 100 000 people is third only to Zimbabwe (562) and Cambodia (560) (WHO, 2001:18) and a TB case fatality rate (death from TB) of 166 per 100 000. This rate is five times higher than the global TB fatality average and is second only to Zimbabwe (Kironde, 2000:335-336).

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[1] TB incidence refers to the number of newly diagnosed cases of TB per 100 000 people.

Factors contributing to the worldwide re-emergence of TB include increased migration, international travel and tourism, increased incidence of AIDS, the emergence of multi-drug resistance[2] (MDR), and weakening of public health care systems in both developed and developing countries (Lock *et al*., 2001:830). Badly administered drug treatments and interruptions to drug supplies have led to a rapid growth of MDR strains of TB that are difficult and expensive to treat (Symonds, 1998:2).

Of the nine provinces of South Africa, the Free State province with approximately 2.5 million inhabitants has the fourth highest incidence of TB. The incidence of TB in this province rose from 398 per 100 000 in 1998 to 460 per 100 00 cases in 2000 (Department of Health, 2002b:1). According to Kironde (2000:339), 52% of these cases were HIV co-infected. The province also had the least success in converting smear positive TB cases during the intensive phase of treatment in 1998 (Department of Health, 1998:28). Table 1.1 depicts the treatment outcome of new smear positive cases in the Free State.

Table 1.1: Treatment outcome (new smear positive[3] cases) in the Free State – 1999

Province	Cure rate	Completion rate	Death rate	Failure rate	Defaulter rate
Free State	67%	75%	8%	2%	15%
South Africa	**60%**	**72%**	**9%**	**2%**	**17%**

Source: Department of Health (2001b)

Pulmonary tuberculosis (PTB), which primarily affects the lungs, is the most common form of infection (De Muynck, 2000:14). The burden of the TB and the risk of infection are produced mainly by the pulmonary form which accounts for over 80% of deaths from the disease. An untreated smear-positive person can, on average, infect between 10 and 15 people every year. One cough from somebody with smear positive PTB can produce 3 000 infectious droplets. However, not all people infected with TB will necessarily fall ill with the disease. The risk of infection is high when continuously

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[2] MDR TB is the most fatal aspect of the TB epidemic. It refers to TB which is resistant to at least isoniazid and rifampicin (Department of Health, 2001a:40) and is man-made: caused by inconsistent or partial treatment, when patients do not take all their drugs regularly for the required period, because they start to feel better, and also because doctors and health workers prescribe the wrong treatment regimens or the drug supply is unreliable (Enarson *et al.*, 2000:5). Another likely main factor contributing to MDR-TB in South Africa is the interruption of treatment during transfer of patients to another district or health facility (SATCI, 2000:12) This form of TB is extremely expensive to treat at R25 000 to R30 000 per patient compared with R200 for a new patient with ordinary TB. MDR patients also require long-term hospitalisation, adding to the already high cost of treatment (Department of Health, 2001b).

[3] Some definitions related to TB:

Smear positive TB case refers to a patient with PTB who had a positive smear or culture-bacteriological result (by means of a laboratory sputum examination) at diagnosis

Cure rate is the percentage of patients who have been cured at the end of treatment.

Completion rate indicates the percentage of patients who have successfully completed treatment but whose treatment outcome could not be confirmed.

Death rate refers to the percentage of patients who have died from TB.

Failure rate is the number of patients who have failed to convert from being smear positive to smear negative at the end of treatment.

Defaulter/interruption rate refers to the percentage of patients who have failed to complete the full course of treatment.

being exposed to a person with smear-positive PTB indoors (Department of Health, 1998:17). While all groups are susceptible to PTB, studies (for example, Lock *et al*., 2001:830) have shown that young women and men have always been hardest struck.

This cross sectional descriptive and explanatory study concerns the social dimension of TB control. The purpose of this study is to examine, firstly, the relationship between socio-demographic characteristics, on the one hand, and the health-seeking behaviour and experience of living with TB of clinic-based pulmonary TB diagnosed patients in three areas in the Free State province, on the other. Demographic characteristics are divided into background information about the respondent (i.e. category of patient, gender, level of education, employment status, income) and the type of housing and infrastructure/services. The examination of background information is important to this study, because it is hoped that it will be possible to identify patient characteristics and factors contributing to delay in seeking health care and to 'bad' experiences of TB treatment.

The second part of the study examines the impoverishing effect (i.e. causing loss of employment and income) and the social ramifications (i.e. stigmatisation, isolation and rejection) of TB throughout the patient 'career'. This part attempts to analyse what Mechanic & Volkart (1961:52) termed "illness behaviour". According to these authors, illness behaviour refers to "*the way in which symptoms are perceived, evaluated, and acted upon by a person who recognises some pain [or] discomfort..*" The illness experience of respondents is described and analysed according to four of the five stages that demarcate critical transition and decision-making stages in medical care and behaviour. These stages are the symptom experience, assumption of the sick-role, medical care contact, the dependent-patient role, and recovery and rehabilitation (which was not empirically investigated). Each stage presents new problems and requires different kinds of decisions and medical actions. This study has focused on PTB diagnosed patients above 16 years.

1.2 Rationale for the study

Against this background, the threat of TB has provided a major momentum into the study of factors in determining patients' health behaviour. For perhaps the first time, the world is faced with a health threat against which the only effective barrier is not only medical, but also behavioural. Despite being curable through medical procedures, the need to determine factors involved in decision-making relating to TB treatment is perhaps one of the greatest challenges facing medical sociology. A number of investigative processes have been employed in the search for greater understanding of these processes, including the application of formal models of health behaviour decision-making, such as the Health Belief Model or Theory of Reasoned Action (*see Chapter 2*).

It is also clear that during the past two decades an extensive body of research has examined the role of patients in TB control. Furthermore, it is evident that the beliefs, attitudes and perceptions of individuals, as influenced by their demographic, socio-cultural and economic backgrounds are some of the main factors affecting decisions to seek or not to seek help and/or to comply or not to comply with treatment recommendations. However, no studies have empirically examined the role of these factors throughout the TB patient 'career' within theoretically-based frameworks. This scenario presents an interesting study area for the sociologist and is one of the major reasons for undertaking research on this topic.

The researcher's interest in the topic also arose from being a member of the research team of the Centre for Health Systems Research & Development (CHSR&D) engaged in a series of rapid situational analyses of the TB control programme in the Free State province. This process has been part of the ongoing collaboration between the CHSR&D, the Initiative for Sub-district Support (ISDS) of the Health Systems Trust (HST)[4] and the Free State Department of Health. The researcher also attended an informative workshop on TB and TB control presented by the ISDS. Useful information and material emanated from this workshop, which further generated interest in the topic.

1.3 Problem statement

A significant number of studies focused on the role of socio-economic and socio-cultural factors on TB control efforts, as well as social patterns accompanying the identification of initial symptoms, and the seeking, finding and carrying out of medical care (Collins, 1992:26; Fife & Wright, 2000: 50-51; Rupel & Garro, 1992:627; Mata, 1985:61; Meulemans *et al.*, 2000:65; WHO, 2002a:4; Wilkinson, 1999:159). These are important elements of the 'career' of the TB patient. Meulemans *et al.* (2000), for example, provide an entire volume of references to studies addressing issues related to, among others, the perception and knowledge of TB, etiological beliefs, patient delay, health-seeking behaviour and stigma.

Other studies (Barnhoorn & Andriaanse, 1992:296; Needham *et al.*, 2001; Ngamvithayapong *et al.*, 2000; Rupel & Garro, 1992) indicate that a variety of background characteristics (e.g. gender, age, marital status, educational level, socio-economic status) and personal traits (i.e. knowledge, attitudes and beliefs about TB) have all been reliably related to various measures of health behaviour (early/late presentation to health care providers or health care facilities, and adherence/non-adherence to treatment). A few other studies explore the effect of stigma on TB (Fife & Wright, 2000; Meulemans *et al.*, 2000), which to a large extent, is caused by the link between the disease and HIV/AIDS.

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[4] Health Systems Trust is a dynamic independent non-government organisation (NGO) established in 1992 to support the transformation of the South African health system. The HST is primarily a developmental organisation committed to helping improve the functioning of the health system. The trust actively supports the current and future development of a comprehensive health care system through strategies designed to promote equity and efficiency in health and health care delivery (Health Systems Trust, 2003).

It is highly unlikely that an effective short-term chemotherapy will be widely available in South Africa in the next 10 years. Thus, behaviour change remains the current viable means of limiting the further spread of TB infection. Studies around the world have shown that behaviour interventions such as health education can bring about a reduction in high-risk behaviour. Despite TB being contagious, Metcalf (1991:1) already noted more than a decade ago that the disease has not yet ignited the same public alarm as acute diseases such as HIV/AIDS. The continuing increase in TB infection rates in the country also suggests that health education, information and communication efforts have either been limited or not effective on a broad enough scale to achieve a significant public impact.

Despite the knowledge that socio-economic, cultural and behavioural factors influence patient compliance, Rupel & Garro (1992:627), maintain that little research has been conducted on this aspect of TB. It is also remarkable that social, cultural and economical factors, which appear to produce the disease (Cockerham, 2001:160; Grange, 1999:12; Lock *et al.*, 2001:831), have been given little priority. Other studies on TB (Barnhoorn & Andriaanse, 1992; Liefooghe *et al.*, 1997; Liefooghe *et al.*, 1995; Needham *et al.,* 2001) only explore certain aspects relating to the ‘career’ of TB patients.

As TB is a social disease *par excellence*, it is of paramount importance that the conditions under which people are exposed to the disease be addressed. On the **societal level**, social interventions (i.e. policies directed at alleviating poverty, the creation of employment opportunities, the improvement of sanitation facilities and access to clean water) in TB seem to be at least one avenue to explore. On the **individual-patient level**, intervention strategies should focus on individual patients, as well as on their unique social, economic, cultural and occupational circumstances.

1.4 Key research questions

The following key research questions that arise from the research problem give further direction to the social dimension on which the study focuses:

- What are the typical characteristics of the illness ‘career’ of pulmonary TB patients, and which events and factors constitute the major markers and stages in the course of this career?
- Which demographic and biographic characteristics (patient category, gender, age, migration history, work history) predispose people to TB?
- Which socio-cultural and socio-economic factors and circumstances affect susceptibility to TB, and facilitate or hinder appropriate health-seeking behaviour (i.e. living and working conditions, income, poverty status, marital status, family structure and infrastructure – water, electricity and sanitation and home conditions)?
- What is the risk-profile of pulmonary TB patients?

- What are the knowledge, perceptions, attitudes and beliefs of pulmonary TB patients about the disease?
- What are the health-seeking and treatment compliance patterns of pulmonary TB patients?
- What are the effects (i.e. loss of employment, financial implications and stigmatisation) of TB on patients?
- What is the role of health promotion and health education in TB control?

1.5 Pilot study - rapid situational analyses

In essence, this study is part of a more comprehensive three-year study: *The Joint research project on tuberculosis control in the Free State, South Africa: from infection to cure*. This comprehensive study focuses on the patient career, the socio-economic environment and the health care system. The study is conducted in the context of the South African–Flemish Bilateral Scientific and Technological Cooperation Programme.

As part of the research on the TB control programme in the CHSR&D, a series of rapid situational analyses of the TB control programmes were conducted in three health districts in the Free State province, namely Tshepo district (Janse van Rensburg *et al.*, 2000), Kopano and Hlanganani districts (Engelbrecht *et al.*, 2000). These rapid situational analyses are regarded as pilot-studies to the current study. Furthermore, various local academic departments and academic institutions in Flanders (Belgium) also informed the research topic. Some of the findings from the situational analyses that directly or indirectly have a bearing on this study, included:

- Migrant status was found to be one of the main reasons for defaulting because of migrant workers not staying in one place long enough to complete treatment.
- Some patients not knowing what their treatment entails.
- Some patients not being on DOTS[5] – thus, not being supervised when taking medication.
- Long delays of patients who experience symptoms of TB before reporting such symptoms.
- Poor provision of health education and health information.
- Lack of vigorous public awareness campaigns.
- Confusion around the link between TB and HIV/AIDS.

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[5] The aim of the Directly Observed Treatment Short-course (DOTS) strategy - formulated by WHO in 1991 and adopted by South African revised National TB Control Programme in 1996 (Bamford, 1999:316) - is to ensure that every TB patient should have the support of another person (e.g. family member, neighbour, colleague or employer) to ensure that they swallow their medication daily. At the management level, the aim of the DOTS strategy is two-fold: Firstly; it aims to treat 85% of detected smear positive TB cases; secondly, it aims to detect 70% of such cases (World health Report, 2001a:3).

The pilot study provided several lessons to the researcher. First, it was realised that, to reach the targeted number of TB patients, the fieldwork would need to be done in the mornings. Second, the questionnaire proved to be too long. Third, questions that were not clear were identified.

1.6 Research aims and objectives

This study has three main aims. The first aim is to profile the 'career' of tuberculosis patients. In this regard, the focus is broadly on the socio-economic and socio-cultural variables impinging on the health-seeking behaviour and adherence to treatment of pulmonary TB patients. Secondary to this aim, the intention is, as stated earlier, to provide all stakeholders with insight into the life circumstances and experiences of pulmonary TB patients. The third main aim is to propose criteria for innovative behavioural prevention strategies and health-seeking behaviour for TB patients.

The following six specific objectives pursued by the study are:

- to construct a socio-demographic and risk profile of pulmonary TB patients;
- to gain an understanding of the socio-economic factors (i.e. poverty, unemployment, housing, sanitation) and socio-cultural factors (i.e. traditional beliefs, attitudes, knowledge and practices of illness) and dynamics impacting on communities' susceptibility to TB;
- to assess and describe the knowledge, perceptions and beliefs of pulmonary TB patients in respect of the disease;
- to investigate patients' perceptions of the quality of health services, including accessibility, acceptability, and appropriateness of TB control services and the constraints experienced in seeking and undergoing treatment;
- to identify and describe the social ramifications (i.e. stigmatisation, isolation, rejection and loss of employment) experienced by pulmonary TB patients;
- to make suggestions for practical intervention in problem-solving, decision-making and policy-making.

1.7 Conceptualisation

Conceptualisation is regarded as one of the most important components of the research process, as it enables readers to understand the context in which words are being used, or their unusual or restricted meaning (Cresswell, 1994:106). Defining terms adds precision to a scientific study and, as Babbie (1999:109) states, answers to research questions can only be found if there is consensus in respect of the meaning of terms used. The following key terms feature in study:

- **Living with TB** is a concept used by the author and is defined as the manner in which TB patients experience the disease over a longer period. This, according to various researchers (Bhatia *et al.*, 2002; Fife & Wright, 2000; Liefooghe *et al*., 1995; Mata, 1985), refers to the outcome of spells of sickness with TB, which exposes patients to negative experiences such as loss of job, or being blamed for their illness, rejection and isolation.

- **Patient 'career'** refers to the broad path from initial experience of symptoms through the intensive and follow-up phases to the variable outcomes of the TB treatment process. More specially, the TB patient 'career' refers to the five critical stages, which were proposed by Suchman (1965), demarcating critical transition and decision-making points in medical care and behaviour: symptom experience; assumption of sick-role; medical care contact; dependent-patient role; and the recovery or rehabilitation stage.

- **Health behaviour** refers to those activities undertaken by people believing themselves to be healthy, for the purpose of maintaining their health and preventing disease or detecting it in an asymptomatic stage (Weiss & Lonnguist, 1997:108). These activities might include exercising, eating a healthful diet, having a regular dental check-up, and getting vaccinations against diseases.

- **Illness behaviour** consists of the ways in which given symptoms may be perceived, evaluated, and acted (or not acted) upon by different individuals. More simply, Mechanic (1995:1208) defines illness behaviour as "*the varying ways individuals respond to bodily indications, how they monitor internal states, define and interpret symptoms, make attributions, take remedial actions and utilize various sources of informal and formal care.*" These activities generally include complaining about symptoms and seeking help or advice. According to the *"doctrine of specific etiology,*" coined by Dubos in 1961, "*illness is postulated as consisting of distinct and discrete clinical states, each with specific pathological manifestations and each caused by a different agent"* (Blaxter, 1990:4).

- **Sick-role** behaviour is a fundamental concept in medical sociology introduced by Talcott Parsons in 1948 and elaborated in 1951 (Weiss & Lonnquist, 1997:129). The sick role involves the activities undertaken for the purpose of getting well, by those who consider themselves ill. It includes receiving treatment from appropriate therapists, and generally involves a whole range of dependent behaviours, and leads to some degree of neglect of one's usual duties (Parsons, 1978:19-21). The sick role is also regarded as a social role, in other words, there are institutionalised expectations that are usually upheld by others for the behaviour of people who are sick: Thus the sick person would be: entitled to some exemption from normal social activities and under some circumstances would be required to give up or curtail activities (Fox, 1989:17).

- **Help-seeking or health-seeking behaviour** occurs when persons do something to get help for their symptoms or distress (Keenan, 2001:249; Leigh & Reiser, 1980:4; Liefooghe, 2000:43). Help-seeking behaviour is one of the many facets within the topic of illness behaviour (Mechanic, 1978:249). This behaviour may be subcategorised into medical (seeing a doctor or visiting a clinic) and nonmedical (talking with a family member or friend).

- Closely related to the concept of help-seeking behaviour is that of treatment delay. **Treatment delay** is defined as "*the period between the onset of symptoms and initiation of treatment"*. The delay consists of two major elements: patient delay and health care providers' delay (Liefooghe, 2000:43). **Patient delay** indicates the period from the onset of symptoms until presentation to a health care facility or provider. **Health care providers' delay** refers to the period of delay from when the patient presents himself or herself at a facility until treatment is initiated (Liefooghe, 2000, 43; Pronyk *et al*., 2001:624).

- **Adherence** has come to be the preferred term in recent literature to the term 'compliance'. The term 'compliance' "*exaggerates patient agency, for it suggests that all patients possess the ability to comply – or to refuse to comply – with anti-tuberculosis therapies*" (Farmer, 1997:349). In this thesis, therefore, the preferred terms are adherence and non-adherence instead of compliance and non-compliance to describe patient behaviour. For the purpose of this thesis, adherence refers to the continuous uninterrupted taking of prescribed medication.

- **Stigma** is defined as the subjective experiences of negative images and myths about an illness. This includes social rejection, internalised shame and social isolation. Stigma is not a singular concept expressed and experienced in a common way. Rather, it is a complex phenomenon expressed both subtly and overtly. It is subjectively experienced in multiple ways that are dependent on the nature of the stigmatising condition and social conditions of the individual. Erving Goffman (1963) long ago recognised that various types of illnesses are associated with stigma, or membership of a social category that results in a spoiled identity, setting the individual apart from others. According to Misztal (2001:316), stigmatised people are faced with definite limits to their claims about themselves that will be accepted by others. In this regard, Goffman (1963:121) indicates that people who are stigmatised have to follow societal rules for a "*good adjustment.*" Stigmatisation has a negative impact on both the individual's self-concept and on the social response of others. Illnesses are stigmatising because they represent potential or existing physical limitations; they are associated with particular negative images and myths, and therefore assume symbolic meaning (*American Thoraric Society*, 1996:154; Fife & Wright, 2000:50-51).

1.8 Analytical framework: The 'career' of the patient

The overall analytical model for this study is based on Suchman's (1965) analysis of the stages of illness experience. The concept of illness behaviour, as stated earlier, refers to "*the way in which symptoms are perceived, evaluated, and acted upon by a person who recognises some form of pain*…" Mechanic & Volkart (1961:52). This definition of illness behaviour creates the impression that an individual's response to symptoms is a straightforward entity. However, many people still fail to respond to symptoms, even if very serious, and many others seek medical help for minor complaints (Weiss & Lonnquist, 1997: 126). According to Suchman (1965), illness experience (or patient 'career') is analysed according to five stages of medical care and behaviour: (1) symptom experience; (2) assumption of the sick role; (3) medical care contact; (4) dependent-patient role; and (5) recovery and rehabilitation (see Figure 1.1.).

Each stage involves major decisions that must be made by the individual. These, in turn, determine whether the sequence of stages continues or the process is discontinued. The decisions taken, demonstrate how individuals draw upon their knowledge and experience bodily states to recognise illness and do something about it (Cockerham, 2001:133). In the case of TB, getting inside the experience of such a disease may be key to understanding patient motivation, non-compliance with therapy and altered patterns of social engagement. While some diagnoses are traditionally associated with short prognoses (Price, 1996:275), TB treatment lasts from six to eight months minimally. However, treatment in re-treatment and multi-drug resistant patients might last up to two years (Rieder, 2002:10-11). While the focus on the illness experience is primarily on Suchman's (1965) stages, it is also drawn from other authors in the ensuing discussions.

1.8.1 Stage I: Symptom experience

According to Suchman (1965:114), the illness experience is initiated when an individual first senses that something is wrong –a perception of pain, discomfort, general unease, or some disruption in bodily function. Three distinct processes occur at this time:

1. *The physical experience of the symptom* in the form of pain, discomfort, change of appearance, or disability actually felt.
2. *The evaluation and interpretation of the symptom,* which involves the cognitive recognition that physical symptoms of an illness are present.
3. *The emotional response to the symptom*, which may include concern for the social implications of the illness and a possible disruption in ability to function. This concern or fear accompanies both the physical experience and the cognitive interpretation and evaluation.

In response to the assessment of symptoms, the individual may make the following five decisions relating to medical care:

1. *Denial that the symptom needs attention* or what Suchman (1965:115) calls "*flight to health*." Borrowing from the Health Belief Model (HBM), the reaction to the symptoms would depend on the perceived seriousness of the symptom, perceived susceptibility to it, belief in the efficacy of professional help, and perceived barriers to the behaviour (Kaplan *et al*., 1993:52-53; Rubel & Garro, 1992:627; Weiss & Lonnquist, 1997:116-118).
2. *Delay in seeking and securing treatment* until the symptoms become more obvious. Here, the individual does not to disturb others unnecessarily.
3. S*elf-treatment or self-medication,* which involves attempts by the individual to get relief by taking advice from lay persons. An individual may be advised to take folk medicine, home remedies, and over-the-counter medications.
4. *Hypochondriac behaviour* – where the individual links his or her sickness to certain social, cultural or psychological reasons.

5. *Acceptance of illness* – where the decision involves accepting the symptom experience as indicative of an illness. It is only after this acceptance of the illness that the individual is likely to enter Suchman's second stage of the sick role.

Thus, individuals who experience their symptoms as mild and do not have any prior knowledge about them, would either ignore the symptoms or resort to self-treatment. Conversely, individuals who experience the symptoms as 'serious' and a threat to their lives, could seek appropriate treatment. In brief, action (to seek help or delay seeking help) at this stage is, to a large extent, influenced by previous exposure to and/or knowledge about the symptoms. Studies, such as the one of Mirowsky *et al.* (2000), have also shown that persons with lower incomes know less about their bodies and are less likely to define their problems in ways that result in consultation with professionals.

1.8.2 Stage II: Assumption of the sick role

If the individual accepts that the symptoms are a sign of illness and are sufficiently worrisome, then the transition is made to the second stage, the assumption of the sick role. This concept encompasses the decision that one is sick and needs professional help. The following behavioural patterns of the patient may be evident at this stage:

1. *Rejection of the sick role.* The lay referral structure of the individual assumes greatest importance at this stage; the individual continues to follow the advice of lay persons by means of self-treatment and self-medication. Therefore, exposure to the experiences, attitudes and advice of relatives or

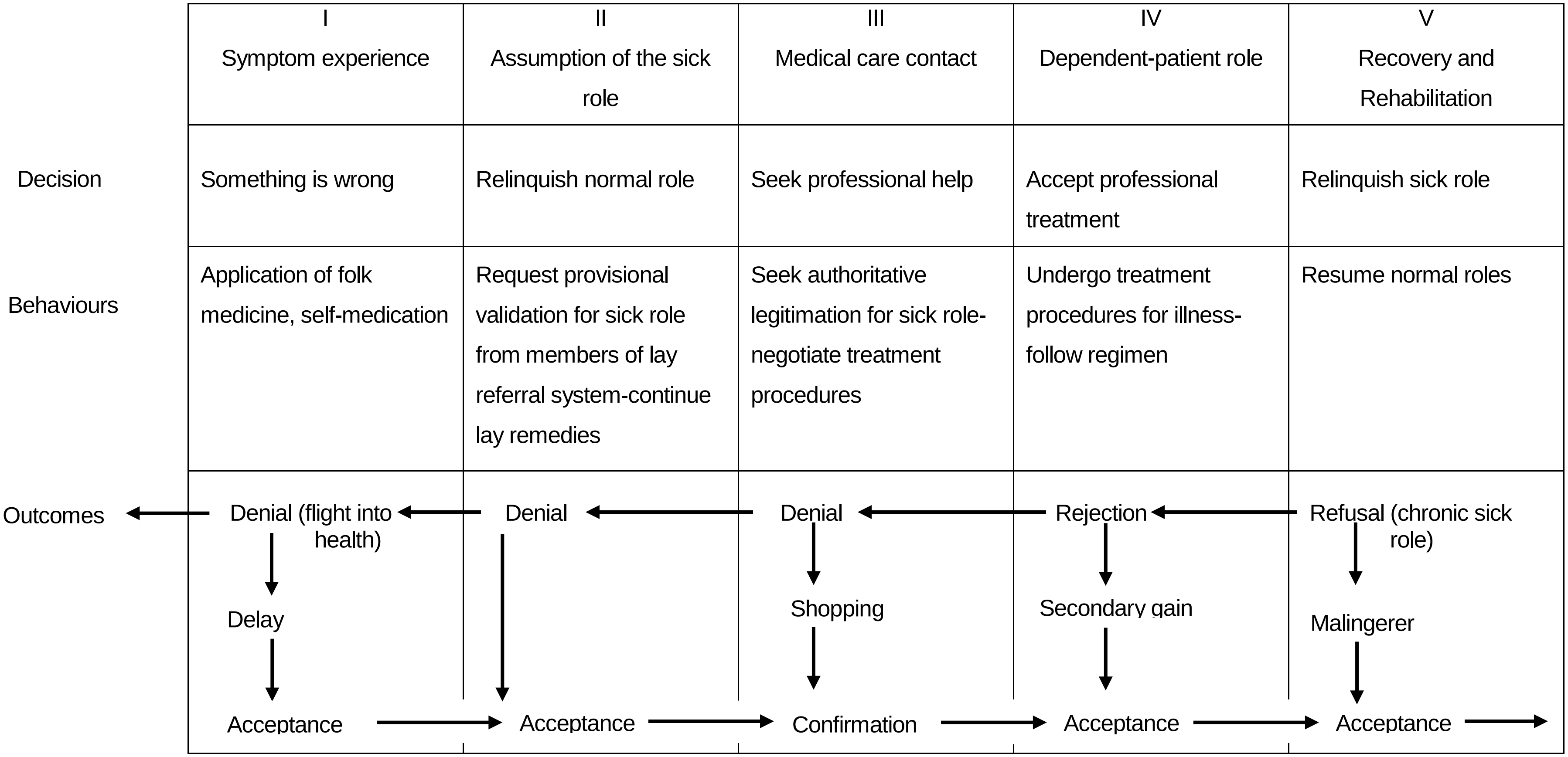
friends about the particular symptom, may also have effects on the ultimate health behaviour of the individual. This reliance on the information and advice of significant others and on self-treatment, delays contact with health providers and may have serious consequences for the individual.

2. *Acceptance of the sick role.* Here, the individual can either seek professional help immediately and enter into the third stage, or, as with the normal pattern, only consult a professional after having discussed the symptoms with significant others in the immediate social environment. The lay person's reaction and acceptance of the individual's condition will provide him or her with what Suchman (1965:115) calls a form of "*provisional validation.*" This temporary permission and acceptance provides the individual an opportunity to exempt himself/herself from normal obligations and activities. Society is willing to legitimise the sickness as long as the individual follows culturally determined conventions of being ill, such as trying to regain health as quickly as possible, or accepting medical help in overcoming the illness (Christopoulos, 2001:93). The ill, after all, are expected to seek and then undergo treatment. It is only after this confirmation is obtained that the individual can legitimately assume the sick role. This would then lead to the third stage, namely medical contact.

Perhaps, it is important to pause briefly and look at the background of the sick role. The concept of the sick role was first introduced by Talcott Parsons in 1948 and elaborated in 1951. Within such a paradigm, Parsons proposed an influential and much quoted set of institutionalised social expectations associated with the sick role to distinguish people who are ill from those who are well. Briefly, according to his theory, the sick person has some social privileges but also some social obligations: exemption from other normal social roles depending on the nature and seriousness of the illness; is not responsible for the illness; should be motivated to get well; and should seek and co-operate with the treatment offered (Parsons, 1951:436-37).

Other commentators on the sick role regarded it as a limited and conditional set of expectations that attach to people socially defined as sick. Expectations are held, depending on, as already stated, the nature and severity of the condition. It should be noted that the expectations are not behaviours, but rather factors that influence behaviour in response to being defined as sick. They are parameters around which one finds considerable variation with social class, ethnicity, and interaction contexts (Christopoulos, 2001:93; Weiss & Lonnquist, 1997:129-130).

Figure 1.1: Analytical framework: Suchman's stages of illness experience



	I Symptom experience	II Assumption of the sick role	III Medical care contact	IV Dependent-patient role	V Recovery and Rehabilitation
Decision	Something is wrong	Relinquish normal role	Seek professional help	Accept professional treatment	Relinquish sick role
Behaviours	Application of folk medicine, self-medication	Request provisional validation for sick role from members of lay referral system-continue lay remedies	Seek authoritative legitimation for sick role-negotiate treatment procedures	Undergo treatment procedures for illness-follow regimen	Resume normal roles
Outcomes	Denial (flight into health) Delay Acceptance	Denial Acceptance	Denial Shopping Confirmation	Rejection Secondary gain Acceptance	Refusal (chronic sick role) Malingerer Acceptance

Sources: Cockerham (2001:134); Suchman (1965); Van Rensburg (1980).

1.8.3 Stage III: Medical care contact

The third stage, medical care contact, involves the decision to seek professional medical care. By deciding to seek professional help, the individual relinquishes the lay referral structure and enters the professional medical care system. The sick individual seeks a medical diagnosis and prescribed course of treatment from a scientific professional practitioner[6] rather than from a lay source. In consulting a practitioner, the individual seeks authoritative sanctioning to become “legitimately” ill. However, the illness experience may be confirmed or denied by the practitioner. In such instances, the individual may react in the following two ways: The individual may accept the diagnosis and continue with his/her normal activities in society or may reject the practitioner’s initial diagnosis or course of treatment, and begins a “lay search” for another practitioner’s diagnosis that might prove more acceptable.

The medical contact stage may be prolonged when the individual reject the practitioner’s initial diagnosis or search for another practitioner’s diagnosis. This activity of patients is called *shopping*. According to Van Rensburg (1980:24), ‘shopping’ is in line with general health care procedures, but deviates when a second practitioner is consulted without the knowledge of the first one. In reality, though, this seems an almost impossible task as patients may encounter various barriers in attempting to follow the correct procedure. If both the patient and practitioner agree that treatment is necessary, the individual proceeds into the dependent-patient stage.

Suchman’s third stage of illness experience was labelled as “medical care contact” and described as the point at which an individual sought professional medical care. However, of late, medical sociologists are much aware of the variety of options available to persons who have entered the sick role (Weiss & Lonnquist, 1997:133). While some individuals may simply carry on with normal activities, others may withdraw from almost all activities and become extremely passive and dependent. Some may concoct home remedies (self-treatment) and take them, seek out faith healers or traditional healers, while others immediately consult a doctor. The underlying reason for the selection of source of care depends on previous experience, the perceived efficacy of the health care provider, and the availability and convenience of services. Contact with the doctor represents, for many sick individuals, a last resort – “having reached the limit of anxiety or tolerance concerning the symptom” (Leigh & Reiser, 1980:12).

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[6] Traditional healers are widely used by many South Africans. Despite the seemingly exotic nature of their practice, the traditional healers' underlying strategies (probing deeply into the psychological, spiritual, and social contexts of illness and using healing ceremonies and natural medicinal preparations) seem to be effective in certain circumstances (Hewson, 1998:1029). According to Tsiane (2003), the traditional healing practice in the country is embedded with issues which are difficult for a person with either the Christian or western approach to comprehend. To date, it is difficult to subject the practice to scientific principles. However, this does not suggest non-existence of the practice. He maintains that it is unfortunate that lack of understanding of the practice causes it to be simply dismissed as superstition. What compounds the problem is that endless negatives are labelled against the practice.

1.8.4 Stage IV: Dependent-patient role

The fourth stage of the patient ‘career’ is the dependent-patient role. The underlying decision-making at this juncture is to transfer control to the physician and to follow prescribed treatment. Not until this stage is reached and the physician has recognised an individual as ill, does the sick individual become a “patient.” The patient legitimately assumes the sick-role, is exempted from normal duties, and is expected to want to get well (Leigh & Reiser, 1980:17). According to Suchman (1965:116), the patient does not automatically accept the doctor’s recommendations. A potential patient usually looks at the dependent-patient role with “ambivalence.” The patient may want to avoid this stage, but might see it as the only possible route of return to normal health. Significant factors during this phase are those which affect the individual’s adjustment to being a patient – the physical, administrative, social, or psychological barriers that interfere with the course of treatment.

While it is expected of the sick person to make every effort to get well, some of them enjoy the benefits of the sick role (for example, increased attention and escape from work responsibilities) and may attempt to malinger[7]. Eventually, however, the acute patient will either get well and move on to stage five or terminate the treatment (and perhaps seek alternative treatment). The sick individual must also get accustomed to several significant changes in lifestyles and interaction, prolonged regimens of medication (as in the case of TB), continuing bureaucratic hassles with the medical care system, and sometimes disabling pain. Above all, Weiss & Lonnquist (1997:143) maintain that sick individuals may experience the following five major concerns at stage four:

1. *Impairment of personal cognitive functioning.* Patients may be concerned that their illness will progress to a point where their cognitive functioning ability may be impaired or that medications will have a “dulling” effect on memory.
2. *Loss of personal independence.* The possible threat to the individual’s independence may let the patient value it even more. Thus, the thought of relying on others (becoming a burden) may be devastating.
3. *Changes in body image*. Illnesses such as TB create dramatic alteration in physical image if at an advanced stage; and a major readjustment may be needed.
4. *Withdrawal from key social roles.* An extra emotional burden is created when remuneration is affected by disruptions in work pattern. The withdrawal from key family responsibilities may also lead to anxiety about creating more work for other family members.
5. *The future.* The chronic patient faces many questions about his/her future and the extent to which there will be further incapacitation or physical or mental limitations.

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[7] Malingering is defined as the “*initiation, production or encouragement of illness for a deliberate end,*” or the “*the planned fraudulent faking of illness”* (Asher, 1995:157).

The individual's behaviour – to continue to conform or not to conform with the sick role – after being identified as a patient, is often a result of complex interpersonal interactions between the patient and his/her immediate social environment. The patient may either receive sympathy and support, or be subjected to social ills such as rejection or isolation. In the case of diseases such as TB, which carry with them an enormous social stigma, people may deny infection or seek care in such a way that the knowledge of their condition is not made public. From a health care perspective, stigma increases the stress associated with diseases and contributes to secondary psychological and social morbidity (Fife & Wright, 2000: 50-51). As a result, it can be argued that the impoverishing effect of and stigma associated with TB, affect the quality of life and physical well-being of people infected with the epidemic. Generally, stigmatised people lose social status, while their life chances and opportunities are lessened.

1.8.5 Stage V: Recovery and rehabilitation

The underlying decision in the final stage of Suchman's schema is to relinquish the sick role and move back to normal role obligations. The course of treatment comes to an end when the patient is declared as being cured from the illness or withdraws from active medical care. In both instances, the individual is expected to resume his/her normal roles. This may not happen in the case of a chronic illness, or when the individual decides to malinger in an illness experience even though "*technically well*" as Cockerham (2001:133) notes.

In the case of acute patients, the process of relinquishing the sick role and moving back to normal obligations may be without any major hassles. But for chronic patients, the extent to which prior role obligations may be resumed ranges from those who forsake the sick role to those who will never be able to leave it. Those who cannot forsake the sick role have to adapt to a new role of "*chronic invalid"* or long-term rehabilitee. The recovery process may be slow and demanding, and may involve recurring episodes of illness.

Suchman further proposes that patients; on returning to their normal role obligations; may be given a period of grace during which inadequate social functioning is acceptable. During rehabilitation the patients may go through a new path of re-socialisation in which new relationships with those around them must be established. This is especially the case where the individual is himself/herself in a rehabilitation centre.

1.9 A review of the patient 'career' in the context of TB

A review of the model of the patient 'career' in the context of TB reveals that many prospective TB patients are often confused about the difference between "symptom" and "disease." The most recognised symptom of TB is coughing. However, a person with a constant cough rarely considers TB to be the likely cause of his/her problem. It is generally the symptom that is considered rather than the disease itself. According to Mata (1985:61), the help-seeking behaviour of patients is based on the following three underlying reasons:

- The disease is only recognised in its advanced stage, when other symptoms that seriously affect the normal life of the patient accompany primary symptoms. People tend to refuse to accept the existence of TB at its early stage, and attempt to remedy the symptoms.
- There seems to be reluctance among people to accept the sputum sample as a method for detecting such an important disease as TB.
- Patients would die rather than be rejected by their families and society. There is constant fear that the long period of treatment would inevitably lead to friends and neighbours discovering that they have the disease and then reject them.

Subsequent to Mata's (1985) arguments, Danusantoso (2002) provides an overview of the patient 'career' in what he calls the "*tragic chain of events*":

> *Whenever TB begins to develop in a poor man, often he will just ignore the mild initial symptoms, attributing them to ill weather. It is not until he feels that this 'discomfort' begins to hamper his efforts to earn a living that he begins to look for relief, by first trying cheap 'traditional' herbal medicines. When these do not help, next on the list come the cheap symptomatic [over-the-counter] OTC Western medicines, one after the other. And when all these turn out to be useless, then he will turn to traditional healers or paramedics. If he still has the available means, he will see a doctor. One can only guess how many most valuable months even years would have been lost and the lung damage caused by the TB bacilli. Above all, is the mounting number of persons this poor man will infect.*

This quotation ignores the role of service providers in the illness career of TB patients. At each stage new problems and difficulties arise, not only as a result of the behaviour and decisions of the individual patient, but also from service providers. According to Dujardin *et al.* (1997:2), examination of TB patients is often the weakest link in the chain of events that leads to the cure of patients. For example, suspect individuals are often not identified, or positive sputum is missed by a laboratory technician and drugs are out of stock.

While it is expected of the person occupying the sick role to co-operate with culturally "valorised" regimens of treatment, and demonstrate a desire to 'get better' in certain cultural ways (Kleinman & Seeman, 2000:230), this is not often the case with TB patients (Liefooghe, 2000:43). In order to recover from TB infection, patients are expected to obtain the correct prescribed treatment and take the full treatment regimen regularly to be finally cured (Dujardin *et al.,* 1997:2; Rieder, 2002:76). However, studies (Johansson *et al.,* 1996; Meulemans *et al.*, 2000; Ngavithayapong *et al.*, 2000) have shown that TB patients do not often comply with treatment. This has often been attributed to service providers who fail to explain the importance of the diagnosis properly (Dujardin *et al.*, 1997:2).

TB treatment has various outcomes: Some patients are cured; some complete the course of treatment and, more fatally, some die. However, there are also TB patients who experience recurring episodes of the illness, despite having been previously declared as cured. A particular concern for such patients may be the chance of contracting MDR TB, which is even more fatal. The importance of Suchman's stages of illness experience may allow both researchers and service providers to identify the problems that may arise at different stages and may be used as a tool for dialogue between all parties involved in TB control.

1.10 Value of the study

Generally, for a number of reasons this study is a contribution to the field of sociology. Firstly, TB is no longer a challenge to the medical profession only, but also to social scientists. Controlling the epidemic requires as much social scientific knowledge and skills as it requires medical knowledge and skills. Secondly, as early as 1992, Rubel & Garro (1992:627) stated that the role of socio-cultural factors in TB control has been inadequately explored. While many studies on TB have been conducted in South Africa over the last decade, few, if any, focus comprehensively on the social dimension of TB control. Furthermore, debates at recent conferences[8] of the International Union Against Tuberculosis and Lung Diseases (IUATLD) illustrate the research community's intention to find a new short-term drug. In this regard, this study is timely since it may be useful to highlight, as asserted by Dubos (in Lock *et al.*, 2001:831), that socio-cultural and socio-economic factors are lethal combinations.

Thirdly, at practice level, this study has much to offer in terms of assisting health care providers and patients in their day-to-day interactions. This is an important aspect when the long treatment period (six months minimally) is taken into consideration. Fourthly, this investigation may assist health care workers in understanding the socio-economic and socio-cultural barriers to TB control. In this way, the rate of TB patients who present late may be decreased. Fifthly, the study also attempts to enhance the health education and health promotion campaigns of the South African National TB Programme. The study also intends to provide policy-makers, health authorities, managers and workers with insight into the life circumstances and experiences (including experience within the health system and care environment) of pulmonary TB patients. It is hoped that a better understanding of TB patients' health-

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[8] 4th World Congress on Tuberculosis. Marriot Wardman Park Hotel, Washington, DC, USA, 3-5 June 2002 and the 14th Conference of the International Union Against Tuberculosis and Lung Disease, African Region, Durban, 11-14 June 2002.

seeking behaviour and treatment adherence. As Mechanic (1968:115) has acknowledged in his earlier observations on illness behaviour, "*the study of the patient's perspective is an indispensable aspect of the analysis of health and disease.*" Such an endeavour may enhance patients' self-esteem and increase clinicians' awareness of patients' expectations and preferences.

At the policy level, this study offers practical suggestions on the management of contacts (contact tracing[9]). Finally, this study is also of national significance since it attempts to propose criteria for behavioural change strategies that may be critical in the control of the epidemic in South Africa. The goal of studies such as these is to help clinicians providing TB patients with the type and amount of information that match their needs. User-friendly information may lead to increased awareness of the disease and, consequently, to better compliance and better health outcomes.

1.11 Structure of the report

This thesis is divided into three broad sections. Section One focuses on the research design. Section Two is based on the literature study. Section Three focuses on the research strategy and methodology, the presentation of the findings and on the conclusions and recommendations.

Against the background, research problem, aims and objectives, and analytical framework outlined in Chapter 1, this thesis comprises the following eight chapters:

- **Chapter 2** devotes attention to three models of health behaviour, namely the Health Belief Model; the general theory of help-seeking behaviour, and the Theory of Reasoned Action. These models play a key role in the data analysis in Chapters 7 and 8.
- **Chapter 3** deals with the issue of adherence. Here, special attention is devoted to conditions and factors (e.g. economic, demographic, psychological and socio-cultural) that affect adherence to treatment regimens.
- **Chapter 4** contains a review of prevention mechanisms and campaigns in South Africa, taking a look at behaviour change interventions. The discussions in this chapter are integrated with the key constructs of the theories discussed in Chapter 2.
- **Chapter 5** provides a detailed overview of the study design, methods and procedures that were adopted for the empirical investigation. Motivations for the survey and focus group as a research strategy and research method are provided. The content of the interview schedule and training of interviewers is discussed.

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[9] **Contact tracing** refers to the identification and finding of people who have been in contact with a smear positive TB patient. Such contacts usually include people living in the same house with the sick patient and are at risk of becoming infected with TB. Concepts related to contact tracing are **passive** case finding and **active** case finding. Passive case finding refers to a situation where health care providers wait for possible TB suspects to present themselves. Conversely, active case finding refers to a situation where health care providers actively go out (by means of personal visits) to find new cases of TB.

- **Chapters 6, 7 and 8** contain the presentation, analysis, systematisation and interpretation of the survey and focus groups data. To a large extent, the data is presented according to the analytical framework discussed in Chapter 1. An attempt has also been made to integrate the conceptual, interpretative and explanatory models in the analysis of the data. Chapter 6 attempts to provide a socio-demographic and socio-economic profile of the respondents. Chapter 7 focuses in more detail on the ‘career’ of the patient, including the experience of the health care environment. Chapter 8 presents findings related to factors that contribute to non-adherence.
- **Chapter 9** provides some conclusions and recommendations on the improvement of TB control at the patient, health care practice and policy levels. Problem areas are identified, and possible explanations provided. The conclusions are then made; following the requirements of the theoretical models.

SECTION TWO

Chapter 2:

Theoretical perspective: Models of health behaviour

"Life requires making decisions. The basis for hundreds of decisions made each day often is little more than one's personal experience, informed by common sense. However, some decisions are so important – the consequence of making the wrong decision so grave – that people have sensibly required more systematic evidence before a decision is made" (Hornberger, 2001:9).

2.1 Introduction

The link between sociological theory and medical sociology is important to the sub-discipline. Sociological theory allows medical sociology to remain unique among the health-related social and behavioural sciences. After World War II, Western governments came to realise the importance of social factors for health. As a result, the focus in medical sociology considerably moved away from dependence upon medicine for defining and guiding research agendas (Cockerham, 2001:3-4). Generally, as indicated in Chapter 1, medical sociology or the sociology of health and illness studies such issues as how social and cultural factors influence health and people's perceptions of health and healing (Cockerham, 2001:115; Fife & Wright, 2000: 50-51; Leigh & Reiser, 1980:5; Zaidi, 2000:65; Wilkinson, 1999:159), and how healing is done in different societies (Cockerham, 2001:116-118). Indeed, social structures and cultural practices have concrete consequences for peoples' lives (Freund & McGuire, 1991:2) and their health behaviour.

Chapter 1 outlined the methodology followed in this study. It also provided a conceptualisation of the terms that appear in this thesis. Together with socio-demographic and socio-economic characteristics that affect individual people's chance of infection with TB, five dimensions of the 'career' of the TB patient were identified: (1) symptom experience, (2) assumption of the sick-role, (3) medical contact, (4) dependent-patient role and (5) recovery and rehabilitation stage. In Chapter 2, a theoretical framework is presented, focusing on the Health Belief Model (HBM), the Help-seeking Behaviour Theory and the Theory of Reasoned Action (TRA).

TB is a public health threat that can be challenged and even wiped out by public health promotion programmes. However, only programmes that are based on a clear understanding of the targeted health behaviours and their environmental context are most likely to succeed. In this regard theories of health behaviour can play a crucial role to help in understanding the nature of targeted health behaviours. Furthermore, they can explain the dynamics of the behaviour, the processes for changing the behaviour, and the effects of external influences (socio-economic status and cultural beliefs, for example) on the behaviour (National Institute of Health, s.a).

An important perspective in studying health-related behaviour is to consider how it changes with the health status of the individual. Generally, there are three stages in the progress of disease: health behaviour which is behaviour aimed at preventing disease (e.g. eating a healthy diet); illness behaviour which is behaviour aimed at seeking a remedy (e.g. going to the doctor); and sick-role behaviour which is an activity aimed at getting well (e.g. taking prescribed medication or resting) (Weiss & Lonnquist, 1997:106,128). The latter two received attention in Chapter 1. Health behaviour, which is the focus of this chapter, was first conceptualised as any activity undertaken by people believing themselves to be healthy, for the purpose of preventing health problems (Sarafino, 1990:179). However, Cockerham (2000:159) argues that health behaviour also involves activities undertaken by people for the purpose of maintaining or enhancing their health, preventing health problems, or achieving a positive body image. This definition goes beyond the one provided by Kasl & Cobb (1966), which focused only on preventing health.

In an attempt to further expound the concept of health behaviour, Alonso (in Weiss & Lonnquist, 1997:108) has identified four separate dimensions. Firstly, *prevention* is aimed at minimising the risk of disease, injury and disability. Secondly, *detection* involves activities to detect disease, injury or disability before symptoms appear and it includes medical examinations. Thirdly, health *promotion* activities consist of efforts to encourage and persuade individuals to engage in health-promoting behaviours and to avoid health-damaging behaviours. Fourthly, *protection* involves health protective activities at the societal rather than the individual level (Weiss & Lonnquist, 1997:108).

Firstly, as stated above, the Health Belief Model is discussed. This model is an important psychosocial approach first proposed by Rosenstock in 1966 and elaborated, amongst others, by Becker & Maiman in 1975 (Siegrist, 1988:711). According to the Resource Centre for Adolescent Pregnancy Prevention (RECAPP, 2002), the model was developed in response to the failure of a free TB health screening programme (*see text box 2.1)*. The HBM is derived from the theories of psychologist Kurt Lewin, who suggested that people exist in a life space composed of regions with both positive and negative valences (values). According to Lewin, an illness would be a negative valence and would have the effect of pushing a person away from that region. Conversely, people are attracted toward regions of positive valences. Within this framework, human behaviour is viewed as being dependent upon two primary variables: the value placed by a person upon a particular outcome and the person's belief that a given action will result in that outcome (Cockerham, 1992:92-93; Sarafino, 1990:189).

The HBM postulates that the perceived seriousness of an experienced symptom, perceived susceptibility to it, perceived benefits of action, and perceived barriers to action will account for health behaviour (Jones, 1991:48; Kaplan *et al.,* 1993:52-53; Rubel & Garro, 1992:627; Sarafino, 1990: 189-190; Twaddle & Hessler, 1987:148). The concept, "cues for action", was later added and refers to the factors that "stimulate behaviour." In 1988, the concept, "self-efficacy", was added to address the challenges of habitual unhealthy behaviours such as smoking and overeating (RECAPP, 2002). However, the focus in this chapter and thesis is only on the first five dimensions of the HBM. Many factors that appear to influence adherence or non-adherence with medical advice fit well into the HBM. Yet, for logical reasons the issue of adherence is addressed in Chapter 3.

Secondly, an overview of two other models used to understand health beliefs and health behaviours as related to TB is provided. These models are David Mechanic's general Theory of Health-seeking Behaviour and the Theory of Reasoned Action (TRA). It should be noted that it is not implied that these models are exhaustive of the health behaviour models. As Siegrist (1988:713) points out, "*there is no single model with sufficiently high predictive power.*" The HBM and the TRA[1] are two commonly applied theories (Jane, 2001:1; Manhart *et al*., 2000:1373) in the prevention of various illnesses. Conversely, the choice of the theory of Health-seeking Behaviour is based on the fact that it overlaps between the HBM and the TRA. Furthermore, the theory of Health-seeking Behaviour can be regarded as "*a social-psychological model that gives a clearer conception of the processes involved when someone seeks help*" (Mechanic, 1978:268).

Generally, these three theories were chosen for this study because of their broad examination of the health history, attitudes, beliefs, and behaviours of individual patients and health promotion. They also have the added advantage of explaining the difficulties encountered in getting patients to recognise health risks and/or long-term adherence (as in the case of TB treatment) with health care recommendations. According to Chew *et al.* (2002:180), these models of health beliefs and health behaviour examine cognitive factors which contribute to adherence with health behaviour recommendations.

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[1] It should be noted that a new model representing the synthesis of the HBM and the TRA has been developed. The new model was developed as the theoretical framework for an investigation of the factors affecting participation by Mexican-migrant farm workers in TB screening. This synthesised model was developed to allow for a more culturally specific approach while providing previously tested concepts useful for the analysis of screening behaviours (Jane, 2001:2).

Help-seeking behaviour is closely related to its forerunner, illness behaviour (Leigh & Reiser (1980:4). Mechanic (1978) proposed ten determinants (discussed in paragraph 2.3) on which the decision to seek medical care is based. The TRA was developed in 1967 and revised by Ajzen & Fishbein during the early 1970s. By 1980 the theory was used to study human behaviour and develop appropriate interventions (Kaplan, *et al.*, 1993:53). In 1988, the Theory of Planned Behaviour (TPB) was added to the existing model of the TRA to address the inadequacies that had been identified (University of South Florida, 1999a).

The underlying argument in this chapter is that health care policy makers, medical practitioners and health care providers, in the context of TB control efforts, often fail to understand why so few people actively and effectively take their advice and recommendations. This failure is further entrenched by not realising that, in Africa, diseases such as TB tend to be interpreted within a framework that is essentially naturalistic and impersonal. Reporting on his study of African health beliefs conducted in Southern Africa, Green (1999:15) provides further clarification on this argument:

> *Those involved in promoting public health in Africa should take the trouble to learn about the existing medical systems before trying to supplant them with what sound to most Africans like Western scientific mumbo-jumbo.*

Perhaps Mark Twain's words (cited in Landry & Solmon, 2002:335): "*habit is habit, and not to be flung out of the window, but coaxed downstairs a step at a time*," provide a clearer explanation of what policy makers, health authorities, managers and workers should understand about the health behaviour of patients. According to Landry & Solmon (2002:335), this reference to "*a step at a time"* approach acknowledges that behavioural change requires time and motivation for the activation of processes of change that enable individuals to move through stages of change.

2.2 The Health Belief Model

The HBM is the oldest and most widely used model. It was originally developed to explain preventive health behaviours, such as checkups and immunisations. This model was also developed in an effort to understand why some people fail to take measures known to prevent disease. The model focuses almost exclusively on cognitive influences on behaviours, and stresses the importance of an individual's subjective interpretation (Cockerham, 1992; Kaplan *et al.,* 1993:52). In many instances, the subjective interpretation of an individual can be more important than objective medical diagnosis.

Generally, beliefs are defined as those things, which people know or think to be true. Correct beliefs are a necessary preliminary to taking effective action, but beliefs do not necessarily predict either attitudes or behaviour. For example, there is a general belief that excessive alcohol consumption and smoking cause TB. Holding this belief is loosely associated with attitudes to drinking alcohol and smoking. However, it is not at all associated with alcohol consumption or being a smoker (Blaxter, 1990:148). Health beliefs and their associated range of "*misconceptions and doubts*" are seen to be "*in conflict with…prescribed* [*health*] *programs*" and "*weaken the patient's trust*" (*American Thoraric Society*, 1996:257).

Text Box 2.1: THE DEVELOPMENT OF THE HEALTH BELIEF MODEL

The factors which led to the development of the HBM are twofold: Firstly, there is the health setting of the 1950s and, secondly, the professional training and background of the originators. The health setting during the early 1950s for the US Public Health Service was primarily oriented toward prevention of disease and not treatment of disease. Medical care, which was largely considered appropriate public health work, was not the focus during that time. Thus, the public health concern for problems connected with patients' symptoms and their adherence with medical regimens was slight. The originators of the HBM were concerned rather with the widespread failure of individuals to engage in preventive health measures.

Godfrey Hochbaum initiated the first research on the HBM in 1952 by an attempt to identify factors underlying the decision to obtain a chest x-ray for the early detection of TB. The TB screening programme provided adults with free TB screening x-rays from mobile units conveniently located in various neighbourhoods. When few adults came out for the free services, programme organisers began investigating why more adults did not come out. Hochbaum, however, began to study what motivated the few who did come out. The results indicated that the respondents' *perceived risk* of disease and *perceived benefits* of action were crucial factors in their motivation.

The Health Belief Model emerged as a promising theoretical framework from which to better understand and predict the complexity of human behaviour in a health promotion context. The earliest application of the model was in the area of primary prevention. Later, the model was applied in both secondary prevention (treatment of a disease at an early stage to prevent the disease from progressing) and tertiary prevention (disease prevention which lessens or eliminates the seriousness of the effects of a disease such as rehabilitation).

Sources: Landry & Solmon, 2002; RECAPP, 2002; University of South Florida, 1999.

As stated earlier, the HBM contains four major types of beliefs that influence the likelihood of taking action that is relevant to a given disease or condition (*see Figure 2.1)*. Firstly, the individual's readiness to take action is determined by the perceived likelihood of *susceptibility* to the particular illness ("I" could get TB). The more vulnerable they perceive themselves to be; the more likely they are to take preventive action. Secondly, the perceived *severity* and consequences (organic and social) of the disease also influence behaviour. Thirdly, the individual's evaluation of the perceived *benefits* of the advocated health behaviour, weighed against perceptions of physical, psychological, financial, and other costs. Fourthly, perceived *barriers* to the behaviour also influence action (Jones, 1991:48; Kaplan *et al.*, 1993:52-53; Rubel & Garro, 1992:627; Sarafino, 1990: 189-190; Twaddle & Hessler, 1987:148). These concepts were proposed as accounting for people's "*readiness to act.*" An added concept, *cues to action*, would activate that readiness and stimulate overt behaviour (Jane, 2001:2). The final concept, *self-efficacy*, which means one's confidence to successfully perform an action (Landry & Solmon, 2002:335) was added to "*help the HBM better fit the challenges of changing habitual unhealthy behaviours"* (National Institutes of Health, s.a.:1) such as smoking, excessive alcohol consumption and eating unhealthy food.

The application of the HBM is relevant to the study of TB, or more specifically, the career of the TB patient. This relevance has been prompted by the fact that TB "*is one of the frequent fatal infectious diseases*" (Enarson *et al*., 2000:46) continuing to kill millions of people worldwide despite the availability of effective anti-TB drugs. More specifically, the source of TB infection is nearly exclusively a person who is sick with the disease (Enarson *et al*., 2000:46). Thus, one is tempted to agree with the comment of Dickson & Soucy (2002:2) on TB control efforts in Canada, when they explain:

> *Deaths from tuberculosis, both globally and within Canada, are on the rise. We have the technology to diagnose, the drugs to treat and the financial capability to combat this deadly disease. All we need is the political will to follow through.*

In the context of South Africa, in fact, globally, one can contend that the above statement has omitted a central feature in TB control, namely the health behaviour of patients. Despite the availability of all the elements in the South African TB Control Programme, the country has not been spared from the devastating effects of TB. Enarson *et al.* (2000:25) argue that the successful treatment of TB patients requires that they understand the nature of the disease and its treatment. It is only when this happens that patients will be more likely to follow the required procedures to achieve a cure. This seems to be a straightforward issue. However, in reality, this is not the case. As Meulemans *et al.* (2002:251) state: "*Not everyone feels strongly about missing an appointment, adjusting medication or avoiding supervision*."

The HBM and other behavioural models acknowledge the modifying role and influence of demographic (age, gender and marital status) economic (employment status, income and education), socio-psychological (personality, social class and peer pressure) and structural variables (knowledge about the disease and prior contact with it) on health behaviour (Cockerham, 1992:93; Jones, 1991:48; Meulemans *et al.*, 2002:73; Sarafino, 1990:190). This is also emphasised by Van Rensburg & Ngwena (2001:380) when they remark:

> *Health and disease are not primarily matters of health care. They are as much the result of prevailing environmental influences, cultural patterns, and behavioural risks. Therefore they do not necessarily respond to biomedical and health care interventions. Also health reforms play*

> *but a small part in the improvement of health. More important for health are the general living and working conditions of that population and the lifestyles of its members.*

There is no doubt that human action requires resources. These may be internal in the form of capacities or may be external in the form of the availability of services, money and other similar resources. Behaviour in response to symptoms depends, to some extent, on resources available. The major index of resources as distributed in societies is socio-economic status measured by income, education, and occupation. Education reflects the level of knowledge about alternative courses of action available, as well as skills in utilising social facilities (Twaddle & Hessler, 1987:149). Indeed, several studies have shown that persons with lower incomes know less about their bodies and are less likely to define their problems in ways that result in consultation of professionals (Twaddle & Hessler, 1987:149-150).

2.2.1 Perceived susceptibility to illness

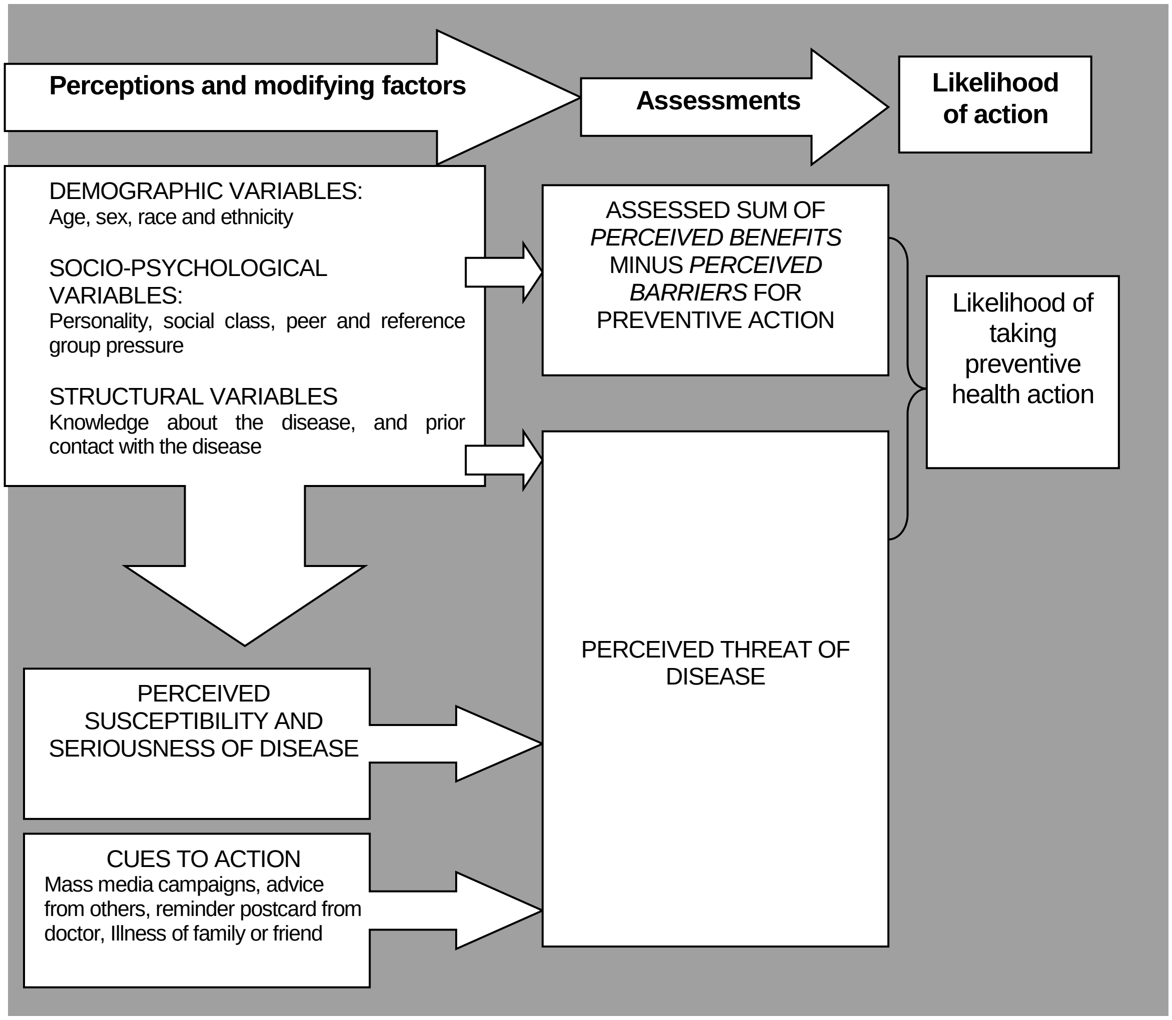
Perceived susceptibility is one of the dimensions of health beliefs (Utah, 1989:277-278) that are argued to be important in explaining health actions. Calnan (1987:141) maintains that this concept is derived from epidemiological models, which identify the range of factors that might influence individuals' vulnerability to disease. The HBM maintains that individuals have differing perceptions regarding their susceptibility to infection (Weiss & Lonnquist, 1997:119), as well as the seriousness of TB. If people are to perform a particular act such as going for TB sputum tests, they have first to believe that they are *susceptible.* They have to believe that the health problem could affect them personally, rather than other people (Hubley, 1993.39), and that a person can have the condition without symptoms (Rutter, 2002).

In a study of self care, which is the most common form of response to perceived symptoms of illness, Haug *et al.* (1991:1011), maintain that perceived susceptibility relates to the respondent's mental and physical health status and daily health practice. They state that:

> *Individuals who perceive their health to be good and who are not plagued by psychological distress would have confidence in their own resilience and be ready to care for their ailments without resorting to professional help. Conversely, individuals with chronic conditions or who experience high numbers of symptoms could view themselves as basically in poor health and thus in need of a doctor's advice for any new ailment.*

In respect of the symptom-experience stage, a common complaint of many health care workers is that people deny having symptoms that indicate a medical problem when, in fact, they are experiencing changes in their physical or psychic status. Though many people do deny that certain signs are symptoms of illness, in many cases denial is, however, not a factor. Many people worry about whether a body change is indicative of a medical symptom if it is painful, incapacitating, or unusual. But different groups in society vary systematically in their perceptions of these changes. An individual's ethnic and cultural background also affects the perception of and response to pain. Another factor that influences whether a body change is considered a medical symptom is how unusual or unexpected it is (Hingson, 1981:67-68). Many symptoms of chronic illness, such as TB, appear slowly and, especially among older people, may be considered an inevitable part of aging rather than a treatable disorder.

Figure 2.1: The Health Belief Model



Adapted from Cockerham (1992:93); Jones (1991:48); Sarafino (1990:190).

Having reviewed a variety of literature on the social, cultural and psychological dimensions of ill-health (Cockerham, 2001; Hingson, 1981; Mata, 1985; Meulemans *et al.*, 2000; Rupel & Garro, 1992), a natural question for one to ask is: Do these dimensions have any influence on health? Helman (1994:104), perhaps, provides the answer in his analysis of diseases. Helman maintained that diseases are seen as "entities" with their own unique personality, and signs and symptoms. The "personality" of each disease is made up of a characteristic cause, clinical picture (signs and symptoms), and results of medical investigations, natural history, prognosis and appropriate treatment. This implies that diseases are regarded as being universal in form, progress and content (for example, the same clinical features of TB can be found in a TB patient in South Africa or in New York). Indeed, TB is commonly known to be caused by a particular bacillus (De Munynck, 2000:14), to reveal itself by certain characteristics symptoms (Department of Health, 2001c:12); to display certain signs on examination; to show up in a particular way on X-rays or sputum tests (Enarson *et al.*, 2000:7-9); and to have a natural history, depending on whether it is treated or not (Helman, 1994:104). However, due to the different social, cultural and psychological factors at play, it is highly unlikely (as suggested by the HBM) that people from different societies will interpret, respond, or comply with treatment recommendation in the same manner.

Considering the HBM in the context of TB, it is evident that societies regard TB as a serious contagious disease (Johansson *et al.*, 1996:180; Liefooghe, 2000:42; Mata, 1985:59; Ngavithayapong *et al.*, 2000:1414). Yet many estimate themselves as having low personal risk. As Caroll (1992:51) points out, individuals are often overly optimistic about their own vulnerability. This obviously creates obstacles to behaviour change. For instance, if an individual believes that the symptoms in question (a persistent cough, lack of appetite and night sweats, for example) are not serious and do not believe that TB (or any other disease) may be the cause, the readiness to seek help will be low.

Studies in Thailand and Pakistan illustrate the perceptions of people regarding their vulnerability to TB infection. A study of AIDS awareness and TB patient delay in Thailand (Ngavithayapong *et al.*, 2001:1417) revealed that both health centre staff and lay people would not think of TB until patients had coughed for months. In similar vein, Khan *et al.* (2000:250) report from a study of 36 TB patients in Pakistan that ten respondents indicated that they "*did not accept the diagnosis of TB when it was first made*."

2.2.2 Perceived severity

The HBM asserts that individuals will take preventive health action only when the individual feels that contracting the disease would have serious consequences (Caroll, 1992:51, Hubley, 1993:39; Weiss & Lonnquist, 1997:117). This assertion is not without contention, as it has been found that some people are not aware of the causes and symptoms of TB (Khan *et al.*, 2000:250). In this regard, past experience with the symptoms may play an important role in effecting health-related action (Siegrist, 1988:711). Nonetheless, the effects a disease will have on an individual's social environment can be considered from the point of view of the difficulties that the disease will create (University of South Florida, 1999a). For instance, in the case of TB, pain and discomfort, loss of employment, financial burdens and difficulties with family (Khan, 2000:251; Liefooghe *et al.*, 1997:812; Singh *et al.*, 2002:696-697; Thomson & Myrdal, 1986:263) may affect health-related action.

The belief system of the individual is an important factor not only in the prevention of disease, but also in the response to symptoms. The likelihood that individuals will take preventive action (perform some health, illness or sick-role behaviour) depends on the outcome of two assessments they make. One of these evaluations pertains to the threat of a health problem, and the other weighs the advantages and disadvantages of taking the action (Chew *et al*., 2002:181).

If the above argument is taken into consideration, one may be tempted to believe that, against the background of the number of TB patients who interrupt their treatment, health education and information dissemination strategies have failed. This also brings us back to the argument of Green's (1999:15) argument, namely that the health beliefs and health practices of indigenous people should be taken into account in the control of diseases such as TB.

2.2.3 Perceived benefits of advocated behaviour

Taking action toward the prevention of disease or toward dealing with an illness is the next logical step after an individual has accepted the susceptibility of a disease and recognised it as being serious. The HBM postulates that even when an individual is ready to act, the decision to act or not, eventually depends on the analysis of the benefits against costs (Caroll, 1992:49; Hubley, 1993:39; RECAPP, 2002). Therefore, the direction of action that a person chooses will be influenced by the beliefs regarding the action.

Benefits that patients may seek from health care providers may not involve the diagnostic or treatment skills of the provider. The most important benefit in seeking care, for most people, is the reassurance that one is not seriously ill. Many people also seek medical care to find social and psychological support. This is usually the case with people who are lonely or anxious. Due to the fact that illness is used as a legitimate excuse for failing to meet goals, aspirations, and responsibilities, other patients may actually desire to be told that they are sick. Being medically diagnosed with illness can prove useful in obtaining financial and other dispensations (Cockerham, 2001:133). In countries such as the United States, there are many benefits for TB patients (see paragraph 2.2.5) which may have an encouraging influence on their health behaviour (Giuffrida & Togerson, 1998:186; Volmink *et al.*, 2000:1348).

2.2.4 Perceived barriers to behaviour

A perceived barrier to the suggested actions is the fourth factor in the HBM that influences disease prevention behaviours (Chew *et al.,* 2002:181). Two meta-analyses (Janz & Becker, 1984; Zimmerman & Vemberg, 1994), point to perceived barriers as the strongest predictor of health behaviour. According to the HBM, despite believing that the benefits to taking action are effective, an individual may still not take action. This may be due to barriers related to the characteristics of a treatment or preventive measure (expensive, inconvenient, or painful). These characteristics "*may lead a person away from taking the desired action"* (University of South Florida, 1999a).

Most of the delay in seeking medical care occurs as people debate whether or not to take symptoms to a provider. People also vary in their beliefs of which symptoms should be brought to medical attention. It is often difficult to distinguish symptoms of very serious medical disorders from symptoms of trivial consequence. For example, vomiting and headache may represent nothing more than vomiting and headache, or they may be symptoms of severe ulcers or abdominal disorders. As a result, potential patients have to make complex judgements about whether or not to seek medical care. These judgements involve comparing the benefits, risks, and costs of seeking medical care with benefits, risks and alternatives of alternative behaviours, such as waiting to see if the symptoms subside, self-treatment with over-the-counter medications or home remedies, or contacting an alternative type of healer (Sumartojo, 1993:1311).

Deficiencies in the health care system that pose barriers to patients' care, and which may provoke friction between patients and providers, include long waiting at clinics, overcrowded facilities, substandard attitudes, and inadequate patient services. Poor recording and scheduling may inconvenience patients (*American Thoraric Society*, 1996:257; Dujardin, 1997:2). Needham *et al.* (2001:258) found that transportation (to health facilities), numerous health encounters prior to diagnosis, and time costs also serve as barriers to seeking appropriate TB treatment.

2.2.5 Cues to action

The HBM recognises that the presence of an internal catalyst (symptoms of illness) or external catalyst (media campaigns) triggers cognitive processes involved in considering the various components of health behaviour (Jane, 2001:2). Such a catalyst has been referred as a "cue to action" (Landry & Solomon, 2002:334) or what Weiss & Lonnqusist (1997:117) refer to as "triggers for action." A cue to action might be media coverage about a disease, advice from others, a health care provider's reminder, or an illness of a family member or friend (Volmink *et al.,* 2000:1348; Weiss & Lonnquist, 1997:117).

Above all, an individual's perception of the levels of susceptibility and seriousness also provide the force to act. Benefits (minus barriers) provide the path of action. However, it may require a cue to action for the desired behaviour to occur (University of South Florida, 1999b). In this regard, the Self-Determination Theory (SDT), conceptualised by Deci & Ryan (1985), provides a framework that furthers the understanding of how individuals can be encouraged to make decisions that will have a positive effect on their health in the long-term. The Self-Determination Theory encompasses contributions of the HBM and the Transtheoretical Model[2] (Stages of Change Model - SCM).

The fundamental goal of any health education process is to motivate patients to adopt behaviour that is beneficial to their health (Dick & Lombard, 1997:1). Regarding 'cues to action', the mass media have succeeded in increasing factual knowledge and public awareness of health issues, although their success in changing established attitudes and behaviour are not clear-cut. Television, in particular, is the most cited source of health information (Chew *et al*., 2002:183). Other cues to action (radio, newspapers) also have important roles to play in providing information regarding diseases such as TB.

In a review of studies conducted in the United States on financial incentives and adherence, it was found that ten out of eleven studies showed that some form of financial incentive promoted adherence better than any alternative (Giuffrida & Togerson, 1998:186; Volmink *et al.*, 2000:1348). These researchers further argued that financial incentives were likely to be cost-effective if treatment benefits accrued also to society. The treatment or prevention of TB provides an ideal example in this regard. If TB patients do not comply with treatment, the cost of treatment may become more expensive for the individual patient. However, there is a great possibility of the development of drug-resistant strains and the infection of other people in later stages of the disease cycle (Giuffrida & Togerson, 1998:189).

In addition to incentives of free food, clothes and transportation tokens, TB control programmes in the United States went a step further in enticing patients to comply with treatment. While one programme paid out approximately $US100 per month per patient, others provided certificates on completion of treatment, assisted in obtaining housing, financial assistance, and treatment for substance abuse (Volmink *et al.,* 2000:1348).

Despite the merits of using financial incentives as cues to action, Makherjee (2002) states that incentives, especially in monetary terms, are something that should be avoided. He argues that incentives are not sustainable, and that there is a greater need for a network of motivated people working purely on the understanding of the disease. Mukherjee (2002), nonetheless, acknowledges that giving patients food may encourage them to comply, but he warns that food can in itself be a

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[2] The Transtheoretical Model, often referred to as the Stages of Change Model (SCM), was developed to address behaviour change. The SCM has been an effective tool in the development of interventions that are people-specific (Chew *et al*. 2002:335).

difficult entity to manage in a programme. A review of health promotion and/or health intervention strategies concerning TB is provided in Chapter 4.

2.2.6 Limitations of the Health Belief Model

Critics (Becker, 1990; Champion, 1984; Lauver, 1992; Rupel & Garro, 1992) of the HBM have pointed out a variety of limitations. Champion (1984:75-78) and Lauver (1992:283-285), for example, have indicated that there has been a lack of uniformity in testing the model, especially in the way the variables are operationalised. In addition, Jane (2001:3) argues that the model does not apply numeric coefficients to the concepts of susceptibility, severity, benefits and barriers. nor does it delineate the specific nature of the relationships among the variables. Another key limitation is that the HBM is structured to focus on preventive health action relative to a particular disease or illness. To use the model, Weiss & Lonnquist (1996:118) indicate that perceptions of a particular disease, and perceptions of the efficacy of taking action to prevent the disease, must be assessed. The HBM has also been criticised for being less applicable to understanding preventive health actions in general, or in predicting the likelihood of engaging in general health-promoting behaviour unrelated to fear of a particular disease.

A “serious” methodological limitation of research using this model is that it is basically retrospective in nature (Siegrist, 1988:711) and that it lacks consistency in the use and testing of the model. Not all variables, for example cues to action, have been included in all studies utilising the HBM. The nature and importance of cues are more difficult to evaluate in retrospective studies, because subjects are questioned about behaviours performed in the past (Jane, 2001:3). Other factors related to the individual, such as demographic variables, personality factors, social support, or previous health experience, may play a role in influencing behaviour (Fife & Wright, 2000: 50-51; Rupel & Garro, 1992:627; Weiss & Lonnquist, 1996:118), but they are not an explicit part of this model (Jane, 2001:3). Furthermore, researchers such as Rupel & Garro (1992:628-629) have criticised the HBM for not accounting for normative or cultural factors that may be important in explaining health-seeking behaviour.

In spite of all the criticisms, the HBM has been used successfully for over 30 years to understand health behaviours in a variety of circumstances (University of South Florida, 1999a). As Kirscht (1988:38), in his analysis of the HBM states, it is “*complex and variable in its history, yet surprisingly robust and useful*.”

2.3 Help-seeking behaviour

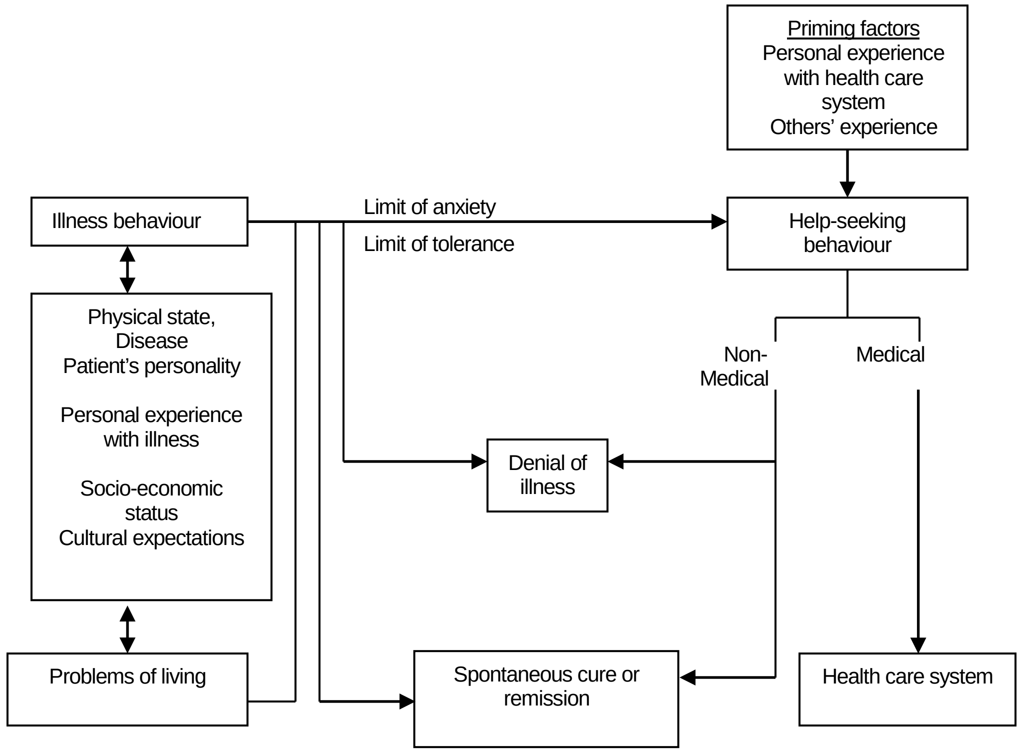
Help-seeking behaviour occurs when a person decides to do something about a symptom. This behaviour may be subcategorised into medical (seeing a doctor or visiting a clinic) and non-medical (talking with a family member or friend). Leigh & Reiser (1980:4) argue that the latter often leads to medical contacts "*through advice and referrals."* The control and management of illness often depends on the willingness of people to seek medical care when it is needed. Many health care providers complain, however, that medical care is often sought "inappropriately". Many people fail to seek medical care, or do so only after having waited for such a long period that treatment is rendered more difficult or ineffective. Failure to seek medical care, and delay in seeking medical care, are not confined to less serious diseases or disorders, but also to more serious diseases (Hingson, 1981:66-67).

While recognition of a symptom is a necessary condition to motivate help-seeking behaviour, it is not in itself sufficient for a definition of illness. In reviewing factors affecting help-seeking behaviour, Mechanic (1978:286) argues that, "*the meanings persons give to symptoms are the product in some measure of their life situation*." Similarly, Cockerham (2001:131) points out that some illnesses may have obvious symptoms, while others may not. Yet, there are still cases of persons who, despite recognising the symptoms, delay seeking health care. Mechanic proposed the following ten determinants on which the decision to seek medical care is based:

1. Visibility and recognition of symptoms;
2. The extent to which symptoms are perceived as dangerous (as in the case of the HBM);
3. The extent to which symptoms disrupt family, work, and other social activities;
4. The frequency and persistence of symptoms;
5. Amount of tolerance for the symptoms;
6. Available information, knowledge, and cultural assumptions;
7. Basic needs that lead to denial;
8. Other needs competing with illness responses;
9. Competing interpretations that can be given to symptoms once they are recognised; and
10. Availability of treatment resources, physical proximity, and psychological and financial costs to take action.

A central theme of Mechanic's general Theory of Help-seeking Behaviour is that illness is a culturally and socially learned response. Individuals, Cockerham (2001:132) notes, respond to symptoms according to their definition of the situation. Others, such as family members, friends and colleagues, may influence the definition of the situation. But more important, is the role played by learning, socialisation, and past experience as mediated by a person's social and cultural background (Cockerham, 2001:132). While a household contact is widely recognised as a risk factor for infection with TB, this has also not acted as a spur for such contact to seek appropriate help. Perhaps, advice on behavioural change could be more effective when based on a clearer understanding of cultural norms informing health beliefs, attitudes and practices.

Figure 2.2: Help-seeking behaviour



Source: Leigh & Reiser (1980:10)

It is clear from Mechanic's model that seeking medical care is not just a single act of contacting a health care worker or health care institution. Instead, it is a process of events, decisions, and behaviour that can occur in different persons or even in the same person over varying durations of time. Hingson (1981:67) distinguishes between three separate stages of care seeking: (1) *symptom perception* – the time between the emergence of some change in physical or psychological state and the individual's recognition of that change as a medical symptom (2) *decision-making* - the time the individual takes after noticing a symptom to decide whether or not medical care is needed, and (3) *actual care seeking* – the time that elapses between the individual decision to seek care and the actual contact with a health care provider. These care-seeking stages usually occur sequentially, but behaviour during the process is not uniform. Numerous factors such as the actual travel to a hospital both promote and impede health-care seeking during each stage (Hingson, 1981:67).

Other researchers have concentrated on examining the structure of medical health-seeking behaviour. McWhinney (cited in Leigh & Reiser, 1980:9), proposes a taxonomy of medical health-seeking behaviour which he calls "*patient behaviour*," using the doctor-patient contact (called health care provider-patient contact in this thesis) as the reference point. As postulated by the Health Belief Model, patient behaviour is often the result of complex interpersonal interactions between the patient and his immediate environment (Figure 2.2). This classificatory scheme, Leigh & Reiser (1980:9) further suggest, is useful in assessing clinical situations. An assessment of clinical situations, though not a central focal point in this thesis, is a crucial factor regarding the adherence or non-adherence of TB patients.

Closely related to the concept of help-seeking behaviour is that of treatment delay. Treatment delay is defined as "*the period between the onset of symptoms and initiation of treatment"*. The delay consists of two major elements: patient delay and health care providers' delay. Patient delay refers to the period between the onset of symptoms and the seeking of health care. Health care providers' delay indicates the period between the first visit of a patient and a diagnosis being made (Liefooghe, 2000:43). Delay in the diagnosis and treatment of TB is a major problem to the patient as it increases the risks that the disease will have advanced beyond a stage at which it could have been cured. It is also a major social problem that results in unnecessary human suffering, premature mortality and increased medical costs (Meulemans *et al.*, 2000; Ngavithayapong *et al.*, 2000:1415-1417).

Studies by Liefooghe *et al.* of TB counsellors (1999) and adherence (1997) report that of the sample of 1 657 newly diagnosed TB patients, only 20% started treatment within one month of the start of the symptoms. The studies further reveal that 45% had symptoms for more than 6 months and 11% for more than a year (Liefooghe, 2000:44-45). Another study assessing health-seeking behaviour among patients in rural South Africa confirms that there is considerable delay between the onset of illness and the initiation of treatment among pulmonary TB patients. A substantial proportion of this delay was attributed to patient delay (Pronyk *et al.*, 2001:624).

Aggleton (1990:15) highlights the role of lay beliefs about health in contributing to patient delay. Lay beliefs are the more popular perceptions of health – the views of those who are not professionally involved in health issues (Haugh *et al.*, 1991:1011; Jones, 1991:47). It is also important to understand that lay beliefs about health may vary according to the status and social background of the individual (Blaxter, 1990:13-16). Some societies explain the onset of illness by recourse to *supernatural forces*

(Helman, 1994:123-127). Illness may sometimes be perceived as *retribution* for wrong-doing. A distinction is also made between lay beliefs, which suggest that illness is caused by forces outside the individual (exogenous beliefs) (Lupton, 1995:90), and lay beliefs, which imply that illness has its origins within the person concerned (endogenous beliefs). Exogenous beliefs refer to the role of external forces such as germs, contagion, and bad air, debilitating work and stress as factors responsible for illness. Endogenous beliefs refer to inborn dispositions, heredity, and genetic defects as the causes of ill-health (Green, 1999:39-49).

Similarly, self-care (or self-treatment) which is "*the first step in the health-seeking process* (Liefooghe *et al.*, 1997:817; Twaddle & Hessler, 1987:145), is also seen to be one of the reasons for delay of appropriate treatment (Rubel & Garro, 1992:626). The vast majority of actions people take to prevent illness or to treat everyday health problems are done without expert help. The individual or the family respond directly, without lay or professional help, to ordinary health problems. Some responses to illness are not merely physical. If a person's belief system attributes illness to non-physical causes, such as emotions and spiritual factors, it is logical for that person to choose non-physical approaches (prayer, for example) to treat the illnesses. Non-physical responses to illness are often mixed in interesting combinations. For instance, the treatment of a person who has flu and takes a bowl of oxtail soup lies in the"*soothing emotional connotation of the food*" (Freund & McGuire, 1991:182).

The existing socio-cultural barriers and taboos associated with TB have been found to be major hindrances to patients seeking help for the disease (Mata, 1985:58). Individuals initially ignore their symptoms, but seek treatment only when their symptoms increase in severity (Khan *et al.*, 2000:250). In addition, Ngamvithayapong *et al.* (2000:1417) suggest that TB affects women more negatively than men. Women are particularly reluctant to seek treatment because of cultural inhibition (Needham *et al.*, 2001:258). This often leads to social ostracism, and compromises economic and social security (Meulemans *et al.*, 2000:73).

A study conducted in the Honduras regarding the compliance of TB patients, proved that the problem is not simply administrative or logistical. It was realised that a very important factor in addressing the TB problem was the public's negative image of the disease, and the consequent rejection of anything related to it, including medical diagnosis and treatment. The seriousness of this problem is illustrated by the fact that many of the patients who were tested for TB gave false addresses, and could not be traced if results were positive. Some patients who had been diagnosed with TB left their villages with their families, without any trace. Many patients stopped their treatment, and obstinately refused to visit health personnel. Others even went to the extent of seriously threatening nurses against attempting future house calls (Mata, 1985:58).

More serious, though understandably so, is the link between TB and AIDS[3] (Department of Health, 2001c:38; Enarson *et al.*, 2000:4 Frieden, 1994:1721). Respondents in the study conducted by Green (1991:193) associated TB with AIDS. This association, according to the respondents, adds stigma and social rejection to the already unfortunate situation. Comments from some suggest that TB could actually be a symptom of AIDS: "*This illness makes a person slim because he/she loses appetite. One becomes a laughing stock as people start associating the patient with … AIDS*." It is perceptions such as these that pose serious challenges to TB behavioural change interventions.

2.4 Theory of reasoned action

The theory of reasoned action (TRA) is one of the most widely studied social cognition theories (Bennett & Bozionelos, 2000:308) and key psychological constructs (Hargger *et al.*, 2002:3). The TRA was developed by social psychologists Ajzen & Fishbein in 1980 (Ajzen & Fishbein, 1980). The goal of the TRA is to be able to predict and understand directly observable behaviours that are primarily under control of the individual (Jane, 2001:4), and explain how individuals make decisions about performing certain behaviours (Werner & Mendelsson, 2001:785). Perhaps, this will help us understand why the TB patient often decides not to follow treatment recommendations.

The theory was also designed to explain all human behaviour that is under voluntary control (Kaplan, *et al.*, 1993:533). The TRA attempts to explain the relationship between beliefs, attitudes, intentions and behaviour. It is based on the assumption that people are usually rational and makes predictable use of information available to them in a systematic manner in order to weigh the cost and benefits of a particular action (Gillmore *et al*., 2002:886; Ajzen & Fishbein, 1980: 40-54).

The TRA hypothesises that an individual's stated intention to engage in a given behaviour is the most immediate predictor of that behaviour (Ajzen & Fishbein, 1980:54-55). Intention is proposed to represent a person's immediate behavioural orientation toward engaging in a given target behaviour, such as seeking help for a persistent cough. The TRA posits that "*the intention construct completely mediates the effects of two social cognitive variables on behaviour: attitude and subjective norm* (Hargger *et al.*, 2002:4; Jane, 2001:5). Attitude reflects a personal disposition toward engaging in the behaviour and, in Ajzen & Fishbein's (1980:54) words, is the individual's general feeling of

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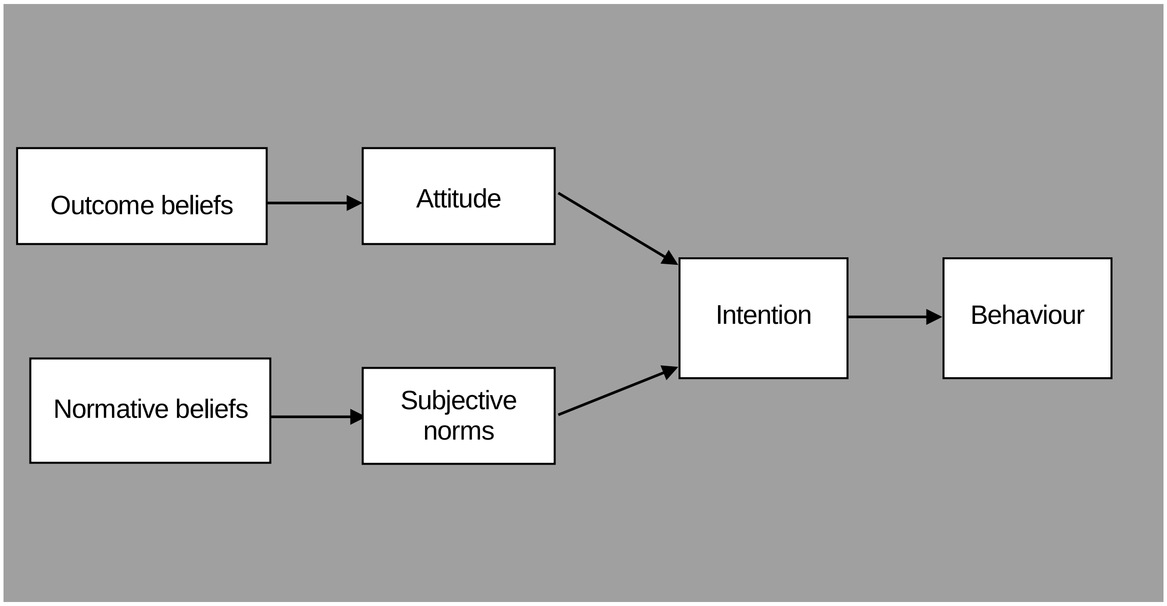
[3] Since the first reported case of HIV in South Africa, this epidemic has become the greatest risk factor for TB disease. HIV prevalence among adult TB patients is usually 2-3 times higher than among the general population. It is usually the young productive age groups of the population who are at risk (Department of Health, 2001c:38). TB is an opportunistic disease manifesting itself when resistance levels (regulated by the body's immune system) are low. As HIV/AIDS destroys the immune defence mechanisms of the body, HIV-positive persons become increasingly susceptible to TB (Enarson, *et al*. 2000:4). HIV-infected people have a 30 times higher probability (10% risk each year) of infection with TB than non-HIV-infected individuals (10% life-time risk) (Frieden, 1994:1721). More sadly, interactions between the immune system and TB bacteria give HIV a boost and accelerate the progression rate of AIDS. Indeed, *the towering twin threats to global tuberculosis control are the continued explosion of HIV-related tuberculosis and the increasing prevalence of drug resistance. The former threatens to overwhelm treatment capacity in many parts of the world, while the latter raises the spectre of incurable disease that can be transmitted in the community*" (*International Journal of Tuberculosis and Lung Disease,* 1999:1).

"*favourableness or unfavourableness.*" Attitudes can consist of either good or bad feelings about the specific behaviour in question. More specifically, these attitudes refer to people's feelings about themselves performing the behaviour. A key distinction is that an individual's attitude about someone else performing the behaviour may be very different from the feelings about himself/herself performing the behaviour (Kaplan *et al.*, 1993:533-535).

Figure 2.3: Theory of Reasoned Action



Source: Gillmore *et al.* (2002:886); Kaplan *et al.* (1993:54)

Conversely, a subjective norm is a normatively-based cognition (Werner & Mendelsson, 2001:785). Consistent with the theoretical bases of the HBM, the TRA postulates that both attitudes and norms are formed on the basis of sets of beliefs (Gillmore *et al.*, 2002:886). Each normative belief has two components: referent norm (what does my best friend think I should do?) and motivation to comply with this referent (how much do I want to do what my best friend wants me to do?), and represent the people's evaluation of whether significant others (e.g. close friends) want their to engage in the target behaviour and their motivation to comply with these others (Hargger *et al.*, 2002:4; Jane 2001:5). Thus, if people's first thoughts when seeing someone drinking alcohol are "*drinking alcohol makes you look cool*", then this is the belief that will determine their attitude about drinking alcohol (Kaplan *et al.,* 1993:54). The constructs (behaviour, intention, attitude, perceived general norm, outcome of beliefs and normative beliefs) have been organised as a testable causal model (Figure 2.3).

It has been suggested that an extension of the TRA not only perceives social pressure (subjective norms), but also personal feelings of moral obligation to perform or refuse to perform the behaviour. Conner & Armitage (1998:1441) defines perceived moral obligation or moral norms as "*an individual's* *perception of the correctness or incorrectness of performing a behaviour*." Given the social, economic and psychological difficulties that TB patients experience, one can but wonder whether thinking about the 'correctness' or 'incorrectness' of their behaviour is an issue for TB patients.

Finally, in contrast with the HBM and the general Theory of Help-seeking Behaviour, the TRA proposes that external factors such as demographic characteristics have little effect on intention. However, as Werner & Mendelsson (2001:785) suggest, external factors may be related to intention only if they influence the direct antecedents of intentions. Another criticism is that the theory is based on the assumption that human beings are rational and make systematic decisions on available information. Unconscious motives are not considered (University of South Florida, 1999a). The TRA focuses on explaining intentions rather than behaviour and, thus, has not in general been as successful as the HBM in predicting preventive health actions (Weiss & Lonnquist, 1996:119).

2.5 Summary and concluding remarks

Both the HBM and the TRA have been used as descriptive and explanatory models in studies of health behaviour. These two models, it seems, have common characteristics. Both focus on individual decision-making and the process of determining whether or not to participate in specific preventive health actions. These models are also based on a "*value-expectancy theory of behaviour,"* which assumes that behaviour depends on the value an individual places on a particular outcome, as well as the individual's calculations of the probability that a given action will result in that outcome. Both models posit that beliefs about behavioural consequences predict behaviour. Variables in the HBM, it was noted, contribute to explaining and predicting the health-related behaviours of populations. The TRA includes a normative component and incorporates a methodology aimed at eliciting the basic concerns and beliefs of a group under investigation.

The components of the HBM in relation to TB can be illustrated as follows: Before one will accept a diagnosis of TB, and before one will follow a prescribed treatment regimen, one must believe that one can have the condition without symptoms *(is susceptible),* that TB can lead to death (the *severity* is great), and that taking prescribed medication (for six months at least) will reduce the risk of re-infection *(benefits)* despite negative side effects or excessive difficulty *(barriers).* Print materials or DOT-supporter visits might promote consistent adherence *(cues to action).*

The general Theory of Help-seeking Behaviour emphasises the importance of social, cultural and economic factors in seeking help. Help-seeking behaviour occurs when an individual does something to obtain help for his/her symptoms. This may be medical (seeing a health care provider) or non-medical (talking with a friend) (Collins, 1992:26; Fife & Wright, 2000: 50-51; Rupel & Garro, 1992:627; Mata, 1985:61; Meulemans *et al.*, 2000:65; WHO, 2002a:4; Wilkinson, 1999:159). However, as has been noted, the presence of a symptom, on its own, is not a sufficient condition for seeking medical help. The interpretation of the action by the patient in the light of an individual's own unique social background and experience, together with the prevailing community expectations, determines the action. It has been noted that diseases such as TB are not simply clinical or epidemiological problems, but encompass larger psychosocial ramifications – personal, economic, political and social factors deeply embedded in the web of causation

Finally, while the need to persuade people to consult health care providers when they experience symptoms remains paramount, it is difficult to end this chapter without reconsidering those who have already contracted TB. The factors that influence the rate and progression of the disease are quite clear. The effect of dysfunctional health behaviour of TB patients on control efforts is also known of late. Thus, evidence suggests that countries will have to mobilise substantial social psychological resources to counter the dysfunctional behaviour of TB patients.

Chapter 3:
Treatment adherence: what is needed?

> "Patients cannot be assumed to be a group of willing supplants, rushing with open arms to seek aid" (Zola, 1981:241) and "no matter how severe the consequence, there is no assurance that all patients will take their medications as prescribed" (Cramer, 1998:7).

3.1 Introduction

As observed in Chapter 2, behaviour in medical and para-medical settings is complex. Many factors determine how a person behaves in the context of health care providers and health care institutions. Various studies (Dick, 1994; Kane, 2002; Love, 2002; Meulemans, 2000) have reported on the failure of people to comply with treatment regimens. This problem is a longstanding one. Indeed, non-adherence has become a general feature of human behaviour. Other studies (Demissie *et al.*, 2003; Kyngäs, 2000) have also shown that non-adherence is not only a feature of relatively minor complaints. Chronic conditions, such as TB, are also frequently associated with low levels of adherence (Olle-Goig, 2000; Ngamvithayapong, 2000).

Regardless of the type of disease, the general public approaches health care providers and facilities with an expectation of high quality health care services. Treatment outcomes – sometimes called patient outcomes – are considered the "*end result*" of health care provision (Wojner, 2001:6), and include changes in patients' current and future health status. Against the background of increasing numbers of TB cases and poor completion rates, the NTCP in South Africa adopted WHO's worldwide strategy of Directly Observed Treatment, Short Course (DOTS) in 1996 (Bamford, 1999:316). The aim of the DOTS strategy is twofold. Firstly, it aims to treat successfully 85% of detected smear positive TB cases. Secondly, it aims to detect 70% of such cases (WHO Report, 2001:3). This is to be achieved through five elements of the WHO's DOTS strategy, namely political commitment, laboratory improvement, direct observation of treatment, improved drug supply, and improved reporting systems. DOTS programmes often also encompass other interventions, including incentives and enablers offered to patients, the tracing of defaulters, and the use of legal sanctions to enforce adherence, patient-centred approaches to health care delivery, staff motivation and supervision, and the raising of additional external funding (Buchanan, 1997; Jaramillo, 1999; Volmink *et al.,* 2000). Therefore, DOTS is about more than just the direct supervision of tablet taking, which for the first was introduced by tuberculosis specialists more than 40 years ago (Volmink *et al* ., 2000).

Chemotherapy of TB is the "*most powerful weapon"* in tuberculosis control*,* as it reduces morbidity and fatality (Rieder, 2002:9). South Africa is not exempt from the potential ravages of TB with its debilitating effects on communities and development. The treatment protocol implemented by the NTCP in South Africa advocates short course therapy given 5 days a week. The treatment regimens consist of an intensive and continuation phase, totaling 6 months in new patients and 8 months in re-treatment patients (Department of Health, 1998:46-48). Effective treatment keeps the patients from dying of TB and stops the transmission of infection to other members of society (Rieder, 2002:10-11). TB treatment services are offered free of charge at the primary level in all public sector facilities, yet poor completion rates continue to rise. It has been found that 17% of TB patients in South Africa did not complete their treatment course (defaulted) in 1999 (Department of Health, 2001a).

Many factors, including misconceptions and misguided expectations regarding TB and a lack of understanding of the course of illness, may lead to non-adherence (Gardner, 2001:1). On the surface, it appears that treatment outcomes for TB patients are an indication of the quality of care they receive. However, various authors (Mata, 1985:58; Khan *et al.*, 2000:248; Meulemans *et al*., 2000: 73; Needham *et al*., 2001:258) acknowledge that the complex interactions of a wide range of personal, socio-economic and infrastructural factors determine patient behaviour. In fact, TB may not be cured and may recur in patients who do not take their medications for the full treatment period. These patients may also become resistant to the drugs and, in this manner, become a threat to other persons (Giuffrida & Togerson, 1998:189). Drug-resistant tuberculosis is difficult and expensive to treat. Thus, the most important step to prevent drug-resistant disease is to ensure that patients take all their medication as prescribed. This threat of TB has provided a major momentum into the study of factors that determine patients' health behaviour. For perhaps the first time, the world is faced with a health threat against which the effective barrier is not only medical, but also behavioural (Cockerham 2001:131). Furthermore, increased interruptions lead to more serious illness among TB patients and increased infectivity within communities where patients find themselves (Needham *et al*., 2001:256). Clearly, improvement is needed, especially within resource-poor settings such as the Free State province.

The main purpose of Chapter 3 is to attempt to identify and discuss the factors contributing to non-adherence by focusing on selected studies. Before this, a review of the global situation regarding DOTS is presented. Finally, the chapter ends by devoting attention to what is needed to counter the challenge of non-adherence (an aspect addressed in more detail in Chapter 4).

3.2 The shift from the concept of ‘compliance’ to ‘adherence’

There is growing concern that TB control does a dis-service to TB patients (Narayan & Narayan (1999:508; Pungrassami *et al.*, 2002:271). Despite the money spent, despite the expertise and dedication of many of the health care professionals involved, there are some fundamental difficulties in the concept of compliance, which have profound effects on the individuals involved. Many people have benefited from contemporary TB control initiatives and, even more important a greater number of people could benefit if more attention is paid to adherence. Perhaps, it is a good idea to try and understand what is meant by the concept of ‘compliance’ before defining ‘adherence’, and discuss how the latter has arised.

The various synonyms for the concept of compliance make a universal definition almost impossible. Recent literature is raging with discussion over the appropriateness of using the term ‘compliance’ (Stein, 2000). Some authors prefer to define ‘non-compliance’, as “*any departure from intended treatment*” (Pocock, 1989:179). Sociological critiques have asserted that the concepts of compliance and ‘adherence’ do not do justice to the complexity and sophistication of lay theorising about illness (Bissell *et al.*, 2003). It has been suggested that health professionals should seek to develop `concordance' with their clients (Working Party, 1997:8). ‘Concordance’ is defined in the following terms:

> *Concordance is based on the notion that the work of the prescriber and patient in the consultation is a negotiation between equals and the aim is therefore a therapeutic alliance between them. This alliance, may, in the end, include an agreement to differ. Its strength lies in a new assumption of respect for the patient's agenda and the creation of openness in the relationship, so that both doctor and patient together can proceed on the basis of reality and not of misunderstanding, distrust and concealment* (Working Party, 1997:8).

There seems little doubt that concordance is pro-user engagement, building partnerships and privileging the patient's voice in the consultation room. Indeed, the ideal situation in a health care provider-patient relationship is one in which both parties arrive at a negotiated agreement about the course of action to be taken. However, one can argue that this ideal has yet to be realised. Literature on illness behaviour indicates that patients conceive of illness very differently than doctors (Albrecht *et al.*, 2000; Bird *et al.,* 2000; Christopoulos, 2001; Mechanic, 1995). In this regard, Good & Good (2000:246) note that studies of clinical narratives begin with the basic notion that doctors, in conversation with patients, “*emplot disease and its treatment,”* and establish therapeutic plots for patients. These authors further maintain that patients are critical readers and interpreters of treatment plots, “*directing – often in collaboration with their clinicians – how the shifts in therapeutic course will* *affect their lives* (Good & Good, 2000:246). Patients certainly have the potential to use their practical experience and their "*insider*" knowledge in building medical facts (Arskey, 1994:462).

In a recent study, Stevenson (2003) used data from consultations and interviews with patients and general practitioners (GPs) in focus group discussions with 20 GPs, enabling them to ground their views of the practical application of shared decision-making in their own and other participants' real-life practice. The following ideas were discussed: what constitutes shared decision-making in practice, negotiation about treatment, perceptions of patients' viewpoints and perceived barriers to shared decision-making. It was found that agreement with shared decision-making in theory might not translate into practice. Stevenson also found that insufficiency of time was perceived to affect the provision of information (an essential part of shared decision-making), and to lead doctors to assume that they had the patient's agreement. As one of the participant GPs illustrates, existing assumptions may affect the interaction:

> *... When you know patients very well you sometimes do kind of have a preconceived idea of what's going on, and very often don't allow them to sort of put their point of view"* (Stevenson, 2003:292).

Brown (1995:40) further asserts that "*there may be significant bargaining"* between patients and health care providers over the provision of a diagnosis, but such processes may render the nature of medical knowledge problematic for both providers and recipients of health services (Chapple *et al*., 2002:1216). For the GPs, the view that physicians have no legitimate role to play in the discussion or recommendation of treatments may be difficult for many physicians to accept, since it runs counter to decades of professional medical training and practice in which clinical experience expertise and knowledge, have been assumed to be the quintessential skills that physicians have to offer (Charles *et al*, 1999:656).

In an attempt to arrive at a definition that was clinically significant, Burman *et al.* (1997:1169) based their definition on the results of a survey on non-compliance with DOTS. They defined non-compliance as meeting one or more of the following criteria:

1. More than 2 consecutive weeks of therapy were missed; or
2. treatment was prolonged for 30 days longer than planned owing to missed doses; or
3. incarceration by the TB control programme for presenting an immediate threat to public health.

Text Box 3.1: Who are the primary actors in medical decision-making: patients or health professionals?

According to Vermeire *et al. (*2001:336), it is "*patients who should be the primary actors in medical decision making, and health professionals should adopt a supportive role. In essence then, compliance is an elusive, flexible goal. Patients, especially those with chronic illness, make decisions about treatments that fit into their own beliefs and personal circumstances. Health professionals need to shift the emphasis away from attempting to encourage patients into taking the medication they prescribe, towards, learning how they can contribute to the decisions that patients currently make about their medications*."

Yet evidence shows that it often leads to catastrophic consequences in cases where patients took decisions about their treatment. For example, extracts from Meulemans's book (2000:54-56) - *Tuberculosis in Pakistan: the forgotten plague* - indicates how a young Pakistani has struggled with TB for 15 years. All this because of the wrong decisions he took. Abdul started to have fever, coupled with coughs and pains in the chest in 1984. One of his friends advised him that this could perhaps be TB. He ignored this advice (**bad decision 1**). His highly superstitious parents took him to a *"Peer"* (a holy person who treats with prayers) who thought that his illness had been caused by their own relatives. His health continued to deteriorate and after three months of receiving treatment from the "*Peer"*, he went to Bethania Hospital on the advice of a neighbour. After all the tests, the doctor informed Abdul that he had TB and should be hospitalised. Abdul refused to be hospitalised straight away but promised to return after seeking his family's permission. Upon his return, he asked for medication and received a dose for a week. He totally ignored the doctor's advice about the TB treatment (**bad decision 2**). After the death of his father, Abdul's health declined further. His mother and brother took him to a TB hospital for check-up. Abdul was admitted to this hospital but since he was not happy with the doctors and nurses there, he asked to be taken back to Bethania Hospital (**bad decision 3**). He was admitted to a male ward but "*only followed the treatment for one month and then left the ward"* (**bad decision 4**). Whilst an out-patient, Abdul failed to complete the twelve-month course, stopping the treatment after feeling better (**bad decision 5**). In 1987, Abdul's health started to decline again. He returned to Bethania Hospital once again for the treatment. He once again did not take his treatment regularly (**bad decision 6**). In 1988, Abdul's 16-year-old sister also contracted TB, followed by their brother. Both were cured after having taken the required treatment at Bethania Hospital. Abdul's health deteriorated to such an extent that he almost died. He was once again taken to Bethania Hospital and discharged after two months. Again Abdul interrupted treatment (**bad decision 7**). In Abdul's own words, he has *"been fighting this disease now fifteen years*" (Liefooghe, 2000:54-56).

The above case study illustrates the long-term effects of the decisions taken by patients. Premature halting of treatment may lead to the development of drug resistance, with the danger that, for the patient in question, the disease indeed becomes incurable as in the case of Abdul. In addition, one can only guess what will happen to many of the family members, neighbours and friends exposed to infectious patients in cramped, confining environments and resource-poor settings that are widespread in South Africa.

According to Demyttenaere (2003:70) non-compliance, on the one hand, can be manifested in several ways: (1) failure to attend an initial appointment; (2) failure to have the prescription filled; (3) having the prescription filled, but failing to take the medication; (4) not following the frequency or dose instructions of the prescription, errors of purpose, or use of inadvertent combinations. Compliance, on the other hand, is usually classed as 'good' (75–100% of medication intake), `fair' (25–75% of intake) or `poor' (0–25% of intake). Generally, however, compliance has been defined as "*the extent to which a patient's behaviour coincides with medical advice"* (Giuffrida & Togerson, 1998:186) or "*the extent to which patients carry out a recommended treatment regimen*" (Hill, 2002:15). Most of the literature suggests that these definitions of compliance imply that the client is passive, lacking autonomy, and that the health care professional is coercive, brainwashing, paternalistic, and controls society (Ogden, 1999:217; Sumartojo, 1993:1311; Stein, 2000). The alternate terms of 'adherence' and 'non-adherence', which have a less negative connotation, are used interchangeably. Other terms for compliance that have gained less popularity include 'consensual regimen', 'mutual contracting', 'intelligent non-compliance' (Stein, 2000), and 'concordance' (Meulemans, 2000:75).

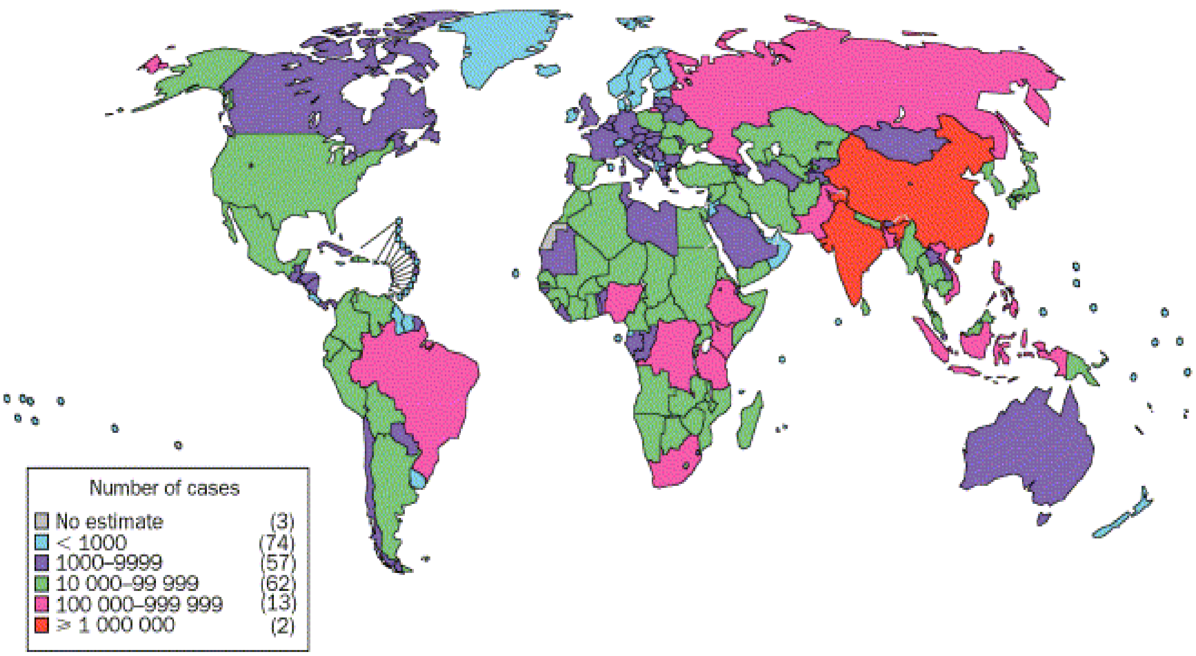
It is impossible to discuss the concept of compliance without, at least, some reference to Zola (1981). In an article titled *Structural constraints in the doctor-patient relationship: the case of non-compliance*, Zola (1981:241) suggests that, from a medical perspective, compliance means "*how to get patients to follow a regimen which is in their best interest."* He further states that health researchers and providers are distorting the understanding of compliance in two ways. He notes: "*We do not sufficiently appreciate what following a medical regimen means to an individual, nor do we fully acknowledge the role that health personnel have in contributing to the very non-compliance we seek to reverse."*

In the recent literature the term 'adherence' has come to be preferred to the term 'compliance', a term first used in the 1960s and which has formed the basis of a professional discourse on the topic since the 1970s (Lerner, 1997), given that the latter has the "*unfortunate connotation that the patient is docile and subservient to the provider*" (Sumartojo, 1993:1311). According to Farmer (1997:349), the term 'compliance' also "*exaggerates patient agency, for it suggests that all patients possess the ability to comply – or to refuse to comply – with anti-tuberculosis therapies*". In this thesis, therefore, the preferred terms are 'adherence' and 'non-adherence' instead of 'compliance' and 'non-compliance', to describe patient behaviour. For the purpose of this thesis, adherence refers to the continuous, uninterrupted taking of prescribed medication.

3.3 The global DOTS situation by 2002

TB emerged some 15 000 to 35 000 years ago (Navin *et al*., 2002:1). Yet, only more than a decade ago, less than 20 countries were implementing a sound TB control strategy. The situation in developing countries, especially sub-Saharan Africa, was deteriorating rapidly. Then, it was estimated that 7-8 million new cases and 2-3 million deaths were occurring annually in the world (Raviglione, 2003:4). As a result of this disturbing global situation, various cues to action (i.e. TB control efforts and intervention strategies) were established over the years. Today, sub-Saharan Africa still has the highest incidence rate (290 per 100 000 population). However, the most populous countries of Asia have the largest numbers of cases: India, China, Indonesia, Bangladesh, and Pakistan together account for more than half the global burden. Eighty percent of new cases occur in 22 high-burden countries (Figure 3.1) (Frieden *et al*., 2003:890). By 2020, nearly 1 billion people will be newly infected, and despite the existence of effective treatments, 200 million will get sick, and 35 million will die from TB (*Centre for Disease Control (CDC)*, 2003).

Figure 3.1: Estimated number of new tuberculosis cases by country, 2001



Source: Frieden (2003:890)

Controlling TB is cost-effective in the long run. The World Bank has ranked the DOTS strategy as one of the "*most cost-effective of all health interventions*." (CDC, 2003). Currently, DOTS has been adopted by nearly 150 countries worldwide (Narayan *et al*., 2003:136) and more than 10 million patients globally have now been treated under DOTS (Frieden & Driver, 2003:82). Most countries implementing the DOTS strategy have shown that they can achieve high cure rates (global average 80% for the 1999 cohort), but the prospects for detecting 70% of sputum smear-positive cases are less certain (Dye *et al*., 2003:36). However, to achieve this, all the elements of the framework of TB control as represented by the DOTS strategy, should function optimally. An essential component of the DOTS strategy, identified by WHO (1999), is to have a reliable supply of quality drugs. These anti-TB drugs can be given as single-drug formulations or as fixed-dose combination formulations (FDCs). Interestingly, the WHO and the IUATLD advocate the replacement of single-drug preparations by FDC tablets as the primary treatment for TB.

In order to intensify control efforts and curb the slow pace of the implementation of DOTS, WHO's Global TB Programme convened an ad hoc committee in March 1998. Most of the recommendations of the Committee were implemented by 2002. According to Raviglione (2003:7-8), the following five major constraints were identified, with solutions within brackets:

- Insufficient political will and commitment (a "global charter" among all key partners to co-ordinate efforts)
- Lack of financing or ineffective use of financial resources (ideas on how financing for TB control are to be maximised)
- Lack of trained human resources (support from the WHO and the IUATLD and incentives to attract and retain staff)
- Lack of good management at programme level (proper balance between the integration and specificity, and between centralised and decentralised functions)
- Quality and supply of anti-TB drugs (creation of a global drug facility to procure and distribute quality drugs).

By 2000, 148 out of 210 countries had adopted the DOTS strategy (Raviglione, 2003:10), but only 27% of all estimated sputum smear-positive patients were notified under DOTS in that year (Dye *et al*., 2003:35). The DOTS coverage ranged from 7% in Brazil to 100% in countries such as Kenya, Tanzania and Uganda. It is also evident that the majority of the 22 high-burden countries had not achieved full service coverage (Raviglione, 2003:10). The implication is that, unless the DOTS strategy can reach beyond traditional public health reporting systems, case detection will not rise much above 40% in these high-burden countries (Dye *et al*., 2003:35). The number of countries implementing the DOTS strategy increased by seven during 2001, bringing the total to 155 (out of 210). By the end of 2001, 61% of the world's population lived in parts of countries providing DOTS (WHO, 2003a).

The latest WHO Report (2003) indicates that the global incidence rate of TB is growing at approximately 0.4% a year, but much faster in sub-Saharan Africa and in countries of the former Soviet Union. TB rates in Russia are increasing at an alarming rate, as are rates of drug resistance. This increased rate is attributed to the economic decline and the general failure of TB control and other health services since 1991. Other factors contributing to the increase include the inability to support the needed infrastructure for TB diagnosis and treatment financially, the unavailability of quality drugs, high levels of TB transmission in prison settings, and a reluctance to adopt the DOTS strategy as recommended by the WHO (CDC, 2003). Chaulet (1987:22) also confirms that, in developing countries such as Russia, adherence to anti-TB chemotherapy poses specific problems because of the epidemiological and socio-economic context in which it occurs.

Table 3.1: The 22 highest-burden countries responsible for 80% of the global TB incidence: cumulative incidence, percentage of population covered by DOTS in 2000, and case detection rate under DOTS in 2000

	22 High-burden countries	Cumulative incidence	Population covered in 2000 (%)	Case detection rate under DOTS in 2000 (%)
1	India	21	30	11
2	China	37	68	33
3	Indonesia	44	98	19
4	Nigeria	48	47	12
5	Bangladesh	51	92	24
6	Ethiopia	54	85	29
7	Philippines	57	89.6	45
8	Pakistan	60	9	3.0
9	South Africa	63	77	67
10	Russian Federation	65	12	2.7
11	DR Congo	67	70	51
12	Kenya	68	100	43
13	Vietnam	70	99.8	80
14	Tanzania	72	100	45
15	Brazil	73	7	0.8
16	Thailand	74	70	46
17	Uganda	75	100	50
18	Myanmar	76	77	48
19	Mozambique	77	100	40
20	Cambodia	77	99	44
21	Zimbabwe	78	100	52
22	Afghanistan	79	15	9.2
	Total	**79**	**55**	**26**

Source: Raviglione (2003:10)

Over 10 million TB patients have now been successfully treated under DOTS. China and India are some of the countries that obtained much success in terms of DOTS expansion and coverage. Attempts to promote DOTS expansion in China started with coverage of less than 5% of the population in 1991. By 1994, DOTS had been extended to 90% of the population (Zhao *et al.,* 2003:16). In the areas where DOTS has since then been implemented, approximately 30 000 deaths have been averted each year (WHO, 2002b). India, on the other hand, not only has a long and distinguished tradition of research in the field of TB (Narayan *et al*., 2003:135), but has also been determining progress in global TB control. India has the second largest and the fastest-growing DOTS programme in the world (Narayan *et al*., 2003:137), placing 60 000 patients on treatment every month (*Ministry of Health and Family Welfare*, 2003). The rapid expansion of DOTS coverage in India has saved nearly 200 000 lives and more than $400 million in indirect costs (WHO, 2002b). The successes achieved with DOTS by countries such as Peru (which achieved an average annual reduction in pulmonary TB incidence of at least 6%) and the United States, indicate that the approach can be effective in a wide variety of social, political and economic contexts (Frieden & Driver, 2003:82).

3.4 South African National Tuberculosis Control Programme (NTCP)

Effective drugs can only reach patients through a programme which needs to standardise diagnosis and treatment according to international recommendations, and provide the necessary health service and technical infrastructure (Edginton, 2000). Significant progress has been made in the implementation of a NTCP. The revised programme incorporates the DOTS strategy, formulated by the WHO in 1991 and adopted by South African revised NTCP in June 1996 (Bamford, 1999:316). The aim of the DOTS strategy is twofold. Firstly, it aims to treat successfully 85% of detected smear positive TB cases. Secondly, it is aims to detect 70% of such cases (WHO, 2001:3).

South Africa is one of 22 countries around the world designated by the WHO as international "TB Hot Spots" due to the very high levels of TB infection. The number of infections is rising rapidly as a result of the HIV/AIDS epidemic (Wilkinson, 1999: 155). The long-term trends of TB (expressed by the annual incidence rates from 1990 to 2001) are striking. They start with an incidence rate of 145/100 000 in 1990 (Van Rensburg *et al.*, 1992:181), then displays a continued and relatively sharp rise, reaching peak in 1998 with an incidence rate of 338/100 000 and an extreme high of 362/100 00 in 2001 (Department of Health, 2002a:1).

Treatment outcomes in new smear positive pulmonary TB patients in South Africa reveal that the national cure rate has slowly improved from 56.6% in 1997 to 62.9% in 2000. However, the cure rate in the Free State shows a rapid increase from 49% in 1997 to 66% in 2000. Despite slow decreases from 18.6% in 1997 to 15.8% in 2000, interruption rates remain high in the country as a whole. This perhaps explains the steady increase in the percentage of pulmonary TB patients (from 6.3% in 1997 to 8.3% in

2000) who died while on treatment. The Free State had the third highest percentage of deaths (10.2%) after Gauteng Province and Mpumalanga, in 2000 (Department of Health, 2002a:1-3). Studies of treatment outcomes by the WHO (2001) demonstrate completion rates of 81% and cure rates of 73%. The proportion of 8.3% of TB patients, who died while on treatment in South Africa in 2000, compares far more favourably with the 15.9% reported in Bolivia (Olle-Goig, 2000:151), but far less favourably with the 3.6% reported in Southern Mexico (Garcia-Garcia *et al.*, 2002).

Table 3.2: The role of certain factors and events in tuberculosis control in South Africa since 1970

Year	Event
1970	Compulsory BCG vaccination of all newborn infants
1994	South Africa enlisted expert help for the first time. Dr Karel Styblo, ex-director of scientific activities of the International Union Against Tuberculosis and Lung Diseases was invited to perform a rapid appraisal of the TB situation
1995	Introduction of the Tuberculosis Register
1996	Establishment of initial NTCP adoption of the DOTS strategy
	National review of TB
1997	Establishment of Demonstration Training Districts
1999	Introduction of combined TB drugs
2000	Establishment of TB/HIV pilot districts and implementation of treatment policies for MDR TB
	Signing of the Amsterdam Declaration for accelerated action against TB
2002	Launch of Medium Term Development Plan (MTDP)
	Multi-million Rand agreement between the Tuberculosis Research Lead Programme (TBLRP) of the Medical Research Council (MRC) of South Africa and the Centers for Disease Control and Prevention (CDC) of the USA
2003	Launch of the National Advocacy and Social Mobilisation Plan

Sources: (Department of Health, Health Systems Research Co-ordination and Epidemiology Directorate; *Epidemiological Comments*, 1990-2001; Department of Health, 2003a: 6-7; Kironde, 2000).

Table 3.2 illustrates the role of certain factors and events in tuberculosis control in South Africa since 1970. An important milestone in TB control efforts was the introduction of compulsory BCG vaccination of all new-born infants in 1970. Twenty six years later, the first NTCP was established, followed by the launch of the National Advocacy and Social Mobilisation Plan in 2003.

With funding from the United States Agency for International Development (USAID), Clapper & Maine supports the NTCP and several local organisations such as the TB Alliance DOTS Support Organisation (TADSA), the Medical Research Council (MRC), and Operation Hunger, to strengthen TB control and prevention efforts. This includes developing more effective monitoring and reporting systems, training providers, strengthening DOTS programmes, and analysing the epidemiology of multi-drug resistant TB (Clapper & Maine, 2001).

During apartheid, poorly funded and inadequate health services were directly responsible for under-treatment of patients. A national TB control programme existed from 1979 within the previous government health structures. However, "*the complexity of attempting to co-ordinate vertically controlled TB services for 18 fragmented health authorities of the various 'affairs' for different races, and for 'homelands' and 'independent' states rendered it unworkable*." Furthermore, the control programme policies, expert advice and resources of organisations like the WHO and the International Union against Tuberculosis and Lung Disease (IUALTD) were not available in this country until the new dispensation. Although health education was emphasised, the quantity and quality of information and health messages on TB were limited. In any case, they could only work if patients had the resources to carry out the expected behavioural changes (Fourie, 2002).

Since the advent of the new dispensation, TB control made major strides. TB coordinators were appointed in all provinces (WHO, 2002b:109) and the introduction of the Tuberculosis Register in 1995 enabled control efforts to challenge poor performance (Fourie, 2002). The process of establishing Demonstration Training Districts (DTDs) was to assist health workers with the implementation of the DOTS strategy. The increasing number of health districts adopting the elements of this strategy therefore measures the expansion of the DOTS strategy. In 1997, only 17 TB DTDs (out of a total of 174 districts) had been established. By March 2001, the number of DTDs had increased to 148 (which is 84% of the districts) (Kironde, 2000:345, SATCI, 2000:8). At the end of 2001, DOTS coverage was extended to 77% of the country (WHO, 2002b:109). Yet, in spite of worldwide implementation, the efficacy of DOTS remains questionable (Pungrassami *et al.*, 2002:271). Thus, it is not unusual to find authors such as Narayan & Narayan (1999:508) calling for a paradigm shift from DOTS to Community Orientated Tuberculosis Services (COTS).

A strategic plan for TB control, the Medium Term Development Plan (MTDP), has been developed and launched by the Minister of Health (WHO, 2002b:109). The objectives of the MTDP are taken from the objectives of the NTCP and adapted to the time frame of 2005. The MTDP provides a template for mobilisation of human and financial resources needed to expand tuberculosis control as part of the national health system in order to achieve the targets the country committed itself to towards its own community and to the international community (Parliamentary Monitoring Group, 2002). The plan also sets out a specific deadline to compel all key players to recognise that a sustained and focused commitment is required (Department of Health, 2003a:4).

3.5 Factors contributing to non-adherence: evidence from selected studies

This section reviews selected studies on the factors contributing to non-adherence. A number of studies (Demyttenaere, 2003; Gad *et al.*, 1997; Sumartojo, 1993; Vermeire *et al.,* 2001) have attempted to address this. According to Christensen & Johnson (2002:94), the core of an interactive theoretical framework is that factors that influence adherence will be better understood by considering the interactive effects of patients' characteristics, the type of adherence intervention, and the characteristics of the illness and medical treatment context. In a review of TB literature on the scope of non-adherence, Sumartojo (1993:1312) concluded:

> *Knowledge about factors associated with poor adherence may also suggest how interventions can be planned to improve adherence. Studies of adherence predictors are important for at least one additional reason. Good research on predictors will challenge or support the conventional wisdom about the causes of nonadherence.*

In a study of adherence to anti-TB drug regimens in Egypt (Gad *et al.*, 1997:244), more than one-third (34.9%) of the patients were not adhering to the anti-TB drug regimen. Factors found to be increasing drug adherence included: disease symptoms, knowledge about the disease, family history of TB and hospitalisation. A fundamental suggestion coming from this study is that more information about the disease and the importance of adherence should be provided to TB patients at the time of diagnosis and initiation of therapy.

Comprehensive reviews of the adherence literature have generally concluded that there is little or no predictable or consistent association between patients' characteristics and adherence (Bisell *et al.*, 2003; Christensen & Johnson, 2002; Hill, 1995; Stein, 2000; Sumartojo, 1993; Vermeire *et al.,* 2001). Socio-demographic, economic, and disease related factors are inconsistently associated with non-adherence and thus of little use in predicting adherence behaviour (Gad *et al.*, 1997:245; Hill, 1995:15; Sumartojo, 199:1312). In trying to illustrate this point, Sumartojo (1993:1312) indicates that the use of demographic factors poses two important problems. Firstly, demographic factors are not inherently causal and may represent other factors of the patient (for example, lack of financial resources and lack of access to good medical information), which may be the real cause of non-adherence. Secondly, there is the fact that intervention by TB programmes will not be able to modify demographic characteristics. Studies examining gender, education, income, medication side effects, illness severity, polarity, episode frequency, and family TB history have also failed to establish such associations (Gad *et al.,* 1997; Sumartojo, 1993).

The study by Gad *et al.* (1997) reveals that adherence to anti-TB therapy was significantly higher among those who had good knowledge about TB. The study also found that when patients know about the natural history of TB, its complications and the importance of complying with drug therapy, their adherence to the prescribed regimen is improved (Stewart, 1984:174). Another study in India (Barnhoornn & Andriaanse, 1992) found that there was a ascorrespondence between the adherence behaviour of patients and their knowledge of specific aspects of the disease. Although it is generally assumed that elderly patients are more likely to be more non-compliant than younger patients, because of the high number of medications prescribed and the complexity of dosing regimens, this relationship has not been fully established (Cramer, 1998:9). It has also been demonstrated in patients with epilepsy that adherence behaviour does not correlate with intelligence, memory, personality disorder, age, or education (Demyttenaere, 2003:71).

Barnhoorn & Adriaanse (1992) studied factors responsible for non-adherence among TB patients in India. The data from this study reveal that social support from the family, neighbours and/or health care providers is an important predictor of compliant behaviour. As Barnhoorn & Adriaanse (1992:302) state, patients who know that the attitude of their families regarding the regular intake of medicine is positive, are more likely to be compliant. Vermeire *et al.* (2001:335) also confirm that social factors, such as positive attitude by others in the community, improve adherence.

It is interesting to note that adherence to anti-TB drugs, a major determinant of treatment outcome, is also of special concern in HIV-positive patients. Rocha *et al*. (2003) found that HIV-positive patients, treated as outpatients, have high rates of non-adherence. Results from 18 descriptive studies in published articles and 57 in conference proceedings further indicate that more complex regimens were related to decreased adherence, but were often successfully mitigated by regimen aids. Social and psychological factors reflecting emotional adjustment to HIV/AIDS, provider support, and access to institutional resources was associated with better adherence. Personal attributes showed a mixed relationship; gender was not consistently related to adherence, but younger age, minority status, and a history of substance abuse were often related to non-adherence (Forgarty *et al.,* 2002:96).

Many factors that have been shown to affect adherence can be supported or hindered by provider–patient communication, including the provider–patient relationship, patients' beliefs, social and cultural norms, family and social support, mood, and behavioural management. The interaction perspective in personality and social psychology attempts to identify personality traits that predict behaviour. This perspective maintains that it is the "*interactive effect of personal factors and contextual factors that most strongly influence"* behaviour. This approach serves as an alternative to the common practice of treating all patients in the same manner, irrespective of the differences among them (Christensen & Johnson, 2002:95).

A highly innovative structural model of stigmatisation and adherence for TB (*see Figure 3.1*) proposes that compliance has to be viewed not only from a social stratification perspective but also from a stigmatisation[1] perspective (Meulemans *et al.*, 2000:85). Social stratification as a determinant of non-compliance is a traditional sociological interest. Conversely, stigma is a notion that has also been widely studied in sociology in relation to social deviance (Furuya, 2002:281). A basic thesis of the sociological literature on stigma is that individuals who (for some reason) have failed to conform to social norms could be persistently denied full acceptance by the society. Individuals, who once deviated from social norms, could thus be forced (or induced) to remain deviant, since the stigma attached to their past might prohibit or discourage them from now conforming to the norms (Goffman, 1963; Furuya, 2002; Jimenez, 2003; Meulemans *et al.*, 2000). However, Johnson (1995:283) states that people are given a negative social label that identifies them as deviant not because of their behaviour, but because of their personal or social characteristics (having TB, for example) that lead to their exclusion by others.

The model[2] below outlines four variables that play a significant role in whether a patient will or will not be adherent. Firstly, the model hypothesises that older patients are more stigmatised than younger ones. Secondly, the model also hypothesises that women are more stigmatised than men. Thirdly, it is proposed that the lower the support from the family, the higher the degree of stigmatisation. Fourthly, the model assumes that the less there is as to the curability of TB, the greater the stigmatisation (Meulemans, 2000:86). In Pakistan, TB is directly associated with a subculture of poverty. Patients from the lower strata of society have the least interest in complying with a medical regime. "*Therapietrouw*" (loyalty to or adherence with therapy) was found to be negatively affected by stigmatisation. Stigmatisation implies that people are rejected, turned down and excluded in their environments on the basis of particular characteristics, in this case TB.

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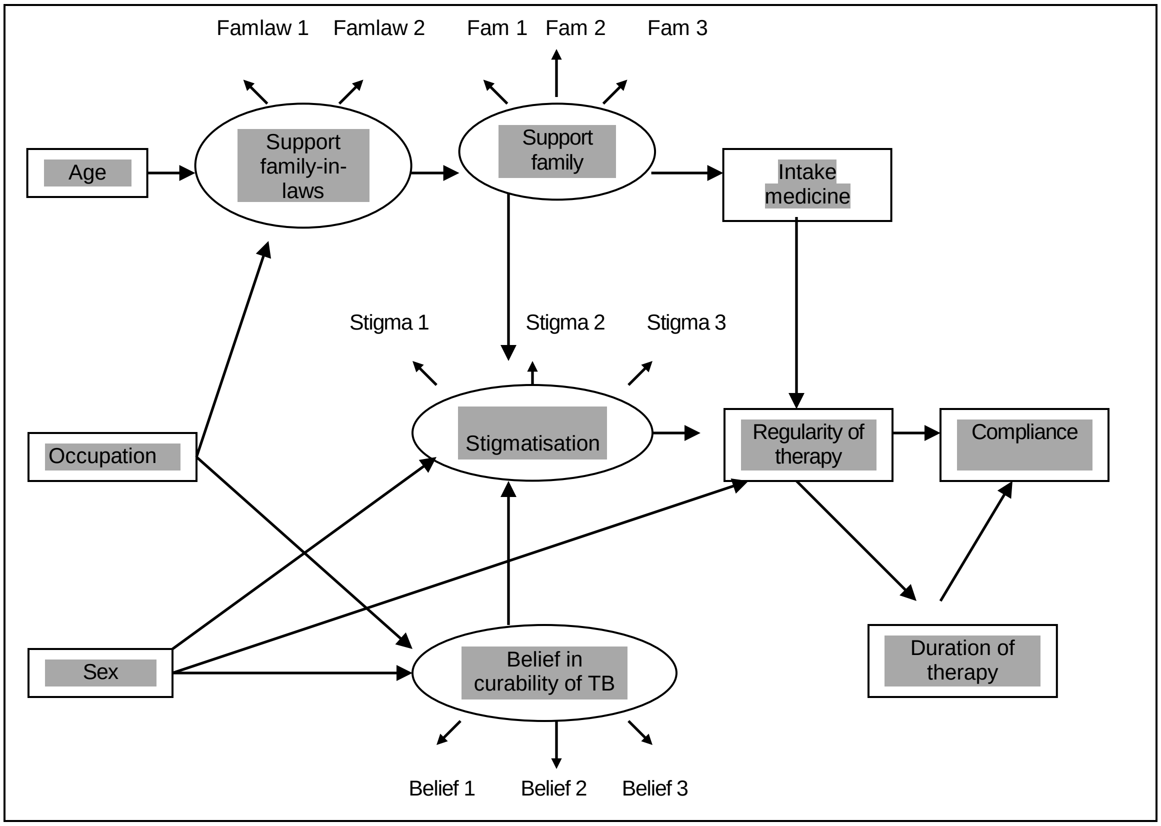
[1] Stigmatisation was recognised initially by Goffman (1963) as a concept worthy of scientific inquiry. This concept has recently earned the attention of health researchers, as they grow increasingly aware of the global impact that disease-associated stigmas have upon individuals and societies. Policy makers have also organised new efforts to explore the relationship between stigma and public health (Jimenez, 2003:81).

[2] Consult Meulemans *et al.* (2000) for a more detailed discussion on the model.

Figure 3.1: Model of stigmatisation and compliance for TB



(**Source**: Meulemans *et al*., 2000:79)

One study (Jimenez, 2003), which examined the consequences of stigmatisation that occurred during a TB outbreak among Puerto Rican clients enrolled in a Chicago drug treatment centre, focused on three factors that contributed to stigmatisation (and ultimately non-adherence). The first factor concerns the fear elicited by TB that aroused reactions among community members. These fears were derived from earlier experiences. The second factor involves traditional health measures enacted in response to the TB outbreak. The creation of an on-site TB clinic to provide routine medical follow-up to infected addicts facilitated their labelling and also their risk for stigmatisation. A third factor concerns the re-articulation of group boundaries occurring among inhabitants, whereby TB-impacted persons were marginalised in order to reaffirm the status of others whose identity had been compromised by the epidemic. These factors, one may contend, hold major implications for public health policy in general.

Other factors contributing to non-adherence include psychiatric disorders and treatment factors. The treatment factors include the diagnosis, duration of the treatment, number of medications prescribed, frequency of dosing, absence of symptoms, effect of drugs and the fear of adverse effects (Vermeire *et al*., 2001:335). In this regard, theories such as the Health Belief Model (HBM) and the Theory of Reasoned Action (TRA) (*see Chapter 2*) presume that adherence to medical regimens requires social support and freedom from physical and social barriers (Hovell *et al*., 2003:1790). The HBM, in particular, aids our understanding of adherence with treatment regimen. For example, it presumes that patients must believe that they are vulnerable to the disease or its consequences, and that the consequences of the disease on their well-being could be serious. Patients must also believe that by following a particular set of health recommendations, the threat or severity of the condition will be abolished or reduced.

The objectives of TB treatment are two-pronged: to cure the patient in the shortest possible time, and to interrupt the chain of transmission of the tubercle bacilli. Indeed, first and early diagnosis[3] should limit the disease propagation, and more potent new drugs may allow shorter treatment regimens (Housset & Fuhrman, 2003:180). Besides early diagnosis, it is also evident that the shorter the duration of treatment, the better the patients' adherence rate. Based on new pharmaceutical insights in the Netherlands, it was decided that the treatment of pulmonary TB, when caused by fully susceptible bacilli, can be decreased from 9-12 months six month duration by shortening the continuation phase (Van Loenhout-Rooyackers & Veen, 1998:8, 10). Practically, however, this can only be done when treatment adherence is perfect.

Other study results suggest that adherence rates may be adversely affected by unreported side effects rather than the number of medications prescribed (Grant *et al.*, 2003). This study determined medication adherence and predictors of sub-optimal adherence in a community cohort of patients with diabetes and tested the hypothesis that adherence decreases with the increased number of medicines prescribed. Patients reported very high medication adherence rates regardless of the number of medicines prescribed. Among patients on multiple medicines, most patients with sub-optimal adherence were perfectly adherent to all but one medicine. Unreported side effects and a lack of confidence in immediate or future benefits were significant predictors of sub-optimal adherence. It was concluded that health care providers should not feel deterred from prescribing multiple agents in order to achieve adequate control of diseases such as hypertension.

The pressing question that remains in respect of TB treatment is: Will TB patients who have reported severe side effects continue to take their medication? Gregson (2002:461) attempts to answer this question when he states that, generally, treatments are abandoned not because they do not work well enough, but because they are "*too much trouble to take*." Imagine having to take TB treatment for six months on an empty stomach for most part of this period, as is the case with many TB sufferers in South Africa. Clearly, adherence will be poor because most patients will choose to stay away, rather

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[3] Most of TB symptoms and X-ray findings are indistinguishable from those caused by other respiratory conditions. Thus, diagnosis is dependent upon laboratory tests. Evidence of TB — acid fast bacilli (AFBs) — can sometimes be detected under a microscope after applying a special stain (dye) to a specimen (smear) of the patient's sputum, bronchial fluid or other biological samples. A positive result is proof that the patient has an active TB infection, but smear results often come back negative even when the patient turns out to have active TB (Wilson, 2003).

than complicate their health by taking tablets, which lead to even worse hunger spells. The studies of Schiffman & Zervakis' (in *Doctors Guide*, 2000) on the taste properties of drugs, found that the innate desire to taste food and derive pleasure from that sensation is so strong that people sometimes stop taking life-saving medication simply because it tastes bad or ruins the flavour of otherwise enjoyable foods. They maintain that distortions in taste and smell are far more than a nuisance, especially for patients whose conditions necessitate proper nutrition and a tightly controlled medication regimen. There is also the possibility that patients with sensory distortions can suffer from malnutrition, accidental poisonings, and chronic diseases like hypertension and diabetes which require the ability to taste, and thus regulate, salt or sugar intake.

According to Stein (2000), non-adherence may result from differing interests or expectations of the patient and the health care provider. Misperceptions or dissatisfaction with the patient-health care provider relationship may also be a cause of non-adherence. Indeed, the doctor-patient relationship has for a long time been regarded as important variable in adherence, as well as patients' beliefs about medications and medicine in general (Vermeire *et al*., 2001:335). More than two decades ago, Zola (1981:242) already warned:

> *...It is no longer safe to assume that patients regard the treatment they are asked to undertake as being entirely for their own good and in their best interests. Since the office hours, appointments, and location of visit, are arranged for the doctor's convenience and not the patient's, the same may well be seen for the very treatments the patients receive. I refer to all the publicity about unnecessary surgery, the money being made off medicare and medicaid,* [and] *the adverse side effects of many drugs. Together they create an unspoken suspicion in many patients' minds as to how much of what they are receiving is really their own interests.*

The medical system in itself has also been identified as an important factor in adherence. Contemporary health policies are also important in determining adherence. Current TB control standards and practices, especially those that call for the use of isolation procedures when interacting with persons who are infectious, may alienate patients and compromise public health (Jimenez, 2003:104). The treatment plan itself may even be a cause of non-adherence, especially if it requires a great deal of behavioural change. Furthermore, previous failures of therapy (possibly also related to non-adherence) may discourage patients into giving up on present or future treatment plans (Stein, 2000). Hill (1995:15) found that 50% or less of medication is taken as prescribed, and that the daily dose frequency is inversely associated with adherence: once a day (73%), twice a day (70%), three-times-daily (52%), and four-times-daily (42%). Indeed, it is difficult for some patients with TB to accept that they are ill, especially if the disease requires an alteration in their life style. Patients in this state of denial have no motivation towards adherence with health care behaviours, because they do not feel that they are ill.

3.6 Direct observation: what is needed?

Thus far, the global situation regarding DOTS and the perceived factors contributing to non-adherence, has been discussed. It has already become clear from this discussion that existing policies and practices are not sufficiently effective to ensure that South Africans, and other nations worldwide, are saved from the ravages of TB. In the quest for solutions to this problem, two questions are asked: "Which mechanisms are needed to effectively respond to the challenge of non-adherence?" and "Which strategies or processes can be implemented in order to meet these challenges?" The latter question is addressed mainly in Chapter 4.

While international health organisations and organisations, such as the WHO, the UN and the IUATLD, play a major role by leveraging and supporting government efforts and the public sector through funding, technical support and political commitment. It is, however, just as important, for individual countries to take full responsibility for the success of their TB control programmes. The DOTS strategy requires strict technical rigor in order to achieve its goals. As TB control is essentially, and above all, a management problem; control programmes need good managers with supportive supervisory staff (Frieden, 2003:82). Some time ago, Benatar (1986:248) called for the creation of a "*national, non-discriminatory, unitary health service ... to make possible the control of tuberculosis.*" Twelve years later, in April 1998, the *Mail & Guardian* (1998:1) pointed out that South Africa "*lacks the will*" to halt TB. Today, the same cannot be said as the country has made great strides in fighting the epidemic. One such strategy, the Medium Term Development Plan, may prove to be invaluable if managed and implemented properly.

One essential aspect that can improve adherence is advice regarding the long duration of treatment. Similarly, advice on the dangers of default is crucial in encouraging patients to complete their treatment regimen (Khan *et al.,* 2000:252). It is noteworthy that educational strategies, alone, do not appear to be enough to effect change in non-adherence. Reviews examining psychosocial interventions to improve treatment adherence (Chew *et al.,* 2002; Jaramillo, 1999; Narayan & Narayan, 1999) found that psycho-educational interventions focusing primarily on the dissemination of knowledge about the illness, treatment or medication, without focusing on attitudinal or behavioural changes, did not result in improved adherence. Concrete problem-solving and motivational techniques were more likely to aid in improved medication adherence. Therefore, besides illness education, patients should receive concrete problem-focused strategies, such as reminders, self-monitoring tools, cues, and reinforcements as aids towards improving adherence. It is concluded that a sustained health promotion approach would, with the necessary effort and resources, integrate easily into any existing health system. Specifically, one of the approaches should be the development of adherence education which takes a minimum amount of time and incorporates universal strategies that can be included into a standard health-care provider visit (Demyttenaere, 2003:72).

Over the years it has become evident that, for patients to develop effective handling of their illness, actions and support from health care providers are crucial. In this regard, nursing, the largest group of health care providers in South Africa is provided with a unique opportunity to challenge the problem of non-adherence. Indeed, the size, focus, process, and accountability of nursing make it the most qualified of all the health care professions for assisting society with the problem. As a result of its size and amount of patient contact nursing has the greatest potential of all the health care providers for affecting patients' health care behaviours. In addition, patient education is also an important element of nursing care (Snoek & Visser, 2003:2).

In spite of the effectiveness and cost-benefits of DOTS (Chaulet, 1987:22), some critics (Bock *et al.,* 1999:298; Chaulk & Pope, 1997:150; Fallab-Stubi *et al*., 1998:526; Zwarenstein *et al*., 1998:1341) argue that the strategy is authoritarian and expensive. Another author (Perry *et al.,* 2002:237) goes further and suggests that, in some circumstances, periodic urine testing may offer a practical alternative to DOTS. Practically, one can contend, South Africa is one of the countries that will find it difficult to implement urine testing to monitor adherence to TB preventive therapy. Health care providers in the country are already heavily burdened by their workload. The question remains: Who will manage these tests? Will it be the health care providers at the health care institutions, or the DOT supporters visiting patients at their homes? An attempt to answer these questions makes it clear that this exercise will either lead to extra costs on the part of the patient (i.e. having to travel to the clinic) or lead to duplication of services (DOT supporters are in the first place supposed to ensure that patients comply with treatment).

Of greater concern is whether the international community, through agencies such as the WHO and the IUATLD, has fully exploited the intrinsic advantages of the DOTS strategy. Current literature (CDC, 2003; Dye *et al*., 2003, Narayan *et al*., 2003; Raviglione, 2003; WHO, 2003) indicate that not all countries have achieved the same level of DOTS coverage. How long will countries, such Brazil with only 7% DOTS coverage, have to wait before they are 'bombarded' with yet another TB control strategy? Surely, the best option is to exploit all the benefits of the DOTS strategy, and to provide support to the countries which are struggling in this regard. It has been shown that DOTS programmes achieve mortality rates which are far lower than non-DOTS programmes. DOTS has saved more than a million lives in the past 10 years (Frieden & Driver, 2003:82). The strategy has also been shown to transform the outcomes of TB treatment from cure rates of below 50% to over 80% (Dholakia, 2003).

3.7 Conclusion

South Africans are currently dying from a curable disease, despite numerous efforts to reduce the incidence of TB. The establishment of the NTCP in 1996 and the adoption of DOTS are illustrative of these efforts. Despite positive interventions by Government in making all TB treatment free of charge for all patients, the epidemic remains a threat. Testing for TB by means of sputum test has become part of the package of care offered free of charge to all South Africans at the primary health care level in all public sector facilities. Therefore, it seems common sense to assume that patients will make use, without any difficulties from their side, of this service. Unfortunately, this is not happening, hence the need that adequate resources are provided to implement behaviour change intervention programmes effectively. This is especially the case if one considers the relatively long time the illness ‘career’ can last.

Certainly, the call for a paradigm shift in TB control, focusing on the socio-economic, cultural and socio-behavioural aspects of TB, cannot be disputed. However, alternatives such as Community Orientated Tuberculosis Services should be treated with caution. In fact, Narayan & Narayan (1999) failed to explain how the Community Orientated Tuberculosis Services strategy operates in practice. It is about time that TB control programmes move beyond slogans if they intend to reach their targets. This implies developing well-meaning slogans and campaigns such as DOTS into tangible gains. This cannot be done in the midst of an environment in which new initiatives are developed before having fully exploited the benefits and cost-effectiveness of existing ones (especially in the context of poor, developing countries). Nonetheless, while the long-term solution lies in improving socio-economic conditions, countries such as Peru and Vietnam have demonstrated that well-functioning control programmes can reduce both the morbidity and mortality associated with TB.

It is evident that many conditions contribute to non-adherence. Surely, the way in which patients respond to illnesses such as TB depend largely on their economic, demographic, psychological and socio-cultural environment. It is also evident from this chapter that adherence is not rooted in the patients’ personalities, but rather in their interaction with health care providers. It is therefore suggested that, when developing a treatment plan for an individual, consideration must be given to the patient’s perceptions, the degree of support/supervision required and available, and the degree of behaviour change needed. The complexity, convenience, and required duration of the treatment should also be considered. As already indicated, short, simple and easy to follow regimens have a higher adherence rate. However, in the absence of such treatment plans for TB patients, encouraging them to complete their treatment and providing all the necessary support may be invaluable to society at large. It should also be noted that, as Meulemans *et al*. (2000) have also asserted, both the social stratification perspective and the stigmatisation perspective play a significant role in providing insight into the mechanisms of rejection of norms and non-adherence of TB patients.

Statistics on completion rates (standing at 81%) by the World Health Organisation (2001) are encouraging. Yet, far better completion rates can be achieved. The 8.3% deaths and 15.8% interruption rate experienced in South Africa may be the ‘tip of the iceberg.’ But the recognition by health authorities and the collective effort to stop the spread of TB, point to the acknowledgement that, for South Africa to rise to the standard set by countries such as India in TB control, effective control measures cannot simply be assumed.

It is advocated that each country should develop appropriate intervention models. While they should uphold the highest values of TB control, the models also have to reflect the needs of the communities they serve. This means that communities should be effectively involved in TB control efforts rather than being mere passive recipients.

Chapter 4:

Prevention mechanisms and campaigns of tuberculosis in South Africa: a review of behaviour change interventions

> "Information does not equal prevention, and even the most comprehensive public information campaigns have achieved limited success. Furthermore, encouraging individuals to change their behaviour is only a partial solution to socially created health problems" (Atkins & Wallack, 1990:7).

4.1 Introduction

This chapter is a review, not of the effects of TB on people, but of interventions aimed at behaviour change. This requires a shift in perspective: from regarding TB as something out there – to acknowledging that human behaviour has much to do with the upsurge of the epidemic. This chapter also provides an appraisal of interventions at both the national and the provincial level in South Africa. The introductory quotation again emphasises the need to address social inequalities which continuously expose the poor to disease. Ogden (1999:215) notes that, in practice, changes in the historical, political and bacteriological landscape have impacted changes in public health perspectives. However, the growing evidence of a strong link between social inequalities and TB has not yet been translated into policies or programmes that are able address it.

In chapter 2, the Health Belief Model, the Health-seeking Behaviour model, and Theory of Reasoned Action attempt to explain the individual's use of cost and benefit analysis to form intentions to behave. A challenge remains to translate health knowledge and healthy intentions into healthy behaviours. Chapter 2 also points out the contradiction between cultural values and habits, and conventional TB control measures. Inappropriate health information, compounded by poor knowledge and lay, indigenous, traditional belief systems, contributes to high risk behaviours that inhibit health education campaigns. Empirical evidence has shown that health communication campaigns are effective in initiating or changing important behaviours related to health. Aggressive efforts to promote health and prevent disease have risen higher on the social agenda in South Africa. Over the past decade an enormous quantity of health information has been released. Most local television programmes have a health segment, many newspapers include a health section, and magazines and radio programmes have been permeated with health information. Adding to the impact are many health tips communicated daily through the Internet (Chew *et al*., 2002:183).

In targeting behaviour it is necessary to tackle the systematic factors that increased susceptibility to risk in the first place. Raising public awareness about the importance of lifestyle modifications to prevent disease has, for the most part, had a positive effect. The positive response of the public to the identification of risk factors is undeniable. *Soul City* – a weekly television drama – is one of the more notable socio-behavioural interventions with an extensive research component in South Africa (Kelly, 2002:101). Other notable campaigns include the Department of Health's National Advocacy and Social Mobilisation Plan and the WHO's global school health initiative.

Understanding the disease is a cornerstone of health education; it is a fundamental requirement for the development of intervention strategies. Narayan & Narayan (1999:489) argue that the orthodox biomedical perspective[1] on TB "*generates a restricted view of the challenges of educational approaches in tuberculosis control as it focuses primarily on motivating patients to take regular treatment and not become defaulters*." In order to overcome this shortcoming, responses should be in line with the factors responsible for the occurrence, the spread and the maintenance of the disease. Thus, if the causative factors were social, then the responses needed to be social as well. As an alternative to the orthodox biomedical paradigm, Narayan & Narayan (1999:489) propose a new socio-epidemiological perspective, which focuses on the larger socio-economic-political-cultural context in which the disease spreads and thrives in the community.

The most effective way of describing the benefits of TB prevention programmes is to measure their effects in terms of the number of infections prevented through the intervention. In order to assess the full impact of the intervention, not only infections averted for those TB patients involved in the intervention, but also secondary infections (i.e. contacts) averted need to be considered. However, there is little, if any, research that has focused on the impact of interventions in terms of the base indicator of infections averted. There have also been no comprehensive attempts to understand the impacts of responses to TB and the effectiveness of prevention programmes in South Africa. This chapter highlights the need for widespread dissemination of accurate information about the causes, prevention and health management of TB to counter the many myths and misconceptions surrounding this disease.

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[1] The orthodox biomedical perspective views TB as a chronic mycobacterial infection requiring early diagnosis by sputum microscopy and culture; radiological investigation; and chemotherapy, consisting of prompt, regular and extended treatment by a combination of anti-TB drugs (Narayan & Narayan, 1999:489).

4.2 Health education: what does it entail and what is its' relevance for TB?

Health education is aimed at rendering patients more informed and aware of all aspects of diseases and their treatment. It also entails the basic rules to prevent the spreading of infections to others in the family or the community (Narayan & Narayan, 1999:493). In the past, health education was used as a term to encompass a wider range of actions inspiring social mobilisation and advocacy. These methods are now encompassed in the term 'health promotion' and a more narrow definition of health education is proposed here to emphasise the distinction (WHO, 1998b:4). Health Canada (2003) regards health education as comprising:

> *"...conspicuously constructed opportunities for learning involving some form of communication designed to improve health literacy, including improving knowledge, and developing life skills which are conducive to individual and community health. Health education is not only concerned with communication of information, but also with fostering the motivation, skills and confidence (self-efficacy) necessary to take action to improve health. Health education involves communication of information concerning the underlying social, economic and environmental conditions impacting on health, as well individual risk factors and risk behaviours, and use of the health care system …"*

People often associate health promotion with posters and pamphlets. This is a simplistic view akin to associating medical care with white coats and stethoscopes. Until recently, health promotion has relied heavily upon the dissemination of health information, targeting health messages to the public in the expectation that this would somehow bring about the desired changes in people's lifestyles. Although this approach has produced some shifts in attitudes and health behaviour, these have been slight and slow. It has become increasingly evident that to be effective, information campaigns should not take place in isolation; they have to be combined with a variety of other activities. Health promotion has become a multifaceted exercise which included education, training, research, legislation, policy coordination and community development (Health Canada, 2003).

Health education concerns itself with promoting the health of both the well and the sick. The main types of health education activities, according to Coutts & Hardy (1985:14), include:

- Community health education programmes directed by health education officers
- Health promotion by the media
- Education of patients, conducted by health care workers
- Schools health education programmes carried out by teachers
- Self-help relating to health information and health care, enabled by voluntary groups, community workers or health care professionals.

The most commonly expressed goals of health education (Coutts & Hardy, 1985:14) are to:

- Contribute to self-fulfillment of individuals and promote their well-being as individuals
- Enhance the ability of people to cope effectively with health promotion, health maintenance and illness control
- Reduce undesired risks of disease and illness
- Help people maintain personal and civil integrity while receiving health care
- Create more active individual and community participation in the health system by increasing personal competence in self-care and social skills in working within the formal health system.

Health education plays a crucial role in the development of a healthy environment and society. Yet, with limited resources, it is not easy to implement successful campaigns that make a real difference to the way people lead their lives and the choices they make. As *SANTA News* (2000:4) reports: "*It is a needless tragedy that 1 million people perish each year awaiting the advent of newer miracle drugs and vaccines*."

Text Box 4.1: Exploring the concept of health education in the context of TB

Health education

1. Is a life-long process from birth to death
2. Gives people information about the way their bodies work
3. Helps people recognise and express their emotions appropriately
4. Helps health people to learn about preventing infection with TB
5. Instructs TB patients how to carry out their health care provider's orders
6. Makes people aware that social and economic conditions contribute to the spread of TB and decrease in life expectancy
7. Aims to change people's behaviour and lifestyles
8. Helps families to learn how to cope with a family member affected by TB
9. Enables people to reach their own decisions in health matters

Adapted from: Ewles & Simnett (1985:26)

Information giving includes such health education activities as preparing a leaflet, giving a talk, displaying a poster or producing a television documentary. The emphasis is upon presenting factual information in a way that makes it interesting and easily understood. The educational approach to health education acknowledges, as in the case of the Health Belief Model, that beliefs, values and feelings may influence what people are prepared to do about their health. This approach also emphasises that health education should take into consideration the affective (emotional) as well as cognitive (thinking) aspects of learning (Coutis & Hardy, 1995:21, 25-26).

Poor education on TB is singled out as an important obstacle to TB control programmes in achieving their goals (Dick *et al*., 1996:174-175). Conversely, educational materials presented in a format that is both familiar and readable increases the likelihood that it will be comprehended (Cabrera *et al.*, 2002:118). Ewles & Simnett (1985:183-185) suggest that answers to the following questions need to be found when designing appropriate and useful health educational materials:

- Are the materials ethnically acceptable?
- Is the information sound?
- Is it relevant to the consumers?
- Will the consumers understand it?
- Does it meet the specific aims of the health education programme?
- Is it the most appropriate kind of material?

Jaramillo (1999:399-400) proposes three different levels of causality – biological, health-behavioural and socio-economic – to explain TB (see Table 4.1). This integrated view of causality in TB, he argues, helps to point out the control measures that need to be taken at different levels of organisation, and thus suggests a more comprehensive agenda for research and for action to control the disease. For a better understanding of how these different levels of causality interact, they are linked to the three stages of the natural history of TB, in accordance with the biological perspective. The current evidence available to explain TB and the approaches proposed to deal with the respective causal levels, are located in the intersection between each level of causality, and each stage of the natural history of TB (Jaramillo, 1999:400)

The health-behavioural model is the least well studied of the three levels of causality, particularly at the infection and breakdown risk stages. Jaramillo (1999:401-402) attempts to clarify this when he asks: “*What is, for example, the real impact of covering the mouth when sneezing and coughing (the most elementary strategy for preventing TB transmission). Is a health education intervention promoting this behaviour worthwhile*?*”* Obviously, all health promotion initiatives are important as they may not only help community members, but also health care workers to create the organisational culture necessary to improve the efficiency of TB control programmes.

Table 4.1: Levels of causality of tuberculosis and approaches to control at different stages of its natural history

Stages in the natural history of tuberculosis	Levels of causality/*approaches*		
	Biological/*medical*	**Health behavioural / *health education***	**Socio-economic/*socio-economic policies***
Infection risk	Inhalation of aerosol contaminated with bacillus/*mask filters and ultraviolet lamps*	Coughing/sneezing without covering mouth; house designs without appropriate ventilation and sunlight	Overcrowding; occupation/*access to resources to build and live in healthy house designs*
Breakdown risk	Loss of immune control on dormant bacillus (e.g. HIV infection)/*preventive therapy, BCG vaccination*	Exposure/*covering the mouth when coughing and sneezing; healthy house designs* Therapy/*safe sexual behaviour; diet rich in protein*	Lack of food; education and supportive environments for safe sexual behaviour
Death risk	Destruction of vital tissue by immune reaction/*chemotherapy*	Delay in diagnosis, treatment non-adherence/*promotion of early diagnosis and treatment*	Lack of access to health care/*limited access to health care services*

Source: Jaramillo (1999:399-400).

As stated in Chapter 2, the fundamental goal of any health education process is to motivate patients to adopt behaviour that is beneficial to their health. Educational interventions may contribute to increased adherence rates (Dick & Lombard, 1997:1-2), increase case-finding, and reduce diagnosis delay and the infection risk of contacts (Wilkinson *et al.,* 1997:750). Another aspect where education can play an important role is in the reduction of the discrimination suffered by TB patients (Crandall & Moriarty, 1996:74). This discrimination results from the prejudice and the stigma attached to the disease. The provision of information about mechanisms of TB transmission could produce a significant reduction in the levels of prejudice against TB patients (Dick & Lombard, 1997:1).

TB patients need the support of their family, friends and community. Love (2002:12) suggests that patients who live with supportive family members are more likely to complete treatment. Thus, it is important to involve not only family members, but also employers when providing information to patients. Recently, *City Press* (2003:4) reported on an employer who shocked his employees when he dismissed one of them for having TB. This clearly indicates the need for stakeholders to intervene at workplaces. Already, much has been done in the context of HIV/AIDS as employers are operating in an increasingly complex legal environment in respect of HIV/AIDS in the workplace. The legislation applicable in the HIV/AIDS context includes the individual's right to privacy, unfair discrimination, and dismissal on grounds of an employee's HIV status (Randall, 2002:87). As far as it could be determined, no evidence of any legislative intervention in respect of TB in the workplace could be found in South Africa. This situation needs to be addressed as many individuals living with TB may be subjected to negative treatment by employers.

Despite advances in science and technology, infectious diseases such as TB pose a more deadly threat to human life than war. The distinction between human behaviour and social response is important in understanding the range of methods and foci that are employed in TB prevention. As Kelly (2002:100) points out:

> "*It is frequently argued that prevention responses are not simply a product of individual behaviour and choice and that appealing to and educating individuals is likely to have limited impact as long as contextual mediators of risk behaviour are not addressed.*"

4.3 Tuberculosis prevention in South Africa: some examples

4.3.1 The South African National Tuberculosis Association

The South African National Tuberculosis Association (SANTA) – the largest non-profit, volunteer-based organisation involved in TB control in South Africa – was formed in 1947. SANTA was primarily established to provide beds for TB sufferers, to establish branches, and to give care to TB sufferers and their families (Kironde & Bamford, 2002:298). During the early stages, SANTA was much involved in the launching of health education programmes, the management of TB prevention schemes, the training of health education and the presentation of TB prevention programmes in schools in the country. Recently, SANTA is also involved in the DOTS (Directly Observed Treatment Short Course) (*SANTA News*, 2001:10).

SANTA is involved in various local, regional and international campaigns to fight TB. Of note is the so-called Massive Effort Advocacy Campaign – an international forum aimed at promoting awareness and sustaining media attention at the global and country level (*SANTA News*, 2000:6-7). International collaborations such as these not only increase knowledge and awareness about TB, but also increase the links between preventable diseases and poverty. It is sad to note that SANTA's national office and hospitals are likely to undergo considerable restructuring. As also echoed by Kironde & Bamford (2002:298), it is hoped that the work of this valuable organisation will continue with TB patients and at the primary health care level.

4.3.2 Information, education and communication programmes

According to Harrison *et al.* (2000:286), information, education and communication (IEC) have been crucial in raising awareness about HIV/AIDS in South Africa. While there is agreement with the argument that a high level of awareness about HIV/AIDS exists among the population at large, the same cannot be said about TB. Moreover, not many people are aware of the causes and symptoms of TB (Khan *et al.,* 2000:250). Growing awareness of patients' desire for information has resulted in the production of numerous information leaflets and booklets about TB. However, none of these materials have been formally evaluated for their impact on individuals and communities. Conversely, many studies (Beaver & Luker, 1997; Glazer *et al.,* 1996; Guidry *et al.,* 1998) have evaluated patient information leaflets for individuals with breast cancer. All these studies suggest that information material have variable quality (Rees *et al*., 2003b:264).

Poster: TB awareness

Tuberculosis (TB) is a disease that usually affects the lungs and is passed on by coughing. Most people on TB treatment cannot infect others.

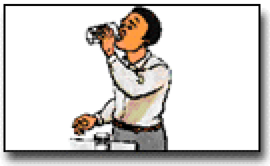
A person who has TB may have the following symptoms:

- coughing for more than three weeks
- coughing up blood
- losing weight and appetite
- sweating at night
- feeling tired
- pain in the chest.

If you think you have TB you should go to a clinic. You will be asked to cough up fluid (sputum) which will be tested to show if you have TB or not. TB can be cured whether you have HIV or not. Pills, must be taken regularly for at least six months.

It is not always easy to remember to take pills for such a long time.

- To help people with TB in their treatment, the Department of Health is using a system called DOTS.
- DOTS is a system that encourages treatment supporters such as co-workers or community members to help people with TB to take their pills regularly.



Actions you can take include:

- helping people with TB by becoming a treatment supporter
- giving care and support to people who have TB or HIV and AIDS
- completing your treatment if you have TB.

Adapted from http://www.aidsinfo.co.za/

Most countries, including South Africa, have launched national public education campaigns using newspaper advertisement, leaflets, television and radio to convey information about TB (Chew *et al*., 2002:183). Television and other media are increasingly being used in creative ways to present health information and to stimulate awareness, attitude change, and behaviour change. In a television documentary - "*Precious breaths, South Africa's needless deaths*" - aimed at raising awareness, TB patients in South Africa related their stories. This included the testimony of the young Jaco Joseph, a 12-year old boy with MDR-TB: "*My mother should have taken her tablets. It's through her that I am sick*" (Department of Health, 2003b). Such documentaries could help people understand South Africa's needless TB epidemic and help the country avoid needless deaths. Indeed, it is tragic that South Africa remains one of the 22 high TB burden countries and that people are still dying from the disease while it has been treatable for the past fifty years.

In particular, the mass media have publicised TB through television programmes such as *Soul City*, a weekly drama series that covers a range of health issues (Kelly, 2002:108). Basic information about the epidemic and its consequences are disseminated in this manner. The *Soul City* Institute for Health and Development Communication (SC IHDC)[2] is a social change project which aims to impact on society at the individual, community and socio-political levels. *Soul City* is a dynamic and innovative multi-media health promotion and social change project. Through drama and entertainment *Soul City* reaches more than 16 million South Africans. It has also been broadcast in many parts of Africa, as well as Latin America, the Caribbean and South East Asia. *Soul City* examines many health and development issues, imparting information and impacting on social norms, attitudes and practice. Its impact is aimed at the level of the individual, the community and the socio-political environment (*Soul City*, 2003).

The *Soul City* television series is broadcast on South Africa's most popular television station (SABC 1). It has consistently achieved top audience ratings and has won numerous prestigious awards for excellence in television drama. *Soul City* was in its sixth series in 2003. In 1996, Series 2 focused on HIV/AIDS, housing and land, TB and smoking. Each *Soul City* series is made up of:

- A prime time television series – 13 one hour episodes (Series 1-3 were half hours)
- A daily radio drama – 45 fifteen minute episodes

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[2] SC IHDC is South Africa's premier edutainment project. A non-governmental organisation, it was established in 1992 at a time when South Africa was on the curve of democratic change. It is a health promotion organisation, subscribing to the principles of the World Health Organisation's Ottawa Charter. According to the Ottawa Charter, health is a product of a range of intersectoral actions that include building an enabling environment, advocacy for health public policy, community action, developing personal skills and the reorientation of the health services towards the health promotion approach (*Soul City*, 2003).

- Booklets – three full colour booklets per series
- An advertising/publicity campaign which keeps people talking and thinking about *Soul City*
- An advocacy campaign around one of the major topics

Text Box 2: Soul City Instutute for Health and Development Communication: South Africa's Premier Edutainment Project

The Soul City Philosophy and Methodology

While many health projects focus on influencing the individual alone, Soul City IHDC views good health as a product not simply of individual choices, but as the product of an enabling environment in which the structural barriers to achieving health and development are removed. Soul City IHDC also views health and development as integrally related: poor health impedes development and development is central to improving global health.

Key principles of the approach

Developing effective educational media is not just about *what you* do but *how you do it*. Two elements, **research** and the **creation of partnerships**, are at the heart of this approach.

- **Research.** Through vigorous research SC IHDC consults both audiences and experts. All materials are thoroughly tested with audiences to ensure that the materials are effective. Through formative research the lived experiences and voices of the communities are captured, giving the materials resonance and credibility.
- **Partnerships.** Materials are developed in partnership with organisations active in the issues dealt with. This ensures shared ownership and involvement ensuring that the material is both appropriate and that it will be used. Where possible, programmes are integrated into wider local initiatives and strategies to achieve the maximum impact.

Additional principles that govern this approach include:

- **Drama can teach**. Human beings have always learnt through stories which can provide positive models for behaviour. Drama creates identification and gives a human face to issues such as HIV/AIDS.
- **Use media to access maximum audience**. This means prime time for radio and TV.
- **A mix of media (multi-media) works well**. Different media reach different audiences and have different strengths. For instance radio tends to be more accessible to rural people than television although these trends are changing.
- **Create a sustained intervention or 'ongoing vehicle'** which brings popularity and credibility over time. This reduces lag time and draws in audiences at the outset of the dramas. It also allows the project to deal with a range of issues over time.
- **Promote and market** the intervention to ensure the maximum audience.
- **Brand all material** with one core identity to tie the different media together.

Source: (*Soul City*, 2003)

The radio series is broadcast on all nine SABC regional radio stations (in nine of South Africa's official languages). It is also broadcast on many community radio stations. The booklets are serialised in newspapers throughout South Africa in synergy with the electronic media. The booklets are inserted into the newspapers at the end of the serialisation. They are also distributed through clinics and other government distribution channels, non-governmental and community-based organisations, business and educational facilities. At least 3 million booklets are distributed per series. The television and radio series are powerful vehicles to shift social norms and impact on knowledge, attitudes and practices. The booklets deal with the series topics in greater detail and can be kept by readers for future reference *(Soul City*, 2003). The *Soul City* intervention strategy can be regarded as a flagship initiative aimed at educating and promoting health and related issues.

Another notable IEC effort in South Africa, based on the television series, is a magazine called "*Stop TB because you can*", produced in comic book form employing either drawings or posed photographs. This book is published in English, Afrikaans, Zulu, Xhosa and Sesotho, and can be used by all members of society (Department of Health, 2002). The same photo-novel format has been used in Mexico and Central America. According to Cabrera *et al*. (2002:118), "...*These popular comic books held the potential of being not only entertaining, but also informative".* Photo-novels mirror communities' everyday social, cultural and economic realities and, as a result, can effectively reach multicultural audiences.

A study focusing on efforts to develop a patient education tool targeting Spanish-speaking Latino immigrant patients to facilitate communication with TB clinicians in the United States made use of the photo-novel format (Cabrera *et al*., 2002). This study describes the stages used to develop a culturally sensitive pamphlet for a low-literate population experiencing numerous barriers to communicating with health care providers. These stages included: (1) a patient survey to assess the TB-related knowledge, attitudes, beliefs and behaviours of US-born and immigrant patients; (2) development of content and format of the photo-novel. Three different soap opera stories (photo-novels) were developed to incorporate the themes from the KABB study and assessment of Latino immigrants being treated for TB. The story plots involved characters that were at various treatment 'careers'; (3) critical review of medical material by TB experts; (4) field testing among Latino immigrant patients and (5) final review, revision and distribution to health department clinics. Though the impact of this study has not yet been assessed, Cabrera *et al.* (2002:122) argue that patients educated in this manner would be more receptive to messages about TB and modify cultural beliefs and attitudes that act as a barrier to adherence with medical regimen. Such health care initiatives, one may contend, have the potential to make health care providers fully aware of the source of miscommunication which often leads to interruption.

Non-governmental organisations (NGOs) and community-based organisations (CBOs) have high potential in improving TB control at the community level. Very little is known about these organisations' involvement in TB control. However, TB control programmes could take advantage of existing community resources to enhance community knowledge of TB. Community members already directly involved with TB patients could collaborate with health workers to provide patients with accurate information regarding length of treatment and known side effects. Various community members, including village leaders, schoolteachers, religious leaders, trade unions and women's organisations, have the potential; if mobilised successfully; to raise awareness of the signs and symptoms of TB and the availability and benefits of its treatment. However, Maher (2003:180) maintains that awareness campaigns will only have a positive impact if diagnosis is available and treatment is readily accessible.

According to Kironde & Nasolo (2002), NGOs can assist in achieving active community participation in health service delivery in general, and in tailoring TB control initiatives in particular. They further maintain that NGOs can bridge the gap between the formal health sector and the community. This is especially the case where formal health care personnel may view the involvement of lay-persons in the delivery of TB services as a dilution of their authority.

NGOs, such as the TB Alliance DOTS Support Association (TADSA) – formed in 1997 and operating in the Western Cape, have played an important role in dealing with the high TB burden and poor patient adherence with treatment in that province. TADSA is currently operating on a national level after being contracted by the NTCP to carry out training in order to ensure uniformity in all DOTS Training and Demonstration Districts (DTDDs) (Kironde & Bamford, 2002:298). TADSA has also worked with *Doctors of the World*[3] to improve the quality and availability of community-based services for patients suffering from or at risk of TB, and in South Africa, where the two epidemics are intrinsically intertwined and are overwhelming the public health infrastructure. To respond to this growing crisis, Doctors of the World partnered with TADSA and the South African Department of Health to create and implement community-based TB and TB/HIV training programmes in all nine provinces of South Africa. The cornerstone of this effort is the training of lay community volunteers and Department of Health personnel in community-based strategies for TB and HIV control. Doctors of the World contribute to the success of this undertaking through provision of expert assistance in medicine, public health, and management. Community-based treatment for TB in South Africa relies on the assistance of treatment supervisors - trained lay persons who can be physically present to observe each TB

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[3] *Doctors of the World-USA* is an independent, non-profit, non-sectarian organisation working at the intersection of health and human rights. Founded in the United States in 1990 by the late Dr. Jonathan Mann, *Doctors of the World* is an autonomous U.S. affiliate of *Médecins du Monde*, the French health and human rights organisation. This organisation is also part of an international network, comprising twelve independent delegations around the globe, whose aim is to provide the world's most vulnerable populations with medical assistance. This organisation is dedicated to creating sustainable programmes that promote and protect health and human rights in the United States and abroad. The organisation provide medical and public health assistance and mentoring to those in greatest need and, within the framework of health care services, contributes to the processes of peace, reconciliation, and human rights. Over the last decade, the organisation has deployed American volunteers to provide health care services, training and advocacy to over 25 countries throughout the world (Dowusa, 2003).

patient as he or she swallows each dose of TB medication for a treatment period of six to eight months, and who can search for patients who fail to appear for scheduled doses of medication. Such personal attention helps ensure that the long medication regimen necessary for the cure of TB is completed, despite the patients' temptation to stop treatment when they begin to feel better (*Doctors of the World*, 2000).

The foci of the above campaigns vary greatly in terms of content and also in terms of methodology. In an attempt to evaluate the cost-effectiveness of HIV/AIDS intervention campaigns, Kelly (2002:108-109) distinguished between two types of campaigns: "*above-the-line"* and "*below-the-line"* campaigns. The above-the-line campaign attempts to impact directly on specific knowledge, attitudes and practices by specifically promoting these. Conversely, above-the-line approaches, such as a campaign to curtail smoking (as a risk factor for TB) using radio advertising, is potentially more valuable in economic terms than a campaign that attempts to build support for TB patients by promoting the red ribbon. Kelly (2002:109) points out that the wearing of the red ribbons, which is a below-the-line approach, may be a measurable outcome, but the impact of the wearing of the ribbon on its own would be insufficient to bring about the final intended outcome.

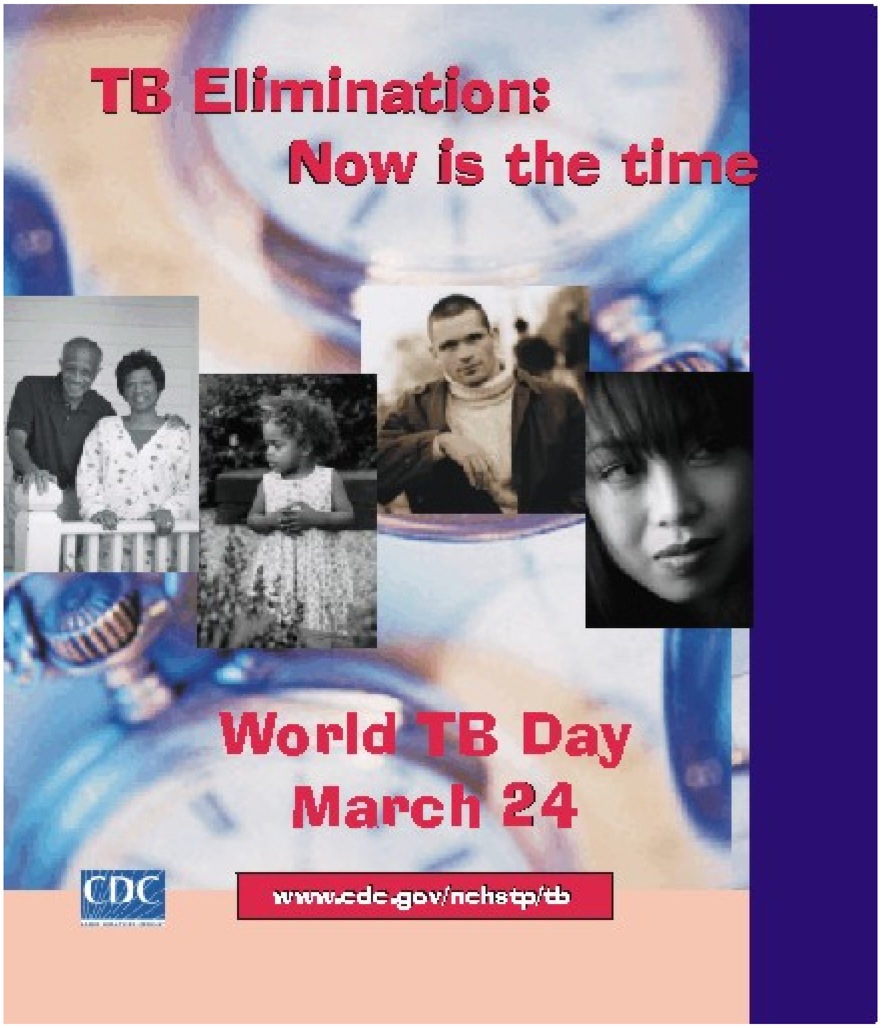
It is agreed that, through the promotion of educational messages on many levels, a health promotion programme may stimulate subtle cultural changes, which will support efforts such as increased adherence with treatment regimens, or improved provider attention to case follow-up. However, it became evident that the mass media in South Africa is not doing enough to inform the public about diseases such as TB. Given South Africa's high rate of illiteracy, the use of photo-novels as a health communication strategy may also be questioned. There is a currently a need for a more sustainable strategic design of TB communication messages in the country. More specifically, public health communicators in the country should take note of the concern of Wray *et al.* (2004:50):

> *"Public health communicators have become very able at developing good messages that have some hope of influencing their audiences, but they may be far less effective at achieving the exposures needed. Perhaps we need better work on understanding how exposure can be achieved, and how to maximize effects from limited exposure, to complement our work on developing messages and their theory. We cannot understand the real-world conditions under which messages might be effective if individuals are never exposed to them."*

4.3.3 World Tuberculosis Day

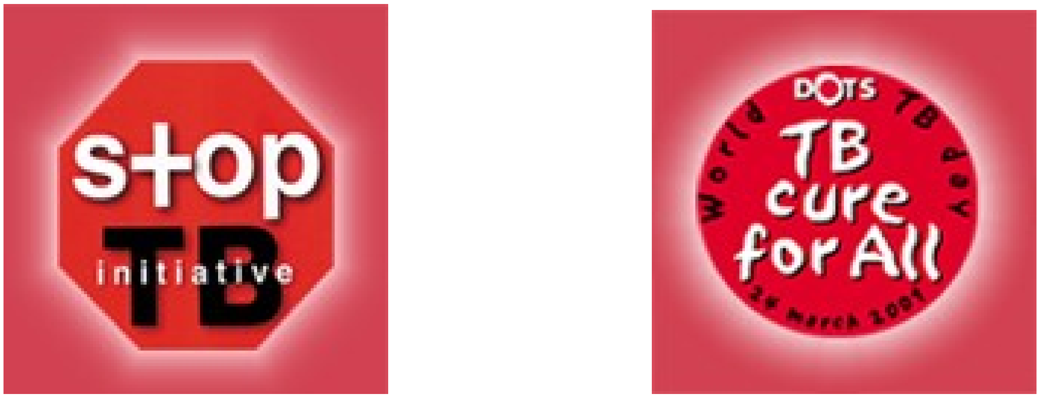
The World TB Day is held each year on 24 March and is intended to promote awareness, knowledge, and motivation for action against TB globally. The origin of this day goes back to the 1982 celebration of the centenary of Dr. Robert Koch's discovery. The International Union Against Tuberculosis (IUAT) accepted proposals for the establishment of an International TB Day after the commemorative ceremonies and events organised by governments and NGOs. Each year has its own theme. Past years' themes included: "*Stop TB, use DOTS"* (1999); "*Forging new partnerships to Stop TB*" (2000); "*DOTS, TB sure for all"* (2001); and "*Stop TB, fight poverty*" (2002). These themes suggest that tackling TB, one of several illnesses that affect the poor, is one way of achieving greater global prosperity (*Stop TB Organisation*, 2002).

Poster: World TB Day



Recently, the Department of Health made use of the 2003 Cricket World Cup in South Africa[4] to raise awareness and educate people about TB. The Stop TB Partnership launched a Stop TB message campaign targeted at the spectators and audiences of the 2003 World Cup Cricket. The campaign was organised by the Stop TB Partnership Secretariat and Meropa Communications, a South African Public Relations firm, with support from the National TB Programmes of India and South Africa. Called "Hit TB for a 6!", the campaign involved television Public Service Announcements (PSAs) by leading cricketers, a series of PSAs aired by dozens of community radio stations covering the match play, wearing of Stop TB pins and other paraphernalia by tournament participants, discussion of Stop TB messages by radio and TV commentators, and numerous other activities. The campaign concentrated on three basic messages: TB is curable, the cure is called DOTS, and the treatment is free at public health centres – so, if you have symptoms of the disease, get tested now. An added advantage of this tournament is that it offered a “near-perfect” audience for such a campaign, with six participating high-TB burden countries (Bangladesh, India, Kenya, Pakistan, South Africa and Zimbabwe) as well as teams representing three main TB donors (Canada, England and The Netherlands). In the sub-continent especially - where a third of all global TB cases are found -- cricket is hugely popular and public attention was riveted on the media coverage of the event (*Stop TB Organisation*, 2003).

Picture: Emblems used in TB campaigns



Source: *World Health Organisation Eastern Mediterranean Region*, 2002.

Event-based interventions such as the World TB Day activities are costly. Kelly (2002:102) further warns that such interventions are often intentionally serving the purpose of “*being seen to be doing something*” and largely conducted on the basis of common sense thinking with little reference to evaluation. Indeed, health care workers in the country have long understood that efforts to communicate messages about TB have not been big enough and sustained enough (Department of Health, 2003a). Thus, outcomes evaluation is important because it can show how

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[4] Kenya and Zimbabwe also served as venues for first-round matches

well the intervention programme has met its objectives and what might change to make it more effective.

It would seem that Gauteng is one of the few provinces in South Africa that made good use of activities surrounding World TB Day. Thale (2002) analysed the effects of a national TB campaign launched by the Minister of Health on World TB Day, in 2001. During the launch of the campaign, the Minister called for an annual review of progress in the war against TB. The campaign is part of a focus on preventive as opposed to curative health. The aim of the campaign is to reduce new infections, increase cure rates and eliminate the rate of treatment interruptions by intensifying educational campaigns around the treatment of TB and monitoring patients. The campaign also enlists the support of volunteers who monitor patients to ensure that they continue taking treatment, even when they feel better. To date, according to Thale (2002), the patient education campaign in the city of Johannesburg, is finally showing promise: in the third quarter of 2001, the cure rate rose to 78%, and the death rate dropped to 6,5%. This initiative was given a further impetus when South Africa hosted the 14th Conference of the International Union Against Tuberculosis and Lung Disease (IUATLD) Africa Region in Durban, from 11 to 14 June 2002.

4.3.4 National Advocacy and Social Mobilisation Plan

Advocacy is the process employed to overcome the major structural barriers to public health. These barriers may take any form: legislative, policy or regulative measures (Coulson, 1999:296). The NTCP launched the first National TB Advocacy and Social Mobilisation Campaign 2003-2005 with the theme “*Stop TB because YOU can*.” The activities started with the TV documentary, "*Precious breaths, South Africa's needless deaths*" – discussed earlier in the chapter. The official launch took place on World TB Day at which occasion the Minister of Health signed South Africa's united pledge to support the “*Stop TB because I can*" campaign (*Stop TB Organisation*, 2003).

The new Advocacy and Social Mobilisation Plan is not only a critical factor in reaching the targets of the South African NTCP, but aim to ensure that every South African knows the basics about TB. The main objective of the plan is to mount sustained and highly visible campaigns in the fight against TB. This communication strategy also aims to help the NTCP attain its goals of better and earlier case finding, higher cure rates and lower treatment interruption rates. An important achievement of the strategy thus far, is the establishment of a newsletter, *TB Indaba*, that will inform the public about developments in the NTCP. As the public will also have the opportunity to comment, the Minister of Health, Dr. Manto Tshabalala-Msimang, states that a newsletter is a way of talking to one another. More importantly, she continues:

> *"TB Indaba should be a vehicle for best practice. It should be a forum for lively debate. It should be a first contact point for new partners in the struggle against TB ... We have learned over the last few years that the methods of TB control are more complex than they sound. It takes skill, it takes particular resources and it takes support from many quarters to record and sustain success. Communication is one of the critical ingredients of success that we often forget to include"* (Department of Health, 2003a:1).

The timing of this effort is excellent, as it coincides with the launching of the renewed strategies by different provinces in the country. Already four of the nine provinces in the country have recorded their best practices as a result of the advocacy plan. The advocacy plan of Gauteng relies on the dual approach of awareness and instant testing. Health workers have left their clinics and have established temporary testing sites in the community. Making use of the "Test is Best" logo – designed by a contracted advertising agency – health workers not only spread information about TB symptoms, and testing and treatment, but also provide instant testing. Shebeens (informal liquor selling places) are also targeted by addressing patrons about TB and about the conditions for successful treatment (Department of Health, 2003a:7).

Awareness on wheels is at the heart of Kwazulu-Natal's (KZN) advocacy campaign. The head of Communicable Disease Control in KZN indicates that they decided to focus their campaign on a mobile population. He argues that most TB patients listen to the radio and also use public transport. As a result, for six months of each year 50 taxis are transformed to vehicles for TB advocacy. The TB adverts that decorate these taxis are hard to ignore and emphasise that TB is curable. The Western Cape with one of the highest incidence rates of TB in the world, advocacy campaign is based on empowering community organisations. These organisations are provided opportunities to build their organisational skills to help in the fight against TB. Finally, in the Free State, the Harmony Mine Company has responded to the threat of TB by keeping cough registers at its mineshafts. Any miner who has a cough is encouraged to go to the dressing station (mini-clinics at shaft sites) for a sputum test. The mine hospital has trained 150 peer educators who, in turn, are able to teach their co-workers (Department of Health, 2003a:8). The use of trained individuals from a particular group to educate their peers, such as at Harmony Mines, is an increasingly popular method for bringing about behavioural change. Peer education programmes both empower and educate people (Harrison *et al.,* 2000:287).

A disturbing trend that emerges from an electronic review of information, education and communication campaigns on the dual HIV/AIDS-TB epidemic reveals that a high level of advocacy is on HIV/AIDS (for example, the South African *HIV/AIDS and TB Newsletter*). TB is so infectious, because the bacteria that cause it are carried by airborne particles. Sitting next to an infected person during a 15-minute bus ride probably will not lead to transmission, but repeated or prolonged contact — sitting near that person as part of a regular commute, or on a long-haul flight — could. "*Obviously people are far more worried about AIDS, but basically if you don't have sex and are not an IV drug abuser and don't have a blood transfusion, there's no other way you can get AIDS. But we've got to breathe*" (*Time Europe*, 2000). The director of the NTCP in South Africa believes that the high advocacy on AIDS is an asset rather than a handicap. She feels that organisations and individuals already involved in the fight against HIV can play an important role in TB control (Department of Health, 2003a:4).

4.3.5 School health initiative

Research demonstrates that school health programmes can simultaneously reduce common health problems, increase the efficiency of the education system and advance public health. The global school health initiative emerged when the Expert Committee on School Health Services laid the first theoretical groundwork for concerted worldwide action. Consequently, WHO's Global School Health Initiative – guided by international charters and declarations - has become one of the organisation's primary health promotion efforts. The initiative offers a framework to mobilise and strengthen health promotion and education activities at the local, national, regional and global levels. Increasing the number of schools that can be called "Health-Promoting Schools", which are schools characterised by constantly strengthening their capacity as healthy settings for living, learning and working. The World Health Organisation (1998a:2) summarises the activities of a Health-Promoting School as schools that

- strive to improve the health of school personnel, families and community members, as well as students
- foster health and learning with all the measures at their disposal
- engage health and education officials, teachers and their representative organisations students, parents and community leaders in efforts to make the school a healthy place
- strive to provide a healthy environment, school health education and school health services along with school/community projects and outreach, health promotion programmes for staff nutrition and food safety programmes, opportunities for physical education and recreation
- implement policies and practices that respect an individual's self-esteem, provide multiple opportunities for success, and acknowledge good efforts and intentions as well as personal achievements.

In 1997, South Africa and China benefited from the WHO's technical support for country-level action to create Health-Promoting Schools in 1997. The WHO worked with the two countries to use priority health issues such as TB and HIV/AIDS as entry points for the development of such schools. Experiences gained in these efforts are being diffused through Regional Networks of Health-Promoting Schools (WHO, 1998a:4).

The *Soul City* educational materials also focus on schools. These materials are carefully researched and tested both by experts in the topic fields, and by the target audience. While all the *Soul City* materials are educational, some of the materials have been designed specifically for use in educational settings, with groups of learners and a facilitator. These educational settings range from the primary school classroom (Soul Buddyz materials) to the high school classroom (life-skills materials), to the formal and informal adult learning environment (education and training materials) (Soul City, 2003).

The Soul Buddyz (formerly called "Soul Buddies"), a co-production with SABC Education, is a multi-media "edutainment" vehicle for children 8-12 years old to promote their health and well-being. The Soul Buddyz project was launched in 1999, building on the successful multimedia strategy of the *Soul City* series. While the *Soul City* series is popular with all ages, its messages were not designed specifically for a very young audience, particularly not for eight to twelve year-olds. Soul Buddyz has been developed specifically with this age group in mind, because attitudes are often formed during this critical time and yet, in the context of a rapidly transforming society with technological changes as well as social changes, the needs and aspirations of children between the ages of eight to twelve years are often neglected (*Soul Buddyz Update*, 2002).

It is commonly known that TB is most prevalent among young adults worldwide. Sadly, no visible public campaign is in place, and no information has been made available in the public domain regarding any intervention plans in the near future aimed at this risk group. One of the most effective means of reaching the public, especially the youth and young adults, is to convey educational messages through popular music and drama at schools. However, as stated earlier, much publicity is on HIV/AIDS. In this regard, the Department of Education, in collaboration with the Department of Health and other stakeholders need to make use of the principles of effective health communication to plan and create sustained initiatives that focus on priority diseases such as TB at school level.

Intervention campaigns such as the Soul Buddyz that are dependent on the goodwill of broadcasters are at high risk of not being sustainable. This is especially the case where such intervention campaigns have to pay high airtime fees for TV. Social cognitive theory posits that behaviour change can come about in response to programmes that build on the potential of the mass media to socialise audiences to pro-social behaviour and life skills (Bandura, 1986:43).

However, the question remains whether the reach and frequency of the Soul Buddyz are large enough to lead to changes in the beliefs, attitudes, norms and values of diseases such as TB?

4.4 Behaviour intervention education: lessons for South Africa from elsewhere

Audience research shows that carefully-designed entertainment media messages can spur audience reflection, promote public discussion and dialogue on social issues, and move audience members to consider new patterns of behaviours. Entertainment-education is the process of purposely designing and implementing a media message both to entertain and to educate, in order to increase audience members' knowledge about an educational issue, create favourable attitudes, shift social norms, and change overt behaviour. The larger purpose of entertainment-education programming is to contribute to the process of directed social change, which can happen at the level of an individual, community, or society (Japhet & Goldstein, 1997; Singhal & Brown, 1996; Valente & Saba, 1998).

Table 4.2: Elements of successful behaviour intervention programmes

Element	
Outcomes	Aim for effect on exposure to risk factors
Design	Positive association between intervention design and outcomes
Objectives	Include a narrow focus with few behavioural goals
Theoretical basis	Be based on a social learning or other cognitive-behavioural theory
Content	Include basic, accurate information on risk; repeat essential messages
Normative process	Strengthen group norms
Skill-based focus	Include experimental activities, especially the modelling and practice of communication skills found to strengthen behavioural outcomes
Duration	Sufficient time for 3-5 intensive sessions needed for skills acquisition
Community emphasis	Focus on the community and cultural aspects, design culturally appropriate/relevant and language-appropriate interventions, promote integration into community
Participation	Create forums for open discussion (guided by DOT supporters), solicit participant involvement

Adapted from Harrison *et al.* (2000:285).

Health campaigners often face a dilemma when material is perceived to be potentially offensive to their audiences. In addition, the disparate objectives of the mass media and public health pose many problems both for health professionals and for media professionals. For example, the objectives of the mass media, amongst others, include entertaining, persuading, or informing the public, and making a profit. Conversely, the objectives of the public health are to educate, improve public health, and change society. Health education material may appear to be offensive when traditional beliefs and practices are depicted negatively. Green (1999:221) is a case in point: "*Usually the problem is reported is that the natives are ridden with superstition; Western health education is needed to lead them out of darkness."* It is not proposed that Western intervention approaches are redundant. Nor is it implied that traditional health-promotion methods are the only route to go. A balanced view of TB prevention is needed, especially in the context of a culturally diverse society such as South Africa. Indeed, it is a truism of health education that programmes and interventions will be more effective when they are culturally appropriate to the populations they serve (Kreuter *et al.,* 2003:25).

It is clear that countries need to develop intervention approaches specific to their context. However, there are several innovative intervention campaigns elsewhere in the world from which South Africa could learn much. For example, a study on AIDS education in Kenya concluded that structured AIDS education that integrates with formal and continuing education is an effective way of bringing about long-term and lasting behaviour changes. The programme has five subjects, namely demystifying the AIDS epidemic, adolescent development and courtship values, marriage, family development, and the future with AIDS. These topics integrate well with similar topics in the syllabus that are taught in secondary schools. The AIDS education reaches 3 million people on a weekly basis by means of feature articles in one of Kenya's daily newspapers (Mungai, 1998:2).

In Chapter 3 mention was made of the effectiveness of "TB Clubs*"* in improving nonadherence with TB regimens in Ethiopia. One innovative approach, in the remote rural district of Estie, is the establishment of "TB Clubs", which have made an important contribution to the district TB programme. The aim of the clubs is to explore ways to improve TB treatment adherence and outcomes. The TB clubs were formed by groups of TB patients who live in the same kebele (the smallest administrative area of a district) and who met while attending out-patient appointments. The District Medical Officer assisted the clubs to establish themselves and promoted their involvement in TB control activities. Each club, which has between three and ten members, elects a leader. The leader ensures that all members attend the TB clinic and arranges weekly club meetings at which members can support each other and share problems (Getahun & Maher, 2001:490). The club leader refers anyone who is failing to make good progress or who is experiencing drug side effects to the local health facility. With assistance from community elders, religious leaders, community health agents and local health workers, the TB clubs have also identified people in the community with suspected TB, encouraged them to seek diagnosis and treatment, and assisted in promoting adherence to treatment and also in tracing defaulters. Using educational materials provided by the Ministry of Health, TB club members have also assisted to educate the community about tuberculosis, in collaboration with health workers and community health agents (Getahun & Maher, 2000:174-176). Results of the study on the effectiveness of TB clubs show that the understanding of the disease after the introduction of the clubs has changed. The attitude of TB patients of hiding their disease from the public has also changed and they are now openly talking about the disease (Demissie *et al.,* 2003:2015-2016).

While there are no similar studies with which to compare the Ethiopian study on TB clubs, this approach has shown what can be achieved if TB patients are at the centre of TB control efforts and if there is effective community involvement. There is no doubt that South Africa, with limited resources, can benefit much by establishing similar clubs. Perhaps, TB patients and the public in general, will be more motivated to read health education booklets and pamphlets.

Another innovative pilot project was conducted in Saudi Arabia with the aim of training and developing human resources in health education, the enhancing of health education research and developing a plan for establishing a health promotion/education centre. A survey was conducted among all health inspectors (n=73) in one Health Directorate and working in different parts of the region. Only 44 (60%) health inspectors showed interest in attending a three month training programme in health education, and were willing to become health educators afterwards. After another screening process 14 (32%) health inspectors were finally selected and found suitable for training. After training, the health educators were sent to 14 supervisory primary health care centres in the selected region with a view to planning, implementing, monitoring and evaluating health education activities. The success of this health education project in Saudi Arabia has been reflected in the creation and establishment of a modern new health education centre (Abdelgadir *et al*., 1995:275).

To understand which of the intervention campaigns mentioned earlier South Africa needs to adopt, it is necessary to understand that, whichever campaigns are adopted, there is a need to make TB education comprehensive, integrated, multidisciplinary, problem-based and sociologically and epidemiologically orientated. In trying to determine what policy makers aim to achieve with certain approaches, Narayan & Narayan (1999:498) found that the narrow biomedical perspective continues as a result of the ignorance of the determinants and deeper causes of TB (for example, poverty, illiteracy, poor environment, marginalisation, and poor housing). These authors further observe:

> *"It is rather unfortunate that, in more recent times, the WHO and other international funding agencies have failed to establish their programmes for tuberculosis on a broad base and have advocated ideas such as DOTS that are at best 'reductionist' and at worst totally inadequate for the treatment of the complex social pathology of tuberculosis in society. This continued 'technomanagerialism' at the cost of a comprehensive, integrated social strategy is particularly disappointing and, as usual, the poorest among the tuberculosis patients will bear the consequences of this public health reductionism"* (Narayan & Narayan, 1999:499-500).

Narayan & Narayan (1999:499) further observe that not enough is being done to facilitate a more comprehensive anti-TB programme that would strike at the roots of the problem. But that does not mean that nothing is done by the WHO[5]. As a knowledge-based organisation with a global mandate, the WHO has been generating and disseminating information on the relationship between health and economic development (WHO, 1999). There are, however, no doubts about the argument of Narayan & Narayan (1999:507) that culturally sensitive, interactive, low-cost educational approaches must be promoted. Indeed, South Africa can benefit much from a more holistic, more responsive and more sustained TB educational campaign.

Finally, the role of traditional healers in IEC is an emerging area that requires consideration. It is estimated that traditional healers provide about 80% of all health services in Africa. Considering their influence as opinion leaders in health and, often spiritual matters, Green (1999:266) asks: "...W*hat good does it do to alienate them from formal health programmes.*" A study conducted in the Hlabisa health district in KwaZulu-Natal shows that it is possible to involve traditional healers as supervisors in the advocated DOTS strategy. The study further shows that traditional healers are accepted, effective and convenient as supervisors (*Medical Research Council,* 2001). Despite findings from the Hlabisa study suggest that traditional healers are a potentially important resource to integrate into TB control programmes, there is substantial reluctance to accept the idea of working with traditional healers

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[5] There are many examples of how WHO's work already benefits poor people: the campaign to eradicate river blindness, the DOTS strategy to combat TB, implementation of essential drug policies, to cite but a few. Neither is a concern for poverty and equity new in the WHO. Promoting equity has been a cornerstone of health for all for over 20 years. Moreover, addressing inequities in health is central to the work of several WHO regions and features prominently in the health-for-all targets set by many member states. These efforts are underpinned by a series of World Health Assembly resolutions. In 1998, for example, when the WHO recommitted itself to ensuring universal access to health services, resolution WHA51.7 emphasised the importance of reducing social and economic inequities by paying most attention to those most in need or affected by poverty. Resolution WHA52.23 (1999) requested the Director-General to strengthen the capacity of the health sector to participate in multi-sectoral efforts which address the root causes of ill-health, such as poverty (WHO, 1999a).

(Colvin *et al.,* 2003). Health educational and advocacy programmes could be more effective if designers and implementers of such programmes possess an empirically based understanding of existing traditional beliefs and practices (Airhihenbuwa, 1991:156). This is especially true in the context of public health programmes in which only adherence with complex treatment regimens and/or adoption of new behaviours are desirable, as in the case of TB. Certainly, it may be easy for some experts to dismiss the role of traditional healers in TB control, but policy makers cannot proceed with health education campaigns "*as if they were driving a bulldozer that would plow under such superstitions to clear the way for science."*

4.5 CONCLUSIONS

South Africans are currently succumbing to a curable disease despite numerous efforts to reduce the incidence of TB. The establishment of the NTCP in 1996, and the adoption of DOTS are illustrative of these efforts. Despite positive interventions by the government in making all TB treatment free of charge for patients, the epidemic remains a growing threat. Testing for TB by means of sputum tests has become part of the package of care offered free of charge to all South Africans at the primary health care level in all public sector facilities. Therefore, it seems common sense to pre-empt this potentially curable disease by insisting on that short, painless, simple sputum test. Yet, this is not happening, hence the need that adequate resources are provided to implement behaviour change intervention programmes effectively. This is especially the case if one considers the relatively long time the illness 'career' can last.

This chapter has shown that much has been achieved by the NTCP in South Africa regarding the prevention and control of TB. The most outstanding aspect regarding health education campaigns in the country in general, and behaviour change interventions on TB, in particular, is the lack of formal documentation of what is happening. However, it is evident from this review that real progress toward enhancing intervention programmes involves moving beyond the strategy of providing information to individuals, to promoting the role of environmental factors (for example, socio-cultural and economic forces) as health determinants. Policy makers should understand that the success of their efforts would primarily be determined by the extent to which the social paradigm is understood and responded to, as alluded to in the introduction.

There remains a gap between the level and depth of analysis of the problem of TB, on the one hand, and its causative factors and their influence in the construction of interventions, on the other. Thus, any health educational intervention cannot be isolated from the socio-economic context. If health education initiatives are aimed at promoting informed choices by individuals, they must help people not only to change risky behaviours, but also to understand the relatedness of the proposed three different levels of causality – biological, health-behavioural and socio-economic. The creation of an educated public on TB may enable people to understand, challenge and follow medical advice, and to participate in political debates where the sustainability of TB control programmes may be discussed and ensured.

Some of the known information, education and communication campaigns in South Africa include the World TB Day, “Soul City” and the recently launched Advocacy and Social Mobilisation Plan. Despite these, there remains a dearth of detailed data on health promotion about TB. This aspect needs further study. The establishment of the *TB Indaba* newsletter by the Department of Health is an important milestone for the NTCP’s advocacy plan. To ensure sustainability, the NTCP must not grow complacent and relegate its achievements to “good” documents without any relevance to the empowerment of people.

Several potential strategic intervention models exist, including those currently in use to address AIDS infection (Kelly, 2002; Mungai, 1998) which may counter the risk of TB infection and non-adherence. Research has shown that successful health communication programmes involve more than the production of messages and materials (National Institute of Health, s.a:2). Such programmes use research-based strategies (TB clubs programme in Ethiopia, for example) to shape products and the channels that deliver them to intended audiences. Sound IEC development should draw upon theories and models. Theoretically, the Health Belief Model, the Help-Seeking Behaviour model and the Theory of Reasoned Action may provide invaluable tools for understanding and developing health interventions directed at TB patients. These theories can also provide powerful tools that transcend the bio-medically-orientated approaches to TB control in order to provide a richer understanding of the dynamics of the target community. In this vein, future IEC materials need to be comprehensive, culturally sensitive and be multidisciplinary. More outcomes-based research is also needed to evaluate the effectiveness of intervention programmes.

To ensure long-term success in the fight against TB, new relationships between first-line health care providers and patients need to be forged. The intrinsic tension between health care providers and patients can be used as a catalyst for innovation and creativity. Communities need information about TB, its symptoms, and the services available. They need counselling to dispel myths and fears that create the stigma associated with TB. At the school level, health information and education regarding TB should become an integral part of the school health education curriculum. While increased patient awareness and understanding of the disease will enhance adherence with the treatment regimen (Department of Health, 2003a:6), it is equally important to impart proper knowledge, skills and attitudes in TB treatment to all grades of health care workers. Indeed, one should guard against inviting people to assume responsibility for their health and then turning around and faulting them for illnesses and disabilities which are the outcome of wider social and economic circumstances. Such a "*blaming the victim*" attitude is based on the unrealistic notion that the individual has ultimate and complete control over life and death (Health Canada, 2003).

It would be a great mistake to believe that increased knowledge will be translated into changes in attitude and alterations in behaviour. To facilitate health promotion activities, it is imperative to understand the health concerns and learning styles of these underserved clients. Further research is needed to assess the impact that IEC materials will have on TB patients. Randomised controlled trials need to be conducted to examine how posters, leaflets and booklets influence TB patients' treatment outcomes. As Rees *et al.* (2003a:257) have found, the information-seeking behaviours of patients and their families should be taken into consideration when identifying their needs for information. In this regard, the WHO and other international agencies provide data, guidelines and standards, and technical assistance, to help countries identify and meet their priority health challenges.

SECTION THREE

Chapter 5:
Research design

5.1 Introduction

This is a descriptive and exploratory cross-sectional study of the illness ‘career’ of TB patients in the Free State. The empirical exploration of the illness ‘career’ of TB patients is based on the analytical model described in Chapter 1 and the theoretical models discussed in Chapter 2. This study investigates the socio-economic and socio-cultural variables impinging on the health-seeking behaviour and adherence to treatment of pulmonary TB patients, and in this way, achieves the aim of the study.

In this chapter, the research design, sampling, instrument construction, selection and training of fieldworkers, data collection methods, data analysis, and strengths and limitations of the study, are discussed.

5.2 Research design

The overall study design is descriptive and explanatory, but also directed towards recommending interventions at the policy and practice levels. The data collection process entailed using face-to-face interviews, focus group discussions (FGDs) and record reviews. These were the preferred type of data collection procedure for the study. There are several advantages inherent in these methods. One advantage of the face-to-face interviews is that it is economical, produces rapid turn-around in data collection, and has the added ability of being able to identify attributes of a population from a small group of individuals. Cross-sectional surveys, in particular, offer the opportunity to assess the relations between variables and differences between subgroups in the population (Visser *et al.*, 2000:225). The purported benefits of the focus group technique are that it can often be easier and less expensive than other traditional interview techniques, and the group setting can generate insights into social forces of interest. Such a group setting may also encourage honesty and spontaneity, and provide access to more useful information, including respondents’ emotional reactions (Kerr *et al.*, 2000:180-181). Record reviews also produce rapid data, and are also economical to conduct.

5.3 Study areas

The survey was conducted at nine Primary Health Care (PHC) clinics with a high burden of pulmonary TB, in three geographic areas or health sub-districts in the Free State province (South Africa. First was the **Goldfields**, a gold mining, urban area with 1 982 registered TB patients in 2000. Second was **Qwaqwa**, a previously “independent” black homeland area, predominantly rural, with 1 397 TB cases in 2000. Third was **Thaba Nchu**, a typical small town, in the vicinity of a large informal African settlement with 590 TB cases in 2000 (Van Rensburg & Redelinghuys, 2001). Together, the selected areas represented the broad spectrum of socio-economic and socio-cultural variables impinging on TB patient ‘careers’. The three areas were also selected because they were not part of the situational analyses discussed in Chapter 1. The Centre for Health Systems Research & Development (CHSR&D), in collaboration with various organisations, had already previously embarked on a series of research projects in the selected areas. This established relationship with the three areas further prompted their selection.

These areas are mainly composed of black people. The health facilities in the areas comprise three district hospitals, two regional hospitals and 52 fixed clinics. The general welfare of the population in these areas is hampered by poverty, unemployment, family violence and crime (Van Rensburg & Redelinghuys 2002). It should be noted that the selection of the three study areas was not aimed at making comparisons.

5.4 Sampling and research participants

5.4.1 Respondents for individual interviews

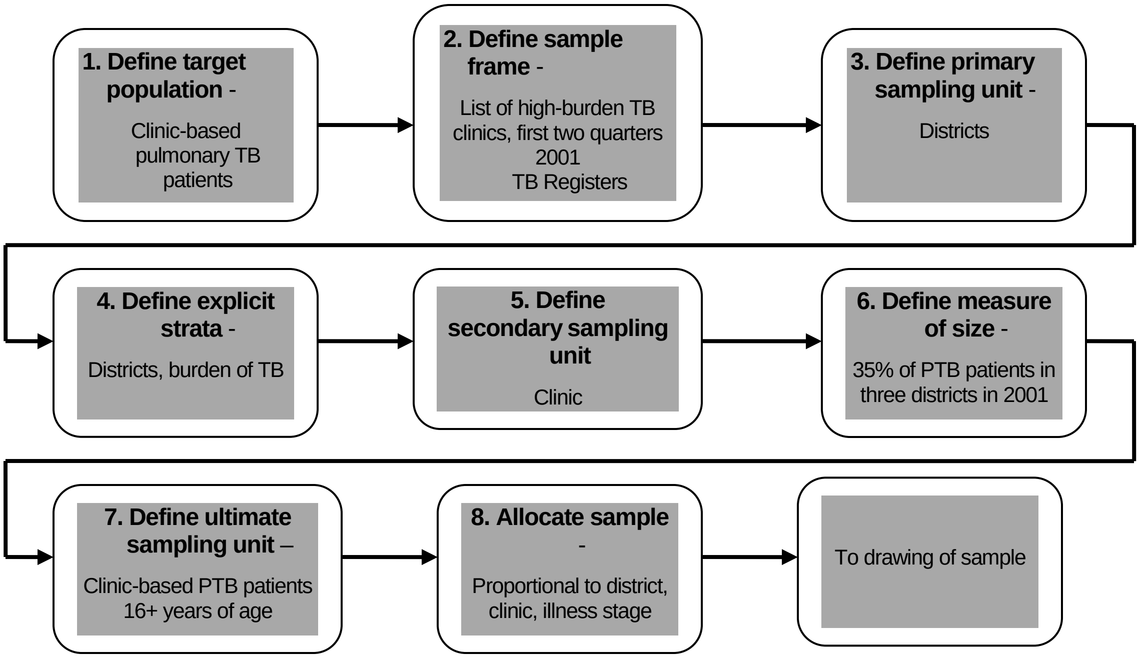
The researcher paid several visits to each of the selected clinics prior to the sampling in order to meet the Clinic TB coordinators and secure the necessary permission for the investigation. Letters from the Free State Department of Health and relevant district managers, authorising the investigation proved to be invaluable during these visits because of the suspicion that strangers may raise. The Free State Provincial TB coordinator also played a prominent role in informing, not only the selected clinics, but all districts about the study. However, great care had also been taken for the investigation not to be seen as an evaluation of services.

In addition to the submission of the research protocol to the Research Committee of the Faculty of Humanities (UFS), the following safeguards were employed to protect the respondents’ rights:

1. The research objectives were articulated verbally and in writing to the participants, including a description of how the data would be used.

2. Permission to proceed with the interview, as articulated, was received from the respondents after being informed that they had a right not to participate (voluntary participation).
3. The anonymity of respondents was protected by not taking down patients' names. In this regard, special care was taken not to reveal the names of the participating clinics, but only the sub-districts

Figure 5.1: Steps in the sample design



Tables 5.1 to 5.3 outline the three major steps that the sampling process entailed. For the purposes of confidentiality, the nine clinics that served as case study sites are denoted as Goldfields 1 to Goldfields 3. The same applies to the clinics in the Thaba Nchu and Qwaqwa areas.

Step 1: Selection of the three clinics with the highest burden in terms of PTB case findings in each study site.

Table 5.1: Selection of clinics per district according to number of PTB case findings – first two quarters of 2001

Study site	Highest PTB burden		2nd highest PTB burden		3rd highest PTB burden		Total
Goldfields	Goldfields 1	157	Goldfields 2	91	Goldfields 3	61	309
Qwaqwa	Qwaqwa 1	53	Qwaqwa 2	30	Qwaqwa 3	28	111
Thaba Nchu	Thaba Nchu 1	121	Thaba Nchu 2	52	Thaba Nchu 3	41	214
Total		**331**		**173**		**130**	**634**

Step 2 – Proportional division of 220 clinic patients according to total number for all three clinics in each site.

Table 5.2: Proportional allocation of clinic-patient sample according to numbers of PTB patients in selected clinics per district

Study site	Number of PTB case findings per site	Proportion of sample %	Sample size
Goldfields	309	48.7	107
Qwaqwa	111	17.5	39
Thaba Nchu	214	33.8	74
Total	**634**	**100**	**220**

Step 3 – Stratified random sample in each district between the three clinics.

Table 5.3: Proportional allocation of clinic-patient sample according to numbers of PTB patients in selected clinics per site

		Highest burden			Second highest burden			Third highest burden		
Study site	**Proportion of initial sample**	**Number of PTB**	**Proportion of site total**	**Sample size**	**Number of PTB**	**Proportion of site total**	**Sample size**	**Number of PTB**	**Proportion of site total**	**Sample size**
Goldfields	48.7%	157	50.8%	**54**	91	29.4%	**31**	61	19.8%	**22**
Qwaqwa	17.5%	53	56.5%	**19**	30	27.0%	**10**	28	25.3%	**10**
Thaba Nchu	33.8%	121	47.7%	**42**	52	24.3%	**18**	41	19.2%	**14**
Total	**100.0**	**331**		**115**	**173**		**59**	**130**		**46**

The population of the study were clinic-based pulmonary TB (PTB) patients, 16 years and older. The patients interviewed at clinic level were sampled using a multistage design. In this regard, a sampling frame - list of clinics with a high burden of pulmonary TB patients during the initial two quarters of 2001 – was obtained from the Department of Health. The focus was on high burden clinics, given the need to recruit as many patients as possible into the study. Thereafter, a *stratified random sample* was utilised to ensure that specific characteristics are represented. The sample was stratified according to the category of patient, and patients were sampled in proportion to the total number of each type of patient on the TB register at each clinic. Visser *et al.* (2000:225) maintain that stratified sampling "*provides greater control over the composition of the sample, assuring the researcher of representativeness of the sample in terms of the stratified variables*." In total, the nine clinics had 634 pulmonary TB patients. A sample size of 220 patients was calculated taking 35% of the total number of pulmonary TB cases (see Tables 5.1-5.3). These patients constituted the ultimate sampling units. The sample size was, to a large extent, limited by financial constraints. The patients were stratified according to the following patient illness stages/careers[1] (proportions in brackets):

- New patient - intensive phase (32%, n=71);
- New patient - continuation phase (36%, n=79),
- Re-treatment patient – intensive phase (15%, n=33)
- Re-treatment patient – continuation phase (17%, n=37).

Table 5.4: Category of patient by gender (%)

	Male **n (%)**	**Female** **n (%)**	**Total** **n (%)**
Category of patient:			
New patients	76 (63)	74 (75)	150 (68)
Re-treatment patients	45 (37)	25 (25)	70 (32)
Total	*121 (100)*	*99 (100)*	*220 (100)*
Type of re-treatment patient:			
After previous cure	24 (53)	13 (52)	37 (53)
After previous treatment completion	8 (18)	7 (28)	15 (21)
After previous treatment interruption	10 (22)	2 (8)	12 (17)
After previous treatment failure	3 (7)	3 (12)	6 (9)
Total	*45 (100)*	*25 (100)*	*70 (100)*

Table 5.4 presents the characteristics of the interviewed patients by patient category and gender. Fifty-five percent of interviewed patients were male and 45% female. The majority of patients were new

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[1] **New patient**: A patient who has never had treatment for TB or who has taken anti-TB drugs for less than 4 weeks.
Intensive phase: Period of 2-3 months of taking anti-TB drugs.
Continuation phase: Period of 4-7 months of taking anti-TB drugs.
Re-treatment patient: A patient who has previously taken anti-TB drugs or who has missed 10 doses during the first 6 months of initial treatment.

patients (68%), while almost a third were re-treatment patients (32%). Of the re-treatment patients, just more than half were on re-treatment following previous cure (53%), while just more than a fifth (21%) were on re-treatment following treatment completion.

5.4.2 Respondents for the focus group discussions

The population of the study were clinic-based pulmonary TB patients. For the sample of the focus group discussions (FGDs), patients still on treatment were selected randomly from the TB registers. Each FGD was conducted with between 7 and 8 participants at each of the nine selected clinics. People under the age of 16 years of age and patients with treatment for less than 2 months, were excluded because they were perceived to be "less experienced in having TB". It should be noted that none of the 220 patients who formed part of the survey were selected for the FGDs, as they were no longer on treatment.

Table 5.5: Characteristics of focus group participants

Characteristic	n	%
Gender		
Male	45	53
Female	40	47
Total	*85*	*100*
Category of patient		
New patients	61	72
Re-treatment patients	24	28
Total	*85*	*100*
Employment status		
*Employed	7	8
Unemployed	78	92
Total	*85*	*100*
Lived with someone who has/had TB:		
Yes	31	36
No	54	64
Total	*85*	*100*

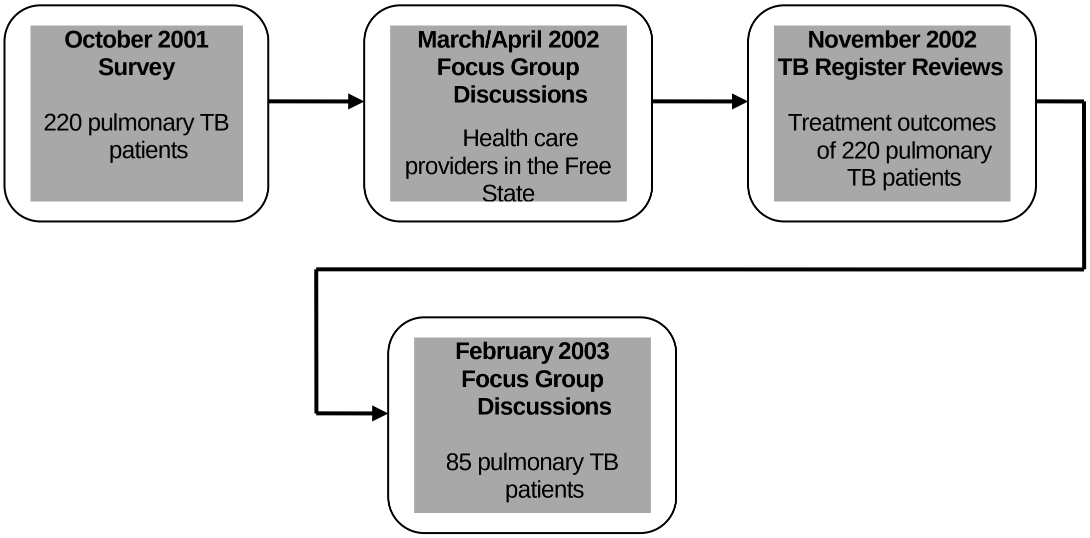
*Includes 3 pensioners.

For the sample of the FGDs, patients who were still on treatment were selected randomly from the TB registers in terms of their different TB illness stages. Each FGD was conducted with between 7-8 participants at each of the selected nine clinics. People under the age of 16 years and patients with treatment for less than 2 months, were excluded because they were perceived to be "less experienced" in having TB. In total, 85 patients participated in the FGDs. Table 5.5 reflects the characteristics of the focus group participants. Of the 85 participants in the nine groups, 53% (n=45) were males. The ages of the participants ranged from 18 to 57 years. The vast majority of the patients (72%, n=61) were new patients (patients who had never before been treated for TB), and only 8% (n=7) were employed. Thirty-six percent of the participants indicated that they were living or had lived with someone who had TB before they could be diagnosed with the disease.

5.5 Data collection

This study made use of the following data sources: survey among 220 pulmonary TB patients, focus group sessions with health care providers in the Free State, treatment outcomes of the 220 patients from TB Registers, and focus group discussions with 85 pulmonary TB patients.

Figure 5.2: Time frame of data collection



5.5.1 The survey: training of fieldworkers

Four fieldworkers conducted the individual face-to-face interviews. Three of them were females and one male. Three of the fieldworkers were research assistants at the CHSR&D, and one was recruited because of his previous involvement in various research projects. Thus, all the fieldworkers had previous experience in conducting interviews.

The fieldworkers underwent four days of training conducted by the researcher. During the first day, the fieldworkers were explained the purpose of research in general, the purpose of this investigation, the potential impediments that they might encounter in the field, and the dangers of interviewing TB patients. They also received training on the basics of TB on this day. On the second day, the researcher went step-by-step through the interview schedule with the fieldworkers. The fieldworkers were asked to interview one another after this exercise. The third day involved a visit to a local clinic where each fieldworker conducted two practical interviews with TB patients. After this, they provided feedback on the interview schedule and the attitudes and behaviour of patients. This feedback session proved invaluable with regard to the logistical arrangements for the survey and for adapting the questionnaire. The fourth day was reserved for the logistical arrangements.

Information from the patients was collected over a period of one month, i.e. during October 2001. The face-to-face interviews were conducted in the native language of the patients, and edited immediately by the researcher for quality assurance and validation of responses. If any discrepancies were found, the relevant fieldworker was asked to obtain the information from the patient. The interviews lasted approximately one hour. Data quality was achieved by immediately checking the completed questionnaire for omissions and accuracy. If any major discrepancies were found, the patient concerned was re-interviewed.

The data on the treatment outcomes of the selected 220 patients were collected by two researchers from the CHSR&D during November 2002, twelve months after the survey. The data were obtained from the TB Registers at the nine clinics. As stated earlier, the focus group discussions were facilitated by the researcher and one experienced co-facilitator or note-taker. The researcher conducted the discussions, while the co-facilitator was responsible for observing non-verbal interactions and documenting general contents of the discussion, as well as statements made by particular individuals.

5.5.2 Focus group discussions

The moderator telephonically informed the staff of the selected clinics about the study. He also personally visited the respective clinics three days before the FGDs, to draw the sample and to make the necessary logistical arrangements. All the participants gave informed consent to be interviewed.

The focus groups discussions were facilitated by the principal researcher and an experienced fieldworker during February 2003. Before each focus group discussion, the researcher welcomed and told the participants about the purpose of the discussion. The participants felt confident and at ease, and spoke freely as they already knew one another. All the focus group discussions were conducted at the nine selected clinics. This was done to avoid already stressed patients having to travel to another central venue. Experiences from the survey which preceded the focus group sessions indicated that TB patients become hungry after having taken TB medication. It was therefore feared that most of those selected for the focus groups discussions would not be able to remain for the duration of the sessions after having taken their medication. For this reason, it was decided to provide food parcels worth R35.00 to each participant during the sessions. Thus, the food was not meant to coerce participants.

The focus group sessions, which lasted about an hour, were conducted in the languages of the participants (i.e. Sotho and Tswana), and audio-taped with the participants' consent. Field notes were written immediately after each focus group session. The recordings were later transcribed, and translated into English. Another researcher who did not participate in the study itself re-translated the English version. Thereafter, the transcripts were compared, and the necessary adaptations were made.

5.5.3 Data collection instruments

(i) Interview schedule

The choice of an interview schedule as the preferred data collection method in the survey was not considered to be a short and easy method of understanding the lives of TB patients, but was the 'best' available technique to achieve the research objectives. Furthermore, the interview schedule was decided upon for the following reasons:

- A large percentage of the patients were expected to be illiterate and could, as a result, not read the questionnaire.
- Most of the respondents were expected to regard research as being 'alien', and so misunderstandings could arise. This unfamiliarity could induce apprehension and avoidance, with low response rates if mailed questionnaires had been used.
- Interviewers could immediately further elaborate and interpret some of the questions.

Extensive use was made of literature and other relevant interview instruments in the construction of the interview schedule (see Appendix A). For comments and inputs, the instrument was also submitted for comments and inputs to various researchers of the CHSR&D, Belgian academics, and health care managers and workers in the Free State. To a large extent, the analytical framework discussed in Chapter 1 was used to construct the interview schedule. As stated earlier, the instrument was piloted by four interviewers among eight TB patients, and was adapted afterwards. The interview schedule was divided into four broad sections, namely background or socio-demographic information, household habitation, socio-economic details and the patient 'career'. The following **indicators** from the four sections were analysed:

Section A: Background information

- Category of patient; gender; age; marital status; and risk profile

Section B: Household habitation

- Type of dwelling; number of inhabitants; availability of facilities/infrastructure; migrant status; and the TB status of fellow household members

Section C: Socio-economic details

- Educational level; employment status and occupation **prior to** and **after** illness with TB; monthly personal and cumulative household income **prior to** and **after** illness with TB; situation of the unemployed (“not working”); and effect of TB infection of patient on employment

Section D: Patient ‘career’

- *Symptom experience phase* (knowledge and perceptions of TB; initial symptoms; and response to initial symptoms)
- *Assumption of the sick-role phase* (discussion of initial symptoms; advice received; and nature of health-seeking behaviour)
- *Health care contact phase* (first health care provider/facility contacted; diagnostic delay; difficulties experienced in seeking health care; experience of diagnosis; reaction of people after hearing of illness
- *Dependent-patient role* (current health status; support networks; and stigmatisation)
- *Recovery or rehabilitation stage* (treatment outcome)

Most of the questions are of a close-ended nature, and responses have been coded in advance, according to the most obvious expected answers, and according to answers received from the pilot study. Open-ended questions are also used in those cases where responses required more detail and discussion.

The interview schedule was translated into Sotho and Tswana by the principal researcher. It was then pre-tested by asking another researcher to translate it back into English. A number of errors and misinterpretations were also eliminated during the training of the interviewers. This process also eliminated a number of difficulties in the statistical analysis.

(ii) Focus group discussion guide

The focus group discussions began with general questions before focusing on more specific questions as the interview progressed (the funnel approach), using a topic guide to ensure that the same areas are covered in each focus group. The questions covered whether participants knew about TB before being diagnosed with it, how they learnt about TB, health education strategies, perceived factors contributing to non-compliance, strengths and weaknesses of health promotion campaigns, and suggestions on how TB health promotion campaigns can be improved and sustained. First the transcripts were re-read several times to get a first-hand impression of the content. The transcripts were analysed qualitatively and categorised logically for identification of patterns in and between the concepts, using content analyses. The transcribed data was then categorised according to the themes that guided the discussions (see Appendix C).

5.6 Data analysis and reporting

This section reports on the general procedures followed in the analysis of the data. More specific procedures are discussed at relevant sub-sections dealing with the empirical findings. The survey data was coded, defaulted, and captured electronically by research assistants at the CHSR&D using the Statistical Package for the Social Sciences (SPSS). Thereafter, the researcher ran programmes to validate the reliability of data. Firstly, information of the respondent was corrected when missing. Secondly, routine computer programmes were run to check the flow of skip patterns in the questionnaire.

The data analyses were based on the 220 PTB patients who were selected for this study. Frequencies were calculated for each item in the questionnaire. Chi-square analyses were used to determine the association between knowledge and perceptions of TB, delay behaviours, health-seeking behaviour and social support, for example, and patient characteristics such as patient category, gender, age, education and employment status.

Bivariate analysis was also used to compare adherent and non-adherent patients in terms of certain key characteristics, which include socio-demographics and a number of possible determinants of adherence. The Chi-square and t-test were used to assess the statistical significance of these differences in the case of categorical variables and continuous variables respectively. Multiple logistic regression was employed in investigating the determinants of adherence controlling for the possible effects of other variables. In this regard, data were analysed using SPSS 10.1 and Stata8 statistical software.

Already, some of the data were presented at a series of workshops in the Free State attended by health care managers and providers; to senior management of the Department of Health in the Free State; and at several national and international conferences (see Appendix F for some of the outputs of this study).

5.7 Strengths and limitations of the study

This study confined itself to interviewing clinic-based pulmonary TB diagnosed patients at nine clinics in the Free State, South Africa. This confinement of the study to three case study sites decreases the generalisability of findings and, as a result, the researcher experienced this as a limitation. Furthermore, retrospective cross-sectional studies, such as this one, look backwards in time for exposures or factors related to the research topic. There is, therefore, a total reliance on the responses of respondents about things that happened in the past and this may lead to recall bias. Patient recall regarding the onset of symptoms may be inaccurate, despite the structured interview approach and repeated qualitative probing to validate responses. It was also not determined when treatment started after presentation to a service provider.

Cross-sectional studies look for “correlation” between variables assumed to be “effects”: dependent variables and variables assumed to be casually prior (independent variables). Cross-sectional studies may also be more prone to confusing correlation (co-variance) with causation. Other studies (Blaxter, 1990; RECAPP, 2002) have highlighted the importance of risk behaviour, such as smoking and alcohol consumption, in fuelling diseases such as TB. However, no such information was gathered in this study. It would perhaps be an ideal for future research to include these behaviours to assess the extent of exposure.

Chapter 6:
Research results: Profile of the survey patients

> "Individuals who enjoy good health rightly think of themselves as fortunate. But luck has little to do with the broad patterns of disease and mortality that prevail in each society. The striking variations in health conditions among countries and cultural groups reflect differences in social and physical environments. And increasingly, the forces that shape health patterns are set in motion by human activities and decisions" (Eckholm, 1977:18-19).

6.1 Introduction

There is an inextricable link between tuberculosis and poverty (Danusantoso 2002; Grange 1999; Strebel & Seagar 1991; Symonds 1998; WHO, 2002a). The South African Population Policy, adopted in April 1998, has come a long way in addressing the living conditions of the South African population. This was not an easy task as strategies aimed at poverty eradication and the reduction of inequality has to deal with the influence of past population strategies that served as tools of oppression, exploitation, and segregation. Many people are "*still poor and vulnerable, and unable to benefit from the sustainable development envisaged in the population policy*" (National Population Unit, 2000:12). The poor continue to live in poor shelters; they have limited access to potable water, inadequate sanitation or a lack of sanitation and waste disposal facilities, and they use polluting energy sources (Department of Welfare, 1998). These factors are directly linked to the high prevalence of preventable diseases such as tuberculosis (Cockerham, 2001; Grange, 1999:12).

This section of the thesis reports on the empirical findings of the investigation. The survey was based on a random sample of 220 pulmonary TB patients which was stratified proportionally according to patient categories. The aim of this chapter is to construct a profile of the sample. In this regard, the focus is on the socio-demographic characteristics (i.e. gender, age, marital status) and socio-economic characteristics (i.e. type of household, occupation, income, education, and availability of infrastructure/services) of the patients. This is followed by findings aimed at eliciting the risk profile of the patients (e.g. history of employment on mines and imprisonment). Although not explicitly documented in either the Health Belief Model (Jane, 2001:3) of the Theory of Reasoned Action, factors related to the individual, such as demographic variables, economic variables and personality factors are known to influence health behaviour (Rupel & Garro, 1992:627; Weiss & Lonnquist, 1997:118; Fife & Wright, 2000: 50-51).

6.2 Patient categories

The Short-Course Chemotheraphy[1] (SCC) has an initial phase of 2-3 months, and a continuation phase of 4-7 months (Department of Health, 1999:5). The reliability of the data obtained on patient category can be assessed primarily by comparison with provincial data and national surveys. The distribution of patient categories in different age/gender groups is shown in Table 6.1.

Most of the patients (68%) had no history of prior TB treatment. This rate is significantly lower compared with 90% found by Dick (1994:813) and 84% by Wilkinson *et al.* (2002). Two-fifths (41%) of the men aged 16-34 years and two-thirds (67%) of the women aged 50-64 were new patients (continuation phase). Table 6.1 further indicates that the prevalence of re-treatment patients was higher among men (37%) than among women (25%).

Table 6.1: Distribution of patient categories by gender and age, %

			Male					**Female**		
Category			**Age**					**Age**		
	16-34	**35-49**	**50-64**	**64+**	**All**	**16-34**	**35-49**	**50-64**	**64+**	**All**
New patient – intensive phase	11 (31)	16 (46)	7 (20)	1 (3)	*35* *(39)*	21 (58)	13 (36)	2 (6)	--	*36* *(36)*
New patient – continuation phase	14 (34)	16 (39)	11 (27)	--	*41* *(34)*	23 (61)	9 (24)	6 (16)	--	*38* *(38)*
Re-treatment patient – intensive phase	1 (6)	11 (61)	6 (33)	--	*18* *(15)*	5 (33)	9 (60)	1 (8)	--	*10* *(10)*
Re-treatment patient – continuation phase	8 (30)	13 (48)	5 (19)	1 (4)	*22* *(22)*	4 (40)	6 (60)	--	--	*10* *(10)*
Total	*34* *(28)*	*56* *(46)*	*29* *(24)*	*2* *(2)*	*121* *(100)*	*53* *(54)*	*37* *(37)*	*9* *(9)*	--	*99* *(100)*

P= 0.472

Table 6.2 shows that almost similar proportions of men (53%) and women (52%) with a history of prior treatment were previously cured. There was a vast difference between men (22%) and women (8%) who had previously interrupted their treatment. This is a serious concern since

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[1] SCC is a combination of potent anti-TB drugs (isoniazid, rifampicin, pyrazinamide, streptomycin and ethambuthol).

defaulters not only have to deal with the resurgence of infection, but the threat of MDR TB, which is more fatal.

Table 6.2: Type of re-treatment patient by gender

	Male		Female	
Category of re-treatment	**n**	**%**	**n**	**%**
After previous cure	24	53	13	52
After previous treatment completion	8	18	7	28
After previous treatment interruption	10	22	2	8
After previous treatment failure	3	7	3	12
Total	*45*	*100*	*25*	*100*

P=0.108

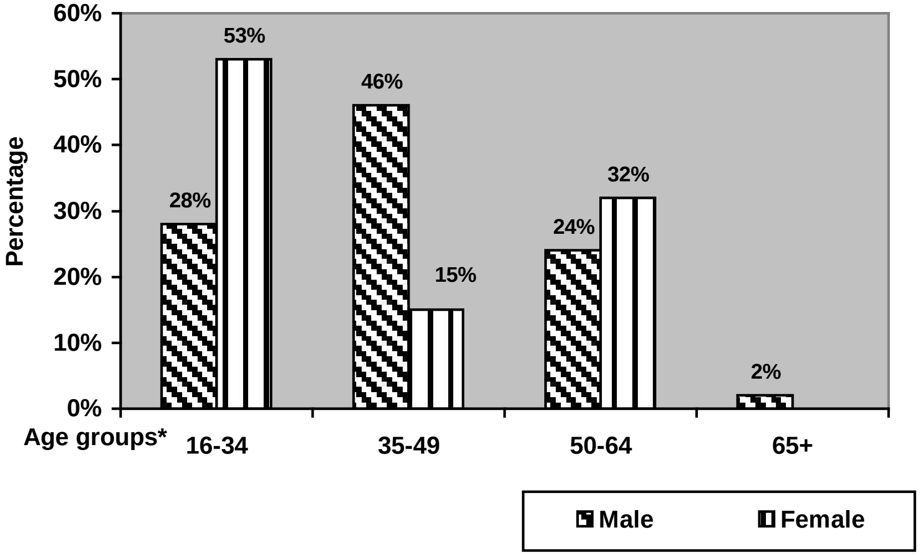
6.3 Socio-demographic characteristics of the study sample

The sample is described according to the socio-demographic variables identified in paragraph 6.1

6.3.1 Distribution of sample by age and gender

An important feature of the population composition is the age and gender distribution. The term gender here encompasses features of males and females that are socially constructed and distinct from those features that are biologically determined (sex-linked). The difference in notification rates in men and women partly reflect epidemiological differences such as differences in respect of exposure, risk of infection, and progression from infection to disease (WHO, 2002b).

Figure 6.1: Age and gender distribution of the study sample



NOTE: These age categories are used in the South African National Censuses.
P=0.120

The gender structure of the patients shows a relatively uneven gender distribution of 55% (n=121) males and 45% (n=99) females. This is similar to the findings of other studies (Needham *et al.* 2001; Pronyk, 2001). A study on PTB patients in Botswana showed a significantly uneven gender distribution of 69% males and 31% females (Steen & Mazonde, 1999). This confirms the assertion that, in most parts of the world, more men than women are diagnosed with TB (WHO, 2002b). In two of the study areas, Qwaqwa and Thaba Nchu, there are more females than males. The gender distribution in the Goldfields again favours males. The higher number of males in the Goldfields is attributed to the large mining industry and the accompanying migrant labour force (Van Rensburg & Redelinghuys, 2001)

According to Bhatia *et al.* (2002:430), age is one of the most important determinants of susceptibility to TB disease in all societies. They argue that the natural "*senescence*" of the immune system with advancing age results in reactivation of latent infection in the elderly. Only 2% of the 220 patients were older than 64 years. The mean age was 38 years (range 16-67 years). Female patients were significantly younger than males (35 years compared with 41 years, respectively). This is similar to the mean age of PTB patients in a study by Steen & Mazonde (1998). The age-gender distribution of the sample population is represented graphically, in Figure 6.1. The modal age is 43 years for males and 36 years for females. This confirms the notion that, traditionally, TB is most prevalent among adolescent and young economically active adults. Bhatia *et al.* (2002:430) provide an explanation for this trend: "*In terms of exposure, young people* *at these ages becomes independent, more mobile, integrate into the world of adults, thus exposing themselves to the prevalent risk of TB in society, rather than in the micro-environment of their family*."

6.3.2 Marital status

The marital status of the patients is shown in Figure 6.2. Many (42%) of the sampled patients was single, and slightly more than a third of them (35%) were married. Almost similar proportions of the patients were either widowed (10%) or divorced (9%).

Figure 6.2: Marital status

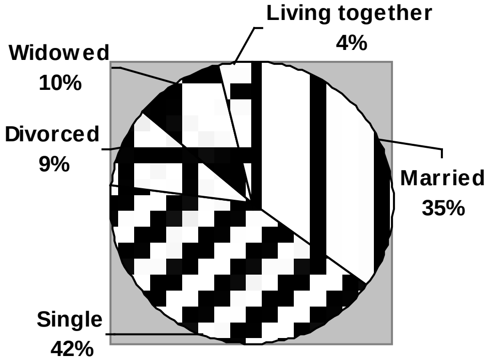


Table 6.3 shows that there was a statistically significant association between marital status and gender (P=0.014). More than double the portion of males (55%) than females (22%) were married. Half of the women (50%) and more than a third of the men (37%) were single. Approximately 8% of the men and 11% of the women were divorced, and 10% of men and 17% of women were either cohabiting or widowed. Studies by Macintyre (1992) and Martikainen (1995) suggest that marriage is supportive of good health. It also seems that being a single mother is a particularly disadvantageous position for women, as well as for their health (Whitehead *et al.,* 2000).

Table 6.3: Marital status by gender

	Male		**Female**	
Marital status	**n**	**%**	**n**	**%**
Married	54	45	22	22
Single	44	37	49	50
Divorced	10	8	11	11
Widowed	4	3	4	4
Live together	9	7	13	13
Total	*121*	*100*	*99*	*100*

P=0.014

6.4 Socio-economic profile of the sample

Socio-economic conditions are the major determinants of infection in South Africa. Authors of decades ago, like Dubos & Dubos (1953:vii), also confirm this. It has been widely stated, that "*social status in the economic sense is the most important factor in controlling TB*" (Yach, 1988:72). Higher social status and better physical mental health are linked. Health and well-being coincide because both help individuals to succeed: "*Mostly, though, they coincide because the opportunities, orientations, abilities, and resources that create or result from achievement also sustain health and well-being. Social standing takes form in education, employment, occupation, daily work, earnings, income, household prosperity, neighbourhood, poverty, and so on*" (Mirowsky *et al.,* 2000:47). Difference in status means difference in hardship, stress and in psychological resources to fight against TB. The socio-economic status of the patients is reflected by their educational level, employment and occupational status, income and household characteristics.

6.4.1 Educational level

Studies around the world (Kaplan *et al.,* 2003; *Luo*-Ping *et al.*, 2004; Valle *et al.*, 2004) have found that there is a strong correlation between educational level and the success or failure of intervention programmes. Education shapes lifestyle directly as well as indirectly, by increasing the sense of personal control. Of the four elements of social status, education acts as the most consistent predictor of healthy lifestyle. Compared with the poorly educated, well-educated people more frequently engage in proven healthy behaviours (Mirowsky *et al.*, 2000:55). Education instils better health habits which in turn improve health.

The educational level of the patients in this study is shown in Table 6.4. The information contained in the table reflects the highest level of education completed according to gender, age, employment status and monthly per capita income. Educational levels are almost similar for both males and females, except for their primary school (grades 1-6) qualifications (23% of males compared with 15% of females). A relatively small proportion of females (2%) have completed a post-school qualification compared with none of the males. Only 9% of both males and females have never been to school.

The relationship between age and the level of education is statistically significant (P-value <.006). Small proportions of the young (aged 16-34) and middle-aged (aged 35-49) patients have no educational qualifications (5% and 7%, respectively) compared with 74% of the older group (aged 50+). Nearly a fifth (19%) of the young patients have completed matric, compared to 4% with the group aged 35-49 and 3% of the group aged 50-64. The median year of education completed for both males and females is Grade 8. Thus, the level of education shows a more pronounced decline with age. The level of education did not have a significant impact on employment status. However, self-reported per capita monthly income exhibited more profound relationships with highest level of education completed. As expected, the higher the level of income, the greater was the level of education. This situation holds several serious implications for the control of diseases such as TB and, perhaps, explains the continuing increase in TB infection rates.

Table 6.4: Distribution of the highest education completed according to gender, age, employment status and monthly per capita income

Background Characteristics	No education n (%)	Grade 1 – Grade 6 n (%)	Grade 7 – Grade 11 n (%)	Grade 12 (matric) n (%)	Diploma/ other post-school complete n (%)	Total n (%)	P
Gender							0.280
Male	11 (9)	28 (23)	70 (58)	12 (10)	-	*121 (100)*	
Female	9 (9)	15 (15)	59 (60)	14 (10)	2 (2)	*99 (100)*	
Age							0.000
16-34	4 (5)	8 (9)	53 (61)	21 (24)	1 (1)	*87 (100)*	
35-49	6 (7)	21 (23)	61 (66)	4 (4)	-	*93 (100)*	
50-64	9 (24)	14 (37)	14 (37)	1 (3)	-	*38 (100)*	
65+	1 (50)	-	1 (50)	-	-	*2 (100)*	
Employment status							0.633
Employed	4 (6)	13 (19)	43 (64)	6 (9)	1 (2)	*67 (100)*	
Unemployed	16 (11)	30 (20)	86 (56)	20 (13)	1 (1)	*153 (100)*	
Income							0.006
R1– R1000	2 (5)	12 (30)	23 (58)	3 (8)	-	*40 (100)*	
R1001-R3500	2 (8)	1 (4)	19 (79)	1 (4)	1 (4)	*24 (100)*	
R3501+	-	-	1 (33)	2 (67)	-	*3 (100)*	
Total	*20 (9)*	*43 (19)*	*129 (59)*	*26 (12)*	*2 (1)*	*220 (100)*	

The educational qualifications of the sampled TB patients are relatively low. After four decades of racially skewed education, schooling is one of South Africa's greatest challenges. Almost 20% of the adults in the country have received no education at all, and almost 17% have not completed primary school (Statistics South Africa, 2003). According to Van Rensburg & Redelinghuys (2001), 18% of the population in the three selected areas did not have formal education and 33% had an education level of between Grades 1-6.

Education not only reflects the level of knowledge about alternative courses of action available, but also the skills in utilising social facilities (Twaddle & Hessler, 1987:45). Knowledge alone, however, does not make patients more compliant (Liefooghe 2000:54). Other factors such as hunger, availability of transport money, and the attitude of health care providers may have a significant influence on the behaviour of patients. Nonetheless, low levels of education might not only be detrimental to efforts towards health education and awareness regarding tuberculosis, but also towards the treatment and management of the disease.

6.4.2 Literacy and exposure to mass media

In order to gauge the literacy level of the patients, they were asked whether they were able to read and understand a letter or newspaper in their own language. Results are tabulated in Table 6.5. Broadly, the data indicate that the largest proportion of the patients (81.8%) could easily read a letter or newspaper in their own languages. Relatively few patients said they could read a letter or newspaper with difficulty in their own language (8.2%) or not at all (10%). Regarding exposure to mass media, only a third of the patients (33.4%) read a newspaper the week prior to the survey, while large proportions listened to the radio (75%) and watched TV (70.5%).

Table 6.5: Literacy and exposure to mass media according to gender, age and education

Background Characteristics	***Literacy*: Can read and understand a letter or newspaper in your home language?**			***Exposure*: Have done the following in the past week? ***		
	Easily **n (%)**	Difficulty **n (%)**	Not all **n (%)**	Read a newspaper **n (%)**	Listened to the radio **n (%)**	Watched television **n (%)**
Gender						
Male	98 (81)	11 (9)	12 (10)	42 (35)	97 (80)	84 (69)
Female	82 (83)	7 (7)	10 (10)	33 (33)	68 (69)	71 (72)
Age						
16-34	76 (87)	7 (8)	4 (5)	33 (38)	69 (79)	72 (83)
35-49	81 (87)	5 (5)	7 (8)	35 (38)	64 (69)	62 (67)
50-64	22 (58)	6 (16)	10 (23)	7 (18)	30 (79)	20 (53)
65+	1 (50)	--	1 (50)	--	2 (100)	1 (50)
Education						
No education	2 (10)	--	18 (90)	1 (5)	11 (55)	10 (50)
Grade 1 –Grade 6	30 (70)	9 (21)	4 (9)	3 (7)	26 (61)	22 (53)
Grade 7 – Grade 11	120 (93)	9 (7)	--	54 (42)	104 (81)	99 (77)
Grade 12	26 (100)	--	--	16 (62)	22 (85)	23 (89)
Diploma / other post-school completed	2 (100)	--	--	1 (50)	2 (100)	1 (50)
Total	*82*	*8*	*10*	*34*	*75*	*71*

NOTE: * Only includes the "yes" responses

An understanding of media exposure is important for TB awareness campaigns. In fact, both the Health Belief Model (HBM) and the Help-seeking Behaviour Theory (HSB) (*see Chapter 2*) emphasise the role of knowledge (which, to a large extent is conveyed by the mass media). The

HBM, in particular, recognises that the presence of an external catalyst (media campaigns) triggers cognitive processes involved in considering the various components of health behaviour (Jane, 2001:2).

Table 6.5 further indicates that younger patients (16-49 years), as compared with older ones (65 years and older), reported being able to read and understand a letter or newspaper easily in their own language (87% versus 50%). Older patients also reported a low level of exposure to conventional mass media. As expected, only 10% of those without any formal education could read and understand a letter or newspaper in their own language. However, it is interesting to note that only small proportions of the patients who completed matric/Grade 12 and higher, had read a newspaper, or listened to the radio, or watched TV a week before the survey.

6.4.3 Employment and occupational status

Table 6.6 shows the relationship between employment status and occupational distribution, and gender. Overall, the number of patients who were unemployed before diagnosis with TB increased from 35% to 70% afterwards. The results show that there was a statistically significant relationship between employment status and gender before diagnosis with TB (P=0.005), and even a much stronger relationship between occupational distribution and gender (P=0.000). Far more males were unemployed before diagnosis with TB than females (64% compared with 40%, respectively). Slightly more males than females were also unemployed after diagnosis with TB (P=0.226, 21% compared to 15%, respectively). Of note is the significant increase in the number of patients who were self-employed after contracting TB (from 25% to 66% of males and 48% to 74% of females).

Regarding occupational composition, there was a slight decrease in the percentage of patients in both skilled labour and service categories after having contracted TB. There was a significant relationship between occupational composition and gender both before diagnosis (P=0.000) and afterwards (P=0.007). More male patients than females were employed in skilled labour occupations before diagnosis (64% *versus* 44%) and semi-skilled occupations (28% *versus* 14%). Similarly, more males were still employed in skilled and semi-skilled occupations at the time of the survey. Table 6.6 further illustrates that far more females than males were service workers before and after diagnosis with TB. This is understandable, because, due to limited career options, many black women are often forced to seek employment from white families as domestic “servants.”

Table 6.6: Employment status and occupational distribution by gender, %

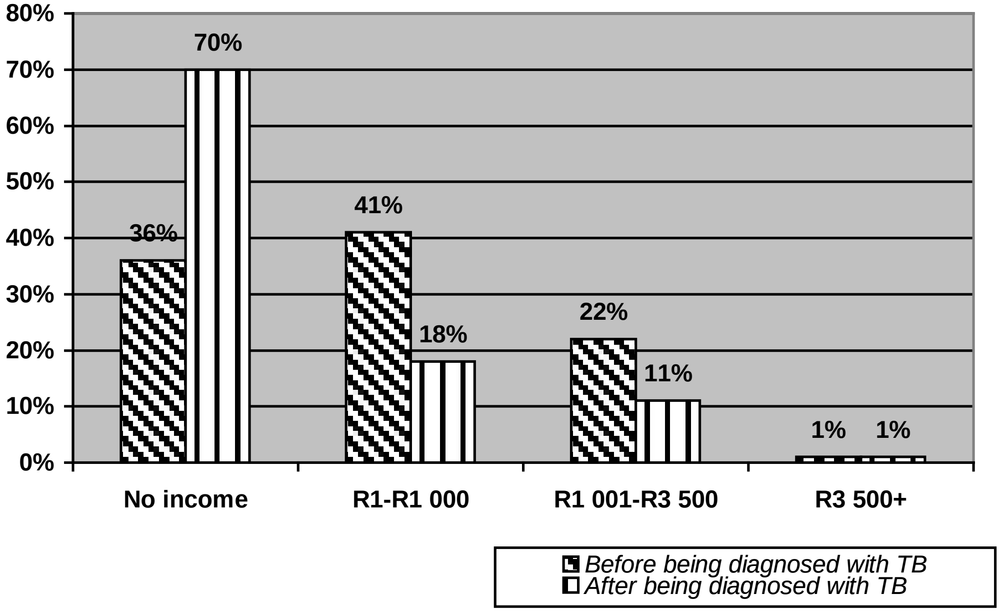
	Before diagnosed with TB				After diagnosed with TB			
	Male	**Female**	**All**	**P**	**Male**	**Female**	**All**	**P**
Employment status				0.005				0.226
Unemployed	64	40	35		21	15	70	
Full-time – formal	7	5	53		3	1	18	
Part-time – formal	2	4	6		6	3	2	
Informal employment	3	3	3		4	7	5	
Self-employed	25	48	3		66	74	6	
Total	*101*	*100*	*100*		*100*	*100*	*101*	
Occupational composition				0.000				0.007
Skilled labour: Professional, technical, sales and clerical workers	64	44	56		51	38	47	
Semi-skilled or *unskilled labour*: Operatives, craft and kindred workers	28	14	24		44	27	37	
Service workers: Domestic and other service workers	8	42	20		5	35	16	
Total	*100*	*100*	*100*		*100*	*100*	*100*	

6.4.4 Income distribution

Generally, a single monetary indicator, such as income or expenditure, is employed in assessing the extent of poverty and inequality (Ravallion, 1996:1328-1334). Income is argued to reflect consumption opportunities and is, therefore, a popular measure of poverty (Hagenaars, 1991:135-146). Income is one of the important determinants of health. Lack of income usually curtails people's ability to participate fully in social activities and renders them vulnerable to external risks (Lock *et al.*, 2001:665), such as dismissal. This section gives an overview of reported income distribution and average income levels across a few demographic characteristics and sectors of the economy. The self-reported incomes of the patients are represented by the per capita income earned (Figure 6.3) and the income earned per household (Figure 6.4) before and after being diagnosed with TB.

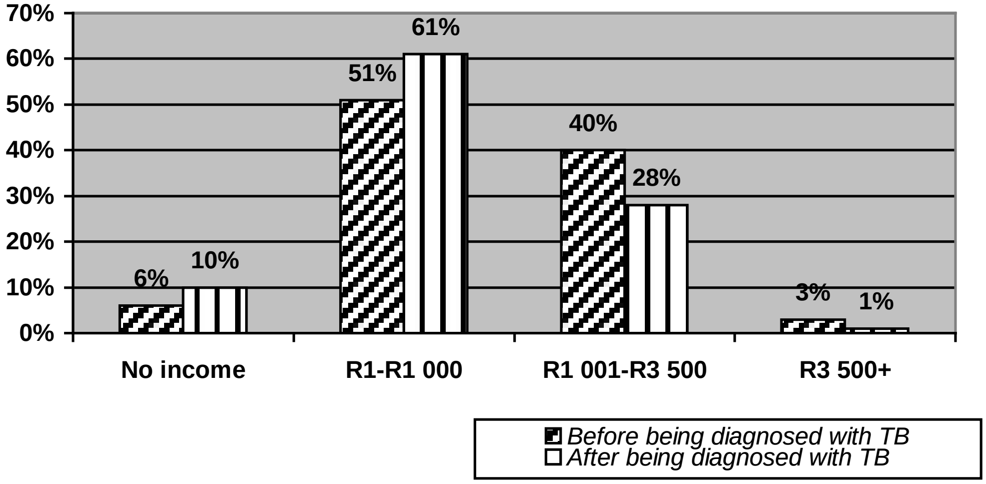
Figures 6.3 and 6.4 below show that considerable income changes occurred in the monthly per capita income and the monthly household income of the patients. In Figure 6.3, it is apparent that the patients' incomes were negatively affected after being diagnosed with TB. Only 36% of the patients did not earn any income immediately prior to being diagnosed with TB. The proportion of patients who did not earn any income after being diagnosed with TB doubled to 70%. Two-fifths (41%) of the patients earned less than R1 000 per month before being diagnosed with TB, and only less than one fifth (18%) afterwards. No change was recorded for the income category R3 500+, which remained at 1% prior to being diagnosed and also afterwards. It is not really known whether these income patterns are a result of being ill with TB.

Figure 6.3: Monthly per capita income



Studies by Kasl & Cobb (1982), Pearlin *et al.*(1981) and Sandifer & Stein (1985) have found that the people who are unemployed have poorer physical and mental health than others with similar backgrounds who remain employed. Low income, poverty and economic hardship erode health (Mirowsky *et al.*, 2000:50-51), thus raising the risk of TB infection, impairment and death. The data below, concerning income of households, also gives an indication of the economic circumstances of the patients' households. The largest proportion of the 220 households had a monthly income of between R1-R1 000 (51% before being diagnosed with TB and 61% afterwards). The results also indicate a slight difference between those households that did not have any income before the patients fell ill with TB (6%) and at the time of the survey (10%).

Figure 6.4: Monthly household income



6.4.4.1 Mean and median income levels

Table 6.7 provides the mean and median self-reported monthly per capita and monthly household income levels by socio-demographics (gender, education, and occupational category). These measures of central tendency allow us to speculate which groups and sectors of the economy are better off due to higher wage levels.

Table 6.7 shows that the mean income after diagnosis with TB, for females (R400) is far lower than that of males (R1000). There were slight increases in both the male and female mean and median income levels, after diagnosis with TB. The age differences are also noteworthy, with the mean and median income levels of the age group 50-64 years significantly higher than other age groups. The mean and median income levels of the age group 35-49 years, after diagnosis with TB, decreased. This is perhaps the most striking aspect of Table 6.7.

The mean and median income levels by occupational category show that there is considerable variation in average incomes among occupations. As expected, the occupational category with the highest mean income, both before and after diagnosis with TB, is skilled labour (R111.50 before diagnosis and R1434 afterwards). Semi-skilled occupations show a decrease in mean and median income levels, both before diagnosis with TB and afterwards.

Generally, and surprisingly, there has been a notable improvement regarding mean and median monthly per capita income. The reason behind this unusual finding could be related to the finding that, after being diagnosed with TB, two-thirds (66%) of the patients indicated that they received support (including financial support) from family members (*see Table 6.9*). Indeed, it is a common practice in African families to look after one another.

Table 6.7: Mean and median per capita income levels in Rand before and after being diagnosed with TB

	Mean		Median		Minimum		Maximum	
	Before	**After**	**Before**	**After**	**Before**	**After**	**Before**	**After**
Gender								
Male	1094.15	1251.58	973	1000	80	100	5000	5000
Female	797.07	942.80	480	600	60	60	4150	4150
Age								
16-34 years	844.75	1177.55	635	900	60	60	5000	5000
35-49 years	1117.14	1024.32	1000	840	150	120	4150	4150
50-64 years	901.69	1476.22	800	1500	80	876	2800	2800
65+ years	1500	-	1500	-	1500	-	1500	-
Occupational category								
Skilled labour	1110.50	1434.00	905	1145	80	100	5000	5000
Semi-skilled labour	1068.66	940.95	960	876	200	120	2600	2600
Service workers	545.37	701.81	300	700	60	60	2070	1500
Total	*985.36*	*1130.96*	*800*	*1000*	*60*	*60*	*5000*	*5000*

Table 6.8 shows that there was considerable inequality in the manner in which male and female patients' self-reported monthly household income was affected, after diagnosis with TB. For male patients, the mean household income level before diagnosis with TB decreased from R1349.90 to R994.19 afterwards. This is a decrease of more than R355. The mean household income level of female patients after diagnosis with TB shows a much lower decrease of R160 (from R1053.19 to R892.30). Generally, the mean household income levels of patients before diagnosis decreased from R1 214.50 (range R50-R5 150) to R946 (range R20-R5 150) afterwards.

Table 6.8: Mean and median household income levels in Rand before and after diagnosis with TB by gender

	Mean		Median		Minimum		Maximum	
	Before	**After**	**Before**	**After**	**Before**	**After**	**Before**	**After**
Gender								
Male	1349.90	994.19	1150	815	80	50	5000	5000
Female	1053.19	892.30	810	570	50	20	5150	5150
Total	*1214.50*	*946*	*985*	*642*	*50*	*20*	*5150*	*5150*

6.4.5 Financial, work and living circumstances after being diagnosed with TB

Patients were asked questions regarding their financial, work and living circumstances after being diagnosed with TB. Of the 67 patients who were still employed at the time of the survey, 23 (34%) indicated that they were on sick leave while under treatment. Nineteen (85%) of the 23 patients on sick leave sick leave earned a full salary, and the remaining four (16%) were paid for a limited period only. This is a further indication of the difficulties experienced by TB patients in the course of their illness career. Slightly more than one-third of the patients (37%) reported being main breadwinners, while only a paltry 4% had access to medical aid. In a study on the socio-economic impact of HIV/AIDS, Booysen *et al.* (2002) indicate that access to medical aid is regarded as the single most important predictor of poverty.

In response to the question as to whether they personally lost any income as a result of being diagnosed with TB, patients reported that they personally lost on average R683.31 monthly. According to the patients, their families were losing, on average, R2 535.84 per month after their income-generating ability was affected by having to accompany the patients or by staying away from work to care for them at home (Table 6.9). Families were losing between R20 and R36 000 per month in this way. Not only does being ill with TB imply loss of money; the opposite is also true: on average, patients received R397.69 in the form of grants or remittances as a result of their TB status. The study did, however, not determine how some patients accessed state grants, whereas others did not. This was not the purpose of the study.

Table 6.9: Reported monthly financial situation after being diagnosed with TB

	Reported personal income lost per month as a result of illness	Reported income family lost per month as a result of illness	Grants/remittances obtained per month as a result of illness
Mean	R683.31	R 2 535.84	R397.69
Range: Minimum	R 10.00	R 20.00	R 50.00
Maximum	R800.00	R36 000.00	R570.00

The perceived impoverishing impact of TB on the lives of the infected is clearly illustrated in Table 6.10. Only a few patients reported that their personal financial situation (2%) and their household's situation (2.3%) had improved after being diagnosed with TB. A larger proportion of patients indicated that their households' financial situation deteriorated (48%) rather than improved (2%).

Table 6.10: Whether personal and household finances improved after being diagnosed with TB

	Personal finances		Household finances	
	n	**%**	**n**	**%**
Remained the same	128	58	109	50
Improved	4	2	5	2
Deteriorated	88	40	106	48
Total	*220*	*100*	*220*	*100*

6.4.6 Situation of the unemployed ("not working")

As indicated earlier, 70% (n=153) of the patients were unemployed at the time of the survey. These unemployed patients were asked whether they had been employed when their employers became aware of their TB status. A quarter (25%, n=38) of the 153 indicated that they had been employed. When asked how they came to lose their jobs, the answers (see Figure 6.5) most frequently mentioned were resignation (50%, n=19), dismissal (unilateral termination of employment contract by employer) (24%, n=9) or retrenchment (reduction of personnel due to financial constraints) (21%, n=8). Retirement or having gone on maternity leave was mentioned by only a small minority of patients (3% in both instances).

Figure 6.5: How job was lost

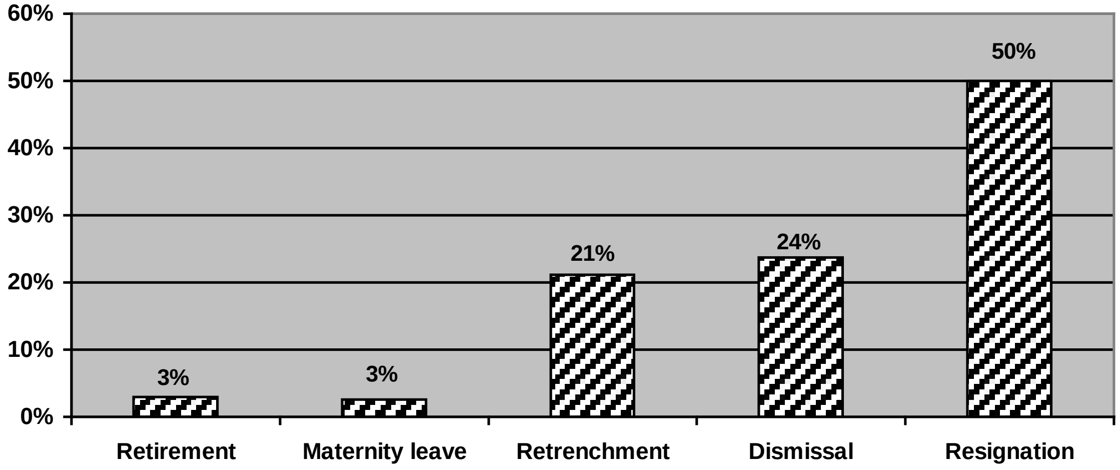


Table 6.9 shows how the unemployed patients made a living. The majority (66%) of the patients depended on family members for a living. Hawking/selling is the second most frequent means of livelihood mentioned by patients (14%).

Table 6.11: How the unemployed make a living

Source of living	n	%
Supported by family	101	66
Hawking/selling	21	14
Pension/grants/sick pay	7	4
Supported by friends	5	3
Unemployment Insurance Fund (UIF)	5	3
Investments	4	3
Begging	4	3
Nothing	3	2
Casual worker	2	1
Letting property	1	1
Total	*153*	*100*

6.5 Risk profile

Although any individual is at risk of being infected with TB, there are people who are more vulnerable. Factors that play an important role in the transmission and occurrence of the epidemic are many and complex. Foremost among these are HIV/AIDS, people working in mines and those living in overcrowded circumstances such as prisons (Department of Health, 2001b:2). Other risk factors include living with migrants and, perhaps more potent, living with untreated TB patients. It should be noted that the factors examined here are not inclusive of all the factors that can increase the risk of infection with TB. Notable omissions from this survey are data on four major habits: smoking, alcohol consumption, exercise and diet. As Blaxter (1990:114) states: "...*The assumption is that an individual who smokes and drinks heavily, and is careless of the health implications of exercise and diet, is leading a generally unhealthy life…"*

6.5.1 Situation pertaining to employment in mines and imprisonment

The battle against TB on mines is a difficult one, because it is aggravated by the presence of silicosis. A paper by Corbett (2001) at the *8th Conference on Retroviruses and Opportunistic Infections* found that silicosis, an occupational disease and strong TB risk factor, is one of the pre-existing health problems in South Africa.

According to the WHO (2003b), it is estimated that the world's prisons hold 8-10 million prisoners daily. A disproportionate number of prisoners come from socio-economically disadvantaged populations where the burden of disease may already be high and access to medical care limited (e.g. substance abusers, the homeless, the mentally ill, ethnic minorities, asylum seekers, immigrants). Prison conditions can also fuel the spread of disease through overcrowding, poor ventilation, weak nutrition, inadequate or inaccessible medical care.

Repeated prison transfers also encourage the transmission of TB infection. As indicated by the Department of Correctional Services (*Sowetan*, 2001:3), TB is one of the major causes of deaths in South African prisons after HIV/AIDS. The number of deaths in prison soared from a paltry 6 in 1995 to 103 in 2000.

Patients were asked a few questions to determine whether they had ever worked on a mine or had ever been in jail. Slightly less than a quarter (24%) had once worked on a mine and 11% had been jailed before. The mean duration of employment on mines was 9 months (range 1-36 months) and of imprisonment 6 months (range 1-30 months). The case for intervention is particularly strong for miners and prisoners, since old occupational health problems and overcrowding are currently significantly contributing to the impact of TB.

6.5.2 Migrant and TB status of other household members

Mobility may be an important factor that adds to disease infection (Bhatia *et al.*, 2002:430). Figures 6.6 and 6.7 illustrate the migrant and TB status of other household members. Only a few patients (11%) indicated that they lived with persons who were migrant labourers. Figure 6.7 reveals that a quarter of the patients (25%) reported that at least one other household member had TB at the time of the survey or previously.

Figure 6.6: Whether other household members are migrants

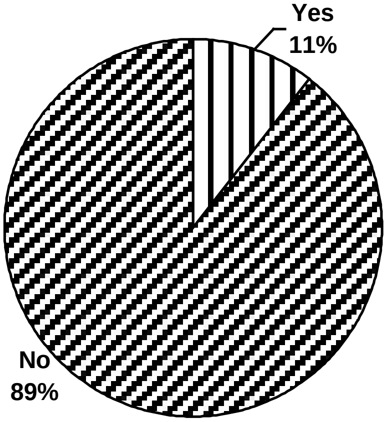


Figure 6.7: Other household members having TB

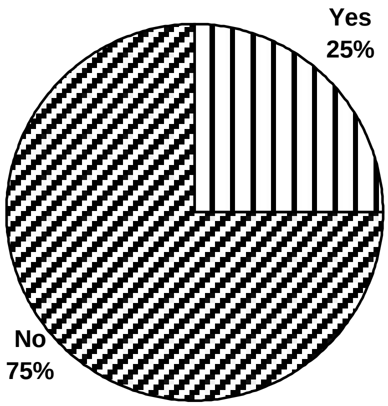


Table 6.12 presents the findings on the relationship between migrant and TB status of other household members. As can be seen, there was no statistically significant association between migrant status and gender (P=0.298). However, 12% of the male patients reported living with a single migrant compared with only 7% of the females. With regard to TB status, the number of other household members having TB was significantly related to gender (P=0.051). Male patients were more likely to live with one other household member who had TB before or at the time of the

survey (82% *versus* 67%). Conversely, female patients were more likely to live with two or three other household members who had TB before or at the time of the survey.

Table 6.12: The relationship between migrant and TB status of other household members by gender

Number of migrants	**Male** **n (%)**	**Female** **n (%)**	**P**
None	101 (87)	92 (93)	0.298
One household member	14 (12)	7 (7)	
Two household members	1 (1)	-	
Total	*116 (100)*	*99 (100)*	
Number of other TB patients			0.051
One member	98 (82)	66 (67)	
Two members	16 (13)	25 (25)	
Three members	5 (4)	7 (7)	
Total	*119 (100)*	*99 (100)*	

6.6 Household characteristics

6.6.1 Type of housing

In considering the chances of contracting TB, the type of housing has been used as a useful indicator for several dimensions of social class. The type of housing represents not only income, but also capital resources, security and broad standards of housing in a particular neighbourhood (Blaxter, 1990:91-92). Generally, those people most susceptible to diseases such as TB are the ones who lack decent housing (Mohamed, 2001:25). In respoect of the domestic environment specific attention was given to the type of housing, number of rooms, and the number of inhabitants (household size). This was done in order to determine whether there is any overcrowding and, thus, the risk of infection with TB.

The Project for Statistics on Living Standards and Development (SALDRU) survey of 1993 indicated a strong correlation between income and housing. The survey shows that 36% of very poor South Africans live in shacks and traditional dwellings. Despite several improvements by the government since then, many South Africans still live in shacks or traditional dwellings (Department of Welfare, 1998:13). Table 6.13 shows that the sampled patients are relatively well off in terms of housing as almost 70% live in modern houses on separate stands. Studies by Keithley *et al.* (1984) and McCarthy (1985) have particularly associated respiratory symptoms and infections with the design of dwellings.

Table 6.13: Housing characteristics

Characteristics		
Type of housing	**n**	**%**
Modern house or brick structure on a separate stand or yard	152	68
Traditional house/hut/structure made of traditional materials	18	7
Informal house/shack in backyard	17	8
Informal house/shack in informal/squatter settlement	12	6
Informal house/shack in a separate stand	6	3
Hostel	8	4
House/room in backyard	4	2
Flats	1	1
Workplace	2	1
Total	*220*	*100*

Results of the environmental scan (Van Renburg & Redelinghuys, 2002) indicate that the numbers of people living in informal settlements are fairly low in both Thaba ‘Nchu and Qwaqwa (10%). On the other hand, a large number of people in the Goldfields (35%) live in informal dwellings. Half of the Goldfields population (51%) live in formal dwellings on separate stands, and this is also the case for the Free State as a whole, where 50% of people live in such dwellings. The numbers of people living in formal type dwellings are high in both Thaba ‘Nchu and Qwaqwa where more than three-quarters of people (87%) live in formal structures, compared with 50% in the Free State as a whole (Van Rensburg & Redelinghuys, 2002).

6.6.2 Household size and number of rooms

Overall, the 220 sampled TB patients lived with 738 other people (958 in total). The total number of rooms available to all these household members, including the patients, was 445. This translates into an average of 4.4 persons per household and 2.1 persons per room. This was a clear indication that the households of the patients were crowded and held a potential threat to high infection rates. In fact, TB infection spreads more rapidly in crowded, enclosed settings (Bhatia *et al.,* 2002:249). Table 6.13 shows that almost half and one-fifth of the patients lived in two-room and three-room dwellings (48% and 20%, respectively).

Table 6.14: Household size and number of rooms

Household size	N	%
One member	21	10
Two members	28	13
Three members	27	12
Four members	43	20
Five to eight members	91	41
Nine to thirteen members	10	4
Total	*220*	*100*
Total number of rooms used		
One room	57	26
Two rooms	106	48
Three rooms	45	20
Four rooms	10	4
Five rooms	1	1
Six rooms	1	1
Total	*220*	*100*

6.7 Availability of services

Infrastructural services, such as electricity, water, sanitation and refuse removal, are central to the daily activities (cooking and washing, for example) of households. Access to reliable energy, clean water and sanitation plays an important role in improving quality of life and reducing poverty (*The Government of South Africa*, 1998). This assertion is further corroborated by the WHO and the World Bank's comment on the link between diseases such as TB and poor living conditions:

> *"As good health is crucial to protect the family from poverty, so better health is central to poverty reduction. Improving the health of the poor must become a priority, not only for public health but also for other sectors of development - economic, environmental and social. As Kofi Annan said: We shall not finally defeat … tuberculosis … or any infectious diseases that plague the developing world until we have also won the battle for safe drinking water, sanitation and basic health care …. The best cure for all these ills is economic growth and broad-based development*" (World Health Organisation & World Bank, s.a.:3).

6.7.1 Electricity

Table 6.13 provides data about the availability of services. The vast majority of patients (80%, n=176) had access to electricity, compared to 70% in the October Household Survey, 65% in the South African Demographic Health Survey, and 54% in the three study areas. Thirty-five (80%) of the 44 patients who did not have access to electricity reported using candles for lighting and nine

(21%) used paraffin. Nearly 2 out of 5 patients (39%), who did not have access to electricity, used paraffin as the main source of energy for heating, while 11% had no heating at all. Half of the patients (50%) without electricity used paraffin, wood (25%) and coal (23%) as the main source of cooking. According to *Statistics South Africa* (2001), more than half (53%) of households in South Africa relied mainly on electricity, paraffin (21%) and wood (20%) for cooking. The results show that the sampled patients were better off in terms of electricity compared with the general population in South Africa.

6.7.2 Water and sanitation

Provision of dependable water supplies and sanitation services make people less vulnerable to poor health and infection with TB. The data from Table 6.15 indicate that the patients in this study were better off in terms of access to piped water in house/yard (85%, compared to 50% in the three study areas) and flush toilet in house/yard (69%, compared with 36% in the three study areas). Whereas the overwhelming majority of the patients (85%) came from households with piped water in the house/yard, 15% and 1% came from households that used public taps and water carriers/tankers, respectively.

Different types of sanitation facilities are found in South Africa. Firstly, there are waterborne toilet facilities that can be found either inside or outside the house (flush and chemical toilets) and, secondly, those usually situated outside (bucket and pit latrine) (Bomela, 2001:7). The most widely used toilet facilities in this study seemed to be flush toilets in the house/yard (69%), followed by pit latrine (20%).

Table 6.15 Comparing availability of services: survey and environmental scan

Service			Environmental scan
	n	%	%
Electricity			
Yes	176	80	54
No	44	20	46
Total	*220*	*100*	*100*
Fuel for lighting			
Candles	35	80	40
Paraffin	9	20	60
Total	*44*	*100*	*100*
Fuel for heating			
No heating	5	11	-
Paraffin	17	39	-
Coal	10	23	-
Flame, fire, wood	12	27.	-
Total	*44*	*100*	-
Fuel for cooking			
Paraffin	22	50	-
Coal	10	23	-
Flame, fire, wood	11	25	-
Gas	1	2	-
Total	*44*	*100*	-
Source of drinking water			
Piped water in house/yard	186	84	50
Public tap	33	15	47
Water carrier/tanker	1	1	3
Total	*220*	*100*	*100*
Sanitation facility			
Flush toilet in house/yard	151	68	36
Bucket latrine	21	10	10
Pit latrine	43	20	48
No facility/bush/veldt	5	2	6
Total	*220*	*100*	*100*
Refuse removal			
Refuse removal at least once a week	169	77	45
Veldt/remove themselves	23	11	48
Backyard/no refuse removal	16	7.	7
Less than once a week	2	1	-
Dumping site	5	2.	-
Burn	5	2.	-
Total	*220*	*100*	*100*

6.7.3 Refuse removal

Table 6.15 indicates that the majority of the patients (77%) lived in households where refuse was removed at least once every week by the local authorities, compared with 45% of the population in three study areas. The remainder of the patients comes from households without systematic methods of refuse disposal. Only 11% of the patients in this study had to remove their refuse by themselves compared with 48% in the three study areas. A small minority of patients made use of their backyards (7%) or dumping sites (2%) to dispose of household refuse. A similar proportion of the population in the three study areas (7%) made use of their backyards as a place to dispose of refuse. Slightly more than 2 in 5 households (45%) in the three study areas were situated in areas where refuse was removed at least once a week by the local authority.

6.8 Household durable goods

The assets of households are illustrated in Table 6.16. Approximately 8 in every 10 households had radios (87%). A television was available in 65% of the patients' household and a telephone (both fixed and cellular) was available in 40% of the patients' households. Other goods most commonly available at the patients' households included refrigerators (n=136, 62%), and land to cultivate (n=76, 35%). Only a small minority of the patients (n=22, 10%) had bicycles. It is also evident that own transport (motor cars/vehicles) was in short supply among the sampled patients (n=16, 7%).

Table 6.16 Household durable goods

Durable goods	n	%
Radio	191	87
Television	143	65
Refrigerator	136	62
Land to cultivate	76	35
Fixed telephone	49	22
Cellular phone	39	18
Bicycle	22	10
Motor car/vehicle	16	7
Washing machine	14	6
Cattle/sheep	4	2
Personal computer	1	1

6.9 Conclusion

The impact of personal and environmental factors on health in general has been widely examined (Hardey, 1998; Jones, 1991; Macinko & Starfield, 2001; Utah, 1995; Van Rensburg *et al.,* 1992).

Demographic and socio-economic factors are often related to the manner in which TB patients perceive and experience the effects of the disease. The data presented in this chapter were aimed at constructing a profile of the sample by focusing, amongst others, on the demographic and socio-economic characteristics of the patients.

Of the 220 patients, 121 (55%) were males and 99 were females. The median age was 38 years (range 16-67 years). According to Diwan & Thorson (1999:1000), about two-thirds of all known people with tuberculosis are men. The modal age class is 16-34 years for females and 35-49 years for males. Two-thirds (70%) of the female and 46% of the male patients fell in the age category of 16-39 years. More males (37%) than females (25%) were re-treatment patients. A third (35%) of the patients were married. On average, the patients lived in families of 4.4 persons per household with an average of 2.1 persons per room. Further background information on the patients revealed that 11% had been in prison before, 24% had previously worked on a mine, and 25% lived with other household members who had had TB before or at the time of the survey.

The majority of the patients indicated that they had access to electricity (80%), piped water (85%) and to refuse removal services at least once a week (77%). However, a third (35%) reported having no proper sanitation. While the average monthly per capita income of patients increased from R985.36 immediately prior to illness with TB to R1 113.16 afterwards, the mean cumulative monthly household income decreased from R1 214.50 before being diagnosed with TB to R946.85 afterwards.

Two-thirds (66%) of the unemployed patients indicated that they depended on family members for a living. More men (75%) than women (53%) reported a history of employment immediately prior to falling ill with TB. By the time of the survey only 34% of the men and 27% of the women were still working. It also became evident that more female patients were employed in the service sector. All the patients (both men and women) who reported losing their jobs after falling ill with TB were asked how they lost their jobs. Foremost among the reasons provided is that they resigned (50%).

Close, prolonged contact increases transmission among household members, because the individual with pulmonary TB aerolises a number of bacteria, which can be inhaled by those nearby. Household contacts have the highest risk of becoming infected, especially those sharing sleeping (Strebel & Seagar, 1991). While the NTCP in the country advocates passive case finding, the high number of contacts (25%) in this study calls for a more vigorous approach in actively tracing contacts. Socio-economic conditions are the major determinants of infection in South Africa. The economic circumstances of patients, as reflected by the reported household and per capita monthly income, impact negatively on the prevalence of TB (Collins, 1992; Lock *et al*., 2001)) and on the lives of patients. Such poor economic living circumstances also curtail patients' ability to participate fully in social activities. If infected people are breadwinners, their illness will reduce the household income, thereby adversely affecting the living standard and quality of life of all the members (Department of Welfare, 1998). Considering the profound impact that TB has on an individual patient's life, an uncommon feature that became evident in this study was the drastic increase in the per capita monthly income of the patients after being diagnosed with TB. In conclusion, this Chapter has shown that the patients in this study were relatively well-off regarding their housing, availability of electricity, and water.

Chapter 7:
The TB patient 'career': Critical stages for intervention

7.1 Introduction

Social, behavioural and cultural factors have emerged as highly significant in the transmission, diagnosis, treatment and prevention of TB. For the Free State, however, the role of these factors has yet to be adequately addressed either in terms of the dynamics of transmission, or in the planning and implementation of control strategies. In contrast to the substantial knowledge base which exists in respect of both the TB bacillus and anti-TB chemotherapy, little is as yet known of the understandings, beliefs and behaviours relating to the aetiology of disease; the inter-relationship of habitat, livelihood, environment and biology; or the diagnosis and treatment of illness of PTB patients in the Free State. The success of control programmes, however, depends substantially on the understanding of these very issues.

This part of the thesis reports on the illness 'career' of the TB patient, one of the primary aims of this study. To a large extent, the data in this chapter are presented according to the analytical framework (Suchman's stages of illness experience[1]) that was discussed in Figure 1.1. These stages are: symptom experience; assumption of the sick-role; medical care contact; the dependent-patient role; and the rehabilitation/recovery stage. To accomplish the goal of this Chapter, it is divided into four sections. Section 1 discusses findings pertaining to the symptom experience stage. In this section the focus falls on the knowledge, beliefs and perceptions about TB. The first step in the process of seeking a diagnosis is the recognition that some aspect of development is not proceeding as expected. The HBM postulates that the perceived seriousness of an experienced symptom will account for health behaviour (Jones, 1991:48; Kaplan *et al.,* 1993:52-53). Factors affecting the perception of a symptom are commonality (the frequency with which it occurs in a given population), familiarity (the familiarity of the symptoms to the average member of the community), predictability of the outcome of the illness, and the amount of threat likely to result from the illness (Leigh & Reiser, 1980:5). Section 2 focuses on the health-seeking behaviour of patients. In Section 3, the health care contact stage expounds on the health care providers that were chosen and the diagnoses made. In Section 4, the focus is on the

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[1] Stages of illness experience are also referred to as the 'patient career'.

dependent-patient role. Responses were correlated with demographic information. Each illness 'career' is followed by a discussion section.

Generally, this Chapter will also attempt to present the empirical findings related to the following questions:

- What is the first reaction to initial symptoms?
- What is the knowledge concerning causes and transmission of TB?
- Which health care providers/facilities are consulted first by patients?
- How long after the first symptom experience do patients consult health care providers (patient delay)?
- How do patients react to the diagnosis?
- What is the quality of life after diagnosis?

7.2 THE SYMPTOM EXPERIENCE STAGE: KNOWLEDGE AND PERCEPTIONS OF TB

One of the major aspects of the symptom experience stage is the decision that something is wrong. According to Suchman (1965:114), there are three distinct analytical aspects of this stage. Firstly, there is the physical experience (pain, discomfort, and change of appearance). Secondly, there is the cognitive aspect (the interpretation and derived meaning for the individual experiencing the symptoms). The third aspect refers to the emotional response of fear or anxiety that accompanies the former two aspects.

These activities generally include complaining about symptoms and seeking help or advice. A person who feels stomach pains and complains to friends or consults a doctor is displaying illness behaviour. It should be noted that two persons having much the same symptoms might behave quite differently. One may attempt self-medication or immediately seek medical aid; the other may ignore the symptoms (Cockerham, 2001:113; Coe, 1987:112). This section evaluates the knowledge, beliefs, and perceptions of TB patients regarding their understanding of TB pathogenesis, sources of information, treatment options, and expectations.

7.2.1 Initial symptom recognition

Patients were asked what their main initial symptom was. As Table 7.1 shows, a persistent cough was the most frequently mentioned first initial recognised symptom (n=78, 35%), followed by painful/swollen body or feet (n=43, 20%), sweating (n=38, 17%), and loss of appetite/weight (n=24, 11%). A wide variety of different symptoms was mentioned by less than 10% of the patients for each symptom.

Sweating was the most frequently mentioned second main symptom (n=54, 29%) and third main initial symptom (n=23, 18%).

Table 7.1: Main initial recognised symptom

	First symptom		*Second symptom		*Third symptom	
Symptom	**n**	**%**	**n**	**%**	**n**	**%**
Persistent cough	78	35	30	16	19	15
Painful/swollen body or feet	43	20	24	13	13	10
Sweating	38	17	54	29	23	18
Loss of appetite/weight	24	11	28	14	35	27
Fatigue	17	8	20	11	20	15
Headache	7	3	9	5	3	2
Vomiting	5	2	3	2	6	5
Coldness	4	2	8	4	6	5
Bloody/green sputum	4	2	7	4	1	1
Shortness of breath	-	-	4	2	4	3
Total	*220*	*100*	*187*	*100*	*130*	*101*

Note: *The second and third symptoms do not add up to 220 as some patient might have experienced only one or two symptoms.

An attempt was also made to determine how the initial symptom(s) was interpreted by the patients. Table 7.2 shows how the initial symptom was interpreted as a result of previous knowledge about TB and school attendance. Among those who had attended school, there was a significant association between interpretation of initial symptom(s) and knowledge of TB before own diagnosis (P=0.020). Table 7.2 further indicates that among the school attendants who knew about TB before their own diagnosis, 55% and 22% interpreted the initial symptoms as indicative of flu/fever or TB, respectively. Only one patient who had not attended school and who knew about TB interpreted the symptoms as indicative of TB. Among the school attendants, slightly more patients who did not know about TB before their own diagnoses than those who knew about TB, indicated that they regarded the initial symptoms as normal (n=15, 14%; and n=9 (10%).

Table 7.2 Interpretation of initial symptoms by previous knowledge about TB and school attendance

Interpretation	**Attended school**		**Did not attended school**	
	Knew what TB was*		**Knew what TB was****	
	Yes	**No**	**Yes**	**No**
	n (%)	**n (%)**	**n (%)**	**n (%)**
Flu/fever	51 (55)	59 (56)	5 (62)	7 (58)
TB	21 (22)	6 (6)	1 (13)	-
Normal symptoms	9 (10)	15 (14)	-	1 (8)
Uncertain	6 (7)	15 (14)	2 (25)	2 (17)
Other illness	5 (5)	6 (6)	-	-
HIV/AIDS	A1 (1)	1 (1)	-	1 (8)
Bewitchment	-	2 (2)	-	-
Chemical- /alcohol-related	-	2 (2)	-	-
[1]Total	*93 (100)*	*106 (100)*	*8 (100)*	*12 (100)*

*P=0.014; **P=0.596; [1]There is one missing value

7.2.2 Knowledge, beliefs and general perceptions about TB

Only 46% of the 220 patients indicated that they knew about TB before their own diagnosis with the disease. Thus, more than half of the patients (54%) did not know about TB before being diagnosed. The majority (n=135, 61%) of the patients indicated that they knew someone with TB before themselves being diagnosed with the disease. More than half reported observing a TB case in the family (54%), friends (16%) or neighbours (14%). When asked how long medical TB treatment usually lasting when a person had TB for the first time, the majority (n=180, 82%) of the patients indicated that medical treatment for TB usually lasting 6 months when a person had TB for the first time. The remaining proportions of the patients indicated that it lasted fewer than six months (n=14, 6%), between 7 to 12 months (n=19, 9%) and 4 years (n=7, 3%). Table 7.3 shows that patients who had attended school had a significantly higher level of knowledge about TB prior to their own diagnosis than did those who did not attend school. As expected, patients with a higher level of education were more likely to have a high level of knowledge of TB prior to their own diagnosis with the disease.

Table 7.3: Prior knowledge about TB by educational level

Education	**Knew about TB**	
	Yes	**No**
	n (%)	**n (%)**
No education	8 (40)	12 (60)
Grade 1 –Grade 6	13 (30)	30 (70)
Grade 7 – Grade 11	61 (47)	68 (53)
Grade 12	4 (67)	2 (33)
Diploma/ other post-school complete	16 (73)	6 (27)
Total	*102 (46)*	*118 (54)*

P=0.017

Patients were also asked whether they agreed or disagreed with some statements about TB. As shown in Table 7.4, 94% of the patients agreed that TB could be cured, whereas 16% agreed that TB can be caused by witchcraft. The latter percentage is slightly lower than the 19% found in a Botswana study (Steen & Mazonde, 1999). More than half of the patients (59%) agreed that TB could actually be a symptom of HIV/AIDS.

Table 7.4: Patients' responses to statements about TB

Statement	Agree n (%)	Disagree n (%)	Uncertain n (%)
One can stop taking TB medication when one feels better	25 (11)	192 (87)	3 (2)
Someone with TB who is not on treatment can infect other people	199 (91)	15 (7)	6 (3)
TB can be cured	206 (94)	8 (4)	6 (3)
TB affects men, women and children	212 (96)	5 (2)	3 (2)
People living with a TB patient need to be examined	197 (89)	17 (8)	6 (3)
TB could actually be a symptom of HIV/AIDS	129 (59)	41 (19)	50 (22)
TB can be caused by bewitchment	35 (16)	167 (76)	18 (8)
Traditional medicines can also cure TB as effectively as the medicines given to me at the clinic	34 (16)	169 (77)	17 (8)

The focus group participants pointed out that they were "*confused*" because they had been told that TB can be spread by being in close contact with an infected person over a long period. Yet, when the patients asked about the chances that their family members might also be infected, they were told not to worry. The following quotations capture the concern of the participants:

Female: I was just asked with whom I was staying. The consequence of this is that all my household members are now infected with TB.

Male: You see, it is confusing. Some [TB patients] are told to bring their contacts, but others not.

Female: I once asked the sister at the clinic how I will know whether I have not already infected my older children. I was told to only bring my children under the age of five. The older ones, I was further told, first have to cough before I could bring them to the clinic.

7.2.3 Knowledge about causes, transmission and prevention of TB

The causes of TB, and knowledge or understandings of transmission and prevention, were obtained from the interview survey among 220 PTB patients. Table 7.5 compares the given responses for cause of TB generally and in their own case. When asked the question of how one can get TB, 83 (38%) of the patients said from other TB patients generally; and 64 (29%) in their own case. Forty nine (22%) did not know how people become infected with TB in general and 77 (35%) did not know how they personally got TB. Other causes of TB, both generally and in their own case, that were most frequently mentioned by the patients were lifestyle-related (smoking, alcohol/substance abuse) and air pollution.

Table 7.5: Patients' perceptions of causes and transmission of TB

Factor transmitting or causing TB	**Generally** **n (%)**	**In own case** **n (%)**
From other TB patients	83 (38)	64 (29)
Don't know	49 (22)	77 (35)
Life style: smoking, alcohol abuse, eating habits	49 (22)	37 (17)
Air pollution: dust, lack of hygiene	30 (14)	14 (6)
Work-related: chemicals, paint	8 (4)	22 (10)
Imprisonment, overcrowding	1 (1)	4 (2)
Total	*220 (100)*	**218 (100)*

Note: * 2 missing values

Respondents were asked how TB can be prevented. As this was an open-ended question, 15 responses were provided. These responses were then divided into four categories: TB cannot be prevented; health-related action (consulting health providers more often, taking medication as prescribed, for example); health-preventive action (eating healthy food, maintaining a hygienic lifestyle, for example), and having the same health promotion campaigns as HIV/AIDS. Table 7.6 presents the findings on the relationship between reported prevention mechanisms of TB and gender (P=0.212). Although there is no statistically significant relationship between the reported preventive measure and gender, more females than males stated that TB could not be prevented (32% compared with 28%, respectively). Generally, 32% of the sampled patients believed that TB could not be prevented, 28% by taking health-related action, and 25% by engaging in health-preventive action. Only 15% indicated that TB should have the same advocacy campaigns as HIV/AIDS.

Table 7.6: The relationship between reported prevention measure of TB and gender

Reported prevention measure	**Male** **n (%)**	**Female** **n (%)**	**Total** **n (%)**
TB cannot be prevented	34 (28)	36 (36)	70 (32)
Taking a health-related action	39 (32)	23 (23)	62 (28)
Taking health preventive action	33 (27)	22 (22)	55 (25)
Having the same health promotion campaigns as HIV/AIDS	15 (12)	18 (18)	33 (15)
Total	*121 (55)*	*99 (45)*	*220 (100)*

P=0.212

From the focus group discussions it is evident that the main sources of information for the patients were: leaflets at the clinic, radio, newspapers, and nurses at the clinic and family members. However, information regarding re-current TB seems to be lacking. The participants also felt that not enough was done in respect of visiting patients at their homes:

Female: When I caught the disease in 1999, social workers were sent out to visit me. This does not happen nowadays. My child also has TB... this could have been prevented...

Male: With the previous government, sisters use to go out and visit people at their homes. Why has this practice been stopped?

Male: Nurses have to go out. People only respond to issues when affected. If they don't feel any pain, they will not be interested. That's life; people have to be constantly reminded of the dangers of TB.

7.2.4 Discussion

Although the Health Belief Model focuses almost exclusively on cognitive influences on behaviours, it also stresses the importance of an individual's subjective interpretation (Cockerham, 1992; Kaplan *et al.,* 1993:52). Thus, the manner in which the patients interpreted the initial symptoms will determine the type of behaviour embarked upon. Ultimately, the patients may make predictable use of information available to them in a systematic manner in order to weigh the costs and benefits of a particular action (Gillmore *et al*., 2002:886; Ajzen & Fishbein, 1980: 40-54). However, it is evident that the presence of a symptom is not a sufficient condition for seeking health care. The action to seek help, as stated earlier, is usually determined by the interpretation of the symptom in the light of their background and personal experiences.

Data regarding the community's perceptions of TB, with implications for TB control activities, relate to the cause, recognition, and ultimate health behaviour in response to the disease. The findings discussed above indicate that the main initial symptoms were a persistent cough, painful/swollen body or feet, and sweating. There was a significant association between initial symptom recognition and previous knowledge of TB. Generally, it is sad to find that only 46% of the 220 patients knew about TB before their own diagnosis with the disease. This is especially discouraging when it is considered that the respondents had an average age of 38 years. A significant association was also found between prior knowledge of TB before own diagnosis and school attendance. It is clear that patients who had attended school and knew about TB before own diagnosis were more likely to interpret the initial symptoms as indicative of TB than patients who had not attended school. This finding confirms what the theoretical models imply - the modifying role and influence of structural variables (knowledge about the disease and prior contact with it) on health behaviour (Cockerham, 1992:93; Jones, 1991:48; Meulemans *et al.*, 2000:73; Sarafino, 1990:190).

The sampled patients had a fair understanding of the causes and transmission of TB. It seems that aetiology, as also asserted by Suchman (1965:118), is viewed largely in terms of those factors increasing exposure or lowering resistance rather than in terms of direct causal agents or processes. For many of the patients, the disease can be contracted from infected TB patients, and from excessive consumption or substance abuse. However, it is also disturbing that some patients did not know how TB is transmitted. Another disturbing finding was that 11% of the patients indicated that one can stop taking TB medication when one feels better, and 32% reported that TB cannot be prevented. This clearly undermines TB control efforts.

From the literature review it became evident that the flow-on from knowledge to behavioural change is at best tenuous. Knowledge and behaviour change have no simple and direct relationship, and other intervening and circumstantial variables (including other contradictory beliefs and household economic factors) may lead to behaviour consistent or inconsistent with knowledge. There needs to be a more effective means of imparting information to communities affected by diseases such as TB.

7.3 ASSUMPTION OF THE SICK-ROLE

When one is defined as sick, there are various ways one can respond to signs and symptoms. While some people may simply carry on with their normal daily activities, others may withdraw completely from all activities and become extremely passive and dependent. This stage involves the discussion process whereby the individuals experiencing symptoms present their problem to other members of their social group (i.e. family members and friends) and seek their approval to be ill.

7.3.1 Pre-diagnosis health-seeking behaviour

Almost all the patients (88%, n=193) reported discussing their symptoms with someone before seeking medical care. According to Table 7.7, the majority (66%) of the patients discussed their initial symptoms with relatives, usually the husband/wife/partner (26%), parents /grandparents (24%) and other relatives (16%). Friends are the second important social group with whom patients discuss their initial symptoms with (13%).

Table 7.7: Influential person with whom initial symptoms were discussed

Influential person	**n**	**%**
Husband/wife/partner	50	26
Parent/grandparent	47	24
Relative	30	16
Friend	25	13
Health worker at workplace	15	8
Colleague/employer	9	5
Neighbour/community member	8	4
Private doctor	7	4
Traditional healer	1	1
Tenant	1	1
Total	*193*	*102*

Note: There are 7 missing values

A large portion (71%) of the influential persons with whom patients discussed their initial symptoms recommended that the clinic should be visited, or emphasised the seriousness of the symptoms (61%). Slightly more than half (52%) of the patients interpreted the symptoms as indicative of illness. In all cases, the patients followed the advice of the influential person whom they discussed their initial symptoms. The following are also interpretations made by influential persons:

- Recommended that the clinic be visited (n=136, 71%)
- Emphasised the seriousness of the symptoms (n=118, 61%)
- Interpreted symptoms as indicative of illness (n=115)
- Recommended self-medication (n=96, 50%)
- Recommended that a doctor be seen (n=96, 50%)
- Offered a diagnosis of the symptoms (n=49, 25%)
- Indicated that the symptoms were normal/not serious (n=48, 25%)
- Recommended over-the-counter medication (n=19, 10%)
- Recommended traditional healing (n=7, 4%)

It is also interesting to note that during this stage, 133 (61%) of the patients had to stay in bed (60% of the males and 64% of the females), and 33 (43%) of those who were employed stayed away from work. In both instances, the reason could be that the patients were too ill.

7.3.2 Home remedy used

Most of the delay in seeking medical care occurs as people discuss whether or not to take symptoms to a care provider. Potential patients have to make complex judgements involving the comparison of the benefits, risks and costs of seeking medical care. Depending on the benefits, potential patients often resort to alternative behaviour such as self-treatment.

In this study, a quarter (26%) of the patients tried some form of home remedy before seeking medical care. It is evident from Table 7.8 that traditional medicines such as *lesoko, sehalahala* and *mohalakane* were the most frequently mentioned home remedies used by the patients (52%). The second most popular home remedy among patients were benarade mixed with other substances (20%), followed by over-the-counter medication (9%). It is disturbing, however, to note that three patients used methylated spirits, a substance known for its dangers to mankind when taken.

Table 7.8: Home remedy used

Type of home remedy	**n**	**%**
Traditional medicines* (*lengala, lesoko, sehalahala, mohalakane, African potato*)	29	52
Benarade plus other substances	11	20
Over-the-counter medication	5	9
Bluegum (mixture of plant and water)	4	7
Methylated spirits	3	5
Uncertain	2	3
Ghapa (self-inflicted vomiting)	1	2
Eating zambuk ointment	1	2
Total	*56*	*100*

*These traditional medicines are usually boiled with water before being used

7.3.3 Discussion

The lay discussion phase of illness prior to seeking professional diagnosis and treatment contributes positively to the medical care process. As Suchman (1965:120) asserts, “*few individuals, it would appear, are confident enough of their own knowledge to make the judgement that they need medical care by themselves.”* The results indicate that almost all the patients reported discussing their symptoms with someone before seeking medical care. The discussant was most likely to be a relative, followed by a spouse or partner. The majority of the patients indicated that their discussants recommended that a clinic should be visited. Sadly, 25% of the patients were told that the symptoms were normal. In this regard, the lay beliefs about the symptoms take precedence over medical knowledge about them (Haugh *et al.*, 1991:1011; Jones, 1991:47). These findings support the general Theory of Health-seeking Behaviour of Mechanic (1978), which claimed that family members, friends and colleagues, may influence the definition of the illness situation. In this regard, Cockerham (2001:132) emphasises the role played by learning, socialisation and past experience, as mediated by a person’s social and cultural background.

The analysis of the assumption of the illness stage reveals another notable finding: 61% of the 220 patients had to stay in the bed for some time during this stage as a result of TB. This clearly shows that TB affects the lives of patients at a very early stage. Depending on the benefits, as the theoretical models imply, patients will resort to self-treatment. In this study, 26% of the patients used home remedies before seeking medical care. There is a need for further research to more fully investigate the dangers of these home remedies. Remedies such as methylated spirits are known for its harm to mankind.

7.4 HEALTH CARE CONTACT STAGE

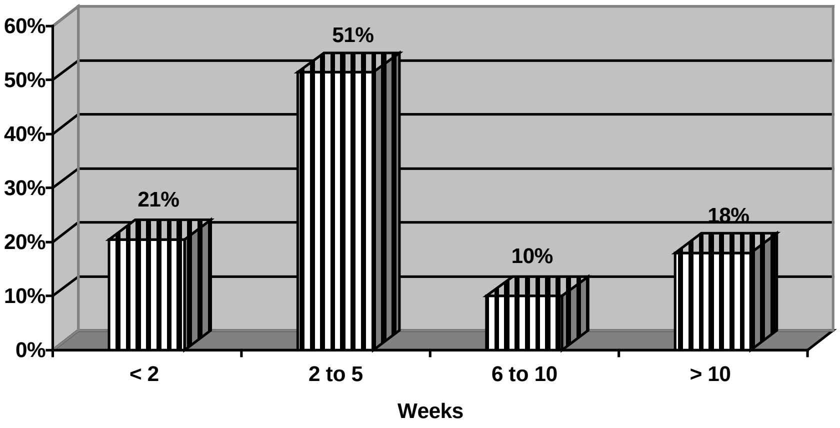
At this stage of illness, interest is in obtaining medical care (medical diagnosis and prescribed course of treatment) from a professional rather than a “lay” consultant. This section focuses on patient delay in seeking health care, health care actions taken, medical diagnosis, and information provided after diagnosis.

7.4.1 Patient delay in seeking health care

There are a number of measures to assess patient delay, some which relate specifically to the medical and public health field. Delay time remains a difficult variable to measure, because “*symptom onset is often vague, the patient does not recall the exact time of onset”* (Caldwell & Miaskowski, 2002:5). In this study, patient delay is defined as the period between the onset of symptoms and contact with health care providers. Patients who sought help from health care providers in less than two weeks after noticing their symptoms are regarded as having had no delay. However, it is important to note that another study (Meyer-Weitz *et al*., 2000) measure non-delay as less than seven days.

In this study patient delay is confined to the patients’ response to the question: For how long did you have the symptoms before seeking health care?” According to Figure 7.1, only 21% (n=45) of the patients sought help from health care providers in less than two weeks after noticing the first initial symptoms. The majority of the patients (n=113, 51%) waited between two to five weeks, while 10% (n=23) of the patients indicated that they waited between six to ten weeks, and 18% waited more than ten weeks after noticing symptoms before seeking health care (range: 1 day to 156 weeks). The median total delay was 3 weeks and the mean 6.9 weeks.

Figure 7.1 : Patient delay in presentation



Bivariate results between patient delay and various socio-demographic variables did not show any significant relationships, and are thus not reported here. Table 7.9 shows the mean delay in contacting a health care facility/provider according to patient characteristics. The results indicate that, on average, there was no difference in delay behaviour between new and re-treatment patients. The mean delay analysis further indicates that male patients waited one week longer before seeking help than females (7.3 compared with 6.3, respectively). Younger and single patients also waited longer than older and married patients, respectively. Regarding education, it is interesting that, on average, those who had no formal education waited only for 4 weeks compared with the 15 weeks of those who had matriculated (Grade 12). As expected, the mean delay of patients who were employed before diagnosis with TB in seeking help was two weeks longer than those who were unemployed (7.7 weeks compared with 5.3 weeks). Similarly, patients who earned an income above R3 500 before diagnosis with TB had a mean delay of 15 weeks compared with the six weeks of those who earned between R1 and R1 000, and the nine weeks of those who earned between R1 001 and R3 500.

Table 7.9: Mean delay by patient characteristics

	Mean delay (in weeks)
Category	
New patient	6.8973
Re-treatment patient	6.9429
Gender	
Male	7.3814
Female	6.3469
Age	
16-34 years	9.4524
35-49 years	4.6848
50-64 years	6.9474
65 and older	2.0000
Marital status	
Married	6.3846
Single	7.9452
Educational level	
No education	4.4737
Grades 1-6	6.5357
Grades 7-11	6.1206
Grade 12	15.3182
Diploma/degree	4.1667
Employment status before diagnosis	
Employed	7.7643
Unemployed	5.3421
Monthly per capita income	
R1-R1 000	6.4773
R1 001-R3 500	9.7500
R3 500+	15.0000

The reasons most frequently mentioned by those who did delay, were the feeling that the symptoms resembled an ordinary flu/fever (57%), prolonged self-medication (24%), and not having money for transportation to the clinic (9%).

Thought it was an ordinary flu/fever/cold	(n=99, 57%)
Self-medication	(n=42, 24%)
Did not have transport money	(n=16, 9%)
Symptoms are common at workplace	(n=11, 6%)
Doubts the quality of care at the clinic	(n=3, 2%)
Prevented from seeking health care by work obligations	(n=2, 1%)

Was very ill (n=2, 1%)

Prolonged self-medication is a prime determinant of patient delay. Among patients who did not use a home remedy, 24% immediately contacted a health care provider/facility after noticing the initial symptoms. Among those who used a home remedy, only 11% immediately contacted a health care provider/facility. Those who used a home remedy were more likely to delay longer than those who did not.

7.4.2 Health care actions taken by patients

Patients were asked a series of questions concerning the nature of their first medical contacts. The description of the initial medical contact provides an indication of the types of health care facilities and providers in South Africa. Table 7.10 shows that clinics/community health care centres (46%), followed by general practitioners (39%) were the most frequently contacted health care facilities/providers after experiencing initial symptoms. Only 15% of the study group visited a hospital after experiencing initial symptoms.

The data in Table 7.9 show that only three of the six variables reflected a significant statistical difference between the different health care facilities/providers contacted (P<0.10). Of the types of health care facilities/providers contacted, patients with no education and an educational level up to Grade 6, more often visited clinics/community health centres than those with higher levels of education. More unemployed patients than employed patients chose clinics as the first health care contact. Patients with a high monthly per capita income (>R3 500) were more likely to visit a private doctor or a hospital than those earning less).

To explore the reasons for the choice of first health care facility/provider contacted, patients were asked ‘Why did you first contact this health care facility/provider? Respondents were permitted to provide only one answer, and their responses were assigned to one of seven categories coded after the survey: 1) free service, 2) convenience (i.e. near home/work and suitable open times), 3) most appropriate facility/provider for TB treatment, 4) long-term relationship with health care facility/provider, 5) taken by ambulance, 6) dissatisfied with previous health care facility/provider, and 7) recommended by family member/friend.

Table 7.10: First health care facility/provider contacted with initial symptoms

	Health care facility/provider			
Variable	**Clinic/*CHC**	**Hospital**	**Private doctor**	**P**
Category	**n (%)**	**n (%)**	**n (%)**	0.790
New patient	70 (47)	21 (14)	59 (39)	
Re-treatment patient	30 (42)	12 (17)	28 (40)	
Gender				0.328
Male	54 (45)	22 (18)	45 (37)	
Female	46 (47)	11 (11)	42 (42)	
Age				0.805
16-34 years	42 (48)	10 (12)	35 (40)	
35-49 years	43 (46)	15 (16)	35 (38)	
50-64 years	14 (37)	8 (21)	16 (42)	
65 and older	1 (50)	-	1 (50)	
Educational level				0.049
No education	10 (50)	5 (25)	5 (25)	
Grades 1-6	22 (51)	11 (26)	10 (23)	
Grades 7-11	58 (45)	13 (10)	58 (45)	
Grade 12	10 (39)	4 (15)	12 (46)	
Diploma/degree	-	-	2 (100)	
Employment status before diagnosis				0.038
Employed	56 (39)	24 (17)	63 (44)	
Unemployed	44 (57)	9 (12)	24 (31)	
Monthly per capita income				
R1-R1 000	42 (47)	14 (29)	-	0.014
R1 001-R3 500	18 (20)	6 (12)	-	
R3 500+	30 (33)	29 (59)	3 (100)	
Total	*100 (46)*	*33 (15)*	*87 (39)*	

* Community Health Centre

Of the seven categories available for analysis (Table 7.11), most appropriate facility/provider for TB treatment was the most frequently reported reason for first contacting the mentioned health care facility/provider (50%). Free service was the second most reported reason (17%), followed by recommended by family/friend (10%). The self-reported reason showed no statistically significant correlation with the demographic and socio-economic variables.

Table 7.11: Self-reported reason for contacting health care facility/provider

Self-reported reason	**n**	**%**
Most appropriate facility/provider for TB treatment	108	50
Free service	37	17
Recommended by family member/friend	21	10
Taken by ambulance	17	8
Convenient: near home/work and suitable open hours	14	7
Long-term relationship with health care facility/provider	14	7
Dissatisfied with previous health care facility/provider	4	2
**Total*	*205*	***101*

* Five respondents provided answers that are not applicable
** Does not add up to 100 due to rounding

7.4.3 Diagnosis

The importance of the patient–doctor encounter, not only for patient satisfaction and compliance, but also for a successful health outcome has been established in modern medicine. Within this research area, the gender of both the patient and the doctor has been used as an analytical tool in relation to the success of the encounter (Thorson & Johansson, 2004:38). A medical diagnosis provides patients with not just a sense that their symptoms are being medically recognised, but also the opportunity to seek benefits and compensation (as expounded by the Health Belief Model) if they could demonstrate that their diagnosis was service related (Zavestoki *et al.*, 2004).

Table 7.12: Diagnosis during first health care contact by gender

Diagnosis	**Male** **n (%)**	**Female** **n (%)**
Tuberculosis	75 (62)	49 (50)
Respiratory illness (sore lungs, coughing blood)	11 (9)	21 (21)
No diagnosis	18 (15)	12 (12)
Flu	13 (11)	10 (10)
Pneumonia	2 (2)	4 (4)
Other illnesses	2 (2)	3 (3)
Total	*121 (101)*	*99 (100)*

Note: The total percentage does not add up to 100 due to rounding

An examination of the diagnosis made after the first visit in this study reveals that four out of five (87%) of the visits produced a diagnosis. It is encouraging to note that in more than half (56%) of the visits, the diagnosis was TB (Table 7.12).

Patients were also asked how they experienced being informed that they had TB. Table 7.13 depicts the responses of the respondents according to gender. Overall, the most frequent patient reaction to the disclosure of their TB diagnosis was one of shock or surprise (38%) and acceptance (36%). Only

17% of the patients reported that they were not worried because TB is curable, and 3% expressed fear of dismissal from their jobs and medical expenses. There were no significant differences between the reactions of men and women to the disclosure of their TB diagnosis.

Table 7.13: Reaction to diagnosis with TB

Reaction	**Gender**		**Total**
	Male **n (%)**	**Female** **n (%)**	
Shocked/surprised, never thought would ever be infected with TB	48 (40)	35 (35)	83 (38)
Accepted my condition	39 (32)	39 (39)	78 (36)
Not worried because TB is curable	22 (18)	15 (15)	37 (17)
Worried: TB is not curable/about dying	8 (7)	10 (10)	18 (8)
Feared dismissal from job and medical expenses	3 (3)	-	3 (1)
Total	*120 (100)*	*99 (0)*	**219(119)*

P=0.330
* 1 missing value

7.4.4 Provision of health information after diagnosis

The Health Belief Model holds health information as an important cue to action (Jane, 2001). Similarly, the Theory of Reasoned Action assumes that people usually make use of information available to them in a systematic manner in order to weigh the cost and benefits of a particular action (Gillmore *et al*., 2002:886; Ajzen & Fishbein, 1980: 40-54). The treatment guidelines of the National Tuberculosis Control Programme in South Africa contain a series of health information that should be conveyed to the patient after diagnosis.

In order to determine what information was provided to the respondents after the disclosure of their TB diagnosis, their responses were assigned to eight pre-coded categories. The respondents who received information had to indicate whether the information was helpful or not. An examination of gender and the information provided after disclosure of diagnosis revealed a positive or direct correlation with only three of the eight categories. Data from Table 7.14 indicate that female patients were more likely than male patients no to have received information on the nature and causes of TB (46% *versus* 31%), the infectiousness of TB (33% *versus* 21%), and the role of alcohol abuse and substance abuse (26% *versus* 15%).

Table 7.14: Information provided after disclosure of diagnosis by gender

Information provided	Was helpful		Was not helpful		No information		P
	Male	Female	Male	Female	Male	Female	
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	
Nature and causes of TB	77 (69)	49 (54)	-	-	35 (31)	42 (46)	0.030
Infectiousness of TB	89 (80)	61 (67)	-	-	23 (21)	30 (33)	0.045
The necessity of completing treatment	94 (84)	77 (85)	2 (2)	-	16 (14)	14 (15)	0.434
Side effects of treatment (i.e. medicine makes you feel ill)	57 (51)	44 (48)	1 (1)	-	54 (48)	47 (52)	0.608
Nutritional matters (i.e. the importance of taking food before taking tablets)	93 (83)	77 (85)	-	1 (1)	19 (17)	13 (14)	0.478
The role of TB in HIV/AIDS	55 (50)	45 (50)	1 (1)	2 (2)	55 (50)	44 (48)	0.748
The role of alcohol abuse and substance abuse in TB	95 (85)	67 (74)	-	-	17 (15)	24 (26)	0.048
Multi-drug resistance	66 (59)	51 (56)	2 (2)	4 (4)	44 (39)	36 (40)	0.541

Results from the focus groups sessions reveal mixed reactions to the question as to whether they received information regarding TB after the disclosure of their diagnosis. Some patients indicated that they were provided with information about the causes and transmission of TB, how to take medication, alcohol and substance abuse, and smoking habits. Many patients also indicated that they were not informed about any aspect related to TB, other than how to take their medication. One patient noted rather bitterly that “*there are no health promotion campaigns about TB in our area. Even at the clinic, we are not told enough about TB. The only information I received, was how to take my medication.”*

7.4.5 Discussion

The theoretical models assert that individuals will take preventive health action only when feeling that contracting the disease will have serious consequences (Caroll, 1992:51, Hubley, 1993:39; Weiss & Lonnquist, 1997:117). This study describes the health-seeking behaviour of the 220 patients in the Free State. As in the case of other studies (Pronyk *et al*., 2001; Steen & Mazonde, 1999), this study confirms that there is considerable delay between the onset of symptoms and contact with health care providers. Similar to the study of Pronyk (2001:624) on health-seeking behaviour conducted in the Limpopo Province, this study indicates that the public health system is the most common first choice of care for TB patients, with 61% of the patients presenting to a public clinic or hospital first. Unlike the Limpopo study, this study indicates a substantial use of private practitioners as a point of first contact in the study areas (39% compared with the 13% in Limpopo). The role of private practitioners in the diagnosis and management of TB is more substantial in countries such as India (Uplekar & Rangan, 1993) and Vietnam (Lonnroth *et al*., 1999). None of the patients in this study mentioned having visited a traditional healer, far from what was expected. An earlier study on traditional attitudes toward TB in South Africa had suggested a higher preference for traditional healers (Moloantoa, 1982:30). This may perhaps be due to the fact that the study of Moloantoa was conducted prior to the introduction of free primary health services.

In this study only 21% of the patients waited less than 2 weeks before they sought help from a health care provider. The overall mean time to consult a health care facility/provider was 7 weeks. Liefooghe *et al.* (1999) report that of a sample of 1 657 newly diagnosed TB patients, only 20% started treatment within one month of the onset of the symptoms. This figure compares favourably with the one in Botswana where the median total delay was 12 weeks (Steen & Mazonde, 1999). The results of this study further indicate that the majority of the patients delayed seeking health care because they regarded the symptoms as normal, or they resorted to self-treatment. Similar findings were reported by Liefooghe *et al.* (1995). No significant differences on socio-demographic characteristics and patient delay were found. Leigh & Reiser (1980:4) indicate that "*whether or not symptoms lead to help-seeking behaviour may be influenced by the patient's socioeconomic class*." Contrary to this, there was no significant correlation between socio-economic status and patient delay

Far more males than females were diagnosed with TB on their first visit to a health care provider. Also, females were more likely not to have received important information after disclosure of their diagnosis than males. This finding lends credence to the concern that gender inequalities can lead to poorer access to health care and cause delays in diagnosis of tuberculosis in women (Thorson *et al.,* 2000:1823).

For many patients, seeking health care from a doctor or clinic is a last resort. Although TB services are free at all primary health care facilities in South Africa, it should be noted that the majority of the people making use of such services are poor. Thus, visiting a clinic or doctor can be a daunting task for many. Facilitation of early health care seeking remains critical in curbing the threat of TB among South Africans. According to Zavestoski *et al*. (2004:165), patients are likely to be affected by the view of the diagnosis. Patients who receive a diagnosis that carries a stigma are likely to resist the diagnosis by seeking a second opinion, or refusing the treatment associated with the diagnosis. Patients may seek specialised medical care specifically for the purpose of acquiring a diagnosis with greater public acceptance. Stigmatised diagnoses strain an individual's social relations and, as implied by the Health Belief Model, may serve as a barrier to appropriate health action. As asserted by Steen & Mazonde (1999), increased knowledge of patients' health seeking behaviour and their self-perceptions of disease is useful to health workers and should have implications for health education messages.

7.5 DEPENDENT-PATIENT ROLE

It is only until this stage of the patient ‘career’ is reached that the sick individual becomes a “patient.” The results from the previous stages have shown that, from early on, the lives of TB patients are tremendously affected by the disease. The adjustment to being a patient is also not an easy feat for many individuals. This section focuses on the self-reported impact of TB, stigma, social support, the perceived health status of patients, and the limitations imposed by TB on daily activities.

7.5.1 Self-reported impact of TB

In order to determine the impact of TB on patients during the health care contact stage or, more precisely, after the disclosure of the diagnosis, patients were asked whether they had to stay in bed during this period, and for how long. The patients who indicated that they were employed, were asked whether they had been absent from work during this period. In both instances, the focus was on gender differences. The reason for this focus is that many studies have highlighted the different impact that TB has on men and women (Long *et al.*, 2001; Meulemans *et al.*, 2000; Needham *et al.*, 2001; Ngamvithayapong *et al.,* 2000).

Table 7.15: Self-reported impact of TB

Variable	**Gender**		**P**
	Male **n (%)**	**Female** **n (%)**	
Stayed in bed?			0.056
Yes	64 (53)	65 (66)	
No	57 (47)	34 (34)	
Duration of stay in bed			0.063
3 days	54 (34)	48 (74)	
4-7 days	10 (16)	12 (19)	
> 7 days	-	5 (8)	
Absent from work?			0.785
Yes	14 (34)	9 (31)	
No	27 (66)	20 (69)	

Data presented in Table 7.15 show that there was a significant statistical association between gender and having stayed in bed (P=0.056), and between gender and the duration of stay in bed (P=0.063). The days stayed in bed ranged from 1 to 30 days (average 1.8 days). Significant associations were not found between gender and absence from work.

According to the participants who were employed at the time of their diagnosis with TB, their feeling of being in good physical condition was affected by the negative attitude of their employers towards them:

Male: Immediately after I told my employer about my TB status, I was told to leave.

Male: I was also told to leave because they [employers] thought that my illness was affecting my productivity. They forced me to go to the company doctor who declared me unfit. The doctor should, at least, have advised me on applying for a disability grant.

Female: When I informed my bosses about my status, I was told to pack my belongings and leave immediately... I was also instructed to never set my feet on the premises again...

7.5.2 Stigmatisation

Stigma is subjectively experienced in multiple ways that are dependent on the nature of the stigmatising condition and the social conditions of the individual. Goffman (1963) long ago recognised that various types of illness are associated with stigma or membership of a social category that results in a spoiled identity setting the individual apart from others. Once a stigma becomes evident to others, persons become labelled as outsiders, and expectations and assumptions are associated with the individual from whom patterns of response from others emerge during interaction (Fife & Wright, 2000:50).

Regarding self-perceived stigma, data presented in Figure 7.2 show that only 12% (n=27) of the patients reported that they were generally treated differently (negatively) as a result of their TB status. The fact that the majority of the patients (n=189, 88%) felt that they were not treated differently as a result of their TB status indicates the general acceptance of the disease among the social contacts of the patients.

When asked what the most embarrassing/bad treatment they ever experienced was, the 25 affected patients responded as follows:

- People isolate themselves/run away from me (n=19, 76%)
- Accused of using my TB status as a disguise because I do not want to work (n=2, 8%)
- Accused of not being infected with TB but with HIV/AIDS (n=2, 8%)
- Not allowed to sleep in the house (n=1, 4%,)
- Was dismissed from work (n=1, 4%)

Figure 7.2: Felt treated differently

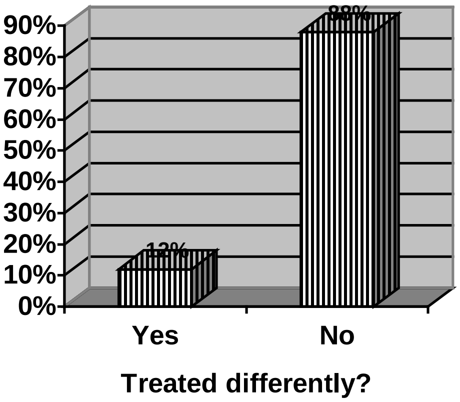
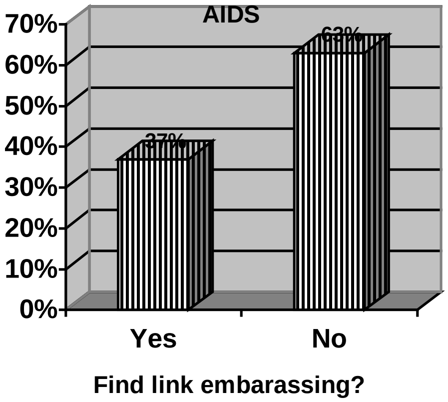


Figure 7.3: Link between TB and AIDS



Infection with HIV is an important risk factor for TB. According to Tiemessen *et al.* (2000:328), mortality in African settings in the first six months of TB treatment is almost four times higher in HIV-positive patients. It is also a known fact that people infected with TB have a physical appearance (i.e. thin body) similar to that of HIV/AIDS sufferers. On the basis of this, patients were asked whether they found the link between TB and HIV/AIDS embarrassing. .

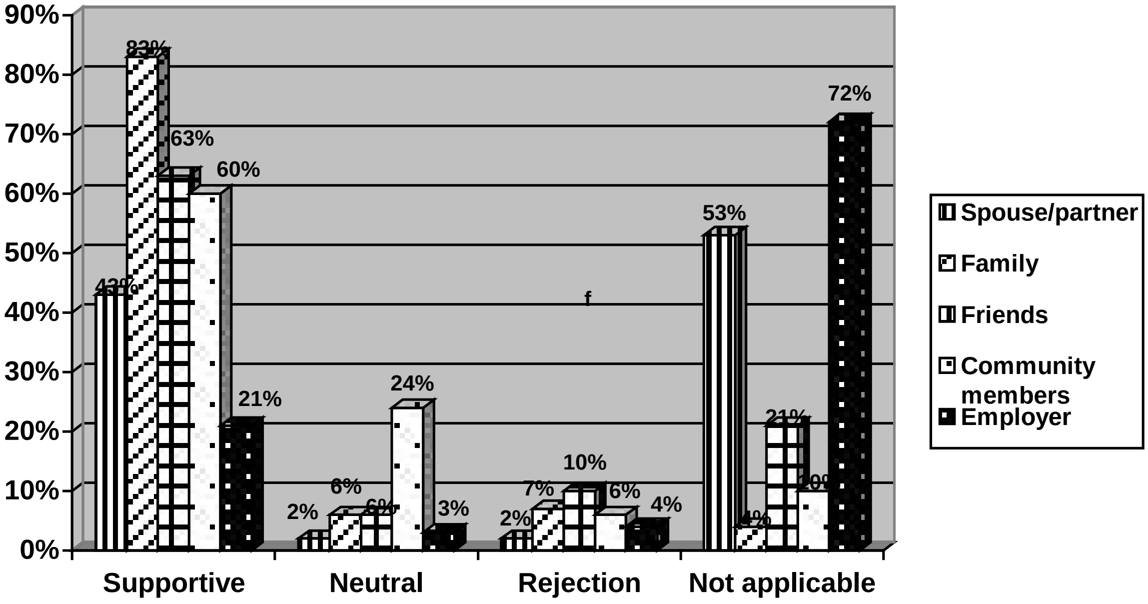
The majority (n=138, 63%) of the patients indicated that they did not feel embarrassed by the link between TB and HIV/AIDS (Figure 7.3). The most frequently mentioned reasons provided by patients for not feeling embarrassed, were that they know their HIV/AIDS status (22%) and know that TB is curable (17%). Patients who felt embarrassed by the link between TB and HIV/AIDS mostly mentioned that people might think they had AIDS (17%), and that most TB patients turned out to be HIV positive (15%) as the reason for their concern. Chapter 8 further explores the impact of stigma on the treatment outcomes of patients.

7.5.3 Social support

Social support, defined as resources provided by a network of individuals and social groups, may have both direct effects (support improves health) and moderating effects (support buffers the negative impact of literacy on health) on health status and health service utilisation. The positive resources and support in individuals' social networks can improve their ability to acquire and understand medical information (Lee *et al*. 2004:1309), and is an important factor affecting quality of life (Burgoyne *et al.*, 2004:1358). It is commonly distinguished between primary support group (spouse/partner, family and friends) and secondary support group (community). However, no such differentiation is made here, because there is usually a close bond between the community and the individual in the South African context.

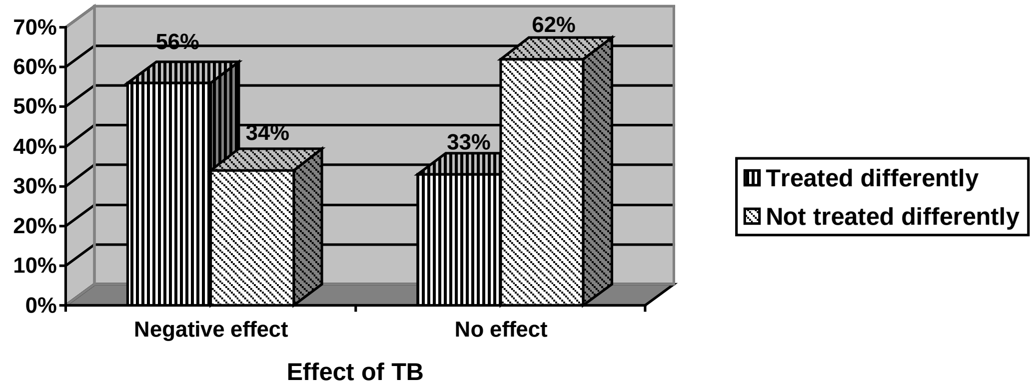
Patients were also asked what the reaction of their spouses/partners, family members, friends, and community members was when informed about their TB status. It should be noted that, according to the Health Belief Model, the reaction of these social support groups may be perceived as a threat. A positive reaction from others is extremely important for the acceptance process of the disease. Figure 7.2 show that only 2% of the patients experienced a negative reaction from their spouses/partners. Family members (83%), friends (63%), and community members (60%) reacted positively. However, 10% of the patients stated that their friends reacted negatively.

Figure 7.4: Reaction of partner, family and friends to TB status



It was further necessary to assess the impact of TB on the patients’ standing (image) in the family and on the relationship with their spouse/partners. Figure 7.5 below shows the findings regarding the relationship between the effect of TB on standing in the family in respect of generally treated differently. There was a statistically significant relationship between the effect of TB on the standing in the family and patients who reported that they were generally treated differently as a result of their TB status (P=0.019). Those patients who reported that they have generally been treated differently as a result of their TB status were more likely to report a negative effect on their standing in the family than those who were not treated differently (56% compared with 33%, respectively).

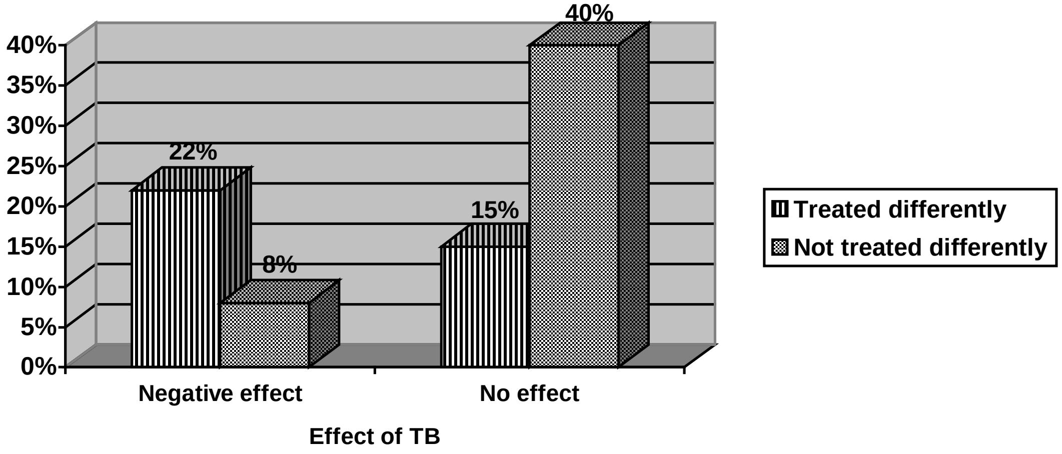
Figure 7.5: Effect of TB on standing in family in respect of whether generally treated differently



p=0.019

Similarly, Figure 7.6 shows that there was a statistically significant relationship between the effect of TB on the relationship with spouses/partners of patients and patients who reported that they had generally been treated differently as a result of their TB status and those who had not been treated differently (P=0.022). Those patients who reported that they had not generally been treated differently as a result of their TB status were more likely to report that TB had no effect on their relationship with their spouses/partners than those who were treated differently (62% compared with 34%, respectively).

Figure 7.6: Effect of TB on the relationship with spouse/partner in respect of whether generally treated differently



p=0.022

The network of family, friends, colleagues and experts to whom patients have access is an important factor that may restore and maintain the quality of life and the health of individuals. Patients were asked to indicate their satisfaction or dissatisfaction with each source of support at the time of the survey.

Table 7.16 presents the sources of support and the perceived level of dissatisfaction ranked according to importance. As can be seen, friends, family members, neighbours and health care workers were the sources of support with which the patients were mostly dissatisfied.

Table 7.16: Dissatisfaction with sources of support

Source of support	**n**	**%**
Friends	22	26
Family	15	18
Neighbours	15	18
Health care workers	10	12
Traditional healers	8	9
DOT supporters	5	6
Spouse/partner	5	6
Employer	4	5
Colleague	1	1
**Total*	*85*	*101*

***** Total does not add up to 100% due to rounding.

7.5.4 Self-reported health status

Reported health status was measured by asking the question, “In general, how is your health?” using a 5-point scale (excellent, good, uncertain, fair, or poor). The responses: excellent and good – were coded as good, and the responses: fair and poor, were coded as poor. The results of the cross tabulations between reported health status and various socio-economic variables are presented in Table 7.17. As can be seen, the majority of the patients indicated that their health was good (60%) compared with 38% who believed that their health was in a poor state at the time of the survey.

There was a significant statistical association between employment status at the time of the survey and reported health status (p=0.001). A further look at this sub-group shows that those patients who were employed at the time of the survey, exhibited a higher frequency of a ‘good’ perceived health status than those patients who were not employed (78% compared with 52%, respectively). Significant associations were not found between gender, age, category of TB (new/re-treatment), educational level, and per capita monthly income and reported health status.

Table 7.17: Reported health status by biographic and socio-economic characteristics

Variable	Good	Uncertain	Poor	P
	n (%)	n (%)	n (%)	
Gender				0.381
Male	69 (57)	4 (3)	48 (40)	
Female	63 (64)	1 (1)	35 (35)	
Patient category				0.319
New patient	93 (62)	2 (1)	55 (37)	
Re-treatment patient	39 (56)	3 (4)	28 (40)	
Age				0.590
16-35 years	54 (62)	1 (1)	(37)	
36-49 years	59 (63)	1 (1)	33 (36)	
50-64 years	18 (47)	3 (8)	17 (45)	
65 years and older	1 (50)	-	1 (50)	
Educational level				0.126
No education	8 (40)	2 (10)	10 (50)	
Grades 1-6	24 (56)	2 (5)	17 (40)	
Grades 7-11	80 (62)	1 (1)	48 (37)	
Grade 12	18 (69)	-	8 (31)	
Diploma/degree	2 (100)	-	-	
Current employment status				0.001
Employed	52 (78)	-	15 (22)	
Unemployed	80 (52)	5 (3)	68 (44)	
Monthly per capita income				0.590
R1-R1 000	30 (75)	10 (25)	-	
R1 001-R3 500	19 (79)	5(21)	-	
R3 500+	3 (100)	-	-	
Total	*132 (60)*	*5 (2)*	*83 (38)*	

7.5.5 Reported limitations of TB on daily activities

Table 7.18 presents reported limitations of TB on daily activities by gender and age. To analyse these relationships a composite scale of effect was developed. A score of one was assigned to respondents who answered “stopped doing it,” “limited a lot,” and “limited a little” to the question: Does TB currently limit you in your daily activities? A score of 0 was assigned to those who indicated no limitation. The item daily activities was measured by **strenuous activities**: running, lifting and carrying water, riding a bicycle uphill, bending or kneeling, **moderate activities**: preparing food, using a broom, dressing and undressing or walking short distances, and **light activities**: getting out of bed into the chair, preparing and cleaning vegetables when sitting on a chair.

Table 7:18: The relationship between reported limitations on daily activities by gender and age

Strenuous daily activities	**Limitation** **n (%)**	**No limitation** **n (%)**	**P**
Gender			0.071
Male	96 (79)	25 (21)	
Female	68 (69)	31 (31)	
Age			0.011
16-35 years	59 (68)	28 (32)	
36-49 years	67 (72)	26 (28)	
50-64 years	36 (95)	2 (5)	
65 years and older	2 (100)	-	
Total	*164 (75)*	*56 (25)*	
Moderate daily activities			
Gender	47 (39)	74 (61)	0.706
Male	36 (36)	63 (64)	
Female			
Age			0.367
16-35 years	31 (36)	56 (64)	
36-49 years	32 (34)	61 (66)	
50-64 years	19 (50)	19 (50)	
65 years and older	1 (50)	1 (50)	
Total	*83 (38)*	*137 (62)*	
Light activities			
Gender			0.657
Male	31 (26)	28 (28)	
Female	90 (74)	71 (72)	
Age			0.100
16-35 years	21 (24)	66 (76)	
36-49 years	21 (23)	72 (77)	
50-64 years	16 (42)	22 (58)	
65 years and older	1 (50)	1 (50)	
Total	*59 (27)*	*161 (73)*	

Overall, 75% of the 220 patients reported a limitation on strenuous daily activities, 38% on moderate daily activities, and 27% on light daily activities. With reference to gender, males and females differed significantly in respect of the reported limitations of TB on strenuous activities (p=0.071). A higher frequency of male patients (79%) than females (69%) reported a limitation on strenuous activities. There was no statistically significantly difference between gender and reported limitation on moderate (p=0.706) and light daily activities (p=0.657).

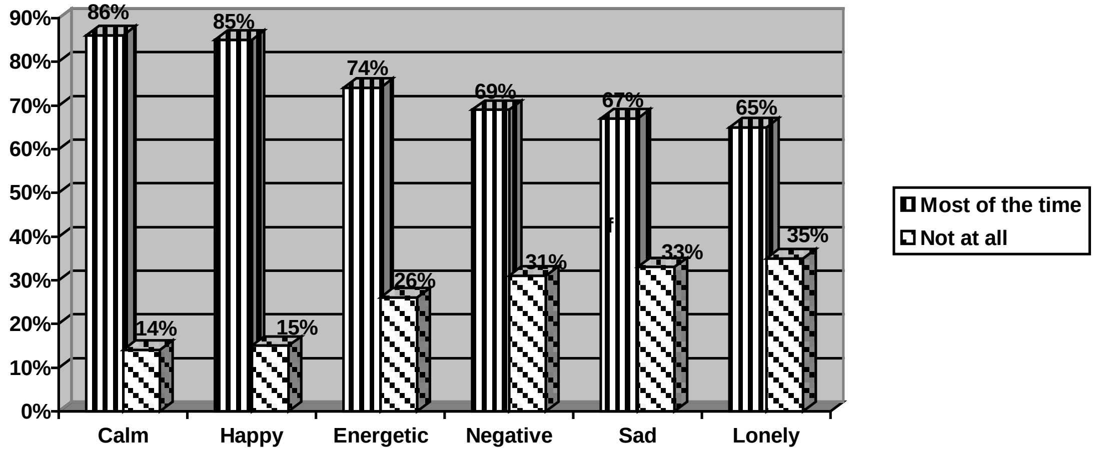
There was also a statistically significant association between age and reported limitation on strenuous daily activities (p=0.001), and light daily activities (p=0.100), but not on the moderate activities (p=0.367),). Data from Table 7.18 indicate that the limitation of TB on strenuous daily activities increased with age. Similarly, more patients in the age categories 49 - 64 and 65 and older reported that TB limited their ability to perform light daily activities.

7.5.6 Coping strategies of TB patients

TB affects many aspects of patients' lives. Many patients continue to have adverse consequences long after the diagnosis is made. In fact, patients with symptoms of depression and anxiety and suboptimal social support may find it more difficult to cope with the disease. In order to determine their emotional state, patients were asked whether they had been having any of the following feelings during the month preceding the survey: full of life/energetic; sad/distraught/depressed; negative; calm/peaceful; happy or loney? Responses were assigned to a 4 point scale: "all the time," "most of the time" and "sometimes" (recoded as "most of the time"), and "not at all."

Figure 7.7 shows the findings regarding how patients generally felt during the month prior to the survey. Of the 220 patients, 189 (86%) indicated that they had been calm, 85% were happy, 74% had been energetic, 67% had been negative, 67% had been sad, and 65% had felt lonely during the month before the study. Cross-tabulations were also run between emotional state during the month before the survey and patient category and gender. Far more female patients than males reported having felt generally sad during the month before the survey (75% vs. 60%; P=0.037). Male patients were also more likely to have reported having felt happy most of the time than females (90% vs. 78%; P=0.012). Statistically significant associations were also found between feeling either sad or calm and patient category. More new patients than re-treatment ones reported feeling sad most of the time during the month before the survey (71% vs. 57%; P=0.037). Conversely, more re-treatment patients than new ones reported having felt calm (93% vs. 83%; P=0.043).

Figure 7.7: Emotional state during past month



When asked about their coping strategies, 81% of the patients reported that they did what had to be done (taking medication daily), 77% tried to get advice from the clinic, and 75% tried hard to prevent other things from interfering with efforts to become cured. Only 5% of the patients reported that they drank alcohol in order to think less about TB. Other responses are presented in Table 7.19.

Table 7.19: Coping strategies of TB patients

Coping strategy	Usually do this a lot n (%)	Usually don't do this n (%)
I do what has to be done – one step at a time – to get rid of TB. (I drink my medication every day to get rid of TB)	179 (81)	41 (19)
I try to get advice from the clinic about what to do about TB.	170 (77)	50 (23)
I try hard to prevent other things from interfering with my efforts to become healed from TB.	165 (75)	55 (25)
I get sympathy and understanding from someone.	163 (74)	57 (26)
I try to get emotional support from friends or relatives.	157 (71)	63 (29)
I made a plan of action to address TB in my life.	156 (71)	64 (29)
I talk to someone about how I feel.	153 (70)	67 (30)
I ask people who also had TB what they did to cope.	96 (44)	124 (56)
I drink alcohol in order to think less about TB	11 (5)	209 (95)

7.5.7 Discussion

The results of this study show that more females than males had to stay in bed during the dependent-patient stage. A substantial proportion of patients (30%) also reported being absent from work. Of the 220 patients only 12% felt that they were treated negatively as a result of their TB status, and 37% indicated that they were embarrassed by the link between TB and HIV/AIDS. Sadly, a fifth of the patients indicated that they were treated negatively by their spouses/partners because of their TB status. Fear of being associated with TB may lead to delays in seeking health care and prolonged periods of illness, unpleasant treatment and, ultimately, death.

As a chronic illness, TB is not only characterised by periods of remission and recurrence, but also limitations on the performance of daily activities. Thus, it can be contended that whether the patients postpone seeking help or not, TB will ultimately have an effect on their lives. In the case of postponement, the results may be more catastrophic. The limitations imposed on activities by the illness were largely those that required much physical effort, such as lifting heavy objects (75%). As expected, older patients were much more affected in performing strenuous daily activities than younger patients. Only 5% of the patients resorted to alcohol to cope with their illness. However, it is encouraging to observe that the vast majority of the patients sought help from the clinic when experiencing difficulties.

7.6 EXPERIENCE OF THE HEALTH CARE SYSTEM

This section forms part of the dependant patient role, but has been isolated for analytical purposes. The focus here is on the experience of the health care system by patients. More specifically, the following sub-sections are dealt with: DOTS, the possible barriers to treatment adherence, the side effects of TB medication, the accessibility, the quality of care and user-friendliness.

7.6.1 Direct Observed Treatment (direct supervision of tablet-taking)

As stated in Chapter 3, DOTS is about more than simply the direct supervision of tablet-taking (Volmink *et al.*, 2000). DOTS play an important role in patient treatment outcomes (*see Chapter 8*).

Most of the patients (91%) indicated that their tablet-taking was supervised. Seven in ten patients (74%) reported that their tablet-taking was supervised at the clinic. The other places mentioned included: at the patient's home (17%), DOT supporter's home (6%), workplace (2%), and both at the clinic and at home (1). Of the 201 patients who reported that their tablet-taking is supervised, 97% indicated that they met daily (from Mondays to Fridays) with their DOT supporter, 2% met once a week and only 1% met three days a week. When the patients were asked whether they were satisfied with the arrangement with their DOT supporter, only 12% expressed dissatisfaction. When patients were asked the source of their dissatisfaction, 65% of the patients cited that they preferred to take their medication at home. Other patients were unhappy with the distance of the clinic from their homes (19%), and having to wait too long before being helped at the clinic (15%).

7.6.2 The use and effects of TB medication

The sick role involves the activities undertaken for the purpose of getting well. This includes receiving treatment from appropriate therapists by those who consider themselves ill. However, the daily realities of long-term anti-TB therapy can present many challenges. For many patients, the need to maintain high levels of adherence, and coping with non-stop, unpleasant side effects may reduce the overall quality of their lives. To the affected patient, the perceived costs may appear to outweigh the benefits. It is in these circumstances that stopping to take treatment appears attractive.

Patients were asked a series of questions concerning their treatment. Firstly, they were asked whether they were provided with TB medication to take home. A significant number of patients (n=82, 37%) indicated that they were provided with medication to take home. Of these, 63% said that they were provided with one week’s supply of treatment, 18% with longer than one month’s supply, 5% with between two to three weeks’ supply, and 2% with one month’s supply. In response to the question as to whether they were able to eat each time before taking their tablets, it is encouraging to find that 85% of the patients could eat at all times before taking their tablets, 14% could eat sometimes, and only 1% could not eat at all the times.

Figure 7.8: Ever forgotten to take tablets?

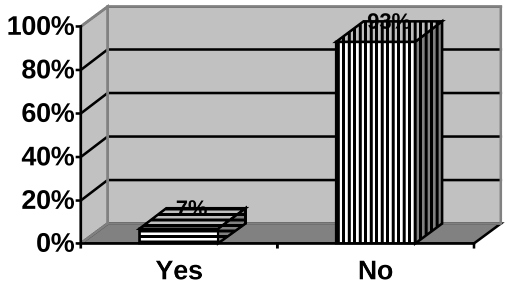
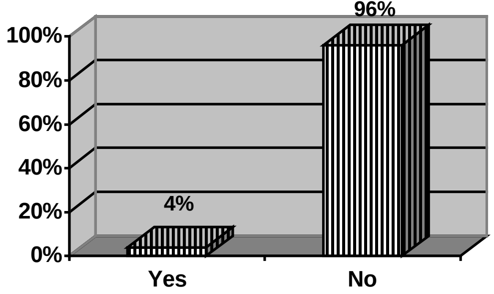


Figure 7.9: Ever purposely refrained from taking tablets?



Results from Figure 7.8 show that only 7% of the patients reported that they once forgot to take their tablets. Figure 7.9 depicts that 4% of the patients once purposely refrained from taking their tablets.

Table 7.20 illustrates the side effects experienced by the patients. A large number of patients indicated that they were not experiencing any side effects at the time of the survey (67%). The following side effects were reported by the patients: body pains (12%), vomiting (8%), and mental disorientation.

When asked how they dealt with the bothersome side effects, almost the same proportion of patients either informed the nurses at the clinic (36%) or did nothing (34%).

Table 7.20: Side effects experienced and how dealt with

Side-effect	**n**	**%**
No side-effect	147	67
Painful body/eyes	27	12
Vomit	17	8
Mental disorientation	12	6
Hunger spells/big appetite	10	5
General fatigue	3	2
Loss of breath	2	1
Total	*220*	*100*
How dealt with side effects?		
Informed nurses at the clinic	26	36
Did nothing	25	34
Treated myself	13	17
Ate much more food	6	8
Used traditional medication	3	4
Total	*73*	*100*

7.6.3 Accessibility of health care services

Two aspects related to accessibility are, firstly, socio-organisational access that focuses on whether organisational health care structures match the needs of society (e.g. fees for service, office hours), and secondly, geographic access which refers to the physical and temporal distance of consumers to health care (Wilson & Rosenberg, 2002:138). In the context of this study, accessibility is evaluated by travel times, waiting times to receive health care provider services, and client satisfaction with treatment.

Table 7.21 further shows that the majority of the patients usually walked to the clinic (75%), or took a taxi (19%), or went by car (6%). When asked how much time they spent in travelling to the clinic, 43% of the patients stated that they travelled to the clinic in between two to 15 minutes, 39% in between 16 to 30 minutes, and 18% for more than 30 minutes (range 2-180 minutes). The average travelling time to the clinic was 26 minutes. An interesting question that emerges from these results, especially when looking at the range of travelling time to the clinic, is how is it possible for a patient to spend 180 minutes (three hours) to reach a health care facility? A possible answer is that this might be a patient travelling from the farms, and that the patient has reported the actual time it takes to reach the clinic after other routine errands have been done in town.

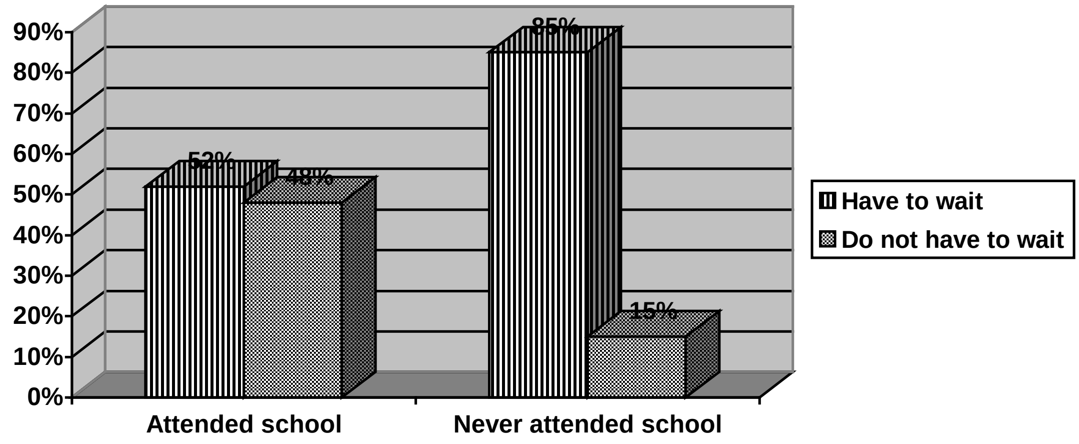
Table 7.21: Overview of health care-related variables

Mode of travel to clinic	**n**	**%**
Walk	165	75
Taxi	43	19
Own car	12	6
Total	*220*	*100*
Time spent travelling to clinic		
0-15 minutes	94	43
16-30 minutes	83	39
>30 minutes	43	18
Total	*220*	*100*
Perception of how generally treated at clinic		
Poorly	14	6
Uncertain	7	3
Well	199	91
Total	*220*	*100*
Have to wait before being helped at clinic?		
Yes	199	55
No	101	45
Total	*220*	*100*
Ever sent home without being helped?		
Yes	13	6
No	208	94
Total	*220*	*100*
Reason for being sent without being helped		
No medication at the clinic	11	84
Nurses were not available	1	8
Not helped because I complained about the treatment	1	8
Total	*73*	*100*

It is also encouraging to note that most of the patients indicated that they were treated well when visiting the clinic (91%), compared with only 6% who believed they were treated poorly. Slightly more than half of the patients (55%) said they usually had to wait before being treated at the clinic, and only 6% said that they were once sent back home without being helped. Out of the four reasons provided for not being helped, the non-availability of medication was the most frequently mentioned response (n=11, 84%), followed by the non-availability of nurses (n=1, 8%), and because of having complained about the treatment (n=1, 8%).

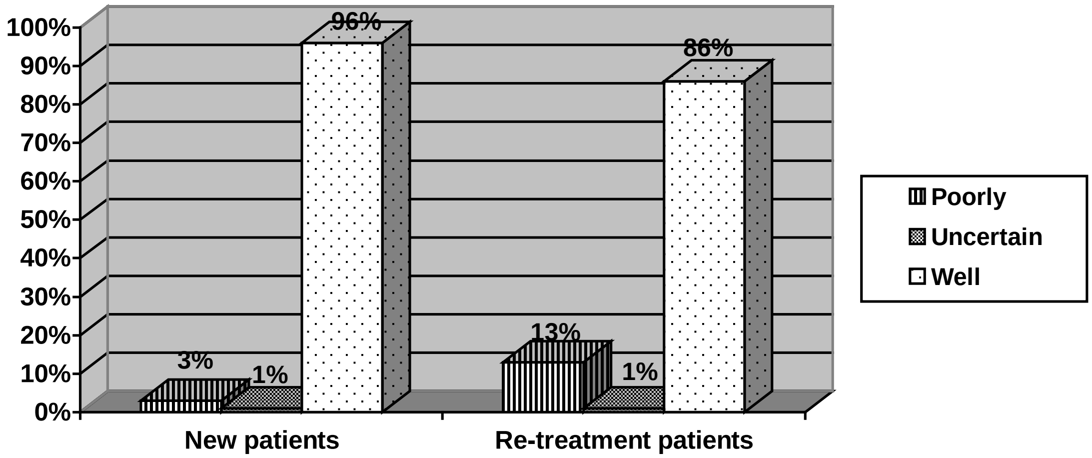
A series of cross-tabulations was run to determine the association between the variables in Table 7.21 and demographic and socio-economic characteristics. Consequently, only two statistically significant associations were found (see Figure 7.10 and Figure 7.11): between school attendance and waiting time at the clinic (P=0.005), and between category of patient and perceived treatment at the clinic (P=0.027). Data from Figure 10 show that patients who have never attended school are more likely to have waited before being helped than those who have attended school (85% versus 52%, respectively). From Figure 11, it is clear that re-treatment patients were more likely to have indicated that they had been treated poorly at the clinic than new patients (13% versus 3%, respectively).

Figure 7.10: Having to wait before being helped by school attendance



p=0.005

Figure 7.11: Perception of how treated at clinic by patient category



p=0.027

7.6.4 Future prospects

Finally, it was also determined what patients thought about their future. In order to measure this, patients were asked: How do you see your future and what are your plans for the future? The responses were grouped into two categories: "foresee a hopeless future," and "foresee a bright future." Responses such as "I want to get married," "I want to study" were coded as "foresee a bright future."

Table 7.22: Future prospects by patient characteristics

	Future prospects		
Variable	**Foresee a hopeless future**	**Foresee a bright future**	**P**
	n (%)	**n (%)**	
Category			0.203
New patient	20 (13)	130 (87)	
Re-treatment patient	14 (20)	56 (80)	
Gender			0.216
Male	22 (18)	99 (82)	
Female	12 (12)	87 (88)	
Age			0.020
16-34 years	9 (10)	78 (90)	
35-49 years	13 (14)	80 (86)	
50-64 years	12 (32)	26 (68)	
65 and older	-	2 (100)	
Educational level			0.138
No education	4 (20)	16 (80)	
Grades 1-6	11 (26)	32 (74)	
Grades 7-11	18 (14)	111 (84)	
Grade 12	1 (4)	25 (96)	
Diploma/degree	-	2 (100)	
Employment status before diagnosis			0.174
Employed	7 (10)	60 (90)	
Unemployed	27 (18)	126 (72)	
Monthly per capita income			0.365
R1-R1 000	6 (15)	24 (85)	
R1 001-R3 500	1 (4)	23 (96)	
R3 500+		3 (100)	
Total	*7 (10)*	*60 (90)*	

Table 7.22 presents the findings on the relationship between future prospects and various demographic and socio-economic characteristics. Only one variable differed statistically significantly between those patients who "foresee a hopeless future" and those who "foresee a bright future" (P<0.10). The analysis

revealed that older patients (age group 50-64 years) were more likely to report foreseeing a bleak future than younger patients (age group 16-34) (p=0.020). There were no significant differences between various other socio-demographic variables and future prospects. Worth mentioning though, about the patients with no education, is that the majority (80%) foresaw a bright future (p=0.138). In respect of employment status, more employed patients have foresaw a bright future compared with those who were unemployed (90% versus 72%, respectively).

7.6.5 Discussion

It was found that the vast majority of the patients in this study were in a DOTS programme, and actually received treatment under supervision. Patients receiving DOT were more likely to be supervised at the clinic on a daily basis from Mondays to Fridays. The dissatisfaction expressed by some patients with the arrangement of having to take their treatment at the clinic should not be overlooked, especially in the light of the high number of non-adherent patients in South Africa. It is important to provide DOT at a time and place that is convenient and acceptable to patients. Continued apathy in this area could not only potentially delay achieving global targets for TB control, but also undo, in the long run, the hard-earned achievements of the TB control programme in the country. In this regard, various studies (Wilkinson, 1994; Zwarenstein *et al.,* 1998) have suggested that trained midwives, community volunteers, and shopkeepers can provide DOT.

One of the specific aims of the study was also to assess the side effects experienced by patients. Sadly, 15% of the patients in this study indicated that they could not eat at all times before taking their medication. This finding is not surprising given the evidence concerning the level of material disadvantage experienced by black people in South Africa. The non-availability of food may serve as a barrier in the management of the treatment regimen. What is even more disturbing is the fact that 71% of the patients stated that they had at one stage forgotten to take their medication. Only 4% stated that they purposely stopped taking their medication at one stage.

In respect of health care provided at the clinic, most the patients indicated that they were satisfied. However, re-treatment patients were more likely to have experienced poor treatment at the clinic than new patients. This may perhaps be due to the fact that re-treatment patients have experienced the health care system before and, therefore, are in a better position to make an informed assessment of the service provided. As expected, younger patients were more likely to foresee a better future after illness with TB than older ones.

7.7 CONCLUSION

The illness career of an individual with TB has been characterised as a long-term experience in which, faced with the intolerable incompatibility of life and death, the individual relies on the family and friends to overcome daily challenges. Diagnosis with TB, for many individuals, means that the ordeal has just begun. TB patients must not only cope with physical disabilities and the side effects of treatment, but also with the psychological traumas of fear of recurrence and social stigma, and the disappointment of a considerably reduced range of future possibilities for career and marriage.

Generally, the elements which affect TB transmission and morbidity include socio-demographic variables such as gender, age, occupation, and educational status, human behaviour and health practices, which are influenced by perception, awareness, and recognition of the illness, the environment where the individual resides (housing structure and lack of hygiene), and the existing health care system (health facilities and resources available, including traditional medicine). Despite the illness being so heavily medicalised and stigmatised, it is encouraging to find that few of the patients in this study were treated negatively by their spouses/partners, family members or communities. In the era of highly active anti-retroviral drug therapy (HAART), understanding the influence of interpersonal as well as informational and emotional social support on clinical outcomes is important for the purposes of service delivery.

Poor knowledge regarding TB is persistent among various endemic communities, as is the case in this study. In addition, specific sections of the community, such as females, socially and economically underdeveloped classes, and people with low levels of education, know least about the disease and eventually they will be at greater risk from disease. These results may be used in the development of group-specific health education messages. The study also emphasises the Health Belief Model variables of efficacy regarding the benefits and barriers to healthy behaviour, susceptibility, and cues to action, as well as the central theme of Mechanic’s general Theory of Help-seeking Behaviour - that illness is a culturally and socially learned response (Cockerham, 2001:132). It further emphasises the assumption of the Theory of Reasoned Action that people are usually rational and make predictable use of information available to them in a systematic manner in order to weigh the cost and benefits of a particular action (Gillmore *et al*., 2002:886; Ajzen & Fishbein, 1980: 40-54). Thus, it is imperative to understand the patient perspective on the illness ‘career.’ This should, if it is not already so, be a fundamental aspect of health care in general.

Finally, this chapter has outlined the path from the initial symptom recognition through help-seeking and eventual diagnosis for TB patients. One of the fundamental observations in the context of the patient ‘career’ is, certainly, the nature of TB as a disease and the routes that TB patients often take, suggest an extension to the illness stages proposed by Suchman (1965). The literature review and empirical findings indicate an extended illness ‘career’ in which the following may occur: Patients may be cured and become again ill with the disease (re-treatment); they may fall out of treatment (default), and, even more strenuously, may embark on an entirely new and different illness ‘career’ of multi-drug resistance TB treatment. It is hoped that future research on TB can explore the model of Suchman in order to develop new pathways.

Chapter 8:
Determinants of treatment adherence[1]

8.1 Introduction

Chapter 7 reported the empirical findings on the 'career' of the TB patient. As expounded in the literature study, patients do not automatically accept doctors' recommendations. Significant factors during the *dependent-patient phase* affect the individual's adjustment to being a patient – the physical, administrative, social, or psychological barriers that interfere with the course of treatment. Also, as stated earlier, some patients enjoy the benefits of the sick role (for example, increased attention and escape from work responsibilities) and may attempt to malinger (Leigh & Reiser, 1980:17; Suchman, 1965:116; Weiss & Lonnquist, 1997:143).

The main aim of this Chapter is to provide insight into the determinants of treatment adherence among pulmonary TB patients. Although acute patients can decide at any time in their illness careers to stop taking treatment (and perhaps seek alternative treatment), it should be noted that non-adherence could only take place after a professional health care provider has recommended treatment and lifestyle changes to a patient. From the literature review in Chapter 3 it is evident that a combination of many factors may lead to non-adherence.

For analytical purposes specific to this Chapter, bivariate analysis was used to compare adherent and non-adherent patients in terms of certain key characteristics, which include socio-demographics and a number of possible determinants of adherence. The chi-square and t-test were used to assess the statistical significance of these differences in the case of categorical variables and continuous variables respectively. Multiple logistic regression was employed in investigating the determinants of adherence controlling for the possible confounding effects of other variables. Data were analysed using SPSS 10.1 and Stata8 statistical software.

The purpose of this chapter is to identify those factors that explain adherence to treatment or lack thereof amongst TB patients in the Free State province of South Africa. Firstly, it is reported on the perceptions of respondents on whether they felt confident or doubtful about completing treatment at the time of the survey. Secondly, it is reported on the quantitative evidence of determinants of adherence based on the treatment outcome of patients. This is followed by a

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[1] I am grateful to Prof. Frikkie Boise for his comments on this Chapter, and his co-authorship of an article accepted for publication: Quantitative and qualitative evidence of determinants of treatment adherence. *Acta Academica*. Please see Appendix 6 for information on the outputs of this study.

report on the qualitative evidence of determinants of adherence. These results are discussed in section 8.5, while section 8.6 concludes.

8.2 Perception about completing treatment

In an attempt to determine treatment adherence, patients were asked how confident or doubtful they are about completing treatment at the time of the survey. The responses to how confident/doubtful were measured using a five-point scale: very confident, confident (recoded as confident), uncertain, doubtful, and very doubtful (the latter two recoded as doubtful). The patients were also asked to provide an explanation why they thought that they were confident or doubtful about completing their treatment. The following four categories of responses were provided: wants to be health again, treatment is effective, wants to work or study again, and does not want to die.

Table 8.1: Confident/doubtful about completing treatment by explanation and gender

Explanation by male*	**Confident n (%)**	**Uncertain n (%)**	**Doubtful n (%)**	**Total n (%)**
Wants to be healthy again	30 (25)	-	1 (50)	31 (25)
Treatment is effective	81 (68)	-		81 (67)
Want to study or work again	1 (1)	-		1 (1)
Do not want to die	7 (6)	-	1 (50)	8 (7)
Total	*119 (100)*		*2 (100)*	*121 (100)*
Explanation by female**				
Wants to be healthy again	34 (35)	-	-	34 (34)
Treatment is effective	61 (62)	-	-	61 (62)
Want to study or work again	-	-	-	-
Do not want to die	3 (3)	1 (1)	-	4 (4)
Total	*98 (100)*	*1*		*99 (100)*

*P=0.054, **P=0.000

A multivariate analysis were run to determine the relationship between how confident/doubtful about completing treatment by explanation for being confident/doubtful, and gender (see Table 8.1). As can be seen, the relationship between how confident/doubtful about completing treatment by explanation for being confident/doubtful, and male and female patients is statistically significant (*p*=0.054 and *p*=0.000, respectively). The table further illustrates that more females than males (35% compared to 25%, respectively) indicated they were confident about completing treatment, because they "*wanted to be healthy again*". However, slightly more males than females (6% compared to 3%, respectively) were confident about completing treatment because they "*did not want to die"*. None of the female patients stated that they were doubtful about completing their treatment compared to two of the male patients. There were no statistically significant differences between patients who were confident/doubtful in terms of various demographic and socio-economic variables (not reported in table format here).

8.3 Quantitative evidence on determinants of adherence

For the purpose of this analysis, adherence was defined as the continuous uninterrupted taking of prescribed medication. In terms of treatment outcomes, adherence refers to successful outcomes and cases where treatment was interrupted for at least two months. Successful outcomes include cured patients who are smear negative at, or one month prior to, the completion of treatment and at least one previous occasion, as well as patients who have completed treatment, but whom smear results are not available on at least two occasions prior to completion of treatment.

Table 8.2 describes the treatment outcomes for the total study population. More than half (55%) of the patients were cured and 24% had completed treatment. The data also show that thirteen (6%) of the patients have died one year later after the survey was conducted and eleven (5%) has interrupted their treatment.

Table 8.2: Patient treatment outcomes

Outcome	n	%
Cured	120	55
Completed treatment	53	24
Failed treatment	12	6
Interrupted treatment	11	5
Transferred out	10	5
Died	13	6
Missing	1	1
Total	*220*	*100*

Note: Failed treatment refers to patients who remained or became again smear positive at five months or later during treatment. Transferred out refers to patients who had been transferred to another clinic and for whom the treatment outcome is not known. Died refers to patients who died for any reason during treatment. The total does not add up to 100 due to rounding.

Table 8.3 reports the results of the bivariate analysis. This analysis focuses on a comparison of the 173 patients with successful outcomes and the eleven patients who interrupted their treatment (n=184), a sub-sample that constitutes almost 80% of the 220 patients interviewed in the study. The two groups of patients (adherent and non-adherent) are compared here in terms of a wide range of socio-demographic and household characteristics of the patients, as well as variables approximating the determinants of adherence expounded in the literature (Farmer, 1997; Pablos-Méndez *et al.*, 1997; Jaramillo, 1999; Malotte *et al.,* 2001; Thorson & Diwan, 2001; Demissie *et al.,* 2003; Hovell *et al.*, 2003; Jaiswal *et al.,* 2003). The descriptive statistics of these variables and the meaning of index variables are described in detail in Appendix 1 for the sub-sample of patients.

Table 8.3: Comparison between adherent and non-adherent patients

Variable	Adherent (%)	Non-adherent (%)	P
Mean household size	4.3	4.7	0.267
Gender			
Male	91 (52.6)	10 (90.9)	
Female	82 (47.4)	1 (9.1)	0.013
Mean age (years)	37.7	42.7	0.077
Marital status			
Married	66 (38.1)	5 (45.4)	
Single	107 (61.8)	6 (54.5)	0.629
Housing			
Formal	132 (76.3)	9 (81.8)	
Informal	29 (16.7)	1 (9.1)	
Traditional	12 (6.9)	1 (9.1)	0.786
Mean years of education	7.8	7.1	0.255
Mean monthly household income (Rand)	1205	1345	0.670
Financial support received while on treatment (Rand)	478	305	0.233
Access to medical aid	9 (5.2)	0 (0.0)	0.437
Re-treatment patient	50 (28.9)	7 (63.6)	0.016
Paid to access treatment	1 (0.6)	1 (9.1)	0.008
Main breadwinner	64 (36.9)	5 (45.4)	0.574
Currently employed	58 (33.5)	5 (45.4)	0.419
Previously employed	25 (14.4)	2 (18.1)	0.735
Income loss due to illness (Rand)	1832	5415	0.075
Travel time to clinic (minutes)	25	28	0.346
Away from home during treatment	15 (8.7)	3 (27.2)	0.045
Number of migrants in household	0.1	0.3	0.008
Ever in jail	16 (9.2)	4 (36.3)	0.005
Able to eat before taking tables	158 (91.8)	10 (90.9)	0.911
Access to piped water in dwelling	141 (81.5)	11 (100.0)	0.117
Tablet taking supervised	156 (91.2)	10 (90.9)	0.971
Experienced side effects	172 (99.4)	11 (100.0)	0.800
Crowding index	2.2	2.2	0.491
Stigma index	0.236	0.545	0.042
TB knowledge index	5.156	5.545	0.150
Service quality index	1.628	1.666	0.576

According to the results presented in Table 8.3, a total of nine variables differed statistically significantly between adherent and non-adherent patients (P<0.10):

- Female patients were more likely than male patient to adhere to treatment.
- Younger patients were more likely to adhere to treatment compared to older patients.
- Patients who were on re-treatment were more likely to not adhere to treatment.
- Those patients that had to pay a fee to access health care services for diagnosis or treatment were more likely to not adhere to treatment.
- Those patients that reported a higher loss in income due to their illness were more likely to not adhere to treatment.
- Patients that were away from home during the course of their treatment and patients from households included a larger number of migrant workers were more likely to not adhere to treatment.
- Non-adherence was also more likely amongst patients who had spent some time in jail during their lives, this indicator having been used here to approximate risk behaviours not assessed in detail in the questionnaire (e.g. alcohol and substance abuse).
- Finally, non-adherence was also more likely amongst patients who reported perceived stigma (the stigma index is defined in Appendix 1).

Table 8.4 reports the results of the multiple logistic regression used to determine the relative importance of various determinants of adherence when controlling for the effect of other variables. The overall model was statistical significant (P=0.059) and explained 44% of observed differences in adherence. The dependent variable is a dichotomous variable, where 1=adherence and 0=non-adherence. The independent variables included in the model consisted of a wide range of socio-demographic and household characteristics of the patients, as well as variables approximating the determinants of adherence expounded in the quantitative literature. After adjusting for possible confounding effects, a total of eight variables featured as statistically significant determinants of adherence (P<0.10). These include only two of those variables that in Table 8.5 exhibited statistically significant differences between adherent and non-adherent patients.

As was the case with the bivariate analysis, the likelihood of adherence was higher where perceived stigma was lower. In addition, the likelihood of adherence was significantly higher amongst patients that were not on re-treatment. The results also point to the importance of the socio-economic circumstances of patients in explaining differences in adherence. Patients who had access to more financial support in the form of social grants, a pension, remittance income, a salary or other income while on treatment, were more likely to adhere to treatment. Patients that were in most instances able to eat before taking their tablets, or who were members of smaller households (smaller households generally face relatively lower resource constraints) were also more likely to adhere to treatment. Employment status, moreover, posed a barrier to adherence, with patients that were currently employed being more likely to not adhere to treatment. Importantly, patients whose tablet taking was supervised were more likely to adhere to treatment.

Table 8.4: Multiple logistic regression results: determinants of adherence

Variable	Odds ratio (OR)	P	Confidence interval (95%)		
Household size	0.407	0.044	0.170	-	0.978
Gender (male=1, female=2)	12.433	0.145	0.420	-	368.443
Age	0.966	0.643	0.833	-	1.120
Marital status (married=1, single=2)	1.088	0.936	0.142	-	8.340
Years of education	1.078	0.710	0.725	-	1.605
Monthly household income (Rand)	1.000	0.488	0.999	-	1.001
Financial support received while on treatment (Rand)	1.004	0.029	1.000	-	1.008
Re-treatment patient (yes=1, no=0)	0.141	0.095	0.014	-	1.407
Paid to access treatment (yes=1, no=0)	0.012	0.153	0.000	-	5.214
Currently employed (yes=1, no=0)	0.031	0.039	0.001	-	0.840
Previously employed (yes=1, no=0)	1.151	0.920	0.074	-	17.783
Income loss due to illness (Rand)	1.000	0.375	1.000	-	1.000
Travel time to clinic (minutes)	1.014	0.718	0.941	-	1.093
Away from home during treatment (yes=1, no=0)	0.259	0.430	0.009	-	7.418
Number of migrants in household	0.860	0.932	0.027	-	27.711
Ever in jail (yes=1, no=0)	0.375	0.415	0.035	-	3.963
Able to eat before taking tables (yes=1, no=0)	46.962	0.077	0.658	-	3,353.973
Tablet taking supervised (yes=1, no=0)	30.327	0.100	0.521	-	1,764.489
Crowding index	2.876	0.351	0.313	-	26.415
Stigma index	0.221	0.045	0.051	-	0.965
TB knowledge index	0.151	0.075	0.019	-	1.207
Service quality index	1.355	0.700	0.289	-	6.355
Sample (n)					170
LR chi2 test (P)					33.17 (0.059)
Pseudo R^2					0.436

Note: Access to medical aid and piped water were excluded from the analysis, given that not one non-adherent patient had access to medical aid and that all non-adherent patients had access to piped water. The indicator for experience of side effects likewise was excluded, given that all non-adherent patients experienced side effects.

The association between adherence and the TB knowledge index (defined in Appendix 1), although statistically significant, did not exhibit the anticipated sign. One would have expected the likelihood of adherence to increase as the patient's knowledge of TB increases. However, adherence was here associated with less knowledge of TB, which may reflect some spurious correlation, given the relatively crude nature of the knowledge index employed for this purpose (see Appendix 1).

8.4 Qualitative evidence on determinants of adherence

As stated earlier, the participants reported their ideas freely, and it was easy for them to respond to the questions. All the questions posed to the participants seemed to be relevant. However, despite the relaxed atmosphere during all the FGDs, the questions related to the side effects of TB drugs, lack of family support, and the stigma attached to the disease, evoked much stronger reaction from the participants.

8.4.1 Knowledge of TB and educational campaigns

Mixed reactions emerged from the group discussions regarding the knowledge of TB. In most instances, it appears that the participants who previously had TB, and/or lived with a contact (someone who has TB), is more likely to know what TB is, than someone who has personally no history of TB treatment or any of his/her close contacts. However, a further analysis reveals that the participants' understanding of TB was not always in agreement with biomedical knowledge.

Female: Yes, I know what TB is all about. I have heard many people talking about it. But for me, it is a family thing. It has been there for some time in the family. I think I have inherited it from my parents ...

Male: My mother passed away while still taking TB treatment ... I have TB for the past three years despite having completed treatment on all occasions. If you have TB you have got it, there is nothing that can cure it. That is the way of this disease.

Concern was expressed about how it is possible for one person to become ill with TB for more than once (recurrent TB).

Male: I am really disappointed. I have been cured before, but no one at the clinic can tell me why this disease keeps on coming back. The only thing that I am told, is how to take my medication...

Female: My grandmother first had TB. She has since passed away. I was previously cured, but after six months, I became ill again. I was sent to Santoord [TB hospital][2]. On my return, my brother was also diagnosed with TB. He later also passed away... this thing wants to eat us all. Something has to be done. I really do not know why it keeps on coming back.

Subsequently, participants were asked to mention the health information/intervention campaigns that they know of. A substantial number of participants mentioned nurses, doctors, radios,

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[2] Santoord was the last specialised TB hospital to be closed in the Free State.

newspapers, television, family members, and friends as their most important sources of information about TB. Only a few participants were aware of health education activities concerning TB being carried out in their area.

8.4.2 Side effects of drugs

When asked what factors lead to non-adherence with treatment regimen, the source most strongly emphasised by the majority of the participants tended to be the physical side effects of TB medication. Another contributing factor includes the patient's negative subjective experience with the medication, which is not often communicated to the health care provider for fear of reprisal. The following quotations capture the feelings cited by the participants:

Male: These tablets let one's body itches for the whole day. I know someone who interrupted his treatment because of this problem. I told the nurses about the side effects and they gave me other tablets. But the problem is my situation is even worse now … I console myself by rubbing myself with cabbage or orange bags*.*

Female: Since I have started taking this TB medication, my body is full of pimples and sores. The rash is very painful. The nurses told me that it is the nature of TB… the side effects will go away with time. The itching is bearable from Monday to Friday [treatment is not taken over weekends]. But when we start taking treatment on Monday, the irritation start all over again … it seems as if these tablets do not want you to stop taking them…

Patients mentioned that after they started taking TB medication, it had been the worst period for them when they were most in need of help and support, especially with regard to the side effects. They were plagued by feelings of guilt and self-reproach, because of being a burden to nurses. The following example illustrates how the reaction of health care providers also can influence the effect of TB on patients:

Female: … and when we report these side effects, nurses will always retort: 'Hey you! You are a nuisance and childish, you have to experience side effects, because you have been drinking alcohol,' even if that is not the case*.*

8.4.3 Hunger and lack of family support

The majority of the patients who were employed at the time they fell sick, mentioned that they resigned or were dismissed. In most cases these patients were breadwinners who not only have to face hostile family members, but also a spell of hunger as a result of the medication.

Male: The problem is that we have to come to the clinic everyday for medication. What is the role of the DOTS supporters? Sometimes we are tired … These tablets make you very hungry; even now I am hungry … Some patients may just decide to stay away from the clinic if there is no food at home.

Female: We sometimes need to be pushed, but we do not get support from family members. These tablets are eating everything left in your stomach. At times I really feel like not coming to the clinic.

There also seems to be the danger that family members will shun their company in the household.

Male: I have been afraid to tell them at home about my TB status. Ever since they found out that I have TB, I have to cook my own food in my tiny sleeping room. I have been instructed not to take utensils that I use out of my room ... I am also not allowed to come into close contact with the children...

8.4.4 Stigma

The existing socio-cultural barriers and taboos associated with TB have also been found to be major factors leading to poor completion rates. This problem is exacerbated by the link between TB and AIDS.

Male: I arrive early in the morning so that people could not see me. I used to conceal my illness from people. It was only my mother and wife who knew why am I am so often visiting the clinic. People think that we are the filthiest people … it was really difficult to accept that I have TB.

Female: If people can see you carrying your [treatment] card, they will start to gossip about you. I have once overheard someone saying, ‘look at that beautiful girl who is carrying a TB card.’ I use to conceal the card in a brown envelope.

Male: Ever since I have been diagnosed with TB, my life has turned up-side down. My wife once packed all her belongings, because she told me I am dishonest about my status. She strongly believed that I know I am infected with AIDS and not TB. Even if we can go now to my place, you will detect that things are not OK between us … I previously defaulted, but realised it is not going to help.

It is evident that certain perceptions about TB not only contribute to non-adherence, but also have the potential to discourage prospective patients from taking anti-TB drugs:

Female: There is a widespread perception in the community that the very same TB tablets cause AIDS...

8.4.5 Patient behaviour

It is interesting to observe that the participants did not only see factors outside their control as leading to non-adherence. Alcohol abuse by TB patients, together with the clinic operational times, was perceived to be the most common reasons for non-adherence and treatment interruption.

Male: The clinic operation time is a hindrance. How would someone who starts drinking early in the morning visit the clinic? Some patients consume alcohol daily. They would rather decide to interrupt their treatment, than discarding their drinking habit.

Female: It is the third time that I am sick with TB. I used to drink non-stop, from early in the morning till sunset... This went on for three months. Alcohol is really a big problem...

Further, many participants mentioned the harm of alcohol for the body. They described that people who consume alcohol excessively usually do not eat well. As a result, this weakens the body, which could lead to other diseases. One participant said:

Male: If you do not eat, you give TB the power. If you eat well, it will not affect you that badly. I know, because I have also experienced the negative impact of alcohol on one’s health.

The majority of the participants expressed that it is pure stubbornness for patients not to adhere to their treatment regimen. Some participants indicated that for patients to adhere, they needed economic resources and certain personal resources, such as feeling able to focus exclusively on the treatment plan.

8.4.6 Health services factors

Regarding health services factors, the following were mentioned as encouraging non-adherence: non-availability of TB medication at clinics, the attitude of health care providers, and the delay in diagnosis.

Female: The biggest problem at this clinic is the non-availability of treatment. There was a time when we did not receive treatment for two weeks [showing card]. I marked my card in red in order to remember the days we did not get treatment. I really wanted to make sure that my card is not being completed for treatment that I did not receive. What are the stock control measures at this place? We are being slowly murdered.

[On inspecting the card, the indication is that the patient had not received medication for 13 days].

Male: Sometimes one finds it difficult to wake up because of tiredness. When you send someone to collect your medication at the clinic, there is no co-operation from the nurses. They insist that one has to come to the clinic irrespective of your circumstances … Inasmuch as we understand that we had to come to the clinic, our physical strength prevents us to do this at times …

Participants reported having different experiences regarding the attitude of health care providers.

Male: The attitude of nurses is also not helping the situation. When you are in the waiting room, you will wait and wait and wait. Sometimes they are just sitting and chatting. The fewer they are in the consultation room, the better. They [nurses] also have a tendency to harass TB patients in front of others.

Male: I have been treated well since I started my treatment at this clinic. The nurses are very helpful. They treat us like their own children...

Moreover, participants mentioned late diagnosis as a factor that encourages non-adherence. They reported that they would go between two to four times to a doctor before they are diagnosed with flu. Some participants indicated that doctors do not often inform them about the diagnosis, "*They are only interested in giving us injections*." More sadly, it is evident that some of the participants consulted various conventional health care providers before being diagnosed with TB.

Female: I went to three different doctors. The first one told me I have flu. The symptoms persisted, and after three days, I returned to him. He gave me another injection. The second one did not even bother to tell me what the problem was ... I vomited all the medication. It was only after the last doctor at the clinic sent me for to X-rays, that I was diagnosed with TB ... The problem is you have to pay R80.00 each time you consult a doctor.

Another patient who was very emotional about the delay in being diagnosed expressed his views in the following way:

Male: My wife also has complained for about six months about chest pains. She was just given tablets all the time [breathing heavily]. Even me too, I was just told it is flu, flu, flu and flu ... After three months; I went to a private doctor. The pains in my body

> became even worse. I went to another doctor. My body only reacted [pains became bearable] after this doctor gave me tablets. I was referred to the clinic and from there, to the hospital. They just looked at me at the hospital. I had to remind them about the X-Rays. I spent two additional nights in the hospital ... and only realised later that I should have been discharged the same day after my X-rays have been taken. It seems as if nobody cares about us ...

8.4.7 What is needed to improve adherence?

In response to the question: what would improve adherence, participants mentioned information provision, education and altering the treatment plan. In particularly, the majority of the respondents felt that TB health education campaigns should be provided the same ‘platform’ as HIV/AIDS. The participants expressed the need for such campaigns to focus on all members of society, and not only on TB patients. They also reported that educational programmes both in-school and out of school, can provide channels to influence pupils and students through the curriculum. The participants further indicated that former TB patients could be used as ambassadors of TB control initiatives. These patients could be invited to give speeches at church and community gatherings.

The participants concluded that the treatment plan is too long. There was also a strong feeling that more effective drugs, with fewer side effects should be provided. The groups considered the services provided by DOT supporters to be limited to the provision of medication. They believed that it would be beneficial to delegate more responsibility (i.e. provision of information and health education) to DOT supporters.

8.5 Discussion

Increased adherence is one of the main goals of any TB Programme, including the South African NTCP. Internationally, a range of strategies has been employed to improve adherence. Some of these strategies are aimed at changing the behaviour of health staff, e.g. training, motivation and supervision. Other strategies, in turn, have been aimed at the patient, e.g. education, reminders and prompts for attendance, financial incentives, supervision of tablet taking and the tracing of defaulters (Volmink & Garner, 1997:1405). Results from the quantitative and qualitative research reported here suggest that there are still several impediments that need to be addressed in order to achieve this objective, both in terms of provider- and patient-related barriers to adherence. These impediments present a potential opportunity for health care authorities, managers and health care providers to play a greater role in the management and treatment of TB patients. However, for increased rates of adherence to happen in practice, patients’ views and any barrier to adherence need to be understood to implement appropriate interventions to improve adherence to treatment.

The evidence points to the importance of the socio-economic circumstances of patients in explaining differences in adherence. In fact, early research reported the strongest predictors of adherence to be economic rather than cognitive or cultural factors (Farmer, 1997:347), a point of view shared by Jaramillo (1999:393). Patients who had access to more financial support while on treatment were more likely to adhere to treatment, as were patients that were in most instances able to eat before taking their tablets. This raises the question as to whether incentives and enablers offered to patients in the form of food coupons or bus tokens could be employed in overcoming these impediments to adherence (Buchanan, 1997:2016), especially for TB patients from poor communities. According to Jaramillo (1999:402), therefore, poverty alleviation will play an important role in achieving TB control in developing countries.

Yet, economic factors can also act as an impediment to adherence. The quantitative evidence shows that the likelihood of adherence is lower amongst patients who were employed while on treatment, or among those patients who reported a higher income loss due to being on treatment. Thorson & Diwan (2001:165), likewise, reports that male patients in particular were likely to interrupt their treatment due to work commitments. (The results of this study also show that female patients are more likely to adhere to treatment than male patients, although gender was not a significant determinant of adherence when controlling for the effect of other variables.)

In addition, structural economic factors also seem to play a role in explaining lack of adherence, in particular the labour migrant system and internal migration. Patients that were away from home during the course of their treatment and patients from households included a larger number of migrant workers were more likely to not adhere to treatment, i.e. to have interrupted their treatment for two months or longer. According to Kok *et al.* (2003) the internal migration patterns in South Africa by 1996 continued to mirror the internal migration patterns of the apartheid era. Furthermore, persons who have migrated before are likely to continue to migrate, given that “migration *becomes institutionalised through the formation and elaboration of networks*” (Kok *et al.* 2003:26). This highlights the need to devise appropriate strategies to ensure the successful transfer of migrating patients from one health facility to another, so as to ensure that these patients complete their treatment.

In the qualitative evidence reported here, TB patients were asked to reflect on their own experiences. The participants had good knowledge of TB being a contagious disease, but there were also some whose understanding of TB was not in agreement with biomedical knowledge.

The mass media, nurses, family members and friends were identified as the main sources of information concerning TB. However, the majority of the participants were not aware of any health education activities concerning TB in their area. This finding is in conflict with the South African National TB control Programme aim that patients, relatives and the community must receive quality information on TB (Department of Health, 200b). The situation at primary health care clinics makes it virtually impossible for patients to be given group education each month when their situation is reviewed.

Despite being contagious, Metcalf (1991:1) already noted more than a decade ago that TB has not yet ignited the same public alarm as acute diseases such as HIV/AIDS. Considering the profound influence that TB has on patients in terms of effort and time – with some patients suffering for more than five years – a feature of the disease that became evident in this study is the irritation that goes with the treatment. The side effects revealed by participants included a painful body, and pimples and sores on the body. Some study results suggest that adherence rates may be adversely affected by unreported side effects rather than the number of medication prescribed. A study by Grant *et al.* (2003:1408) revealed that unreported side effects and a lack of confidence in immediate or future benefits were significant predictors of sub-optimal adherence. It was concluded that health care providers should not feel deterred from prescribing multiple agents in order to achieve adequate control of diseases such as hypertension.

The pressing question that remains with regard to TB treatment is: will TB patients who have reported severe side effects continue to take their medication? Gregson (2002:461) attempts to answer this question when he states that, generally, treatments are abandoned not because they do not work well enough, but because they are "*too much trouble to take*." Imagine having to take TB treatment for six months on an empty stomach for most part of this period, as it is the case for many TB sufferers in South Africa. Clearly, adherence will be poor, because most patients will choose to stay away, rather than complicating their health by taking tablets, which lead to even worse hunger spells. Schiffman & Zervakis' (in *Doctors Guide*, 2000) studies on the taste properties of drugs found that the innate desire to taste food and derive pleasure from that sensation is so strong that people sometimes stop taking life-saving medication simply because it tastes bad or ruins the flavour of otherwise enjoyable foods.

A study by Herman *et al.* (2000:74-75) showed that as the treatment regimen becomes more complex (swallowing between one to four large tablets daily for six to eight months), the more difficult it becomes for patients to adhere to treatment regimens. Some patients may fear that they will develop psychological or physical dependence on medication. In such instances health care providers may be viewed as being unhelpful and, as stated by Kane (2002), be seen as part of the pervasive negative influences impeding the road to a cure. Of serious concern is the revelation that patients did not receive their medication for almost two weeks, because it was not available at the clinics. This not only endangers the lives of already suffering patients, but also is a huge blow to the government's commitment to uninterrupted supply of quality anti-TB drugs and sustained TB control.

Another notable finding was the role of stigma and social support, which featured in both the quantitative and qualitative evidence as a significant determinant of non-adherence. Studies from the Philippines (Nichter, 1994) and Vietnam (Johansson *et al.,* 1996; Long *et al*., 2001) indicate that adherence behaviour is associated with social support from the family or other persons. This study shows that participants' families sometimes isolated them. One common form of isolation, which was also noted by Long *et al* (2001), is the separation of cooking utensils and bowls. The importance of stigma and social support in improving the outcomes of treatment for TB was emphasised by Liefooghe (2000:52) and Thorson & Diwan (2001:167). According to Love (2002:12), patients who live with supportive family members are more likely to complete treatment. This study also shows the need for a constructive family environment, which may increase the support and guidance available to patients. Stigma is also re-enforced by the required daily visits to primary health care clinics. Liefooghe *et al.* (1995:1686), Long (2000) and Demissie *et al.* (2003:2011) further show that the community is isolating many patients and that adherence is the product of societal attitudes towards the disease. Demissie *et al.* (2003:2009) further reports that the TB club approach to the delivery of treatment in rural North Ethiopia has had a "*significant impact on adherence to treatment and in building positive attitudes and practice in the community regarding TB*".[3] Based on the qualitative evidence, the association of TB with HIV/AIDS appears to be the main source of stigmatisation. In addition, the physical appearance of TB patients (i.e. slim body), which resembles that of AIDS patients, further compounds stigmatisation. With high rates (52%) of TB-HIV co-infection in the Free State (*SATCI*, 2000:14), the associated stigma may lead to adverse treatment outcomes.

The participants in the focus group discussions also perceived the illness behaviour of patients as a factor that encourages non-adherence. Although it is commonly known that poverty is an important risk factor for TB globally (Long *et al.,* 2001:74), this study shows that TB patients are often abusing alcohol, which impedes their treatment adherence, evidence of which was also reported by Pablos-Méndez (1997:168), Malotte *et al.* (2001:103) and Hovell *et al.* (2003:1794). In fact, the South African Demographic and Health Survey of 1998 (Department of Health,

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[3] TB patients from the same village are organised into 'clubs' of 3 to 10 patients by the local health care worker. The members of each TB club have the same clinic dates for follow-up and the leader of the club ensures that all members attend the TB clinic and inform the clinic staff about absent members. In addition, TB clubs have regular and ad hoc meetings at which they supported each other and shared experiences of the disease with fellow members of their TB club. Leaders of these clubs also solicit the help of community leaders in encouraging patients to complete their treatment (Demissie *et al.,* 2002: 2012).

2002:238) indicates that 28% (n=8.3 million) of South Africans 15 years and older consumes alcohol.

The health provider-patient relationship is an important determinant of adherence (Zwarenstein *et al.,* 1998; Vermeire *et al.,* 2001; Jaiswal *et al.,* 2003). Health care providers at the clinic level are an essential link between the programme and the patients. They are responsible for providing treatment and maintaining registers. From a TB control point of view, informed and motivated frontline health workers may contribute to positive treatment outcomes. Conversely, de-motivated and ill-informed health workers may contribute to interruptions of patients and the resulting transmission of TB in affected communities. This study has revealed some important dysfunctional aspects of attitudes of health care providers to TB patients. According to Stein (2000), non-adherence may result from differing interests or expectations of the patient and health care provider. Misperceptions or dissatisfaction with the patient-health care provider relationship may also be a cause of non-adherence.

The evidence presented in these pages also supports the importance of the traditional key component of DOTS, i.e. the direct supervision of tablet taking. Patients whose tablet taking was supervised were more likely to adhere to treatment all other things being equal. Thus, this will remain a key component of the DOTS strategy in improving adherence and cure rates, given the larger evidence on the role of direct supervision in enhancing adherence (Jaramillo, 1999:394; Chaisson *et al.,* 2001:611).

Finally, and perhaps most importantly, the quantitative evidence shows that re-treatments patients are less likely to adhere to treatment, thus, highlighting the risk of non-adherence in exacerbating the MDR problem in South Africa. Hence, particular care needs to be taken in addressing the above impediments to adherence amongst re-treatment patients.

8.6. Conclusion

The success of TB control programmes depends on various factors. This study shows that knowledge and awareness of the disease, the support patients receive from others, economic factors as well as health care providers' attitude also play an important role. In fact, the behaviour of the different actors in the TB control programme contributes to poor treatment adherence. Non-adherence with treatment regimens remains a major challenge facing TB patients, their families and the health care fraternity. It results in poor treatment outcomes accompanied by high economic costs.

Of the 220 patients who participated in the survey, most were cured (55%); completed treatment (24%); died (6%), or had interrupted treatment (5%). The results also further indicate that the following patients are more likely to not adhere to treatment: males; old patients; re-treatment patients; patients who spent time in jail; patients who experienced a higher loss of income due to their illness; and those who experienced perceived stigma. The quantitative evidence shows that stigma, the socio-economic circumstances of the patient, and migrancy play an important role in explaining non-adherence. In addition, patients whose tablet taking was supervised were more likely to adhere to treatment.

Based on the qualitative evidence, some of the perceived factors affecting adherence included lack of knowledge about TB, non-sustainability of educational campaigns, side effects of drugs, hunger and lack of family support, stigma attached to TB, the attitude of health care workers, and the long delay in obtaining a diagnosis. The evidence reported here highlights the fact that adherence is a function not only of the availability and quality of health care, but also of a variety of personal, socio-economic, infrastructural and community factors.

Chapter 9:
Conclusions and recommendations

9.1 Conclusions

South Africa is currently experiencing a widespread TB epidemic. This situation, as stated earlier, is compounded by the link of TB with HIV/AIDS whereby each speeding the other's progress. HIV/AIDS prevention and health promotion campaigns, it can be contended, provide numerous lessons from which could be learned from. For the country and provinces, such as the Free State, to respond effectively, preventing new infections and providing care and support to those already infected with TB, it is vital to garner the support and expertise of international agencies, other countries and local communities. Indeed, a comprehensive understanding of the disease by policy-makers, health care providers, patients, and communities must be the cornerstones of every TB control programme in the country. Though there are limitations to the study, it is of utmost importance that the recommendations listed below be considered by policy makers, health care providers, patients and community members.

As stated in Chapter 1, the main aims of this study were, firstly, to profile the ‘career’ of TB patients; secondly, to provide all stakeholders with insight into the life circumstances and experiences of pulmonary TB patients; and thirdly, to propose guidelines for innovative behavioural prevention mechanisms. It was argued that despite the knowledge that socio-economic, cultural and behavioural factors influence patient adherence, little research has been conducted on this aspect of TB. It is also remarkable that social, cultural and economical factors, which appear to produce the disease, have been given little priority. Chapter 1 developed an analytical framework for understanding the ‘career’ of the patient. The analytical framework was based on the five illness stages of Suchman:(1) symptom experience, (2) assumption of the sick-role, (3) medical contact, (4) dependent-patient role and (5) recovery and rehabilitation stage.

Chapter 2 developed a theoretical frame of reference for understanding patient behaviour. The focus was on the Health Belief Model; the Help-seeking Behaviour Theory and the Theory of Reasoned Action. In so doing, it provided an understanding that the Health Belief Model and the Theory of Reasoned Action both focus on individual decision-making and the process of determining whether or not to participate in specific preventive health actions. Both models posit that beliefs about behavioural consequences predict behaviour. It was further indicated that the general Theory of Help-seeking

Behaviour emphasises the importance of social, cultural and economic factors in seeking help. Drawing on Mechanic, it was shown that the presence of a symptom, on its own, is not a sufficient condition for seeking medical help. The interpretation of the action by the patient in the light of an individual's own unique social background and experience determines the action. The chapter concluded that countries will have to mobilise substantial social psychological resources to counter the dysfunctional behaviour of TB patients.

Chapter 3 focused on adherence with treatment regimen. It was noted that South Africans are currently dying from a curable disease, despite numerous efforts to reduce the incidence of TB. The chapter moved on to argue that despite positive interventions by the Government in making all TB treatment free of charge, in the words of Zola (1981:241): "*patients are not willing supplants , rushing with open arms to seek aid*". It was argued that this situation ccertainly calls for a paradigm shift in TB control with the emphasis on the socio-economic, and cultural and socio-behavioural aspects of TB. It was also emphasised that new initiatives must only be developed after having fully exploited the benefits and cost-effectiveness of existing ones. The chapter further pointed out that many conditions contribute to non-adherence. It was suggested that, when developing a treatment plan for an individual, consideration must be given to the patient's perceptions, the degree of support/supervision required and available, and the degree of behaviour change needed. An argument was made, in closing Chapter 3, for each country to develop appropriate intervention models. It was indicated, more specifically, that the models have to reflect the needs of the communities they serve, meaning that communities have to become involved in TB control efforts rather than being mere passive recipients.

Chapter 4 pointed out that the most outstanding aspect in respect of health education campaigns in the country in general, and a behaviour change intervention on TB, in particular, is the lack of formal documentation of what is happening. In addition, it was emphasised that policy makers should understand that the success of their efforts would primarily be determined by the extent to which the social paradigm is understood and responded to. It was shown that several potential strategic behaviour change intervention models exist, which may counter the risk of TB infection and non-adherence. A further point of clarification concerning health communication programmes was made. It was noted that successful health communication programmes involve much more than the mere production of messages and materials. It was argued that sound IEC development should draw upon behaviour change theories such as the Health Belief Model, the Help-Seeking Behaviour model and the Theory of Reasoned Action. Together, these models provide invaluable tools for understanding and developing health interventions directed at TB patients. While the importance of imparting proper knowledge, skills and attitudes in TB treatment to all stakeholders involved, it was also emphasised that increased knowledge does not necessarily translate into changes in attitude and alterations in behaviour. Owing to the contention that culturally sensitive and interactive educational approaches must be promoted, it was indicated that the information-seeking behaviours of patients and their families should be taken into consideration when identifying their needs for information.

In Chapter 5, the research the research design, sampling, instrument construction, selection and training of fieldworkers, data collection methods, data analysis, and strengths and limitations of the study, were discussed. It was indicated that the overall study design is descriptive and explanatory, but also directed towards recommending interventions at the policy and practice levels. In adopting the survey and focus group research methods, it was explained that there are several advantages inherent in these methods. The data, based on the 220 PTB patients, were analysed using SPSS 10.1 and Stata8 statistical software.

Chapter 6 presented the findings of the survey. The data presented in this chapter were aimed at constructing a profile of the sample by focusing, amongst others, on the demographic and socio-economic characteristics of the patients. It was shown that the most of the respondents were young and unemployed. It was also shown that illness with TB impacted negatively on the income generating ability of patients. The aim of Chapter 6 was to provide useful information to allow health care managers and providers to understand the social and economic impact of TB on patients.

Chapter 7 presented the findings on the illness ‘career’ of the patient. It was shown that the illness ‘career’ of individuals with TB is characterised as a long-term experience in which the individuals had to rely families and friends to overcome daily challenges. In an attempt to provide a meaningful separation of events constituting the illness experience, the illness ‘career’ of the TB patient was divided into five different phases from experiencing symptoms, to assuming the sick role, to contacting a health care provider, to being a patient and, finally, relinquishing the sick role. The findings in Chapter 7 indicated that the patients in this study not only had to cope with physical disabilities and the side effects of treatment, but also with the psychological traumas of fear of recurrence of the disease and social stigma, and the disappointment of a considerably reduced range of future possibilities for career and marriage. It was also indicated that few of the patients in this study were treated negatively by their spouses/partners, family members or their communities. Living with TB in “modern” society where stress, AIDS and an array other social and psychological factors are seen to threaten the individuals, is an enormous burden. As such, the focus needs to be much more on specific sections of endemic communities, such as females, the socially and economically underdeveloped classes, and people with low levels of education. In conclusion, the analysis of the TB patient ‘career in Chapter 7 has pointed to an extension of the illness ‘career’. It was suggested that this finding needs further investigation.

The main aim of Chapter 8 was to provide insight into the determinants of treatment adherence among pulmonary tuberculosis patients. The quantitative evidence showed that stigma, the socio-economic circumstances of the patient, and migrancy played an important role in explaining non-adherence. In addition, patients whose tablet taking was supervised were more likely to adhere to treatment. Based on the qualitative evidence, some of the perceived factors affecting adherence included lack of knowledge about TB, non-sustainability of educational campaigns, side effects of drugs, hunger and lack of family support, stigma attached to TB, and the attitude of health care workers and the long delay in obtaining a diagnosis. Based on this evidence, recommendations were made regarding a number of provider-, patient- and community-centred interventions that can improve adherence.

9.2 Recommendations

The following recommendations, unless stated otherwise, are based on the most significant findings of this study.

9.2.1 High-risk groups

According to the WHO (2002a), some groups are more at risk to developing and dying of TB. Several studies have found that TB affects the young or, economically active groups. The difference in rates of infection, generally, is largely due to social and life style determinants. Patients with a previous history of TB treatment (re-treatment patients) also seem to be a high-risk group for TB infection. The intensive phase (initial two months) of the patient ‘career’ is the most critical as the information available and the experience of the health care system in general, may determine the behaviour of the patient.

Although it is understandable that the Department of Health cannot cover all sectors, it will be advantageous to be involved in partnerships with mines and prisons in TB control. Poorly supervised or incomplete treatment of TB is worse than no treatment at all. When miners and prisoners fail to complete standard treatment regimens, or are given the wrong treatment regimen, they may remain infectious. They may also infect their families and community members that they come in to contact with. Thus, it is of utmost importance that the Department of Health strengthens the current collaboration, if any, with TB programmes in the mining sector and prisons.

As inferred from the findings, the close contacts of infected patients should be targeted for TB screening. This is even more crucial if one considers the period patients take before consulting a health care provider. It is assumed that by the time a patient finally receives appropriate treatment many individuals might have been infected already. While TB control policies encourage passive case findings of newly infected TB cases, it is recommended that a more proactive approach be adopted using DOT supporters.

Targeting high-risk individuals may prove to be worthwhile in the long run. Providing opportunities for dialogue between post-TB patients and high-risk individuals may prove to be successful, as the smoking cessation interventions have indicated. In this manner, resources will be focused more effectively. Targeting high-risk populations could also be used as part of a more broadly based campaign. Misuse of alcohol is also an important factor in the spread of TB. In this regard, Social Welfare Services, community-based organisations, NGOs and faith-based organisations have to assume social responsibility for this problem.

Regarding the symptom experience stage of the patient 'career', the following is recommended:

- People should be made aware of the early signs and symptoms of TB, especially among high-risk groups.
- The danger of prolonged self-treatment and of the use of home remedies should be explained.
- Far too many symptomatic patients are still misdiagnosed. There is an urgent need to investigate the reasons for the high rate of delayed diagnosis.

9.2.2 Social support

The long and cumbersome "career' of TB patients suggests that patient need effective social support networks to counter the threat of non-adherence. Social support networks, once established, set in motion a process of cumulative causation that tends to perpetuate early health-seeking behaviour and treatment adherence. In Chapter 1 it was emphasised that as a social disease, social interventions (i.e. policies directed at alleviating poverty and the creation of employment opportunities) in TB seem to be at least one avenue to explore. However, it should be noted that the root of poverty often is not just lack of money, but also lack of social networks and support.

Liefooghe (2000:53) indicates that patients enter the TB treatment relationship with their own beliefs and pre-conceived ideas. They are surrounded with a network that may or may not be supportive for their treatment. By providing information and assistance, social support networks reduce the threats to adherence and other concerns and needs faced by TB patients besides their health. However, it should be noted that the Health Belief Model emphasises that the reaction of these social support groups may be perceived as a threat. The study of Barnhoorn & Adriaanse (1992) found that social support from the family, neighbours and/or health care providers are an important predictor of adherent behaviour. In fact, patients who know that the attitude of their families regarding the regular intake of medicine is positive are more likely to be adherent (Vermeire *et al.,* 2001:335).

In order to be effective, policies intending to modify patterns of health-seeking behaviour and adherence among South Africans must take into account the function of social networks. The challenge facing South African communities is to empower persons with TB and their families to address their own unmet needs and to lobby within their own communities to ensure that these needs are met. Families should be discouraged from avoiding contact with TB patients (Liefooghe, 1997:815). The literature review has also shown that the predominant cognitive/affective reactions towards TB were personal threat, social rejection and social stigma. The powerful force of social rejection and social stigma cannot be underestimated. These inhibiting factors require urgent attention to improve voluntary presentation and adherent behaviour.

NGOs, such as the TB Alliance DOTS Support Association (TADSA), SANTA, and others, can play a much more significant role in the fight against TB. NGOs and CBOs have high potential in improving TB control at the community level. In addition, various community members, including village leaders, schoolteachers, religious leaders, trade unions and women's organisations, have the potential; if mobilised successfully; to raise awareness of the signs and symptoms of TB and the availability and benefits of its treatment. The idea of utilising similar “TB Clubs” as in Ethiopia should not be ignored. Getahun & Maher (2000) has found that with assistance from community elders, religious leaders, community health agents and local health workers, the TB clubs in Ethiopia have not only identified people in the community with suspected TB and encouraged them to seek diagnosis and treatment, but also assisted in promoting adherence and in tracing defaulters.

9.2.3 TB communication, knowledge and awareness

The literature has demonstrated that Information, education and communication (IEC) have been crucial in raising awareness about HIV/AIDS in South Africa. While there is agreement with the argument that a high level of awareness about HIV/AIDS exists among the population at large, the same cannot be said about TB (Harrison *et al.* (2000:286). Moreover, not many people are aware of the causes and symptoms of TB (Khan *et al.,* 2000:250). Growing awareness of patients’ desire for information has resulted in the production of numerous information leaflets and booklets about TB. However, none of these materials have been formally evaluated for their impact on individuals and communities.

Currently, the South African Department of Health distributes to public health facilities IEC. There has been very little follow-up on these IEC activities and the supposition is simply that people will read the relevant brochures and reduce personal risk of infection in consequence. It would be an error, however, to assume that increased efforts in health education would resolve the gap between biomedical and lay understandings of illness, since improving or increasing knowledge does not necessarily result in changes in perception or behaviour.

Health messages might emphasise cognitive aspects such as the physiological consequences of delay and strategies for making decisions to seek care. In addition, teaching patients how to evaluate their symptoms may allow patients with atypical TB symptoms, or symptoms that are not what they had expected, to make more appropriate decisions about seeking health care. To address the problem of denial and anxiety, an education message acknowledging the problem and suggesting various coping strategies may be appropriate. Further, the conduct of formative and evaluation research may help in analysing the audiences' needs and cultural aspirations, in producing relevant and user-friendly media materials, and in understanding the intended and unintended effects of the entertainment-education intervention.

In respect of TB communication, knowledge and awareness, the following is recommended:

- Studies at national, provincial and community level need to be undertaken to evaluate the impact and effectiveness of the current health education prevention mechanisms and campaigns.
- The mass media should be utilised more often to address areas of concern such as poor and incorrect knowledge, and myths and misconceptions about TB. In areas where access to the mass media is low, community-level communication approaches need to be strengthened.
- Health messages should be formulated in terms of existing cultural beliefs and practices. In this way, they would take advantage of common ground that already exists. They also need to be comprehensive, culturally sensitive, multidisciplinary, and be sustained on a long-term basis.
- Noting the 'terrible' link between TB and HIV/AIDS, it is high time that TB should ignite the same public alarm as acute diseases such as HIV/AIDS. In this regard, it is recommended that organisations and individuals already working in the field of HIV/AIDS should be integrated into TB prevention and health promotion campaigns.
- The current information brochures and posters on TB should adopt a much more multilingual approach. It is recommended that these brochures and posters should not only be available at public health facilities, but also at schools, taxi ranks, and taverns.

9.2.4 Treatment adherence

Based on this evidence, recommendations are made regarding a number of provider-, patient- and community-centred interventions that can improve adherence.

Apart from alleviating poverty in order to curtail the socio-economic barriers to adherence, raising public awareness about the importance of life style modifications to prevent TB, and widespread dissemination of accurate information about the causes, prevention and health management may counter the myths and misconceptions surrounding the disease. In order to enhance patient adherence rates, TB control programmes in resource-poor settings, such as the Free State province, have to take into account the dysfunctional behaviour of health care providers, close contacts and TB patients.

Patients should be encouraged to highlight the difficulties they face, rather than being afraid of being victimised. In this regard, the training of health care providers involved in TB at the primary health care level should incorporate aspects related to patient behaviour.

This study revealed some important factors encouraging non-adherence. Regarding the attitude of health care providers, expanded communication skills training and optimal patient care, according to treatment guidelines, are needed. This is especially the case in the light of the emergence of multi-drug resistance TB. Such training should not only focus on nurses, but also on doctors. It is highly unlikely that an effective short-term chemotherapy will be widely available in South Africa, or in the world, in the next ten years. Thus, behaviour change remains a viable means of improving treatment adherence and limiting the further spread of TB infection.

Studies around the world have shown that behaviour interventions such as health education can bring about a reduction in high-risk behaviour. The continuing increase in TB infection rates in the country also suggests that health education; information and communication efforts have either been limited or not effective on a broad enough scale to achieve a significant public impact. It is, therefore, recommended that current education programmes concerning TB should be revised by the South African Tuberculosis Control Programme to overcome the most important barriers in treatment adherence. More sustained health education campaigns should be directed towards patients, health care providers, patients' close contacts, and the broad community. Ultimately, it is patient adherence that will govern the effectiveness of current TB therapy. It is hoped that this investigation will alert health care providers of the importance of this issue and provide an impetus for further investigation. Longitudinal studies with larger sample sizes will determine which factors influence decisions whether to take medications, the causes of early discontinuation, as well as what longer-term TB adherence entails.

9.2.5 Future research

Many aspects of social support and social networks were not adequately addressed in this study. Attention has, however, been drawn to the kind of support TB patients receive from family members, friends and the community. Results from this study can provide a useful framework for additional research in this area. For example, research is needed to more fully examine which aspects of social capital have the greatest impact on the lives of TB patients. Research and interventions are also needed to determine how to develop and build social networks or support groups in communities.

As stated before, there is a clear need for a thorough assessment of current health intervention strategies in South Africa. A comprehensive review is necessary to gauge the depth and breadth of prevention and behavioural change interventions. There also seem to be several areas of emerging importance that require study. One of these emerging areas is the introduction of antiretroviral therapy in the public health sector. An ineffective antiretroviral programme has the potential to cause extremely serious harm to an already overburdened public health care system. Creative approaches must be devised to ensure that primary health care programmes such as TB do not suffer as a direct result of the introduction of antiretroviral therapy.

It has been noted in Chapter 1 that TB is no longer a challenge to the medical profession only, but also to social scientists. Controlling the epidemic requires as much social scientific knowledge and skills as it require medical knowledge and skills. The development of effective intervention strategies that focus on all aspects of the lives of TB patients remains one of the greatest challenges facing medical sociology and other disciplines. It is believed that South Africa does have the resources in terms of skills and expertise to take a leading role in the fight against TB. It is suggested that the Free State Department of Health embark on a more vigorous approach in, not only informing provincial TB initiatives, but also national and international agendas of TB. Locally initiated health promotion strategies will have a far reaching effect than those from elsewhere. Finally, it is again emphasised that health care interventions, alone, will not win the battle against TB. Of even greater significance, is the need to recognise the patient perspective in TB control efforts.

APPENDIX 1:

DESCRIPTIVE STATISTICS FOR ADHERENT AND NON-ADHERENT PATIENTS

Descriptive statistics for adherent and non-adherent patients

Variable	Sample (n)	Mean	Standard Error	Confidence interval (95%)
Adherence (yes=1, no=0)	184	0.940	0.018	0.906 - 0.975
Household size	184	4.337	0.158	4.025 - 4.648
Gender (male=1, female=2)	184	1.451	0.037	1.379 - 1.524
Age	184	38.022	0.832	36.38 - 39.66
Marital status (married=1, single=2)	184	1.614	0.036	1.543 - 1.685
Years of education	184	7.837	0.251	7.342 - 8.332
Monthly household income (Rand)	184	1,213.641	75.079	1,065 - 1,361
Financial support received while on treatment (Rand)	184	467.891	56.212	356.9 - 578.7
Access to medical aid (yes=1, no=0)	183	0.049	0.016	0.018 - 0.081
Re-treatment patient (yes=1, no=0)	184	0.310	0.034	0.242 - 0.377
Paid to access treatment (yes=1, no=0)	184	0.011	0.008	-0.004 - 0.026
Main breadwinner (yes=1, no=0)	184	0.375	0.036	0.304 - 0.446
Currently employed (yes=1, no=0)	184	0.342	0.035	0.273 - 0.412
Previously employed (yes=1, no=0)	184	0.147	0.026	0.095 - 0.198
Income loss due to illness (Rand)	184	2,047.120	590.654	881.7 - 3,212.4
Travel time to clinic (minutes)	179	25.626	1.642	22.38 - 28.86
Away from home during treatment (yes=1, no=0)	183	0.098	0.022	0.055 - 0.142
Number of migrants in household	180	0.122	0.026	0.071 - 0.173
Ever in jail (yes=1, no=0)	184	0.109	0.023	0.063 - 0.154
Able to eat before taking tables (yes=1, no=0)	183	0.918	0.020	0.878 - 0.958
Access to piped water in dwelling (yes=1, no=0)	184	0.826	0.028	0.771 - 0.881
Tablet taking supervised (yes=1, no=0)	182	0.912	0.021	0.871 - 0.954
Experienced side-effects (yes=1, no=0)	184	0.995	0.005	0.984 - 1.005
Crowding index	183	2.265	0.087	2.094 - 2.437
Stigma index	184	0.255	0.043	0.171 - 0.339
Tuberculosis knowledge index	184	5.174	0.068	5.039 - 5.308
Service quality index	184	1.630	0.047	1.538 - 1.723

Notes: The *crowding index* was calculated by dividing the average household size by the number of rooms for sleeping. The *stigma index* represents the number of times the patient indicated that the general reaction of his spouse/partner, family members, friends, community members or neighbours, employer and co-workers on learning about their illness was negative or constituted rejection. The *tuberculosis knowledge index* represents the number of times the patient disagreed or strongly disagreed with the statement that one can stop taking TB medication when one feels better and the number of times the patient agreed or strongly agreed with the statement that (a) someone with TB who is not on treatment can infect other people, (b) that TB can be cured, (c) that TB affect men, women and children, (d) that people living with a TB patient need to be examined, (e) that TB could be a symptom of HIV/AIDS. The *service quality index* represents the average score out of 5 on six questions related to the satisfaction of the patient with (a) the distance to the clinic, (b) the waiting time before being helped, (c) the general appearance of the clinic, (d) the support or friendliness of the clinic staff, (e) the amount of time health care workers spent with the patient during their consultation, and (f) the examination of their illness.

APPENDIX 2:

Introductory letter & interview schedule

UNIVERSITEIT VAN DIE VRYSTAAT
UNIVERSITY OF THE FREE STATE
YUNIVESITHI YA FREISTATA

Centre for Health Systems Research & Development

Sentrum vir Gesondheidsisteemnavorsing en Ontwikkeling
FACULTY OF THE HUMANITIES/FAKULTEIT GEESTESWETENSKAPPE

✉ 339 BLOEMFONTEIN 9300
REPUBLIC OF SOUTH AFRICA
REPUBLIEK VAN SUID-AFRIKA
REPHABLIKE YA AFRIKA BORWA
✉

☎ SA (051) 401-3343/2181
☎ Fax/Faks: SA (051) 448-0370
E-✉: matebsz.hum@mail.uovs.ac.za

TUBERCULOSIS PATIENT CAREER SURVEY

You have been selected to participate in a survey designed to collect information on aspects relating to tuberculosis (TB) patients. The Centre for Health Systems Research & Development (CHSR&D) at the University of the Free State in collaboration with Free State Department of Health is conducting the research. This study is part of a joint three-year research project on TB control in the Free State.

The information that will be collected will be useful for planners and policy makers in developing strategies to control TB in the Free State. In particular, it is hoped to gain a better understanding of the interrelations between TB, economic conditions, cultural conditions and help-seeking behaviour. Participating in the survey will give you an opportunity to share your experiences and views on a variety of issues related to TB. Thus, the success of this survey entirely depends on your kind co-operation. The information collected will be handled with the greatest confidentiality and your anonymity will be guaranteed. Thus, your name and/or address do not appear on the questionnaire. We are simply interested in your personal, honest opinion.

We thank you for your valuable contribution and time.

Should you have any queries concerning any aspect of the survey, you are welcome to contact the researcher:

____

Mr. SZ Matebesi **Tel (051) 401 3343**
Researcher: Centre for Health Systems Research & Development

Fieldworker: ____

Date of interview:

		2001

Patient register number:

				Y	Y

District:

Qwaqwa	1	Thaba Nchu	2	Welkom	3

Facility:

Phuthaditjhaba	1	Gaongalelwe	2	Thabong	3
Namahali	4	Mafane	5	Khotsong	6
Riverside	7	Dinaane	8	Welkom LA	9

A: PARTICULARS OF RESPONDENT

CATEGORY OF PATIENT AND DOTS

(*FIELDWORKER, please obtain information from health worker/patient record)*

1. Category of patient

New patient – intensive phase	1
New patient – continuation phase	2
Re-treatment patient – intensive phase	3
Re-treatment patient – continuation phase	4

2. **If re-treatment patient**, please specify

Re-treatment after previous cure	1
Re-treatment after previous treatment completion	2
Re-treatment after previous treatment interruption	3
Re-treatment after previous treatment failure	4

BIOGRAPHIC INFORMATION OF PATIENT

3. Gender

Male	1	Female	2

4. Age

_________________years

5. Marital status

Married	1	Single	2	Divorced	3	Living with partner	4	Widowed	5

6. Have you ever attended school?

Yes	1	No	2

7. ***If yes***, what is the highest standard/grade/year of highest educational qualification?

Less than one year completed	1
Sub A/grade 1	2
Sub B/grade 2	3
Standard 1/Grade 3	4
Standard 2/Grade 4	5
Standard 3/Grade 5	6
Standard 4/Grade 6	7
Standard 5/Grade 7	8
Standard 6/Grade 8	9
Standard 7/Grade 9	10
Standard 8/Grade 10	11
Standard 9/Grade 11	12
Standard 10/Grade 12	13
Further studies incomplete	14
Diploma/other post-school complete	15
Further degree complete	16

8. Can you read and understand a letter or newspaper in your home language…

Easily	1	With difficulty	2	Not at all	3

9. Have you read a newspaper or magazine in the last week?

Yes	1	No	2

10. Have you listened to the radio in the last week?

Yes	1	No	2

11. Have you watched television in the last week?

Yes	1	No	2

12. Have you ever worked in a mine?

Yes	1	No	2

13. ***If yes***, please explain (**when, how long**)

____

14. Have you ever been in jail?

Yes	1	No	2

15. ***If yes***, please explain (**when, how long**)

____

B: SOCIO-ECONOMIC DETAILS

HOUSEHOLD HABITATION DETAILS

16. Where is your current home? ***(Fieldworker please obtain detailed info on township /town/location of farm, etc.)***

____

17. For most of the time until you were 16 years old, where did you live? (**Read out options)**

City	1	Town	2	Rural area/farm	3

18. How many inhabitants are staying with you in the same house?

Gender and relation to patient *1. Wife/husband/partner* *2. Daughter/son* *3. Brother/sister* *4. Parent* *5. Aunt/uncle* *6. Other (please specify)* *E.g. M – 1*	**Age**	**Migrant labourer?** *E.g Farm in Bethlehem area or mine in Welkom*		**Currently has or previously had TB**		
		Yes	**No**	**Yes**	**No**	**Uncer-tain**
1.		1	2	1	2	3
2.		1	2	1	2	3
3.		1	2	1	2	3
4.		1	2	1	2	3
5.		1	2	1	2	3
6.		1	2	1	2	3
7.		1	2	1	2	3
8.		1	2	1	2	3
9.		1	2	1	2	3
10		1	2	1	2	3
11.		1	2	1	2	3
12.		1	2	1	2	3

19. Indicate the type of **main** house that the household occupies?

Modern house or brick structure on a separate stand or yard	1
Traditional house/hut/structure made of traditional materials	2
House/room in backyard	3
Informal house/shack in backyard	4
Informal house/shack in informal/squatter settlement	5
Informal house/shack in a separate stand	6
Other (Please specify)	

20. What is the total number of rooms used for sleeping in the main house?

________________rooms

21. Are the following facilities/infrastructure available at your house/Does your household have?

Electricity	Yes -1	No –2 –***specify main energy source for…*** Lighting ______________________________________ Heating ______________________________________ Cooking ______________________________________
Flush toilet in house/yard	Yes – 1	No – 2 - ***specify sanitation method***
		Bucket latrine – 1
		Pit latrine – 2
		No facility/bush/veld – 3
Piped water in house/yard	Yes - 1	No –2 ***– specify source of drinking water***
		Public tap – 1
		Water carrier/tanker –2
		Borehole/well –3
		Dam/river/stream/spring –4
		Rainwater tank –5
Refuse removal at least once a week	Yes – 1	No –2 ***- specify refuse removal arrangement*** ____
Radio	1	2
Television	1	2
Refrigerator	1	2
Personal computer	1	2
Washing machine	1	2
Bicycle	1	2
Fixed telephone	1	2
Cellular phone	1	2
Cattle/sheep	1	2
Land to cultivate	1	2
Motor car/vehicle	1	2

22. How many times **a week** are you able to eat/drink the following?

	Not at all	**Rarely**	**Sometimes**	**Most of the time**	**Very often**
1. Milk	1	2	3	4	5
2. Orange juice	1	2	3	4	5
3. Eggs	1	2	3	4	5
4. Meat	1	2	3	4	5
5. Fish	1	2	3	4	5
6. Baked beans	1	2	3	4	5
7. Cabbage	1	2	3	4	5
8. Potatoes	1	2	3	4	5
9. Spinach	1	2	3	4	5
10. Apples	1	2	3	4	5
11. Oranges	1	2	3	4	5

23. Generally, how satisfied/dissatisfied are you with your meals?

Very satisfied	1	Satisfied	2	Uncertain	3	Dissatisfied	4	Very dissatisfied	5

EMPLOYMENT, INCOME AND MEDICAL AID

The following questions relate to your and your family's employment and income generating situation <u>prior to becoming ill with TB</u>.

24. Were you employed (including informal employment and self-employed?

Yes - full-time – formal	1	Yes – part-time – formal	2	Yes – informal employment	3	Yes – self-employed	4	No – unemployed	5

25. ***If yes***, what type of work did you do?

____

26. ***If yes***, what was your average daily/weekly/monthly income before any deductions? ***(Fieldworker in the case of part-time establish number of days worked per week)***

R________________

27. Approximately how much was the cumulative household income per month (***including grants and remittances***)? ***(Write down names of household members 16 years or older and assist respondent in adding up total)***

Adult household member	**Average monthly income in rand** ***(if not able to get exact amount an as accurate as possible estimation will do – include all sources of income e.g. from agricultural activity, grants, remittances, employment, etc.)***
1.	
2.	
3.	
4.	
5.	
6..	
7.	
8.	
9.	
10.	
Total	

The following questions relate to how your and your family's employment and income generating situation changed <u>due to your falling ill with TB</u>.

28. Did you lose income due to falling ill with TB, i.e. because you could not work as before?

Yes	1	No	2

29. ***If yes***, please explain how long/how many days/weeks you could not earn income.

____

30. ***If yes***, please explain how much money was lost in this way?
R________

31. Did your falling ill with TB affect your family members' income-generating ability? ***(Fieldworker, e.g. by accompanying the patient to seek health care, or by staying away from work to care for patient at home, etc.)***

Yes	1	No	2

32. ***If yes***, please explain how long/how many days/weeks members of your family could not earn income.

____

33. ***If yes***, please explain how much money is lost to your family in this way?

R______________

The following questions relate to your current employment situation (while under treatment at the clinic)

34. Are you currently employed (including informal employment and self-employed)?

Yes - full-time – formal	1	Yes – part-time – formal	2	Yes – informal employment	3	Yes – self-employed	4	No – unemployed	5

35. ***If yes***, what type of work do you do?

____

36. ***If yes***, what is your average daily/weekly/monthly income before any deductions?

R________________

37. ***If employed***, do/did you earn sick leave while under TB treatment? (**Fieldworker – whether employer keeps/kept on paying him/her while on sick leave**).

Yes	1	No	2

38. ***If yes,*** did you…?

Earn full salary while on sick leave with TB?	1
Got paid for a limited period only	2
Other (*Please specify*)	

39. ***If currently unemployed,*** were you employed at the time of your employer learning of your illness with TB?

Yes	1	No	2

40. ***If yes (to above question about employer learning about TB),*** how did you come to loose your job?

____

____

____

41. ***If unemployed***, how do you make a living?

____

42. What sources/amounts of income do you have while under TB treatment?

Source	**R per month**
Grants	
Pension	
Remittance	
Salary	
Other (*Specify*)	

43. Do you lose income while under TB treatment?

Yes	1	No	2
Please specify amount R_________per month			

44. Do you personally receive any social transfers such as grants or remittances as a result of your TB condition?

Yes	1	No	2

45. ***If yes***, how much do you receive monthly in the form of grants/remittances?

R_____________________ per month

46. Please make a list of your dependants (people who are dependant on your income for basic life necessities)

First name	**Relationship** 1. Wife/husband/partner 2. Daughter/son 3. Brother/sister 4. Parent 5. Aunt/uncle 6. Other (please specify)	**Age**	**Amount**
1.			
2.			
3.			
4.			
5.			
6.			
7.			
8.			
9.			
10.			
Total			

47. Are you the breadwinner in your family?

Yes	1	No	2

48. Approximately how much is the cumulative household income per month? **(*Including grants and remittances) (FIELWORKER: write down names. Write down names of household member 16 years and older – add up total)***

Adult household member	**Average amount of income in rand** (If not able obtain exact amount, an as accurate as possible estimation will do (include all sources of income e.g. from agricultural activity, grants, remittances, employment, etc.)
1.	
2.	
3.	
4.	
5.	
6.	
7.	
8.	
9.	
10.	
Total	

49. What monthly income do you consider to be absolutely minimal to sustain your household?

R______________ per month

50. Since you have been diagnosed with TB, has your <u>personal</u> financial situation…?

Remained the same	1	Improved	2	Deteriorated	3

51. Please explain

____

____

____

52. Since you have been diagnosed with TB, has your <u>household</u> financial situation…?

Remained the same	1	Improved	2	Deteriorated	3

53. Please explain

____

____

____

54. How would you rate the standard of living of your household compared with that of your immediate neighbours?

Better	1	The same	2	Worse	3	Uncertain	4

55. Please explain

____

____

____

56. Indicate whether you belong/belonged to a medical aid?

Yes	1	No	2

57. ***If yes***, please name medical aid.

____

58. ***If yes***, did your medical aid cover the costs of your TB treatment?

Partially	1	Completely	2	Not at all	3	Uncertain	4

59. How much did your medical aid thus far contribute to the costs of your TB treatment?

R________________per month

C: PATIENT CAREER:

C.1 SYMPTOM EXPERIENCE

Knowledge and perceptions of TB

60. What were the main initial symptoms of your illness?

____

____

61. When you experienced these initial symptoms for the first time, what did you think it was?

____

____

____

62. What did you first do regarding the initial symptoms?

____

____

____

63. Did you know what TB was before you being diagnosed with it?

Yes	1	No	2

64. How long does medical TB treatment usually last when a person has TB for the first time?

_________________________months

65. Did you know someone with TB, before you were diagnosed with it?

Yes	1	No	2

66. What is/was your relation to this person?

____

67. In your view, how does someone become infected with TB? (**Interviewer, please record all answers even in Sotho**)

____

____

____

68. In your own case, how did you become infected with TB?

____

____

____

69. In your view, how can TB be prevented?

____

____

____

70. Please state whether you agree or disagree with the following statements:
Strongly agree (SA), **Agree** (A), **Uncertain** (U), **Disagree** (D), **Strongly disagree** (DA)

Statement	**SD**	**D**	**U**	**A**	**SA**
1. One can stop taking TB medication when one feels better	1	2	3	4	5
2. Someone with TB who is not on treatment can infect other people	1	2	3	4	5
3. People in my family treat me differently because I have TB.	1	2	3	4	5
4. TB can be cured	1	2	3	4	5
5. TB affect men, women and children	1	2	3	4	5
6. My neighbours treat me differently because I have TB.	1	2	3	4	5
7. People living with a TB patient need to be examined	1	2	3	4	5
8. TB could actually be a symptom of HIV/AIDS	1	2	3	4	5
9. The association between TB and HIV/AIDS leads to social rejection	1	2	3	4	5
10. My spouse/partner treats me differently because I have TB.	1	2	3	4	5
11. TB can be caused by bewitchment	1	2	3	4	5
12. Traditional medicines can also cure TB as effectively as the medicines given to me at the clinic	1	2	3	4	5

C.2 ASSUMPTION OF THE SICK-ROLE

Pre-diagnosis & health seeking behaviour

71. Did you discuss your initial symptoms with someone else before seeking health care?

Yes	1	No	2

72. **If yes**, who was the most influential person who advised you about your initial symptoms?

Spouse/partner	1
Parent	2
Relative	3
Friend	4
Neighbour	5
Employer	6
Nurse at work	7
Other (*specify*) ____	

73. **If yes**, what was the reaction/response/judgment/opinion of the most influential person you related your initial symptoms to? (**Please note more than one response is possible**)

Reaction/response/judgment/opinion	**Yes**	**No**
1. Interpreted symptoms as indicative of illness	1	2
2. Emphasised the seriousness of the symptoms	1	2
3. Recommended self-medication	1	2
4. Recommended that a doctor must be seen	1	2
5. Recommended that the clinic must be visited	1	2
6. Indicated that the symptoms are normal/not serious	1	2
7. Offered a diagnosis of the symptoms	1	2
8. Recommended traditional healing	1	2
9. Recommended over-the-counter medication	1	2
10. Other (*specify*) ____		

74. How did you react/respond to this advice?

____

____

____

75. Did you try any form of home remedy before seeking medical care?

Yes	1	No	2

76. **If yes**, what home remedy did you use?

____

____

____

77. **If employed**, have you been absent from work during this period?

Yes	1	No	2

78. **If yes,** how often have you been absent from work?

Very often	1	Rarely	2	Sometimes	3	Most of the time	4	Always	5

79. What was the reason for your absence?

____

____

____

80. Did you have to stay in bed during this period?

Yes	1	No	2

C.3. HEALTH CARE CONTACT

Health care consultation

81. How long did you have a persistent cough before seeking health care (**clinic, hospital or medical doctor, excluding traditional healers**)?

________________________days/weeks/months

82. **If applicable**, why did you delay in seeking health care?

____

____

____

83. Which health care facility/provider did you first contact when you experienced symptoms of what you now know is TB?

1. Clinic/community health centre	1
2. Mobile clinic	2
3. Hospital	3
4. General Practitioner (private)	4
5. Pharmacy	5
6. Traditional healer	6
Other (*specify)*	

84. Why did you first contact this health care facility/provider?

____

____

____

85. What were the diagnosis, treatment and outcome of the treatment you received at the health care facility/provider that you first visited?

Diagnosis	Treatment	Outcome

86. What difficulties/problems did you experience in seeking health care?

____

____

____

87. What made you decide to visit this clinic?

____

____

____

88. Did you have to pay any fee on admission at this clinic?

Yes	1	No	2

89. ***If yes***, how much did you pay and to whom?

Amount paid	**Person who received the money**
R	

90. Did you have to pay any other fee since admission at this clinic?

Yes	1	No	2

91. ***If yes***, how much did you pay and to whom?

Amount paid	**Person who received the money**
R	

92. How did you experience the clinic the first time you visited it when you first became ill with what you now know is TB?

____

____

____

93. Did you have to stay in bed during this period?

Yes	1	No	2

94. **If yes**, for how long?

______________days

95. **If employed**, have you been absent from work during this period?

Yes	1	No	2

96. **If yes,** how often have you been absent from work?

Very often	1	Rarely	2	Sometimes	3	Most of the time	4	Always	5

Diagnosis

97. How did you experience being informed that you have TB?

____

____

____

98. Were you informed about your illness when you were diagnosed?

Yes	1	No	2

99. **If yes**, who provided you with information about your illness?

____

100. Please state whether you were informed about the following?

Information provided	**Yes, was helpful**	**Yes, was not helpful**	**No information**
1. Nature and causes of TB	1	2	3
2. Infectiousness of TB	1	2	3
3. The necessity of completing treatment	1	2	3
4.. Side effects of treatment (i.e. medicine makes you feel ill)	1	2	3
5. Nutritional matters (i.e. the importance of taking food before taking tablets)	1	2	3
6. The role of TB in HIV/AIDS	1	2	3
7. The role of alcohol abuse and substance abuse in TB	1	2	3
8. MDR	1	2	3

101. When you first learned about your TB diagnosis, did you inform anyone?

Yes	1	No	2

102. **If yes**, who did you inform?

____

103. What was the general reaction of the following people after hearing about your illness?

People	**Supportive/ sympathetic**	**Uncertain/ neutral**	**“Negative”/ rejection**	**Not applicable**
Spouse/partner	1	2	3	4
Please explain				
Family members	1	2	3	4
Please explain				
Friends	1	2	3	4
Please explain				
Community members/ neighbours	1	2	3	4
Please explain				
Employer/Your ‘boss’	1	2	3	4
Please explain				
Co-workers	1	2	3	4
Please explain				

104. Generally, do you feel that you are treated differently as a result of your TB status?

Yes	1	No	2

105. ***If yes***, please mention the most embarrassing/bad treatment that you have experienced/ experiencing? (**FIELDWORKER: Please also find out who treated the patient badly**)

106. There is an association between TB and HIV/AIDS. Do/did you feel embarrassed by this association?

Yes	1	No	2

107. Please explain (**(FIELDWORKER: An explanation is needed for any answer above)**

____

____

____

____

THE DEPENDENT-PATIENT ROLE

108. In general, how is your health?

Excellent	1	Good	2	Uncertain	3	Fair	4	Poor	4

109. Compared to **one year ago**, how would you describe/rate your health in general now?

Much better now than one year ago.	1
Somewhat better now than one year ago.	2
About the same as one year ago.	3
Somewhat worse now than one year ago.	4
Much worse than one year ago.	5

110. Please explain

____

____

____

111. In terms of your daily life, to what extent has your illness with TB affected you regarding?

	Not applicable	**Negative effect**	**Moderate effect**	**No effect at all**	**Uncertain**
1. Your ability to carry out family obligations	1	2	3	4	5
2. Your relationship with your spouse/ partner	1	2	3	4	5
3. Your standing in your family	1	2	3	4	5
4. Your independence	1	2	3	4	5
5. Your important life plans	1	2	3	4	5
6. Your personal appearance	1	2	3	4	5
7. Your status in the community	1	2	3	4	5
8. Your relationship with your friends	1	2	3	4	5
9. Your relationship with your boss	1	2	3	4	5
10. Your relationship with your co-workers	1	2	3	4	5
11. Your ability to work	1	2	3	4	5

112. The following items are about activities you might do during a typical day. Does TB now limit you in these activities?

Activities	**I stopped doing it**	**Yes, limited a lot.**	**Yes, limited a little.**	**No, not limited at all.**
Strenuous activities: Running, lifting and carrying water, riding a bicycle uphill, bending or kneeling.	1	2	3	4
Moderate activities: Preparing food, using a broom, dressing and undressing or walking short distances	1	2	3	4
Light activities: Getting out of bed into the chair, preparing and cleaning vegetables when sitting on a chair, or repairing shoes when sitting down.	1	2	3	4

113. The following question is about how you have been feeling during the **past month**. During the past month have you been feeling….

	All of the time	**Most of the time**	**Some of the time**	**None of the time**
1. Full of life/energetic?	1	2	3	4
2. Sad/distraught/depressed?	1	2	3	4
3. Negative?	1	2	3	4
4. Calm/peaceful?	1	2	3	4
5. Happy?	1	2	3	4
6. Lonely?	1	2	3	4

114. Please state whether you agree/disagree to the following statements:

	Strongly disagree	**Disagree**	**Uncertain**	**Agree**	**Strongly agree**
1. People's ill health is a result of their own carelessness.	1	2	3	4	5
2. No matter what I do, if I am going to get sick, I will get sick.	1	2	3	4	5
3. If I can take care of myself, I can avoid illness.	1	2	3	4	5
4. My improvement is dependent solely on what the doctor/nurse tell me to do.	1	2	3	4	5
5. I am directly responsible for my health.	1	2	3	4	5
6. People who never get sick are just plain lucky.	1	2	3	4	5

115. The network of family, friends, colleagues, and experts to whom you have ready access can be an important factor in restoring and maintaining good health. Indicate your present level of satisfaction with each source of support.

	Not applicable	**Highly dissatis-fied**	**Dissatis-fied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Highly-satisfied**
1. Spouse/partner	1	2	3	4	5	6
2. Parents	1	2	3	4	5	6
3. Other family members	1	2	3	4	5	6
4. Friends	1	2	3	4	5	6
5. Neighbours/community members	1	2	3	4	5	6
6. Health care workers	1	2	3	4	5	6
7. Traditional healers	1	2	3	4	5	6
8. DOT supporters	1	2	3	4	5	6
9. Colleagues	1	2	3	4	5	6
10. Employer	1	2	3	4	5	6

116. Have you been in bed during this period?

Yes	1	No	2

117. **If yes**, how often have you been in bed?

Very often	1	Rarely	2	Sometimes	3	Most of the time	4	Always	5

118. **If employed**, have you been absent from work during this period?

Yes	1	No	2

119. **If yes,** how often have you been absent from work?

Very often	1	Rarely	2	Sometimes	3	Most of the time	4	Always	5

120. **Coping with TB**: We are interested in how patients respond when they confront difficult or stressful events in their life. There is no right or wrong answers, and responses should indicate what you do rather than what "most people" do.

	Usually don't do this at all	**Usually do this a little bit**	**Usually do this a medium amount**	**Usually do this a lot**
1. I take direct action to get rid of TB.	1	2	3	4
2. I try to get emotional support from friends or relatives.	1	2	3	4
3. I do what has to be done – one step at a time – to get rid of TB. (I drink my medication every day to get rid of TB)	1	2	3	4
4. I drink alcohol in order to think about TB less.	1	2	3	4
5. I made a plan of action to address TB in my life.	1	2	3	4
6. I talk to someone about how I feel.	1	2	3	4
7. I ask people who also had TB what they did to cope.	1	2	3	4
8. I try hard to prevent other things from interfering with my efforts to become healed from TB.	1	2	3	4
9. I get sympathy and understanding from someone.	1	2	3	4
10. I think hard about what steps to take to become healed.	1	2	3	4
11. I try to get advice from the clinic about what to do about TB.	1	2	3	4

121 During the **past month**, how often did other people do these activities for you, to you, or with you?

	Not at all	**Once or twice**	**About once a week.**	**Several times a week**	**About every day**
1. Gave you home based care when you felt very ill with TB.	1	2	3	4	5
2. The persons at the clinic supported you when you experienced side-effects of medication.	1	2	3	4	5
3. Gave you money.	1	2	3	4	5
4. Provided you with some transportation (to the clinic, hospital)	1	2	3	4	5
5. Loaned or gave you something that you needed (food, blanket).	1	2	3	4	5
6. Your DOT supporter expressed interest/concern in your well-being.	1	2	3	4	5
7. Loaned you money.	1	2	3	4	5
8. Provided you with a place to stay.	1	2	3	4	5
9. Pitched in to help you do something that needed to get done. Do the washing or preparing food.	1	2	3	4	5

D: TREATMENT

DOTS (DOTS here refers to the daily supervision of tablet-taking)

122. Is your tablet taking supervised by anyone?.

Yes	1	No	2

123. **If yes,** where do you take your tablets?

Clinic	1
Home	2
DOTS supporters house	3
Work	4
School	5
Other (*Please specify*) ____________________	

124. Who supervises your tablet-taking (**relation**)?

____

125. What is the person who supervises your tablet-taking doing for a living?

____

126. How often do you meet with the person who supervises your tablet-taking?

____

127. Is there any costs involved in meeting with the person who supervises your tablet-taking?

		Costs per visit
Yes, I am paying transport to visit him/her	1	R
Yes, he/she is paying to visit me	2	R
No costs is involved	3	

128. Who chose your DOTS supervisor?

____

129. Are you satisfied with this arrangement?

Yes	1	No	2

130. **If no**, what arrangement would you prefer?

____

____

____

131. Are you provided with medication to take home?

Yes	1	No	2

132. **If yes**, for what period are you provided medication to take home?

Once a week	1	Two to three weeks	2	One month	3	Longer than a month	4

133. Are you able to eat each time before taking your tablets?

Yes, each time	1	Yes, most of the time	2	Yes, only sometimes	3	No, not at all	4

134. Has it ever happened that you were away from home for a period of time during your treatment?

Yes	1	No	2

135. **If yes**, where did you receive your treatment during that time?

____

136. Have you ever forgotten to take your medication?

Yes	1	No	2	Uncertain	3

137. **If yes**, what was the main reason for not taking your medication?

____

____

____

138. Have you ever purposively refrained from taking your medication?

Yes	1	No	2

139. **If yes**, what was the main reason for not taking your medication?

____

____

____

____

140. Please describe the **most bothersome** side-effects of medication that you experienced?

____

____

____

____

141 How did you deal with the most bothersome side-effects?

____

____

____

____

142. How confident/doubtful are you that you will be able to complete treatment?

Very confident	1	Confident	2	Uncertain	3	Doubtful	4	Very doubtful	5
Please explain ____________________ ____________________ ____________________ ____________________ ____________________									

Accessibility, quality of care, and user-friendliness

143. How do you travel to the clinic that you visit for your TB treatment?

Walk	1	Bicycle	2	Car	3	Taxi	4	Bus	5	Other	

144. How long (in terms of minutes) does it take you to reach the clinic?

________minutes

145. If car, taxi or bus, do you have to pay for the transport to the clinic and back?

Yes	1	No	2

146. **If yes**, how much on average do you pay per visit to the clinic?

R_________________per visit

147. **If no**, who pays for the transport?

____

148. How are you treated at when you visit the clinic (**mention name of facility**)?

Very poorly	1	Poorly	2	Uncertain	3	Well	4	Very well	5

149. Do you always see the same nurse on each visit?

Yes	1	No	2

150. How much time does the sister usually spent with you?

__________________minutes

151. Have you ever been sent home without being helped?

Yes	1	No	2

152. **If yes**, what was the reason for you being sent home without being helped?

____

____

____

____

153. Do you have to wait before being attended to at the clinic?

Yes	1	No	2

154. Please rate your satisfaction/dissatisfaction with the following?

	Very satisfied	**Satisfied**	**Uncertain**	**Dissatisfied**	**Very Dissatisfied**
1. Distance to the clinic	1	2	3	4	5
2. Waiting time before being helped	1	2	3	4	5
3. The general appearance of the clinic	1	2	3	4	5
4. Support/friendliness of health care workers	1	2	3	4	5
5. Amount of time spent with you during consultation	1	2	3	4	5
6. Examination of your illness	1	2	3	4	5

155. Please mention the single most important aspect that you are **satisfied** with about the TB treatment you receive at the clinic?

____

____

____

____

156. Please mention the single most important aspect that you are **dissatisfied** with about the TB treatment you receive at the clinic?

____

____

____

____

FINALLY

157. Are there any other problematic aspects of your treatment for TB at this clinic that you would like to mention?

____

____

____

____

____

158. How do you see your future and what are your plans for the future?

____

____

____

____

____

Thank you very much for your time and collaboration!

APPENDIX 3:

Focus group discussion guide

Clinic:
Date:
Time:
Number of participants:

Question 1: Did you know what TB was before you being diagnosed with it?

- Where did you learn about it?

Question 2: Do you know of any health promotion campaigns related to TB in your area?

- Are they helpful? Why not?

Question 3: How do you experience the views and attitudes of the following people regarding tuberculosis?

- Nurses at clinics
- Family members
- Community members

Question 5: There are TB patients who do not complete their treatment. From your own experience as a TB patient, what are the possible factors leading to non-adherence?

Question 6: In your view, how can these problems be addressed?

Question 7: Health prevention and promotion efforts regarding TB include pamphlets and booklets at clinics. Are enough been done in terms of health education related to TB?

Question 8: If you could make suggestions to the Department of Health on how to improve its TB campaigns, what would you say?

APPENDIX 4:

Norms and standards of TB treatment in South Africa

TUBERCULOSIS

DESCRIPTION OF SERVICE

Following national protocols, the clinic staff diagnose TB on clinical suspicion using sputum microscopy, provide IEC and active screening of families of patients with TB, promote voluntary HIV testing, treat, dispense and follow-up using DOT and complete the TB register.

NORMS

1. Achieve a minimum of 85% cure rate of new sputum positive TB cases.
2. Achieve a passive case finding rate per 100,000 population to be defined.
3. Achieve two days turn around times of sputum results in more than 90% of cases.
4. Every clinic has at least one staff member who has or has had opportunities for continuing education in TB management.
5. Receive a six monthly assessment of quality of care by a supervisor who also evaluates the degree of community involvement in planning and implementing care.

STANDARDS

1. References, prints and educational materials

1.1 The latest edition of the TB training manual for health workers.
1.2 The South African TB control programme practical guidelines.
1.3 TB register manual, latest edition.
1.4 Tackling TB at work – Guidelines from South Africa's national TB control programme.
1.5 A resource list of HIV/AIDS services.
1.6 DOTS and training material (e.g. Provincial or NGO). A hospital referral protocol.
1.7 Leaflets and pamphlets in local languages for distribution.
1.8 TB posters on the walls in local languages changed yearly.
1.9 Flow charts on TB diagnosis
1.10 The latest EDL manuals on TB management.

2. Equipment

2.1 Screw top sputum containers

3. Medicines and Suppliers

3.1 Uninterrupted supply of TB drugs recorded on bin cards.

3.2 Clinic knows how to get emergency supplies of TB drugs.

3.3 Combination and single TB tables as per protocols.

3.4 Sterile syringes and needles and water for injection.

4. Competence of Health Staff

Staff are able to

4.1 Initiate and follow up treatment of patient using the latest recommended TB management regimen and protocol.
4.2 Suspect and identify TB by early symptoms such as chronic cough, loss of weight and tiredness.
4.3 Educate with the emphasis on correcting misinformation and seeking to prevent spread of the disease.
4.4 Start direct observed treatment (DOT) supported by volunteers chosen and accepted by the patient.

4.5 Enter all sputum results on TB register and forms.

5. Referrals

5.1 Only patients sick enough to require hospital care are referred for hospitalisation and then sent with a completed TB register form and proposed discharge plan.

5.2 Patients referred to the clinics after discharge from hospital and with a discharge plan are followed up immediately to ensure the discharge plan is effectively implemented.

5.3 Before being transferred to another area the patient receives a completed transfer form and a sufficient supply of medication and when possible the facility to which he/she is transferred is notified by telephone.

5.4 If HIV positive the patient is given a confidential sealed letter with relevant data to give to the new facility.

5.5 Any severe complication of TB or adverse drug reaction is referred for admission.

5.6 Children with extensive TB or gross lymphadenopathy or not improving on treatment are referred.

5.7 Patients with need for additional health or social services are referred as appropriate.

5.8 All cases of MDR TB are referred to the Provincial MDR Committee/Unit.

6. Patient Education

6.1 Patients, relatives and the community receive high quality information on TB.

6.2 Patients are given group education each month when their situation is reviewed.

6.3 Patients are educated about HIV/AIDS/STDs in addition to TB so that they can recognise predisposing conditions and so prevent them.

7. Records

7.1 As TB is a notifiable disease the cases are correctly classified by location of disease, result of sputum smear and by the treatment regimen.

7.2 All registers, smear conversion rate forms and quarterly reports are kept up to date.

8. Community Based Services

8.1 The clinic has an agreement with resulting support from the community health committee about the use of DOT.

8.2 The quality of DOT management within the clinic and the community-based supporters are monitored and evaluated quarterly.

8.3 Active case finding is done on all chronic cough patients and TB contacts through home visits.

8.4 In exceptional cases some MDR cases are allowed by MDR Committee to receive guaranteed intensive care treatment by DOT at community level.

9. Collaboration

9.1 The clinic collaborates with social welfare for social assistance.

9.2 Staff collaborate with NGOs, schools and workplaces in the catchment area to enhance the promotion of TB prevention and care.

APPENDIX 6:

Outputs of the study thus far

ARTICLES IN SCIENTIFIC JOURNALS

Matebesi Z.

2002. The life circumstances and experiences of tuberculosis patients in the Free state, South Africa. *Acta Tropica*, 63(1):64.

Accepted:

Matebesi Z & Booysen F**.**

2004. Quantitative and qualitative evidence of determinants of treatment adherence among tuberculosis patients in the Free State, South Africa

PRESENTATIONS NATIONALLY

- **Matebesi Z.** 2002. *Poverty and the career of the tuberculosis patient in the Free State.* TB Research Project Feedback Workshops. Sasolburg, Bethelehem, Welkom, Harrismith, Bloemfontein, Trompsburg: Free State Department of Health, 22-30 May.
- **Matebesi Z.** 2002. *The human dimension in tuberculosis control***.** 14th Conference of the International Union Against Tuberculosis and Lung Disease, African Region, Durban, 11-14 June.
- **Matebesi Z**. 2003. *The TB patient: Qualitative evidence of the perceived factors affecting treatment compliance.* Conference on Tuberculosis: A multidisciplinary approach to research, policy and practice. CR Swart Auditorium, University of the Free State, Bloemfontein, 11-12 November

PRESENTATIONS ABROAD

- **Matebesi Z**. 2000. *The health of migrants in South Africa*. Population Studies and Training Center, Brown University, Providence: USA, 25-27 October.
- **Matebesi Z.** 2002*. Poverty and the TB patient career – a sociological approach.* 4th World Congress on Tuberculosis. Marriot Wardman Park Hotel, Washington, DC, USA, 3-5 June*.*
- **Matebesi Z**. 2002. *Poverty and the tuberculosis patient career: A sociological perspective*. Biennial International Congress of the European Society of Health and Medical Sociology on Health and Society in Europe, Gronigen, The Netherlands, 28-31 August.
- **Matebesi Z.** 2002*. Living with tuberculosis: A reflection on poverty and gender issues.* Seminar on Tuberculosis in the Free State, South Africa, UFSIA, Antwerpen (Belgium), 3 September.
- Heunis JC & **Matebesi Z.** 2002*. The life circumstances and experiences of tuberculosis patients in the Free State, South Africa.* Third European Congress on Tropical Medicine and International Health, Lisbon, Portugal, 8-11 September*.*

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