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**A Qualitative Understanding Of The Health-Seeking Behaviour Of
Adult In-Patients With Multi-drug Resistant Tuberculosis In A Public
Health Sector Setting**

by

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ABSTRACT

Aim: This study aims to provide a qualitative understanding of the health-seeking behaviour of adult in-patients with multidrug-resistant tuberculosis in a public health sector setting

Methodology: A qualitative methodological approach was used in this study since it allows for an in-depth investigation and understanding of the health-seeking behaviour of MDR-TB patients. The study is seated in the arena of ethnographic inquiry, since ethnography investigates human behaviour as it is understood and experienced within a particular subtext and given reality, as it is created by the people of concern. In this regard, ethnography deals with developing an understanding of shared systems of meaning in societies that share similar social and cultural characteristics and can be applied to the study of any isolated group who have something in common. A total of four (4) 90-minute focus groups discussions were conducted with adult MDR-TB in-patients, comprising two male and two female groups. The data transcripts were analysed thematically in order to identify commonalities and variances among the responses of participants. Comparative analyses were made across the variable gender.

Findings: The findings are discussed within the context of relevant empirical literature and theory, including the Health Belief Model, Health Locus of Control Theory and the Theory of Reasoned Action. These findings were constructed temporally in terms of pre-admission, admission and post-admission behaviour. What has emerged in this study is that health-seeking behaviours that are traditionally defined as “poor patient adherence” and “treatment delay” are mediated by a number of variables operating in both institutional and community contexts. At a community level, large-scale community ignorance and lack of knowledge of MDR-TB, social stigma, conflation of TB and MDR-TB and the lack of recognition of symptoms coalesce to produce poor treatment adherence and treatment delays. This situation is exacerbated by cultural practices that result in patients using dual healing systems and multiple remedies. The net result for TB

sufferers is the advent of MDR-TB. At an institutional level a hierarchical biomedical bureaucracy conspires to produce a hostile, disempowering and inhumane experience for MDR-TB in-patients, which further compromises adherence behaviour and positive health actions.

Recommendations: Within the context of a number of systemic recommendations, a range of practical patient-centered and staff centered interventions are suggested, followed by recommendations for future research and an appraisal of the limitations of this study.

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List of Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
DNHPD	Department of National Health and Population Development
DOT	Directly Observed Therapy
HIV	Human Immunodeficiency Virus
KZN	KwaZulu-Natal
MDR-TB	Multi-Drug Resistant Tuberculosis
TB	Tuberculosis
WHO	World Health Organisation

Chapter One

Introduction

1.1 Background and Rationale for the Study

Despite the availability of effective anti-tubercular treatment since the 1940's, tuberculosis (TB) continues to rank amongst the worlds most serious health problems (Kopanoff, Snider and Johnson, 1988; Rubel and Garro, 1992). TB incidence in Africa is increasing dramatically and under-resourced public health care systems on the continent are struggling to cope. Serious problems exist with regard to the impact of South African TB control programmes, with exceedingly high defaultation and non-adherence rates amongst sufferers being the norm (Glatthaar, 1982). The result of our failure to control TB infection is the emergence of multi-drug resistant TB (MDR-TB), one of the most powerful diseases known to exist, with extremely high infection rates being fuelled by the concurrent HIV/AIDS pandemic.

It has been well documented that the treatment of MDR-TB is far more complex and expensive than that of patients infected with drug-susceptible TB (Simone and Iseman, 1992), with patient care being compromised by a lack of availability of patients previous treatment history, poor recognition facilities for MDR-TB and an overall paucity of health care resources. Patients who have sought treatment often find it difficult to cope with the social and financial burdens of prolonged identification and management strategies, leading to negative health behaviours such as non-adherence, which increases the likelihood of disease spread at a community level (Glatthaar, 1982). Another factor that compromises patient's health status and prognosis is the high prevalence of HIV/AIDS and TB. Apart from the biomedical complications of surviving both conditions, lay interpretations of MDR-TB are strongly associated with HIV/AIDS,

which is not surprising, given the high rates of co-morbidity between the two conditions, especially in Kwa-Zulu Natal with a co-prevalence of 45% (Onyebujoh, 1999).

The Directly Observed Therapy (DOT) strategy has had positive and negative repercussions on treatment outcomes. In fulfilling its primary objective of ensuring adherence to drug regimens, DOT has played an important role in increasing patient's confidence in their ability to execute positive health actions (Nolan, 1997). On the other hand, it appears that the DOT intervention does not adequately address patients need to feel self-motivated and empowered to manage their own health status (Sumartojo, 1993). The literature reviewed suggests that health professionals often have very little insight into patient's decision-making processes (Morris and Schultz, 1992). Adherence is not merely a dimensional entity where the patient must do, as the health professional wants with little option but to comply with treatment advice. Without taking into account the powerful influences of socio-cultural, personal, financial and psychological factors, one may find it extremely difficult to predict patients adherence behaviour as well as ensure that patients are motivated to assume active roles over their health outcomes (Stewart, Bhagwanjee, Mbakaza and Binase, 2000).

Questions that come to mind with regard to such a health crisis relate to the following: is this disease a result of patients poor sense of responsibility with regard to adhering to treatment regimens, is it a disease that has evolved out of the practices or mal-practices of modern medicine, or is the disease a result of social inequities which has robbed people of equal access to wealth, education and health care? Unfortunately there is no simple answer to any of these questions. What has become clear after decades of research and scientific progress, however, is that medical science does not hold the definitive answer to disease conditions, even where effective pharmacological treatment is made available. It is patently clear that our ability to fully understand and indeed manipulate human behaviour lies at the heart of controlling illness outcomes. In this regard, medical anthropology, social science and health promotion, all aimed at understanding the social construction of illness, are critical to our success in controlling the scourge of MDR-TB.

Thus, alongside critical clinical research directed at improving pharmacological efficacy, it is imperative that we begin to understand patient's health seeking behaviour in order to gain insight into what patients perceive as barriers and benefits to treatment. These insights will further our understanding of factors that influence patients health motivations, self –efficacy and knowledge base with regard to specific health conditions (MDR-TB). Gaining an understanding of those processes by which TB/MDR-TB patients define themselves as ill, interpret their symptoms, assign meaning to the specific social consequences of TB/MDR-TB and how these contextual factors mediate their decision to seek/adhere to treatment would yield invaluable information for the design and implementation of relevant and effective health promotion interventions.

A broad range of factors potentially influences health outcomes. To investigate these factors using quantifiable data arguable negates the potential usefulness of such data, since developing meaning out of such data requires a deductive application of theory that might fail to adequately shed light on the complex interactions between illness and behaviour. Since qualitative methods are inherently inductive, and seek to discover rather than test explanatory theories, this paradigm allows the researcher to interpret data with much greater depth and insight than qualitative methods. Within the qualitative paradigm, ethnographic research is concerned with developing an understanding of shared systems of meaning in societies that share similar social and cultural characteristics and can be applied to the study of any isolated group who have something in common. Focus groups will be used since it yields qualitative data that provides insights into the attitudes, perceptions, feelings and opinions of participants.

Empirical research on interventions aimed at enhancing adherence behaviour and treatment efficacy has encountered significant problems relating to the failure in using explanatory and health behaviour models to guide systematic and programmatic research. The danger of not applying theory based research lies in the assumption that certain behaviours occur in specific situations, thus providing little basis for generalization to other situations. Empirical research has also failed to adequately take into account the

multi-faceted and complex nature of health seeking behaviour, with most researchers attempting to find a single, powerful solution to multivariate problems (Sumartojo, 1993).

Socio-psychological theories are thus critical in facilitating an understanding of health behaviour, explaining the dynamics of the behaviour and the effects of external forces on the behaviour. The Health Belief Model, in particular, presents as an ideal theoretical framework for this study since it provides a broad canvas for the exploration of the health-seeking behaviour of MDR-TB patients. The categorical parameters of the model include an assessment of all relevant dimensions of health-seeking behaviour (viz. perceived susceptibility, perceived severity, health motivation, perceived benefits, perceived barriers and self-efficacy) without being methodologically prescriptive. The HBM has accordingly been used, in the context of this study, to facilitate a culture-centred qualitative investigation of the health seeking behaviour of MDR-TB patients, with minimal theory driven presumptions. Therefore the heuristic value of the Health Belief Model, for the purpose of this study, lies in the ideal balance that it provides between theory driven and data driven research.

In summary, the aim of this study was to investigate the health-seeking behaviour of MDR-TB patients, drawn from the in-patient TB unit at King George V Hospital in Durban. A qualitative ethnographic data collection strategy was used, comprising four single-sex focus groups of 10 patients each, i.e. two male and two female groups. Analysis of data was informed by a range of theoretical models, in particular the Health Belief Model, which specifies six categorical constructs that are particularly pertinent to extrapolating the health-seeking behaviour of MDR-TB patients.

Chapter two provides a critical overview of pertinent literature in the field while Chapter three details and justifies the methodology used in this study. Following a thematic analysis of the focus group transcripts in Chapter four, Chapter five offers a synthesis of findings from a theoretical standpoint. Finally, a range of conclusions and recommendations are detailed in Chapter six, together with a critical appraisal of the limitations that constrained this study.

Chapter Two

Literature Review

2.1 Incidence of Tuberculosis

From a global perspective, the magnitude of tuberculosis (TB) infection has reached epidemic proportions. For the current decade, it is projected that approximately 90 million new cases of TB infection will occur and 30 million deaths will result from TB (Bloom, 1994). It is estimated that approximately one third of the world's population (i.e., 1.7 billion people) are infected with *Mycobacterium Tuberculosis* (Kochi, 1991). The 1992 mortality figures indicate an estimated 1.1 million deaths due to TB occurring in Capital South East Asia in 1992, 672 000 deaths in the Western Capital Pacific region and 426 000 deaths in the remainder of the world (Cauthen, Pio and Ten Dam, 1988). TB has a particularly devastating effect in the developing world, where 95% of all reported TB cases occur (Bloom, 1994).

The world-wide incidence of TB is the leading cause of death by infectious diseases (Poss, 1998). Tuberculosis primarily affects adults between the ages of 15 and 64, and it is estimated that 26% of preventable deaths among adults in developing countries is caused by TB (Poss, 1998). Although there has been a decline in the total number of TB cases since 1993, this disease remains an important health concern since the progression of more lethal forms of the disease have come in to being, namely MDR-TB.

In 1996, the incidence of TB infection in South Africa was reported to be 158 689 cases, with almost one-third of these patients being HIV positive (Onyebujoh, 1999). The presence of HIV infection has been shown to be a highly significant factor in the progression from primary TB infection to active disease (Bloom, 1994), with KwaZulu-Natal (KZN) demonstrating the highest co-prevalence of these two conditions in South

Africa. By way of example, 21.5% of all national TB cases were reported in KZN in 1996, with a 45% co-morbidity rate with HIV infection (Onyebujoh, 1999).

2.2 Drug-Resistance and Tuberculosis

Harrow, Rangel, Arriega, Cohen, de Leon Regil Ruiz, De Rimer and Small (1998) ascribes the resurgence of drug-resistant TB to inadequate therapeutic practice, arguing that marginal funding in resource-poor developing countries has compromised therapeutic efforts. In a comprehensive study, Laszlo and de Kantor (1994) reported resistance rates ranging from 7% in Argentina to 43% in Peru. Harrow et al's (1998) study offers three main conclusions, viz. 1) there are high rates of initial and secondary drug resistance among TB cases in Western Guatemala hospital (their study site), 2) drug-resistant cases could not be reliably identified based on epidemiological and clinical characteristics, 3) the treatment of patients infected with multidrug-resistant strains was associated with high rates of failure (30% resistant to any one agent and 15% resistant to 2 or more drugs). Identifiable risk factors of having MDR-TB were cavitory disease detectable in chest radiograph and a history of taking anti-TB therapy for more than two weeks. Individuals infected with drug resistant TB were identifiable only by use of microbiologic tests.

The authors reported that such cases of primary drug resistance were most likely a result of ongoing transmission of resistant strains. An alternative explanation of this degree of drug resistance is that patients were misclassified as new cases because they either forgot or wilfully misrepresented their prior medical history. These possibilities were instigated by systematic and non-biased history taking and searches for medical records of prior therapy. Because many of these patients were poor and lived considerable distances away from hospital, the expenses incurred in travel and lost work precluded regular return visits. Given that patients were only able to receive DOT during periods of hospitalisation, there was a 75% prevalence of unsupervised therapy. Patients in this study were relatively young, poor and uneducated and they presented with advanced disease. The study accordingly demonstrated the urgent need to improve the

implementation of TB control procedures to prevent the emergence of drug resistant TB in the Guatemala region.

In terms of resistance mechanisms, factors that affect the delicate immune system include stress (physical and/or emotional), malnutrition, age (very young and very old), diabetes, long term corticosteroid therapy, immuno-suppressive therapy, lingering malignant disease, viral infections, alcoholism and continuous exposure to tubercle bacilli (Glatthaar, 1982). According to Glatthaar (1982), the cycle of the development of TB starts when the uninfected person becomes naturally infected via droplet infection. The inhaled bacilli cause a primary infection usually in the mid-lung region. There is little tissue destruction or cellular infiltration at the site of infection because cellular immunity has not yet developed. The bacilli then multiply and migrate via the lymphatic system to the blood stream. In a small number of cases the initial infection may progress to active disease. The circulating bacilli cause secondary infection at sites and in organs where the oxygen tension is high. Lesions are formed and the initial one usually heals since the immune system becomes fully developed and healing ensues. However in 15% of secondary lesions living bacilli may remain in the scar, and these have the potential to reactivate later and develop into tuberculosis.

MDR-TB is one of the most complicated forms of TB, the incidence of which is increasing world-wide (Bloom, 1994). Drug-resistant tuberculosis occurs when there is a substantial increase in the proportion of organisms that are resistant to one or more anti-tubercular drugs (Bass & Kirkpatrick, 1988). Patients may develop MDR-TB through primary drug resistant organisms or, more commonly, through secondary/acquired drug resistance resulting from ineffective anti-tubercular drug therapy (Mitchison, 1984).

Management and treatment of the patient infected with MDR-TB is far more complex and expensive than that of the patient infected with drug-susceptible TB (Simone & Iseman, 1992). A detailed history of previous anti-tubercular treatment, with rapid recognition of the major anti-tubercular agents (Carpels, Fissette, Limbana, Van Deun, Vandembukle and Portaels, 1995), is therefore vital in developing a tailored drug regimen

for patients with MDR-TB (Simone and Iseman, 1992). Given the high costs involved in treating MDR-TB patients and the paucity of resources available in developing countries, strong emphasis should be placed on DOT in order to effectively manage newly-diagnosed infectious drug-sensitive TB patients, thereby preventing the development of MDR strains of TB, rather than treating it (Kent, 1993; La Raja, Screm, Talmassans, Pasquadibisceglie, Pitzalis and Pitzus, 1997; Schaaf, Botha, Beyer, Gie, Vermeulen, Groenewald, Coetzee and Donald, 1996).

Of increasing concern is that individuals infected with MDR-TB pose the risk of spreading drug-resistant strains of TB, thereby increasing the morbidity and mortality rate in surrounding communities and among the population in general (Kent, 1993). In addition, the admission of MDR-TB patients for in-patient treatment poses a significant threat with regard to infecting other drug-susceptible TB in-patients with MDR *Mycobacterium* (Rao, 1998).

Medical science research has identified a range of risk factors associated with the development of MDR strains of TB, including *inter alia*, a history of non-adherence to treatment (Ortona & De Luca, 1998), inadequate in-patient ventilation and isolation facilities (Rao, 1998), social circumstances such as poverty, overcrowding and lapses in hygiene (Simone & Iseman, 1992), ineffective drug regimens (Kent, 1993), delay in diagnosis and treatment (Saito & Amitani, 1998), inappropriate treatment duration (Kent, 1993), HIV infection (Bloom, 1994) and exposure to individuals in areas with a high prevalence of MDR-TB (Simone & Iseman, 1992).

In response to the emergence of MDR-TB, the Centres for Disease Control and Prevention (CDC) recommended in 1993 that initial drug regimens for the treatment of TB should include four drugs in areas with a high level of drug resistance (24% Isoniazid resistance) (Liu, Shilkret and Finelli, 1998). The regimen was intended to prevent the development of MDR-TB in areas where primary Isoniazid resistance was increasing. The early phase of treatment is crucial for preventing emerging drug resistance and

determining the ultimate outcome of treatment. Lui, Shilkret and Finelli (1998) indicate that an initial four-drug regimen is highly effective even for Isoniazid resistant TB, and is associated with faster sputum conversion among drug susceptible TB patients. This study evaluated physician-prescribing practices in New Jersey for the initial treatment of TB and compared them with the practices recommended by the CDC. The results indicated that a substantial proportion of TB patients were not treated with the initial four-drug regimen recommended by the CDC. The study also indicated that many physicians were not aware of the recommendations or the level of drug resistance in their communities. Therefore, they recommended that an effort should be made to inform physicians about the importance of initiating four drug regimens to treat TB patients and about the high level of drug resistance in the community they serve.

Paore, Perlman, Perkins, Kochems, Saloman and Des Jarlais (1998) reported a strong link between the human immunodeficiency virus (HIV) and tuberculosis. They report that individuals who use drugs have a higher prevalence of latent tuberculosis infection and are at risk for progression to active tuberculosis. In relation to these findings Funniye, Ganesan and Yoshikawa (1998), studied the clinical characteristics and outcome of pulmonary tuberculosis in African Americans aged 19-69, between May 1992 and April 1994. They found that predisposing factors for pulmonary tuberculosis were identified in nearly half of the cases. Coughs and fevers were the most common symptom. Drug resistance was identified in 29% of the cases and HIV was a major predisposing factor for TB. They also found that drug resistance and mortality were disproportionately high and that the combination of the two (HIV+TB) has a poor prognosis. Aghinira and Erhabor (1998) studied demographic and socio-economic factors in mental disorders associated with TB in Nigeria and found a high prevalence of psychiatric disorders in TB patients (30.2%). Psychiatric disorders encountered include mild depressive episodes, general anxiety disorders and adjustment disorders.

Iseman (1999) reports that drug-resistant TB fundamentally reflects inadequate chemotherapy to prevent increases in the prevalence of resistance therefore physician education and structured treatment programmes are needed. Common errors in standard

practice of health care include adding a single drug to the regimen, failure to identify initial and acquired drug resistance, using an inadequate regimen and not recognising and coping with non-adherence to therapy. Lui, Shilkret and Finelli (1998) found that a substantial proportion of physicians did not initially treat their TB patients according to the recommendations of the Centres for Disease Control (CDC) and American Thoracic Society (ATS), and suggested that physicians should be better informed about the levels of drug resistance in the community they serve to assure that patients adhere to appropriate initial therapy. These authors also suggest that physicians must also be able to identify populations at high risk for TB, especially those infected with HIV.

Campion (1999) has shown that those patients infected with HIV are particularly susceptible to tuberculosis, with outbreaks of TB amongst such persons being particularly explosive. He argues that the effectiveness of a TB programme depends on the ability of every patient to complete the full course of anti-tuberculosis drug therapy. What appears to be problematic however is that patients with MDR-TB need to comply with treatment, which is much longer than short-course chemotherapy, and this could be quite difficult given the fact that many of these patients could not comply with the short course regimens initially. Even with directly observed therapy, which is now used widely, patients sometimes stop co-operating or just disappear.

2.3 Directly Observed Therapy (DOT)

DOT was devised to address the tendency of patients who fail to adhere with the long course treatment necessary to achieve a cure for TB (Nolan, 1997). Formerly in limited use for selected patients in a few public health TB programmes, DOT was expanded dramatically during the recent resurgence of TB and multidrug-resistant TB (MDR-TB) in the United States and is considered to have played a key role in regaining control of the disease (Nolan, 1997). Widespread application of DOT in New York City during the MDR-TB epidemic led to a rise in the completion rate of TB therapy, a fall in TB incidence, and a reduction in the prevalence of MDR-TB in the community (Nolan, 1997). He goes on to say that, even before such dramatic results were reported, other TB

programmes demonstrated the favourable impact of DOT on disease rates, relapse rates and rates of drug resistance when it was deployed over time on a population-wide basis.

In DOT, patients are required to take all medication in the presence of health care workers or other service providers. Some DOT programmes have demonstrated increased completion rates relative to self-administered therapy, however some patients delay seeking treatment to avoid mandatory therapy or detainment (Heymann, Sell and Brewer, 1998). Changes in patient behaviour in response to public health interventions may affect potential gains or even produce paradoxical increases in disease spread (Heymann, Sell and Brewer, 1998). These authors investigated how programme acceptability influences the effectiveness of self-administered therapy (DOT) and confinement in getting patients with active TB to seek, initiate and successfully complete therapy. Their study showed that if DOT discourages as few as 6% of people with TB from seeking care in the first year, it will not be as effective as providing self-administered therapy first.

In contrast, unless mandatory DOT leads to a 32% decline in the number of patients seeking care, it will not be more effective than self-administered treatment in minimising mortality among patients failing to complete initial anti-tuberculosis treatment. Heymann, Sell and Brewer (1998) suggest that their results hold across a wide range of assumptions concerning HIV infection, MDR-TB and the likelihood of cure, death or ongoing tuberculosis for persons failing to complete therapy. Because patients are likely to incur additional time and financial costs when undergoing DOT, they are unlikely to find mandatory DOT as acceptable as self-administered therapy unless other services or incentives accompany it. Hence discussion of treatment options for patients often pits programme effectiveness against patient preferences. These authors suggest that more restrictive treatment programmes are recommended in the belief that they are more effective than less restrictive ones, and that careful attention needs to be paid to cater for patient needs to ensure acceptability of treatment options.

In the United States it has been recommended that every patient diagnosed with tuberculosis should at least first be evaluated for DOT, and that DOT should be

mandatory for patients demonstrating non-adherence with treatment and for those with MDR-TB (Nolan, 1997). The World Health Organisation (WHO) has recently recommended that national TB programmes throughout the world should be able to deliver a standardised 6-month DOT regimen to all smear-positive patients with pulmonary TB. However Nolan (1997) has pointed out that DOT has not eliminated the problem of non-adherence with TB treatment. He makes reference to Burman et al's report that during an 11-year period, non-adherence with DOT occurred at a frequency of 18% and was responsible for 61% of poor outcomes of TB treatment.

Therefore much needs to be learned about patients adherence with medical advice. Nolan (1997) suggests that programmes should be able to provide culturally sensitive care to an increasingly diverse population, to deliver comprehensive services to assist patients and their families about TB, and to provide direct incentives such as bus tokens, food and beverages, and even money to induce patients to continue in a treatment plan. He goes on to say that TB programmes using DOT also need to analyse their own data to ascertain programme-specific determinants of non-adherence. He makes reference to the social stigma the disease carries, for example, in the United States where people feel ashamed to have an outreach worker in a health department vehicle park in front of their house everyday. Although South Africa cannot afford that luxury, similar social stigmas have been found to prevail (Schaaf et al, 1996; Thomson and Myrdal, 1986; Westaway and Wolmarans, 1994).

Nolan (1997) makes reference to our failure to control TB by arguing that, "The fact that we must rely on an inherently labour-intensive activity such as DOT to assure the curative treatment of patients with TB is itself a testimony to fundamental weaknesses in our capability to control TB with current technology" (pg., 1152).

Directly Observed Treatment (DOT) was officially adopted by the South African Department of Health in 1996 in order to observe and thereby ensure that TB patients take the full course of treatment (Van der Walt and Swartz, in press). This process involved monitoring every dose of TB medication taken under the close supervision of a

health care worker. These patients are observed while taking medication. The original intention of DOT was to ensure adherence to treatment and to provide support and encouragement for the patient; however such a practice has resulted in a so called 'depersonalisation policing role' (Van der Walt and Swartz, in press), with health care workers playing a minimal role in adapting to the nature of interaction to suit the special requirements of the individual patient. This programme has had a negative impact on the patient's self-efficacy in that health care personnel are seen to portray a lack of trust in patient's ability to take care of themselves, which is compounded by the inflexibility and rigidity of health care routines.

The Directly Observed Therapy (DOT) regimen for TB control in South Africa primarily assumes the form of clinic-based services, with 76% of all TB patients being treated in community-based clinics (DNHPD, 1993). 24% of all TB patients, who are highly symptomatic, are therefore treated within the hospital setting (DNHPD, 1991). Given that the hospital-based TB treatment is 3 times more expensive than DOT regimen (Floyd *et al*, 1997), in-patient TB treatment places an enormous financial burden on the South African health care system. This indicates the urgent need for providing effective in-patient TB treatment in order to minimise relapse rates and to prevent further spread of the disease, particularly multidrug-resistant (MDR) TB.

It is important to note, however, that while many researchers advocate the importance of utilising DOT in order to ensure the successful completion of a full course of therapy, other researchers have found significantly differing results since its implementation. In Botswana, for example, the case rate of TB increased by 120% over the period 1989-1996, despite a decade of implementation of DOT and the short course DOT strategy (Kenyan *et al*, 1999). Factors impacting on patients' acceptance of and adherence to treatment therefore need to be taken into consideration when developing effective public health strategies for the prevention and treatment of TB, particularly MDR-TB.

Yew (1999) provides strong support for DOT in the prevention of MDR-TB, and says that adherence to therapy in patients with tuberculosis is a major determinant of

outcomes. Even though there are no currently known predictors of adherence, Yew proclaims that DOT, education; holistic care, enablers and incentives are still the best strategy, for assuring patient's adherence to treatment. Yew (1999) goes on to say that to enhance the delivery of DOT, short course chemotherapy must be strongly advocated while the monitoring of patient dependable drug supply and adequate programme funding are other important elements of the entire strategy. Since the global resurgence of TB and associated rampant drug resistance in the 1990's, DOT has now become the World Health Organisation's (WHO) primary strategy for effective TB control, ensuring treatment success and for preventing the development of acquired drug resistance (Yew, 1999). The recent WHO/International Union against Tuberculosis and Lung Disease (IUATLD) global project on anti-TB drug resistance has revealed that in countries where 33-90% of the population used the DOT strategy, lower levels of drug resistance are reported. Despite greater initial costs, DOT is a more common strategy than self-administered therapy because it decreases the re-treatment associated with therapeutic failure and acquired drug resistance. Finally Yew (1999) says that DOT might be further enhanced by the use of drugs developed with a long duration of action or more potent bactericide sterilising activities.

2.4 The Dynamics of Non-adherence in Tuberculosis Control

There is a substantial body of evidence to suggest that the emergence of MDR strains of TB are largely attributed to poor patient adherence with TB treatment protocols (see, for e.g., Cuneo and Snider, 1989; Kent, 1993; Kopanoff, Snider and Johnson 1988; Liefoghe *et al*, 1995; Mitchison, 1998; Pablos-Mendez *et al*, 1996; Rao, 1998 Sumartojo, 1993). Not suprisingly, therefore, there has been an increasing call for behavioural and social scientists to investigate the determinants of patient non-adherence in order to inform effective intervention strategies for this target population (Sumartojo, 1993).

Factors shown to contribute to patient non-adherence with TB treatment (thereby resulting in increased resistance to anti-tubercular drugs) include self-medication, either

with recognised curative drugs or with folk remedies, the misuse of Isoniazid in terms of its length of application (Jaramillo, 1998) and social circumstances such as poverty, overcrowding, homelessness, substance abuse, a poor community TB infrastructure and contradictory norms of families and social groups (Sumartojo, 1993).

The social consequences of TB is increasingly being recognised as an important contributory factor to patient non-adherence with TB treatment and the length of delay in seeking health care, thereby leading to the possibility of developing MDR strains of TB (see, for e.g. Jaramillo, 1998; Johansson *et al*, 1996; Rubel & Garro, 1992). Much evidence points to the direct and indirect social costs accruing from seeking TB treatment, including *inter alia*, cost of transportation to clinic facilities, family disintegration (Sumartojo, 1993), rejection by families and relatives (Rubel & Garro, 1992), social isolation and discrimination, fewer opportunities for marriage or separation and divorce, especially for women (Jaramillo, 1998), loss of employment and income (Johansson *et al*, 1996) and negative social stereotypes regarding the disease (Westaway & Wolmarans, 1994).

Christensen-Szalanski and Northcroft (1985) examined the effects of temporal considerations upon a person's perception of the cost and benefit of treatment and his or her adherence with it. The nature of the study was to re-evaluate the role of time in the understanding of adherence behaviour. A review of literature in this area, by these authors, demonstrated that variations in temporal availability of costs and benefits could systematically alter the perceived value of those costs and benefits. Specifically, those studies that were reviewed suggested that the degree to which treatment programmes benefits are delayed into the future or costs have accrued in the past could alter a patient's willingness to begin a treatment regimen once begun.

Christensen-Szalanski and Northcroft (1985) explain that expectancy models of adherence behaviour such as the Health Belief Model are concerned with the subjective world of the individual, as well as the notion that the perceived values for the anticipated events will be representative of those that patients would have if or when they actually

occur. They go on to refer to the contrasting findings of economics research, which suggests that the value of the future event may not be representative of the events value to the person when it actually occurs because the time delay associated with future events reduces the events “current value” to the person, which is referred to as the “discounting effect”. Such an effect illustrates how a person’s preference for complying with a treatment regimen can suddenly change because the passage of time alters the relationship between a person’s current value for the adherence behaviour and for a competing behaviour (Christensen-Szalanski and Northcroft, 1985).

An understanding of the discounting effect of delay on a person’s attitude about future events can improve the understanding of patient adherence and the Health Belief Model on two different levels. First, on a theoretical level, it can be used to integrate the Health Belief Model with other existing models that account for similar types of behaviour, such as operant conditioning models for self-control. In terms of the Health Belief Model, it is generally assumed the greater the change in a persons beliefs about the consequences of complying with a regimen, the greater the effect will be on a persons adherence behaviour (Christensen-Szalanski and Northcroft, 1985). However, these authors go on to argue that depending on the time frame of the consequences about which the beliefs are being modified, a very large change in a persons beliefs may have little or no effect upon the persons adherence.

The discounting effect of time may make it more difficult for a treatment programme to alter a persons current adherence behaviour when the programme focuses attention on the distant future consequences of non-adherence, rather than on an immediate consequence of non-adherence. These authors refer to two patient contract agreements for improving patient adherence with medical regimens; one is a ‘token economy’, which is of value to the patient upon successfully completing certain components or stages of the treatment. The second type of contract is ‘deposit contract’ whereby the patient deposits something of value with the provider prior to beginning the treatment with the understanding that all or parts of the deposit will be lost if the patient fails to adhere with the treatment once it has begun.

Several explanations unrelated to the Health Belief Model have been offered to account for the success of these contracts in improving patient adherence. They include a) the patient is forced to attend to the problem of following the therapy; b) the patient is made an active participant in the treatment and c) the patient has a better self-image. Others have proposed that patient contracts are successful because they establish in a patient an internal locus of control over the environment.

Marlotte, Fen Rhodes and Mais (1998) suggest that theories of human behaviour may assist in the design of adherence intervention. One such theory, the theory of reasoned action, postulates that changing a persons behaviour is primarily a matter of changing the persons underlying beliefs about that behaviour. These authors investigated the effects of monetary incentives in the return for a TB skin test reading in a sample of active injection drug and crack cocaine users. Their results confirmed that incentives could have a substantial impact on adherence. In the case of tuberculosis, the treatment costs for individuals who develop the active disease because of poor adherence with chemoprophylaxis, along with treatment costs for contacts infected by these individuals, may be considerably greater than the cost of incentives.

Jones, Jones and Katz (1988) investigated the effects on adherence of clinical and telephonic intervention, based on the Health Belief Model using emergency department hospital patients. They found that clinical and telephonic intervention as well as a combination of the two interventions were strongly associated with increased adherence and that the availability of child care, knowledge of the presenting problem, nature and duration of the illness and demographic variables were also related to adherence.

Researchers have studied varying interventions to improve adherence with tuberculosis treatment. Lang, Ulmer and Weis (1986) studied the effectiveness of using the patient's language on their medication calendar. They found that while initial adherence with therapy was good, dropout rates after the first and second month were extremely high,

thus illustrating that there are many other factors that influence patient adherence to treatment regimens.

Other studies such as the one by McCallum, Wiebe and Keith (1988) sought to assess the effects of prior adherence experience and attitudes towards general health and tuberculosis on intentions to adhere with a tuberculosis regimen. Their analysis used the Health Locus of Control Scale and measures of health beliefs, knowledge, intention to adhere, and prior experience with medical regimens. They found that adherence was related to perceived barriers to action for subjects having no prior experience with medical regimens, and that for those with medication experience, adherence was predicted by benefits of action, internal locus of control and chance locus of control.

Campion (1999) comments on the use of legal action in New York City to ensure treatment of tuberculosis by saying "...while the use of regulatory powers by the New York City Department of Health appears to be reasonable and fair, as a model, this program poses some real hazards, including the unavoidable elements of coercion, and the danger that the power of detention will come to be seen as the answer to disease control programs that are failing". One could argue that since the development of curative drug regimens, medicine and technological advancement has promoted only a marginal decline in the global TB incidence. Surprisingly, a disease that was once thought to be obsolete has now come back with a vengeance. Failures in controlling such epidemics are not so much attributable to treatment failure per se, but to factors relating to the patient's psychological and social wellbeing.

We are now faced with mutations (MDR-TB) that are so treatment resistant, that health care facilities have limited resources to facilitate appropriate treatment for patients. These circumstances have 'forced' health care authorities to institute one of the most extreme measures of prophylactic care (detention) to aid in adherence and control of this epidemic.

Of particular importance is the evidence that suggests that health care workers fear the disease due to the risk of occupational transmission of TB, particularly MDR-TB (see, for e.g., Hatch & Moline, 1997; Johansson *et al*, 1996; Krishnan & Janicak, 1999). Such health care worker perceptions often lead to uncaring and unsupportive staff attitudes towards patients, which may impact negatively on patient adherence to and acceptance of treatment (Rubel & Garro, 1992).

Organisational disempowerment has allowed health care professionals to succumb to the set of rigid and elaborate hospital rules which protects them from the potential anxiety of having to take creative decisions, as well as robbing them of the opportunity and satisfaction of developing problem solving skills (Van der Walt and Swartz, in press). These authors go on to describe psychologically, how health care workers frustrations and anger originate as a consequence of what they may see as irresponsible and unmotivated patients. Such anxieties, which may occur at an intrapsychic level are alleviated by converting it into an interpersonal conflict.

The resultant feature of such circumstances has led to an organisational 'defensive projection' whereby health care workers split off their 'irresponsible impulses' and attribute them to the patient. What becomes apparent in such a situation is that on the one hand the health care worker expects the patient to take responsibility for her own health, and on the other DOT's principle form of implementation treats the patient as if she were untrustworthy and incapable of acting in a responsible manner.

Other factors that may influence health care workers social distance from patients, is the nature of the disease itself as well as its transmission. The disease MDR-TB is the most lethal variation of TB and what complicates matters is that its transmission, unlike HIV/AIDS, can occur simply through breathing infected air particles. Therefore the very real threat of contracting TB/MDR-TB from patients has consequences for how health care personnel interact with patients.

The nature of their anxieties stem from the contradictory roles of the health care worker as carer and as combatant against an epidemic in which a non-adherent patient can contribute to the death of others. The patient, in coping with her anxiety, refuses to participate in important decisions (non-adherence), which then can be seen as forcing responsibility and anxiety back to the hospital. The patient therefore feels disempowered for being treated in such a way, and as a consequence refuses to adhere to advice or guidelines, therefore refusing to accept personal responsibility, which is then borne by the health care worker who sees it as her failure to 'motivate' the patient successfully.

While ineffective communication between the patient and health care provider has been reported as a major barrier to positive health outcomes, including treatment adherence (Levinson & Chaumeton, 1999; Martin & Barkan, 1989; Ong et al, 1995; Sumartojo, 1993), it is important to note that the perspective of the health care professional has dominated treatment adherence research, with little regard for the patients decision-making processes (Morris & Schultz, 1992). There is an inherent tendency to "blame" the patient and to view non-adherence as irrational and deviant (Playle and Keeley, 1998). Traditionally, therefore, treatment 'adherence' simply means that patients must do as the health professional wants, with little option but to comply with the advice or instructions that they receive (Donovan, 1995). Patients' perceptions, however, as well as their personal and social circumstances, have been shown to be crucial in their health-seeking behaviour and decision-making processes (Stewart, Bhagwanjee, Mbakaza and Binase, 2000). The establishment of supportive patient-provider relationships, aimed at empowering patients to assume active roles in their health care (Berkman, 1995) and developing a sense of control over their health outcomes (Sobel, 1995), is therefore crucial in significantly improving patient adherence with therapeutic regimens (Van den Borne, 1998).

2.5 Factors Contributing to Treatment Delay

A large body of literature addresses the cultural beliefs and understanding of TB, which has been linked to patients' decisions regarding when, and from whom, to seek assistance

(see, for e.g., Jaramillo, 1998; Rubel and Garro, 1992; Sumartojo, 1993; Vecchiato, 1997). In East Africa, for example, attribution of tuberculosis symptoms to witchcraft or other folk illnesses is associated with delays in seeking professional treatment as well as with remarkably high rates of default once treatment has begun (Ndeti, 1992). Further, many individuals infected with TB, while acknowledging their symptoms, fail to timeously seek care from bio-medical facilities due to their beliefs in the efficacy of folk remedies prescribed by traditional healers (Jaramillo, 1998; Vecchiato, 1997). Rubel and Garro (1992) argue that incidents of treatment delays in South Texas were attributed to patients' beliefs that their illness (termed 'susto') could not be identified or treated by a physician. Treatment, in this study, thus typically began with self-medication utilising 'over-the-counter' remedies, followed by lifestyle changes such as retiring early, reducing smoking and drinking and leading what they perceived to be a healthier lifestyle.

The meaning ascribed to and the interpretation of symptoms by patients is therefore an important consideration in determining whether patients will seek professional treatment and whether they will remain in treatment (Rubel and Garro, 1992). Thus, following Barnhoorn and Adriaanse (1991), patients who report more knowledge and understanding about their symptoms and available health care resources for TB treatment are more likely to complete a short-term course of anti-tubercular treatment.

Hunter and Arbona (1985) report that many studies have shown that a failure to take tuberculosis medication may be due to numerous reasons, which include: the illusion of health when symptoms disappear, a failure to understand the disease, fear of side-effects related to unexpressed hostility to the physician, unwillingness to regard oneself as ill and reluctance to accept the discipline of a drug regimen for a prolonged period of time.

Hunter and Arbona (1985), in their study of tuberculosis in Puerto Rico, found that patients who were diagnosed as suffering from tuberculosis were isolated at home by the family or even more severely, isolated alone in a house, therefore supporting the fact that

shame, denial, concealment and stigma are still forces to be reckoned with in controlling the TB epidemic.

2.6 Patients Decision-Making Capacity

O'Dowd et al (1998), argue that patients with decision-making capacity have the right to make their health care decisions even if those decisions seem ill informed or irrational to the caretaker. However they go on to say that, to determine whether a patient does have decision-making capacity, three basic issues need to be considered. Firstly, the patient must be informed; being informed is not a clear-cut process since information can mean different things to the physician and the patient. In most cases, O'Dowd and colleagues found that despite doctor's assurances of providing adequate information, they had to go back to basics and make sure the patient is getting the information he/she needs to make an informed decision. Next the patient must show evidence of weighing the risks and the benefits when considering the options and finally the patient has to express a choice (O'Dowd et al, 1998).

O'Dowd et al (1998) also make reference to what they call the "wolf, wolf" syndrome, which occurs when patients have been threatened by their doctors or health care workers, with dire consequences in the case of non-adherence or refusal of treatment. When these patients do not suffer those consequences, they tend to become even more sceptical the next time around. Such patients may focus on the fear of pain in the here and now rather than on the long-term goals to be attained (O'Dowd et al, 1998).

Campion (1999) says that mandatory confinement because of dangerous contagious diseases has long been accepted as necessary, at least sometimes, to protect the health of the public. The treatment of tuberculosis is a classical example of having to balance the public health interests of society against the freedom of the individual (Campion, 1999). He goes on to say that in some of the largest cities in the USA, about one third of new cases of tuberculosis are the result of recent transmission rather than reactivation of disease acquired years earlier. Aerosolised droplets from a patient with active tuberculosis can infect others after only casual contact, particularly in crowded, poorly

ventilated places such as shelters, bars and prisons (Campion, 1999). Thus in response to the resurgence of tuberculosis in New York City, the Commissioner of Health was given added powers, including the power to detain patients, not only while they were infectious, but also if necessary, until they completed their full course of therapy (Campion, 1999).

Sending patients to a lock up facility for treatment is an extreme measure, and the threat to civil liberty is particularly serious since most of the patients likely to receive such orders are impoverished and powerless (Campion, 1999). Gasner et al (1999) argues that the use of regulatory powers by the New York City Department of Health has been reasonable and fair. Campion (1999) reports that while almost all detained patients completed treatment, such a programme poses serious hazards since it relies specifically on trust. The element of trust is based on the notion that those in charge will base their decisions on the best interests of the patient and avoid bias and punishment. Although there is an element of coercion, the goal is to use the least restrictive means that will work, noting that judgements about who is not likely to comply with out-patient treatment are imperfect (Campion, 1999).

Even with greater legal power, Campion (1999) says that the effectiveness of any tuberculosis programme still depends on co-operation, not coercion, and since DOT requires co-operation, its effectiveness depends on a supportive relationship between patient and observer. He argues that the greatest danger of the power of detention is that it will come to be seen as the answer to disease control programmes that are failing, and therefore should be considered as a last resort. Campion however seems to subscribe to the biomedical paradigm in searching for the control of tuberculosis, since he advocates that research efforts need to be directed at finding more effective anti-tuberculosis medications that will permit regimens to be shorter and make adherence easier. He goes on to argue that it is a cynical error to presume that, among the poor, tuberculosis is somehow inevitable or that its conquest must await some remarkable improvement in social conditions and in human behaviour. It is interesting to note that notwithstanding these sorts of comments, biomedicine has yet to succeed in the 'control' of tuberculosis, yet those working at the other end of the spectrum, who have been dedicated to

researching areas of human behaviour, social science and anthropology, have made headway in understanding how these aspects impact on the control and spread of infectious diseases.

2.7 Tuberculosis ‘Control’

Glatthaar (1982) highlights a number of problem areas in tuberculosis control. These include the failure to find the true number of patients with infectious disease, failure to administer supervised ambulatory therapy, failure to reduce endogenous reactivation and failure to prevent and reduce infection. Kleeberg (1982) points out that both qualitative as well as quantitative differences exist between decision making for the individual patient and decision making for the community, and that by stopping the communication of fear we will probably succeed in diminishing the taboos attached to TB. Hunter and Arbona (1985) argue that the primary problem in controlling tuberculosis is case finding combined with sustained patient management.

Kent (1982) reviewed the minimum basic requirement of a case finding and treatment programme. He says that Passive case finding is essential to maintain high levels of suspect recognition, since medical attendants must enquire about every patient complaining of a cough and its duration. He recommends that as an absolute minimum, the full name and address should be recorded and three specimens of sputum should be collected, in the event of one being suspected of suffering from TB. Kent (1982) goes on to say that the most important facet of active case finding is undoubtedly health education, and that everyone should know that a cough lasting more than a month is liable to spell tuberculosis and that tuberculosis is readily curable, but only if so diagnosed. Kent (1982) argues that too often the approach adopted with the patient is too casual to be effective, with no real effort being made to ensure co-operation, much less to involve family members in the problem. He also contends that, too often, too little attention is paid to the difficulties which adherence imposes on the patient, many of which could be resolved with just a little effort. Time and again default goes unnoticed

and, if noticed, is not followed by any action because adequate steps have not been taken to trace the patient (Kent, 1982).

Acquinas (1982) contends that supervision of medication by staff is considered vital in securing a favourable outcome; intermittent chemotherapy facilitates this, as it is relatively convenient for a patient to attend a clinic for a shorter duration. Aquinas (1982) also makes reference to the adverse reactions of drug regimens, noting that patients must weigh these reactions against the risk of not treating the active disease. The majority of adverse reactions, as outlined by this author, were of a minor nature, including cutaneous reactions, gastro-intestinal symptoms and dizziness. Drugs such as Isoniazid, Rifampicin and Pyrazinamide affect liver functioning and patients who are susceptible to liver problems should be assessed prior to treatment. Streptomycin is the only drug that has been found not to cause liver damage (Acquinas, 1982). The most common (though rare) reaction to Rifampicin is thrombocytopenia and Aquinas (1982) suggests that note should be taken of patients who complain of purpuric spots, however small. The 'flu syndrome' is the commonest reaction to intermittent therapy and includes chills, malaise, fever and bone aches and pain, however these symptoms can be managed with only short periods of interruption of the offending drugs, if this is necessary (Acquinas, 1982).

2.8 Cultural Understanding and Explanatory Models of Illness

While medical science has suggested a range of factors for explaining and understanding the development of MDR-TB and how patients choose to manage the disease, an empirical lacuna exists with regard to understanding and utilising patients' explanatory models of illness for developing meaning-centred and culturally-sensitive TB treatment regimens. The concept of explanatory models of illness was developed by Kleinman (1980) and refers to how an individual interprets his/her illness and symptoms in terms of its aetiology, nature, expected course, treatment and curability. Explanatory models of illness vary across cultures and it is common for patients to ascribe to more than one model, which informs the nature of their health-seeking behaviour. That is, rather than

the symptoms themselves, it is the varying interpretation of their meaning and what they imply for a functioning social life that motivates individuals to seek care. Thus, by neglecting patients' explanatory models of their illness, patients' efforts to cope with the symptoms or adapt to treatment recommendations may be misconstrued by health care providers as ignorance, lack of concern, vacillation or non-adherence (Rubel & Garro, 1992).

The timely diagnosis and treatment of tuberculosis is an important public health concern in both developed and developing nations (Poss, 1998). Our health care practices, patients adherence to treatment and the organisational behaviour of health care workers have been considered as the main issues concerning tuberculosis control influenced by culture (Jaramillo, 1998). Studies have shown that the culture-based explanation patients give to their illness influence the paths followed and the barriers experienced by patients in seeking health care (Camolet, Rakolomalala and Rajaonariora, 1998; Jaramillo, 1998; Poss, 1998).

Implicit cultural models of illness are the basis for the reasoning processes which link plausible explanations with potential solutions to health care problems (White, 1982). The connection of cultural explanations with preferred health-seeking strategies suggests that health care decisions be predicated on underlying cultural 'theories' of illness. There are however, a great number of factors (cultural, psychological and social), which contribute to the underutilization of health care services, including social stigma, modes of expression and communication of illness and socio-economic variables. Kleinman (1977) has illustrated how Western biomedical models of illness have shaped the way illness is defined. He explains that Western disciplines " must learn from anthropology that culture does considerably more than shape illness as an experience; it shapes the very way we conceive of illness".

Therefore culture can be seen as shaping disease in the first instance by shaping ones explanation for the disease. The past decade has witnessed an increased convergence of anthropological and cross-cultural research into the way in which culture influences the

perception, classification, process of identification, explanation, experience of symptoms, course, decisions regarding and treatment of sickness (Kleinman, 1976; Fabrega, 1974). The process of explaining causes, origination and course, as well as symptoms and treatment are said to be mediated by the patient's utilisation of a popular cultural system of articulating and explaining illness (Kleinman, 1977).

Kleinman has found it increasingly important to distinguish two interrelated aspects of sickness, namely *disease* and *illness*. According to Kleinman (1977):

“Disease can be thought of as a malfunctioning or maladaptation of biological or psychological processes. Illness is the personal, inter-personal and cultural reaction to disease. Illness is by definition a cultural construct “. (pp. 9).

Therefore the culture-centred approach (Pedersen, 1999) provides a useful framework for taking into account a patient's explanatory model of illness as well as the health care providers understanding of illness. This explanatory model of illness makes reference to how one interprets illness episodes in terms of cause, description of precipitating events and initial symptoms, description of expected course and understanding of available treatment modalities (Hahn, 1995). Kleinman (1980) has stressed that patients are capable of holding more than one explanatory model of illness. As a result, it is not uncommon for patients to use alternative forms of care, for example, indigenous healing, in conjunction with western modes of healing. Helman (1994) has explained that an understanding of the patient's explanatory model of illness and taking it into consideration in treatment planning improves the effectiveness of treatment and treatment adherence.

However some researchers have argued that structural rather than cultural factors may be the main explanation for the questionable behaviour of health care workers and patients suffering from tuberculosis in less developed countries. Farmer (1997), for instance suggests that when taking into account the role of cultural explanations of illness,

ignoring the influence of structural dynamics sets the stage for incorrectly attributing focus strictly to cultural variables when addressing illness and disease.

Health care providers often have understandings about TB that is different from those of the people they treat. The different interpretations may result in misunderstandings or conflict between provider and patient and lead to inadequate treatment of illness. Farmer (1997) argues that structural barriers, inadequate access to care, racism and environmental factors have played a primary role in the TB epidemic that disproportionately affects the poor. Poss (1998) uses Kleinman's explanation of explanatory models of illness to explain how patients make sense of their illness within a cultural context. The study of explanatory models focuses on the patient's explanations of the aetiology, symptoms, severity, social significance and treatment of the illness.

Poss's (1998) study investigated Mexican migrant farm-workers explanatory models about TB in order to understand how they view this disease and to improve existing tuberculosis screening and treatment programs targeted at them. The ascribed aetiology of tuberculosis varies by culture. She found that the explanatory models of the migrant farm-workers in her study bear similarities to the medical model of tuberculosis. Many subjects in the study articulated an infectious aetiology for tuberculosis, variously described as 'little animal', a germ, a microbe, bacteria or viruses and described methods of transmission such as breathing or coughing. They also believed that anaemia, smoking and pesticides were risk factors in the development of TB. Farm-workers in her study uniformly believed that TB is a serious illness and the majority felt that they personally could contract it. Many knew someone who has TB or who has died from it. Some expressed the feeling that there was nothing they could do to prevent getting TB, whilst others listed a variety of preventative measures, several of which may have roots in hot-cold aetiologies of the disease, including avoiding air conditioning, getting chilled, and abrupt changes in climate (Poss, 1998).

Symptoms of TB that were identified as similar to the medical model included cough, fatigue, fever, night sweats and weight loss. Most recognised the positive role of

medication in the treatment and reported using it when seeking treatment from doctors, once diagnosed with TB. The majority of her respondents did not know how long medical therapy lasted, and several believed that there was no treatment for advanced stages of TB. In terms of the social implications of TB, some respondents believed that there were severe social repercussions from being diagnosed with TB and viewed it as being as bad as HIV/AIDS (Poss, 1998). Since there were varying opinions about the stigma conferred by the diagnosis of TB, Poss (1998) says that health care providers should be sensitive to the possibility that patients may refuse screening and treatment for TB because of fear of the social consequences.

In Honduras, Mata (1985, cited in Poss, 1998), found that 'abberant' behaviour such as exposing oneself to the early morning dew, the night air, or bathing after physical effort were considered causes of the illness. Methods of transmission cited by Honduran respondents included talking or sharing eating utensils with an infected person. Ndeti's (1972) Kenyan study found that patients reported that TB could be caused by desires of their ancestors, excessive physical exertion, and witchcraft. Similarly, Barnhoorn and Adriaanse's (1992) study of adherence with TB therapy among patients in India showed that non-complaint patients were more likely to believe that witchcraft or past sins were the cause of TB than patients who adhered to therapy. Leifooghe et al's (1995) study in Pakistan, found that most participants believed that TB was an infectious disease spread by sputum, while others thought it was caused by previous injury to the lungs, taking cold baths or prior sins.

Nichters (1994) study revealed that participants believed that TB could result from germs, fatigue, poverty, exposure to cold and wind, or any factor that seriously weakened or shocked the body. Methods of transmission cited included the notion that TB was spread 'through the air' and inherited through the blood of the father or mother. In South Africa, factors named as causes of TB included cold weather, smoking and malnutrition (Metcalf et al, 1990), with 85% of participants believing that TB was infectious and could be spread through the air. Over 90% of these respondents listed cough, weight loss and night

sweats as symptoms, but a smaller number thought that blindness, rash and hair-loss were all indicative of TB.

Most Honduran respondents believed that TB could be cured with medication, but feared discovery of their condition by neighbours if they submitted to the lengthy treatment regimen (Poss, 1998). Home remedies for suspected TB included skunk oil, boa constrictor oil, shark oil and mangoes. Ndeti (1972) found that TB patients supplemented the hospital drug treatment with traditional herbs or used herbs instead of medication. In addition many believed in the ability of witchdoctors to cure TB. Studies in many cultures suggest that TB is a socially stigmatised illness and this may result in infected persons concealing their diagnosis or attributing their symptoms to less stigmatised pulmonary problems like pneumonia or asthma (Poss, 1998). Research in the Philippines also revealed that persons affected with TB are stigmatised, although perhaps to a lesser extent than in other developing countries (Poss, 1998). Respondents in Nichters (1994) study reported that TB could not reduce chances of finding a marriage partner or a job and those family members were not isolated by their kin.

Westaway and Wolmarans (1992) mentioned that in response to anti-tuberculosis therapy, delayed recovery has been found to be related to depression, easily hurt feelings and feelings of helplessness. They found that in South Africa there is an urgent need for a measure of depression which is reliable, valid, easily administered and simple to score to aid in managing psychological disorders that co-exist with physical illnesses such as TB, which should lead to better patient management. The stress of medical illness and hospitalisation can result in some degree of depression. With reliable measures of depressive phenomenon amongst populations with lower literacy rates, such information can provide a focus for health care workers, strengthen patient-system interaction, and lead to more effective patient management (Westaway and Wolmarans, 1992).

According to Steen and Mazonde (1999), although Botswana's national TB programme is generally regarded as well functioning, TB is the most common cause of death in the country. There is an established relationship between TB and HIV infection, with HIV

predisposing TB. In an attempt to control TB, emphasis on better drugs and more sophisticated diagnostic tools is not sufficient. Social and cultural factors also contribute heavily towards the outcome of TB control. Steen and Mazonde (1999) report that a better understanding of patients motivations and actions is essential to understanding a disease like TB and its treatment, since such insights could possibly help to reduce delays in diagnosis, improve treatment adherence and inform health education interventions. A study by Schroder (1985), cited in Steen and Mazonde (1999), revealed that 20% of TB patients had visited a traditional healer or faith healer as the first step in their treatment, 37% used alternative treatment after allopathic TB treatment had been started or planned to undergo such treatment. Similarly Haram's (1991) study found that while patients were receiving clinic treatment, they simultaneously sought traditional treatment.

In terms of beliefs and practices with regard to TB in Botswana, Steen and Mazonde (1999) report that traditional medicine in Botswana classifies disorders according to perceived causes. Illness may be caused by GOD, by spirits of ancestors by witchcraft or by pollution. Pollution is usually believed to originate in the female body and is caused by the breaking of taboos, advertently or otherwise (Steen and Mazonde, 1999). Women may also transmit pollution to their unborn children through blood or to babies through breast-feeding. The idea of transmission of pollution through blood, semen or breast milk bears a certain resemblance to modern concepts of transmission of infectious diseases (Haram, 1991). In the case of pollution, breaking a taboo is seen as the 'real' cause of the disease, whereas abnormalities of the blood cause the actual symptoms.

Apparent differences in the understanding of causes of TB may account for the way in which healers ascribe meaning to an illness. While a modern doctor may describe how the disease has been transmitted, a traditional healer would ascribe 'meaning' to the disease, which he/she may relate to bewitchment by a neighbour, therefore specifying a cause of the illness (Steen and Mazonde, 1999). With the introduction of Western medicine in Botswana from the 1920's onwards, people tended to make distinctions between "European diseases" which are best treated by a Western doctor and "Tswana diseases" which are best treated by a traditional practitioner. Even with a "Tswana

disease”, treatment by Western doctors may relieve symptoms, but treatment by a traditional doctor is then always considered necessary for treating the real cause of the disease and bringing about a lasting cure (Steen and Mazonde, 1999). Traditional healers in Botswana engage in various forms of treatment, some of which involve sucking out blood either with their own lips or through a horn (after an incision is made) and application of herbal mixtures (Steen and Mazonde, 1999). Other avenues of healing include faith healing where patients are treated by praying and the use of ‘holy water’, often as enemas.

Steen and Mazonde (1999) report that the first cases of TB in Botswana occurred in the 1930’s and were related to migration of males to South African mines. The classification of TB as a “European disease TB” or a “Tswana disease TB” was dependant on the circumstance surrounding the patient and the healer. TB may also be given names depending on the assumed cause, like ‘ya maini’ (TB from the mines), TB ‘ya boloi’ (witchcraft) or TB ‘ya sejeso’ (witchcraft poison). Another form of TB is said to occur from a child being delivered in a wrong position, thereby polluting the mother’s womb, and a man who has sexual intercourse with her may get the condition called ‘thibamo’. Unless both child and parents receive traditional treatment, they can potentially develop a serious cough, and the husband is susceptible to the cough if he sleeps with his wife three months after delivery (Steen and Mazonde, 1999).

These findings provide important insights with regard to the dual utilisation of modern and traditional health sectors and of TB patient’s perceptions; in this regard, patient’s perceptions of disease as reported in the literature show that few have a clear understanding of TB from a biomedical point of view. Very few perceive germs as the cause of their illness. Most of the causes offered by patients in this study are known risk factors for TB, such as mine work. None of the sample of patients in this study said they suffered from ‘thibamo’, although it had been given as an explanation by traditional or faith healers. Half of the patients did not propose any cause of their disease, and this revealed that they did not have clear ideas about germ theories as risk factors. The study has outlined the necessity for specific health education programmes, which should take

more account of the patient's self-perceptions. The authors argue that while TB does not currently carry a social stigma in Botswana to the extent that it does in other developing countries, they anticipate that social stigma will inevitably increase as the population grows more aware of the link between HIV and TB.

With regard to social support via family members, traditional treatment in Botswana is always group orientated (Steen and Mazonde, 1999). In this regard the involvement of the family in treatment, especially if adherence problems are anticipated, is highly recommended. They also report that modern health care facilities had been visited as the first step of action by 95% of patients and they attribute this to highly accessible and subsidised health facilities, a high awareness that prolonged coughing may be due to pulmonary tuberculosis, and the benefit envisaged from modern treatment with its rapid conversion of symptoms.

But there is an increasing tendency to use modern medicine as a 'quick fix' solution, whereas traditional medicine is utilised for providing ultimate answers to questions about the meaning of misfortune, and for dealing with the 'real' causes of the illness (Steen and Mazonde, 1999). In terms of preference for traditional health care, this study found higher utilisation in those with lower education levels, and higher utilisation for men who had not worked in mines, despite their average level of education being significantly higher than that of men who had worked in mines. Interestingly, slightly more than half the patients who had attended traditional or faith healers had been advised to go to the clinic with this being attributed to a network of communication between traditional or faith healers and modern health workers.

Hunte and Saltana (1992) studied factors relating to treatment choices and the cultural meaning of medications in Pakistan. They found that the villagers in their study actively search for powerful substances to cure their illnesses, often taking several types of medication in quick succession. Many patients acknowledged the various roles of health practitioners, indigenous and cosmopolitan, but it is the substances that practitioners prescribe that most often take priority in informing the choices made by villagers (Hunte

and Saltana, 1992). Health-seeking behaviour in Pakistan usually begins within the household, where illness is initially perceived and defined, and treatment is initiated by family members themselves. This is a popular type of health care which, involving no formal health practitioners, either indigenous or Cosmopolitan, is home-based and is most frequently administered by village housewives. Often termed “ self-care”, home-based treatment is one of the least studied forms of health-seeking behaviour (Hunte and Saltana, 1992). What has been alluded to in this study is that home-based preparations are largely herbal in nature, and are part of an intricate pharmacopoeia (Hunte and Saltana, 1992). The knowledge of specific herbal recipes for common illnesses are passed down from generation to generation, and is part of a non-literate tradition in which women are the primary ‘carriers of knowledge’ (Hunte and Saltana, 1992).

A great number of cases of self-care reviewed in this study entail home-based herbal preparations, with only a small proportion of home-based care involving ‘modern’ over-the-counter drugs. Illnesses that were reviewed included body pains, general weakness, gynaecological problems, respiratory problems and digestive problems amongst women and children. Examination of villager’s behaviours clearly indicated that they usually seek cosmopolitan health practitioner’s prescriptions rather than purchase the medication themselves through lay referral systems (Hunte and Saltana, 1992). Individual illness episodes often entail successive cosmopolitan treatments, which unfortunately result in the mixing of powerful medications. In addition, meaningful communication between doctor patient, doctor/pharmacist, and pharmacist/patient is often weak due to status differences, along with patient overload and other factors (Hunte and Saltana, 1992). Due to poor communication, cosmopolitan medicinal courses of treatment are often not completed, illness persists, and additional modern medicines are obtained from other practitioners, hence resulting in the over-prescription of antibiotics and other drugs (Hunte and Saltana, 1992).

2.9 Health-seeking Behaviour and TB

In examining patterns of health-seeking behaviour, various individual treatments have been sought out, ranging from home/self treatment, treatment prepared by indigenous healers and cosmopolitan medicine. Results indicated in most cases that a single or combinations of treatment approaches were used, depending on which produced the most desired results (Hunte and Saltana, 1992). This eclectic approach to health care is similar to situations reported from a variety of settings throughout the world. Janzen, cited in Hunte and Saltana (1992), has characterised this phenomenon as a 'juggling' of alternatives, while others have termed it a process of 'trial and error' in health-seeking behaviour. When the authors examined the sequential nature of their cases, they found that health care was frequently initiated with home/self treatment followed by cosmopolitan treatment with indigenous practitioners being visited for treatment at almost any time during the illness episode, especially when supernatural aetiology was suspected (Hunte and Saltana, 1992). Regardless of sex or age, however, villagers expected quick results from health treatments and if not achieved, they quickly switched to another treatment (Hunte and Saltana, 1992).

Diet was perceived as a major factor in any health treatment amongst villagers whereby food substances are classified according to their humoral qualities, as are many illnesses, with the opposite humoral quality being consumed in an attempt to restore balance (Hunte and Saltana, 1992). With regard to switching from one doctor to another in the hope of a rapid cure, it is often very difficult for non-literate individuals to remember exactly how to take their medications, since doctors provide patients with quickly written prescriptions, and leave it to the pharmacists to provide verbal instructions as to the specific medication (Hunte and Saltana, 1992).

Moloantoa (1982) found that symptoms that motivated patients in Ga-Rankuwa Hospital (South Africa) to seek medical care with regards to tuberculosis were: persistent cough (90%), chest pain and vomiting (90%), loss of weight (90%), coughing and vomiting (80%), aching joints (69%), and abdominal pains and vomiting (58%). In his study of

traditional attitudes towards TB, he found that while all of his respondents had very limited medical knowledge of TB, and were very sceptical of medical treatments, more men than women were sceptical about medical treatment, and complained more about female nursing staff and their attitudes. Respondents conception of the causes of TB were revealed as: excessive drinking of beverages containing yeast (e.g. home made beer) (80%), heavy smoking, which fills the chest with smoke (80%), smoking dagga (50%), inhalation of benzene, with the fume burning up the lungs (20%), not eating enough food (60%), adultery/infidelity of one spouse causing 'thibamo' (5%), witchcraft (60%), no idea what causes TB (20%) and genetic (25%), just to name a few (Moloantoa, 1982)

Respondents ideas on the prevention and cure of TB were as follows: separate eating utensils (20%), not spitting all over the place (20%), quitting smoking and drinking less alcohol (75%), eating good food (60%), visit clinic or hospital (60%), home treatment (75%) and visiting a traditional healer to prevent and cure TB (65%) (Moloantoa, 1982). The reasons given for disliking hospital treatment were: hospital staff very harsh and in too much of a hurry (63%), hospital too rigid one gets more infected in a hospital (51%), concerns that everybody sees them getting treatment and they gossip, especially in clinics (67%) (Moloantoa, 1982).

2.10 Understanding Health Behaviour: Models of Illness and Health

From the literature reviewed, it is patently clear that an understanding of MDR-TB patient's explanatory model(s) of illness would be critical in understanding their health seeking behaviour. In this regard, a number of socio-psychological theories have been developed for explaining and understanding patients' frame of reference for seeking health care, not least of which is the Health Locus of Control Theory (Wallston *et al*, 1978) and the Health Belief Model (HBM) (Becker, 1974).

Health Locus of Control Theory (Wallston *et al*, 1978) suggests that those individuals who regard their health as largely being within their own control are more likely to engage in health maintaining behaviours (such as adherence to treatment), while those

who view their health as relatively independent of their behaviour and largely within the control of others, are more likely to engage in health damaging behaviours (such as treatment delay). It is also important to note that health locus of control beliefs will only influence the health-related behaviours of those patients who place a high value on their health (Bennet and Murphy, 1997).

The Health Belief Model was one of the first models that adapted and applied theory from the behavioural sciences to health problems, and it remains one of the most widely recognised conceptual frameworks of health behaviour (Glanz, 1999). The Health Belief Model was founded on the work of Kurt Lewin, who suggested that the life space in which individuals live is comprised of regions, some having negative valence (that which one would seek to avoid), some a positive valence (that which one would seek to approach), and a neutral valence (that which one would neither seek to approach nor avoid) (Gorin and Arnold, 1998).

The model was first introduced in the 1950's by psychologists working in the US Public Health Service (Glanz, 1999). Their focus was on increasing the use of then available preventative services, such as chest X-rays for TB screening and immunisation for infectious diseases. Originally the Health Belief Model was developed to help explain health related behaviours and focussed on why certain behaviours predominate. Later on it was adapted to provide a useful framework for designing behaviour change strategies.

Basically this model suggests that before an individual takes action, she must decide that her behaviour creates a serious problem in that she is personally susceptible to its health harm, and that moderating or ceasing the behaviour would be beneficial (Gorin and Arnold, 1998). The individual's knowledge of a disease and its potential outcome provides a useful basis to gauge one's perceived susceptibility and perceived severity of harm. This model specifically addresses the "cues to action" that motivates the decision-making process and self-efficacy about executing the target behaviour (Gorin and Arnold, 1998). The concept of self-efficacy, which was recently added by Rosenstock and others in 1988, deals with one's confidence in the ability to successfully perform an action.

Therefore, the Health Belief Model (Becker, 1974) focuses on two related appraisal processes: the threat of illness and the behavioural response to that threat. These appraisal processes involve a consideration of both the individual's perceived susceptibility to an illness and its anticipated severity. Behavioural evaluation involves a consideration of the costs and benefits of engaging in behaviours likely to reduce the threat of disease i.e. the benefits that patients perceive could be obtained from seeking assistance and the perceived cost (direct and indirect) of doing so.

The HBM has been used both to explain change and maintenance of health behaviour and as a guiding framework for health behaviour interventions. Later, the model was extended to apply to peoples responses to symptoms and to their behaviour in response to diagnosed illness, particularly their adherence with medical regimens (Glanz et al, 1997). The HBM is a value expectancy theory. When value expectancy concepts were gradually reformulated in the context of health related behaviour, the translations were the desire to avoid illness or to get well (value) and belief that specific health action available to a person would prevent illness (expectancy) (Glanz et al, 1997).

In his pioneering study, Hochbaum (1958), attempted to assess individuals 'readiness' to obtain X-rays, which included assessing their beliefs in the personal benefits of early detection. In his study, perceived susceptibility to TB comprised of two elements. Firstly, the respondent's belief about whether contracting TB was a realistic possibility for them personally and secondly, the extent to which they accepted the fact that a person can have TB in the absence of all other symptoms. To measure perceived personal benefits, two elements were included, which dealt with whether respondents believed that X-rays could detect TB prior to the appearance of symptoms and whether they believed that early detection and treatment would improve prognosis. In short, the results of his study revealed that four out of five people who exhibited both beliefs (susceptibility and benefits) took the predicted action while four out of five people who accepted neither belief had not taken the action.

Glanz et al (1997), suggest that the HBM addresses issues concerning individual control over ill health by accounting for whether patients regard themselves as susceptible to the condition, if they believe it to have potentially serious consequences, if they believe that a course of action available to them would be beneficial in reducing either their susceptibility to or the severity of the condition, and if they believe that the anticipated barriers to (or costs of) taking action are outweighed by its benefits. The dimension of perceived susceptibility attempts to measure an individuals subjective perception of her own risk of contracting a health condition by addressing the individuals acceptance of the diagnosis, personal estimates of re-susceptibility and susceptibility to illness in general. Perceived severity addresses feelings concerning the seriousness of contracting an illness or leaving it untreated as well as evaluation of both medical and social consequences.

Perceived benefits include addressing forces that lead to certain behaviours, whereby a particular course of action is dependant on beliefs regarding the effectiveness of the various actions in reducing the disease threat as well as factors such as non-health related benefits (e.g. quitting smoking to save money). Therefore an individual exhibiting an optimal level of beliefs in both severity and susceptibility would not be expected to accept any recommended health action unless that action were perceived as potentially efficacious. Perceived barriers deal with the potentially negative aspects of a particular health action, which may act as impediments to undertaking the recommended behaviour. The result is a non-conscious cost benefit analysis, wherein the individual weighs the actions expected effectiveness against perceptions that it may be expensive, dangerous (having negative side effects or iatrogenic outcomes), or unpleasant (painful, difficult, or upsetting, inconvenient, time consuming etc).

Fincham and Wertheimer (1985) have found that despite the vast number of studies examining adherence, the prediction of patient non-adherence or even the identification of non-compliant patients has proven to be an elusive goal. Various theoretical models of adherence and health behaviour have been formulated, defined and refined over the past three decades (Fincham and Wertheimer, 1985). Fincham and Wertheimer's (1985) review suggests that the Health Belief Model (HBM) is unique among these theoretical

models in that it incorporates many aspects of other models, as well as having the capacity to predict health, illness and sick role behaviours. The eclectic nature of the research applications of the HBM offers proof that the HBM is a functional prediction measurement tool in many settings and for many types of health related behaviour. These authors argue that the model provides evidence of utility in predicting health, illness and sick role behaviours. These behaviours have ranged from participation in screening and immunisation programmes to adherence with both short and long term medication therapy. Therefore the purpose of their study was to test the ability of the HBM to predict one segment of the adherence continuum i.e. initial drug therapy defaulting, for a range of illnesses. Initial drug therapy defaulting was defined as patients dropping out of a treatment regimen before the regimen has ever started. This aspect of medication non-adherence has been termed “total non-compliance” (Fincham and Wertheimer, 1985).

The results of their study give support for the predictive ability for the HBM as a prediction instrument for initial drug therapy defaulting. Another implication of the study was that prediction of initial drug therapy defaulting could be accomplished, with a fair amount of accuracy, through an instrument that operationalised HBM variables. The researchers recommended that future research should address the clinical significance of initial defaulting on patient’s well-being. They also found that patients who defaulted believed less in the benefits of medical care but yet sought out care from physicians. This ambivalence combined with the acknowledgement that they did not always receive information concerning how to take newly prescribed drugs were the most powerful predictors of the initial drug therapy defaulting. The authors conclude that this combination of negative health beliefs, a lack of understanding of how to take a newly prescribed drug, and the negative impacts of situational and socio-economic factors should be examined in other settings to determine if other potential problems in the delivery of health care are related to this combination of factors (Fincham and Wertheimer, 1985).

Douglas Reid and Christensen (1988) argue that while certain elements of the HBM have been supported empirically, the model in its entirety has not. The model has been

criticised for being incomplete, in that the relationship among its predictive elements has not been articulated well enough. The HBM framework has not routinely tested other important determinants, for example the intention to comply. Even though present modifications of the model have included intent to comply, as a health motivation variable, Douglas Reid and Christensen (1988) report that it has been examined in only one other empirical study. They go on to say that the HBM is recognised as an adaptation of a value-expectancy model, yet the concepts of expected value of a particular outcome and the likelihood of its occurrence have not been theoretically developed or tested. They suggest that the lack of standardisation among measurements of psychosocial variables be among the reasons for the inconsistency found in various HBM study findings.

Douglas Reid and Christensen (1988) postulate that the Theory of Reasoned Action (TRA) addresses some of the shortcomings of the HBM. This theory focuses on theoretical constructs concerned with individual motivational factors as determinants of the likelihood of performing a specific behaviour (Glanz, Lewis and Rimer, 1997). The Theory of Reasoned Action, which was first introduced in 1967, is concerned with the relations between beliefs (behavioural and normative), attitudes, intentions and behaviour (Glanz et al, 1997). Fishbein (1967) developed the TRA through an effort to understand the relationship between attitudes and behaviour. Fishbein found that attitudes towards behaviour are a much better predictor of that behaviour than attitude toward the target at which the behaviour is directed (Fishbein and Ajzen, 1975). Operationalization of the TRA constructs was developed from a long history of attitude measurement theory, rooted in the concept that an attitude is determined by expectations or beliefs concerning the attributes of the object or action and by evaluation of those attributes (Glanz et al, 1997).

Bennet and Murphy (1997) contend that the TRA considers that the primary determinant of behaviour is an intention to engage in that behaviour. They argue that the assumption of the Theory of Reasoned Action is that the individual has the resources, skill, or opportunities to engage in desired action. This is frequently not the case. Glanz et al (1997) asserts that the most important determinant of behaviour is a person's behavioural

intention. The direct determinants of an individual's behavioural intention are his attitudes towards performing the behaviour and his subjective norm associated with the behaviour. Thus, a person who holds strong beliefs that positively valued outcomes will result from a behaviour will have a positive attitude toward that behaviour. Conversely, a person who holds strong beliefs that negatively valued outcomes will result from a behaviour will have a negative attitude toward that behaviour (Glanz et al, 1997). The TRA assumes a causal chain: behavioural beliefs and normative beliefs are linked to behavioural intention and behaviour via attitude and subjective norm, and evaluations of each outcome are measured on bipolar "good"- "bad" scales (Glanz, 1997).

Bennet and Murphy (1997) argue that the model fails to address factors such as contextual variables, which may also impact on decision-making. They cite an example of how intentions may not translate into action with Abrahams (1995) study of condom use by adolescents and young adults. They reported that among these groups, the correlation between intentions to use condoms during intercourse and their actual use was significant for men but not for women, reflecting findings that young women are frequently disempowered in sexual negotiation, so that their behavioural intentions are not translated into action. Glanz et al (1997) argue that the success of the theory in explaining actual behaviour is dependent upon the degree to which behaviour is under volitional control (i.e., occurring in situations where individuals can exercise a large degree of control over the behaviour). However it is not clear that the TRA components are sufficient for predicting behaviour in which volitional control is reduced, for example, a person who has a high motivation to perform a behaviour, may not actually perform that behaviour due to intervening environmental conditions (Glanz et al, 1997).

Douglas Reid and Christensen (1988) argue that the TRA establishes a link between behavioural intention and behaviour, and specifies the inter-relationship and causal processes among the variables. Secondly, it addresses value-expectancy concepts through the salient belief strength and outcome evaluation variable. Thirdly, it recognises the importance of social influences on the individual, namely perceptions of others, subjective norms, and the individual's degree of motivation to comply with others. Their

study of the drug-taking behaviour of hypertension patients indicated that patients took their medication faithfully until the symptoms subsided. Only then did they forget to take their medication. Amongst non-adherent patients, this would argue for the dynamic decision-making model, which suggests that the patients perception of the importance of adherence changes over time and that they consciously or unconsciously reassess their decision to comply because of their exposure to new information e.g. the symptoms went away (Douglas Reid and Christensen, 1988). They go on to say that after reassessment, if prospects for recovery appear good, further drug taking may be considered less necessary, unnecessary, expensive or inconvenient.

Prior behaviour has been shown to be one of the best predictors of future behaviour, along with the situational variables, which modify patient's intentions towards further drug taking over time. Maintaining patients perceptions of the likelihood of success and the value of treatment over time was seen as an important key in improving patient's adherence behaviour (Douglas Reid and Christensen, 1988). Perception of barriers was the second highest predictor of adherence. There is thus a need for health care workers to reduce the perception that medication taking is difficult or inconvenient. This problem can be addressed by selecting more acceptable dosage forms, including long acting drugs, and/or reducing dosage intervals (Douglas Reid and Christensen. 1988)

Jones, Jones and Katz (1991) have found that past reports and more recent estimates have indicated that the rate of non-adherence (i.e. missed appointments) ranges from 15 to 60 % in acute and chronic patients receiving a Health Belief Model intervention. Research on appointment keeping has attempted to isolate demographic and attitudinal concomitants of adherence and there have also been attempts to increase adherence via letters or telephone prompts overt commitments or incentive and reinforces (Jones, Jones and Katz, 1991). The fact that adherence decreases with increased complexity of treatment recommended is well documented and, in addition, adherence decreases when the regimen is of longer duration (Jones, Jones and Katz, 1991). There are however, several variables associated with chronic illnesses that have been associated with increased adherence, e.g. demographic variables such as older age, knowledge of the

illness and increased likelihood of a positive relationship with a previous health care provider (Jones, Jones and Katz, 1991).

Looking at illness experiences, these authors found that chronic patients were more likely to report previous self-treatment or treatment by a health care provider, and to perceive that the illness episode was potentially serious. They also found that chronic problems exert a cumulative effect on the patient's behaviour (i.e. above and beyond the duration of the current episode), as well as the recurrence of the problem (or perceived susceptibility on the part of the patient), and is an important influence on adherence behaviour (Jones, Jones and Katz, 1991).

Norman (1995) reports that patient's response to the provision of health checks has been mixed, with earlier studies reporting disappointing attendance rates. He says that, "if attendance rates are to be improved, then it is imperative that the factors associated with the uptake of health checks are identified" (pg. 461). He describes one model of the decision-making process, which has attracted considerable attention in this area as the Health Belief Model. Norman (1995) alludes to the fact that there have been relatively few studies which have applied the HBM to predict attendance at health checks in general practice. Norman and Fitter (1991) found that attendance at health checks was predicted by perceptions of severity and worries about attending. He says that the way in which the service is offered to patients may redefine behaviour so that different sets of beliefs are seen to be important in determining behaviour.

Norman's (1995) analysis of the predictors of patients intentions to attend a health check revealed that those patients who held a strong intention to attend were more likely to believe in the efficacy and benefits of health checks and less likely to be worried about attending. He suggests that in order to increase patients interest in attending a health check, invitation letters need to emphasise the benefits of attending and to address the potential barriers to attendance.

Summary

In this chapter I have provided an overview of the literature reviewed on TB incidence, drug resistance, treatment and control, and cultural understandings and explanatory models of illness. Furthermore this chapter has provided a review of the literature on patients health seeking behaviour, as well as providing insights into various models of health behaviour.

From the literature reviewed, it is clear that TB is a serious world-wide health problem. Of concern is the spread of MDR-TB, since this disease has more lethal implications with regards to treatment and control. A complicating factor in treatment is the high co-morbidity (45%) between HIV and TB of which Kwa-Zulu Natal has the highest prevalence (Onyebujoh, 1999). This in effect influences the outcome of many cases with regards to success and failure of TB treatment, since HIV further compromises the individual's ability to cope or manage TB/MDR-TB.

Factors related to the persistence of TB and the progression of TB to MDR-TB were multifaceted and included the following: inadequate therapeutic practice, lack of funding for adequate treatment, financial costs incurred by patients undergoing treatment, stress related to having the disease, malnutrition, alcoholism, age, other medical conditions, poor in-patient care and facilities, social circumstances such as overcrowding, poverty and poor hygiene control, cultural understandings of illness, and lack of knowledge of the disease.

With regard to treatment strategies, DOT has had both success and failure with regards to the treatment of TB. Its success has been attributable to stricter control and regulations in its implementation, and its failures were related to health care professionals failing to address patient constraints such as time, financial costs as well as social circumstances and cultural influences that affect patients decision making processes when undergoing such treatment. Factors shown to influence patient non-adherence with TB treatment included self-medication, misuse of TB drugs, social circumstances (e.g. overcrowding,

poverty, homelessness, isolation, discrimination, loss of income and employment etc.) and poor family support. Many believe that what complicates matters with patients undergoing treatment, are the direct and indirect social costs accrued from seeking treatment. However the literature also suggests that improving the patients understanding of the disease helps counter some of the social consequences of the disease and thus improves patient adherence to treatment (Christensen-Szlanski and Northcroft, 1985; Jaramillo, 1998; Rubel and Garro, 1992; Sumartojo, 1993 and Westaway and Wolamarans, 1994)

Another major barrier to positive health outcomes, including treatment adherence, is ineffective communication between patients and health care providers. It is important to note that the perspective of the health care professional has dominated treatment adherence with little regard for the patient's decision-making process (Morris and Schultz, 1992). Patient's perceptions as well as their personal and social circumstances have been shown to be crucial in their health seeking behaviour and decision-making process (Stewart, Bhagwanjee, Mbakaza and Binase, 2000). The meaning that patients ascribe in interpreting the disease plays a crucial role in determining whether patients seek professional help or whether they remain in treatment programmes. Such meanings that patients ascribe to illness stems from the explanatory models individuals hold which vary across culture. It is these varying interpretations of meaning of illness and what they imply for a functioning social life that motivates individuals to seek care (Rubel and Garro, 1992).

The connection of cultural explanations of illness, with preferred health seeking strategies suggests the importance of understanding the cultural context of illness when making health care decisions. The culture centred approach addresses such an understanding of patient's perceptions and behaviour with regard to identifying and treating illness. This model provides a useful framework, since it deals with how one interprets illness episodes in terms of cause, description of precipitating events and initial symptoms, description of expected course and understanding of available treatment modalities (Hahn, 1995). However, Farmer (1997), contends that when taking into account the role

of cultural explanations of illness, one needs to address the influence of structural dynamics (e.g. patient provider care and treatment strategies, adequacy of access to care and environmental factors) when addressing illness and disease.

In explaining and understanding patients frame of reference for seeking health care several socio-psychological theories were reviewed, such as the Health Locus of Control Theory (Wallston et al, 1978), Health Belief Model (Becker, 1974) and the Theory of Reasoned Action (Fishbein, 1967). A discussion of the literature suggests that despite its shortcomings the Health Belief Model provides a useful framework for addressing issues concerning individuals control over ill health, by taking into account the process of appraisal involved in considering the threat of an illness and the behavioural response to that threat. This model provides useful insight into the understanding of individual's health seeking behaviour and patient's decision-making processes (Douglas Reid and Christensen, 1988; Fincham and Wertheimer, 1985; Glanz et al, 1997; Jones, Jones and Katz, 1991 and Norman, 1995).

Chapter Three

Research Methodology

3.1 Introduction

I begin this chapter by providing an overview of the aim and the research methodology used in this study. With regard to the latter, I provide a rationale for the qualitative methods used. Thereafter, an overview of the research design, data collection techniques, method of analysis and ethical considerations for the study is provided.

3.2 Aim

This study aims to provide a qualitative understanding of the health-seeking behaviour of adult in-patients with multidrug-resistant tuberculosis in a public health sector setting

3.3 Research Design

3.3.1 Qualitative research

A qualitative methodological approach was used in this study, as it will allow for a greater in-depth investigation and understanding of the health-seeking behaviour of MDR-TB patients than could be generated by quantitative research methods (Krueger, 1994; Liefoghe *et al*, 1995). This method of deconstruction associated with post-structuralism looks for meanings that are taken for granted, hidden and suppressed (Derrida, 1978; Parker, 1988, 1989; Simpson, 1989 cited in Richardson, 1996). Qualitative research lays down its claim to acceptance by arguing for the importance of understanding the meaning of experience, action and events as these are interpreted through the eyes of participants, researchers and sub-cultures, and for a sensitivity to the

complexities of behaviour and meaning in the contexts where they typically or 'naturally' occur (Richardson, 1996).

Qualitative methods are privileged within the qualitative paradigm, because they are thought to address a number of reservations concerning the uncritical use of quantification, in particular, the problem of inappropriately fixing meanings where these are variable and renegotiable in relation to their contexts of use. According to Richardson (1996), from an epistemological standpoint, the gathering, analysis and interpretation of data should always be carried out within a broader understanding of what constitutes legitimate inquiry and warrantable knowledge.

Qualitative methods are inherently inductive; they seek to discover rather than test explanatory theories, they are naturalistic, favouring in vivo observation and interviewing of respondents over the decontextualizing approach of traditional scientific enquiry (Padget, 1998). As such they imply a degree of 'closeness' and an 'absence of controlled conditions' that stand in contrast to the distance and control of scientific studies. According to Manicas and Secord (1982), qualitative research is predicated on an, 'open systems' assumption where the observational contexts (and the observer) are part of the study itself. In contrast, quantitative research favours a 'closed system' approach where every effort is made to neutralise the effects of the observational context (including the observer) (Padget, 1998).

Qualitative studies seek to convey the complex worlds of respondents in a holistic manner using 'thick description' rather than particularistic categories and variables. Padget (1998) goes on to say that, "doing qualitative research requires an unparalleled degree of immersion by the researcher as the instrument of data collection" (pg.3). Qualitative researchers seek to avoid normative assumptions and even go to great lengths to identify these as threats to the integrity of a study. Whereas preexisting theories may influence the study, the approach is one of theory generation and emergent (rather than preexisting) conceptual frameworks (Padget, 1998).

3.3.1.1 Generalisability

Morse (1997) argues that theory derived from qualitative research is different from theory derived from quantitative research. She argues that qualitatively derived theory has been 'tested' in the process of development and is therefore more representative of reality and involves less conjecture than quantitatively derived theory. Because of this important fact, qualitatively derived theory may move directly towards implementation, and in doing so does not test theory per se but components of theory. Morse (1997) suggests that this has important ramifications for the evaluation of qualitative research and its role in knowledge development. While it was previously considered that qualitative research was so context bound that it was not generalizable, it is now evident that qualitative research is generalizable according to its level of abstractness (Morse, 1997).

Morse (1997) emphasizes that the aim of a qualitative researcher is ultimately to make links, or to help the reader make links, between what he or she has observed in one situation and what is occurring in other situations. Qualitative researchers investigate naturally occurring phenomena and describe, theorize and analyze them contextually in the 'real world' rather than in controlled situations, thereby yielding important findings for practice (Morse, 1997). Realities or meanings come about as people go about their daily lives, interpreting things or events that happen to them. Through interacting with others, meanings or realities are modified to enable a person to cope with his or her world. As persons constantly interact with others, meanings are continuously modified and shared and individual behaviour is aligned with that of others as well as groups. Thus people in interaction are forming and transforming their lines of action in terms of those of others.

Morse (1997) states that prevention evaluation is yet another use of qualitative methods in program evaluation, yielding important insights into why attitude and behaviour changes occurred, or how prevention programs that have worked can be enhanced through the use of qualitative methods.

3.3.1.2 *Applicability*

Morse (1997) takes the view that researchers who conduct qualitative research in the health sciences should understand that the state of knowledge development is such that research results may well find their way into clinical applications regardless of the researchers explicit assumption about their origins. This factor inherently alters the health science researchers disciplinary responsibility in such a way that it extends beyond the reach of traditional evaluative criteria and into the domain of how findings might reasonably be interpreted or even used (Morse, 1997). Thus, a critique of qualitative research within the health sciences properly extends beyond the mere consideration of adherence to the methodical rules to an examination of the much more complex question of what meaning can be made of research findings.

Within the health sciences, most qualitative research is applied, in the sense that it aims to develop knowledge that would eventually influence one or another health care practice (Simmons, 1995). Since we seek to understand how people experience certain assaults of the body, mind and spirit, in the hope of being able to alleviate unnecessary suffering or harm and promote as much well-being as is possible under the circumstances, research ought to be judged against its moral defensibility (Morse, 1997). This demands that the researcher advance convincing claims of why we need knowledge that is extracted from people, and the purpose and use of having such knowledge once obtained.

Morse (1997) emphasizes that when doing qualitative research in sensitive areas such as communicable diseases, one must account for the possible uses of the findings even before one knows what they will include. She elaborates as follows:

“Our rationale must link the findings to potential benefits for the health care of those we serve before we find it defensible to place any marginalized group at risk of social censure or antipathy because of the new knowledge we extract or because of the manner in which we make the knowledge accessible to those

whose purposes may be distinct from a humanitarian health care agenda” (pg. 123).

Qualitative health researchers therefore cannot put forward their findings with the comfortable assurance that no one will apply them to practice before they become scientifically 'proven'; researchers in this field are obliged to consider their findings 'as if' they might indeed be applied in practice (Morse, 1997). Since qualitative research is based on assumptions that are socially constructed, they are likely to be shared by others in the field, as well as by research participants. Therefore qualitative research serves to re-create them 'as if' they were factual. Since there is no absolute standard against which to measure qualitative research so as to account for the notion of truth or representativeness within the real world, or ensure confidence that research findings are indeed entirely valid, qualitative research accepts that there is value in recognising that some kinds of knowledge exist as 'probable truth'. Morse (1997), points out that qualitative research endeavors not to seek truth, but to create meaning, to construct images from which people's fallible and tentative views of the world can be altered, rejected, or made more secure.

3.3.2. Ethnography

This study is seated in the arena of ethnographic inquiry, since it describes and explains a given culture, as it exists within a specified time. Following Janesick (1998) ethnography investigates human behaviour as it is understood and experienced within a particular subtext and given reality, as it is created by the people of concern. She goes on to say that it is an approach that is driven by an insistent curiosity in human definition and a need to seek solutions to problems and thereby service human need. Therefore, ethnographic data analysis is a tool for discovering cultural meaning. Through the reflective accounts of participants the researcher describes the empirical situation rather than pre-selected study variables. As such the work becomes a cultural translation of symbols and the relationship between them and a relational transcription that seats others within their own cultural context (Janesick, 1998).

For Richardson, (1996), ethnography is the comparative, descriptive analysis of the everyday, of what is taken for granted. In this regard, ethnography deals with developing an understanding of shared systems of meaning in societies that share similar social and cultural characteristics and can be applied to the study of any isolated group who have something in common (Petersen, 2000). She also makes reference to distinct features of ethnography which are characterised by: “ (i) its holistic and contextual nature, (ii) reflexivity, (iii) the use of emic and etic data, and (iv) its value in relation to the development of theory” (Petersen, 2000, pg. 99). In the first instance (i.e. holistic and contextual nature), data needs to be interpreted within an understanding of the context within which observations and interviews take place. She goes on to say that, “A contextual understanding of human behaviour therefore demands that the researcher moves beyond description to understanding why the behaviour takes place and under what circumstances” (Petersen, 2000, pg. 99-100).

The primary method of data gathering is still that of participant observation. An understanding of the validity of other people’s description of the world and of how these descriptions are historically constituted throws into question your own taken for granted assumptions and thus prompts their ethnographic analysis (Richardson, 1996). He goes on to point out that ethnography is directed towards the analysis of contemporary collective processes as these manifest in the day to day relations between particular persons.

A second feature of ethnography, reflexivity deals with the role the researcher plays in the research process and when interpreting the data and this together informs the effect the researcher has on the social phenomenon being studied. Richardson (1996) emphasizes that an understanding of the validity of other people’s descriptions of the world and how these descriptions are historically constituted, throws into question one’s own taken for granted assumptions and thus prompts their ethnographic analysis. The emphasis on the quality of the field data, using this method, allows for reanalysis in the light of new field data or a different theoretical position. Thus, the comparative thrust of

ethnography resides in the way that both data and analysis are inevitably made to play reflexively against the analyst's own understandings.

Through participant observation, this method facilitates the researchers involvement to such a degree that the researcher needs to constantly question not only what people are doing, but how they came to be doing it, and most important, to question one's own ideas about the 'what' and 'how' (Richardson, 1996). In utilizing this method, it is critical that the researcher engages in participation as much as observation, since during analysis, the researcher is able to recognize and to incorporate into her analysis the awareness that it is informed not only by the data that has been gathered, but by the ideas that the analyst brings to the collection of data.

Therefore ethnography provides a medium of analysis in which collective relations between people at large inform what particular persons, considered as historically located subjects, do and say (Richardson, 1996). The idea is that everyone, everywhere, including ourselves, forms the locus of the relations in which we engage with others and in which others engage in us. The challenge of this approach is to know as much as possible about the people whose ideas and behaviour are the objects of analysis. This can be facilitated through interviews or focus group interviews, which are then analysed by content to reveal the ideas of each informant as well as any inconsistencies and contradictions within and across the focus group interviews. Richardson (1996) points out that ethnographic analysis is self-consciously historical and comparative, recognizing that continuity and change are aspects of a single phenomenon, with ideas being transformed in the very process of their constitution. To understand what people are doing you have to analyze how they come to be doing it, and to understand the 'how' you have also to analyse the 'what'.

Thirdly, Petersen (2000) argues that using emic and etic data (insider and outsider perspective of reality), is vital in the process of analysis since the emic perspective takes into account participants views of situations, whilst the etic perspective addresses the researchers interpretation of this reality. Finally, the role of emergent data, apart from

relying on theory and literature, allows the researcher to refute or develop new hypotheses where necessary (Petersen, 2000).

3.3.3 The role of theory:

Socio-psychological theories are critical in facilitating an understanding of health behaviour, explaining the dynamics of the behaviour and the effects of external forces on the behaviour. The Health Belief Model, in particular, presents as an ideal theoretical framework for this study since it provides a broad canvas for the exploration of the health-seeking behaviour of MDR-TB patients. The categorical parameters of the model include an assessment of all relevant dimensions of health-seeking behaviour (viz. perceived susceptibility, perceived severity, health motivation, perceived benefits, perceived barriers and self-efficacy) without being methodologically prescriptive. The HBM has accordingly been used, in the context of this study, to facilitate a culture-centred qualitative investigation of the health seeking behaviour of MDR-TB patients, with minimal theory driven presumptions. The heuristic value of the Health Belief Model, for the purpose of this study, lies in the ideal balance that it provides between theory driven and data driven research.

3.4 The Study Site

King George V Hospital is one of the major urban TB treatment centres in KZN. 697 in-patients are currently resident at this hospital, 7% (47) of who are infected with MDR-TB and 16.6% (116) of whom are repeat admissions and are therefore at particular risk of developing drug-resistant TB. The average in-patient residency is between 6-8 months, with each medical officer managing two TB wards (i.e. one acute and one chronic ward). Currently MDR-TB patients are not isolated from the general TB patient population at this hospital, posing considerable risk with regard to the spread of MDR-TB infection across the general patient population, with potentially devastating consequences at a community level.

3.5 Participants

The study population thus comprised of all adult MDR-TB patients at King George V Hospital (N=47). Due to the relatively small population available, saturation sampling was employed (n=47). Further, given well established gender differences on a range of TB-related issues, such as treatment adherence rates (Sumartojo, 1993) and social consequences of the disease (Liefoghe *et al*, 1995), gender was treated as an independent variable in this study. Thus, all male (n=31) and female (n=16) MDR-TB patients were treated as separate sample groups. All research participants were Black, with Zulu being their first language.

3.6 Data Collection

3.6.1 Focus groups: Justification

In order to gain an understanding of patients' interpretation of their illness, the precipitating events leading to their illness and hospitalisation, their treatment pathways and perceived socio-economic barriers to treatment efficacy, focus group discussions were utilised as a qualitative data collection tool. A total of four (4) focus groups were conducted with adult MDR-TB in-patients, comprising two male and two female groups.

Focus groups produce qualitative data that provides insights into the attitudes, perceptions, feelings and opinions of participants. The benefit of open-ended discussions with participants is that it provides an arena in which participants are able to choose the manner in which they respond and also for the researcher to facilitate the use of observation of participants in the group discussion, which will be informative during the analysis of the data. The focus group also presents a more natural environment than that of an individual interview because participants are influencing and influenced by others, just as they are in real life, therefore providing socially orientated research capturing real-life data (Kreuger, 1994).

One of the unique elements of focus groups is that there is no pressure by the moderator to have the group reach consensus. Instead attention is placed on understanding the thought processes of participants as they consider the issues under discussion (Kreuger, 1994). The usefulness of focus group discussions surfaces in its ability to yield in-depth information and this enables the researcher to 'get in tune' with the respondents and discover how people construct reality from an ethnographic standpoint.

In terms of the validity of focus groups, Kreuger (1994) suggests that they have high *face validity*, which is due in large part to the believability of comments from participants. People open up in focus groups and share insights that may not be available from individual interviews, questionnaires, or other data sources. Focus groups offer a unique advantage in qualitative research, since this method of yielding data acknowledges that people are influenced by the comments of people around them, and by using such a method these people are placed in natural, real-life situations as opposed to experimental situations, typical of quantitative studies (Kreuger, 1996). The dynamic nature of this group interaction is impossible to capture in a one-to-one interview situation, and goes to the heart of understanding the relational construction of reality that is a central feature of ethnographic research.

The format for focus group discussions allows the moderator to probe, and this flexibility to explore unanticipated issues is not possible within more structured questioning procedures. As mentioned earlier, the advantage of having a high *face validity* allows for data to be easily understood since the results can be presented in lay terminology embellished with quotations from group participants (Kreuger, 1996). Another advantage is that focus groups enable the researcher to increase the sample size of qualitative studies without dramatic increases in resources or time required of the interviewer.

As with other information gathering techniques, focus group discussions have their limitations. Firstly, the researcher has less control in the group interview as compared to individual interviews. The focus group discussion allows the participants to influence and interact with each other, and, as a result, group members are able to influence the course

of the discussion (Kreuger, 1996). Secondly, since group interaction provides a social environment, comments must be interpreted within that context and care must be taken to avoid lifting comments out of context and out of sequence. Researchers must also be aware that participants occasionally modify or reverse their position after interacting with others. Therefore the method requires carefully trained interviewers, using techniques such as pauses and probes, and the ability to know when and how to move to new topics. And finally, the discussions must be conducted in an environment conducive to conversation. These factors often present with logistical problems and may require the provision of incentives to facilitate participation. Given that the participants in this study were in-patients, no serious logistical problems were experienced, with a group incentive taking the form of a meal that was provided at the end of each group.

3.6.2 Procedure

3.6.2.1 Phase 1: Consultation:

Key experts in the fields of research methodology and MDR-TB were consulted in order to devise a conceptual framework for the study, including the Deputy Medical Superintendent of King George V Hospital and a senior researcher from the MRC's National TB Programme. In addition, a comprehensive literature search was undertaken utilising the MEDLINE and Centres for Disease Control databases.

The Deputy Medical Superintendent and the head matron of the TB Unit at King George V Hospital were consulted in order to appraise them of the purpose and perceived benefits of the study, as well as to negotiate suitable fieldwork times and venues. The assistance of the head matron was enlisted in order to brief the MDR-TB patients about the purpose of the study and to gain their informed consent for participation.

3.6.2.2 Instrument development phase:

A reading of the literature suggests that the following content areas were of relevance in understanding the health-seeking behaviour of MDR-TB patients:

- ❖ accessibility and appropriateness of biomedical facilities for TB control (Yeats, 1986; Johansson *et al*, 1996)
- ❖ knowledge regarding TB and its treatment, including DOT (Jaramillo, 1998; Thomson & Myrdal, 1986)
- ❖ cultural beliefs regarding TB (Sumartojo, 1993, Liefoghe *et al*, 1995)
- ❖ social consequences of TB (Jaramillo, 1998)
- ❖ socio-economic status (Sumartojo, 1994)
- ❖ gender differentials (Diwan *et al*, 1998)

A semi-structured 90-minute focus group schedule was devised in order to address the objectives of the study (see Appendix 2). Core themes to be addressed in the focus group were developed on the basis of a review of relevant empirical literature (see, for e.g., Johansson *et al*, 1996; Liefoghe *et al*, 1995; Sumartojo, 1993), consultation with identified national and international experts in the fields of research methodology and MDR-TB and two (2) semi-structured interviews conducted with key management personnel at King George V hospital (i.e. the Deputy Medical Superintendent, and the head matron).

Given that the methodological constructs of the study were based on the ethnographic approach, the structure of the focus groups was relatively open-ended. This allowed for the exploration of themes, with the facilitators providing appropriate cues when necessary, without the use of predefined categories. The strength of using such an approach is that it provides valuable insight into human behaviour as it is understood and experienced within a specific context, with the least amount of research driven presuppositions.

3.6.2.3 Phase 3: Implementation:

Four (4) focus group discussions were conducted at King Gorge V Hospital, each comprising between 8-10 MDR-TB patients. Separate focus group discussions were run for male and female MDR-TB patients (i.e. 2 focus groups for males and 2 for females). The focus group discussions were audiotaped and conducted in Zulu, given the ethnic background of the subjects. Given my limited understanding of the Zulu language, I was accompanied by two Zulu-speaking fieldworkers (trained Clinical Psychologists at the University of Durban-Westville), who underwent intensive focus group training. The training involved workshops on focus group techniques and skills as well as providing both fieldworkers with information on key aspects of TB and MDR-TB as discussed in the literature reviewed. The role of the researcher was to serve as a co-facilitator, take field notes of my observations, to manage the audio equipment and to clarify any issues raised by focus group participants.

At the end of every focus group, a 3-hour debriefing session was held whereby both fieldworkers and the researcher analysed content areas, affect of respondents, body language and nuances to provide richness to the data. The researcher made a detailed summary of each of those discussions, to complement the verbatim transcripts of the focus group discussions. Upon completion of the fieldwork, an overall discussion was held for 2.5 hours between the facilitators and the researcher. After completing a draft thematic analysis of the data, the researcher held a 4-hour workshop to facilitate a critique of the material. Based on the outcome of the discussion, the data was refined.

Given the relatively small study population and sample size available, the focus group was pre-tested on a random sample of five (5) male and five (5) female repeat admission TB patients who, while not part of the sample group for this study, are arguably at risk of developing MDR-TB. The pretest served to:

- ❖ identify whether any core issues or probing questions offend the sensitivities of the participants;

- ❖ identify any new content areas; and
- ❖ implement any changes in the design that may be deemed necessary.

Following the pretest, a pilot study was conducted with a sample of ten (10) male and ten (10) female repeat admission TB patients, for the same reasons as advanced for the pretest. The pilot study served the same purpose as that of the pretest, as well as to identify any logistical problems in study design.

3.7 Method of Data Analysis

The audiotapes of the focus group were transcribed *verbatim* in Zulu. These transcriptions were then translated in English and back-translated into Zulu, in order to ensure validity of data gathered. The transcriptions were analysed thematically in order to identify commonalties and variances among the responses of participants. Comparative analyses were made across the variable gender.

According to Boyatzis (1998), thematic analysis is a way of seeing, by making observations and coming to the insights 'intuitively'. People use thematic analysis to see something that had not been evident to others, and this is done by perceiving a pattern or theme in seemingly random information. The perception of this pattern allows one to proceed to the next step, which involves classifying or encoding the pattern by giving it a label or definition or description. Thereafter, the third major step involves interpreting the pattern (Boyatzis, 1998). As a process of encoding qualitative information, thematic analysis facilitates the location of themes found in information that at minimum describes and organises the possible observations and at maximum interprets aspects of the phenomenon (Boyatzis, 1998). A theme may be identified at the manifest level (directly observable in the information) or at the latent level (underlying the phenomenon).

By using a data driven approach, which is constructed inductively from raw information, information appreciation is enhanced and with a complete view of the information available, the researcher can appreciate gross (i.e. easily evident) and intricate (i.e.

difficult to discern) aspects of the information (Boyatzis, 1998). However the approach of developing a code on the basis of prior research places the researcher approximately in the middle of the continuum. The theory driven approach is one of the more highly popular approaches, and in this approach the researcher begins with the theory of what occurs and then formulates the signals, or indicators, of evidence that would support the theory. The wording of the themes emerges from the theorist's construction of the meaning and style of communication or expression of the elements of the theory (Boyatzis, 1998).

Combining this approach with the prior data driven approach, provided the researcher with a broader knowledge base when developing themes that were investigated, and such preliminary investigations of existing phenomena increases interrater reliability.

3.8 Ethical Considerations

Written consent to conduct the study was obtained from the Deputy Medical Superintendent of King George V Hospital. In addition, ethical clearance for the study was obtained from the University of Durban-Westville's Ethics Committee and the Department of Health (Pietermaritzburg). Informed consent was obtained from all research participants, including appraising them of their rights to withdraw from the study at any stage if they so desire. Participants were also assured of anonymity in that they will not be identified by their individual responses (Appendix 5).

Chapter Four

Discussion of Results

The aim of the study is to understand the health-seeking behaviour of multi-drug resistant tuberculosis patients in an in-patient hospital setting. The emergent themes were derived from the focus group discussions. Through the process of analysis which has been explicated in Chapter Three (Methodology) and using the conceptual framework discussed in the same chapter, the following emergent themes were conceptualized in understanding MDR-TB patients health-seeking behaviour.

4.1. Lack of Power in Decision Making Process Regarding Health Care

Most of the patients related their experience of treatment within health care settings as disempowering. Participants described the process whereby they were sent from one clinic/hospital to another for periods of time ranging from two to eighteen months, without receiving 'adequate' treatment to control the disease which resulted in their admission to King George V Hospital (KGV), where they had been diagnosed as suffering from MDR-TB. The majority of participants (both male and female) felt that they had inadequate power in terms of health care decisions when being treated at health care facilities.

Patient (male): I had TB first and was put on treatment for six months, and went back for follow-up appointment and was told that I was resistant to TB medication. Treatment was continued for four months and the visiting sister told me that I had MDR-TB, thereafter I went to the city and was transferred to KGV.

Most of the male participants argued that they were not adequately informed about their health status during in-patient treatment and believed that they had a right to have access

to such information. These patients reported feeling disempowered by the level of non-communication by health professionals, believing that it reflected a lack of respect for them as responsible adults regarding their treatment.

Patient (male): Even if medication doses change, I am not told prior. I feel paralysed to challenge the staff because of fear that they may chase me away

Patient (male): I need to be respected. I feel that I was belittled, the staff are not being genuine and we are treated discriminately.

Patient (male): Even if your spit (sputum) converts to negative, nobody tells you about it

Patient (male): We are not even allowed to view our own files

These lived experiences of denial of power to patients in the decision making process regarding treatment could possibly be due to assumptions made by health care professionals that the patients current health status was as a result of treatment defaultation/non-adherence.

Therefore without fully understanding the factors that contribute to treatment defaultation (for those who did default treatment), and the factors that contributed to the development of the condition (e.g. delays in diagnosis, mismanagement of TB cases, socio-cultural influences, etc), health care professionals assumptions about patients who have contracted the disease may have a negative influence on patients ability to make informed health care decisions.

With regard to the DOT regimen, while the majority of male participants believed that DOT was useful as a treatment strategy and was beneficial in the control of TB, a number of them took the view that DOT made them feel irresponsible and untrustworthy.

Patient (male): It had a negative impact on me, because I became an object of ridicule and I felt dehumanized.

Patient (male): It makes you feel less responsible and other people look down upon you with a condescending attitude.

These responses throw light on the issue of TB control through DOT, reflecting a prevailing attitude amongst both of the above participants of feeling dehumanized and stigmatized for being 'unable' to manage the treatment regimen, given that the responsibility for treatment has been taken away from the patient and is now supervised by third party/parties. Such attitudes were characteristic of males who were treated using DOT.

On the other hand, five other male participants overtly supported the use of DOT as a useful strategy in the control of TB. They viewed DOT as providing support, especially given perceptions of irresponsibility on their part in adhering to treatment protocols. One male participant elaborated that he felt quite fearful of some of his medication and felt that it was quite unpleasant to swallow. He believed that the supervision component of DOT was beneficial in helping him take his medication appropriately.

Similarly, the majority of female participants supported the use of DOT as an appropriate treatment strategy. This majority also alluded to the supportive component of DOT in aiding them to tolerate taking their medication and in providing emotional support.

Patient (female): DOT helped me a great deal as I would not have been able to take my tablets regularly on my own. The supervision aspect of DOT helped because it ensured that I took my tablets as per the instructions.

Patient (female): I benefited from DOT because it made me withstand the difficulty in swallowing the tablets.

Patient (female): I found that DOT was helpful since I would have nearly vomited them all. The mere presence of another person helped me a great deal.

One female participant reported that she received support during the DOT intervention from her employers, where she worked as a domestic.

Patient (female): My employers took me to the hospital and were actively involved in my treatment (DOT). I was happy with them issuing my treatment because they took good care of me.

4.2 Poor Professional-Patient Communication

Many patients (both male and female) had a poor understanding of their treatment protocols, especially with regard to distinctions in the treatment of TB and MDR-TB. Most of the participants related this to the delay in their diagnosis of MDR-TB, as well as their length of stay in hospital.

Patient (male): I had TB for six months and took TB treatment, but there was no improvement as I continued to feel weak. I spent six months at SANTA and continued to feel weak and not eating, then I was sent to KGV for five months. I was told that I have MDR-TB but I still receive the same treatment.

Patient (male): I was diagnosed with MDR-TB at KGV hospital and I feel that I am improving. I am worried because my father is sick. During my treatment, I had problems with my ears and my body was itching. I was sent to King Edward Hospital for an ear assessment. My TB treatment was reduced..... I don't know why.

Patients felt they did not have any control over their duration of hospital stay as it all depended on the conversion of one's sputum from positive to negative on three consecutive occasions. And although patients were aware of the importance of adhering to this kind of involuntary detainment for effective management of their disease, this was most difficult to deal with as they felt that life was passing them by.

Female participants related their unhappiness with regard to the duration of their treatment in hospital to boredom, concern over family members and not being given sufficient pass-outs to attend to social responsibilities.

Primary symptoms that most male patients reported being initially concerned about included coughing, sweating, tiredness and colds. Upon seeking biomedical consultation, the process of being diagnosed was described as time consuming and ineffective. In this regard participants believed that once on medication, improvement in their condition was supposed to be rapid. Such responses indicate a lack of understanding of the treatment protocol, especially in terms of the association between duration of use of medication and symptom remission. As a result, some participants indicated a lack of confidence in the treatment protocol since they did not notice any improvement in their health status, as indicated in the following quote:

Patient (male): I have been taking my tablets consistently as instructed between January and November 1999, and they did not work. I was transferred to KGV. My physician did not tell me that I had MDR-TB but the nursing sister.

Also of concern with regard to professional-patient communication was an apparent lack of adequate explanation by health care professionals regarding patient responses to TB treatment. Two male participants reported that once their symptoms persisted after being stopped from taking TB medication (as advised by the Chest Clinic), they became quite concerned which resulted in them consulting other health care professionals for treatment

advice and management. In both cases the patients were referred back to Chest Clinics where they were told that they were suffering from MDR-TB.

Patient (male): I am unhappy that I don't get medication that I ask for from the doctors. When we get illnesses such as the flu for which we need treatment, we report it to the doctor. The doctors prescribe treatment, which we don't get, and when we enquire with the nurses they say that it has been returned.

Patient (male): If I am given drugs, it would be appreciated if I could be told what is it for.

Patient (male): It helps to have treatment explained because it increases our understanding of treatment.

One female participant reported that health care professionals mismanaged her treatment, since she developed side-effects to treatment that were not adequately managed. She further stated that her physician did not inform her of a secondary condition (Hepatitis B), which she had been suffering from. This prompted her to seek medical advice from another health care professional who told her to discontinue some of her medication. She reported that upon returning to KGV on an outpatient basis, nurses 'pressurised' her to continue taking all her tablets (during DOT), however her condition persisted and she was admitted to KGV. This case provides some insight into the development of complications during TB treatment and illustrates why patients require continuous monitoring of their side-effects to prevent further compromise of their health status.

Another female participant reported a similar incident of possible mismanagement of her treatment, though in her case there appeared to be a lack of consultation amongst health care professionals (private practitioners and public sector) over the status of the patient's health.

Patient (female):My illness got worse, I sought help from a public hospital where I was told that my lung had a hole. The hospital contacted my private physician who had been treating me all along. My physician rudely told them that he was professional and could not be told by anyone how to treat his patients. I was subsequently transferred to KGV where I was told that I have strong resistance to TB drugs.

This extract clearly indicates not only the lack of consultation between health care professionals, but also the possibility that private health care professionals might lack the resources/ clinical exposure to identify and treat MDR-TB. Of concern here is the very real possibility that private health care professionals might be failing to identify MDR-TB, thus compromising patient's health status.

The majority of male participants reported a lack of proper protocol in addressing concerns regarding in-patient treatment and care. Complaints that were noted included an apparent lack of mutual respect between health care professionals and patients, patients fear of victimisation and intimidation by nursing staff in addressing their complaints, and a lack of communication between health care professionals and patients related to in-patient treatment and care.

Patient (male): We are not told who to contact when we have complaints

Patient (male): You have to be in silence even if you are being abused.

Patient (male): We are treated as children.

The majority of male participants complained about a general assistant who distributes meals in the wards. They concurred that in situations where they are asleep or not on their beds they are not given a meal. Such complaints also throw light on the lack of appropriate monitoring of service delivery at the institutions. Also, the majority of the

male participants reported a lack of knowledge pertaining to their medication. Patients complained about the lack of adequate explanations given by health care professionals regarding their drug regimens as reflected in the following quotes:

Patient (male): I once asked a nursing sister about my medication, to which she responded by saying “Ask your doctor”. I felt very hurt by this treatment, so much so that I did not bother to ask my doctor.

Patient (male): If I am given drugs, it would be appreciated if I could be told what is it for.

These two quotes reflect the feelings of disempowerment patient’s experience, especially in situations where patients actively seek to play a role in acquiring knowledge about their treatment protocol. In situations such as the above, patient’s are left feeling helpless with regard to understanding the uses of the medication they are given, which may further compromise patients levels of motivation towards treatment. Patients also felt that in this way they were not respected as adults, since health care professionals may have assumed that patients would not understand treatment protocols adequately.

Patient (male): It helps to have treatment explained to us since this increases our understanding of the treatment.

Patient (male): In this way we feel that we are not respected as responsible adults at hospital.

Other side effects described by male patient’s included loss of appetite, ‘isilungelo’ (heartburn) and vomiting. These symptoms were associated with ‘inkunzi’ (strong medication). In describing such symptoms, it was observed that participants began discussing possible ways of preventing the onset of these side-effects, for, example one patient said:

Patient (male): You should take those medications before you sleep, it helped me since I did not have such bad symptoms.

This indicated the presence of a supportive network amongst patients in that they used experiential situations in providing advice to fellow patients, thus attempting to provide 'alternative treatment advice' in the absence of adequate communication about symptom management between health care professionals and patients.

One male participant indicated that he had "defaulted" on his TB treatment since he was told to take treatment for six months, and once this time period had elapsed he stopped the treatment on his own. In his case, his actions are consistent with those who shared a poor understanding of the treatment protocol and the cause for concern is that miscommunications such as these could potentially lead to a greater incidence of MDR-TB.

An important component of in-patient care is the reception that patients receive from health care professionals on admission. This aspect was only addressed by female participants one of who reported being made to feel unwelcome by nursing staff that were on duty on admission, though when she returned to the hospital she was received warmly. This patient attributed a change over of staff shifts as a factor that determined how well patients are received on admission. In this regard, most of the participants concurred that they received inconsistent levels of care on admission from health care professionals.

Patient (female): The nurses are not the same; some are nice and others are insensitive.

4.3 Attitudes Towards TB/MDR-TB and Treatment Regimens

The majority of male participants felt that TB was a form of punishment and viewed hospitalisation as a jail sentence, since they felt that the strict controls within the hospital affected them negatively. Parts of the treatment especially the injections that they received, was described as a form of punishment as well. Such feelings were described in

the contexts of a poor understanding of the side effects of the injections and the associated discomfort.

The majority of participants (both male and female) expressed high levels of fear and concern regarding treatment outcomes. Fear was directly related to the possibility of not surviving the disease, since participants were concerned about the lack of improvement in their health status. Of concern regarding these perceptions, is that poor communication by health care professionals regarding patient's prognosis and response to treatment, may serve to instil feelings of doubt in patients about the efficacy of their treatment regimens, thereby exacerbating patient's sense of despair and doom with regard to treatment outcomes.

Most of the male participants reported that their lifestyle habits (smoking, abusing alcohol and poor eating habits) may have made them vulnerable to MDR-TB or in some cases even worsened their health status. They reported that most of these behaviours were curtailed while ill, but increased once their TB condition improved.

Patient (male):..... I admit that I had been smoking and drinking, but I stopped recently. But I have been eating food indiscriminately. For these reasons I suspect that I might have been vulnerable to MDR-TB.

Patient (male): I have not been looking after myself properly. Until recently, I have been drinking alcohol and smoking cigarettes. When I got better, I heavily indulged in alcohol and my condition worsened. I feel that alcohol made me weak and vulnerable to viruses and bacteria.

With these patients, the need to return to pre-morbid lifestyle functioning pre-empted them from making informed health care decisions to refrain from habits that will compromise their health status. On the one hand, their need to return to their premorbid level of social functioning was perceived by most participants as an external factor beyond their control. When attributing blame for such indulgences, however, patients in

the main attributed this to a lack of provision of adequate information regarding habit restrictions, presumably an act of omission of the health establishment.

Some patients complained about being prematurely discharged from hospital, despite the lack of sputum conversion, which allegedly resulted in a relapse of the TB disease and a return to hospital. Such concerns left certain participants worried about the possibility of spreading TB to their families or to those that they were in close contact with. The apparent discharge of patients who showed insufficient improvement is of particular concern. These patients have the potential to spread the disease as a primary form of infection to unsuspecting family and community members. Further, it is not possible to monitor whether such patients are taking preventative measures in ensuring that they do not spread the disease.

Patient (male): I was admitted for two months and was discharged home. At the time of discharge, my spits (sputum) were still positive. My symptoms carried on and I went back to hospital. I was finally transferred to King George V Hospital (KGV).

Of particular note is that all participants believed that MDR-TB could not be prevented. One participant (male) reported that MDR-TB is curable and attributed “ukungaziphathi kahle kwethu” (patients defaulting treatment) as a primary reason for relapse of the disease. Another participant referred to MDR-TB as ‘AIDS number two’, reflecting his belief in the incurability of the disease. One male participant reported that some patients hide their medication and by doing so pose the risk of re-infecting those who are on treatment. All participants (both male and female) felt that there was adequate ventilation in the hospital environment.

4.4 Psychological Stress Related to TB/MDR-TB

The majority of female patients reported feeling very upset upon being diagnosed with MDR-TB. This reflects adjustment difficulties in the face of a major life crisis with a lack

of adequate psychological support and care. Symptoms that were indicated (hopelessness, sadness, tearfulness and feelings of isolation) were typically indicative of Adjustment Disorders with Depressed Mood/Depression. Four female participants described psychological sequelae congruent with features of Depression, which were reported as low self-esteem, weight loss related to the former, feelings of isolation and loss of appetite.

Patient (female): I was very hurt when the nurse told me that I have the kind of TB that is incurable and that I will eventually die from this disease. I believed that because I was told by a professional nurse. She also told me that even if MDR-TB is cured, it can be asymptomatic or in remission for a while but eventually starts again.

Patient (female): After being admitted to hospital and being told that I have MDR-TB, I feel I have lost a lot of weight as a result of low self-esteem.

Patient (female): I became very sad upon learning about the MDR-TB diagnosis and cried copiously. I was distraught and helpless because I thought I had a peculiar disease.

The level of post diagnostic stress was reported to be quite high by male respondents since they were told that they could die if they do not improve whilst on MDR-TB treatment.

Patient (male): Physicians can discharge you to die at home. One man who used to sleep next to me was recently discharged because he did not improve sufficiently.

In such a situation one would expect health care professionals to provide patients with realistic appraisals of their prognosis, through empathic care, Pre and Post-test counselling, as done for patients tested for HIV/AIDS, would be strongly indicated.

Of concern in such situations, is firstly the lack of adequate supportive services available within the hospital facilities to aid patients by providing emotional support at the time of diagnosis. Apart from those who are not even fully aware of their diagnosis, those who are told seemed to have been quite distraught at the time, and found it quite difficult to accept their conditions.

Patient (female): When I initially came here and was diagnosed with MDR-TB, I looked down upon myself. I even contemplated escaping from hospital. But now I have accepted my condition, which took a long time, and no longer feel the way I used to.

Participant's loss of hope in being cured from the disease as well as the lack of adequate information with regard to prognosis is clearly illustrated in the following quotation:

Patient (male): Firstly you have to take treatment for six months. If you do not improve, you have to take it for another eighteen months and if you do not improve you have to take it for two years. If you still do not improve, only GOD knows!!

It is interesting to note that some of the participants engaged with one another about their experiences of treatment, which indicated the existence of social support networks amongst participants. The majority of the male participants indicated that initially there was an element of 'ukuzenyeza' (low self-esteem), which impacted negatively on their ability to make appropriate health care decisions after falling ill. On the other hand, one male participant used the quote "abantu bathi ngingathanda ibhokisis" in describing how he felt about having the disease, which translated into "by defaulting I have invited my own death". This statement provides some indication as to how the disease is perceived as a 'death sentence' and the feelings associated with it as being those of despair and helplessness. These feelings of helplessness have the potential to precipitate clinical depression amongst patients, which indicates the need for the provision of supportive psychological and social work services within the institution.

Another patient who concurred with the above patient's response, reported that he defaulted treatment exactly because of his feelings of depression and loss of hope in ever recovering from his illness. It is therefore vital that patients benefit from a systematic counselling programme as an integral part of their treatment regimen.

4.5 Perception of Adherence/Non-adherence in the Development of MDR-TB

The majority of participants (both male and female) reported that MDR-TB affects people indiscriminately and that the chances of contracting the disease are not determined by non-adherence to treatment regimens. This view prevailed in spite of participant's reports that health care professionals had told them that defaulting treatment was a major determinant of MDR-TB. Participants reported that health care professional's assumption that participants did not adhere to treatment regimens served to reduce their level of responsibility in the treatment process. Issues that were reportedly not adequately addressed by health care professionals were factors such as delay in diagnosis and treatment, poor communication by health care professionals resulting in a lack of understanding of the disease by patients, as well as the social circumstances that affected patients decision making process in adhering to treatment.

Two male participants reported that the side-effects of treatment contributed to their defaulting on treatment. Not being able to manage such symptoms appropriately influenced these two patients in making health care decisions that would alleviate the consequences of the side-effects of the treatment, without taking into account the long term consequences of such action, which contributed to them eventually compromising their health status.

Both male and female participants felt that health care workers who attributed the development of MDR-TB to the defaulting of treatment have perceived such situations in isolation of other factors that influence treatment decisions.

Patient (male): When I arrived here I was told that MDR-TB is caused by defaulting treatment.

Patient (female): I had been taking treatment for TB and never defaulted my treatment even once. I got hurt when it was alleged that I got MDR-TB through defaulting treatment.

One male participant reported that he felt that he was blamed by a health care professional for mismanaging his treatment when in fact he was unaware of the duration of the treatment protocol.

Patient (male): I was initially told that I had TB and was subsequently put on treatment. When my condition showed no sign of improvement, I went to see a physician who scolded me and said I did not allow my treatment enough time to take effect. He nonetheless referred me to the hospital.

The above extract demonstrates clearly that health care professionals have at times assumed that patients are aware of treatment protocols and may have neglected to adequately inform patients of the process or duration of treatment. This extract also throws light on the process by which the already low levels of self-respect/self efficacy patients have in managing their own health status is reinforced by health care professionals, who often tend to view patients as being helpless and irresponsible.

By contrast, one female participant who had worked for the TB centre reported that she understood the implications of defaulting treatment, although she personally reported not defaulting treatment. The paradox here lies in the fact that health messages and indeed her own perceptions may be falsified by her own development of the disease without having defaulted treatment. This again underscores the need for a counselling programme to ensure a common understanding of the entire treatment protocol between patients and health care professionals.

4.6 Possible Delay in Diagnosis of Primary Conditions

One male participant reported that a physician initially treated him for a fever. After being referred to the chest clinic he was told that he was healthy. After the patient allegedly insisted that he be further examined, a diagnosis of TB was returned. After being treated for nine months, his condition persisted and he was then diagnosed as suffering from MDR-TB. This patient accordingly ascribed the development of his MDR-TB to a failure by health care professionals to initially identify their condition and provide appropriate management immediately. The majority of male participants supported this view.

One male participant reported that he felt that health care professionals failed to diagnose MDR-TB early on and treated him for TB instead, which resulted in the disease becoming stronger. This was felt to affect the prognosis of his condition, which impacted significantly on his quality of life. Other conditions reported by patient's that were treated prior to the diagnosis of TB was fever, influenza and in some cases pneumonia. Most of the participants felt that X-RAYS provided the most conclusive results, especially for patients being assessed for TB, and that this was not done on them.

Similarly, the majority of female participants reported initially being treated at health care facilities for influenza, severe coughs and colds. These participants strongly believed that their health status might have been compromised due to the delay in diagnosis. Of concern is the lack of early detection facilities in aiding health care services to make appropriate diagnosis and referrals, so as to prevent patients who are possibly suffering from TB/MDR-TB, from experiencing treatment delays.

Patient (female): I initially felt I had flu and sought treatment at a local clinic where I was given cough mixture and tablets. I failed to show any signs of improvement. Subsequently I was diagnosed as suffering from TB and was put on TB treatment for four months. When my condition did not improve I was then transferred to KGV...my new physician

diagnosed me as suffering from MDR-TB.

Patient (female): Professionals lack of knowledge of MDR-TB and their inability to detect the disease early in its onset is a problem. Nurses also gave me different instructions for my treatment.

Most participants (both male and female) described incidents of a similar nature, where the diagnosis of TB was made only after an extended period of time/clinic visits/ other therapeutic interventions. Understandably, not every cough or fever is indicative of TB. It is therefore expected that where clinical assessment does not suggest the immediate need for more objective investigations, TB might not be immediately diagnosed. This is especially understandable in view of our scarce health resources and the sheer pressure exerted on understaffed and ill-equipped primary health care centres. Notwithstanding this, the cumulative effect of these factors have resulted in patient's being mismanaged and treated for 'common illnesses', when in fact they may have been suffering from TB/MDR-TB at the outset. This further erodes participant's trust in their treatment efficacy and undermines their relationship with and faith in health care professionals and health services.

The amount of time lost, which contributed to the delay in diagnosis could explain or possibly contribute to the lack of these participants faith in treatment. Early detection and diagnosis of MDR-TB, as well as adequate explanations regarding treatment protocols, would circumvent treatment delay and improve patient adherence and therapeutic efficacy. One male patient reported the following:

Patient (male): Ubudedengu babezempilo (attributing blame to health care professionals for mismanaging treatment), especially in terms of treatment as a source of the disease. If treatment were initially geared towards MDR-TB, then I would have recovered speedily.

4.7 Patients Understanding and Perceptions of MDR-TB and TB

The majority of patients (both male and female) claimed to have a poor knowledge of MDR-TB and believed that even medical practitioners had a poor understanding of the disease. They consequently felt that it was possible that treating them as 'normal' TB patients because medical practitioners were unable to diagnose them on time had wasted a lot of time. They felt that if MDR-TB had been made as a primary diagnosis, rather than only after a person had resisted conventional treatment, the disease would be easier to manage with better results in a shorter time span. Patients understood the differences between TB and MDR-TB in the following ways:

- ◆ Medication: MDR-TB patients receive injections in conjunction with pills.
- ◆ The duration of hospital stay: MDR-TB patients can stay in hospital for 18 months to two years if they show no signs of converting from positive to negative. TB patients usually spend only six months in hospital.
- ◆ The strength of the virus: They felt that the MDR-TB virus was much stronger than the 'normal' TB virus.
- ◆ Physical appearance: It is possible for MDR-TB patients to look physically fit and healthy, whereas 'normal' TB patients tend to waste away.

One male patient described his condition as 'strong TB', after he did not improve successfully on treatment. The term 'strong TB' was used by some participants in describing TB conditions that did not successfully improve while on treatment, whilst others used the term to describe MDR-TB. It is interesting to note that the subjective meaning of both TB and MDR-TB have been described using the same terminology (i.e. 'strong TB'), which could possibly contribute to participants relatively poor understanding of the differences between TB and MDR-TB.

A few patients believed that MDR-TB patients recover more quickly than TB patients do. Such a viewpoint appeared to be based on the slight improvement in their symptoms that was noted when they shifted to medication for MDR-TB. Most male participants reported

that they had no knowledge of MDR-TB prior to their admission to hospital. This reflects the lack of knowledge of the disease at a community level, which could possibly be responsible for many cases of late detection of the disease amongst sufferers and the uncontrolled spread of the disease within poor communities. Three male participants felt that their treatment was effective, given that their symptoms were more manageable. However they had little knowledge of the prognosis of their condition and felt that they could be cured of the disease, and anticipated a positive outcome provided that they adhered to the treatment regimen.

The majority of male and female participants reported that when they first began receiving treatment for TB, they were unaware of the possibility of developing MDR-TB. They explained that their lack of knowledge of MDR-TB had left them quite unconcerned about their prognosis, but that when their conditions did not improve (which was usually described in terms of their sputum not converting to negative and symptoms of weakness and loss of appetite), they were then reportedly diagnosed as suffering from MDR-TB. Thus these participants felt that only once their TB condition did not improve, was there cause for concern. This lack of knowledge among known TB patients regarding MDR-TB could be hypothesized as a factor contributing to patient's lack of power and full participation in their treatment decisions, resulting in poor treatment outcomes.

Perceptions of MDR-TB affecting patients mental states were evident amongst male participants, as one participant described MDR-TB as 'very strong', suggesting that it can even cause mental illness. He admitted to experiencing symptoms of confusion as suggestive of impending mental illness. Others who disagreed with this assertion perceived MDR-TB as 'strong and incurable'. Another patient who had been on TB treatment since 1976 reported that his response to treatment had been erratic over the years, and that in November 1999 he was diagnosed as suffering from MDR-TB. He feels he has been improving on his present medication and injections. In cases such as these, the time period that has elapsed between this patients first TB treatment and his diagnosis of MDR-TB (22 years) casts doubt on the health care services capacity to identify MDR-TB speedily and to make appropriate referrals timeously.

By contrast, most female participants attributed the persistence of TB symptoms, after the completion of TB treatment, to the possibility of the disease becoming more complicated, rather than the possibility of having acquired MDR-TB.

Patient (female): I was admitted at KGV in December 1999. Prior to coming to KGV, I stayed for six months in another hospital where I was being treated for TB. I realized that my condition was becoming worse when my coughs showed no sign of abating, I was transferred to KGV.

Most female participants demonstrated a poor understanding of MDR-TB, also stating that they understood it merely as 'strong TB'. One female participant however reported that she understood MDR-TB as a disease in which people never fully recover or return to their previous level of physical functioning. Differences in symptom presentation were noted amongst certain female participants. Two female participants reported that they felt internal symptoms of the illness prior to seeking medical intervention. One female participant reported that she felt something move across her stomach, as if she was pregnant. The other female participant reported that there was a sore inside her body and she coughed which she referred to as 'ubomvu'. These two responses indicate 'somatic' components related to the illness.

4.8 Alternative Sources of Diagnosis and Treatment Sought

Most of the male participants reported that they had consulted a traditional healer either prior to or whilst receiving biomedical treatment. The reason for consultation with traditional healers was varied, including the supplementing of biomedical treatment, treating the possible source of illness e.g. bewitchment (Idliso), and establishing a diagnosis. Participants shared mixed feelings regarding the use of traditional healing, as reflected in the following quotes:

Patient (male): I initially saw a traditional healer when I fell ill. I also used traditional medicine between my hospitalisations and when I went back to hospital, I felt much better.

The above extract indicates the strong influence of traditional forms of healing as a means of diagnosing diseases as well as in the treatment process. Subscribing to such forms of treatment plays an important role in patient's health care decisions, since with regard to diseases like TB and MDR-TB, symptom identification and management can either be successful or lead to complications, which could have lethal consequences.

In three cases, participants who consulted traditional healers reported that their symptoms still prevailed after being treated. They thereafter sought biomedical treatment. One could hypothesise that this may be due to the participant's need for symptom eradication, or that the condition could not be linked to a specific cause through traditional interpretations, which is reflected in the following quotes:

Patient (male): I saw a traditional healer initially. I took traditional medicine but did not improve. When I went to hospital and was given medication I did start to improve.

Patient (male): I saw a traditional healer who told me that I had 'idliso' (bewitched). He prescribed me some medicine, but my condition did not improve. I only noted improvement when I was treated in hospital.

Patient (male x 3): I was cured for 'idliso' (bewitchment) and not for TB by a traditional healer.

Patient (male): I went to see a traditional healer for diagnosis only.

The above anecdotes demonstrate that consultation with traditional healers was based on identifying the source of the illness and not merely on symptom eradication. Western

medicine could be conceptualised as focussing more predominantly on dealing with the symptoms of a specific condition, rather than initially addressing the cause of a condition. This may possibly explain the lack of faith of some patients in adhering to biomedical treatment for fear of the symptoms reappearance, since the cause of the condition has not been adequately identified or explained to them.

One male participant who reported that he went to see a traditional healer before attending the clinic related his experience as follows:

Patient (male): I saw a traditional healer and was helped. I believe I was bewitched. The traditional healer gave me something to use to get rid of the 'idliso'. He clearly explained to me how the medication would get rid of 'idliso'. He warned me that it might even kill me. Upon using the substance given to me by the traditional healer, I literally saw 'idliso' coming out. I then went to the clinic because I was feeling weak and was bleeding profusely.

This extract clearly demonstrates the importance of the role of providing information to patients regarding their treatment. The complexity related to patient's decision-making processes is clearly explicated in this extract. Having been made aware of the dangers of the prescribed treatment, the patient made an informed decision to use the treatment in aiding to manage his illness. The above situation illustrates that seemingly irrational actions of patients could actually reflect informed, rational choices made by them regarding the dual and parallel treatment of their illness.

Similarly, five female participants reported seeing a traditional healer, suspecting that they were bewitched, prior to coming to hospital. They reported that only when treatment proved unsuccessful did they go to a hospital. One female participant, who reportedly took traditional medicine for diabetes, together with Western medicine for TB, believed that the interaction between both medications was the cause of her MDR-TB.

Patient (female): I initially thought I had idliso (bewitched) for which I took traditional medicine. I refused to take treatment (TB medication). However now that I am still not better, I no longer believe that I was bewitched.

Certain participants (male) described what they viewed as cultural illnesses namely 'izibhobo' and 'amahlaba' (sharp pains) and 'umkwebhelo' (hernia), as untreatable by Western medicine. These participants reported seeking help from traditional healers. Only once such treatment proved ineffective did they consult western medical practitioners for treatment. Subjective interpretations of illnesses were also prevalent amongst staff at the hospital, since one male patient reported that a nurse told him that he was too young to suffer from Diabetes. Such an assertion illustrates the influence of subjective interpretations of illness amongst health care professionals, which impacts on the dualism of retaining such interpretations in the light of biomedical practice.

This participant further elaborated that such perceptions, especially coming from an individual who is trained in Western medicine, made him skeptical of Western medicine as an appropriate treatment strategy in managing his illness. He therefore reported using traditional as well as western medicine interchangeably and noted a marked improvement.

Another issue of concern is whether the use of medication from both disciplines (traditional and western) is beneficial to a patient's health status, and if so whether it is disease specific. Concerns such as these are supported by the accounts of other patients. Another male participant also reported seeking help from a traditional healer, and used the same medicine reportedly used by other participants, with no reported success.

4.9 Lack of Knowledge Amongst Community Members Regarding TB/MDR-TB

Three male participants reported a lack of understanding of TB/MDR-TB amongst community members, which resulted in patients being stigmatized and marginalized by community members with regard to their health status. One participant regarded the

communities' perception of the disease as being due to bewitchment as misinformed. Community influences can have a negative impact on treatment outcomes, since in situations where the disease is causally related to cultural illnesses such as bewitchment, the consequence is usually a delay in identification of the disease, which impacts negatively on the patient's prognosis.

Patient (male): People in the communities don't understand this disease, which results in people spreading the disease within the communities.

Patient (male): The government needs to teach people about DOT because other people who contract TB think that they are bewitched. There is a lack of information in the communities.

Another perception of MDR-TB by community members, as indicated by two male participants, was that:

Patient (male): People in the community say I am HIV/AIDS positive. Some of my family members say subtle statements and look down upon me.

In this case members of the community may be interpreting the symptoms of MDR-TB as being part of the HIV/AIDS syndrome. This is entirely understandable given the high level of co-morbidity between HIV/AIDS and TB and suggests that the social stigma generally faced by TB sufferers is likely to be exacerbated with the explosion of the HIV/AIDS pandemic in South Africa.

Some patients have also reported that when their families visit them, they feel hurt by the restricted contact made with them, due to the fear of transmission of the disease to them. The majority of female participants felt that discriminated against by community members. They also reported that community members often attributed their condition to HIV/AIDS. However, immediate family members were perceived as being supportive

and understanding of their condition, which was markedly different to the treatment reported by male participants.

4.10 Social and Financial Consequences of MDR-TB

One male participant complained of a lack of recreational facilities within the hospital environment and likened his hospitalisation to a form of imprisonment. The majority of male participants complained of boredom and recommended that special facilities should be provided for MDR-TB patients given the very long amount of time spent in hospital. Facilities that were requested included having games such as 'umlabalaba'(draughts), snooker, table tennis and soccer.

Another male participant felt that he had to abandon his studies due to MDR-TB and felt that he could have continued with his studies whilst being on treatment in the hospital. Upon consulting with his doctor about continuing his studies in hospital, the patient reports that he was refused permission to do so, without a reasonable explanation. In such cases, patients power in deciding on their future plans can directly affect their level of motivation during in-patient treatment, which could result in negative perceptions regarding treatment, as well as feelings of hopeless and helplessness within the hospital environment.

Most male participants also reported a significant loss of income due to their hospitalisation. Two participants reported that their wages were discontinued after a prolonged period of illness. While they understood that they had been paid according to their sick leave benefits, they were quite concerned about the effects that their lack of income would have on their families. One male participant reported that he had to take his children out of school due to his loss of income. The financial strain caused by patient's extensive hospitalisation has produced added stress for in-patients, who have no alternative means of financial support to provide for their families. Many previously employed patients are thus faced with the possibility of losing their jobs given the lengthy hospitalisation period.

Patient (male): I used to send money home to my family instead I now expect them to send me money.

Patient (male): I had been working prior to my hospitalisation and since being hospitalised my employers have discontinued paying my wages. Consequently I could not support my family and feel left behind. In fact being in hospital is like being in prison.

The majority of male participants also reported a break up of their relationship with their partners, because of their extensive hospitalisations. One male participant reported that he was recently given a pass-out and found his girlfriend pregnant with another man's child. He reported that he could not blame her as she was unaware of the duration of his treatment programme.

One female participant reported that she heard that if one suffers from MDR-TB one should not work hard. She said that as a result she stopped working as a domestic worker when she recovered. Such misconceptions about the disease thus contribute to a further and unnecessary loss of financial support, underlining the need for proper and comprehensive education for patients. As with male participants, females reported some form of social stigmatization within their communities regarding their disease. A common stigma attached to female participant's illness was that of suffering from HIV/AIDS. This indicates the need for health care authorities to embark on public health promotion interventions about MDR-TB in order that symptoms are identified early on and to prevent labeling within a community context.

Patient (female): ... I basically avoid people in the neighborhood for fear that they could spread rumors about my condition.

Patient (female): ...Following my failure to recover at the local clinic like others, someone in my community is spreading the rumor that I am HIV positive.

Again, as was the case with male participants, four female participants reported a lack of understanding of their condition amongst family members, which resulted in family members being fearful of visiting them.

Patient (female): Initially my family did not want to see me. As the time wore on, they gradually started to visit me here. Two of my brothers who used to get along with me very well have neglected me and have never visited me here. Some of my family members suspect I may be HIV positive. They refuse to believe the HIV test result.

Patient (female): My husband has not spoken to me since my hospitalization. Further, none of my family members has been here to see me. I have tirelessly been trying to contact them to no avail.

The above extracts indicate the social restrictions and harsh social sanctions that certain participants have endured as a consequence of the disease. It is important to note that family members need to be educated in terms of the modes of transmission of the disease, and the methods of prevention, which may possibly decrease levels of fear held by family members, while promoting appropriate health behaviour by the patient. Again, this underscores the need for social work services to be an integral part of the TB treatment regimen.

Chapter Five

A Discussion and Integration of my Findings

In this chapter I offer an integration of the findings of this study (as detailed in Chapter 4) using various socio-psychological theories in order to facilitate an understanding of patients health behaviour, explain the dynamics of the behaviour and the effects of external forces on their behaviour. The Health Belief Model, in particular, provides a broad canvas for the exploration of the health-seeking behaviour of MDR-TB patients. However other models, which include Health Locus of Control Theory and the Theory of Reasoned Action, are also integrated into the discussion.

The categorical parameters of the HBM, facilitates an assessment of all relevant dimensions of health-seeking behaviour (viz. perceived susceptibility, perceived severity, health motivation, perceived benefits, perceived barriers and self-efficacy) without being methodologically prescriptive. The HBM has accordingly been used, in the context of this study, to facilitate a culture-centred qualitative investigation of the health seeking behaviour of MDR-TB patients, with minimal theory driven presumptions. The heuristic value of the Health Belief Model, for the purpose of this study, lies in the ideal balance that it provides between theory driven and data driven research.

5.1 Perceived Susceptibility

Based on Gorin and Arnold's (1998) evaluation of this construct of the Health Belief Model (HBM), perceived susceptibility deals with an individuals appraisal of whether or not his/her behaviour is perceived as harmful to ones health, and whether or not moderating or ceasing such behaviour would be beneficial. An important aspect of this construct is the individual's knowledge of the disease and its perceived outcome, as this is the determinant of an individual's perceived susceptibility and perceived severity of harm. Therefore perceived susceptibility attempts to measure an individuals subjective perception of her own risk in contracting a health condition by addressing the individuals

acceptance of the diagnosis, personal estimates of re-susceptibility and susceptibility to illness in general (Gorin and Arnold, 1998).

In terms of this categorical parameter, several deductions can be made with regard to patients perceived susceptibility to MDR-TB. Firstly, in describing patients' knowledge of MDR-TB, both male and female participants generally had a poor understanding of MDR-TB. The majority of male participants perceived the differences between TB and MDR-TB as being related to the differences in the treatment of the two conditions. Prior to hospitalisation, male participants reported no knowledge of MDR-TB. Both male and female participants regarded their lack of knowledge of the disease as a significant variable in informing their cues to action; thus, in the absence of knowledge of the disease, they reportedly felt unconcerned about their prognosis, and it was only during treatment that they became aware of the seriousness of the disease, and this through the conversion of their sputum as a prognostic indicator of MDR-TB.

Although both male and female patients understood that there was a possibility of contracting MDR-TB, they did not view themselves as being personally susceptible to the disease. Particularly instructive in this regard was the view that the disease was 'indiscriminate', in that 'anyone could become infected' (viz. primary or secondary infection). Most of the male patients believed that their vulnerability to MDR-TB, increased because of their indulgence in smoking, alcohol use and poor eating habits. Further, patients attributed a lack of provision of adequate health information regarding the need for lifestyle changes, as an act of omission of the health establishment, which by implication was perceived to be responsible for the development of the patient's health condition. These perceptions therefore indicate that these patients regard their health as relatively independent of their behaviour and largely within the control of others, which would predictably result in low health motivation and negative health outcomes (Wallston et al, 1978 Health Locus of Control Theory).

Differences were evident with regard to female's perceptions regarding susceptibility, since they attributed the development of MDR-TB to a direct consequence of TB

becoming more complicated after the completion of their TB treatment. These responses could also be interpreted as patients regarding their health as relatively independent and largely within the control of others (i.e. health care professionals). Similarly, both male and female participants regarded environmental conditions (e.g. poor hygiene control within the hospital) as increasing their susceptibility to contracting MDR-TB, again a fault of the hospital establishment.

Secondly, patient's subjective perceptions, regarding their level of risk in contracting MDR-TB was evident in their understanding of modes of contracting MDR-TB. Male participants described several ways of contracting MDR-TB, which ranged from working under extremely dusty conditions, contracting the disease whilst incarcerated, as well as contracting the disease within the hospital (e.g. via blankets, food intake and toilets). Female participants concurred with males about poor hygiene control within the hospital environment, especially with regard to sanitation. Patients complained of having to wash their dishes in an area where faeces, urine and sputum are dumped, as well as having to reside in dusty wards, which are exposed to environmental dangers such as snakes, which they believed increased their susceptibility to contracting MDR-TB.

These patient reports of poor environmental and hygiene control within the hospital, if valid, are a cause for serious concern. With regard to perceived susceptibility, however, patient's perceptions of these conditions as causal risk factors in the development of MDR-TB may actually reflect denial and difficulty in accepting the diagnosis of MDR-TB. Thus, those participants who did not adhere to treatment regimens adopt the view that their behaviour is unrelated to their health status and determined by factors beyond their control (Wallston et. al, 1978 Health Locus of Control Theory), thereby externalising responsibility as a response to a life threatening diagnosis.

Therefore, to conclude, it appears that patient's lack of knowledge of MDR-TB plays an important and largely negative role in informing patient's perceived susceptibility, their perceptions regarding treatment outcomes, and in understanding the implications of re-susceptibility with regard to compromising their health status.

5.2 Perceived Severity

Glanz et al (1997) describe perceived severity as addressing concerns about the seriousness of contracting an illness or of leaving it untreated. Perceived severity also addresses the evaluation of both medical and clinical consequences (such as death, disability, and pain) and possible social consequences (such as effects of the condition on work, family life and social relations).

In terms of patients' perceptions regarding the severity of MDR-TB, the majority of male and female participants expressed high levels of fear related to the possibility of not surviving the disease as well as fear of treatment outcomes. Severity was related to patient's perceptions regarding symptom remission, since this provided patients with signs of whether or not their health status was improving from the treatment administered.

Patients showed a lack of knowledge of MDR-TB, and consequently lacked insight with regard to the disease's severity, since they perceived the condition merely as 'strong TB'. This term was referred to several times by male and female patients', in reference to MDR-TB, as well as in reference to TB that did not improve significantly whilst on treatment. This poor knowledge base resulted in a low sense of perceived severity to MDR-TB pre-admission.

On the other hand, once MDR-TB was diagnosed, there appeared to be a marked shift towards perceiving MDR-TB as life threatening. This was expressed in the form of high levels of fear and concern regarding treatment outcomes. Participants experienced significant concern about the lack of improvement in their health status leading to fear about the possibility of not surviving the disease. Of concern regarding these perceptions, is that poor communication by health care professionals regarding patient's prognosis and response to treatment apparently served to instil feelings of doubt in patients about the efficacy of their treatment regimens, thereby exacerbating patients sense of despair and doom with regard to treatment outcomes.

Green and Kreuter (1999) argue that the two dimensions of the Health Belief Model, belief in susceptibility and belief in severity, could be collectively interpreted as fear of the disease. They go on to say that *fear* is a powerful motivator, and embodies the additional dimension of anxiety beyond the belief itself. The source of such anxiety is the belief in susceptibility and severity in combination with a sense of hopelessness or powerlessness to do anything about a diffuse threat. This combination of factors produces negative perceptions of the potential outcome of treatment (i.e. death, disability and pain). The absence of any immediate course of action the person can take to alleviate the fear (supportive services/networks), compromises the patient's belief in the effectiveness of the action taken to reduce the disease threat. Dillard (1994) argues that recent studies addressing the effects of fear on persuasion, have found that a high level of fear combined with low outcome expectation or low self-efficacy may result in dysfunctional behaviour such as denial of one's own vulnerability to a disease and scape-goating of risk groups.

Some patients complained about being prematurely discharged from hospital, despite the lack of sputum conversion, which allegedly resulted in a relapse of the TB disease and a return to hospital. Such concerns left certain participants worried about the possibility of spreading TB to their families or to those whom they were in close contact with. The apparent discharge of patients who showed insufficient improvement is of particular concern, as these patients have the potential to spread the disease as a primary form of infection to unsuspecting family and community members.

Further, it is not possible to monitor whether such patients are taking preventative measures in ensuring that they do not spread the disease. While patients expressed concerns regarding the seriousness of spreading the disease, it appears that they lack adequate knowledge pertaining to infection control mechanisms and strategies for avoiding infecting others once discharged into their communities. This again reflects the apparent lack of health education messages and poor health communication in general.

The perception of both male and female participants regarding the clinical and medical consequences of MDR-TB was reflected in their beliefs that MDR-TB could not be prevented. One participant referred to MDR-TB as 'AIDS number two', reflecting his belief in the incurability of the disease. The level of post diagnostic stress was reported to be quite high by male respondents since they were told that they could die if they do not improve whilst on MDR-TB treatment. One male participant used the quote "abantu bathi ngingathanda ibhokisis" in describing how he felt about having the disease, which translated into "by defaulting I have invited my own death". This statement provides some indication as to how the disease is perceived as a 'death sentence' and the feelings associated with it as being those of despair and helplessness.

Related to the issue of helplessness, the majority of male participants agreed that health care professionals displayed a poor understanding of their social needs and responsibilities, as reflected, for example, in the standardisation of pass-out periods for all patients. While this general complaint reflects patients' poor understanding of the severity of the disease and its transmission, it also underscores the lack of social support networks for patients whose duration of treatment is quite extensive. This places patients in an invidious position where they have to make choices in terms of adhering to in-patient treatment or absconding from the ward to attend to their social/familial responsibilities.

One male participant indicated that he had "defaulted" on his TB treatment since he was told to take treatment for six months, and once this time period had elapsed he stopped the treatment on his own. In his case, his actions are consistent with those who shared a poor understanding of the treatment protocol and the cause for concern is that miscommunications such as these could potentially lead to a greater incidence of MDR-TB, in addition to poor therapeutic outcomes. Situations such as the above indicate that without an adequate understanding of treatment protocols, patients may be unable to evaluate the medical and clinical consequences of the disease, thereby perceiving the severity of leaving the illness untreated as not compromising their health status.

Female participants attributed the persistence of TB symptoms after the completion of their TB treatment to the possibility of the disease “becoming more complicated”, rather than to the possibility of having acquired MDR-TB. In these situations, participants apparently believed that such events (being diagnosed with MDR-TB) are unrelated to their actions and are determined by factors beyond their personal control. By attributing the development of the disease to TB resistance (assuming it is a biological process that they have no control over), these patients are alleviating their responsibility for acquiring the disease via possible health damaging behaviour (e.g. non-adherence) (Wallston et al 1978, Health Locus of Control Theory).

Perceptions of MDR-TB affecting patient’s mental states were evident amongst male participants, with one participant describing MDR-TB as ‘very strong’, suggesting that it can even cause mental illness. This participant admitted to experiencing symptoms of confusion suggestive of impending mental illness. Consultation with Dr I. Haroon (Principal Medical Officer, King George V Hospital), revealed that for patients on MDR-TB treatment regimens, symptoms of mental illness could be attributed to the following factors: 1) side effects of MDR-TB medication; 2) a pre-morbid history of mental illness and 3) a co-morbid medical condition (e.g. patients who develop mental illness as a consequence of HIV/AIDS).

With regard to the side effects of medication, the following TB/MDR-TB medication package inserts were reviewed; revealing the following documented CNS side effects:

Table 1: CNS side effects of TB medication

Proprietary Name	Composition	CNS Side-Effects And Special Precautions
Rifinah-150	150mg Rifampicin and 100mg Isoniazid	Confusion, drowsiness, ataxia, dizziness, convulsions, toxic encephalopathy, memory impairment and toxic psychosis.
Rolab-Ethambutol	100mg or 400mg Ethambutol hydrochloride HCL	Visual impairments, dizziness, mental confusion, disorientation and possible hallucination.
Rolab-Rifampicin150	Rifampicin 150mg	No reported CNS side effects
Kanamycin Novo injection	Kanamycin Sulphate stabilised solution 1g/3ml	Damage to the eighth cranial nerve resulting in irreversible loss of hearing and neurotoxic reactions.
Etharyl tablets	250mg Ethionamid	Insomnia, drowsiness, peripheral neuropathy and convulsions, administration cautioned for patients with depression or other psychiatric disorders.
Cycloserine	250mg Cycloserine	Nervous system manifestations include convulsions, drowsiness and disorientation with loss of memory, psychosis, possibly with suicidal tendencies, character changes, hyper- irritability, aggression, paresis, hyper-reflexia, paraesthesia, major and minor localised clonic seizures and coma.

While the exact drug-induced side-effects experienced by an MDR-TB patient is obviously difficult to predict, it is imperative that patients be made aware of the seriousness of these clinical consequences and be provided with options to manage such side effects.

In conclusion, patients may very well be correct in believing that their illness may induce symptoms of mental illness where there is an existing pre-morbid psychiatric history, or due to co-morbidity between TB and HIV/AIDS. For the most part however, it is probable that their symptoms are actually drug-induced. Patient's ignorance of these side-effects thus elevate their perceptions of the severity of the actual illness, exacerbating their fear and sense of hopelessness, with deleterious prognostic outcomes. This once again draws attention to the need for clear health communication and counselling by professional staff, and underscores the serious consequences of the lack of such interventions. Further, given the very serious CNS side effects listed above, it is not at all difficult to understand why patients experience difficulty in adhering to their treatment regimens.

Patients (both male and female) who reported deterioration in their social relations within their communities and amongst family members attributed this to a general lack of information about the disease at a community level, as reported in other studies (e.g. Jaramillo, 1998; Rubel and Garro, 1992 and Sumartojo, 1993). Female participants alluded to the fear of seeking medical help since they understood that the possibility of being hospitalised would prevent them from attending to their social responsibilities (i.e. caring for their children, elderly and spouses).

While the literature suggests that female TB/MDR-TB patients suffer greater interpersonal rejection than males due to the social stigma of the disease (e.g. Liefoghe et al, 1995), in this study male participants reported broken relationships with their partners to a greater extent than females, due to extensive hospitalisation and loss of sustainable income to support family members. Overall, the effects of deteriorating social relations have more far reaching consequences, since patients are faced with being

stigmatised and rejected by family and community members (Westaway and Wolmarans, 1994), which adds to their sense of severity of their conditions, especially given their prolonged treatment.

In summary, a number of factors impact on patient's perceptions regarding the severity of MDR-TB, the first of which relates to their fear of not surviving the disease and fear of treatment outcomes, both of which were dependent on patients pre and post diagnostic status. Although patients did express concern regarding the spread of MDR-TB amongst their communities, especially within the context of being pre-maturely discharged, they appeared to lack adequate knowledge pertaining to infection control mechanisms and strategies for avoiding infecting others once discharged into their communities. Patient's high levels of post-diagnosis stress and non-adherence behaviour were related to perceptions of the incurability of MDR-TB, as well as their perceptions and experience of the clinical and medical consequences of the disease, especially side-effects of their medication protocol. Lastly, patients' perceptions of MDR-TB as being severe were exacerbated by their lived experience of a deterioration in social relations, including stigmatisation, lack of social support and an inability to discharge their social and familial obligations and responsibilities.

5.3 Health Motivation

The health motivation construct within the HBM assesses patients desire to maintain a state of good health, based on their evaluation of possible health outcomes (Gorin and Arnold 1998).

With regard to this construct of the Health Belief Model, several pertinent issues arise from the findings of this study. The first relates to patients perceived lack of power in the decision making process regarding their health care. Most of the patients (both male and female) related their experience of treatment within health care settings, including DOT, out-patient clinic consultation and in-patient treatment, as fundamentally disempowering.

The majority of male participants reported being inadequately informed about their health status during treatment, which they ascribed to poor levels of patient-professional communication. Several stark instances of denial of power to patients in the decision-making process regarding treatment were evident. This could be due to assumptions made by health care professionals that the patient's current health status was as a result of treatment defaultation/non-adherence. Therefore without fully understanding the factors that contribute to treatment defaultation (for those who did default treatment), and the factors that contributed to the development of the condition (e.g. possible delays in diagnosis, mismanagement of TB cases, socio-cultural influences, etc), health care professionals assumptions about patients who have contracted the disease may have had a negative influence on patients health motivation and hence on their ability to make informed health care decisions.

With regard to the DOT regimen, the majority of male and female participants felt that DOT was a useful treatment strategy and was beneficial in the control of TB. A few male participants, however, felt that DOT made them feel irresponsible and untrustworthy. The impact of DOT on these participants was to instil feelings of dehumanisation and stigmatisation for being 'unable' to manage the treatment regimen themselves, given that the responsibility for treatment had been shifted away from them to third party/parties. A number of female participants', however, perceived DOT as being supportive in providing them with much needed emotional support when taking their medication.

In summary, while DOT is on the one hand perceived as providing critical support, participants also reported feelings of powerlessness engendered by the treatment protocol. Thus, while DOT is understandably perceived as disempowering, it also plays a crucial role in containing people's anxieties and in providing a sense of social support to vulnerable individuals.

It appears therefore that female participants were more inclined to ascribe to the supportive component of the DOT regimen as a means of engaging in health maintaining behaviour, thus alluding to their dependency upon health care professionals and

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community members for the provision of care. Male participants, who felt that DOT was disempowering, possibly viewed their health as relatively dependent on their own behaviour and not within the control of others. In this regard they were more likely to engage in health damaging behaviours (e.g. non-adherence to the DOT regimen), due to their dissatisfaction with the loss of control over their health status whilst engaged in the treatment regimen.

Another aspect of in-patient care that affected patients' health motivation negatively was the duration and quality of their hospital stay. Patients perceived their stay as a form of punishment, exacerbated by a lack of structured activities which instilled a sense of boredom and not being given sufficient time to attend to social responsibilities during their pass-out periods.

The majority of participants (both male and female) reported that MDR-TB affects people indiscriminately and that the chances of contracting the disease are *not* determined by non-adherence to treatment regimens. This view prevailed in spite of participant's reports that health care professionals had told them that defaulting treatment was a major determinant of MDR-TB. Participants reported that health care professional's assumption that participants did not adhere to treatment regimens was often not true and even in instances when it was true, health care professionals demonstrated a poor understanding of patients legitimate non-adherent behaviour (e.g. social and family circumstances, devastating side effects of medication, poor patient knowledge of MDR-TB and the treatment protocol). This allegedly resulted in negative and sometimes hostile attitudes and behaviour by health care professionals, which served to reduce patient's level of responsibility in the treatment process. To add insult to injury, patients reported that it was extremely difficult to raise these problems with staff in a constructive fashion.

While ineffective communication between the patient and health care provider has been reported as a major barrier to positive health outcomes, including treatment adherence (Levinson & Chaumeton, 1999; Martin & Barkan, 1989; Ong et al, 1995; Sumartojo, 1993), it is important to note that the perspective of the health care professional has

dominated treatment adherence research, with little regard for the patients decision-making processes (Morris & Schultz, 1992). There is an inherent tendency to "blame" the patient and to view non-adherence as irrational and deviant, without considering the process whereby patients weigh factors such as side-effects of treatment, social and financial costs of treatment and the long term consequences of their health action (Playle and Keeley, 1998).

Traditionally, therefore, treatment 'adherence' simply meant that patients must do as the health professional wants, with little option but to comply with the advice or instructions that they receive (Donovan, 1995). Patients' perceptions, however, as well as they're personal and social circumstances have been shown to be crucial in their health-seeking behaviour and decision-making processes (Stewart, Bhagwanjee, Mbakaza and Binase, 2000). The establishment of supportive patient-provider relationships, aimed at empowering patients to assume active roles in their health care (Berkman, 1995) and developing a sense of control over their health outcomes (Sobel, 1995), is therefore crucial in significantly improving patient adherence with therapeutic regimens (Van den Borne, 1998).

Overall, therefore, the health motivation of patients in this study was extremely low, resulting in negative treatment and prognostic outcomes. This low health motivation accrues from a fundamental sense of disempowerment of patients both by institutional health care providers as well as by virtue of the externalisation of the locus of control for their health care decisions at a community level through the DOTS strategy. Petersen (2000) argues that in order to begin developing a more equitable and empowering relationship between patient and health care provider, a shift is needed towards "...a paradigm of care which does not perceive the patient as a passive entity to be acted upon, but rather perceives him/her as being able to contribute actively in the healing process" (pg. 56).

5.4 Perceived Benefits

The perceived benefit of taking health action is based on a person's belief regarding the effectiveness of the various available actions in reducing the disease threat. Therefore, an individual exhibiting an optimal level of beliefs in both susceptibility and severity would not be expected to accept any recommended health action unless that action were perceived as potentially efficacious (Gorin and Arnold, 1998).

Male participants who adhered to treatment protocols anticipated rapid improvement in their health status. Such responses indicate a lack of understanding of the treatment protocol, especially in terms of the association between duration of use of medication and symptom remission. As a result, some participants did not perceive treatment as being potentially efficacious since they did not notice any rapid improvement in their health status. Hunter and Arbona (1985) have shown that a failure to take tuberculosis medication may be due to numerous reasons which include: the illusion of positive health status when symptoms disappear, a failure to understand the disease, fear of side-effects, unwillingness to regard oneself as ill and reluctance to accept the discipline of a drug regimen for a prolonged period of time.

Christensen-Szalanski and Northcroft (1985) provide another way of understanding adherence by arguing that variations in temporal availability of costs and benefits could systematically alter the perceived value of those costs and benefits. With this in mind, it could be hypothesised that participants who anticipated that adherence to treatment regimens would provide 'rapid' remission of symptoms (as experienced during the treatment of TB), expected similar action whilst on MDR-TB treatment. Thus their perception of the benefits of their present course of action was negative due to the lack of rapid improvement in their symptomatology.

The majority of male patients ascribed their development of MDR-TB to a failure by health care professionals in initially diagnosing their conditions and providing appropriate management to prevent disease complications. These participants strongly

believed that their health status might have been compromised due to the delay in diagnosis. In terms of Wallston's Health Locus of Control Theory (1978), these patients ascribe to the influence of *powerful others*, where patients may exhibit a strong belief in the ability of the medical system to cure any relevant illness and consequently disregard health promotion messages. Thus, while some cases might have indeed occurred due to delays in diagnosis, the majority of patients developed MDR-TB due to poor treatment adherence for their original (TB) condition.

Pillay (1993) addresses the issue of delays in diagnosis within the context of a limited availability of services and facilities by arguing that overcrowded facilities often result in patients delaying seeking help because of the inconvenience of spending a considerable amount of time in order to be seen by a doctor for a few minutes. Therefore within such a context, health-seeking behaviour will be determined almost solely by the severity of the illness. Thus, the motivation to visit a doctor for a screening for illness or disease is often quite low, and it is not uncommon that lay or traditional medicine will be substituted in these cases. When considering treatment options, the influence of socio-cultural factors and financial constraints may be the deciding factor as to where (in terms of proximity and convenience) illness or disease is treated and by whom (Steen and Mazonde 1999, Haram, 1991).

Pillay (1993) found that in Zulu society, the severity of an illness is assessed by the behaviour of the person. Sickness was assessed as not severe if the individual was capable of continuing with her daily activities. If she lies down this indicates that the illness is serious which arouses concern by those around her. With minor ailments, if symptoms persist despite the use of home remedies, an outside opinion is sought by taking the person to either a doctor or a traditional healer. In addition to an assessment of the seriousness of illness, the decision to contact a doctor or traditional healer was influenced by other factors as well, including the availability of health services, the financial implications thereof and the perceptions of the person responsible for the decision. The latter was related to decisions (such as hospitalisation) being approved by the head of the household. Heads of households are often away from home (as a result of

migrant labour), which may have occurred with the participants under study and this contributes to further delays in health action.

Patients cultural beliefs and understanding of TB influence their decisions regarding when, and from whom, to seek assistance, often resulting in treatment delays which are traditionally underreported by patients (Jaramillo, 1998; Rubel and Garro, 1992; Sumartojo, 1993; and Vecchiato, 1997). In East Africa for example, attribution of TB symptoms to witchcraft or other folk illnesses has been associated with delays in seeking professional treatment as well as remarkably high rates of default once treatment has begun (Ndeti, 1992). By contrast Rubel and Garro (1992) argue that incidents of treatment delay in South Texas were attributed to patients beliefs' that their illness could not be identified or treated by a physician. Patients therefore began self-medicating themselves using 'over the counter remedies', followed by lifestyle changes.

The majority of male participants in this study reported consulting a traditional healer, either prior to or whilst receiving biomedical treatment. Reasons for engaging in this health action included a need to supplement biomedical treatment, the belief that traditional consultation would provide insight into the possible origins of the illness (e.g. bewitchment or 'Idliso') and the need to establish a diagnosis. Kleinman's (1980) explanatory model of illness explains how patients choose to manage their illness, which refers to how an individual interprets his/her illness symptoms in terms of its aetiology, nature, expected course, treatment and curability. These explanatory models vary across cultures and it is common for patients to ascribe to more than one model, which informs the nature of their health-seeking behaviour. Kleinman (1980) has stressed that patients are capable of holding more than one explanatory model of illness. As a result, it is not uncommon for patients to use alternative forms of care (e.g. traditional healing) in conjunction with western modes of healing.

The findings of this study indicate that consultation with traditional healers was based on identifying the source of the illness rather than for mere symptom eradication. By contrast, Western medicine could be conceptualised as focussing more predominantly on

treating the symptoms of a specific condition, rather than initially addressing the cause/s of a condition. Steen and Mazonde (1999) explain that a western doctor would describe how a disease has been transmitted while a traditional healer would ascribe 'meaning' to the disease (e.g. bewitchment by a neighbour), therefore specifying a cause of the illness. Thus, participants health actions were motivated by their need to understand varying interpretations and meanings of specific health conditions by locating the so called 'source' or cause of their illness which would inform the particular course of action taken. Kleinman (1977) explains that this process of explaining causes, origination and course as well as symptoms and treatment is mediated by the patients cultural system of articulating and explaining illness.

These cultural systems also exert a powerful influence over community members in terms of treatment decisions, such that patients often resort to practices that have been used over generations to 'cure' illnesses, including traditional medicine and home remedies, which often contribute to treatment delays and compromised health status. Modern health care, which is supposedly based on the bio-psycho-social framework, characteristically relates to social issues at a superficial level, without understanding the meaning behind patients health seeking behaviours, which are so easily labelled as "non-adherence" and "high risk behaviour". Holistic interpretations and interventions are thus crucial in effecting patient's participation in their health care and in ensuring positive health outcomes.

It is important to note that many participants in this study who consulted traditional healers in order to identify the 'real' cause of their disease did not continue with the prescribed treatment, since this health action did not reduce the disease threat, but rather exacerbated certain symptoms. As a result, these patients subsequently sought biomedical treatment, perceiving such action as potentially efficacious because of symptom persistence or deterioration. While these findings provide important insights with regard to the dual utilisation of biomedical and traditional health services, the net result is that the perceived benefits of immediate and prolonged biomedical care is constrained, resulting in negative health outcomes.

Hunte and Sultana (1992) provide insight into how patient's use combined treatment approaches and characterised this phenomenon as a 'juggling of alternatives'. They found that health care was frequently initiated with home/self treatment, followed by cosmopolitan treatment, with indigenous practitioners being visited for treatment at almost any time during the illness episode, especially when supernatural aetiology was suspected. Failure in achieving quick results from the chosen treatment strategy often precipitated a switch to other forms of treatment, a finding that was evident in this study.

Since most of the participants within this study reported seeking treatment from biomedical institutions for TB, one has to keep in mind that health care provider's who share similar cultural understandings of illnesses, often ascribe to explaining illness according to biomedical systems by focussing on identification and treatment of illnesses. These differences in interpretation may exacerbate misunderstandings or conflict between provider and patient and lead to patient perceptions of 'inadequate' treatment of illness. Whilst consideration must be given to the above cultural context of patients health seeking behaviour, Farmer (1997) argues that when taking into account the role of cultural explanations of illness, one should be cautious about ignoring the influence of structural dynamics, since this sets the stage for incorrectly attributing focus strictly to cultural variables when addressing illness and disease. Therefore by narrowing one's focus to cultural explanations of illness, the effects of structural factors social consequences such as poverty, social inequality, racism etc. are overlooked as potentially influential factors which impact on health, patients decision making capacities, regarding their health-seeking behaviour and ultimately status and health outcomes.

In conclusion, three central factors influenced patient's perceptions regarding the potential benefit of undertaking positive health actions. Firstly, the desire for rapid remission of symptoms resulted in negative perception of treatment efficacy. Secondly, delays in diagnosis had a negative effect on patient's health motivation, perceived health benefits and desires to continue with prescribed treatment regimens. Finally, patients in this study subscribed to complex explanatory models of illness which did not appear to be taken cognisance of by health care professionals and which compromised perceived

benefits of consistent biomedical care with negative consequences for patients health outcomes.

5.5 Perceived Barriers

Perceived barriers addresses the potentially negative aspects of a particular health action, which may act as impediments to undertaking the recommended behaviour. Gorin and Arnold (1998) describe this construct as a process wherein the individual weighs the actions expected effectiveness against perceptions that it may be expensive, dangerous (having negative side effects), unpleasant (painful, difficult or upsetting), inconvenient, time consuming etc.

Several factors were perceived as barriers to undertaking positive health actions. Firstly, patients demonstrated a poor understanding of drug regimens, which impacted negatively on their capacity to endure treatment side effects. This was exacerbated by a reported lack of feedback regarding their health status during treatment, which again negatively influenced their perception of the efficacy of the prescribed treatment regimen.

Female participants reported that the side effects that they experienced during treatment of their MDR-TB were unexpected and exerted a negative influence on their health actions. In such a situation one could hypothesise that these participants initially evaluated the expected effectiveness of their health actions (undergoing biomedical treatment), without being adequately informed as to the side effects of the prescribed drug regimen. This would explain the extremely negative perceptions of participants regarding treatment effects, which affected patient's adherence to treatment regimens. In this regard, McCallum, Wiebe and Keith (1988), showed that adherence was strongly related to perceived barriers to actions for subjects having no prior experience with medical regimens. MDR-TB drug regimens are very intensive and usually have side effects which participants are not familiar with, thereby having an extremely negative effect on patient expectations of treatment and treatment outcomes.

Similarly, most of the male participants reported never being adequately informed about the effects of their medication. These participants also reported being relatively unaffected by the diagnosis, since they knew very little about the types of medication used and its side effects. Where health professionals did inform them of a few side-effects (effects on hearing and vision), participants claimed to have not experienced such effects. This seemed to further undermine participant's confidence in both the health professional as well as the treatment that they received. One male participant recommended that patients should be given a pamphlet containing information about the treatment protocol to aid in their understanding of the treatment as well as the possibility of side effects from the medication.

Related to the issue of patient's inadequate knowledge regarding MDR-TB and its treatment, the majority of patients (both male and female) reported that they were not informed about their medical progress (e.g. they are reportedly not informed when they convert from positive to negative). They strongly believed that they were 'kept in the dark' with regard to their health status. Further, while patients were aware of the names of the different medications used in their treatment, they were not aware of how such medication contributed to the effective management of their disease. Particularly worrying in this regard were patient's accounts that the knowledge they have of the disease was acquired primarily by listening in on discussions between doctors and nursing sisters and from their medical records, which were read by those who were literate. These factors obviously acted as severe barriers to treatment adherence, health motivation and positive health outcomes.

Petersen (2000) argues that, "the social control function of biomedical discourse reinforces the status quo, excluding social change as a meaningful alternative...made possible by the power associated with professional medical knowledge which creates an asymmetry in the doctor-patient relationship in which the doctor assumes responsibility for the patients health" (pg.53). Thus, health care professionals' take over the parenting function from the sick patient, and thereby discrediting the patient's own self-knowledge and self-care as and subverting the patient's autonomy. These social control functions of

health care professionals prevent patients from taking an active role in the management of their health conditions, acting as a further barrier in the treatment process.

Secondly, diagnostic and treatment delays were perceived as barriers to positive health actions with most male participants describing the diagnostic process as time consuming and ineffective. Although these participants followed through on the diagnostic protocol, they were unaware of the possibility of being diagnosed with MDR-TB, since they lacked any formal knowledge of the disease. One could therefore hypothesise that in these cases, participants expected to be diagnosed efficiently with minimal loss of time and inconvenience, and believed that their health actions would be beneficial to their treatment. Their own accounts indicate that the diagnostic process did not meet these expectations and that the actual diagnosis had little meaning, thus serving as a barrier to subsequent treatment adherence.

According to Fishbein and Ajzen's (1975) Theory of Reasoned Action (TRA), the direct determinants of an individual's behavioural intention are his attitudes towards performing the behaviour and his subjective norm associated with the behaviour. Thus a person who holds strong beliefs that positively valued outcomes will result from a particular behaviour will have a positive attitude toward that behaviour. In light of the above, participants initial perceptions regarding their health actions were regarded as positive since they anticipated positively valued outcomes (i.e. early detection and treatment of their health condition). Subsequently, however, delays in diagnosis, lack of explanation/knowledge of their condition, and the presentation of their diagnosis as a death sentence, acted as very real perceived barriers to positive health actions and outcomes.

Patients (both male and female) who claimed to have a poor knowledge of MDR-TB believed that even medical practitioners had a poor understanding of the disease. They consequently felt that it was possible that treating them as 'normal' TB patients because medical practitioners were unable to diagnose them on time had wasted a lot of time. They felt that if MDR-TB had been made as a primary diagnosis, rather than only after a

person had resisted conventional treatment, the disease would be easier to manage with better results in a shorter time span. According to Wallston et al's (1978) Health Locus of Control Theory, one could hypothesise that these patients regarded their health status as unrelated to their health action (seeking biomedical intervention), since they perceived their health condition (diagnosis of MDR-TB) as determined by factors beyond their personal control (i.e. delay in diagnosis of MDR-TB, lack of early detection facilities). This has a direct effect on patient's beliefs in the ability of the medical system to deal with their illnesses effectively, thereby acting as, a further perceived barrier to positive health outcomes.

Thirdly, patient's reactions to the diagnosis of MDR-TB indicated adjustment difficulties in the face of a major life crisis, which acted as a major barrier to treatment adherence. The majority of female participants reported experiencing symptoms such as sadness, hopelessness, tearfulness and feelings of isolation typically indicative of a Major Depressive Disorder, on being diagnosed with MDR-TB. These psychological sequelae have a negative impact on patients' health action (adherence to treatment), since without adequate supportive services, patients are faced with the post-diagnostic decision of evaluating their treatment options and life expectancies against the possibility of enhancing the quality of their already foreshortened lives by defaulting on their present treatment.

Thus, the lack of containment of patient distress in the form of supportive services has a detrimental effect on patient's ability to cope with the post diagnostic stress of MDR-TB. O'Dowd et al (1998) makes reference to the "wolf, wolf" syndrome, which occurs when patients have been threatened by doctors and health care workers with dire consequences in the case of non-adherence or refusal of treatment. In situations where these patients do not suffer those consequences, they tend to become more sceptical and focus on the fear of pain and suffering in the here and now rather than on the long term goals to be attained. This creates a viscous cycle where unattended and unrecognised emotions result in the defaulting of treatment, which frustrates clinicians, whose behaviour further exacerbates the problem.

Petersen (2000) provides valuable insight into this viscous cycle by arguing that health care professionals are subjected to anxieties that require containment within the health care professional-patient relationship. She found that health care nurses experienced anxieties with regard to their competence to deal with illness related problems, reflected in their reluctance to get too involved in patients psychological problems for fear of uncovering problems they would be unable to cope with. Van der Walt and Swartz (in press) also describe how health care workers frustrations and anger originated as a consequence of what they may see as irresponsible and unmotivated patients. Thus without considering the dynamics of patients 'irresponsible' behaviour and reasons for their apparent de-motivation, health care workers may in fact be compromising optimal levels of patient care. Petersen (2000) suggests that both emotional and technical support to health care workers is necessary in such situations so as to optimise patient care.

The above arguments are especially pertinent in the case of extremely contagious conditions like MDR-TB. Hatch and Moline (1997) Johansson et al (1996), and Krishnan and Janicak (1999) suggest that health care workers fear of MDR-TB due to the risk of occupational transmission often leads to uncaring and unsupportive staff attitudes towards patients, which may impact negatively on patients adherence to and acceptance of treatment. The disease MDR-TB is the most lethal variation of TB and what complicates matters is that its transmission, unlike HIV/AIDS, can occur simply through breathing infected air particles. Therefore the very real threat of contracting TB/MDR-TB from patients has extremely negative consequences for how health care personnel interact with patients and contain their own anxieties.

In conclusion, three critical factors influenced patient's perceptions regarding the potential barriers to undertaking positive health actions. Firstly, patients' poor understanding of the treatment protocol, especially with regard to the side effects of medication, were perceived as barriers to positive health outcomes since patients found it extremely difficult to endure treatment side effects. Secondly, diagnostic and treatment delays were perceived as barriers to positive health actions, with patients describing the diagnostic process as time consuming and ineffective. The diagnostic process failed to

meet patient's expectations of swift diagnostic and remedial action. This ultimately compromised patient's self-efficacy, thus serving as a barrier to subsequent treatment adherence. Lastly, patient's reactions to the diagnosis of MDR-TB indicated adjustment difficulties and denial in accepting the diagnosis of MDR-TB, which acted as a major barrier to treatment adherence. Thus, in the absence of pre-and post-diagnostic counselling therefore, it appears that there exists very little real hope of treatment adherence and positive health actions.

5.6 Self-Efficacy

This construct deals with one's confidence in one's ability to successfully perform an action. According to Gorin and Arnold (1998), self-efficacy is defined as "the conviction that one can successfully execute the behaviour required to produce the outcomes"(pg. 47). Therefore in order for an individual to effect action for a beneficial outcome, she must feel competent to overcome perceived barriers to taking action.

Of concern regarding patients self-efficacy is the issue of the lack of proper protocol in addressing patient concerns regarding treatment and care. Complaints that emerged included an apparent lack of mutual respect between health care professionals and patients, patients fear of victimisation and intimidation by nursing staff in addressing their complaints, and a lack of communication between health care professionals and patients related to in-patient treatment and care. It could be hypothesised that these conditions have a deleterious effect on patients' levels of confidence in their ability to adhere to in-patient treatment protocols, since patients have expressed these complaints as barriers to understanding and sustaining therapeutic relations between themselves and health care professionals.

An interesting finding with regard to female patient's confidence in their ability to successfully perform beneficial health actions, was the reception that they received from health care professionals on admission. Patients who felt unwelcome during the admission process rationalised their perceptions as inconsistencies in the level of care

from health care professionals. Incidents such as the above throw light on the issue of patients' need for support from the point of admission, through to their treatment duration to help rejuvenate their confidence levels.

At a systemic level, health care settings perpetuate organisational disempowerment by allowing health care professionals to succumb to a set of rigid and elaborate hospital rules which protect them from the potential anxiety of having to take creative decisions, as well as robbing them of the opportunity and satisfaction of developing problem solving skills (Van der Walt and Swartz, in press; Petersen, 2000). These authors go on to describe, how health care workers frustrations and anger originate as a consequence of what they may see as irresponsible and unmotivated patients. Such anxieties, which may occur at an intrapsychic level, are alleviated by converting it into an interpersonal conflict. One could therefore hypothesise that such 'conflict' has manifested itself in the inconsistent levels of care patients feel during their admission and treatment experiences, which undermine their self-efficacy and full participation in their treatment protocol.

The majority of male participants reported experiencing 'ukuzenyeza' (low self-esteem), which impacted negatively on their ability to make appropriate health care decisions after falling ill. Feelings of low self-esteem are a further barrier to health action and have the potential to precipitate clinical depression amongst patients, which indicates the need for the provision of supportive psychological and social work services within the institution.

Westaway and Wolmarans (1992) show that in response to anti-tuberculosis therapy, delayed recovery was found to be related to depression, easily hurt feelings and feelings of helplessness. They found that in South Africa there is an urgent need for a measure of depression which is reliable, valid, easily administered and simple to score to aid in managing psychological disorders that co-exist with physical illnesses such as TB, which should lead to better patient management. Thus a structured therapeutic intervention would enable health care workers to strengthen the patient-system interaction, enhance patient self-efficacy, leading to more effective patient management and better health outcomes.

In summary, patient's collectively expressed feelings of disempowerment in their ability to address concerns regarding their in-patient treatment and care. This was exacerbated by a lack of mutual respect, fear of victimization, intimidation and lack of communication between health care professionals and patients. Female participant's perceptions of being made to feel unwelcome by staff had a negative impact on their levels of self-confidence in seeking and adhering to treatment, whereas males regarded their feelings of low self-esteem as impacting negatively on their ability to make appropriate health care decisions.

Chapter Six

Conclusion and Recommendations

6.1 Conclusions

The primary theoretical framework that was used in this study in order to understand patients health-seeking behaviour was the Health Belief Model. In terms of the Health Belief Model, patients with an optimal sense of perceived *susceptibility* and *severity*, and who evaluate the *barriers* and *benefits* of proposed health actions positively, would be likely to demonstrate reasonable levels of health motivation and self-efficacy, and thus be likely to engage in health promoting behaviour. What this means is that, by believing that one can have a condition (is susceptible), that the condition could compromise one's health status (i.e. the severity is great) and that taking a proposed health action will reduce the risk (benefits) without adverse bio-psycho-social consequences (barriers), a person will exhibit optimal levels of health motivation and self-efficacy and hence engage in the said health action.

What I will now offer is a synthesis of patients health-seeking behaviour through the lens of the HBM, constructed temporally in terms of pre-admission, admission and post-admission behaviour. What has emerged in this study is that for patients who are in the community (*pre-admission*), a number of factors coalesce to produce low levels of perceived susceptibility and severity to MDR-TB. These factors include, inter alia, large-scale community ignorance and lack of knowledge of MDR-TB, social stigma, conflation of TB and MDR-TB and the lack of recognition of symptoms at a community level. As a consequence, patients exhibit a low sense of health motivation, with the perceived benefits of seeking health care being low and the perceived barriers being high, due especially to social stigma and cultural factors. The net result is that patient's often conceal their diagnosis and delay seeking treatment. For those that do seek health care, the situation is further complicated by cultural influences, including the use of home remedies and/or consultation with traditional healers, usually resulting in the use of dual

healing systems and multiple remedies. The net effect is that treatment adherence for ordinary TB is compromised, thereby increasing the probability of conversion to MDR-TB. While the DOT strategy is a systemic attempt to improve treatment adherence at a community level, the findings of this study demonstrate that some patients feel disempowered by DOT in that the locus of control for their health shifts away from them. Therefore whilst DOT attempts to mobilise community support in ensuring treatment adherence, it could actually have a paradoxical effect on patient's health-seeking behaviour.

Once *admitted* into the ward, health care personnel presented patients with a doom and gloom scenario, with the illness being portrayed as a death sentence. Rather than promoting health motivation within a supportive and containing milieu, this portrayal of MDR-TB served to produce a heightened sense of perceived susceptibility and an exponentially elevated sense of perceived severity. The effect on patients (as would be predicted by the HBM) was a marked drop in *health motivation* and indeed, an elevated sense of fear and virtual paralysis. Thus, in the absence of proper counseling for patients with a terminal diagnosis, *health motivation* plummets whilst *susceptibility* and *severity* is elevated. Not surprisingly, the prospects for health promoting behaviour are very slim, with patients using denial as a defense against an overwhelming threat and externalizing the source of the problem onto health care personnel and the hospital environment.

This scenario is exacerbated by a disempowering and dehumanizing organizational culture within the institution, with minimal emphasis being placed on the patient as a whole person (which was indicated by a lack of empathic and holistic care), and further exacerbated by the lack of attention to patients fullest human development (which was indicated by a lack of recreational and learning activities). The resultant effect was a drastic decline in patient's *self-efficacy* and *health motivation*, the perpetuation of a vicious cycle of hostility between patients and health care personnel and ultimately, negative health outcomes.

Thus, patient's evaluation of the *perceived benefits* and *perceived barriers* to prescribed health actions (treatment adherence) is negative. In terms of the HBM, therefore, the resultant scenario is high *perceived severity* and *susceptibility* to disease, low *health motivation* and *self-efficacy*, with *barriers* to treatment appearing as insurmountable and the *benefits* of treatment negligible, which results in health damaging behaviour by in-patients in the TB unit in King George V Hospital.

While this study did not focus on *post-admission* behaviour, it would be very likely that these patients would leave King George V Hospital and go out into the community with a diagnosis of death hanging over their heads, convinced that they are destined to die. In this context it would not be unreasonable to assume that these patients would continue to engage in health damaging behaviours (e.g. smoking, alcohol use, unhygienic sputum disposal etc.), based on their beliefs of a foreshortened future and faced with the prospects of limited social support and even social rejection. Rather than engaging in health promoting behaviour, it is very likely that patient's sense of paralysis and denial will continue, as would their tendency to use splitting as a defense, where the source/cause of the problem will be externalized. While the health outcome for the patient will be devastating, perhaps more importantly, there appears to be very little hope, based on the finding of this study that these patients will actually engage in health promoting behaviours that will protect people within their communities from primary MDR-TB infection.

In summary, it is ironic that whilst these patients were treated within an in-patient facility for a lengthy period of time, which provides a golden opportunity for promoting health-seeking behaviour, their in-patient treatment experience was characterized by hostility, disempowerment and dehumanization, with deleterious consequences for both high-risk and general population groups.

6.2 Recommendations

6.2.1 Systemic interventions

Given the paucity of resources within our health care system, health care professionals are faced with performing multiple duties (at professional and non-professional levels) that have compromised their availability to deal with the full range of patient needs. These responsibilities have created high levels of frustration and burnout amongst health care professionals (Petersen, 2000), resulting in the provision of services, which are characterised by an emotional unavailability to people in need. Within this context, the biomedical bureaucracy serves as a defense, which contains the anxieties and frustrations of health care personnel. The net result, for the patient entering such a system, is to experience the full brunt of a hostile and uncaring institutional environment as exemplified in the experience of the participants in this study.

Fundamental interventions are therefore required to change the orientation of the South African health care system away from a disease-focussed biomedical approach to a whole-person centred humane one. This requires an injection of substantial resources as well as the concerted vision and effort of policy-makers and senior health care personnel, informed by the input of social and behavioural scientists. It is obviously difficult to foresee such a dramatic shift in the orientation of our health care system occurring in the short to middle term.

With regard to TB control specifically, a scientifically-based national TB/MDR-TB policy is required that is backed up by a health infrastructure capable of implementing policy imperatives (Hill and Fraser, 1995). However, several weaknesses exist in the implementation of present TB policy as insufficient attention has been given to the psycho-social, socio-cultural and environmental factors that impact on effective TB/MDR-TB control, more specifically amongst marginalised population groups (e.g. women, poor and rural communities). The focus on investing resources in search of a reliable pharmacological solution to existing epidemics and the investigation of

comparative demographic variables has not been matched by the development and implementation of an informed national TB policy. Thus, without an understanding of local knowledge and health beliefs, as well as behavioural responses to health problems and factors influencing health-seeking behaviour, national TB/MDR-TB policies may be rendered irrelevant, inappropriate and ineffective.

Therefore, in order to understand how people from diverse cultural backgrounds relate to the formal health sector, it is imperative that policy developers, including health care providers, gain an understanding of local knowledge and health behaviours within the context of cultural beliefs and practices. Rather than viewing these constructs as barriers to service delivery (Hill and Fraser, 1995), they should be used as mechanisms for developing integrated and participatory TB/MDR-TB control programmes that intersect with the local psycho-social, behavioural and environmental determinants that guide health behaviour.

Thus, strategies to produce a fundamental reorientation of the institutional culture of the TB unit at King George V Hospital are constrained by the above macro-context. Nevertheless, this section offers a range of practical recommendations that address the needs of both patients and staff, as a means of creating a more person-centred approach to the management and care of MDR-TB patients at King George V Hospital. A final and important constraint that should be borne in mind in considering these recommendations is that they arise from a synthesis of accounts of patients only. Further research, directed at understanding the dynamics underpinning the practices of staff and at unravelling the organisational ethos of the institution would obviously add immense value to the realisation of a comprehensive and systemic institutional intervention.

It is clear from the findings of this study that biomedical interventions are a necessary but insufficient condition for the control of TB infection at an institutional level. Consequently, health-promoting programmes that are based on an understanding of the dynamics underpinning the health-seeking behaviour of MDR-TB/TB patients have the greatest potential to be successful. Based on the aforementioned conclusions, strategies

for enhancing in-patient care must take cognisance of the needs of both patients and staff. Patient-focussed interventions should include the provision of psycho-social support services and as health education programmes based on the full participation of in-patients themselves and deriving from a fundamental reorientation of the treatment programme. In terms of the needs of staff, it is clearly important to provide ongoing continuing education programmes and psycho-social support in order to impact systemically on the orientation and approach of health care personnel and to inculcate a person-centred rather than a disease-centred institutional culture.

6.2.2 Patient-centred interventions

6.2.2.1 Provision of psycho-social support services

There is an abundance of research that demonstrates the positive effects of social support on health behaviour (Westaway and Wolmarans, 1992). Pillay (1993) has argued that the absence of social support is directly related to an increase in psychological and psychiatric symptomatology, as well as physical illnesses. He goes on to say that social networks have been found to influence a variety of health behaviours, including the seeking of medical care, lay referrals and the utilisation of health services. Thus, the perception that others are willing to help increases overall positive feelings, enhances self-esteem and instils a sense of stability and control over one's environment, which in turn may positively influence susceptibility to illness by indirectly strengthening the immune system (Pillay, 1993).

In light of the above, the provision of psychiatric and psychological services for MDR-TB in-patients is highly recommended, given the presence of psychiatric symptomatology as well as emotional distress amongst patients in the face of a major life crisis. The benefits of the group therapeutic modality could also provide much needed support for patients and provide a forum where patients can openly discuss issues, which they can share and learn from participants within the group. Considering that most patients experienced social problems as a direct or indirect consequence of their disease, the skills

of both psychologists and social workers may prove to be indispensable in providing patients with much needed support.

Such interventions should be directed not only at addressing issues at a personal level, but also at an organisational level, in order that grievances may be openly discussed and addressed by a neutral party, thus circumventing patients' feelings of intimidation by health care personnel. With this mechanism in place, efforts to counsel caregivers can be implemented to aid in affording patients the maximum level of social support needed to sustain health care initiatives. Health care professionals should also be provided with basic training in counselling skills in order to facilitate a person-centred approach to their interactions with patients. Especially significant is the need to understand and acknowledge the patient's cultural frame of reference rather than impose a biomedical top-down approach to patient care. In this regard, since the majority of the nursing staff are Zulu speaking and familiar with patient's cultural frame of reference, they are arguably in a good position to implement a holistic appraisal of patient's health behaviour, understand patient's perceptions, fears and concerns and provide culturally-sensitive interventions and support. This is contingent, however, on the provision of both education and support to contain the anxieties of nursing staff, which might otherwise sabotage the most well intentioned interventions, wittingly or otherwise.

6.2.2.2 Health education programmes

Formal health education needs to be integral parts of MDR-TB control programmes and the patient care process in particular, with major emphasis being placed on the prevention, aetiology, transmission and curability of the disease. By building on patients existing level of knowledge and awareness, health education programmes need to focus on identifying and addressing misconceptions and erroneous beliefs that act as barriers to treatment adherence and positive health actions. These health education initiatives should be informed by a culture-centred approach (Petersen, 2000), which enhances mutual understanding and co-operation between patients and health care workers so as to increase the success in MDR-TB control efforts. In particular, familiarity with patient's

explanatory models of illness may assist in providing a better understanding of patient's health seeking behaviour, resulting in well-informed and more successful health care strategies. Given a temporally stable patient base, it would be prudent and effective to adopt a peer-educational model of patient education rather than a didactic one. A further spin-off of such an approach would be to increase patient's level of self-esteem and self-worth in the ward with the added benefit of creating a cadre of MDR-TB patients who could act as peer educators at a community level.

Furthermore, MDR-TB patient's families should also receive regular counselling from appropriately skilled health care workers to facilitate a more insightful understanding of patient's needs, thereby maximising the provision of social support. In this way, families, spouses/partners and friends could also better understand the disease and help clarify misconceptions and erroneous beliefs that could influence not only the level of support patients receive during their in-patient treatment, but also serve to minimise the spread of TB/MDR-TB at a community level.

With regard to community health education initiatives, education programmes need to be designed to target populations with low literacy rates. These programmes should essentially focus on prevention strategies as well as providing community members with much needed exposure to relevant knowledge bases designed to maximise early symptom recognition, facilitate health-promoting behaviour and reduce misconceptions of MDR-TB. Channels for information dissemination could include schools, government clinics and NGO's, using persuasive health media campaigns (utilising newspapers, radio, billboards, posters and pamphlets) tailored to prevailing knowledge, attitudes and practices at a community level. These strategies should be complemented by a targeted peer-education approach in high-risk communities, within the parameters of resource constraints.

6.2.2.3 Review of in-patient occupational programmes

Given patient's complaints of 'boredom' during their in-patient treatment, it is recommended that the ward programme for patients be reviewed to facilitate the provision of recreational activities, which could include sporting activities, music, competitions and informal social activities between staff and patients as well as literacy classes to facilitate a more productive in-patient experience for patients. These interventions are fundamental to the realisation of a person-centred therapeutic milieu.

6.2.3 Staff-centred interventions

6.2.3.1 Reorientation of health care personnel

This can be facilitated through a continuing education programme focussing on, firstly, the need for health care professionals to understand the importance of a shift from biomedical care to person-centred care, emphasising the benefits of psycho-social intervention with regard to patient care. Secondly, the programme should address the need for health care professionals to understand the importance of taking into account the health-seeking behaviour of their patients, to facilitate the understanding that behaviour change is as critical to the control of the TB epidemic as are biomedical interventions.

Thirdly, the education programme should emphasise the importance of understanding the cultural context that informs patient's behaviour. And lastly, the programme should focus on the importance of understanding why institutional care needs to go beyond a hierarchical approach to ensuring adherence to drug regimens by emphasising the importance of taking into account the full range of psycho-social determinants of patients adherence behaviour.

6.2.3.2 *Employee Assistance Programme (EAP)*

In keeping with the trends in the private sector, a comprehensive and ongoing EAP should be designed and implemented, aimed at the fullest development of the human resource base of the health care system, in recognition of the value of social capital in South Africa. In particular, the EAP should focus on providing much needed support to those experiencing difficulties related to their psycho-social well-being as a consequence of occupational stress and particularly to the occupational risk of TB/MDR-TB infection.

This programme should be designed to support health care personnel and contain their anxieties by providing them with occupation stress management, staff group sessions (at least once a fortnight) and burnout counselling. Counselling needs to take into account the full range of psycho-social needs of health care personnel, with incentives being awarded to affirm staff and reward them for good performance.

6.2.4 Recommendations for future research

Notwithstanding the priority for health education as a component of TB/MDR-TB prevention strategies, programme effectiveness related to a strengthening of patient's knowledge base as well as attitude and behaviour change, needs to be evaluated. Since it has been found within this study that patients level of knowledge regarding the disease arguably changes during the process of diagnosis and treatment, it would be important to evaluate the extent to which patients comprehension, intention to adhere to the prescribed treatment and actual changes in behaviour are influenced by health education interventions longitudinally.

The findings of this study would be ideally complemented by ethnographic insights into the perception of health care professionals with regard to their health-caring behaviour. This would enhance our understanding of factors that influence service delivery as well as the quality of care, within the health care system. Future research therefore needs to determine the independent and combined effect of these factors on treatment outcomes,

with attempts at highlighting salient differences between males and females, using varied patient and staff populations, being potentially useful.

The influence of traditional healing as a part of recognised healing systems has been well documented, with the findings of this study demonstrating the existence and use of parallel healing systems, albeit from the perspective of patients. Future and more focussed research on this issue is required, that includes health care personnel and traditional healers as part of the study population. In particular, future research should seek to investigate the influence of locating the cause of an illness as a mediating factor in determining health outcomes. Since this study was located within a suburban in-patient environment, it would be interesting to investigate patients health-seeking behaviour within a community setting so as to provide insight into the factors that mediate patients health care decisions within this context.

One of the shortcomings of using the Health Belief Model lies in its individualistic orientation, since it focuses on theoretical constructs concerned with individual motivational factors as determinants of the likelihood of performing a specific behaviour. Future research should therefore use models that address factors contextual variables that impact on patient's decision-making processes. Such models should also recognise the importance of social influences on the individual and the effects of these factors on patients health-seeking behaviour.

Furthermore, future research needs to investigate the dynamics of organisational disempowerment, since this phenomenon has been profoundly implicated as a negative influence on in-patient care within this study. By using a systems approach, researchers will be able to provide insight into this phenomenon from a sociological perspective, thereby providing critical insights into how the health establishment structurally undermines positive health outcomes and accordingly offer recommendations for systemic change.

While the findings of this study confirm that social stigma impacts negatively on patients health-seeking behaviour, future research should investigate the relationship between communities lack of knowledge regarding MDR-TB and social stigma. Based on the findings of this study, for example patients described contradictory perceptions of the DOT strategy. This indicates that DOT interventions need to be reviewed in order to down-scale patient's sense of disempowerment and up-scale patients' sense of support during the treatment regimen.

Another prominent finding was that many patients delayed seeking treatment for their health conditions. To provide insight into this phenomenon, future research needs to investigate patient's delay in seeking health care interventions, perhaps using retrospective study designs.

Research on non-adherence has traditionally under-reported the influence of the social consequences of TB, which has been recognised as an important contributory factor in patient non-adherence with TB treatment and the length of delay in seeking health care. Expectancy models of adherence behaviour such as the Health Belief Model are concerned more with the subjective world of the individual, than with the impact of socio-cultural influences on patient's adherence behaviour. This highlights the need for research to investigate factors that determine patients non-adherence behaviour, taking into account the process by which psycho-social and cultural dynamics interface in informing patients health-seeking behaviour.

6.3 Limitations of the Study

Qualitative investigations designed to yield rich sources of data through thick description are also subject to a number of constraints pertaining to the reliability and validity of study findings. As highlighted earlier, focus groups have their limitations as a data collection strategy and some of these are highlighted in the following constraints:

6.3.1 Validity of verbal responses

In studies that comprise of variables investigating subjective phenomena (i.e. behavioural intentions, perceptions and beliefs), it can be quite difficult, when interpreting subjective data, to predict whether participant's verbal responses could be relied upon with any great degree of validity as a means of extrapolating actual behaviour. To the extent that it is doubtful whether individuals actually behave the way they say they do, the findings of this should be generalised to actual behaviour with appropriate caution.

6.3.2 Focus group facilitation

Two Zulu speaking fieldworkers (female and male) conducted focus group discussions, with the female fieldworker serving as the facilitator and the male fieldworker as the co-facilitator. Despite intensive focus group training, a factor that could have influenced the findings was the possible gender bias that accrued from having a mixed team of facilitators. Thus, both male and female participants could have been defensive with regard to certain phenomena that were deemed culturally inappropriate for participants to discuss with a facilitator of the opposite gender. This may have resulted in socially appropriate responses and under-reporting of certain issues.

Another problem that emerged for the focus group facilitators was the risk of infection from patients within the groups. The focus groups were thus held outdoors, which led to difficulties in maintaining privacy, minimising distraction and sustaining participant's attention as a consequence of the surroundings.

6.3.3 Data transcription

All focus groups were conducted in Zulu and subsequently transcribed verbatim. These transcripts were then translated into English and back-translated into Zulu in an attempt to ensure validity of the data gathered. While great care was taken during this process, it is important to note that misinterpretations and the loss of subtle nuances of meaning

could have occurred, despite the presence of the researcher during the focus groups and the de-briefings that were held with the fieldwork team immediately after each focus group discussion.

6.3.4 Instrumentation effects

As with other information gathering techniques, focus group discussions have their limitations. The focus group discussion allows the participants to influence and interact with each other, and as a result, group members are able to influence the course of the discussion (Kreuger, 1996). Group interaction provides a social environment; comments must be interpreted within that context and care must be taken to avoid lifting comments out of context and out of sequence. Participants occasionally modify or reverse their position after interacting with others, since they may evaluate the social appropriateness of their responses against that of other participants. While this is undoubtedly a strength of the focus group method, it could be argued that meaning that is derived would differ from that gained by conducting in-depth individual interviews.

Finally, full participation in qualitative research studies often requires the provision of incentives to participants. Given that the participants in this study were in-patients, no serious logistical problems were experienced, with a group incentive taking the form of a meal that was provided at the end of each group.

Given the scale and resources available for this study, limited sources of data were accessed, which would have served to support or refute many of the findings of this study. Therefore I would strongly recommend that future research in this area include data from multiple sources, particularly the perspectives of health care professionals within health care settings, which would provide a greater degree of insight into patients health-seeking behaviour.

6.3.5 Researcher effects

This understanding of MDR-TB patients health-seeking behaviour has been generated by my peculiar interpretation of the emergent data. Specific models of health behaviour, in particular the Health Belief Model, Health Locus of Control Theory and the Theory of Reasoned Action, informed my interpretation. It is important to note that the emergent data can be interpreted in many different ways and therefore, qualitative research “...requires reflexivity on the part of researchers as to their role in the research process” (Petersen, 2000). In this regard, I believe that the use of other theoretical approaches (e.g. systems theory, psycho-dynamic models) could certainly have added to and even changed my interpretation of emergent data.

A numerous of problems which were not fully anticipated during the planning stages of this study, were experienced whilst using the ethnographic method. Primary amongst these was the issue of language as a barrier to understanding patient’s discourse within their cultural contexts. It proved difficult to provide any meaningful description of patient’s reflective accounts, given my limited understanding of Zulu. Given that the translation of verbal responses by the co-facilitator during the group discussion would have been too time-consuming and distracting for participants and that it would have compromised my ability to observe non-verbal cues during the discussion process, I had little other alternative.

Apart from the intensive focus group training held with the facilitators, I had very little control over the process of providing cues to participants since I could not fully understand the content of the discussions apart from what was indicated by patients non-verbally. This further distanced me from the data and put me in the position of interpreting data from a secondary source rather than a primary one. After the process of translation, I found it difficult to extrapolate meaning from certain responses. This could have been due to my lack of understanding of certain cultural constructs and also the facilitator’s subjective interpretation of patient’s responses.

This made the task of contextually understanding patient's behaviour beyond its mere description, understanding why the behaviour takes place and under what circumstances, more difficult to conceptualise. A very real danger in my analysis of the data, therefore, was the possibility that my interpretation was overly-skewed by my own ideas that I brought to the collection and analysis of the data and perhaps under-informed by the data itself.

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Appendix 1:
Operational Definitions

Appendix 2:
Focus Group Schedule

PATIENTS UNDERSTANDING OF THE DISEASE

Question 1: What do you know about multi-drug resistant tuberculosis?

Question 2: Do you think that MDR-TB mainly affects certain people?

Question 3: Do you have an idea of how you contracted MDR-TB?

ATTITUDES AND PERCEPTIONS TOWARDS TREATMENT

Question 1: How did you feel when you were diagnosed with MDR-TB?

Question 2: Do you think that your MDR-TB can be cured?

Question 3: What were your expectations about the treatment and cure of MDR-TB?

FACTORS AFFECTING DECISION TO CONSULT BIOMEDICAL TREATMENT

Question 1: Are there any other forms of treatment that you have consulted prior to seeking treatment from formal health care facilities?

Question 2: What influenced your decision to seek treatment from formal health care facilities when you were first diagnosed with TB?

Question 3: How do you feel about your decision to seek biomedical treatment?

PATIENTS TREATMENT EXPERIENCE

Question 1: Describe the modes of treatment that you consulted when you decided you needed help?

Question 2: Where possible describe the positive and negative aspects of your treatment experience?

Question 3: How have you been treated by staff (doctors and nurses) during the treatment process?

Question 4: How do you understand the role of the staff (doctors and nurses) with regards to treatment?

Question 5: Do you have any suggestions regarding the role that staff could play?

*PERCEPTION OF PATIENTS REGARDING ATTITUDE OF HEALTH CARE
PROFESSIONALS*

Question 1: Do you think the staff treat MDR-TB patients differently from other TB patients?

Question 2: How would you describe your interactions with staff during your treatment?

Question 3: What are your opinions about the in-patient TB treatment you have received?

DYNAMICS OF NON-ADHERENCE WITH REGARDS TO TB AND MDR-TB

Question 1: Could you describe how you felt when your health status was not improving whilst on TB treatment?

Question 2: What do you think are the factors that made it difficult for you to seek or continue treatment for your TB?

Question 3: What do you think motivated you to discontinue treatment when you were first diagnosed as suffering from TB?

SOCIAL CONSEQUENCES OF TB/MDR-TB

Question 1: How did people in your family and community react, when they were told that you had TB?

Question 2: What was their reaction when they found out that you had MDR-TB?

Question 3: Do you think that family and community members understand your condition?

FACTORS AFFECTING MOTIVATION TOWARDS TREATMENT

Question 1: What do you believe to be your role in the treatment of your TB?

Question 2: Do you feel that your condition is improving or getting worse whilst on treatment?

Question 3: Have you in any way lost confidence in making decisions regarding your own health status?

Question 4: How does it make you feel knowing that the duration of your treatment at this hospital is not within your control?

Appendix 3:
Informed Consent Form (Patients)

My name is Sachet Valjee and I am a master student at the University of Durban-Westville. I am collecting data to understand your perspectives and behaviour with regard to multi-drug resistant tuberculosis and your experience of treatment that you have received. I would like you to participate in the group discussions that I will be conducting over the next few weeks. I do not require your name and whatever you have to say will be kept anonymous. Information from the group discussions will be used for research purposes and will help in improving the future treatment of MDR-TB patients.

I agree to participate in this study under the conditions described above.

Signature of participant:

Place:

Date:

Appendix 4:
Focus Group Transcripts

MULTI-DRUG RESISTANT TB

14 MARCH 2000

MALE GROUP

KING GEORGE V

1.

- One participant said, “When we arrive here we are told that MDR-TB is caused by defaulting treatment.” He further mentioned that he initially sweated, lost weight and persistently coughed. After a month he was told that he had TB and then now he is told that he had the type of TB, which resists to other treatment. He started taking treatment in July 1999 and has to take it up to 16 months.
- Another participant stated that he was initially told that he had TB and was subsequently put on treatment. When his condition showed no sign of improvement, he then went to see a physician who scolded at him and said that he did not allow his treatment enough time to take effect. He nonetheless referred him to the hospital. He was admitted for 2 months and was discharged to his home. He claimed that his spits were still positive at that time. His condition persisted and he went back to hospital. He was finally transferred to KGV.
- Another participant said that he is not sure about his condition because he initially took acetic treatment. However, later one it was discovered that he had TB. He took treatment for TB for 6 months. On examination, it was found that he had not improved adequately. Later, he was diagnosed with “strong TB.”
- Another participant stated that in 1998 started coughing. Physicians that he consulted said that he had fever. After 3 months his condition persisted and he sought treatment from the local clinic. The nurse referred to the “chest clinic” where they said he was healthy due to his physical structure. He insisted that they should investigate him. It was discovered that he had TB. He was then treated for TB for 9 months. His condition persisted and was later diagnosed with MDR-TB.
- Another participant said, “Sometime when you present to the clinic with TB, you receive fever treatment. At a later stage X-Rays are done. Until then you get wrong treatment.” In his situation, he got sick and received treatment for flu until X-Rays were done and then it was discovered that he had TB. He was hospitalized for 2 months and then got transferred to another hospital where he stayed for 6 months receiving treatment for TB. He was discharge to his home. He got sick again and sought help from the hospital. He was also transferred to another hospital where he stayed for 6 months. His physician told him that he had MDR-TB last year and was subsequently transferred to KGV. According to him, the difference between MDR-TB and TB is that TB is not as contagious.
- One participant stated, “Chances of survival with MDR-TB are slim to none. However, in my experience, MDR-TB patients recover quicker than TB.”
- Another participant felt that treatment for MDR-TB and TB is what explains the difference between the two conditions. All patients agreed with this assertion.
- Another participant said, “MDR-TB are much stronger than TB patients.”

- Another participant stated, “Firstly, you have to take treatment for 6 months. If you do not improve, you have to take it for another 18 months and if you do not improve you have to take it for 2 years. If you still do not improve – only God knows.”
- One participant said that he initially coughed and that physically there were no changes for a long time. Then, he started sweating. He sought help from the local clinic where his spits were taken for further investigations. The results came back with nothing of note. Finally, X-Rays were done and TB was discovered. He was put on treatment for TB for 5 months. It was noted that tablets were not effective. He was hospitalized and still took the same tablets.
- Another participant stated that he initially sweated and got tired easily. On further examination at the local hospital, it was discovered that he had TB.
- Another participant said that he had been having TB for 2 years. He came to KGV in February 2000.
- Another participant reported that he initially suffered from common cold and pneumonia and sought treatment from a specialist. He could not help him but referred him to the “chest clinic” in 1997. He was given tablets, which were ineffective. After 2 months, he went back to the clinic because he was not improving. The clinic referred him to hospital where he stayed until he was discharged in January 1998. He returned to work but still continued to take his tablets until he was advised to stop them by the “chest clinic.” After 2 months of stopping treatment, TB started again. He sought treatment from SANTA where he stayed for 3 months. He got discharged from SANTA because he improved satisfactorily. He nonetheless continued to take his tablets outside. TB persisted and he went back to the chest clinic. His foreman told the staff that his tablets were not working. His physician chased him away and he sought treatment from another “chest clinic” where he was told that he had MDR-TB. He had been at KGV for 7 months. He complained that when they are given a pass-out, they are not given all their medication.

2.

- All participants agreed that MDR-TB could affect anyone indiscriminately.
- One participant said, “We are told that MDR-TB is caused by defaulting treatment, patients are not to blame but clinics. However, we get blamed for it and this hurts us.” All participants agreed with him.
- Another participant stated that other people do get it through defaulting treatment.
- Another participant reported that he had been taking his tablets consistently and as instructed between January and November 1999 and they did not work. He was transferred to KGV. His physician did not tell him that he had MDR-TB but the nursing sister.
- Another participant said, “Physicians fail to recognize it because they initially treat us for TB and in the meantime the virus establishes itself within us.” He felt that MDR-TB affected his plans. All participants agreed that MDR-TB affected their life.
- One participant said that by now he should have completed his studies. His physician did not allow him to further his studies in the hospital. He abandoned his studies due to MDR-TB only 6 months before he completed them. He was hopeful that he would resume his studies in July 2000.

- Another participant stated that at work he worked under extremely dusty conditions and suspected that he could have contracted the diseases there.
- Another participant concurred with the above assertion.
- Another participant said that he might have contracted the virus in jail but failed to explain how this could have been possible. Most participants admitted that they had been jailed before.
- Another participant suspected that the blankets at hospital perpetuate it. All participants agreed that the hospital was not a safe “haven” for them as it is possible that the conditions at hospital make the virus to thrive.
- Another participant cited that they eat rice and soup constantly and alleged that this maintains the disease.
- Another participant stated that some of the patients do not take their tablets and hide them and, because they are not on treatment, they re-infect them.
- Another participant cited the conditions at the hospital toilets as breeding for the disease to be contracted and to thrive.
- Another participant mentioned carelessness as playing an important role.
- All participants agreed that there was enough ventilation at the hospital.
- Participants felt that during ward rounds they are not told about their progress.
- One participant said, “Even if your spit converts to negative, nobody tells about it.”
- Another participant stated, “We are not even allowed to view our own files.”
- Another participant reported, “We are not allowed to talk to our physicians directly by the nursing staff.”

3.

- One participant said he had not noticed any progress since he had just been admitted to hospital. He complained that he was not given much information concerning his condition.
- Another participant stated that nurses once attempted to inject him without his knowledge.
- Another participant reported, “Even if medication doses change, we are not told prior.”
- Another participant said, “I need to be respected.” He felt that he was belittled; the staff was not being genuine and that it treated them discriminately.
- Another participant said that they felt paralyzed to challenge the staff because “of the fear that they may be chased away.”
- Another participant complained about the carelessness of the nursing staff. He also reported that his family did not believe he had MDR-TB.
- All participants did not know anything about MDR-TB prior to their hospitals.
- One participant said that he asked his physician.

4.

- One participant said that if you are on treatment, MDR-TB could be cured.
- Two participants stated that for them treatment was helping.
- One participant said that he was put off injections but his spit had not converted to negative.

- Another participant reported, “I want to try traditional medicine.”
- Another participant concurred with the above participant but further elaborated. “I initially saw a traditional healer when I fell ill. I also use traditional medicine between my hospitalizations and when I went back to hospital, I felt much better.”
- Another participant confessed to having seen a traditional healer initially. He claimed that he took traditional medicine but improve in hospital.
- Another participant said that he did not notice much improvement with traditional medicine.
- Another participant admitted to having seen a traditional healer. The traditional healer told him that he had idliso. He prescribed some traditional medicine for him. But he did not improve significantly. He only noted significant improvement in hospital.
- Other participants said that they were cured for idliso and not TB by a traditional healer.
- Another participant reported that he went to a traditional healer for diagnosis only.
- One participant said that the only thing he knew about his treatment were the names of his tablets. He self-discovered them. He was never told specifically how they work.

5.

- One participant said, “I was not much affected by the diagnosis of MDR-TB because I did not know what it was.”
- Another participant also claimed that he was not affected by the diagnosis of MDR-TB.
- Another participant stated that he was not affected by the diagnosis of MDR-TB as well because on clarification he realized that it was not so bad.
- Another participant reported that he was not affected because when he came to KGV he was told that treatment for MDR-TB affects eyes and ears. However, he has never seen anyone among the patients who have such side effects.
- One participant mentioned that DOT occurs when a person is given treatment under supervision and as per the orders.
- Four participants were previously on DOT.
- One participant found DOT to be helpful for him.
- Another participant said that it had a negative impact on him because he became an object of ridicule and he felt dehumanized.
- Another participant said, “It makes you feel less responsible.”
- Three participants felt that DOT could reduce the incidence of TB.
- Two participants stated that there are people in the communities who are spreading TB.
- Another participant said that other people look down upon them with a condescending attitude.
- Another participant stated that TB is not a form of punishment.
- Another participant felt that the government needs to teach people about DOT because other people who contract TB think that they are bewitched. There is a clear lack of information in the communities.

- Another participant said that physicians discharge people who default treatment.
- Another participant stated that the government has to be careful.
- Another participant compared his hospitalization to being given a jail sentence.
- Another participant felt that the injection is like a form of punishment.
- Another participant stated that injections affected him.
- Another participant reported that when they report ill treatment by the nurses, they run a risk of being seen as bad people.
- Another participant said, “You have to be silence even if you are being abused.”
- Another participant recommended that pamphlets containing information concerning their treatment have to be designed and given to them.
- Another participant felt that there was no respect and communication between them and nurses.

6.

- The majority of the participants felt that their issues are treated according to their individual merits. For example, the pass-out period is standardized for everyone.

7.

- One participant said, “Except medication, there is no much activity within the hospital and no special treatment.”
- Another participant stated that MDR-TB patients should have special treatment because they spent the longest period of time in the hospital.
- Another participant reported that he had been working prior to hospitalization. Her employers have discontinued paying him his wages. Consequently, he could not support his family and felt left behind in life. In fact, he likened his hospitalization to be imprisoned.
- Another participant identified with the previous participant in that his employers also paid him his salary up to a certain period. Consequently, his children have since stopped attending school due to his TB. He understood that, from a business point of view it would not make business sense for his employers to continue paying him his wages because he was no longer productive.
- Another participant who identified with the previous two participants also reported, “My Company told me that there is nothing they could do for me any longer.” They arranged a pension fund for him.
- Another participant felt bad because “I am sending money home, instead I expect them to send me money.”

8.

- All participants agreed that their hospitalization resulted in the break up of their social relationship with their partners.
- One participant who was married said that his wife went away following his hospitalization spanning back to 1997. His children are now with his extended family.
- Another participant stated that he separated from his girlfriend as a result of his hospitalization.

9.

- One participant cited physician deterioration as a contributing factor toward the break up of relationships.
- Another participant said, “abantu bathi ngingathanda ibhokisi (how can I love a coffin).”
- Another participant reported, “Following such attitude, we default treatment.”

10.

- If they take Inkunzi/short tempered– strongest tablet – cannot eat. All participants agreed. It was also thought to cause “isilungilelo”.
- One participant advised that it helps to take it before sleep.
- Another participant said that he just cannot help it but vomits.

11.

- One participant said that his family depends on him and does not need to go to hospital.
- Another participant reported that he has had no visits from family.
- Another participant cited that lack of motivation leads to alcohol indulgency.

12.

- One participant said that he defaulted treatment for TB. He was told to take treatment for a 6-month period and stopped taking treatment on his own when the 6-month period lapsed.

13.

- One participant said that MDR-TB is not known in the communities. He felt that he had never experienced discrimination personally as a result of his condition but agreed that other patients had experienced it first hand.
- Another participant stated, “People say I am HIV/Aids positive. Some of my family members say subtle statements and look down upon me.”
- Another participant mentioned that when goes out on a pass-out, his children want to come in close contact with him. He is forced to scare them away from him for fear that they may contract the disease from him.
- Another participant reported that given the duration of treatment, other people get demotivated and tempted to try criminal ways to survive.
- Another participant said that he thought that his future was in sports. He used to be a good athlete.

14.

- One participant stated that some people adhere to and comply with their treatment and other activities while others do not.
- Another participant said that he felt discriminated against at work.

15.

- One participant said that fear affected his treatment. (All participants concurred with him). He further elaborated, “From experience, I took my treatment with no apparent improvement.”
- All the participants felt that the strict controls at hospital affected them negatively and tended to liken their hospitalization to imprisonment.
- Some participants complained about meals citing that their diet habits differ. But that is not taken into consideration and the assumption is that their diet habits are the same.

MULTI-DRUG RESISTANT TB 17 MARCH 2000

FEMALE GROUP

KING GEORGE V

1.

- She said that MDR-TB is a type of TB, which does not respond to tablets and requires an injection for 9 months. She was admitted at KGV in December 1999. Prior to coming to KGV, she stayed for 6 months in another hospital where she was being treated for TB. When her coughs showed no sign of abating, she was transferred to KGV.
- She was initially hospitalized and treated for TB with tablets for 3 months. She was discharged but soon came back as her conditions persisted. She stated that she worked for the TB centre. She also said, "MDR-TB affects a person who defaults treatment for TB."
- She initially took tablets for TB as well and was allergic to some of them. Every time she ingested them, she found that she shivered; her eyes reddened and had rash. Her physician discovered that she had hepatitis-B but did not disclose the diagnosis to her. She consulted another physician who, upon learning about her allergy, promptly discontinued some of the tablets she was taking. Nurses pressurized her to take all the tablets including the ones the physician had discontinued. She took them in their presence. On her way back home, she allergy started. As her condition persisted, she was transferred to KGV. She still was not aware that she had MDR-TB at this stage. Her allergy started once again at KGV. She was then put on a depo (injection) preparation. She felt that the injection did not help her significantly and it was discontinued. She has been told that her spit is negative. She felt that her condition has improved.
- Initially, she had been suffering from TB since 1995. She did not completely recover from it and was transferred to KGV in March 2000. The improvement of her condition has been very erratic. She has just been told that she suffers from MDR-TB.
- She said, "I have a stubborn virus caused by defaulting TB treatment."
- She was diagnosed with TB in June 1998 and subsequently took treatment for it. Her physician discontinued her treatment when she showed signs of improvement. In December 1998, her physical complaints started again. Her physician diagnosed her as suffering from pneumonia and was treated for it. In May 1999, her illness started again. She physician put her on treatment and she improved. He nonetheless changed her tablets after 3 months of taking them. Her illness got worse. She sought help in a public hospital where she was told that her "lung had a hole." The hospital contacted her private physician who had been treating her all along. Her physician rudely told them that he was professional and could not be told by anyone how to treat his patients. In January 2000, she was told that her "lung is finished." She was subsequently transferred to KGV. At KGV, she was told that she has "strong TB that is resistant to drugs."
- She did not believe that MDR is caused by defaulting treatment.

2.

- He said, “MDR-TB does not discriminate.” Other participants concurred with her.
- She stated, “MDR-TB can be caused by defaulting and other ways, but I did not default treatment because I was not taking TB treatment. I suspect that I might have contracted it from someone who had it.”
- She mentioned, “In March 1998, I suddenly started coughing and sought treatment from the local clinic. I was given tablets. However, coughing persisted after 1 month of taking tablets and referred to the hospital for further management. At hospital I was given tablets and an injection and a follow-up date. On my follow-up at hospital, the physician requested to invest me for TB and TB was discovered. I was referred to the TB clinic where I was put on tablets. No X-Rays or any other tests were done. After 3 months of taking treatment my spit was still positive and I was not improving. On 21 February 2000, I was admitted in another hospital until 03 March 2000. The physician told me that I had a strong TB and that one of my lungs was damaged.” (She looked very distraught).
- She said, “I initially thought I had idliso (she thought she was bewitched by family members.” She refused to take treatment. However, she no longer adhered to the belief that she was bewitched.
- Initially, her family thought she had idliso. However, they now believe that she has TB.

3.

- She said, “I was very hurt” and further elaborated that one nurse said to her “you have a kind of TB that is incurable and eventually you will die from this disease.” She further said that she believed that because the person that told her this was a professional nurse. She stated that the nurse also told that “even if it (MDR-TB) is cured, it can be asymptomatic or remission for a while but eventually starts again.”
- She admitted to feeling very hurt upon learning about the diagnosis of MDR-TB. She sought an explanation of the condition from a nurse. She initially became very hopeless but is not hopeful about the prospects of her conditions.
- She said that she was told by her physician that she had MDR-TB and that she would have to have to be hospitalized and secluded in her own ward. She appeared to be hopeful about the prospects of her condition.

4.

- She said that she could not see a traditional healer, although she would have liked to see one, owing to fact that her chest was very painful. Family members ascribed her illness to idliso. She sought treatment from the local clinic at her own peril.
- Another participant said that community health workers advised her that if she coughed excessively and continuously she should go to the hospital.
- Another participant stated that one of her family members had TB and that helped her understand her condition better.

5.

- One participant was put on DOT through community health workers.
- Another participant said that her sister who is a teacher administered her DOT.

- Another participant stated that her DOT was managed at work.
- Another participant declared that her brother managed her DOT.
- Another participant cited the local clinic as having been responsible for her DOT.

6.

- One participant felt that DOT helped her a great deal as would not be able take her tablets regularly on her own. The supervision aspect of DOT helped her because it ensured that she took her tablets as per the instructions.
- Another participant felt that she did not think DOT was a great idea as it made her realize that she was not being trusted.
- Another participant stated that she benefited from DOT because it made her withstand the difficulty in swallowing the tablets.
- Another participant concurred with the above participant and further elaborated that had it not been for DOT she would have definitely defaulted treatment. She mentioned a gray tablets – commonly known as imbongolo (donkey) among the patients as very being very difficult to swallow. Other patients agreed with her.
- Another participant also found the DOT to be helpful in that she “would have nearly vomited them all. The mere presence of another person helped me a great deal.”
- Another participant stated that she found the DOT to be helpful in that “my family would never belief that I am taking my tablets on my own.”

7.

- One participant said that she arrived at KGV at 7 a.m. At approximately 8 a.m. she was handed over to the admitting staff. The admitting nurse said that she had not come on the admission date. She had to travel with other patients in an ambulance that brought her to hospital to other hospitals. She was very sick at the time. She returned to KGV in the afternoon and the staff that attended to her then received her warmly (it is quite possible that nurses had changed shifts – the staff that attended to her in the morning was probably off duty).
- Another participant stated that she was well received. She further elaborated that she has not felt discriminated against such that she does not see her illness as different from other patients’. She feels “at home and normal here.”
- Another participant came out clearly and said that she was not happy with treatment at hospital. She claimed that she did not know the time when she should take medication. She further stated, “If you miss your medication for whatever reason and go to the nurse that distributes medication afterwards, she says, “Never follow me with a chart. She mentioned that she knew her medication very well and that she took 8 tablets. One day the nurse gave her 2 tablets. She followed the nurse and insisted on getting all the tablets. She was ill treated by the nurse.
- Another participant said that they are “treated equally in our ward.”
- Another participant stated, “Most of us are not told about our treatment.” She felt that she not given adequate explanation about her treatment by the nurses.”
- Another participant said that nurses laugh at her when she asks for extra meal.
- Another participant said that nurses are not the same, some are nice and others are insensitive.

- One participant said that health standards are not good within hospital. They are asked to wash their dishes in a space near where fesses, urine and spits are dumped. They are also not given good blankets.
- Another participant said that nurses are not the same, some are nice and others are insensitive.
- Another participant cited facilities as lacking in the hospital.

8.

- One participant recommended that the hospital be renovated because it is dusty and a way should be sought to combat snakes.

9.

- One participant said that she heard, "If you suffer from MDR-TB, you should not work hard." She further elaborated that she could not work as domestic worker after recovery.
- Another participant stated, "I had to discontinue attending school due to MDR-TB."

10.

- All participants agreed that they were not happy with the duration of their treatment (hospitalization) and depo preparation.
- One participant said that she attended occupational therapy and found it helpful.
- The majority of the participants agreed that they were discriminated against in their respective communities and that community members often attributed their condition to HIV/Aids.
- Most of the participants did not feel discriminated against in their families.
- One participant said that she was treated indiscriminately but she nonetheless has low self-esteem.
- Another participant also felt that she had lost weight as a result she has low self-esteem.
- Another participant said, "Its my sickness, its my gift from God. I keep telling myself that I'm not different from others."
- Another participant worried that her children were not well looked after and that they were no longer taking their medication.
- Another participant stated, "Its better to be hospitalized – taking treatment collectively helps. Even when you are loose appetite, it helps to see others eating who are in your situation. You get motivated to eat. In fact, life is more important than other things at home."

11.

No response.

MULTI-DRUG RESISTANT TB 8 JUNE 2000

MALE GROUP

KING GEORGE V

1.

- Had TB first, put on treatment for 6 months, went back for follow-up appointment, told that he was resistant to TB medication, continued treatment for 4 months, visiting sister told him that he had MDR, went to city and was transferred to KGV.
- Had TB for 6 months, took TB treatment, but no apparent improvement as he continued to feel weak, spent 6 months at SANTA, symptoms (i.e., weakness and not eating) persisted, has been at KGV for 5 months. He has been told that he has MDR but still receives the same treatment.
- He got diagnosed with "big" TB at KGV. He was initially treated for TB at St Lucia hospital where he stayed for 9 months. When his spit failed to convert and his condition did not improve even with treatment, he was referred to KGV. He has been at KGV for 5 months. He has improved. While at home, he did not know anything about MDR.
- He has been taking treatment for TB since 1996. During this period, he has been defaulting treatment. He has been at KGV for 5 months.
- His improvement from TB has always been erratic. He has been at KGV since November 1999. He is not receiving injection presently. He did not know anything about MDR prior to his hospitalization at KGV.
- He was working for someone when he got sick. His employer sent him to Osindisweni Hospital where he was hospitalized for 2 months. He was diagnosed with TB there. He was then transferred to KGV, where he has been hospitalized for 6 months. He was diagnosed with MDR at KGV hospital. He feels that he is improving. He stated that he was worried because his father was sick. During his treatment, he had problems with his ears and his body was itching. He was sent to KEH for an ear assessment. His TB treatment was reduced.
- He comes from Inanda. He took TB treatment for 6 months. When no apparent improvement noted, he was then transferred to KGV for further management. He was diagnosed as having MDR TB at KGV.

2.

- TB is much better than MDR. "MDR is very strong, it can even cause mental illness." He admitted to experiencing symptoms (e.g., confusion) that suggested that he was becoming mentally ill when he came to KGV.
- Other members of the group disagreed with the assertion that MDR can cause mental illness.
- MDR is very strong and incurable.
- MDR is different from TB in terms of treatment. Although he has been sick for 3 months, he has been at KGV for 2 weeks.

- He has been at KGV for 5 months. He took treatment for TB since June 1999. After completing the course, he was sent to X-Ray, which revealed no positive improvement. He was then transferred to KGV for further management. He was diagnosed with MDR at KGV.
- He has been sick since 1976/7. He was initially seen at Edendale Hospital where he was diagnosed as suffering from TB. He was sent to SANTA where he stayed for 6 months. He was discharged and remained asymptomatic for a year. He started vomiting blood again. He went back to Edendale Hospital and was transferred to Richmond Hospital where he treated for 8 months. Since then he has never been asymptomatic for longer than a year. He was transferred to KGV on 24 November 1999. He was diagnosed as suffering from MDR at KGV. He still does not know anything about MDR. He has improved. He gets injections trice per week.

3.

- The majority of the respondents agreed that MDR affects everyone.
- One of the respondents disagreed with the majority and stated that they are discriminated against at hospital. He admitted that he has been smoking cigarettes and drinking alcohol but stopped recently. He also confessed that he has been eating food indiscriminately. For these reasons, he suspects that he might have been vulnerable to MDR-TB.
- The other respondent was also doubtful or uncertain. He stated that he has not been looking after himself properly. Until recently, he has been drinking alcohol and smoking cigarettes. He further said that when he got better he heavily indulged in alcohol. His condition worsened. He felt that alcohol made him weak and vulnerable to viruses and bacteria.
- The majority of the respondents agreed that they also have not been looking after themselves properly as they have been drinking alcohol heavily and smoking cigarettes when their condition improved slightly.
- Only two participants denied a history of alcohol and drugs. One of them was the youngest member of the group. He was 17 years old.
- Generally, those respondents who had a history of alcohol use agreed that they indulged in alcohol and substances once they got better. Sometimes, they tried to make up for the time they spent in hospital by drinking heavily.

4.

- One participant admitted to having defaulted his treatment.
- The other participant cited "ubudedengu babezempilo" especially in terms of treatment as a source of their diseases. He declared that if treatment were initially geared towards MDR, he would have recovered speedily.
- All the respondents concurred with the above assertion.

5.

- One participant felt that it is not curable.
- Two participants stated that people who get better always come back.
- One participant said that it is curable but "ukungaziphathi kahle kwethu" results in relapses.

- One participant felt that "either you die or come back to hospital."
- One participant stated that it can only be reduced in severity and referred to it as "Aids number two."
- One participant said that other people get better.
- One participant said that MDR-TB cannot be prevented. Once you get it, behave responsibly.

6.

- He received a call at work from the local clinic and was informed that he had MDR-TB. He suspects that the clinic was skeptical to face him with the diagnosis because they mismanaged his illness. He further recommended that communities have to be educated about MDR-TB in much the same way they are educated about HIV/Aids. In that way, they stress associated with MDR-TB diagnosis may be normalised.
- One participant stated that he is "still in the dark". He has been at KGV for one month and has not been fully informed about MDR-TB. He was only told that his life has come to be terminal. He admitted to being very hurt following the diagnosis. He was also told that if he does not improve in hospital he will be discharged to die at home.
- Another participant stated that he is only physically weak and fatigued. Other than that he is well. He is therefore not convinced that he will die. Even if his sleep and dreams, he does not believe that he may not wakeup the following day.
- Another participant said, "Physicians can discharge you to die at home." He cited one man who used to sleep next to him at hospital who was recently discharged without sufficient improvement. He claimed that he was not bothered by the diagnosis.
- The youngest of all the participants stated that he defaulted his treatment for TB. He took them for 6 months. He mentioned being upon learning about MDR-TB diagnosis. He wondered how he got it because he took he was too young to contract it.
- This participant stated that the doctor told him that he would have to be hospitalized for at least 9 months. In he did not improve, another 9 months would have to be added.

7.

- Three of the participants agreed to have initially sought help from traditional healers. The rest of participants went straight to the clinic.
- One of those who initially saw a traditional healer said that he thought he has 'izibhobo', 'amahlaba' (sharp pains) and umkwebhelo. For this reason, he thought physicians were not competent in treating these conditions and accordingly sought help from traditional healers. Upon realizing that he condition was not improving, he went to the clinic. He was diagnosed as suffering from TB and instantly hospitalized.
- The participant who sought treatment from traditional healers reported that he has always suffered from several medical conditions including diabetes. When he sought treatment for diabetes, hospital staff said that he was too young to suffer from diabetes. For this reason, he claimed, he sought treatment for diabetes from traditional healers and developed skepticism and doubts about clinics. He interchangeably used traditional medicine and western medicine and noted tremendous improvement.

- This participant outwardly declared that he does not believe at all in traditional medicine and cited this as a source of conflict within his family. Since he came to hospital, he once used traditional medicine that used by other patients in hopes that he would improve. However, he did not note any significant improvement.
- He saw a traditional healer first and was helped. He believes that he was bewitched. The traditional healer gave him something to use to get rid of "idliso". He also clearly explained to him how the medication would get rid of "idliso". He warned him that it might even kill him. Upon using the substance given to him by the traditional healer, he literally saw "idliso" coming out. He then went to the clinic because he was feeling weak and bleeding profusely. The doctor told him that his insides, especially his lungs, were damaged. The doctor advised him to go to the hospital where he underwent X-Ray examination. Following the findings of the X-Ray, he was promptly hospitalized.
- His neighbor noted that he was not well physically and gave him money to go to the local clinic for medical attention. He stayed in the clinic for 2 months. When he failed to exhibit any observable improvement on TB medication, he was transferred to Osindisweni hospital. Finally, he was transferred to KGV after 6 months when his TB became resistant to TB medication.

8.

- The majority of the participants admitted to having been initially put on the DOT programme.
- The mentioned a variety of people who signed on their behalf including a father, mother and professional nurse.
- One participant stated that the DOT is a good idea. He was concerned that his children could have contracted the MDR-TB from him.
- Another participant felt that his would appreciate if very much if his family members could be tested for MDR-TB.
- He said that he signed on his behalf.
- He stated that the DOT programme is a good idea because there is usually irresponsibility on their part. "Sometimes, if we take treatment without supervision we are likely to take it for a brief period." In this way, the illness may intensify again.
- One participant admitted that some of the tablets are fearsome and unpleasant and it helps if they are administered under supervision by another person.

9.

- One participant stated that he has been at KGV for 1 month and has noted that the hospital staff is trying their best. However, he would appreciate it very much if recreational facilities could be expanded and access to shops be extended. He noted that although there is a tuck-shop within the precinct of the hospital, it has insufficient stock.
- Another participant complained about blankets. More specifically, he was unhappy about the texture (itches) and condition (dirt) of the blankets. He further recommended that patients should be allowed to bring their own blankets to the hospital. He was also not satisfied with food that the hospital provides in terms of amount and nature.

- Another participant said that he was unhappy about that they do not get medication that they ask for from the doctors. Apparently, when they get illnesses such as flu for which they need treatment, they report them to doctors. Doctors prescribe treatment for them, which never get to them. When they enquire with the nurses, they are told that it has been returned.
- Another participant complained about one general assistant who “does not care about us.” She distributes food to patients and “if you are not in your bed for whatever reason or asleep, she passes your bed.”
- All participants concurred with this participant.
- One participant stated that as far as he is concerned they do not experience any problems with light and ventilation.
- Another participant said that one nursing sister came to explain their condition to them.
- All participants disagreed with him.
- One participant stated that he once enquired about his tablets from a certain nursing sister who said, “Ask your doctor.” He mentioned that he was left hurt by this assertion so much so that he did not bother to ask his doctor.
- All participants felt that they need to be educated about their tablets.
- One participant said, “If you are given drugs, It would be appreciated if I could be told what is it for.”
- The majority of the participant felt that they are not respected as responsible adults at hospital.
- One participant stated that some nurse wake them up very early in the morning for no apparent reason.
- Another participant felt that they are treated as children.
- Another participant said that they are not told who to contact when they have complaints.

10.

- One participant said that he sometimes vomits.
- Another participant stated that it helps to have treatment explained to them because that increases their understanding of the treatment.
- Another participant felt that he would appreciate that if they could be given treatment on a full stomach.

11.

- One participant said that he felt better and took his treatment by himself.
- Another participant stated that he did not default his treatment and noted that side effects could lead to defaulting.
- Another participant said that he felt better and defaulted treatment.

12.

- One participant said, “If you have this disease everybody in the community says whatever they want. They say you have HIV/Aids. I come from a very close and

supportive family and that is what has been my pillar of strength” and he called that “isikithi”. He further elaborated that his brothers eat from the same plate with him.

- Another participant stated that some members of his community say “why are you perpetually ill.”

13.

- The majority of the participants stated that initially there is an element of “ukuzenyeza.”
- One participant denied such feelings.
- Another participant felt that his making decision has not been affected.

14.

- All participants agreed that this is problematic, especially if working.
- One participant stated that he still has to “fight” informing his employers about his hospitalization.
- Another participant stated that access to social workers has been available.
- Other participants preferred to have more games such as “umlabalaba”, snooker, table tennis, soccer and other recreational facilities.
- One participant said that he recently got a pass-out. He found his girlfriend being pregnant with another man’s child. He could not blame her nor did he mind considering the duration of the treatment programme.
- The youngest participant said that he had to dropout at standard 9. He felt that he would be felt behind and that by the time he goes back to school all his friends would have finished school.

MULTI-DRUG RESISTANT TB 8 JUNE 2000

FEMALE GROUP

KING GEORGE V

1.

- She initially had flu. She sought treatment from the local clinic where she was given cough mixture and tablets. She failed to show satisfactory improvement. Subsequently, she was diagnosed as suffering from TB and was put on treatment for TB for 4 months. When her condition showed no sign of improvement, she was transferred to KGV. She had been in treatment for TB at KGV for 5 months when her physician was changed. Her new physician diagnosed her as suffering from MDR-TB. She has been at KGV since May 1999.
- She also initially had flu and coughed severely. She sought treatment from the local clinic. She was given tablets and cough mixture. When she did not improve, she was referred to the hospital for further management. At hospital, she was diagnosed as having TB and was put on TB treatment for a year. X-Ray examination revealed no significant improvement. She was subsequently diagnosed as suffering from MDR-TB. She has been hospitalized at KGV since January 2000.
- She initially had colds and X-Ray examination suggested that she had TB. She was put on TB treatment since April 1999. After 4 months on treatment, she developed diabetes. She was hospitalized at Marrianhill for 6 months. Finally, she was transferred to KGV. Recently, her treatment was changed and a diagnosis of MDR-TB made.
- She had flu in January 1999 and was put on treatment. Subsequently, she was diagnosed as suffering from TB in October 1999. When no notable improvement was seen, she was transferred to KGV. At KGV hospital, she was diagnosed with MDR-TB and treatment for MDR-TB was started in March 2000.
- Initially, she felt something was moving across her stomach and as if she was pregnant. She started losing weight as well. She did not cough significantly. In 1998, she was treated for TB for a period of six months. Subsequent X-Ray examination revealed that TB had not subsided and treatment for TB was continued. In April 2000, she was hospitalized at the local hospital and further transferred to KGV where she was diagnosed with MDR-TB recently. She has been at KGV since 22 April 2000 and has satisfactorily improved.
- She initially had hot flushes and coughs. X-Ray examination suggested that her lungs were destroyed and this was attributed to TB. She was put on TB treatment for 6 months. She felt as if there was a sore inside her body and coughed "ubomvu". She completed her treatment. However, she was soon put on treatment again for two months. Finally, she was transferred to KGV where she was diagnosed with MDR-TB.

- Another participant stated, "I was very hurt when I first learnt that I had MDR-TB."
- Another participant said, "I became very sad upon learning about the MDR-TB diagnosis and cried copiously because I was separated from other patients at hospital. I was distraught and helpless because I thought I had a peculiar disease. I felt much better here at KGV because I am always within the company of patients who have the same condition."
- Another participant stated, "The community sister informed the local clinic about my condition. The local clinic transferred me to KGV."

6.

- The majority of the participants were initially put on DOT.
- One participant said that she worked as a domestic worker. Her employers took her to hospital and were actively involved in her treatment. She expressed that she was happy with them issued her treatment to her because they took good care of her.
- Another participant said that her nephew issued the treatment to her in evening. She stated that she was happy with this arrangement because she would not have the courage to adhere to the instructions.
- Another participant said that the DOT benefited her because she would have not adhered to her treatment on her own. She would become doubtful of her treatment every now and then. She sometimes thought that skipping a dose would not cause any problems.
- All participants agreed that the DOT is an effective alternative.

7.

- One participant said, "Since I have been here, I have had different reactions from the nursing staff. People are never the same."
- Another participant stated, "I have just been told today that I have MDR-TB." (This participant looked very distraught throughout the interview).
- All the participants felt that they would like to know more about their treatment. They also stated that they contend with boredom daily and this prompts them to ruminate about their families.

8.

- One participant said, "In view of the pass-outs constraints, she would like have more pass-outs."

9.

- None of the participants admitted to having defaulted their children.

10.

- One participant felt that her interactions with her family members have not changed. She basically avoids people in her neighborhood for fear that they could spread rumors about her condition.
- Another participant said that when she initially fell ill, she received treatment with other children from the local clinic who have since recovered from their illness. Following her failure to recover with them, someone in her community is spreading

the rumor that she is HIV positive. As far as she is concerned there is no discrimination in terms of interactions with her family members.

- Several other participants admitted that they have been labeled as HIV positive or suffering from Aids in their communities.
- One participant said her family members have neglected her. Her husband and brothers have not contacted her since her hospitalization. In fact, the nurses in her local hospital insisted that she should take HIV test. Even at KGV, health professionals insisted that she should be HIV tested. She is presently awaiting findings of that investigation.
- Only one participant said that she has not been discriminated against at home and in the community.
- Another participant stated that she has recently been hospitalized and diagnosed with MDR-TB, she was therefore in no position to comment.

11.

- One participant said, "It is important to make sure that you take your treatment accordingly."
- One participant stated, "When I initially came here and diagnosed with MDR-TB, I looked down upon myself. I even contemplated escaping from the hospital. But now I have accepted my condition and my family accepted it and no longer feel they way I used to."
- Another participant declared, "Initially, my family did not want to see me. As the time wore on, they gradually started to visit me here. Two of my bothers who used to get along with me very well have neglected me and have never visited me here. Some of my family members suspect I may be HIV positive. They even refuse to believe the HIV test result."
- Another participant also revealed, "My husband has not spoken to me since my hospitalization. Further, none of my family members has been here to see me. I have tirelessly been trying to contact them to no avail."
- Another participant said, "Only my mother comes to see me here in my family."

12.

- One participant said, "Everybody in my family has accepted my condition. My husband is very supportive and often come to visit me here."
- Another participant felt that other than missing her family, her job was likely to be affected by the duration of her hospitalization.
- Another participant said, "By the time I get out of hospital, my classmates would be far ahead of me."
- Another participant suspected, "In view of the fact that my husband might have not been fully treated for TB, he may be infecting our children with TB at home. In fact, one of my children was given a referral letter to hospital by health professionals who visited his school. He apparently lost the letter. I would appreciate it very much if all my children could be tested for TB."

Appendix 5:
Ethical Clearance Letters



University of
Durban-Westville

PRIVATE BAG X54001 DURBAN
4000 SOUTH AFRICA
TELEGRAMS: 'UDWEST'
TELEX: 6-23228 SA
FAX: (031)204-4383
☎ (031)204-4111

DEPARTMENT OF PSYCHOLOGY

Tel: (031)204-4423
Fax: (031)204-4611

Dr K. Naidu
Acting Deputy Medical Superintendent
King George V Hospital
28 September 1999

Dear Dr Naidu

Re: Permission to undertake research at King George V Hospital

I am a Masters in Clinical Psychology student in the Department of Psychology at the University of Durban-Westville (UDW) who, as part of my course requirements, wish to conduct a TB study at King George V Hospital. Please find attached a copy of my research protocol, ethical approval from UDW's Ethics Committee and a letter from my supervisor indicating his support for my study.

The implications of my study for your hospital would be with regard to patient involvement only, with no implication in terms of financial costs or use of equipment. The study would require the involvement of hospital patients as follows:

- Selected TB patients would be required to participate in six 90-minute focus group discussions (10 patients per focus group), with fieldwork being conducted over a period of 2 weeks. Times and venues for conducting these focus groups will be negotiated so as not to disrupt the hospital routine.

Please would you inform us at your earliest convenience as to your decision in this matter. You may contact my research supervisor:

Mr. Bhagwanjee: Tel. 204 4973
Fax. 204 4210

Or you may write to me at:

Mr Sachet Valjee
C/O Mr Anil Bhagwanjee
Department of Psychology
University of Durban-Westville
Private Bag X54001, Durban, 4000

Yours sincerely

Sachet Valjee



University of
Durban-Westville

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DEPARTMENT OF PSYCHOLOGY

Tel: (031)204-4423
Fax: (031)204-4611

Dr K. Naidu
Acting Deputy Medical Superintendent
King George V Hospital
28 September 1999

Dear Dr Naidu

We confirm that we offer our support for the study entitled "An investigation into the determinants of health-seeking behaviour of adult multidrug-resistant tuberculosis in-patients in a public health sector setting". We believe that the research protocol submitted by Mr Valjee is scientifically sound and we anticipate that the results of the study will make important practical and academic contributions.

The study has received ethical clearance from the University of Durban-Westville Ethics Committee and we trust that you will see fit to grant this student permission to conduct his research at your hospital.

Yours sincerely

A handwritten signature in cursive script that reads "Bhagwanjee".

Mr Anil Bhagwanjee
Supervisor
Dept. of Psychology



University of
Durban-Westville

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20 September 1999

MR. S VALJEE
DEPT. OF CLINICAL PSYCHOLOGY

Dear Sir/Madam

ETHICAL CLEARANCE : NUMBER 99113B

I wish to confirm that ethical clearance has been granted for the following project subject to:

- permission being obtained from the Superintendent of the respective hospital
- strict confidentiality being maintained

"An investigation into the determinants of health-seeking behaviour of adult multidrug-resistant tuberculosis in-patients in a public health sector setting."

Thank you

Yours faithfully

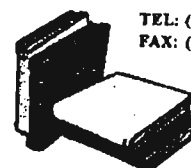
NEHRU NAIDOO
CO-ORDINATOR RESEARCH FUNDING

PS: The following general condition is applicable to all projects that have been granted ethical clearance:

THE RELEVANT AUTHORITIES SHOULD BE CONTACTED IN ORDER TO OBTAIN THE NECESSARY APPROVAL SHOULD THE RESEARCH INVOLVE UTILIZATION OF SPACE AND/OR FACILITIES AT OTHER INSTITUTIONS/ORGANISATIONS

cc. Head of Department

RESEARCH ADMINISTRATION



TEL: (031)204 5000
FAX: (031)204 4883



ALL CORRESPONDENCE TO BE ADDRESSED TO: THE HEAD - RESEARCH ADMINISTRATION

Tuberculosis: refers to an infectious disease caused by *Mycobacterium Tuberculosis*, which typically infects the lungs but may spread to other organs.

Re-admission: refers to those tuberculosis (TB) patients who have been admitted more than once to in-patient health care facilities as a result of a deterioration in their condition.

Multidrug-resistant (MDR) tuberculosis: refers to the spontaneous mutation of bacterial DNA which manifests when the patient fails to consistently follow the 6-12 month prescribed drug regimen, resulting in strains of *Mycobacterium Tuberculosis* that are resistant to two or more anti-tubercular drugs.

Non-adherence: refers to the failure of patients suffering from TB, to complete their prescribed course of TB medication, which may result in the development of MDR-TB.

Health-seeking behaviour: refers to a person's appraisal of behavioural strategies for preventing and managing a perceived health problem.