

**THE EXPERIENCES OF PATIENTS WITH REGARD TO SOCIAL  
AND HEALTH SERVICES FACTORS THAT CONTRIBUTE TO  
DELAYS IN SEEKING TREATMENT FOR TUBERCULOSIS**

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Theresa Rossouw

**KEYWORDS**

Patient

Health services

Delays

Tuberculosis

Social factors

Treatment

Diagnosis

Symptom onset

Disease

Case detection



## **ABSTRACT**

The focus of this research is the experiences of patients with regard to social and health services factors that contribute to delays in seeking treatment for tuberculosis.

The goal of this research study was to do an explorative study in order to establish the experiences of patients with regard to social and health services factors that contribute to delays in seeking treatment for Tuberculosis.

The objectives to meet the goal were an exploration and description of patients' experiences with regards to social and health service factors contributing to delays in seeking treatment for Tuberculosis. Another goal was to make recommendations on social and health service factors that contribute to patients' delays in seeking treatment based on the findings.

The research study had been of a qualitative nature exploring patients' experiences of social and health services factors that contribute to delays in seeking treatment for Tuberculosis. Qualitative research was used in this study using semi-structured interviews with an interview guide. Data analysis was done according to the eight steps as recorded in Tesch in Creswell (1994: 155).

The findings of this research were or include social factors contributing to patients' delays in seeking treatment for TB. There were four categories related to social factors namely socio-economic, substance abuse, psycho-social and interpersonal relations factors.

The findings also indicated that there were health service factors contributing to patients' delay in seeking treatment for TB. These include quality of health care services, attitudes of medical staff and other medical conditions treatment.

It was concluded that social and health services, as mentioned indeed contribute to patients' delays in seeking treatment for Tuberculosis.

Recommendations for practice included better case detection, treatment and health education. In order to address the various social factors as described above it is necessary to treat TB holistically and include a social worker as part of the multi-disciplinary team.



## DECLARATION

I declare that The Experiences of Patients with regard to Social and Health Services factors that contribute to Delays in seeking treatment for Tuberculosis is my own work, that it has not been submitted before for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged as complete references.

Theresa Rossouw



November 2008

Signed:.....

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My husband, Isaac for his unrelenting support and never-ending, unconditional love. Thank you for your steadfast belief in, and continuous encouragement towards me. My husband is a really exceptional and particular unselfish person whom I dearly love, cherish and appreciate.

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## DEDICATION

I hereby dedicate this dissertation to my sweet, adorable & angelic like, 3 year old daughter, Demi Nicole Rossouw, who passed away while I was still working on it.

*“Demi-nini, this one is for you, my child”*

*“Your mommy loves you”*  
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# CHAPTER ONE

## GENERAL ORIENTATION

### 1. BACKGROUND AND MOTIVATION OF THE STUDY

The focus of the research is social and health services factors and how it contributes to patient delays when seeking treatment for Tuberculosis. Tuberculosis is a “human disgrace” that has been in place for thousands of years (Health-e, 2008). The reason why it is considered to be a human disgrace is because it is an illness that is curable and it is not suppose to have escalated to become the epidemic that it is today. The medical science, primary health facilities, health education, funding, volunteers, training and Primary Health Care package that are available, all contribute to the treatment and eradication of tuberculosis.

TB can lead to serious irreversible damage of the lungs, disability and death (National TB Programme, 2006). Tuberculosis is a curable disease, yet millions of people die because of it. There were 1.7 million TB related deaths in 2004 and 98% of these were in the developing world (Centres for Disease control and Prevention, 2000). The serious impact of TB therefore contributed to this research.

Globally, 2 billion people are infected with Tuberculosis, with 8 million to 9 million new active cases a year. New cases of TB reported in 2005 were 8.9 million and 80% of these were in the twenty-two highest-burden countries. These countries are India, China, Indonesia, Nigeria, South Africa, Bangladesh, Pakistan, Ethiopia, Philippines, Kenya, DR Congo, Vietnam, Tanzania, Uganda, Brazil, Afghanistan, Thailand, Mozambique, Zimbabwe, Myanmar and Cambodia. As referred to these countries, twenty one of them are from the developing countries and nine countries are in Africa (National Institute for Health and Clinical Excellence, 2006; Zulu, 2006; WHO, 2006).

Over the last decade the global incidence of tuberculosis has increased dramatically. It is estimated that nearly one billion people will be newly infected, over 150 million will become sick and 36 million will die worldwide between now and 2020 (American Lung Association, 2006).

This is mainly due to four factors which are: Poor control in regions of South-east Asia, sub-Saharan Africa and Eastern Europe; High rates of co-infection of human immunodeficiency virus (HIV); the emergence of multi-drug resistant strains (MDR) and possible genetic factors. South Africa is placed at fifth highest in burden of disease and seventh highest in disease incidence (Fourie, 2006; Anglo-Gold Ashanti, 2006).

TB deaths by WHO Regions for the time period between 1998 and 2004, has increased from 209,000 deaths in 1998 to 587,000 deaths in 2004 (WHO, 1994-2004; TB Alert, 2005). Morbidity and mortality rates are increasing due to delays in TB diagnosis and treatment. TB kills nearly two million people every year, of which 90 % live in developing countries. There had been 1.6 million deaths due to infectious diseases in 2002 (<http://www.globalhealth.org>).

The health care system also faced the challenge of two massive overlapping disease epidemics, namely Tuberculosis and HIV/Aids. Persons infected with HIV are currently 40 million, with 5 million new infections per year. Co-infection with TB and HIV comprised of 12 to 24 million people. South Africa experiences a high burden of TB cases, which is negatively influenced by the high rate of HIV infection in the country. The TB incidence in South Africa is 500 per 100 000 of the population, with 66, 4 % of TB patients co-infected, so a deadly alliance exists between TB and HIV (Van Rensburg, 2004; Zulu, 2006; McGregor, 2000).

Another complication of TB in South Africa is currently an epidemic of Extensively Drug-resistant Tuberculosis (XDR-TB). The outbreak was first reported as a cluster of fifty-three patients in a rural hospital in KwaZulu-Natal. The mortality rate was fifty-two, which is an alarming high figure. The World Health Organisation (WHO) has warned that Extensively Drug-resistant Tuberculosis (XDR-TB), which killed sixty people in the Tugela Ferry area since January 2005, could have a severe impact on mortality in Africa and requires urgent preventive action (Morejele, 2008; WHO, 2006; Quintal, 2007).

The high incidence, mortality rate of TB, as well as complications due to HIV/Aids and XDR-TB highlight the importance of effective treatment of this disease.

The treatment of XDR-TB patients is alarming because the mean survival from sputum specimen collection (diagnosis) was only sixteen days before death. The majority of patients had never previously received treatment for tuberculosis. This strain of TB does not respond to any of the drugs currently available in South Africa for first- or second-line treatment (TB Alert, 2005).

The mortality rate of active tuberculosis if left untreated could be two out of three people. Treated tuberculosis has a mortality rate of less than five percent. Tuberculosis has been treated with combination therapy, Directly Observed Treatment Short Course (DOTS). This treatment is a major treatment procedure in the WHO global TB eradication programme. The WHO advises that all TB patients should have at least the first two months of their therapy observed (and preferably the whole of it observed). The success rate of treatment with properly implemented DOTS exceeds 95% and prevents the emergence of further multi-drug resistant strains of tuberculosis (Sidley, 2006).

The serious impact of TB globally and in South Africa necessitates the exploration and research of this disease in the Western Cape. The most recent statistical evidence of this TB epidemic in Cape Town are 25 754 newly registered cases reported in Cape Town Metropolitan area and 44 145 newly registered cases in the Western Cape, during 2004 and 2005. The incidence rate for Cape Town had been 874 per 100,000 and 967 per 100,000 for the Western Cape (Department of Health, 2006).

The incidence of TB differs however according to various geographical areas. In Ravensmead and Uitsig, two neighbouring areas in Cape Town, the rate of registered new smear positive TB cases increased from 228 per 100,000 in 1994 to 299 per 100,000 in 1998 to 341 per 100,000 in 2002 (<http://www.cdc.gov/eid/content/13/8/1189.htm>, 04/09/2008). Co-infection with HIV/Aids is also an important contextual factor. Khayelitsha, also in the Western Cape recorded that HIV/Aids and TB co-infection complicated the diagnosis and treatment of TB in 3,700 TB/HIV cases in 2006. These are mostly MDR/HIV cases (Centres for disease Control and Prevention, 2000).

It is evident that social factors contribute to the incidence and consequences of TB. Informal settlements where poverty and overcrowding are rife experience the most significant growth in reported cases, with the overall incidence rates in Cape Town now up to 874 per 100,000 populations ranging from 496 per 100,000 in Tygerberg to 1,612 per 100,000 in Khayelitsha (<http://www.cdc.gov/eid/content/13/8/1189htm>, 2008).

Social factors also contribute to patient delays in treatment for TB. Poor and vulnerable people are most likely to get TB and also face the biggest economic and social barriers to accessing TB care and treatment. Many TB patients also experience long delays between the onset of symptoms and seeking care as discovered by Dunn in Equi-TB (2005).

Health care services also influence the incidence and treatment of Tuberculosis. Low detection of TB-positive cases as well as limited information about factors contributing to delayed diagnosis and treatment play a role in the increase of the mortality rate. Early diagnosis and treatment of TB cases are very important in the fight to control and combat the disease (Liam & Tang, 1998:91; Dunn in EQUI-TB, 2005).

## **2. PROBLEM FORMULATION**

The problem formulation phase is the 'focus the project' (Neuman in Fouchè and De Vos, 2005:100). The research process always begins with identifying an area of interest and generating ideas for the study (Graziano and Raulin, cited in De Vos, 2005). To identify this area the researcher is supposed to answer the 'what' question: "What" is it about the topic that I want to find out? Some researchers find this quite a difficult question to answer, since it requires a very specific formulation (Holliday as cited in De Vos *et al.*, 2005:100).

The background of the study addressed the fact that Tuberculosis is a major health problem in South Africa. The statistical evidence regarding TB in South Africa as previously mentioned has also proven that South Africa experienced a rapid increase of TB incidence. Five hundred and fifty eight people, per hundred thousand people were infected with TB, in 2003 and the target for the cure rate was 84% globally and in South Africa 54%. The non-compliance rate was 13% in South Africa, while the global rate is less than 5% (WHO, 1996; WHO, 2003). High TB burden areas in SA are, the Eastern Cape (EC), Kwa- Zulu Natal (KZN), Western Cape (WC) and Gauteng Province (GP). These provinces contribute about 80% of the total burden of TB in South Africa.

When considering the above the improvement of case detection is an urgent and serious challenge for South Africa. The detection of new sputum smear positive cases was 52% in 2003, which is far below the WHO case detection target of 70%” (WHO, 2003: 24).

Delayed diagnosis may result in more extensive disease, complications and higher mortality. It also leads to an increase period of infecting the community with TB. Delays in the diagnosis of TB have been studied in both high and low income countries and vary significantly from 8.1 weeks in New York to 12 weeks in Botswana and 26 weeks in Tanzania (Yimer, Bjune & Alene, 2005).

The delays are in many instances caused by health system related problems such as insufficient managerial capabilities, shortage of financial resources, many cases remain undiagnosed (the undiagnosed patients also contribute to difficulty in control), failure of the health care systems to diagnose patients timely and access to health services. A lack of political commitment contribute to the above factors (Van der Velden, Van Ginneken, Velema, De Walle, & Van Wijnen, 1995; Lienhardt, Rowley, Manneh, lahai, Needham, Milligan & McAdam, 2001).

Tuberculosis is not purely a medical problem and will increasingly be difficult to control in South Africa unless the socio-economic problems of society, which contribute to the rise in its incidence, are addressed. The spread of TB in this country is increased by some uniquely South African socio-economic problems. These include large communities living in informal settlements, rapid urbanization, poverty, unemployment and the rising of HIV infection. Other contributing factors are population growth, poor socio-economic circumstances and the individual perceptions and severity of the disease (Kleinsmith, 1999; Van der Velden *et al.*, 1995; Lienhardt *et al.*, 2001)

Studies on social and health care factors influencing patient's compliance in TB treatment were done in other countries for example Brazil, Malawi and China (Equi-TB, 2005). The researcher finds it necessary to do this research about social and health factors to determine the experiences of people living in the Western Cape (South Africa) considering the importance of early detection, the results of delayed diagnosis and the social and health service factors which has an impact on these delays. The incidence and the effects of delayed diagnosis of TB in the Western Cape necessitate such a study in this region.

### **3. RESEARCH QUESTION**

Green and Thorogood (2005:27) mentions that the 'logic' of developing research protocols suggests first identifying a specific research question and then developing a suitable research design to produce data that will answer the question. They also further mentioned that good research questions are 'researchable' in that they are restricted and specified enough for the proposed study to produce the data to answer them. Creswell (1998:99) is of the opinion that a researcher should condense her or his entire study to a single, overarching question and several sub-questions. These questions are usually open-ended, developing and non-directional, reaffirm the purpose of the study in more specific terms, start with words such as 'what', 'which' or 'how' rather than 'why', and are few in number and are directed in various forms.

The research question for this research had been as follows:

Which social and health service factors, as experienced by patients (in South Africa, Western Cape); contribute to delays in seeking treatment for TB?

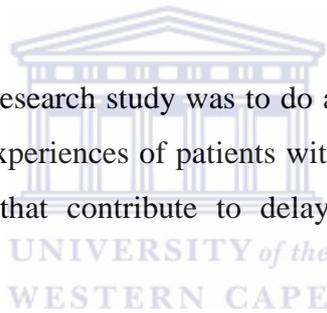
The goal and objectives of this study originate from this question and are discussed in the following section.

#### **4. GOAL AND OBJECTIVES OF THE RESEARCH STUDY**

##### **4.1 The goal of the research**

De Vos, 2005:398, states that goals refer to the broad situation or outcomes that are preferred by the relevant population. Objectives refer to those more exact changes in programmes, policies or practices that are assumed to add to the broader goal. Stating broad goals and objectives explains the planned ends and process of the intervention research project.

The goal of this research study was to do an explorative study in order to establish the experiences of patients with regard to social and health services factors that contribute to delays in seeking treatment for Tuberculosis.



##### **4.2 The objectives of the study**

One of the first stages of the research plan is to portray the aims and more comprehensive objectives of the study. There is a comprehensible understanding between aims and objectives, which as they pointed out, 'is a matter of extent rather than kind'. Objectives are simply 'at the level of operational tasks', which have to be achieved in order to meet aims (Bowling, 2002:138).

The objectives to meet the goal were the following:

- To explore and describe the experiences of patients with regard to social factors that contributes to delays in seeking treatment for TB.

- To explore and describe the experiences of patients with regard to health services factors that contributes to delays in seeking treatment for TB.
- To make recommendations on social and health service factors that contribute to patients' delays in seeking treatment based on the findings.

## **5. RESEARCH APPROACH**

Qualitative research attempts to examine people in their natural social settings and to accumulate naturally occurring data. Qualitative research also describes in language rather than numbers the qualities of social phenomena through interviews (Bowling, 2000:312). Qualitative research, as a research approach, is a method of discernment based on distinct methodological traditions of inquiry that explores a social or human problem. The researcher constructs a complicated, holistic image, analyses words, reports detailed views of informants and conducts the study in a natural setting (Creswell, 1998:15). The research study had been of a qualitative nature exploring patients' experiences of social and health services factors that contribute to delays in seeking treatment for Tuberculosis. The qualitative method of inquiry used in this study was semi-structured interviews and the data analysis was done by analysing words and giving detailed account of the patients' experiences.

## **6. TYPE OF RESEARCH**

Research could be labelled as either basic or applied. Basic (or pure) research seeks empirical interpretation that can be used to devise or improve theory. It is not concerned with solving the urgent problems of the discipline but rather with extending the database of the discipline. Applied research on the other hand, most often is the scientific planning

of induced change in a problematic situation. Basic and applied research is perceived as broad goals of research, and exploration, description and explanation as objectives, mostly of basic or knowledge-generating research as discovered by Fouchè and De Vos (2005:105).

Basic research advances fundamental knowledge about the social world. It can be exploratory, descriptive, or explanatory. Research problems and subjects are chosen with an immense deal of freedom with basic research methods, whereas with applied research methods, research problems are 'only just constrained' to the demands of participants. Exploratory research usually has a basic research goal, and researchers commonly use qualitative data (Fouchè and De Vos, 2005:106; Neuman, 2000:23).

The researcher made use of basic research to explore and gain knowledge regarding the experiences of patients with regard to social and health service factors that contribute to delays in seeking treatment for TB, since it further explored knowledge about the topic at hand. The researcher will make use of the knowledge gained to make recommendations about the services rendered by the health service institutions.

## **7. RESEARCH DESIGN AND METHODOLOGY**

### **7.1 Design**

Bowling (2002:143) mentions that the research design refers to the whole structure or plan of the research. The qualitative approach to design contains quite a few distinctive features, as revealed by Creswell (1998:18-19).

The research design encompasses the procedures and techniques that are suitable to answer the research questions. The design is also a bridge between conceptualising and operationalising research (D’Cruz & Jones, 2006).

The research design that was used in the study include explorative research, in order to explore the experiences of patients with regard to social and health services factors that contribute to delays in seeking treatment for TB. Yegidis and Weinbach (1996:92) reported that exploratory research is appropriate when problems have been identified, but our understanding of them is quite incomplete. The researcher identified that the delays in seeking treatment for Tuberculosis as experienced by patients could be problematic. However there is also a need to understand, which factors contribute to the reasons why patients delay seeking treatment. The research design encompassed therefore sampling of appropriate participants as described above. The design also included semi-structured interviews and qualitative data analysis because the researcher was of the opinion that these are the most appropriate to explore the social and health service factors that contribute to delays of TB treatment.

## **8. DATA COLLECTION**

It is very important to make use of accurate and appropriate data collection methods with TB patients, since people usually have rich, in-depth information to share about their illness. They need to talk about how they became infected, the symptoms experienced, how long it took for them to seek treatment and about which social and health service factors contributed to their delays in seeking treatment. Data collection was done by means of semi-structured interviews. An interview guide was used to assist the researcher during the interviews. (Refer to Addendum 2). The researcher decided to use semi-structured

interviews with a guide because TB, health service factors and treatment are complicated issues to comprehend for people not medically orientated. Semi-structured interviews are used to gain a detailed picture of a participant's beliefs and perceptions about a particular topic. Research on qualitative techniques clearly illustrates the importance of conducting semi-structured interviews in order to understand how patients define their medical conditions and treatment (Bowling, 2000:336).

The interviews had been recorded with the use of an audio-tape (with participants' permission). This enabled the interviewer to attend to the informant, rather than manually recording all the responses, and communicate that the respondent is really listened to. Participants can easily feel intimidated by tape recorders however Bowling (2000:339) perceived that tape recorders are rarely intrusive as people forget about the recorder once the interview gets under way.

Interviews had been conducted in the three major languages of the Western Cape, namely Afrikaans, English and Xhosa. The consent letters had also been drawn up in these languages. An interpreter was used to assist with an interview that was conducted in Xhosa, since the researcher does not understand Xhosa.

The interpreter also assisted with the translation of the consent letter and one set of questions. Consent had been requested and received from the participant, to make use of the interpreter. The interpreter had the basic knowledge and skills in research and the researcher only directed him about what his tasks were to be and how to perform it, with this specific interview.

## **9. PILOT STUDY**

A pilot study is usually informal, and a few participants possessing the same characteristics as those of the main investigation can be involved in the study, merely to establish certain trends. The purpose is to determine whether the applicable data can be obtained from the participants (Strydom, 2005:206).

A pilot study was done approximately three weeks prior to the time that the actual interviews took place. The researcher performed the first three interviews with the first three TB patients, as part of the pilot study. The pilot study proved to be successful. The participants possessed the same characteristics as the rest of the research population.

## **10. RESEARCH POPULATION**

Mason as cited in Silverman (2003:252) states that the population should be a group of particular 'processes, types, categories or examples' which are relevant to or appear within the wider universe.

The research population consisted of ten TB patients, who attend the St. Vincent clinic in Belhar, which forms part of the broader Western Cape Province, in South Africa. These TB patients presented with a delay of three months (as the minimum length of delay) in the time interval between symptom onset and their first medical treatment.

## **11. SAMPLING**

The primary purpose of sampling is to collect specific cases, events, or actions that can clarify and deepen understanding about the research study as reported by Neuman (2005:211). He further states that qualitative researchers' focus is on how the sample or small collection

of cases represents social life. Flick, as cited by Neuman (2005:211) differs from Neuman when he states that people that studied had been selected according to their relevance to the research topic rather than how they represent the study.

Non-probability, purposive sampling was the method used to select participants for this study because the principle for this sample prescribes that all possible cases must be obtained that fit the particular criteria, and various methods should be used. The researcher selected cases with a specific purpose in mind, which illustrates some features that is of interest of a particular study (Neuman, 2005; Silverman, cited in Strydom, 2005:202).

Qualitative interviewing is usually based on small sample sizes, and the sampling techniques preferred include purposive sampling (Green and Thorogood 2005:57). The research encompass of a small sample, because no new data emerged from the interviews.

The researcher has purposely chosen to work with TB patients who have presented a delay of three months (as the minimum length of delay) in the time interval between symptom onset and their first medical treatment. The researcher decided to use three months as the minimum length of delay. This decision was made on information given during an interview that was conducted with Mr. Flip Daniels, the facility manager of St. Vincent Drive Clinic, during 2007. He reported that the length of delay could differ from patient to patient. He has worked with TB patients for more than twelve years and reported that delays in patients seeking medical treatment for the first time after symptom onset can vary from 2 days up to six months. He stated that this information is obtainable from the history sheet, in the patient's file. The researcher decided to use three months as the minimum length of delay. Daniels (2007) stated that: "The length of delay could differ from patient to patient. I have worked with TB Patients for more than

twelve years and can report that delays in patients seeking medical treatment for the first time after symptom onset can vary from 2-days up to six months. This information is obtainable from the history sheet, in the patient's file".

Participants of 18 years and older had been selected. The researcher chose participants older than eighteen, because they are all adults, who can give consent. Each participant was able to communicate in either one of the three official languages as patients of St. Vincent Drive Clinic in Belhar represented all three languages.

## 12. DATA ANALYSIS

Data analysis could only be done after the process of selecting a population and sampling method, completing a pilot study and conducting interviews had been finalized. Data analysis means a search for patterns in data – recurrent behaviours, objects, or a body of knowledge and that the analysis of qualitative research data requisite considerable understanding by the researcher. The researcher had to do comprehensive reading to understand and interpret the data obtained from the participants (Neuman, 2005:440). Coffey & Atkinson (1996:108) further argues that analysis is not simply a matter of classifying, categorizing, coding or collating data. It is not simply a question of identifying forms of words or regularities of action. Analysis is essentially about the representation or rebuilding of social phenomena. It is a repeated process and an automatic activity.

Patton as cited in De Vos, 2005; Denzin & Lincoln, 2003 & De Vos, 2005, agrees with the above-mentioned authors when they stated that, qualitative analysis transforms data into findings or themes which involves reducing the quantity of unprocessed information, sifting significance from trivia, identifying significant patterns and

constructing a framework for communicating the essence of what the data reveal. Researchers also identify themes, describe them, and compare them across cases and groups. Finally they combine themes into conceptual models and theories to explain and predict social phenomena.

Data analysis is according to them also the process of bringing order, structure and meaning to the mass of collected data.

The researcher gathered data, which will be analyzed according to the following eight steps as recorded in Tesch in Creswell (1994: 155).

- The researcher read all the transcriptions through, and a sense of the whole was obtained. Some ideas were then jotted down as they came to mind.
- One interview was then selected and the researcher went through it thinking about the underlying meaning in information. Thoughts that came to mind were then written down in the margin.
- When the above-mentioned task was done for several participants, a list was made of all topics. Similar topics were then clustered together. Topics were then formed into columns, with columns for major topics, unique topics and leftovers.
- The list was then taken and the researcher returned back to the data. Different colour highlighters were used to distinguish between the different topics. The appropriate segment were then coloured in the same colour as the topic.
- The topics were then turned into categories. Grouping together topics that relate to each other later reduced the list of categories. Lines were drawn between the categories to show interrelationships.
- The data material belonging to each category was assembled in one place and a preliminary analysis had been performed.
- Existing data was then sorted again according to their colour schemes.

The research design and methodology were discussed in the above text and the researcher will now continue to discuss another important aspect of research, namely the ethical aspects.

### **13. ETHICAL ASPECTS**

Ethical issues are the concerns, dilemmas and conflicts that arise over the proper way to conduct research. Ethics define what is or is not lawful to do, or what 'moral' research procedure involves (Neuman, 2000:90).

Recognition and management of ethical aspects are very important if successful practice and research were to be achieved. Researchers have two basic categories of ethical responsibility, which include those to participants, both human and non-human, who participate in a project, as well as to the discipline of science in being accurate and truthful in the reporting of their research (Strydom, 2005:56).

Direct involvement of a field researcher in the social lives of other people raises many ethical dilemmas. The dilemmas arise when the researcher is alone in the field and has little time to make a moral decision. It is therefore very important for the researcher to consider the ethical aspects when conducting a research study, in order not to exploit the participants, participating in the research. The researcher should protect the rights of the participants and the ethical aspects ensure that it happens (Neuman, 2005:397).

In order to adhere to the ethical aspects the researcher abided by the general Ethical Code as prescribed by the South African Council for Social Service Professions, 1986, while undertaking the research study.

The rules and regulations as prescribed by the Higher Degrees Committee and Senate at the University of the Western Cape were also followed to ensure that the research study run its course in an ethically correct manner.

There are various ethical issues that the researcher should recognize and manage in order to be ethically responsible and these will be discussed as follows:

### **13.1 Potential harm to participants**

The researcher should consider the consequences of research for those being studied and must evaluate each case, weights potential harm against potential benefits and bears the responsibility for the decision (Neuman, 2005).

Subjects can be harmed in physical, emotional, legal, as well as to a person's career or income. Emotional harm to subjects is often more difficult to predict and to determine than physical discomfort, but often has more far-reaching consequences for participants. The researcher is ethically obliged to change the nature of his/her research rather than expose his/her participants to the faintest possibility of physical and/or emotional harm of which he/she may be aware (Strydom, 2005:58; Neuman, 2000:92).

In this research the researcher attempted not to harm the participants, although emotional harm could be present but was difficult to recognize. There had been no discrimination made against participants with relation to their medical background, gender, class, ethnicity, ability, or sexual orientation. The researcher realised that most of the participants had already been a victim of stigmatization, exploited and discriminated against, because of their disease. The researcher therefore attempted not to discriminate, manipulate or exploit the

participants in any way. Participants were treated with the necessary respect and dignity, by means of communication skills and non-verbal cues, such as body language and facial expressions.

### **13.2 Informed consent**

Informed consent is the principle that individuals should not be forced, or persuaded, or induced, into research 'against their will', but that their participation should be based on voluntarism, and on a full understanding of the implications of participation (Green and Thorogood, 2005; Neuman, as cited in Strydom, 2005:59).

Informed consent ensures the full knowledge and co-operation of subjects, while also resolving, or at least relieving, any likely tension, aggression, resistance or insecurity of the subjects (Strydom, 2005:59).

Patients are aware of their rights and what they are getting involved in when they read and sign a statement giving informed consent, a written agreement to participate given by subjects after they learn something about the research procedure (Neuman, 2000:96).

The researcher handed an information sheet regarding the research topic and the disease that were being investigated to the participants. The reason for this was to inform the participants about what the research encompass before they decided to participate in the study (Refer to Addendum 1).

Participants also had to complete the consent form in which they had been informed of the aims of the study; its sponsorship, where their names were obtained and confidentiality (Refer to Addendum 1). Participation was voluntarily. The researcher had to explain to the participants why they gave consent, what the study entails, since many of them have not been educated. Most of them were not able to

understand the written word and could not be expected to sign documents without explanation what the research entails. The participants were also given the opportunity to ask questions, should they not have clarity regarding the study or the consent form.

Participants were not obliged to answer any specific question and may withdraw at any time from the interview or study. The consent forms had been drawn up in the major languages of the Western Cape, Afrikaans, English and Xhosa. (Annexure one, two and three for the examples of the three consent forms set out in the different languages).

### **13.3 Violation of privacy/anonymity/confidentiality**

The concepts violation of privacy, the right to self-determination and confidentiality can be viewed as being synonymous. Privacy implies the element of personal privacy, while confidentiality indicates the handling of information in a confidential manner. The right to self-determination implies that individuals have the right and competence to evaluate available information, weigh alternatives against one another and make their own decisions (Strydom, 2005:61-62).

A researcher has a moral obligation to uphold the confidentiality of data. This includes keeping information confidential from others in the field and disguising members' names in field notes. Researchers protect privacy by not disclosing a subject's identity after information is gathered by anonymity. Researchers could invade a person's privacy when they probe into beliefs, backgrounds, and behaviours in a way that reveals intimate private details (Neuman, 2005:397; Neuman, 2000:98).

The researcher adhered to the aspect of anonymity since the participants names have not been mentioned throughout the study. Codes were used in the place of their names, for example, code 1, code 5.

Tapes that were used during the study will not be shared with anybody, other than the supervisor. This was shared in the consent and confidentiality agreement.

Tapes will also be stored in a safe place on completion of the project. In the final report of the study examples of the interviews were given, but these and quotes will remain anonymous, participants will not be recognized because pseudonyms will be used. This ensured that the researcher adheres to confidentiality.

#### **13.4 Deception of participants**

Deception occurs when the researcher intentionally misleads subjects by way of written or verbal instructions, the actions of other people, or certain aspects of the setting (Neuman in Strydom, 2005:60). A distinction can be drawn between deliberate and deception which were unintentional. No form of deception should ever be inflicted on participants (Strydom, 2005:61). Deception and covert research may increase mistrust, cynicism, and diminish public respect for social research. The right of a person not to participate becomes a critical issue whenever the researcher uses deception, disguises the research, or uses covert research methods (Neuman, 2000:95).

Participants were in no way deceived about the purpose of the study because all the information about the research was overt and explained to them. Some however did not understand (this was evident during the interviews) the purpose of the research. They might have received the wrong message from the clinician who selected them. The clinician spoke to them first and asked them whether they are willing to partake in the study. It was clear that due to illiteracy and low educational levels that participants' could not fully understand the purpose of the study. Some of them thought the study had something to do with their

grants, which they receive from government. It might be that the clinician told them that the researcher is a social worker and that is why they had this perception. The misleading of the participants by the clinician was unintentionally without cognizance of the researcher. The researcher tried to rectify the situation by explaining that she seeks information regarding the reasons why patients delay their treatment and not about grants. Expectations from the participants during the study were highlighted and participants had the opportunity to ask questions. The researcher made sure that they comprehend all these information before continuing with the study.

### **13.5 Actions and competence of researcher**

Researchers are ethically obliged to ensure that they are competent and adequately skilled to undertake the proposed investigation (Strydom, 2005:63).

Obligation rests also on the researcher towards all colleagues in the scientific community, to report correctly on the analysis of data and the results of the study (Babbie in Strydom, 2005:63).

The researcher had extensive knowledge and skills about the research process and confirmed in advance with the supervisor whether these were sufficient. Data analysis was done correctly by using the steps prescribed by Tesch in Creswell (1994:155). The analysis and the results of the study were also done as scientifically prescribed in this document.

### **13.6 Release or publication of findings**

The findings of the study must be introduced to the reading public in written form; otherwise even a highly scientific investigation will mean very little and will not be viewed as research (Strydom in Strydom,

2005:65). Report writing includes doing all you can to make sure your report is as clear as possible and contains all the information necessary for readers to understand what you have written (Dane in Strydom, 2005:65).

The manager, Ms. Pat Collis, had one request before granting permission for the researcher to conduct her study at St. Vincent Drive Clinic, and that is that the researcher should inform the medical staff at the clinic about the findings of the study. The researcher wrote a report on the findings of the study and left a copy at the clinic. The information in the report will guide health service professionals on rendering an improved service to the patients. Patients on the other hand must also have access to the findings. A presentation will be done to patients because of their illiteracy on a level that they feel confident. Patients can also ask questions and give input.

This study started out to be part of a superior study initiated by the Human Science Research Council (MRC), under the management of Professor N. Phaswana-Mafuya. The findings obtained will be made available to Professor Phaswana-Mafuya in order to incorporate it with their study.

#### **14. METHODS OF TRUSTWORTHINESS**

All research should have criteria against which the trustworthiness of the project can be evaluated and quality in research is dependent on truthful and direct investigations. Validity cannot be assumed. The research process should be critically presented in detail and the presentation of research findings must invite the opportunity for critical reflection (Marshall in Whittemore, Chase & Mandle, 2001; Marshall and Rossman, 1995:45).

Qualitative researchers should ideally consider validity issues throughout the process of inquiry, particularly in the planning and analytic phases. The concept of validity changed qualitative research and is illustrated through the explanation of credibility, authenticity, criticality, and integrity which are considered primary criteria (Whittemore *et al.*, 2001).

Credibility (reliability) refers to an accurate interpretation of the meaning of the data. Do the results of the research reflect the experience of participants or the contexts in a believable way (Carboni in Whittemore *et al.*, 2001)?

The researcher interpreted the data by using the steps prescribed by Tesch in Creswell (1994:155). The meaning was accurately interpreted through analysis of the social and health services factors experienced by each participant. This individual analysis was then combined in order to present a holistic replication of the social and health service factors contributing to TB by all participants.

Authenticity (genuineness) is closely linked to credibility in validity and involves the description of research that replicates the meanings and experiences that are lived and perceived by the participants. The genuineness of the person, phenomenon or situation becomes important criteria for validity. The question to be answered to determine authenticity is: Has the researcher exhibited awareness of the differences in the voices of others (Lincoln in Whittemore *et al.*, 2001)?

Authenticity was achieved by using qualitative research and description of analysis included exact words to highlight the experiences of the social and health services factors contributing to delays in TB patients. Chapter four contain the abstracts that obtained directly from the participants.

Criticality is the contradictory interpretations, assumptions, knowledge and background of researchers that can potentially influence the research. Sincere attention to integrity and criticality is needed as part of the research process. The methods to do this is reflexivity, open inquiry and critical analysis of the researcher's own assumptions, knowledge and background, which can influence all aspects of the research (Marshall in Whittmore *et al.*, 2001).

The researcher constantly reflects on her own assumptions, knowledge and background of TB patients. This reflection included the influence of the literature review, which contributed to the researcher having assumptions and knowledge about TB patients and social and health services factors contributing to delays in seeking treatment. The researcher used consultation sessions with the supervisor in order to deal with her own assumptions and how knowledge influenced her research.

Integrity (Honesty/ Truthfulness) is important in reflection and analysis of qualitative research. Qualitative research is subjective and the researcher is valued as a person who may interpret data uniquely. Integrity should however be applied as evidence to assure that the interpretation is valid and grounded within the data (Johnson in Whittmore *et al.*, 2001).

The researcher attempted to be truthful and honest during the research process by using reflexivity as described above. The analysis of the data had been scrutinized by the researcher and supervisor in order to establish if it represented the patients' reality.

There are also secondary criteria of validity, which includes vividness, creativity, thoroughness, congruence and sensitivity. The researcher will discuss these in the following text.

Vividness involves the presentation of the data as thick, faithful and clear descriptions with imagination. Presentation of rich data contributes to the ability to highlight the most important features of themes, portraying the essence of the phenomenon without overwhelming the reader with excessive detail. Consumers of research will experience and understand the phenomenon or context described (Sandelowski in Whitemore *et al.*, 2001).

The researcher described the themes from data analysis to explain the social and health services factors that contribute to delays in TB treatment, faithfully and attempted to present it as thick data with clear descriptions in chapter four of this study.

Creativity is demonstrated in qualitative research through original practical designs to answer specific research questions, flexibility within the inquiry process and imaginative ways of organizing, presenting and analyzing data (Chapple & Rogers in Whitemore *et al.*, 2001). Creativity in research can enhance findings and challenge traditional ways of thinking. All creativity must however be grounded within the scientific process (Thorne in Whitemore *et al.*, 2001).

The researcher attempted to be creative throughout the whole research process, especially with regard to the organizing, presenting and analyzing of data.

Sampling, efficient data, as well as comprehensiveness in research, approach and analysis contribute to thoroughness (Attention to detail) in qualitative research (Popay, Rogers & Williams in Whitemore *et al.*, 2001). Thoroughness also entails attention to correlation between themes and full development of ideas (Eisenhart & Howe in Whitemore *et al.*, 2001).

The researcher had ensured that her sample and data obtained were thorough by stipulating specific criteria for sampling, for example patients' experiencing a delay of three months or more before seeking treatment for TB.

Qualitative research should be congruent and this should be evident between the research question, the method and the findings, between data collection and analysis, between the current study and previous studies and between the findings and the practice. Study findings should also demonstrate logical congruency as well as similarity with the theoretical or practical perspective expressed by the researcher (Marshall in Whitemore *et al.*, 2001).

The researcher made use of the findings of various other articles, similar studies, text books and journals of other authors, which all relate to the same topic, to substantiate or reinforce the information and findings that were made with her own study. The findings of this study are conformable because the findings of other studies have proven that the findings of this study are not so extraordinary and are possible to be confirmed by another study.

Sensitivity (Compassion) as a validity measure of qualitative research refers to research that is implemented in ways that are sensitive to the nature of human, cultural and social contexts (Altheide & Johnson; Munhall in Whitemore *et al.*, 2001). Concern for human dignity and respect of participants preferably is demonstrated (Lincoln in Whitemore *et al.*, 2001).

The researcher treated the participants on an equal footing and related to them as fellow human beings who has the right to self-determination and who is able to make their own decisions, as discussed under ethical aspects of research.

An audit of qualitative research is important in developing a justifiable stance (Lincoln & Guba in Whitemore *et al.*, 2001). This audit could be valid by evaluating clear presentation of results, evidence and support for assumptions and conclusions drawn by the researcher (Ambert, Adler, Adler & Detzner in Whitemore *et al.*, 2001).

Detailed records, tape recordings of interviews and notes are available if an audit should be done on the research. Conclusions drawn by the researcher are produced in this research document in chapter five. However an audit did not realize in this research because of the level thereof, which is a mini-thesis.

After the discussion of the research methodology the researcher deemed it necessary to provide definitions of the key concepts in this research, which will be discussed in the following section of this chapter.

## 15. DEFINITION OF KEY CONCEPTS

The following are definitions of concepts that will be used throughout the whole document.

- Tuberculosis can be described using the medical definition, as follows: "Tuberculosis is a chronic infectious disease caused by specific mycobacterium and characterized by the formation of lesions in any tissue or organ of the body but mainly the lungs" (Glathaar, 1991:1).
- Adherence could be defined in terms of patient non-compliance or non-adherence and involves the patient not carrying out the treatment regime as the practitioner intended (Edelmann, 2000:130-131).
- There are different delays, namely "patient delay" and "health service delay"

- The theoretical definition of patient delay is the estimated time interval between symptom onset and the first medical consultation (Cheng, Tolhurst, Li, Meng, & Tang, 2004:67).
- The theoretical definition of health service delay is the time taken from symptom onset until the diagnosis was confirmed and treatment started (Cheng *et al.*, 2004:67).
- Health provider is any person consulted by the patient about his/her sickness who prescribed any form of medication. These categories include medication dispensers, pharmacists, and medical staff (Cheng *et al.*, 2004:67).
- Formal health providers are health centers, hospitals & clinics owned by the government or the private sectors (Kongstvedt, 1997: 97-109).
- Social functioning refers to the way people interact with their physical and social environment, and with the people and social institutions with which they are in contact (Morales & Sheafor, 1986:10).
- Primary Health Care refers to Primary care, in health systems and care rendered by physicians in the specialties of family practice, internal medicine, and pediatrics (Kongstvedt, 1997: 97-109).
- MDR-TB -Multi-drug resistant tuberculosis (MDR-TB) is defined as TB that is resistant at least to INH and RMP. Isolates that are multiply-resistant to any other combination of anti-TB drugs but not to INH and RMP are not classed as MDR-TB (Zulu, 2006).
- XDR-TB - Extensively drug-resistant tuberculosis (XDR-TB) is defined as MDR-TB that is resistant to quinolones and also to any one of kanamycin, capreomycin, or amikacin. The old case definition of XDR-TB is MDR-TB that is also resistant to three or more of the six classes of second-line drugs (Quintal, 2007).

## 16. CONTENTS OF RESEARCH REPORT

This report consists of five chapters, which are set out as follows:

- **Chapter one** - General Orientation
- **Chapter two** - Clinical aspects of TB as a disease
- **Chapter three** - Literature Review
- **Chapter four** - The discussion of the findings
- **Chapter five** - Conclusions and recommendations of the study

## 17. CONCLUSION

In this chapter, the researcher has orientated the reader about Tuberculosis. The background and motivation of the study was explained in great detail. The researcher addressed issues such as the mortality rate, incidence, low detection rate of TB cases, the importance of early diagnosis, the socio-economic circumstances that contribute to the spread of TB, statistical evidence to prove that TB infection is on the incline and the services rendered by the health care system had been discussed. The researcher continued the argument by explaining the purpose, goals and objectives of the study and the research questions which will guide it. The research approach, type of research and design were also specified. The data collection method, data analysis, pilot study, sampling, research population, ethical aspects, methods of trustworthiness and key concepts were some of the aspects that were also described. The next chapter, chapter two will contain literature on the clinical aspects of Tuberculosis as a disease, and will be discussed in more detail.

## **CHAPTER 2**

### **TUBERCULOSIS AS DISEASE**

#### **2.1 INTRODUCTION**

In this chapter, the researcher orientates the reader regarding Tuberculosis as a disease. The researcher is of the opinion that this is necessary in order to understand the disease, its effects and complexities thereof, as they contribute to delays in treatment of TB. The specific aspects, which will be discussed, include the definition and causes, the historical background globally and in South Africa, the different types and examinations and tests for diagnosing TB. Attention will also be given to the spread, control and treatment of TB. It is however also important to include the side-effects of the medication, the consequences of not adhering to or finalising treatment, prevention of TB, The DOTS Strategy for the detection and cure of TB as these contribute to delays in treatment of TB.

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#### **2.2 DEFINITION AND CAUSES OF TUBERCULOSIS**

Tuberculosis is defined as a bacterial disease caused by *Mycobacterium tuberculosis* that primarily affects the lungs. This bacterium usually attacks lung tissue and is an airborne illness that is spread by inhaling droplets of mucus that have been expelled by an infected person. This expulsion can come from a cough or a sneeze (The Centers for Disease Control and Prevention, 2000; Mizrahi, 2008).

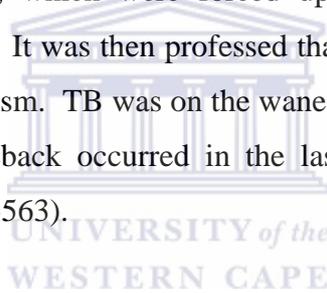
#### **2.3 HISTORICAL BACKGROUND OF TUBERCULOSIS**

It is important to discuss the historical background of TB, since it became evident, that there is a correlation between social factors and TB as far back as the nineteenth century. Another important aspect is

that Tuberculosis was a major cause of mortality for thousands of years, with the earliest known case as early as 2400-3400 BCE (Gandy and Zumia, 2003). Tuberculosis continues to be a major cause of mortality at present, although the circumstances might differ.

The history on *Mycobacterium (TB)* is well documented and it affected human beings before the time of the ancient Egyptians. The most common name for Tuberculosis originated from Dr. Silvius, because of the tubercles found in infected patients.

Tuberculosis had been a major killer among all social classes during the 19<sup>th</sup> century. It was early in the 20<sup>th</sup> century that Dr. Norman Bethune, a Canadian surgeon, found that TB was a disease caused mainly by the social conditions, which were forced upon the working class in a capitalist society. It was then professed that TB could only be defeated by ending capitalism. TB was on the wane in the mid 20<sup>th</sup> century but a devastating comeback occurred in the last few decades (Gandy and Zumia, 2003:561-563).



It is however also important to discuss the historical background of TB in South Africa, since certain social-political factors played a role in the incidence of TB in South Africa.

TB was introduced in Southern Africa at the beginning of colonization. South Africa was a land rich of minerals and natural resources, such as diamonds and gold. A need for mining of these minerals occurred and the colonizers required cheap labour to fulfill this need. Miners had been selected from mostly black racial groups, which were marked as being discriminated and oppressed against. Apartheid followed and this phenomenon continued. The mining industry caused major triggers of TB as an endemic disease in South Africa. A peak was reached in the 1960s, after which there has been a gradual and consistent decline to 45,000 notifications in 1987. Tuberculosis was therefore caused by

social-political factors for example exploitation of black males as cheap labour. Mining therefore gave rise to the spread of Tuberculosis amongst black males of the population (Hurrelmann, & Laaser, 1996: 317-318).

The researcher will orientate the reader in the following sections of the research report on the signs and symptoms, the types, diagnosis and treatment of TB.

## **2.4 SIGNS AND SYMPTOMS OF TUBERCULOSIS**

Symptoms of Tuberculosis vary among patients. Patients may present symptom-free or in a highly broken-down state. The symptoms for TB include a cough that is worse in the morning; hemoptysis (blood in the sputum) can accompany the cough. Patients could present with symptoms such as a mild fever, headaches, chills and night sweats. Other symptoms include chest pain from pleurisy, breathlessness and swollen glands. A general feeling of malaise and fatigue is often experienced by patients as well as signs of pneumonia and extreme weight loss (in advanced stages of the disease) (Centers for Disease Control and Prevention, 2000; The National TB Control Programme, 2006).

## **2.5 TYPES OF TUBERCULOSIS**

*M.Tuberculosis* causes twelve different types of Tuberculosis. Physicians and researchers divide these two types into pulmonary and extra pulmonary. There are five types of TB recognized as pulmonary and seven types recognized as extra pulmonary. Multi-drug resistant (MDR) and Extensively-drug-resistant tuberculosis (XDR-TB) are other forms of TB. These forms of TB will be addressed as follows: (<http://www-micro.msb.le.ac.uk/>).

### **2.5.1 Pulmonary Tuberculosis**

Pulmonary encompass of Primary tuberculosis, which is uncommon and mostly occurs in patients, the young and the elderly, which have a low immune system. It presents as pneumonia and is highly contagious.

Laryngeal TB is the second type of pulmonary TB. This type of TB is also highly contagious and affects the throat in the vocal chord area. Another type of pulmonary TB is Cavitory, which is characterized by classic TB symptoms. These classic symptoms include large cavities, which are formed in the lungs and it is also highly contagious. Miliary TB affects more young and elderly patients because of a low immune system. Symptoms include a very dangerous fever and chest x-rays may show small granules in the lungs. Tuberculosis Pleurisy, as another form of pulmonary TB can develop shortly after the initial infection and is characterized by shortness of breath, chest pain and fluid in the lungs (<http://www-micro.msb.le.ac.uk/>).

### **2.5.2 Extra Pulmonary Tuberculosis**

Extra Pulmonary TB encompasses of Adrenal tuberculosis, which mostly affects the adrenal glands and the hormone production of patients which are also affected. Patients may experience fainting or weakness during times of stress. Lymph node disease is the second type of extra pulmonary TB. Patients may experience enlarged lymph nodes as the infected macrophages congregate there. The nodes may rupture through the skin. Another type of extra pulmonary TB is Osteal tuberculosis and this kind of TB is characterized by affected bone tissue which weakens and causes patients to experience fractures (<http://www-micro.msb.le.ac.uk/>).

Tuberculosis peritonitis can affect the outer lining of the intestine, causing fluid to build up and patients to experience abdominal pain.

Renal tuberculosis is another form of extra pulmonary TB and may cause patients to experience pyuria (the presence of white blood cells in the urine) and eventually affect the reproductive organs of patients. TB meningitis as extra pulmonary TB is characterized by infected patients who display signs of a stroke or a brain tumor. It can further lead to permanent impairment or may eventually prove fatal. Tuberculosis Pericarditis causes an increase in the fluid volume around the heart and can impede its function (Properties of *M.tuberculosis* care of <http://www-micro.msb.le.ac.uk/>).

### **2.5.3 Multidrug-Resistant Tuberculosis (MDR TB)**

MDR TB bacteria develop when TB patients do not take their medicine as they should and does not complete their medicine regimen. MDR TB patients infect people who have contact with them with MDR TB and not TB as such (<http://www.siue.edu/~cbwilso/Mtuberculosis.jpg>, 04/09/2008).

### **2.5.4 Extensively drug-resistant Tuberculosis (XDR-TB)**

Extensively drug-resistant tuberculosis (XDR-TB) is MDR-TB that was not sufficiently treated due to delays and health services factors. The case definition of XDR-TB is MDR-TB that is resistant to three or more of the six classes of second-line drugs (Quintal, 2007).

## **2.6 EXAMINATIONS AND TESTS FOR DIAGNOSING TUBERCULOSIS**

Centers for Disease Control and Prevention (2000) reported on the following diagnostic tests:

Chest X-rays is one of the tests and it reveals cavities, calcification and nodes in the upper lobes of the lungs. These can however not confirm diagnosis. Sputum smears and cultures are other means of diagnosis. Sputum smears are helpful in diagnosing pulmonary Tuberculosis.

These specimens of sputum are obtained during early mornings on three different days. The specimen is prepared on a slide, stained with an acid-fast dye, and observed under a microscope. The slide shows the characteristic acid-fast bacilli. Definite diagnosis of TB requires growing of bacteria and confirming that the culture is *Mycobacterium tuberculosis* using biochemical tests or DNA probes. This process can take several weeks.

Direct bacteriological examination of sputum is the only way to confirm the diagnosis of smear-positive TB. This is achieved by administering chemotherapy to all detected cases, with emphasis on smear-positive cases (Van der Velden *et al.*, 1995: 219-220).

Urine cultures are tests which can be used to diagnose cases of genitourinary Tuberculosis. A Gastric aspirate test involves placing a tiny naso-gastric tube in the stomach early in the morning. Gastric contents are then suctioned and processed for smears and culture. Lymph node biopsy is a test, which involves removing of an enlarged lymph node and culturing a small portion. The remaining portion is stained and observed under a microscope. The presence of a caseating granuloma with acid-fast bacilli (AFB) confers Tuberculosis (Centers for Disease Control and Prevention, 2000).

Culture body fluids is an examination whereby fluid drained from the pleural space, the pericardial space, or the peritoneal space may be positive for AFB on smear and positive for Tuberculosis on culture.

Bronchoalveolar lavage is a diagnostic test performed in patients with suspected pulmonary Tuberculosis when sputum smears are negative (Centers for Disease Control and Prevention, 2000).

Fiberoptic bronchoscope is an examination which involves a flexible tube with the circumference equal to that of a pencil. The tube is slid into the mouth and passed down the back of the throat, into the trachea, and into each lung. A Tuberculin skin test is based on the fact that infection with *M.tuberculosis* produces a delayed-type hypersensitivity skin reaction to certain components of the organism (Centers for Disease Control and Prevention, 2000).

## 2.7 THE SPREAD OF TUBERCULOSIS

The process of how TB spreads is as follows:

TB is spread when a person with active TB coughs, sings or speaks and another person breathes the air contaminated with TB germs. The bacteria then reach that person's lungs. From there it can go to other parts of the body. The body resists the TB bacteria. The bacteria are usually dormant in the body but the person is infected. One of the signs of detecting TB is a positive skin test. The patient with this test does not feel ill and cannot spread TB. Medicine can then be taken to keep that person from getting active TB. If that person does not take medicine, the TB bacteria may come alive and attack the lungs and other parts of the body. This is then called TB Disease. The person will then feel sick with fever, weigh loss or coughing. The person now has active TB germs in his/her body and may give TB to others. The person needs to take medicine to help him/her get better and to prevent from spreading the TB germs to others (<http://www.mass.gov/dph/cdc/factsheets/tuberc.doc>).

## **2.8 THE CONTROL OF TUBERCULOSIS**

### **2.8.1 Case detection - an important treatment tool to control and combat Tuberculosis**

Factors contributing to the rise of TB cases are late presentation, overcrowded living conditions, lack of good nutrition, poverty and HIV/Aids (National TB Control Programme, 2006). Morales *et al.*, 1985 and Bohm (1992:42) concur with this statement by reporting that tuberculosis will be increasingly difficult to control in South Africa unless the socio-economic problems of society, which contribute to the rise in its incidence are addressed (Morales *et al.*, 1995; Bohm, 1992: 42). These aspects are of importance to this study as social factors but will be discussed in chapter three.

Case finding in most TB control programmes is to a large extent “passive” meaning that persons present themselves with suspect symptoms at a health care institution for examination (Van der Velden *et al.*, 1995: 219-220).

Finding, diagnosing and curing more patients will accelerate the decline in prevalence. The total number of patients diagnosed and treated in 2005 is in line with expectations for 2006, but the marked variations in case detection among WHO regions in 2005 will persist without remedial action (WHO Report, 2007).

TB services in Cape Town are delivered as part of the primary health care package in the province. This information is compiled in the Provincial Annual Performance Plan 2006/2007. The services in the plan consist of the following national protocols:

Swartz (2007) stated that: "The clinic staff diagnoses TB on clinical suspicion using sputum microscopy. They also provide Information and Education Campaigns (IEC) and active screening of families of patients with TB. The clinic staff promote voluntarily HIV testing, treat, dispense and follow-up using DOTS and they also complete a TB register". Groenewald (2007) reported that: "Patients go to the local clinic first, where they are tested and others, if necessary, are referred to the hospital if they need in-patient treatment for Multi-drug resistant TB".

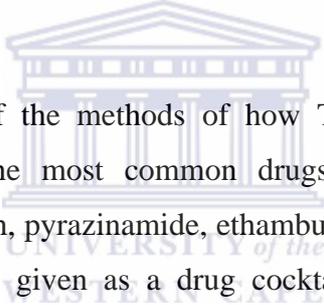
### **2.8.2 TB programmes as important tool to control Tuberculosis**

An effective TB control programme is based on two principles: case-finding of infectious sources and adequate treatment. The aim of control programmes is to cure at least 80% of the detected cases. It also aims to detect not less than 75% of the incident cases. The most important measure in TB control to eliminate sources of infection is to treat patients that excrete TB bacilli (sputum smear-positive TB) (Van der Velden *et al.*, 1995: 219-220). These programmes addressed only physical aspects of TB but when the importance of socio-economic factors as described in case detection is taken into account it is also necessary to include these. The latter might then be a weakness in the implementation of TB programmes.

## **2.9 TREATMENT OF TUBERCULOSIS**

Physicians have realized that tuberculosis was contagious for centuries. However, it was not until recently, within the last 200 years, that effective treatment methods have been available ([http://www.wits.ac.za/myco/html/h\\_tb.htm](http://www.wits.ac.za/myco/html/h_tb.htm)).

TB treatment is presently available and provided free of charge at all public health facilities. Medicines are usually taken from Monday to Friday of each week. If a patient has more than one tablet / medication to take it should be taken all at the same time. Patients should go to the clinic for regular check-ups. Treatment must be completed. It is a mistake for patients to stop taking their medication when they feel better. All treatment or medicine must be taken for the full six months. The risk of developing a drug resistant strain of TB is possible, if treatment is missed. This TB is very difficult to treat and needs more than 18 months of treatment/ medicine, with a long stay in hospital. It takes a long time for TB bacteria to be destroyed. If medicines are stopped too soon and without instructions of the nurse or doctor the disease may start all over again (National TB Control Programme, 2006).

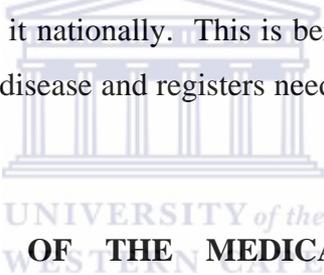


Drugs are one of the methods of how Tuberculosis can be treated successfully. The most common drugs used in treating TB are isoniazid, rifampin, pyrazinamide, ethambutol and streptomycin. These drugs are usually given as a drug cocktail since there are a lot of bacteria that need to be killed, and it also decreases the risk of the bacteria gaining resistance to one particular drug.

While on the drugs, the infected individuals need to stay home from work or school to prevent the spread of TB until they are no longer infectious. It is also important that the patient continue to take the medicine regularly. It may take six months or more for the medicine to effectively kill the TB bacteria, even if the patient begins to feel better after a few short weeks. If the patient stops taking the medicine as they start to feel better (they do not complete the full drug regimen) this can lead to increased drug resistance in the bacteria causing a different and stronger set of antibiotics being used that also cause more serious side effects (TB Alert, 2005; <http://www.cdc.gov/nchstp/tb/faqs/qa-introduction.htm#Introl>).

Supervision of treatment during this phase is of great importance to guarantee adequate treatment. A health staff member should see the ambulatory patient every day, or if not possible, patients should be admitted. The occurrence of multi-drug resistant tuberculosis (MDR), treatment failures and chronic excrement through poor adherence will be enhanced if control measures are inadequate (Van der Velden *et al.*, 1995: 219-220; National TB Control Programme, 2006).

Daniels (2007) stated that: "In Cape Town patients would firstly seek treatment from general practitioners or hospitals. They would then be referred back to their nearest clinic, where tests are performed, diagnosis made and treatment started. Medical staff is obliged to report a positive case to the Health Information officer at Provincial level, who in turn will report it nationally. This is being done due to the fact that TB is a notifiable disease and registers need to be updated for statistical purposes."



## **2.10 SIDE-EFFECTS OF THE MEDICATION AS PART OF TREATMENT OF TUBERCULOSIS**

It is necessary to discuss the side-effects of medication in this study because patients do not comply with the treatment as a result of the side-effects of the drugs they are supposed to use. The side effect should also be addressed by health service providers in order to ensure that patients adhere to the treatment. Side effects of medication include lack of appetite, vomiting, fever for more than three days, tingling fingers or toes, easy bleeding or bruising, dizziness, hearing loss and nausea. Other side effects include a yellowish skin or eyes, abdominal pain, skin rash, pink urine, aching joints and a blurred vision. Not everybody does feel side effects and most of them can be treated (National TB Control Programme, 2006; <http://www.cpmc.columbia.edu/resources/tbcpp/tbcure.html>).

## **2.11 CONSEQUENCES OF NOT ADHERING TO OR FINALIZING TREATMENT**

The consequences of not adhering to or finalizing treatment may prove to be fatal, since TB is able to damage a person's lungs forever and many people die as a result especially if TB is left untreated. Patients will also spread the disease to others if they have TB and do not get treated (National TB Control Programme, 2006).

## **2.12 PREVENTION OF TB**

Awareness is of utmost importance in the fight against TB. Awareness campaigns should encourage people to go for testing for TB (National TB Control Programme, 2006).

TB can only be prevented by curing those who are ill with TB in order to stop the spread of the disease. Patients should cover their mouths when coughing. All babies should receive immunization at clinics, within one year of birth. Patients should eat balanced meals consisting of food like meat, fish, eggs, beans, millets, maize, brown bread, maize meal, vegetables and fruits. Alcohol should be avoided because it lowers body resistance, and affects the treatment. Smoking causes further damage to the lungs and can also cause heart disease and lung cancer. Getting some sunshine, fresh air, exercise and living in a clean environment (The National TB Control Programme, 2006).

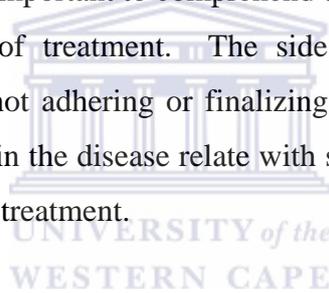
## **2.13 THE DOTS STRATEGY FOR THE DETECTION AND CURE OF TB**

DOTS mean Directly Observed Treatment Short Course (six months). DOTS supporters assist patients to ensure that medicines are swallowed daily and diagnosis is available to every one free of charge. DOTS ensures that good quality standardized treatment/medicines are

available for all TB patients free of charge. It does not involve long periods of hospitalisation; instead a person can take treatment at home, at work, or at school. Five elements are include in DOTS treatment, which encompass political commitment, microscopy services, drug supply, monitoring systems and direct observation of treatment (National TB Control Programme, 2006).

## **2.14 CONCLUSION**

TB is a serious disease with a high incidence and mortality rate. HIV/Aids and MDR TB contribute to the high mortality rate. These factors were discussed in chapter one. TB as a disease, as well as the spread, control and prevention thereof are discussed in this chapter as these factors are important to comprehend the seriousness of the disease and importance of treatment. The side effects of medication, the phenomenon of not adhering or finalizing treatment, as well as social aspects resulting in the disease relate with social and health care factors causing delays in treatment.



# **CHAPTER 3**

## **SOCIAL AND HEALTH SERVICE FACTORS CONTRIBUTING TO PATIENT DELAYS IN SEEKING TREATMENT FOR TUBERCULOSIS**

### **3.1 INTRODUCTION**

The researcher compiled a comprehensive literature review with regards to the various social and health service factors that contribute to patient delays in seeking treatment for Tuberculosis.

The researcher deemed it necessary to highlight the models in which the research was contextualized. The research was based on the biomedical and psycho-socio-environmental models. The biomedical model essentially keeps health in the biological context, while the psycho-socio-environmental model places it in the social context (Ross & Deverell, 2004:14).

The biomedical model was used in chapter two to introduce Tuberculosis as a disease. The psycho-social-environmental model is of importance because it corresponds with psychological, social and economical factors, which contributes to and also influences treatment of TB. This model focuses on the promotion and maintenance of health through socio-environmental and behavioural changes. It emphasizes the role of people's behaviour, the work that they do, their lifestyles, where they live, and their access to health services in determining their health status. There are also other social factors that contribute to why patients delay when seeking treatment for TB (Ross & Deverell, 2004:12).

## **3.2 FACTORS CONTRIBUTING TO PATIENT DELAYS IN SEEKING TREATMENT FOR TUBERCULOSIS**

The literature study indicated that stigma, gender and health seeking behaviour are some of the social factors that contribute to delays in patients when seeking treatment for TB. Other social factors include knowledge about the TB, economic factors and accessibility to health care facilities.

Health services factors that contribute to delays in patients seeking treatment for TB as indicated in the literature study encompass interpersonal relationships between health service providers and patients, attitudes of staff, infrastructural deficits, inadequate health services and training of and by health care workers. These factors are discussed in the following section of the thesis.

### **3.2.1 SOCIAL FACTORS CONTRIBUTING TO PATIENT DELAYS IN SEEKING TREATMENT FOR TUBERCULOSIS**

There are various social factors, which contribute to patient delays in seeking treatment for TB as mentioned above. The researcher discussed stigma as one of the social factors and it is addressed in immense detail.

#### **3.2.1.1 Stigma as social factor with regards to Tuberculosis**

Stigma as a result of TB is still a major barrier to TB screening and treatment in some countries (Bannister, Begg & Gillespie, 2000). Stigma is defined as an undesirable attribute or quality that significantly discredits an individual in the eyes of others; it deters people from seeking care and diagnosis. It encompasses not merely

an attribute, but represents a language of relationships, as labelling one person as deviant reaffirms the normality of the person doing the labelling (Goffman, in Deacon, 2005:15). The patients acquire a 'spoiled identity' and possess a characteristic defined as socially undesirable, which then leads them to be socially devalued and discriminated against (Kelleher & Hillier, 1996).

Moreover, stigmatisation is a dynamic process that arises from the perception that there had been a violation of a set of shared attitudes, beliefs and values. Society thus labels an individual or groups as different or deviant. Stigmatised individuals are vulnerable to feelings of self-hatred which can result when they believe society's negative views of them (Auslander, 1997).

#### **3.2.1.2 Causes of Stigma with regard to Tuberculosis**

The key causes of TB stigma are the judgment, blame and shame that accompanies a TB diagnosis (with the TB patient being held culpable for their infection) the fear of being infected with TB through close contact, poor public health responses to control, as well as the fact that TB is considered as the disease of the poor (Bond, 2006; Waisbord, in Eastwood & Hill, 2004).

Other causes of stigma and discrimination include: Lack of knowledge about TB transmission, diagnosis and treatment, association with conditions already stigmatized, particularly HIV/AIDS, poverty, malnutrition, migration and poor hygienic living conditions. People with TB are often seen as being irresponsible for becoming infected because they are perceived as guilty of infecting others (WHO, 2004).

### **3.2.1.3 Stigma with regards to the dual diagnosis of Tuberculosis and HIV**

Research funded by the Department for International Development in Zambia, reveals to a new stigma with regards to disease. This stigma is with regards to the dual diagnosis of TB and HIV and it is called 'Tuberculosis (TB)-HIV stigma'. TB-HIV stigma leads people to either hide their TB diagnosis, delay seeking treatment or refrain altogether from getting help out of fear that people will think they have HIV (Bond, 2006; Centres for Disease Control & Prevention, 2000).

Studies in Ethiopia, Pakistan, and Thailand indicated that communities stigmatized the TB-HIV diagnosis. Visible TB symptoms such as extreme weight loss, frailty and severe coughing spark speculation about a person's HIV status and contribute to the stigma. TB-HIV stigma leads to TB patients being socially shunned, physically isolated and considered sexually 'immoral' because of the HIV link (Waisbord, in Eastwood & Hill, 2004).

A common nickname for people assumed to have AIDS and for TB patients is 'kanayaka' – a local term meaning “the light is on”, referring to see-through frailty, impending death (since the light of life can go out) and the public symptoms of such diseases (TB Alert, 2005). The high death rate from TB due to AIDS also resulted in the illness being labelled 'Satan's disease' by traditional healers in Zambia, where the number of TB cases reported every year has increased 12-fold since 1985 (Bond, 2006; Centres for Disease Control & Prevention, 2000).

One business woman stated during a study that was done in Zambia that it is on rare occasions that TB patients reveal their status because as a community, when we see that someone has TB, "we say that they have AIDS and they decide to keep it to themselves for fear of being isolated". Patients postpone seeking care due to fears of finding out their HIV status, and suffering stigmatization and social rejection as a consequence of their HIV and TB status becoming known (Eastwood & Hill, 2004; Dunn, 2005; Centres for Disease Control & Prevention, 2000).

#### **3.2.1.4 Stigma and Tuberculosis treatment**

Physical characteristics as a consequence of the type of TB treatment contribute to stigma towards these patients and result in delays of the treatment. People in Zambia believe TB treatment has side-effects like change in skin colour and hair texture, and so everyone will know that one is on TB treatment - and they fear that they will be discriminated against (TB Alert, 2005).

Health care providers stigmatising and discriminating against people with TB can obstruct the delivery of effective treatment. In some cases, even when patients attend DOTS clinics to get diagnosed they are stigmatised. This prevents people from seeking health care attention, which constitutes a direct public health threat to the community (Health-e, 2008; Eastwood & Hill, 2004; Bond, 2004).

#### **3.2.1.5 Stigma and Gender roles with regards to Tuberculosis**

One of the contextual factors contributing to stigma is gender-roles. It appears that women who suffer from TB are stigmatized more than men (Johansson, Long, Diwan & Winkvist (2000:33-51). The consequence of this stigma resulted in women being reluctant to speak of TB as an illness (Yamasakai-Nakagawa, 2001:1072).

An example of this stigma in some communities is that female TB patients and women who are suspected to have active TB are likely to be forced to get divorced, send back to their parents' homes, and have fewer chances of getting married. There is a widespread tendency to blame others for the introduction of TB into a community, with women especially vulnerable to be blamed. This was found in a study comparing Zambia and South Africa (Thamba & Sickinga, 2005; Department of Health, 2003).

Stigma in women also contributes to delays in seeking treatment for TB. Studies in Bangladesh and Vietnam indicated that fear of social isolation from family or community as a result of stigmatisation is a key factor contributing to treatment delay amongst women. Stigma is also a contributing cause to why females are more likely to postpone diagnosis, are offered sputum tests less frequently, and feel more inhibited than men to discuss TB with their family (Eastwood & Hill, 2004).

#### **3.2.1.6 Stigma as a result of Tuberculosis influencing interpersonal relations**

TB diagnosis could contribute to stigma as a social factor. It is perpetrated and reinforced by family, neighbours, and other groups. These interpersonal relationships could be influenced in many settings at the workplace, health care facilities, or within the community (Eastwood & Hill, 2004; National Institute for Health & Clinical Excellence, 2006). People with TB often suffer from discrimination and stigma, rejection and social isolation (TB Alert, 2005).

Marital relationships are influenced because of this stigma. It is not uncommon for a man to leave his wife if she develops TB, and if she is not already married the stigma attached to TB may prevent a woman from finding a husband (TB Alert, 2005).

Family relationships are influenced in various ways as a result of this stigma. One of these factors is inhibiting open communication, which makes disclosure in the family difficult and without disclosure prevention and care become impossible (Brannon & Feist, 1992; Macintyre and Trujillo, 2003).

Another factor is lack of support from friends, family and the community. This decreases disclosure and generates rejection and discrimination, which increases emotional distress experienced by those who have TB (Bond, 2004; Annandale, 2000; North & Bradshaw, 1997 & Niang *et al.*, 2003).

### **3.2.1.7 Health seeking behaviour as social factor with regards to the gender in Tuberculosis patients**

Although gender has been discussed the emphasis was on stigma and gender. The difference in impact of stigma on males and females is only one dimension of significant gender differences in patient delay in TB treatment. This section will focus on gender differences with regard to health seeking behaviour.

Gender roles, characteristics and behaviour is commonly influenced by shared expectations and norms within society about what is appropriate for male and female (Klientjes, Prince, Cloete & Davids, 2005:17). Gender roles, characteristics and behaviour also influence health seeking behaviour, which resulted in delays in treatment of TB as discussed in this section.

Women have a longer delay than men when seeking treatment for TB and this contributes to the fact that TB is the single biggest killer of young women. TB accounts for nine percent of deaths among women between the ages of 15 and 44. Deaths from TB in India are 27-41% higher among young women and children five to twenty four years, compared to males the same age (World Health Organisation, 2006).

A study on TB was performed in rural Jiangsu Province, China, which aimed to obtain an in-depth understanding of factors that influence the health seeking behaviour of TB patients, and access to tuberculosis care in countries with or without National TB Control Program (NTP) in rural China. The results indicated that female and elderly people were perceived to be more reluctant to seek health care and to seek care for cough from village health stations rather than general hospitals (Xu, Fochsen, Xiu, Thorson, Kemp and Jiang, 2004).

Females tend to be overlooked by health promotion programmes because they tend to stay at home rather than come to workshops. Therefore they have a lower awareness of TB symptoms. Women are often scared to tell family they might have TB due to potential rejection. Women in some families cannot leave the home without explaining where they are going, but are too afraid to say they want to go to a TB clinic. They wait up to twice as long to seek treatment, they wait until they are severely ill and more likely to die (TB Alert, 2005).

TB case detection in females is much lower comparing to males because, they delay seeking care in order not to use precious family resources. Alcoholism in females is another social factor. This was found in a study in Spain, regarding determinants of patient delay

among tuberculosis cases in Spain (Daez, Bleda, Alcade, DomAnguez, Caloto, Castells, Cardenal, Gayoso, GutiArrez, Huerta, Lapez, Moreno, Munoz, Navarro, PicA, Pozo, QuirAs, Robles, Sanchez, Vanaclocha & Vega, 2004).

Homelessness is another factor relating to gender differences, which also exist in terms of homeless adults in seeking treatment for TB. Nyamathi, Berg, Jones and Leake (2005) did a study on the predictors of perceived health status of Tuberculosis-Infected homeless adults with latent tuberculosis (TB) in Los Angeles, especially in relation to gender differences. The results indicated that women were more likely than men to report being in fair or poor health as a result of homelessness and they experienced health problems.

Health seeking behaviour in males indicates a typical feature is that they neglected symptoms until the disease reached a serious stage, by which time they tended to go directly to public health services without first visiting private health practitioners. The main reason why men delay seeking treatment was the fear of individual costs of diagnosis and treatment.

Women on the other hand, were described as having a tendency to seek out private services and practice self-medication before seeking care at public services (Johansson, Long, Diwan & Winkvist, 2000:33-51).

The researcher will discuss knowledge as social factor, which result in patients delays of treatment on TB in the following section.

### **3.2.1.8 Knowledge as social factor contributing to delays in Tuberculosis treatment**

It is very important for patients to have knowledge and be educated of Tuberculosis (the causes, spread, symptoms and treatment of TB) in order for them to seek help more rapidly. Knowledge includes the ability to recognize symptoms, identify causes and transmission routes, and familiarity with the availability of cure (Eastwood & Hill, 2004).

A cross-sectional study was done in Uganda (a cross-sectional survey, of 231 newly diagnosed smear-positive tuberculosis patients was conducted in Mulago National referral Hospital Kampala, from January to May 2002) regarding patient and health service delay in pulmonary tuberculosis patients attending a referral hospital. Clinic records in Mulago National Referral TB treatment center in Kampala show that the majority of tuberculosis patients have had symptoms for two or more months before seeking TB treatment, which may be attributed to limited information (Kiwuwa, Charles, Kizza and Harriet, 2005).

Lack of knowledge about and the perceived risk of TB, within reference groups (families, neighbourhood) and communities at large also contribute to behavioural barriers in seeking treatment for TB. Poor knowledge about TB has also been found among older and less educated people in Nepal, and marginalized groups with limited media access in Vietnam. Conversely, patients with higher educational levels are more likely to know symptoms and seek care earlier (Wares, 2003:327).

There is also a correlation between knowledge and delayed diagnosis of TB. Inadequate knowledge about symptoms is one of the reasons why patients postpone seeking care and to be tested for TB. This was demonstrated in studies in Ethiopia, India, Mexico, Nigeria, Pakistan and Thailand (Waisbord, in Eastwood & Hill, 2004; Graham, 2001).

A result of low knowledge about TB is that patients in some communities are more likely to visit traditional healers and pharmacists rather than DOTS providers, thereby delaying diagnosis, as found during a study that was done in Tanzania (Hudelson, 1996).

Knowledge is not the only factor contributing to health seeking behaviour but also other factors, e.g. motivation, awareness, and perceptions, as suggested by a study in India (Kiwuwa *et al.*, 2005). Studies have also reported that low awareness about the risk of TB symptoms is associated with delay in care-seeking. Patients with a higher perception about the severity of the disease are less likely to delay care seeking and diagnosis (North & Bradshaw, 1997)

Low awareness about the risk of TB symptoms is associated with delay in care seeking. It had been discovered that patients with a higher perception about the severity of the disease are less likely to delay care seeking and diagnosis (Wares, 2003:328).

Misconceptions about TB are a perception, which may contribute to the poor cooperation with TB treatment and screening. The myths surrounding TB is that it is curable, it causes impotence, can be contracted by sharing eating utensils, is equal to AIDS, so all TB patients have AIDS and so will die, TB treatment kills, it is

contracted by having penetrative sex with, or eating food that has been prepared by, a woman who has just gave birth, is menstruating or has recently miscarried. Extramarital sexual activities of either parent can cause TB in offspring (Bond, 2004).

Popular myths about TB as a result of inadequate knowledge emphasized the contribution of dusty, polluted air to the onset of TB, as well as drinking and smoking, environmental factors such as poor housing, cold weather and wet weather, but participants generally did not recognize the enormous role of crowded places such as bars, buses and other poorly ventilated places in spreading TB (Thamba & Sichinga, 2005).

Health service factors contribute to knowledge about TB. The methods, through which knowledge can be enhanced, include health education and face to face communication. Health education is an important component of a comprehensive health care service and operates at all levels of prevention, at the primary, secondary and tertiary levels. It is an active process which is directed at changing people's attitudes and influencing their behaviour in health-related matters. Face-to-face communication, group methods, the lecture method, mass media, role models are all ways in which the community can be educated about aspects of health (De Haan, 2002:15).

Health workers provide patients with very limited information during medical consultations and poor and vulnerable people are often missed by health promotion campaigns. Those with the lowest educational level are more likely to delay seeking health care (Dunn, as cited by Equi-TB, 2006).

Another social factor, which result in patients delays of treatment of TB is economic of nature and it will be discussed in the following section.

### **3.2.1.9 Economic factors contributing to delays in treatment of Tuberculosis**

Economic barriers influence the way, in which poor and vulnerable people seek diagnosis and treatment for TB. High levels of economic burden among poor and vulnerable people can result in people not seeking health care at all for TB. These factors increase barriers for effective TB control (Dunn in Equi-TB, 2005).

Worsening socioeconomic conditions were seen both as a cause of TB and a major obstacle to access to care. This was found by Dimitrova, Balabanova, Atun, Drobniowski, Levicheva, and Coker (2006) during a study about the health service providers' perceptions of barriers to tuberculosis care in Russia because the Russian Federation has witnessed a marked rise in rates of tuberculosis (TB) over the past decade.

### **3.2.1.10 Level of Income**

Financial difficulties influence health care-seeking behaviour of TB patients in both program and non-program countries. Many TB patients said they could not afford the cost of TB care, even where services were subsidized, according to a study that was done on the perceptions and experiences of health care patients in seeking TB care in rural Jiangsu Province, China (Xu *et al.*, Fochsen, Xiu, Thorson, Kemp and Jiang (2004).

Patients do not have enough money to pay for care and other costs. These costs include travel costs, guardian costs, food, daily necessities and extra medical expenses beyond those that are free of charge during a study done in Malawi. He also found that, during a

study in China that money is the main reason for delaying seeking health care. TB patients in low-income brackets actually took four days longer to seek health care than wealthier patients (Dunn as cited in Equi-TB, 2005).

Patients in remote areas may not be aware of or able to access free treatment and may end up paying more than they can afford to traditional healers or doctors who are not experts in TB (Dunn in Equi-TB, 2005).

Poverty with experience of scarcities, deficiencies encourages the spread of diseases like tuberculosis and measles, both easily transmitted through person-to-person contacts. Poor people would treat chronic coughs and other common health complaints by themselves by buying goods at grocery stores, in an attempt to cure their illness. It also deters people from accessing services at all stages of care-seeking: from symptoms, to help seeking, health services, diagnosis, treatment adherence and a final positive outcome (Feuerstein, 1997:41).

TB makes patient and families poorer because, the patient will probably be unable to work. Studies suggest on average patients lose three to four months of work time. The annual loss is equivalent to loss of 20-30 percent of the family household income. If a patient dies the family loses about fifteen years of income, the presence of a TB patient in a household entails major reallocation of time and resources towards care of the patient, and away from work. (TB Alert, 2005).

Other social factors as a result of level of income and which are linked to poverty is overcrowding and malnutrition. Overcrowding is common in poor communities and people are likely to live in dark ventilated rooms, and thus more likely to be infected by TB and to

receive large doses of the bacilli. Malnutrition reduces patients' resistance to TB and other diseases such as HIV (TB Alert, 2005).

Accessibility to Health care facilities and Geographical factors, which result in delays of treatment of TB are also social factors, which will be discussed in the following section.

#### **3.2.1.11 Accessibility of Health care facilities as social factor contributing to delays in Tuberculosis treatment**

There are differences in terms of accessibility to health services in rural and urban populations. Economic and environmental factors play a part in the differences in health between urban and rural populations. Generally there is more illness, and death rates are higher, in rural areas than in urban areas (De Haan, 2002:28).

In a study with children delays in presentation (patient delay) was shorter than the delay in diagnosis (health service delay) because easier access to health care facilities. Access to health services may shorten the patient delay while greater awareness of tuberculosis and proper investigation may shorten the doctor delay (De Haan, 2002:53). There should however not be any financial barrier to taking a full course of treatment, delivery of treatment as health care facilities should be close to the home and the treatment should have as few socio-economic consequences as possible (Van der Velden *et al.*, 1995: 219-220).

There is a robust association between external constraints and patient delay. Distance from DOTS clinics for example in rural areas in Gambia, Tanzania and Zambia. This was found during a study that was done on the behavioural barriers in tuberculosis control (Waisbord, in Eastwood & Hill, 2004).

One of the external constraints is transportation costs, which are associated with distance between residence and DOTS clinics. Transport costs also account for variations in timing of diagnosis as verified by a study in Zambia (Equi-TB, 2006). Transport costs also contribute to delays in TB treatment because patients sometimes need to borrow money to get to healthcare services (Waisbord, in Eastwood & Hill, 2004).

The researcher discussed the social factors in the above section and will now continue with the health service factors, which contribute to delays in treatment of TB.

### **3.2.2 HEALTH SERVICE FACTORS CONTRIBUTING TO PATIENT DELAYS IN SEEKING TREATMENT FOR TUBERCULOSIS**

Social factors are not the only factors influencing TB treatment. There are also factors in health services that contribute to delays in TB treatment. These are mainly interpersonal factors between health service providers and patients, as well as infrastructural factors at health care facilities.

#### **3.2.2.1 Interpersonal relationships between health service providers and patients with regard to Tuberculosis**

Interpersonal relationships can enhance or ruin patient success in treating disease, because patients do not want to go to medical treatment or use medication because of negative interpersonal relationships.

### **3.2.2.1.1 Communication between health service providers and patients with regard to Tuberculosis**

Poor interpersonal communication over-sights by health care providers and neglect coupled with the lack of attention and support to patients account for delays in treatment of TB (Waisbord, in Eastwood & Hill, 2004; Westaway 1994:477). A study in China indicated that village health care providers have poor communication skills (Dunn, as cited in Equi-TB, 2005).

However thanks to interpersonal and mediated communication activities within the Primary Health Care (PHC) patients may be equipped with more information to recognize symptoms, know routes of contagion, and be aware that TB care and cure is available (Benator, Doherty, Heunis, McIntre, Ngwena, Pelser, Pretorius, Redelinghuys & Sumerton, 2004).

### **3.2.2.1.2 Attitudes of staff with regard to Tuberculosis**

Tuberculosis control found that inadequate staff attitudes are among the main factors contributing to delay in health seeking. Staff attitudes were described by the participants as not always corresponding to people's expectations of appropriate health services (Johansson *et al.*, 2000:33-51). Inadequate attitudes of health providers coupled with the lack of attention and support to patients account for delay in several countries according to Westaway (1994:477).

Contributing factors to inadequate staff attitudes include the fact that Primary Health Care (PHC) teams work under considerable pressure which threatens individual well-being (Bryar, 1996:198).

Infrastructural deficits are major contributing factors that contribute to patients' delays in seeking treatment for TB, and will be discussed next.

### **3.2.2.1.3 Infrastructural Deficits with regard to Tuberculosis**

The health care system factors that contribute to case finding and treatment delays include lack of flexibility for treatment supervisors, inadequate supplies for treatment centres and centralized treatment delivery.

Waisbord, in Eastwood & Hill (2004) asserts that it was found during studies in South Africa and Vietnam that, both diagnosis and treatment effectiveness require that the infrastructure of TB control programs had a minimally acceptable functioning. That is, drug supply is reliable and sustainable, laboratory facilities are available and sufficiently equipped to perform tests, monitoring systems are in place, and human capacity for different tasks (e.g. supervision, laboratory work) is adequate.

Insufficient funding has an influence on health structures and subsequently treatment of TB patients, as well as conditions of employment of health service workers. This was identified as an underlying problem resulting in a decrease in screening coverage, low salaries, staff shortages, irregularities in drug supplies and outdated infrastructure when they did a study about the health service providers' perceptions of barriers to tuberculosis care in Russia (Dimitrova, Balabanova, Atun, Drobniowski, Levicheva, and Coker, 2006). Clinics also do not have the expensive medical equipment to be able to identify TB cases at an early stage as a result of insufficient funding (Dunn cited in Equi-TB, 2006).

Xu, Dong, Zhao and Bogg (2006) did a study regarding DOTS in China, removing barriers or moving barriers regarding health services. In 1992, China initiated its modern National TB Control Program (NTP) with DOTS strategy through a project funded by a World Bank loan. Key motives for the revised NTP-DOTS were to reduce financial barriers to patients by removing fee charges for diagnosis and treatments. After implementing NTP-DOTS in funding, expenditure after diagnosis decreased slightly, whereas expenditure before diagnosis increased remarkably. This may result in prolonged delays before effective treatment is given.

Ineffective health systems play a major role in reinforcing barriers to poor and vulnerable people. A lack of cooperation and coordination between national, regional, and county health facilities and TB services can prevent patients from gaining accurate diagnosis and treatment. Lack of awareness of TB symptoms by health care providers, low referral rates to TB centres, and extra 'hidden' costs for patients contribute to a less effective response to TB in China (Dunn in Equi-TB, 2005).

Infrastructural factors are also related to referrals by health professionals. Kiwuwa *et al.*, 2005, did a cross-sectional study in Uganda (a cross-sectional survey, of 231 newly diagnosed smear-positive tuberculosis patients was conducted in Mulago National Referral Hospital Kampala, from January to May 2002) regarding patient and health service delay in pulmonary tuberculosis regarding patients attending a referral hospital. Delay in diagnosis of TB is prolonged at the referral centre to referral hospital.

The onset of treatment of patients is influenced by structural barriers in health settings and sometimes this even result in death.

This was the finding of a study in Malawi. Around 14% of patients with confirmed TB never started treatment. The reason for this was that patients waited a long time to receive a positive diagnosis of TB. Fourteen of these cases died within six weeks of their positive TB status being established. Health centre staff was not considered responsive to patients needs even if they did recognise the symptoms of TB. Staff complained about handling what they perceive to be false cases. There were delays between being tested and receiving results. Some participants claimed they received the result after the patient had died (Dunn as cited by Equi-TB, 2005).

Health service providers are also influenced by their conditions of service at health centers. Places where TB control programs have been established experience great pressure to deal with the increasing case load, as more and more people get infected with TB. This pressure influences the quality of health services by health personnel. Health personnel and hospital beds are also in great demand because of the increase in TB cases. A study in Blantyre, Malawi focused on diagnosis and treatment of smear-positive TB patients. The study found that in 10% of patients who were on out-patient treatment presented with a delay of more than two days between admissions to the TB ward and the commencement of anti-TB treatment. The reasons for the delays is partly due to the fact that wards are congested and newly arriving patients may be missed during therapy rounds, especially at weekends when nursing staff are few (Van der Velden *et al.*, 1995:219-220; Harries, Kamenya, Namarika, Msolomba, Salaniponi, Nyangulu & Nunn, 1997:15-17).

Health service professionals can in some cases be influenced by financial incentives. Dunn as cited in Equi-TB (2005) found in their study done in China, that TB control programs do not have enough money to offer attractive financial gain for village and township level health workers to detect and refer TB cases.

In those places where TB control programmes have been established, these programmes are now under great pressure to deal with the increasing case load. TB in HIV-infected persons is more difficult to detect, patients are more often very sick, have complications or suffer more frequently from adverse reactions to drugs. All of this results in an increased demand for health personnel and hospital beds. TB is curable and preventable (Van der Velden *et al.*, 1995: 217-218; Fei & Qingwu, 2006).

TB has an effect on the health of health service workers, which is one of the health service factors contributing to poor conditions of service, and consequently as delays in TB treatment. A study was done in Blantyre, Malawi, to determine delays in diagnosis and treatment of smear-positive tuberculosis and the incidence of tuberculosis in hospital nurses (Harries *et al.*, 1997:15-17).

A study was done about Laboratory Reporting of Tuberculosis Test Results and Patient Treatment Initiation in California (Pascopella, Kellam, Ridderhof, Chin, Reingold, Desmond, Flood and Royce, 2004). The reason for the study was because the role that laboratory reporting may play in treatment initiation has not been documented in studies of treatment initiation delays. They have discovered that timely laboratory reporting of tuberculosis (TB) is important for prompt initiation of appropriate medical therapy for TB patients and rapid public health response. National guidelines and regulations in 39 states specify that laboratories performing TB diagnostic tests and drug susceptibility tests should report test results to the specimen submitters and to health departments within specific time frames.

The study also attempts to describe laboratory reporting time frames and delays and how these delays may impact timely initiation of

treatment for TB patients. This patient-based study examines the time frames for laboratory reporting of TB test results from a cohort of culture-positive TB patients from California in 1998, describes factors that contribute to delays in reporting, and analyzes the association between delayed reporting of laboratory findings of TB and delays in the initiation of anti-TB therapy. They have found that patients whose positive smear results were reported to the submitter more than one day after specimen collection were twice as likely to have delays initiating therapy than patients whose positive smear results were reported within one day. They have also discovered that although laboratory reporting to the submitter was a factor contributing to delayed treatment, many patients with delayed treatment had timely submitter reporting. The results of the study also shown that reporting delays were associated with delays in the transportation of specimens from the collection site to the laboratory performing the smear microscopy, and, consequently, were also associated with laboratory type, with public health and commercial laboratories having longer median reporting times than hospital and HMO laboratories.

Health care providers also received delayed laboratory reports of the first evidence of TB for 47% of AFB smear-negative patients for this population. The findings reveal the crucial role of laboratory reporting of TB test results in TB control. To continue to control and move forward in eliminating TB, it is essential to improve the timeliness and completeness of laboratory reporting of TB test results.

Harries *et al.*, 1997, also found that another aspect that might contribute to health service delays in the same study is an alarming high rate of TB that was found in the hospital nurses, particularly those working in the medical wards and more specifically TB ward.

Inadequate health service is one of the health service factors that contribute to patients' delays in seeking treatment for TB.

#### **3.2.2.1.4 Poor quality health care services contributing to delays in Tuberculosis treatment**

In order to rectify these health care factors it is necessary to do quality control and setting standards for health services. Quality and standard setting has been a central issue in the development of health care. Clinical audits may be carried out in a number of different ways, one of which starts with the establishment of multidisciplinary standards of care, as a solution to poor quality health services (Bryar & Bytheway, 1996:74).

Health staff need the following requirements in order for them to render quality care; regular pay, living accommodation, sufficient medicines and vaccines, standard treatment guidelines, and basic medical instruments and equipment for basic diagnostic and treatment purposes (Beaglehole, 1997:25; Benator, 2004).

Quality of care in health services influences patients' perceptions about the facilities and consequently their cooperation in treatment. The Tuberculosis Research Center (2003-2004) reported in a sociological research, in the form of a community-based study, involving rural and urban population in Tamil Nadu, South India that about half the patients shifted from the facility they approached initially. This was due to dissatisfaction with the system. It was made clear by the study that besides expanding the governmental health care network, especially in rural areas, they must be made more accessible, communicative and convenient. The study also highlights the need to involve the private medical sector in tuberculosis control and to make governmental health facilities more accessible and user friendly.

The poor quality of services could be the reason why a large number of patients are not diagnosed, once they come in contact with health clinics. Several factors contribute to health providers' delay. The inability of health systems to screen people before they develop active TB largely accounts for system delay. The lack of diagnostic tools in health clinics, bad implementation, overall under-utilization of healthcare services, are all explanations for health service delays. Studies in South Africa and Vietnam have found that the inability of health services to screen patients in first contacts contributes to delayed diagnosis (Waisbord, in Eastwood & Hill, 2004; Westaway, 1994:447). For quality and effectiveness TB control programmes needs two basic principles, namely: case-finding of people infected with TB and adequate treatment (Van der Velden *et al.*, 1995: 217-218).

Training is one of the services that can enhance quality of care in TB patients and it will be discussed as follows.

#### **3.2.2.2 Training (Education and Knowledge) with regard to Tuberculosis**

The health care system factors that contribute to case finding and treatment delays include poor training and supervision of health community workers (Thorson, 2001:1533).

Training has an impact on health services in formal health settings. Few clinics have specially trained staff capable of identifying TB cases at an early stage. Village health care providers also have low knowledge and awareness of TB symptoms, and diagnostic skills. This was found during a study in China (Dunn as cited in Equi-TB, 2005).

Training also includes training to the public through health education. The public needs information, if they are to make informed choices and access appropriate health care services. Most people would possibly hear about services by word of mouth (Bryar *et al.*, 1996:148).

The quality of Primary Health Care (PHC) is fundamentally influenced by the educational preparation of and subsequent support for, PHC practitioners. The focus should be on the need for training and education, and how this might best be met. The focus should also be to tackle ignorance and to disseminate up-to-date knowledge (Bryar *et al.*, 1996:99).

The contents of a health education programme should be determined by the needs of the community and not by what the health educator thinks the community needs. Certain factors such as knowledge of the values, beliefs and life-style of the community, the support of community leaders and the involvement of the members of the community are all necessary for the success of a health education programme (De Haan, 2002: 18).

Health promotion of Tuberculosis should be directed particularly at those sections of the population where the risk of infection is highest. The causes, signs, symptoms and the prevention of the disease must be stressed. Information must be given concerning the medical care services, which are available. A community-based study had been conducted, involving rural and urban population in Tamil Nadu, South India. They did research on the factors influencing the care-seeking behaviour of chest symptomatic patients and found that information, education and communication (IEC) materials must be tailored to suit the special needs of the TB patients (De Haan, 2002:123; The Tuberculosis Research Centre, Annual Report, 2003-2004).

Death-preventive and lifestyle change efforts in both developing and developed countries must also focus on changing people's specific behaviours that, with or without their knowledge, are killing them for example with adherence to TB treatment. These attempts are however likely to be resisted strongly by the targeted individuals, who possibly would interpret them as unfair infringements on their personal freedoms. Societies have tried to address health-destroying, life-threatening diseases voluntarily (Soroka, & Bryjak, 1995: 374).

### **3.3 CONCLUSION**

There are certain factors that are of importance in health services, which can influence treatment of TB. These include social and health services factors. Social factors as contributing to delays in Tuberculosis include stigma, knowledge, economic factors and accessibility of health care facilities. Health services factors include interpersonal relationships between health service providers and patients with regard to TB, attitudes of staff, infrastructural deficits, poor quality health care services and training. The researcher has completed a comprehensive literature review with regard to the various social and health services factors that contributed to patient delays in seeking treatment for TB in this chapter and will now continue this discussion by analysing the experiences of patients with regard to these social and health services factors contributing to delays in seeking treatment for TB, in the next chapter.

## **CHAPTER FOUR**

### **DISCUSSION OF FINDINGS/ DATA ANALYSIS**

#### **4.1 INTRODUCTION**

Chapter four consists of the results of data analysis as a result of interviews conducted with patients in order to establish their experiences regarding social and health service factors, which contribute to delays in seeking treatment for Tuberculosis. Data were classified into main themes, categories and sub-categories as result of the analysis. The main themes, as well as categories were verified by using literature as control of data analysis.

#### **4.2 DISCUSSION OF RESULTS FROM DATA ANALYSIS OF SEMI-STRUCTURED INTERVIEWS WITH PATIENTS**

Data analysis of the interviews with patients indicated two main themes namely:

- The experiences of patients with regard to social factors that contribute to delays in seeking treatment for Tuberculosis.
- The experiences of patients with regard to health services factors that contribute to delays in seeking treatment for Tuberculosis.

Certain main and sub-categories were identified and classified under each of the major themes and these are presented in Figure 4.1 and 4.2.

**MAIN THEME: 1**  
**SOCIAL FACTORS CONTRIBUTING TO PATIENTS' DELAYS IN**  
**SEEKING TREATMENT FOR TB**

**CATEGORY 1**  
**SOCIO-ECONOMIC FACTORS**

Sub-categories:

- Occupation
- Income/grant
- Education level
- Living conditions
- Financial Impact
- Poverty

**CATEGORY 2**  
**SUBSTANCE ABUSE**

Sub-categories:

- Alcohol abuse
- Drug abuse

**CATEGORY 3**  
**PSYCHO-SOCIAL FACTORS**

Sub-categories:

- Guilt
- Fear
- Depression
- Uncertainty
- Secrecy/Isolation
- Shame
- Denial

**CATEGORY 4**  
**INTER-PERSONAL RELATIONS**

Sub-categories:

- Social support systems
- Inter-personal relations with extended family, friends and/or community members
- Inter-personal relations with significant others
- Stigma influencing inter-personal relations

**FIGURE 4.1**  
**SOCIAL FACTORS CONTRIBUTING TO PATIENT DELAYS IN TB TREATMENT**

**MAIN THEME 2  
HEALTH SERVICE FACTORS CONTRIBUTING TO PATIENTS'  
DELAY IN SEEKING TREATMENT FOR TB**

**CATEGORY 1  
QUALITY OF HEALTH CARE SERVICES**

**Sub-categories:**

- Inaccurate Diagnosis
- Ineffective communication
- Health education
- DOTS support
- Accessibility of health services

**CATEGORY 2  
ATTITUDES OF MEDICAL STAFF**

**Sub-categories:**

- Positive attitudes of medical staff combating delays in treatment
- Attitudes of medical staff resulting in mistrust and consequently delays in treatment

**CATEGORY 3  
OTHER MEDICAL CONDITIONS AND  
TREATMENT**

**Sub-categories:**

- Other illnesses
- Self-medication
- Relationship between HIV/Aids and TB

**FIGURE 4.2  
HEALTH SERVICES FACTORS CONTRIBUTING TO PATIENT DELAYS IN SEEKING TREATMENT FOR TB**

#### **4.2.1 MAIN THEME 1: SOCIAL FACTORS AS CONTRIBUTING TO PATIENTS' DELAYS IN SEEKING TREATMENT FOR TUBERCULOSIS**

Social factors can contribute to disease and should also be considered in treatment of disease. The social environment provides important information that can be used not only to identify fundamental causes and transmission processes of illnesses, but also to assist in determining the most effective means of treatment and prevention within a particular society, community or environment (Van Rensburg, 2004:204-205).

There are four categories of social factors including the socio-economic, substance abuse, psycho-social and interpersonal relationships that will therefore be addressed through direct quotes and literature control.

##### **4.2.1.1 CATEGORY 1: SOCIO-ECONOMIC FACTORS**

Participants indicated that socio-economic factors had been some of the main reasons why patients' delay in seeking treatment for Tuberculosis. Social or economic circumstances can also prevent people from carrying out new health behaviours, even if they would like to. It can be very rewarding, despite these limitations, to help people to look at their motivations, beliefs, values, and attitudes, and to make and carry out decisions that will lead to improved health and well-being (Ewles & Simnett, 2004:271).

- **Occupation**

Participants revealed that their main concern had been to survive and they did so by having to work, although they were already sick and displayed some of the symptoms of the disease. Most participants were unemployed. The following quotes indicated participants' expressions about their occupation:

“...ek werk nie nou op die oomblik nie...;” “...ek is ‘n gewone arbeider..;” “...so vir ‘n tydjie gewerk op die gebou...;” “...voor ek siek geword het, het ek gechar...;” “...ek char nie meer nie want die mense sien ek is siek en hulle wil nie hê ek moet so werk nie, want verstaan daar is kindertjies in die huis, sien u nou, en toe het hulle gesê ek moet nou eers 'n tyd tot ek gesond is dan kan ek weer kom...;” “...nou kom jy by die werk en die baas sê vir jou sit daai radio daar of hy sê maak gou daar skoon, nou dit werk als op jou...dai maak dat in 'n split second jy kan op die grond slat...daar werk die ander, hy weet nie jy lê daar...lewensdood, verstaan....”

(“...I do not work at the moment...”; “...I am an ordinary worker...”; “...worked on the building site for a little while...”; “...I did char, before I became sick...”; “...I do not char anymore because the people saw that I was sick, and they did not want me to work like that, because you must understand that there is small children in the house, do you see, then they told me I must wait till I am healthy then I can come again...”; “...now you arrive at work and the boss tell you to put the radio there or he tells you to quickly clean there, now all of that works on me...that will cause you to collapse on the ground in a split second...there the others are working, and he does not even know you are laying there...dead, you understand....”

“...dit is die ding ek moet nog gewerk het, ek moet dink aan die kinders wat moet eet, hulle kom uit die skool uit...sien daaroor het ek nie gegaan vir my behandeling nie...”

(“...the thing is this, I still had to work, I had to think of the children that have to eat, and they come from school...see that is why I did not go for my treatment...”)

“...wat ek nou siek is, kan ek nie werk nie, kan ek niks doen nie, kan nie skarrel nie, ek het niks nie, daar is niks wat ek kan doen nie....“....(“I am unable to work now that I am sick, I cannot do anything, cannot scurry around, I have nothing, there is nothing that I can do...”)

Being unemployed or losing your work can have critical consequences for the family and the individual as mentioned by the following author. A family that has been used to a certain standard of living may due to a decrease in or termination of income have to adjust to new socio-economic conditions. A married couple may often experience unwanted conflict as a result of the breadwinner’s inability to secure reliable and permanent employment. This situation may also adversely affect the other members of the family (Bezuidenhout, 2004). The author further asserts that those who may get an opportunity to work find that their energy levels are too low for them to cope with their workload (Bezuidenhout, 2004).

- **Income- Grant**

Participants are always in dire need for money and the urgency for this contributed in various instances to unconventional methods to obtain an income. The need for an income contributed also to a delay in treatment because income was perceived as a priority.

“...ek het nie geworry om sover te gaan om kliniek toe te gaan nie, want my gedagte was net om te skarrel, om elke dag geld te het...”  
 (“...I did not care to go to the clinic, because my mind was just on running around, to have money for every day...”)

Most of the participants specified that the grant is the only means of income, which they receive.

“...ek kry nou 'n grant...”; “...ek leef maar net van die toelaag wat ek kry, die grant...”; “...nee, my vrou werk nie, niemand werk nie...op die oomblik kry ek geen inkomste nie, geen grant ook nie...” (“...I am currently receiving a grant...”; “...I only live from the grant that I receive...”; “...no, my wife also does not work, no-one is working.....I do not receive any income, not even a grant...”).

They also mentioned that the grant is only issued for six months, after which they have to re-apply for the grant. This process lasts several months and there are periods that participants has none or very little means of income.

“...Ja, eerste toe ek ontslaan was van die hospitaal, op 20 April, toe moes ek nou weer teruggegaan het hospitaal toe, om my vorms te gaan haal en toe 107 (Department of Social Development, Bellville District Office) toe...die grant sal nou die einde van volgende maand, gaan dit in werking wees...”; “...die grant is, die 20 ste April, van volgende jaar is dit klaar...”; “...ja, ek gaan heraanzoek doen...”; “...die grant was net vir ses maande gekanselleer...”

(“...Yes, first when I was discharged from hospital, on 20<sup>th</sup> of April, then I had to go back again to the hospital, to fetch my forms and then I went to 107...the grant will be reinstated at the end of next month...”; “...the grant will be finished by the 20<sup>th</sup> of April, of next year...”; “...yes, I am going to re-apply...”; “...the grant had been cancelled for only six months.”).

Chronic illness has significant economic effects. Income for the majority of people suffering from chronic illnesses is derived from Government benefits (Browning & Thomas, 2005:249).

- **Educational level**

The educational level of participants was in general very low. This could be a contributing factor in the delays of patients' in seeking treatment for Tuberculosis and could also be linked to health service factors because participants did not comprehend the illness and impact thereof.

“...ek het nie skool gehet nie...”; “... ek het net standerd drie gemaak...”; “...standerd vier...”; “...ek was standerd drie laas op die skool...”; “...daai was standerd ses...”; “...standard five...”

(“...I did not have schooling...”; “...I only made it till standard three...”; “...standard four...”; “...standard three was the last time I have been at school...”; “...that was standard six...”; “...standard five...”).

Individuals may be forced to cease their formal education at a very young age to add to the family's income. In some instances children leave their homes to earn a living on the street. They drop out of school and in later years they have difficulty competing with their peers on the open labour market (Bezuidenhout, 2004). Literacy is viewed as important, but schooling receives mixed reviews, occasionally highly valued, but often remarkably irrelevant in the lives of the poor (Narayan, Chambers, Sha & Petesch, 2000).

- **Living Conditions**

Participants indicated that they do not have their own homes and need to rely on informal housing, or living on the streets. Expressions used by respondents to prove this statement is as follows;

“...waar gaan ek slaap vanaand, watter kante, want somtyds as ek nou hier geslaap het word ons nou opgejaag, deur ADT, dan moet ons weer trek....”

(“...where am I going to sleep tonight, at which side, because sometimes when I sleep here, then we will be chased away by the ADT, then we must move again...”).

“...gesê ek moet vir my 'n plek slat op die yard...”; “ ...dan slaap ons daar by Furn City, slaap ons op daai stoep...somtyds slaap ek onder afdakkies...” (“...told me to erect a place on the yard...”; “ ...then we sleep there at Furn City, we sleep on that stoep...sometimes we sleep under a verandah”).

Individuals and families who have become impoverished find it difficult to create a safe and healthy living environment for themselves. Often they are driven out of their houses because they are unable to pay the rent or bond premiums. They may have to move to a cheaper home in a lower social class environment, or maybe forced to live on the street, or settle in a squatter camp (Bezuidenhout, 2004).

- **Financial impact on treatment**

The fact that participants are unable to work because of their physical ill-health, has an impact on their financial status. Their grants are also at times reviewed, and they have a lot of debt. All these factors contribute further to patient delays in treatment of Tuberculosis due to a lack of transport fees and subsequently accessibility to health facilities.

“...daar was sekere plekke wat dit my geruk het. Most of the time het ek geld soontoe gehad, na die plekke, ma terugkom, dan moet ek ma stap en dis plus minus oor die drie uur...”; “...dan moet ek altyd geld leen by die mense, wat miskien nou het en as dit daai tyd kom dan moet ek weer daai mense betaal...”; “...met die geldsake het dit bietjie moeilik gegaan want ek het nie geld nie, dan moet ek by 107 (Department of Social Development) wees, dan by Tygerberg (hospital) wees...”; “...lyk die geld is nie genoeg vir alles wat jy nodig het in die huis nie, want dan gaan die geld vir dit en om daai gat vol te maak...”; “...jy leen by mense dan maak dit ‘n gat, want jy moet die mense increase betaal.”

(“...there are certain places where it affected me. Most of the time I had money to go to the places, but when I come back, then I had to walk and that is plus minus three hours to walk...”; “...then I had to borrow money from people and when the time comes I had to pay this one and that one...”; “...it went a bit difficult with the money matters, because I do not have money, I then had to go to 107 and then Tygerberg...”; “...it seems the money is not enough for everything you need in the house, because then the money must go for this and to fill that whole...”; “...I cannot pay for anything...you borrow money from people, then it makes a whole, because you have to pay them back with added increase.”). I

The following three authors concur that financial means is necessary to secure good health.

It had been found that treatment was kept for those who could afford to purchase the drugs themselves, or who belonged to certain medical aid schemes. Health care was thus dependent on financial position and, consequently, the right to life was linked to wealth (Ross & Deverell, 2004:7).

Research has shown that disease, disability and death are far more common in the lowest socio-economic classes and that rates declines steadily as one moves up the social ladder. There are many reasons to account for this: poverty, low standards of education, unemployment, failure to utilize the medical care services or a lack of such services for the lower social classes, and poor environmental conditions all contribute to high morbidity and mortality rates (De Haan, 2002:27).

Little or irregularly obtained income may cause ill health and a high mortality rate among the poor (Bezuidenhout, 2004).

- **Poverty**

It is evident from the quotes of participants that there are a correlation between disease and poverty. Poverty can be a cause and/or result of disease.

There is a vicious circle that exists between poverty and disease. One problem causes another which in turn causes a third and new linkages are formed until we are back where we have started to begin the cycle starts all over again. The cycle starts with disease and goes to poor health which go to low production, then to low income, lack of knowledge, misdirected priorities, superstition traditions, poor sanitation, lack of clean water, low taxation lack of health facilities and goes back to disease (Burkey,1993).

“...dan skarrel ons ma, dan gaan gee ons onse goed in...die kos wat ons so kry by die mense...so het ek begin hoes, hoes, hoes, hoes...somtyds kry ek koud, dan trek ek my dik aan dan kry ek weer warm, dan trek ek my weer uit...”

(“...we would then scurry around, give in some of our stuff...the food that we get from the people....then I started to cough, cough, cough, cough... I will sometimes get cold, then I will dress me warmly, then I will undress myself again...”)

Economic factors such as low income contribute to this cycle of poverty and disease. It is found that there are physical factors relating to disease and poverty, which means certain diseases (including TB) are found to be more prevalent in certain areas (like the tropics – areas with warmer climates). Most of the poor people live in tropical areas. It was further found that social factors also contribute to the continuation of the vicious circle of poverty. Social factors such as the lack of cooperation, lack of social cohesion and lack of local organizational structures. There are also political factors in addition to the above mentioned factors. Factors such as political instability, lack of representational government, over-centralization and lack of local government. There are thus a series of factors like economic, social, physical and political factors which all contribute to the continuation of the vicious circle between disease and poverty (Burkey, 1993).

“...dis net som keer klop ek miskien by die next door bure, vra miskien iets as ek honger is, dan verduidelik ek vir hulle, ek kry ma ‘n toelaag van die staat af...het U nie miskien vir my brood of so, want ek voel nog honger...”; “...ek eet maar ek het nie general kosse nie, soos vleis, aartappels, stysel kosse nie...”; “...want die feit is om eerlik te is, ek het gister dan net brood geet...”; “...sommige kere is dit daar is nie brood of iets wat ek kan eet nie voor ek daai pille drink nie en ek moet. Hulle sê jy moet iets eet, maar by die hospitaal gee hulle ook vir my die TB pap...”; “...die geld wat ek kry van die grant gaan ook maar net van die hand tot die mond...”; “...hier by

my suster is 'n tweeplaat stoof en ek vat dit net so as ek sê gaan koop daai pakke vleise, ek moet nou eletriese geld gee, en ek moet my eie goed het, soos potte, panne...”; “... Ek koop maar soos brood en polonie....”

(“...I sometimes knock on the neighbours’ door, and ask them something to eat when I am hungry, I then explain to them that I only get a grant from government...and enquire if they do not have bread or so, because I still feel hungry...”; “...I do eat but I do not have general food, like meat, potatoes, no starch food...”; “...because to be honest I only ate bread yesterday...”; “...there is sometimes no bread or anything else to eat before I drink my tablets and I must. They say you must eat, but at they also give me this TB porridge at the hospital...”; “...the money that I get from the grant is going straight from the hand to the mouth...”; “...there is a two plate stove at my sisters’ but I take it so that what if I go buy those big packs of meat, I must still have money for electricicity, and I must buy my own stuff such as pots, pans....”; “.....I buy bread and polony...”).

“...die kos wat ons so kry, vir haar ma gegee, die kinders het by haar ma gebly, as ons sente ook het, as haar ma kom, dan gee ons vir haar ma geld vir krag by die huis...so het ons ma geskarrel, net vir die sake van haar kinders, want daar was ook nie inkomste by hulle huis nie...nie note gevat van my siekte nie, net geskarrel...”

(“...we give the food that we get to her mom, the children stayed with her mom, even when we have money, when her mom comes, then we give the money to her mom for electricicity at her house...we scurry around like that, just for the sake of her children, because there were no income at their house...did not take note about my illness, only scurried....”)

Poverty, unemployment and inequality are increasing in South Africa. In most of the world, the link between poverty and poor health remains very strong (Van Rensburg, 2004:209). Without adequate financial means or social support the poor cannot purchase or acquire the nutritional foodstuffs necessary to maintain their health and thus will eventually also suffer from malnutrition (Bezuidenhout, 2004).

#### 4.2.1.2 CATEGORY 2: SUBSTANCE ABUSE

- **Alcohol abuse**

Alcohol abuse contributes largely to delays in diagnosis and treatment of Tuberculosis, as specified by the majority of the participants.

“...dis ek self wat wil aangaan met drink...dit gaan my dood veroorsaak...”; “...ek was so gewees, as ek dokter toe gaan, dan drink ek eers die helfte van die geld uit, dan gaan ek nie dokter toe nie...”; “...waar ek my fout gemaak het as ek my pille moet drink partykeer dan dink ek nee wag ek gaan nog ‘n doppie drink voor ek water gaan drink...”; “...ek sal die dokter se geld gedrink het en ek sal nog altyd vasgetrap het as my vrou nie self vir my gevat het nie...”; “...ek het nie wyn gedrink nie, ma whiskey, daai het ek sommer elke dag gedrink as ek klaar gewerk het...”

(“...it is myself who continues abusing alcohol...it will cause my death...”; “...I used to be like this, whenever I go to the doctor, then I used to drink half of the money fo the doctor’s fees, then I will not go to the doctor...”; “...where I made a mistake was when I had to drink my pills, then at times I would think, no wait I am first going

to drink a glass of alcohol, before I am going to drink water...”; “...I would taken the doctor’s money, and would have still refused to go to the doctor if my wife did not take me herself...”; “...I did not drink wine, but whiskey, that I used to drink everyday as soon as I was finished with work...”).

In many developing countries, alcohol is the single foremost factor causing diseases and non-natural death. Alcohol’s direct effects on health are devastating. People of South Africa have a general drinking habit that is considered as most damaging to health (Morejele, 2008) Alcohol is frequently used to manage and alleviate stress and has a strongly negative impact on household members. High alcohol costs and the spending of male wages on leisure activities bring additional financial burdens to households (Narayan, Patel, Schafft, Rademacher & Koch-Schulte, 2000).

Prevention and management of substance abuse can also be addressed on the primary health level (at the clinics) since TB patients are sufficiently at ease with staff to be able to bring out any problem, of alcohol or drug abuse. Staff can identify alcohol and drug (marijuana) abuse and provide basic counseling for behaviour changes and referral to NGO’s specializing in substance abuse (The Primary Health Care Package for South Africa, 2001; <http://www.doh.gov.za/docs/policy/norms/part1o.html>)

- **Drug abuse**

Some of the participants revealed that drug abuse could have been a contributing factor with regard to delays in seeking treatment for Tuberculosis.

“... het beginne met dagga, dit was eintlik my hobby....toe agterna toe ek in Belhar kom toe los ek dit, maar agterna toe kry ek weer vrinne, toe begin ek weer. Ok daai het ek ma net vir ‘n maand of twee gedoen toe los ek dit ma weer...”

(“...it started out with drugs, it had been my hobby...I stopped using it afterwards when I came to Belhar, but I got friends again, and started again. Ok that I only did for a month or two and have stopped again...”).

“...ek het buttons gerook, maar nie soos andere wat aanhoudend dit doen nie. Dis miskien dit wat my nog sieker gemaak het.” (“...I used to smoke buttons, but not like others who do it constantly. It could be that that made me sicker.”).

Individuals who are introverted, submissive and feel inferior, who lack confidence in themselves and others, and who have a great need for recognition may take drugs to acquire a sense of well-being. Prolonged drug use may result in drug abuse and ultimately in drug addiction (Newcomb & Bentler in Bezuidenhout, 2004).

#### **4.2.1.3 CATEGORY 3: PSYCHO-SOCIAL FACTORS**

There are various psycho-social factors which were mentioned by participants as a result of TB. The importance of psychological and sociological factors and the role they play in the different stages indisease process (Ross & Deverell, 2004:4). Psychological influences result in why people become ill, and how they become respond when they do get ill. Social and psychological factors impact on health and illness and because of the realisation that psychology has a role to play in modifying behaviours implicated in chronic illness (Taylor, 1999:3) in Ross & Deverell(2004:5).

- **Guilt**

Data analysis indicated that guilt was one of the factors resulting from TB and the participants' health behavior contributing to the disease. The health behavior resulting in guilt could also be linked to substance abuse.

“...wat ek maar nou net gedink het is dis nou ek self wat dit gedoen het dat my gesondheid agteruit gaan, want ek wil nie hoor met my dinge nie.”

(“...I think that I am myself to blame for the deterioration of my illness, because I did not wanted to listen with my things...”)

Common reactions to typical problem situations such as ill-health are worry, concern, shame, resentment, hurt, fear and feeling overwhelmed, guilt, helpless, or hopeless. Being able to ventilate such emotions in the presence of an understanding and concerned person is a source of great comfort to many persons (Hepworth et al., 2002). Guilt and self-blame patients may be felt by patients who have experienced individual cases of loss (Adams & Bromley, 1998).

- **Fear**

Participants pointed out that they experienced a fear of the unknown and of dying after discovering that they may suffer from TB. These could be a motivating or demotivating factor in the diagnosis and treatment TB.

“...ek was ‘n bietjie in ‘n vibe in, want ek het gedink ek is mos darem die broodwinner in die huis in...”; “...toe het daai vir my ook so bekommerd gehad dat ek party aande nie lekker kan slaap nie...”; “...ek was baie bekommerd gewees want hoekom ek het altyd gedink as ek nou TB het, wie gaan vir my kinders sorg...”

(“...I had been in a vibe, because I thought I am the breadwinner in the house...”; “...that made me worried even so that I could not sleep nicely during some of the nights...”; “...I was very worried because I always thought if I had TB, who is going to care for the children...”).

“...want in die koerant, toe het hulle gewys hoe gaan die mense dood van die siekte...dit het my bietjie skrikkerig gemaak...”; “...ek moet tog vir U sê ek het nogal bang geraak, daai moet ek nogal vir u sê ek het nogal bang geword. Dis hoekom ek vir U sê ek het nog nie gegaan vir x-strale dat ek kan sien hoe lyk my longe en daai nie, verstaan...”; “...partykeer as ek so alleen is en ek wil net gaan slaap, dan raak ek self so bang...”

(“...because in the newspapers, they showed how the people died because of the disease...it shocked me a bit...”; “...I must tell you that I became afraid, that I must tell you, I became very afraid. That is why I am telling you that is why I have not yet went for x-rays, so that I can see how my lungs look and that, understand...”; “...sometimes when I am alone and I just want to sleep, then I become afraid ...”

“...hoekom wil ek dan net gaan slaap....dan is ek bang, gaan ek nie doodgaan nie...”; “...toe ek terugkom uit die hospitaal uit het ek

baie dinge gesien wat maak die siek, die siek ek kan sien sterk mense, dai het ek elke dag gesien met my eie oë hoe sterf hulle in die hospitaal van die siek...”

(“...I wonder why I want to sleep...then I am afraid, am I not dying...;...I saw a lot of things when I came back out of the hospital, I saw what this disease does, I saw how this disease causes strong people to die in hospital, that I saw with my one eyes....”)

Fear is linked with a perceived threat. Images that arouse fear are sometimes used in health campaigns to promote a change in attitudes towards health. They are intended to frighten people into changing their behaviour, however it was found that too much fear can be counterproductive and result in people rationalizing their risky behaviour by ignoring, denying or minimizing the health threat (Adams & Bromley, 1998).

- **Depression**

Participants admitted to feelings of depression and sadness. Depression is the result of them themselves being infected with the disease, as well as the allegedly negative manner in which they are being treated by others.

“...my mind is net nie correct nie en dan is dit asof iets stoot net op by my...” (“...my mind is not correct, and then it is as if something comes up by me...”)

“... toe het ek eenkeer alleen in my kamer gaan lê, terwyl ek lê dink ek, bietjie seer gevoel..., ek voel ‘n bietjie afgehaal man ek wil net ‘n way instap en nie weer terugkom nie....baie terug gedruk gevoel, so bedruk gevoel, toe gaan praat ek met my een antie daaroor, toe sê sy

nee man moenie so voel nie, dis 'n siek wat almal kry..."; "...ek lê ma my tye en ure om daar in die hokkie, of dwaal maar rond maar ek probeer nie vir hulle pla...."

("...I have once gone to lay alone in my room, while I lay there I thought, I felt a bit heartsore ...I feel a bit sad man, I just want to walk somewhere and never return...I felt very bad, very depressed, I felt so depressed that I went to talk to one of my aunts about it, and she told no man do not feel like that, it is an illness that everyone gets..."; "...I lay for hours in my hockey, or stroll around but I do not hassle anyone...").

Emotional reactions to illness may include depressive or phobic reactions. According to Johnson, depressive reactions are more likely at the acute stages of the illness such as at the onset of the illness or a time of relapse or deterioration. Clinical manifestations of a depressive reaction may include moods of sadness, hopelessness, self-deprecation, reduced activity and social interaction, insomnia, changes in appetite and weight, lack of libido and so forth (Browning & Thomas, 2005:249). Depression, is not mere 'sadness' or a temporary mood of feeling 'low'. It involves a feeling of deep emptiness, of thinking nothing is worthwhile, a wishing to withdraw, feelings of being to blame, of being unloved and unlovable and of being weak and useless, based on assumptions about the self, the world and the future (Adams & Bromley, 1998). Ill health can contribute to depression, sexual difficulties, irritability, low energy, restlessness, inability to concentrate and a host of other problems (Hepworth, Rooney & Larson, 2002).

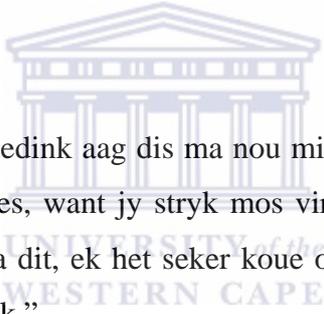
- **Uncertainty**

Participants had been a great deal uncertain whether they are suffering from Tuberculosis or not. They usually experienced

similar symptoms as other illnesses such as colds or flu. Others thought the symptoms are a result of their working conditions. These uncertainties contributed largely to delays in seeking treatment for Tuberculosis.

“...ek het mos gedink dit was miskien verkoue.....” (“...I actually thought it was a cold...”)

“...the doctor actually thinks it was TB, but what he found strange was that it reacted to the pneumonia medication. It reacted to that and it went dormant, but after a while it just flared up again and after the next treatment went dormant again, and after the culture they found it...”



“...het ma gedink aag dis ma nou miskien die werk, want ek was ‘n ironer gewees, want jy stryk mos vir production, toe het ek gedink dis seker ma dit, ek het seker koue opgetel, van die nat reën en die warm gestryk.”

(“...I thought it was the work, because I was an ironer, because you iron for production, so I thought it was it, I picked up a cold, from the wet rain and the warm ironing.”)

“...and since I had sinus problems I just thought it was a post nasal drip. The mucus is running down to my throat, and just coughing it up again...”; “...thought it was the flu, because I am prone to get flu, right through the year...”

Many chronic conditions are surrounded by uncertainty, which may begin at the time when the individual first notices that something is wrong and may continue throughout the entire course of the illness.

Many chronic conditions have a slow and subtle onset, emerging in the form of vague symptoms, and diagnosis may take years. During this time sufferers are convinced that something is wrong, but often find their complaints dismissed by medical practitioners as unimportant or as evidence of malingering or hypochondria. This can be a very difficult time for the individual and his or her family (Ross & Deverell, 2004:15).

- **Secrecy/Isolation**

Participants revealed that they would like to keep the fact that they suffer from an infectious disease, like Tuberculosis, secret, but people sees them coming to and from the clinic and assume they are suffering from TB. They will voluntarily disclose to close family members and friends. The secrecy that they try to adhere to causes isolation and contributes to delays in seeking treatment for TB.

“...nee, kyk hulle weet mos nie eintlik ek het TB nie. Hulle sal my nou nie skel oor TB nie...”; “...dis soos ek kliniek toe loop elke dag, dan kom ek terug, dan kom ek miskien met iets terug wat ek by die kliniek gekry het. Dan weet hulle al klaar...”; “...but my friends I had been a bit hesitant and I did not know what they would think about it, I used to tell one friend when I saw he was ok with it then I knew the others would also be ok with it. So I started telling them one by one... ”

(“...no, they do not really know I have TB. They would not scold over TB...;...it is when I walk to clinic every day, then I come back, then I perhaps come back with something I got from the clinic. Then they know already...”).

A study that done in 2005 in sub-Saharan Africa found that TB patients were comfortable to tell their immediate family that they have TB, but were reluctant to tell anybody else. It had been interesting to find that they were also unwilling to disclose their spouse/partner (Loveday, Thomson & Ndlela, 2005).

- **Shame**

Participants indicated that shame as a psycho-social factor contributed to delays in seeking treatment for Tuberculosis. The majority of participants experienced feelings of shame when diagnosed with TB, but one mentioned that he does not experience shame. This was evident through the following expressions.

“...ek was eintlik skaam en bedruk mos gewees...”; “...jy is skaam, jy wil nie nog vir die ander mense wys jy loop kliniek nie of jy het TB nie...”; “...ons is mos daai soorte, high society, ons wil nie vir die ander wys ons is siek nie...”; “...nee, ek was nie skaam nie, want is almal, die hele Belhar het TB...”

(“...I was actually ashamed and depressed...” ; “...I knew a lot of well-to-do friends, I was not the same as I am now, I was one who used to think of myself as superiour to others...” ; “...you are ashamed, you did not want to show other people that you attend clinic or that you has TB....”; “...we are those type, high society, we did not want to show other people that we are sick...”; “ ... no I was not could ashamed, because everyone, the whole of Belhar has TB.”).

Common reactions to typical problem situations, such as ill-health, are worry, concern, shame, resentment, hurt, fear and feeling overwhelmed, guilt, helpless, or hopeless. Being able to ventilate such emotions in the presence of an understanding and concerned person is a source of great comfort to many persons (Hepworth *et al.*, 2002).

- **Denial**

Participants indicated by means of verbal admissions that they actually denied the fact that they are ill and therefore didn't go for treatment.

“...dis nou so dat ek nie geworry het nie, hoe kan ek sê ek is baie anderste, ek wil nie nog na ‘n dokter toe gegaan het nie en so aan nie...my vrou wat so aangehou het en toe besluit ek ma ek moet dokter toe gaan. As ek nie so gemaak het nie dan sal ek seker al weggewees het al...”; “...dis hoekom ek vir u sê ek het nog nie gegaan vir x-strale dat ek kan sien hoe lyk my longe en daai nie,want ek wil nie eintlik wiet nie, verstaan...”

(“...it is now so that I did not worry, how can I say, I am very different, I do not wanted to go to a doctor and so on...my wife persisted and I then decided to go to the doctor. If I did not do it, I would have been gone by now...;...that is why I say I have not yet gone for x-rays so that I can see how my lungs look and that, because I do not actually want to know, you understand...”).

Denial is a defense mechanism sometimes perceived as being used by those who have experienced a loss to protect against anxiety or the implications of the loss. The reality of the loss may be unrecognized or not accepted (Adams & Bromley, 1998). Signs that can indicate when a person who is or has been critically ill is not coping are as follows; denial, non-complacency and failure to regress from dependence to non-dependence (Thelan in Adams & Bromley, 1998).

#### 4.2.1.4 CATEGORY 4: INTERPERSONAL RELATIONS

Interpersonal relationships are affected by TB. Social support systems, family, significant others, friends and community members are influenced by the stigma associated with TB. These relationships can however also be experienced in a positive manner.

- **Social support systems**

Most of the participants indicated that they enjoy a lot of support from family members as well as members of their church.

It had been found that social support and the emotional and physical help are very important influences on health outcomes, with regard to emotional support provided by intimate ties, the evidence is clear that support plays a role in recovery from illness (Rosenberg & Weissman, 2000).

The following quotes indicated positive social support systems: “...my dogter het haar werk gelos vir ‘n maand toe ek so siek gewees het in die hospital...”; “... daai tyd toe ek gewag het vir my geld, het my dogter vir my so gehelp, met kos en goed...”; “...my kerkmense ondersteun my regtig...”

“...my daughter resigned from her work for a month when I was so ill in hospital...;...that time when I waited for my money, did my daughter help me with food and stuff...”; “...the members of my church really support me...”)

“...ja, hulle help my toe ek in die hospitaal gelê het, hulle het my bygestaan, as ek weekends huis toe gekom het, is hulle daar vir my en gee vir my geld om weer terug te gaan...”

“...yes, they help me, when I lay in hospital, did they support me, when I had to come home during weekends, they are there for me and gives me money to go back again)

“...toe kom haal my susters vir my daar, toe vat hulle my kliniek toe...”; “... hulle vra vir my Mamma wat is verkeerd, dan sê ek ek voel nie lekker nie dan gaan hulle aan met die werk...dan gee hulle vir my my pille, of as ek nie opgaan kliniek toe nie dan gaan die een op dan gaan haal hy my pille by die kliniek...”

“...my sisters came to fetch me there, they took me to the clinic...”; “...they ask me Mom what is wrong, I then tell them I do not feel well, and then they continue with the work...they then give me tablets, or if I do not go to the clinic, then one of them goes up to fetch my tablets at the clinic...”).

The following participants experienced however no social support:

“...ek find my eie way, as ek nie het nie kan ek nie daar binne vra nie want daar is kinders, ek kan nie kos uit hulle monde uithaal nie, want hulle as hulle vir my sê jy is mos nie meer onder ons nie ons kan nie vir jou onderhou nie...”

(“...I find my own way, if I do not have then I cannot ask inside, because there are children whose food I cannot take out of their mouths, because if they tell me you are not under us, we cannot support you...”).

“...nee, toe ek die siek gehad het toe worry sy (saamleefmaat) nie, want ek het daar by hulle gebly, daar gelê, plat gelê, kon niks vir myself gedoen het nie, kan my nie oplik nie, my arms is te pap, my bene is te pap om iets te doen. Ek kan my nie draai nie, my liggaam is te seer....toe los sy my net so...”

(“...no, when I had the disease, she did not worry (life-partner) because I stayed there by them, layed there, layed flat, could not do anything for myself, could not lift me up, my arms were too weak, my legs were too weak to do anything. I could not turn myself, my body was too sore...she left me just like that....”)

Chronic illness can place intolerable strain on the family due to the need for high levels of physical care and support, the emotional connotations of giving and receiving help, and changes in family roles and relationships. Even where family members are willing to and able to provide help, the person with a chronic disabling condition may feel that he or she is a burden and may refuse the assistance that is needed. Also, distressing symptoms such as chronic pain may lead the individual to withdraw from family life altogether. In some instances, both the individual and the family become isolated from the wider community. Marital breakdown is not uncommon in these instances (Ross & Deverell, 2004:15).

It was found that within the community, female relatives played a key role in assisting those who were ill in deciding to go to a clinic for their illness. This study highlighted the need for effective community level support as a number of patients experienced difficulty in accessing TB services (Loveday *et al.*, 2005).

It was found during a study that patients described active family support as a critical factor in their recovery, but that family members, although grateful to be able to provide support, described it as both difficult and demanding. It was also found that church was identified by patients as an important source of social support (Rosenberg *et al.*, 2000).

- **Inter-personal relations with extended family, friends or community members**

Participants indicated that they do not have a lot of contact with extended family, but that TB as a disease has an impact on the relationships that they have with the wider community members and other acquaintances. People often gossip about TB patients and they are discriminated against. This could be a contributing factor to delays in patients; seeking treatment for delays.

Communities supply many of the resources and social supports that are essential for individual's social and psychological well-being. The organizations, associations, families, kin, and friendship groups which comprise communities all can contribute to healthy human behaviour and development (Longres, 1995).

“...daar by die yard, daar verkoop hulle mos ook wyn...U weet mos ‘n mens as hy drink, en hy het nou nie goeie geselskap nie, dan praat hy sommer van die ander een...nou so het dit geloop en versprei, nee ek het ook TB en ou dinges het ook TB man...”

“...there at the yard, they sell wine...you know if a person drinks then he is not good company, then he speaks about the other one...now that is how it spread, no I also have TB and that other thing also has TB...”

“...ek het geen vrou of kinders nie, nou daai maak dat ek stranded is...”; “...die ander familie van my is nie eintlik in Belhar nie, hulle is van ‘n ander plek...”; “...nee, ek het nie so baie kontak met my susters of ander familie nie.”

“...I do not have a wife or a child, now that makes me feel stranded...”; “...my other family is not from Belhar, they are from another place...”; “...no, I dot have such a lot of contact with my sisters or other family”).

Distressing symptoms such as chronic pain may lead the individual to withdraw from family life altogether. In some instances, both the individual and the family become isolated from the wider community. Marital breakdown is not uncommon in these instances (Ross & Deverell, 2004:15).

Families often influence how a family member defines illness and when and how to seek medical care. The emotional reactions, beliefs and behaviours of families also influence the response a family member has to being diagnosed with a chronic illness. Family roles are influenced by disease and it means a change in the family structure. The ill family member’s capacity to perform his or her usual role in the family, changes. This may in turn lead to role tensions, emotional, physical and financial strain, inconvenience, anxiety and depression for both the carer and the family member for whom care is provided (Browning & Thomas, 2005:247).

- **Inter-personal relations with significant others**

Interpersonal relationships between participants and significant others, (including parents, siblings, wives, girlfriends and children) has some unique dynamics and TB as a disease has an impact on it. Most participants indicated that the disease puts an extra strain on relationships, since conflict and rejection because of the disease occurs more frequently.

“...die TB storie hulle skel ook vir my daaroor, maar nou weet ek nie hoekom my Ma, my suster en haar kinders het al vir my geskel daaroor, ma sommer in die pad...”; “...om moeilikheid te avoid, bly ek maar op my nessie, en hulle is op hulle kante...”

“...the TB story they scold me because of it, but I do not know why my mother and my sister and her children they also scold me about it, right there in the street...”; “...to avoid trouble, I stay in my home, and they on their side...”

“...daar is niemand wat belangriker kan wees as my vrou en kind nie, want hoekom myself het nie meer ouers nie...”; “...ek het ‘n meisie gehad, maar met die siek was sy nie daar gewees vir my nie. Sy het my gelos, nou worry ek nie meer met haar nie...”; “...hulle (my ma en my suster) is ‘n bietjie baie badlock met my, verneam as daar nie geld is nie, ma as die geld daar is dan is hulle happy go lucky, ma ek kan mos nie anderste nie ek kan nie gaan steel nie...”

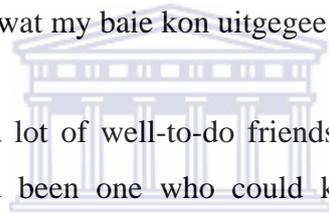
“...there is no-one that can be more important then my wife and child, because myself do not have parents anymore...”; “...I had a girlfriend, she was not there for me with the disease. She left me. Now I do not care about her anymore....”, “...they are a bit bad-luck with me, especially when there is no money when there are money they are happy go lucky, but I cannot do anything, I cannot go steal....”).

“...kyk mens like my nie oor die siek wat ek het...hulle trust my nie, hulle wil wye draaie om my loop....hulle wil my nie help nie...ek voel ‘n bietjie afgehaal man ek wil net ‘n way instap en nie weer terugkom nie...ek het baie sleg gevoel...”

(“...look people do not like me because of the illness that I have....they do not trust me...they make wide turns around me...they do not want to help me...I feel a bit sad man and just want to walk somewhere and never return....I felt very bad...”)

“...ek het baie welaf vriende gehad, ek was nie so soos ek nou is nie, ek was een wat my baie kon uitgegee het...”

(“...I had a lot of well-to-do friends, I was not the way that I am now, I had been one who could keep myself very superiour to others...)

  
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This can be a very difficult time for the individual and his or her family. When a diagnosis is finally made, it often comes as a relief as it legitimises the person’s complaints and experiences, and brings to an end conflicts with others over the reality of the symptoms (Ross & Deverell, 2004:15). Illness affects not only the afflicted person, but family members as well. Changes in family relationships that occur as a result of being sick can greatly affects spouses, children and other family members. Sick people adopt new behaviours, because their physical symptoms frequently impose adjustments and because their interpersonal relationships are changing. This is a redefinition of identity for adults (Brannon & Feist, 1992).

- **Stigma influencing inter-personal relations**

Participants indicated that they are the victims of a lot of stigmatization, which contribute to poor or threatened interpersonal relations and this was the reason why they delayed seeking treatment for TB.

“...netnou stry ons dan skel ons mekaar en dan praat ons van die TB...”; “...ek word geskel daaroor...”; “...ek word sommer gevloek en al daai dinge...”; “...hulle sal miskien sê met daai ou kan ons nie saam eet of drink nie...”; “...hulle praat van daai TB dinges, daai TB gat, party praat mos rof...”; “...ons pick mekaar oor tering...”; “...maar in U se gedagte, Oh in ander woorde jy het nou daai siek, maar ons kan nie vir ons baie in close to met jou is nie...”; “...want jy gaan vir ons aansteek...”; “...nou offer U miskien vir my ‘n koppie tee, nee ek kan miskien nou nie uit daai koppie uit drink nie...”, “...want ek wil nie my vel van my gesig getrek wil hê, omdat ek nou die siek het kan mense nie communicate met my nie...”

(“...we would argue with each other, then we talk about the TB...”; “...I am being scolded because of it...”; “...I am being swears at and all those things...”; “...they may say that they cannot eat or drink with that guy...”; “...they speak about that TB thing., that TB bum, some talk rough...”; “...we pick on each other over TB...”; “...but in your mind, Oh in other words you have the disease, but we cannot keep ourselves close to you...”; “...because you might infect us...”; “...now you offer me a cup of tea, no, I cannot drink out of that cup...”, “...because I do not want my skin to be pulled from my face, because since I have the disease people cannot communicate with me...”).

“...my eie suster het my gesê ma kykie jy het nou die siekte, jy moet nie baie gemeng het met ons nie, jy kan ons kinders aansteek...kry ma jou eie bord, jou eie koppie, jou koslike goete.... jou goete kan nie baie met ons geknoop is nie...daai is mos aan my geraak toe my eie suster my daai sê...”

(“...my own sister told me, listen here, you now have the disease, you must not mix a lot with us, and you can infect our children...get your own plate, your own cup, your own food stuff...your stuff cannot be tied with our stuff...that has touched me when my own sister told me that...”)

“...ek kan nie aan ‘n kospot raak of aan enige ding, daai glas of daai ding, sit hom neer...”

(“...I cannot touch a food pot or any other thing, like a glass or anything, put it down...”)

“...ja, baie het nie geworry nie, hulle het nie geworry om met my te praat nie...miskien buite sit, hulle loop verby my en hulle groet my nie...”

(“...yes, many did not care, they did not care to speak to me...maybe I will be sitting outside, they walk past me and they do not greet me...”).

Stigma can be defined as the identification and recognition of a bad or negative characteristic in a person or group of persons, and treating them with less respect or worth than they deserve due to this characteristic (Deacon, Stephney & Prosalendis, 2005). Experiencing stigma may lead to low self-esteem, reduced willingness to seek medical and social help, and increased difficulty in sharing problems with friends, family and others (Ross & Develler, 2004:206).

Increased stigma associated with TB resulted in delays to accessing treatment and decreased accessibility to services, particularly waiting to be attended to within the clinic. The awareness of the association with HIV/Aids led to increased stigma around TB (Loveday *et al.*, 2005) Most clients considered home visits as conducted by DOTS personnel to be undesirable due to stigma (Ngamvithayapong, Yanai, Winkvist, Saisorn & Diwan, 2001).

#### **4.2.2 MAIN THEME 2: HEALTH SERVICES FACTORS AS CONTRIBUTING TO PATIENTS' DELAYS IN SEEKING TREATMENT FOR TUBERCULOSIS.**

The health system is seen as an institution of 'health service delivery' to promote, protect or restore the health of individuals and populations (Van Rensburg, 2004:7).

##### **4.2.2.1 CATEGORY 1: QUALITY OF HEALTH CARE SERVICES**

Some participants would rate the quality of service that they receive at the primary health institution as good, while other would rate it as bad. Some participants had some experiences to share regarding their treatment at the health care facility and mentioned some practical examples of true events.

“...ek het nog elke dag ‘n inspuiting gekry, maar daai dag kon ek nie ordentlik geloop het nie, na daai suster vir my ingespuit het nie...”;  
“...toe vra hulle vir my by Tygerberg hospitaal, dit is darem baie onmoontlik dat u so baie gaan vir inspuitings...toe sien hulle op die kaart, toe vind hulle uit ek kry te veel inspuitings, by die kliniek...toe

sê ek later vir die susters, by die kliniek, ek wil die dokter gaan sien, maar toe bribe hulle vir my so, om nie vir die dokter te sê nie...”; “...hier op die kaartjie, dai is mos Saterdag en Sondag nê, dan kry ek mos nie pille nie...toe sien ek daar is kringetjies...dit het al drie keer gebeur al...”; “...toe sê die ander suster vir my die goed (potjies) was nie reg toegedraai nie en dit (spuug) het uitgeloop en ek moet nou weer spuug en almal daai dinge...”

(“...I got an injection every day, but that day I could not walk properly, after that sister gave me an injection...”; “...they then told me at Tygerberg hospital, that it is impossible that I can get such a lot of injections...they then look at the card and found that I get too many injections, at the clinic...I then later told the sisters at the clinic and they bribed me so that I do not have to tell the doctor...” “...here on the card, that is Saturday and Sunday, and then I am not supposed to get tablets... I then saw there were circles...it happened three times already....”; “...the other sister told me that the pots were not screwed on correctly and the things (sputum) crawled out, and that I had to spit again and all those things...”)

“...hulle tyd is nie ingestel nie hulle laat jou eers ‘n bietjie hang.... (‘...their time is not tuned in right and they let you wait...’)

“...ek kry goeie diens, my behandeling is altyd op tyd...”; “...hulle (die susters) kom soek my op, daar (kliniek) kan ek nie wegbly nie.”

(“...I always get good service, my treatment is always on time...”; “...they (the sisters) comes to look for me; I cannot stay away from the clinic.”)

“...the sisters actually phoned me today to speak to my mother about the sputum test and why they could not give me medication yet because they are actually waiting on the results to come back so they will inform you if you need to see the doctor, if you come there, they will tell you on such and such a day you will see the doctor and give you a sputum sample they give you the tubes and they give you the dates.”

It is part of the health sector’s mission, goals and objectives to make sure that every effort should be made to ensure the improvement in the quality of services at all levels. Emphasis should be placed on reaching the poor, the under-served, the aged, women and children, who are among the vulnerable (Dept. of Health, White Paper, 1997).

One of the main criticisms of the health care services by TB patients was the lack of respect for confidentiality by health care workers. This was found by Loveday *et al.*, (2005).

- **Inaccurate diagnosis**

The majority of the participants indicated that a wrong diagnosis by the doctor contributes largely to delays in seeking treatment for Tuberculosis. It increases their emotional trauma, causes financial strain and has a negative impact on their physical health.

“...ek was 17 jaar oud, daai kwaal is die afgelope 30 jaar al in my al...ek kan mooi onthou ek het baie dokters en hospitale toe gegaan...hulle kon nooit vasstel wat my makeer het nie...”

(“...I was 17 years old, that illness was in me for the past 30 years...I can still remember I went to a lot of doctors and hospitals...they could never determine what had been the matter with me...”).

“...went to the doctor...diagnosed me with pneumonia, initially and treated me for it. Got better for a while, the beginning of this year the same problem so they send me to a lung specialist....”

“...ek het al later tyd gedink is dit nie miskien kanker wat ek het nie...hulle sê toe as dit lewerkanker is dan gaan ek nie lank lewe nie. Toe roep die dokter vir my, daar is niks verkeerd met die lewer nie, nadat die uitslae gekom het nie...toe sê hulle kyk net hoe maak daai dokter geld...”

(“...I later thought that it could be cancer...they told me if it is cancer of the liver then I will not be able to live long. Then the doctor called me there is nothing wrong with my liver, after the results came through...they then said just look how that doctor makes money.”)

“... they told me ok, that medicine is going to stop the bleeding in me because they have told me that it is inside my liver is bleeding....”

Chronic lung diseases are hard to diagnose. Some of the chronic lung diseases are difficult to diagnose. Even the well-known conditions such as asthma or lung cancer often fail to be diagnosed early. The following list of conditions have been mentioned in sources as possible alternative diagnoses to consider during the diagnostic process for Tuberculosis, these are; pneumonia, lung abscesses, lung tumors, flu (early stage TB symptoms are flu-like), upper respiratory infection and cestodic tuberculosis (similar symptoms to TB but caused by cestode parasites). When checking for a misdiagnosis of Tuberculosis or confirming a diagnosis of Tuberculosis, it is useful to consider

what other medical condition might be possible misdiagnosis or other alternative conditions relevant to diagnosis (<http://www.wrongdiagnosis.com/t/tuberculosis/misdiag.htm>).

In the hospital and clinics in which this study took place, patients with TB and TB/HIV were not effectively diagnosed and treated for TB. Effective implementation of the National TB and TB/HIV guidelines is essential at a regional/district hospital level (Loveday, 2005).

- **Ineffective communication**

Health service providers provide information, which is not always comprehended by patients. This information is in many instances conveyed via medical terms. The result of information conveyed in this manner is lack of knowledge and ignorance in patients and consequently delay in treatment of TB.

Clients commonly hold mistaken about human relationships, sex roles, authority and countless other facets of life. Because misconceptions lie at the roots of many human problems, it is vital to learn to identify them and to include them in assessments. Goals often involve modifying key misconceptions, thus paving the way to behavioural change (Hepworth *et al.*, 2002).

“...Nee, soos hulle vir my gesê het hy slaan oor na HIV toe, hulle het my vertel, die social worker wat ek gesien het daar by die HIV/Aids...;...toe sê hulle vir my dis daai siek ook wat kan veroorsaak dat jy Aids kry...;...hulle het my niks daarvan, van die TB vertel nie...”;...daar was ‘n vrou wat my gevat het na ‘n ander kamer vir die HIV en al dai dinge en vir my explain het nou wat ontstaan TB en dai.”

(“...No, they told me it goes over to HIV, they told me, the social worker whom I saw there by the HIV/Aids...”; “...they then told me that it is that disease that can cause you to get Aids...”; “...they told me nothing about that, about the TB...”; “...there was a woman who took me to another room for HIV and all that things and she explained what causes TB and all that...”)

...hulle het my ook self gesê as die TB verder gaan en ek voldoen nie my behandeling soos ek moet nie, dan gaan ek probleme kry...;...toe sê hulle as ek my pille gedrink het, moet ek nie wyn drink nie. Dit kan my dood veroorsaak ...;...by die kliniek het ek inligting gekry oor AIDS.” “Ja hulle vat jou in ‘n ander kamertjie toe dan verduidelik hulle dit vir jou en dan toets hulle vir jou. ....they actually explained more about the treatment.”

(“...they told me that if the TB continues and I do not complete my treatment as I should, then I will get into trouble...;...then they told me when I have drunk my tablets then I must not drink alcohol. It can cause my death...;...I received information from the clinic regarding AIDS.” “Yes, they take you into a small room and then they explain to you and test you...they actually explained more about the treatment.”).

“...hulle het al vir ons filmpies gespeel sodat ons kan gesien het hoe maak TB jou...dan kyk ek, dan dink ek so, ja dit was die tyd toe ek so lusteloos voel, dit wys jou net en hoe jy nie wil eet nie, en van die sweet, daai weet ek ook van...”; “ ... also you must have a good diet...”

(“...they had played films for us so that we can see how TB makes you...then I look, then I think, yes that was the time when I felt so tired, it just show you and how you did not wanted to eat, and about the sweat, that I also know of...”)

All patients attending clinics for service should receive health education. This forms part of the norms and standards of chronic diseases which prescribe that after diagnosis patients and caretakers are supported and their capacity developed regarding self care, self-monitoring compliance, prevention of complications and management of the disease. Education activities are sensitive to the cultural and economic realities of the patient and home (Primary Health Care Package for South Africa, 2001; <http://www.doh.gov.za/docs/policy/norms/part2b.html>)

Effective communication underpins every health promotion activity. Communication will be participative, gender-sensitive and two-way. Innovative and culturally acceptable methods of communication methods will be utilized (Dept. of Health, The White Paper for the Transformation of the Health System of South Africa , 1997).

It had been found during a study (Association of TB with HIV/Aids) that over 90% of the patients knew that TB was curable if medication was taken and the course of treatment completed. Patients did not know how long the course of treatment was. They have also found that at the clinic and community level the role of nurses as knowledge providers and female relatives as advisors around health issues must be optimized by health service providers (Loveday *et al.*, 2005).

- **Health education**

Health education had in most instances been in the form of distributing pamphlets, presentations, films, and group discussions as indicated by the majority of the participants. Participants are made aware of TB, through health education programmes or campaigns, yet many still cannot conceptualize the seriousness or impact of the disease.

Health education programme seeks to change personal habits and behaviour and thus prevent disease by providing information and education (Adams & Bromley, 1998).

“...hulle het pamflette aan my uitgereik en ek het dit aanvaar soos die susters sê hoe die siek kan ontstaan...;...hoe moet jy vir jou hou sodat jy nie ander persone kan aansteek en so aan nie....;...hulle kan nie sê hoe dit kan gestop word nie, maar dit hang af van jou as pasient as jy dit tydelik bywoon hulle medikasie stelsel...;...hulle het eendag so ‘n meeting gehou in die minor hall in toe praat hulle van hoe die siek is, en klomp mense in die saal in, toe het ek ma geluister en so aan...;...toe het ek ook gedink dis simpel hoe die kwaal jou kan verswak as jy nie die medikasie gereeld bywoon nie...;...jy en die geringste hoes wat jy miskien nou kan jy ‘n long van jou uithoes en automaties doodgaan en so aan...;.... suster het al vir ons verduidelik en hulle het al vir ons filmpies gespeel sodat ons kan gesien het hoe maak TB jou..”

(“...they have issued me with pamphlets and I have accepted what the sisters told me about how this illness can start...;...how you must keep yourself so that you cannot infect other people and so on...;...they cannot say how it can be stopped, but it depends on you as the patient if you attend their medication system on a temporary basis...;...they have one day held a meeting at the minor hall, there was a lot of people in the hall and then they spoke about the disease and so I listened....;...so I also thought it is simple how the disease can weakens you if you do not attend to the medication...;...you you and the smallest cough that that you may cough can cause you to cough out a lung of yours and you may automatically die and so on...;...sister explained to us and they have shown us films to show us what TB can do to you.”).

Modern Westernised society is characterised by the widespread dissemination of information. The growth and power of the media, especially print and television have pervaded all aspects of daily living. There is a growing focus in the media on health promotion, which encompasses an expectation that people should take responsibility for their own health (Ross & Deverell, 2004:10).

Health education is an active process directed at changing people's behaviour in health-related matters. An aim of Health education is to give people the necessary knowledge about the diseases which are common in their community in order that they may take appropriate steps to prevent their occurrence or, if they do occur, to seek early medical advice (De Haan, 1996:18).

Patients are however also educated by their own observations and learning. They had first-hand experience about how TB-infected people suffer and died because of the disease. This however did not encourage them to seek treatment earlier when they themselves presented with the same symptoms.

“...my suster het ook TB gehad, sy is mos nou dood. Ek het nou so twee, drie weke terug vir haar en my ander suster begrawe...;...as sy gegaan het vir daai longoperasie, dan het sy seker ook survive...;...ek het baie ondervinding gehad hoe dit is, gekyk hoe die mense lei, en op ‘n distansie hier kom jy nou en jy ruik so dan kry jy ‘n ander reuk...; my ouma se oudste seun het TB gehad...en so het ek geleer van TB...”

(“...my sister also had TB, she is currently dead. I buried her two to three weeks ago, for her and my other sister...;...if she went for the lung operation, then she maybe would have survived...;...I have a lot of experience about how it is, saw how people suffer and

from a distance, you come and you smell and you get another smell...;...my grandmother's eldest son also had TB...that is how I learned about TB...")

'Health knowledge' refers to what the clientele knows about health, disease and care, i.e. people's health literacy. It includes people's knowledge of the human body and its functioning, the causes and symptoms of disease, and the applicable measures for maintaining and restoring good health, as well as their knowledge of the care system, inter alia, the type of services and facilities available, where and to whom they should go for treatment (Van Rensburg, 2004:8).

Health education should be comprehensive and reach as many people as possible to be effective. The success of health education is also dependant on effective communication as described above. Ineffective health education resulted in a lack of knowledge and ignorance as described by participants.

“...ek het maar baie kere gehoor die mense praat van TB, maar ek weet mos nie hoe begint hy en wanner hy TB is nie...;...ek het niks geweet van TB nie...;...ek het nie eintlik kennis gedra nie van TB nie...;...baie min geweet van die siek...;...die mense sê dat TB is so 'n ding as jy nie jou behandeling gebruik nie, dan slat dit oor na Aids...;...ek kan nie presies sê hoekom moet 'n mens TB kry nie, ma ek dink van my kant af is dit die koue of stof, as jy werk miskien met sement of paint...;...ek het geweet jy kan 'n kiem optel, dit het ek gehoor, en rook maak ook dat jy TB kry het hulle gesê...;...ek het nie geweet dat TB jou dood kan maak as jy nie vir jou behandeling gaan nie, dat jy oorlede kan gaan...”

(“...I have heard many times, that people speak about TB, but I did not know how it began and when it could be TB....;...I knew nothing about TB....;...I did not actually had any knowledge about TB....;...knew very little about the disease...;...the people said that TB is a thing which if you do not use your treatment, then it develops into Aids....;...I cannot actually say what is the reason why you get TB, but I think it is because of the cold or the dust, if you work with cement or paint....;...I knew you can pick up a germ, that I have learned, and smoke also cause you to get TB, they said....;...I did not know that TB can kill you if you do not go for your treatment , that you can pass on...”)

“...ek het gedink daai tyd ok ek het nou die kwaal maar ek het dit nie baie ernstig opgevat nie en ek vat dit so die mense wat die siek gehad het hulle is nou oorlede...en ek het dit ma so aanvaar....;...ma ek het nou nie gedink dit gaan so ernstig en aansteeklik wees nie, en so aan nie....;... het ek nooit dat iemand dit agterkom nie....;...ek was nie seker gewees nie want ek het ook nie geweet van die soort siekte nie....;...ek het ook nie so baie notisie gevat nie ...;...die pyn het net gekom en dan is hy weer weg, ek het nou nie notisie eintlik gevat van die pyn nie....;...ek het nie eens geworry nie...;...as ek ernstiger sieker geraak het dan sou ek besef het hoekom het ek nie maar daai tyd gegaan het nie; ...Ja, as ‘n mens doodgegaan het dan kan ‘n mens nie praat nie...”

(...I thought at the time, ok, I do now have the disease, but did not take it seriously, I just thought that the people who had the disease have all died and I have accepted it....;...but I did not realize that it will be so serious and infectious, and so....;...I never allowed anyone to know....;...I have not been certain about it because I did not know about the type of illness....;...I never took any notice....;...the pain came and then it went, I never took notice of

the pain...;...I did not concern myself...;...if I had to become more severely ill, then I would have thought why did I not go that time... Yes, if a person dies, then you cannot speak...”)

Information is a significant resource for the chronically ill in order for them to manage their lives. It reduces uncertainty, helps the individual to come to terms with the illness and allows for the development of strategies for managing the illness in everyday life. Ross & Deverell (2004:16)

Communication is the key to a successful doctor-patient relationship; giving information clearly in the context of a good rapport between patient and doctor has consequences for the patient's comprehension of his/her condition, treatment and behaviour. Trust and honesty are imperative to adequately help the patient; these attitudes may be conveyed along with the doctor's empathy and interest, as well as by a good understanding of the patient's financial situation and the sociocultural context in which he/she lives (Rosenberg *et al.*, 2000).

- **DOTS support**

Participants are well aware of the volunteers that are employed as part of the DOTS support. They know that the volunteers are there to assist them in completing their treatments. Some of the participants obtain their medication at the houses of some of the volunteers. Patients go to the volunteer who stays the closest to them, for their medication. The volunteers deliver and administer treatment to the patients at their own homes, as well. Most of the participants chose to attend clinic for their treatment, because they also receive food at the clinic.

“...daar is ‘n ander ou wat een huis daar van my af wat altyd sê hulle (vrywillige werkers) bring vir hom sy pille...”; “...ek sien vir hulle baie daar by ons wat so rondloop daar...”; “...ek kan nie sleg praat van die vrou wat my pille vir my gee nie, ek gaan net dan gaan haal ek my pille, dan drink ek sommer my pille daar klaar...dan gesels sy met my en gee my gesig, sy is nou nie afjakkerig nie...hulle gekry ook daar by die TB kamer, wat help met die pille...”; “...sy is ‘n vrywillige werker, ma ek kan nie vir haar gaan sê ek is honger nie, dan gaan sy mos, vra wat van jou all-pay (grant)...”; “...toe gaan ek ma kliniek toe want ek het vir die suster gesê ek gaan my behandeling klaar maak daar...”; “...daar kry jy alles daar, as dit ‘n vrug is of ‘n joghurt...”

“...there is another guy who stays one house away from me, they (voluntary workers) always bring hid tablets...I see them walking around there by us...”; “...I cannot speak badly about that lady who gives me my tablets, I just go and get my tablets from her, I drink my tablets there by her...she then speak to me and gives me face, she is not insulting, but I cannot tell her that I am hungry then she will ask me about my all-pay (grant)...”; “...I then went to the clinic because I told the sister I am going to finish my treatment there at the clinic, because there you get everything, a fruit or a yoghurt....”)

Van Rensburg (2004:427) reports the following with regard to TB. National protocols prescribe the following services: Patients are diagnosed on clinical suspicion using sputum microscopy; they are provided with information, education and counselling; their families are actively screened for TB; voluntary HIV testing is promoted; patients are treated and follow-ups are done using DOTS; and the TB register is completed.

The service description of Directly Observed Treatment (Short Course) Strategy 'DOTS' is encompass within 5 key elements which are; Directly observed treatment by the clinic/treatment supporter for 6 months; short course chemotherapy and uninterrupted drug supply; standard reporting and recording system, diagnosis based on positive sputum microscopy and commitment to the DOTS programme by all (The Primary Health Care package for South Africa, 2001; <http://www.doh.gov.za/docs/policy/norms/part2b.html>, 2008).

Besides encouraging people to be screened for TB, DOTS supporters provide advice and support to TB patients and, crucially ensure that they complete their course of medication (<http://www.southafrica.info/about/health/tbfree.htm>, 2008).

Most providers perceived home-based DOTS to be difficult because of the inconvenience of travel, staff shortages and the high tuberculosis caseloads. Most clients considered home visits to be undesirable due to stigma (Ngamvithayapong *et al.*, 2001).

- **Accessibility to health care facilities**

Most of the participants indicated that they stay within walking distance to the health care facilities. They do not necessarily need a taxi but can walk to the clinic if their health permits it. TB and the symptoms thereof, as well as factors for example the weather influenced the latter. Some of the participants complain about tightness of the chest when walking in cold and wet weather conditions.

“...ek woon 100 meter van die kliniek af, ek het nie ‘n taxi nodig nie, ek stap....”; “...as ek loop sal dit vir my so ‘n halfuur vat...”; “...ek woon nie ver van die kliniek af nie...”; “...as ek op die hoek staan kyk ek straight kliniek toe...”; “...as ek miskien vinnig loop dan loop ek binne twintig minute...”; “...“Soos ek nou van daar bo af stap onder toe, as ek alright is dan stap ek so ‘n halfuur hier af kliniek toe, dan staan ek so ‘n bietjie as hulle my behandeling gee, dan stap ek weer terug, dan stap ek stadig om ma, as dit omweer is dan is die bors baie kortgespanne, dan loop ek baie lank kliniek toe, dan loop ek stadig... ‘n halfuur soontoe en ‘n halfuur terug... as ek nou nie lekker voel nie en ek moet nou by die kliniek wees, dan kan ek die taxi by die hoek vat....”

(“...I stay 100 meters away from the clinic, I do not need a taxi, I walk...”; “...if I walk then it will take me half an hour...”; “...I do not stay far from the clinic...”; “...if I stand on the corner then I can look straight to the clinic...”; “...if I walk hasty then I walk within twenty minutes...”; “... “as I walk from up there down under, if I am alright, then I will walk within half an hour to the clinic, then I will stand if they give me treatment, then I will walk back again, then I walk slowly, if the weather is cold and wet, then my chest is tight, then I will walk very slowly to the clinic, then I walk slowly...a half an hour to and from the clinic...if I do not feel well and I must attend the clinic, then I will take a taxi till the corner...”)

Access to decent public services is the rightful expectation of all citizens especially those previously disadvantaged. All citizens have equal access to the services to which they are entitled. These form part of the norms and standards for health clinics (People first) within the Primary Health Care Package for South Africa 2001; <http://www.doh.gov.za/docs/policy/norms/part1a.html>, 2008).

#### 4.2.2.2 CATEGORY 2: ATTITUDES OF MEDICAL STAFF

Attitudes of medical staff can either contribute or delay treatment of TB patients as discussed in the following text.

- **Positive attitudes of medical staff combating delays in treatment**

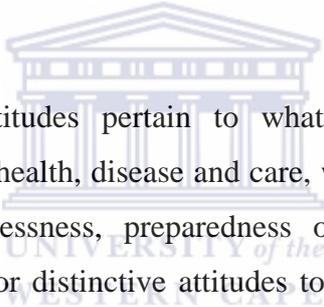
Most of the participants indicated that they are being treated quite well by medical staff especially by the clinic sisters who assist them on a daily basis during their treatment period. The sisters display characteristics of helpfulness, empathy and motivation. The participants mentioned that staff are friendly, enquire about their well-being, they show kindness, caring and are interested in the health of patients.

“...as ek daar by die kliniek kom en die susters is miskien besig met tea time toe te gaan dan sal sy (suster) sê ek moet gou kom vir my inspuiting anders gaan ek darem baie lank wag...”; “...ek word altyd goed behandel deur die susters, as ek da kom dan vra hulle, waarmee kan hulle help...”; “...dan sê ek suster ek het ‘n pyn hier dan gee hulle vir my salf of pille...”; “...dan kry ek ook vitamien pille, hulle gee pappe ook vir die mense, as jy sê jy het niks by die huis nie, dan gee hulle vir jou vir huis toe, of as jy nie die oggend geëet het nie dan maak hulle vir jou 'n koppie milkshake aan...”

(“...when I come to the clinic, the sisters will perhaps be busy to go to tea time, but then then the sister will tell me I must quickly come for my injection, otherwise I will be waiting too long...”; “...I am always being treated well by the sisters, when I arrive there, then they will ask, what can we assist you with...”; “...then I will say

sister I have a pain here and then they will give me some ointment or tablets...”; “...then I also get vitamin tablets, they also give porridge for the people, if you say you have nothing at home, then they will give you to take home as well, or if you did not eat that morning, then they will make you a cup of milkshake...”)

Health teams and workers at all levels should develop a caring ethos and commit themselves to the improvement of the health status of their communities. They should not only be responsible for the patients who attend their health facilities, but also have a sense of responsibility towards the majority of the population in their catchment area (The Department of Health, 2006; The White Paper for the transformation of the Health System of South Africa, 1997).



Health attitudes pertain to what people feel and experience regarding health, disease and care, whether feelings or experiences of powerlessness, preparedness or dependence during disease episodes, or distinctive attitudes towards care and care providers, for example skepticism towards faith healing or negativism about the quality of care in public hospitals (Van Rensburg, 2004:9).

When considering values as attitudes towards or ways of dealing with people, one of the most important of these is the worth and dignity of all people. To this end medical staff needs to treat all clients with respect and understanding regardless of their individual characteristics, group affiliation or socio-economic status (Ross & Deverell, 2004:43).

- **Attitudes of medical staff resulting in mistrust and consequently delays in treatment**

A general dislike as a result of negative attitudes towards doctors and treatment are some of the factors why participants' delayed in seeking treatment for TB. Attitudes are settled or fixed ways of responding to people. They involve what people know or believe and what they feel, as well as what they say and do. Attitudes can be stuck in a rut or can change in response to new experiences or persuasion (Adams & Bromley, 1998).

Participants suppose that doctors hide the status of their illness or disease from them, in order to protect them. They blame doctors for not giving them a positive diagnosis for TB and in this way causing the disease to develop further.

“...is amper so jou eie siek steek hulle weg, hulle is amper so skaam om vir jou te sê, want jy gaan miskien nou paniekerig raak of miskien anderste voel omdat jy die kwaal het...”; “...vir my sê hulle jy het nie die kwaal nie...”; “...toe kom dit so soos my ouerdom hoër word en ek ouer word, begin die kwaal ernstiger raak...”

(“...it is as if your disease, they hide it from you, they are almost shy to tell you, because you are going to panic or perhaps feel different, because you have the disease...”; “...for me they say you do not have the disease...”; “...then it came as my age increase, and I become older, the disease became more serious...”).

‘Health beliefs’ can be described as reflecting what people think and believe regarding health, disease and care. Some people believe that a traditional healer or homoeo-path can treat an ailment

more effectively than a Western doctor. Similarly, health beliefs determine which medication and care providers patients trust or distrust (Van Rensburg, 2004:9).

#### **4.2.2.3 CATEGORY 3: OTHER MEDICAL CONDITIONS AND TREATMENT**

It had been evident during data analysis that other medical conditions and forms of treatment contribute to delays in TB treatment.

- **Other illnesses**

Participants noted that that they had other illnesses, such as asthma and back problems, which occupied their attention and the symptoms of such illnesses, also threw them off track (or confused them) and caused a delay with regard to a positive diagnosis for TB.

“...ek het nie hospitaal toe gegaan met die TB nie, net gegaan met my arm...”; “...die dokter het ook vir my x-strale toe gestuur vir my rug, toe sê hy vir my kykie jou rugwerwels is verskuif...”; “...en ek het ‘n maag ook gehet, ek het so klomp siektes gehet ...”; “... toe het ek nie geweet dis TB wat my so afbreek nie...”; “...ek het ma net gedink, ai jinne my bors, toe is dit my bors wat my vat, en die arthiritis wat vir my vat. Ek het hoëbloed ook, ek het nou nog hoë bloeddruk...”; “... die dokter het my geondersoek, en my bors geluister, toe sê hy vir my ek het asma...”

(“...I did not go to hospital with the TB, I just went with my arm...”; “...the doctor also sent me for x-rays for my back, then he said that look here your back bones have moved...”; “...I also had a stomachache, I had a lot of illnesses...”; “...I then did not realize that it was TB that broke me down like that...”; “...I just thought, it was my chest, it was my chest that took me, and the arthiritis that

took me. I also had high blood pressure, I still have high blood pressure...”; “...the doctor examined me, listened to my chest, and then he told me that I have asthma...”).

- **Self-medication**

Most of the participants indicated that they would first make use of self-medication, such as herbs and over the counter cough medicine, before they would go to the doctor and this contributed to delays in seeking treatment for TB.

“...as ek ‘n medisynetjie gemaak het was dit als...dit vat die hoes weg...”; “...ek het maar baie geld uitgegee, goed gekoop, soos mense ma sê try dit, try Turlington...”; “...kruie gebruik, Rasta kriue en al daai.” (“...whenever I made a medicine, then it was herbs...it takes the cough away...”; “...I have spend a lot of money, bought things, like people told me to try this, try Turlington...”; “...used herbs, Rasta herbs and all that...”

Illness behaviour refers to the way in which disease and symptoms ‘are perceived, evaluated and acted upon by a person who recognises some pain, discomfort or other signs or organic malfunction’ (Ross & Deverell, 2004). Such behaviour includes self-medication, ignoring symptoms, delaying help-seeking, defaulting behaviour, consulting popular literature, or visiting quacks (Van Rensburg, 2004:9).

- **Relationship between Tuberculosis & HIV/Aids**

Participants displayed very low understanding of the relationship between TB and HIV/Aids. They believe that a person will get HIV/Aids if you do not complete your treatment or that TB will

automatically develop into HIV/Aids. Even after they have received counseling for HIV/Aids (this is done before they get tested for HIV/Aids) they still believe the myths surrounding the relationship between TB and HIV/Aids, and suffer the psychological impact of fearing they might get Aids. They are also being stigmatized for having TB as well as presumably having HIV/Aids.

“...ek al reeds gehoor hulle praat as jy nie gaan vir TB behandeling nie gaan jy Aids kry...”; “...hulle het my gestuur na ‘n ander vrou tjie toe in ‘n ander kamer, want sy sê TB is nie net dat jy TB het nie, jy kan ook, Aids kan ook ontstaan deur TB, want daai dametjie het vir my gevra hoe lank is ek en my man van mekaar af weg...;...om die waarheid te sê daar is iemand wat my al geskel het ek het Aids...”, “...jou Aids gat...ek is miskien nie seksueel met vrouens nie maar omdat ek nou die siek het het die kwaal (Aids) nou ontstaan....”

(“...I have already heard, they talk about if you do not go for TB treatment, you will get Aids...”; “...they sent me to this other lady in a room, because she said TB is not that you have TB, you can also, TB can also result because of TB, because that lady asked me how long is my husband away from me...”; “...to tell the truth there is someone who scold me that I have Aids...your Aids bum...I am not sexual with women, but because I have the disease, did the ailment (Aids) started...”).

The effects of the rapidly growing concurrent HIV epidemic further compound the prominence of the tuberculosis epidemic and the proportion of TB patients co-infected with HIV is increasing. There is an urgent need to hasten the integrated management of these two epidemics. The promotion of voluntary counselling and testing (VCT) for HIV in TB treatment centres, provision of

materials for advocacy and health education for TB/HIV/AIDS as well as the development of training and management guidelines for dually infected patients will go a long way towards achieving this goal (The South African Health Review, 2000).

HIV is the strongest known risk factor for the development of TB. HIV breaks down the immune system and makes patients highly susceptible to tuberculosis. These patients in turn can spread TB to others. TB would inevitably increase if HIV is not controlled and highlighted the need for effective coordination between Aids and TB control programmes (Daly, McDonald & Willis, 1994).

HIV is having an impact on TB patients and the provision of services for patients with TB. On becoming ill with TB many patients feared they may have HIV/Aids. This fear led to them delaying accessing health services. TB patients were aware of the link between TB and HIV/Aids. The awareness of the association with HIV/Aids led to increased stigma around TB. This was found during a study on the Association of TB with HIV/Aids (The Department of Health, 2006).

### **4.3 CONCLUSION**

The researcher has attempted to, within this chapter, discuss the results of data analysis as a result of interviews conducted with patients. This was done in order to establish the experiences of patients regarding social and health service factors, which contribute to delays in seeking treatment for Tuberculosis. The researcher did this by effectively classifying the data into main themes, categories and sub-categories. Social factors contributing to patients' delays in seeking treatment for TB had been one of the main themes. This theme consisted of four categories, namely socio-economic, substance abuse, psycho-social and interpersonal relations factors. These categories had been further divided into sub-categories.

The other main theme that was discussed was health service factors contributing to patients' delay in seeking treatment for TB. The categories that were derived from it were as follows: quality of health care services, attitudes of medical staff and other medical conditions treatment. These categories had also been divided into sub-categories.

The researcher completed the discussion pertaining to the experiences of patients' with regard to social and health services factors, which contribute to delays and will now resume the discussion by presenting a summary, conclusion, the limitations of the study and concluding remarks within the next session.



**CHAPTER 5**  
**SUMMARY, CONCLUSIONS, LIMITATIONS AND**  
**RECOMMENDATIONS OF THE STUDY**

**5.1 INTRODUCTION**

In this chapter, a summary of the entire study is outlined. The aim of this research study had been to establish the experiences of patients with regard to social and health service factors that contribute to delays in seeking treatment for Tuberculosis. Conclusions will be drawn from both the literature study and the data obtained and recommendations will be made about the study presented.

**5.2 SUMMARY OF THE DIFFERENT CHAPTERS OF THE STUDY**

**5.2.1 Chapter 1**

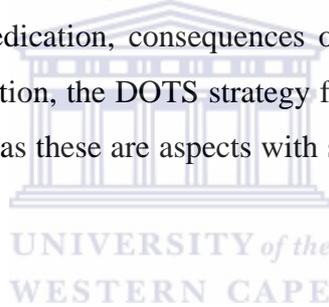
The background and motivation of the research study were discussed within the first part of this chapter. The seriousness of Tuberculosis as a disease had been highlighted. This was done by reporting on the high mortality and morbidity rates of TB and the dramatic increase of the incidence rate. Co-infection with HIV/Aids, multi-drug resistant strains and the epidemic of XDR-TB were also dealt with. Social and health care factors, which contribute to delays in patients seeking treatment for TB, were examined. The problem formulation section of the study focused on the importance of the early detection of TB cases.

The second section of chapter one addressed the research question, goals and objectives, research approach, type of research and research design and methodology of the research study. Data collection methods, pilot study, research population, sampling, data analysis, ethical aspects and

methods of trustworthiness were some of the salient concepts that were investigated. The chapter ended with definition of key concepts and content of research report.

### **5.2.2 Chapter 2**

The researcher orientated the reader regarding Tuberculosis as a disease, within chapter two. The effect of Tuberculosis and the complexities thereof were addressed, as they contribute to delays in treatment of TB. The specific aspects, which had been discussed, include the definition and causes, the historical background globally and in South Africa, the different types, examinations and tests for diagnosing TB. Attention had also been given to the spread, control and treatment of TB. The side effects of the medication, consequences of not adhering to or finalizing treatment, prevention, the DOTS strategy for the detection and cure of TB were highlighted as these are aspects with specific importance to delays in treatment of TB.



### **5.2.3 Chapter 3**

Chapter three consisted of investigating the social and health services factors that contribute to patients' delay in seeking treatment for Tuberculosis. Social factors that were investigated included stigma, knowledge, economic factors and accessibility of health care facilities. Health services factors included interpersonal relationships between health service providers and patients with regard to TB, attitudes of staff, infrastructural deficits, poor quality health care services and training. The researcher did a comprehensive literature review on these factors and compiled it within this chapter.

## 5.2.4 Chapter 4

Semi-structured interviews were conducted with patients at the primary health care centre and the data obtained from those interviews were later analyzed. Chapter four deals with the findings obtained from data analysis. These findings were clustered in two main themes: The social factors contributing to delays in patients seeking treatment for TB and the health service factors contributing to delays in patients seeking treatment for TB. Each of these main themes had main and secondary categories.

It was found during the study that social factors contributing to patients' delays in seeking treatment for TB had been one of the main themes. This theme consisted of four categories, namely socio-economic, substance abuse, psycho-social and interpersonal relations factors. These categories had been further divided into sub-categories.

The sub-categories of social factors include socio-economic factors which consisted of occupation, income/grant, educational level, living conditions, financial impact and poverty and these factors had been contributing to patients' delays in seeking treatment for delays. Other factors contributing to delays were found to be substance abuse which consisted of alcohol abuse and drug abuse, while psycho-social factors consisted of sub-categories such as guilt, fear, depression, uncertainty, secrecy/isolation, shame and denial. It was also found that interpersonal relations included social support, interpersonal relations with extended family, friends, and/or community members, interpersonal relations with significant others and stigma influencing interpersonal relations and these factors contribute to patients' delay in seeking treatment for TB.

The researcher established that the other main theme was health service factors contributing to patients' delay in seeking treatment for TB. It was found that the categories that were derived from it were as follows: quality of health care services, attitudes of medical staff and other medical

conditions treatment. It was also established that sub-categories that were obtained from the category, quality of health service are as follows: inaccurate diagnosis, health education, ineffective communication, accessibility of health services and DOTS. The researcher found that attitudes of medical staff includes, positive attitudes of medical staff combating delays in treatment as well as attitudes of medical staff resulting in mistrust and consequences of delays in treatment. The researcher established that other medical conditions and treatment include other illnesses, self-medication and relationship between HIV/Aids and TB, are all factors contributing to patients' delays in seeking treatment for TB.

### **5.3 CONCLUSIONS FROM THIS RESEARCH**

The goal of this research study was to do an explorative study in order to establish the experiences of patients with regard to social and health services factors that contribute to delays in seeking treatment for Tuberculosis. The researcher is of the opinion that the goal of the research study had been reached since the following objectives were successfully met.

The objectives to meet the goal were the following:

- To explore and describe the experiences of patients with regard to social factors that contributes to delays in seeking treatment for TB.

The goal was reached with regard to the first objective. The researcher has discovered that the following social factors have contributed to delays in seeking treatment for TB. These social factors are stigma, knowledge, economic factors and accessibility of health care facilities.

- To explore and describe the experiences of patients with regard to health services factors that contributes to delays in seeking treatment for TB. The second objective was achieved because the experiences of patients with regard to health services factors that contribute to delays in seeking treatment for TB was investigated and the researcher has found that the following health services factors contributes to delays. These are interpersonal relationships between health service providers and patients with regard to TB, attitudes of staff, infrastructural deficits, poor quality health care services and training.
- To make recommendations on social and health service factors that contribute to patients' delays in seeking treatment based on the findings. Recommendations on social and health service factors are made further on in this work.

The research question for this research had been as follows:

Which social and health service factors, as experienced by patients (in South Africa, Western Cape) contribute to delays in seeking treatment for TB?

The answer obtained through answering the goals and objectives is also the answer to this research question.

The researcher concludes this research that there are indeed social and health service factors that contribute to patients' delays in seeking treatment for TB. Some of the factors found in this research were similar than those found during the literature study such as stigma and lack of knowledge. It is very important for patients to have knowledge and be educated on their level of education.

Economical factors such as a low income influence the way in which poor and vulnerable people seek diagnosis and treatment for TB. High levels of economic burden among poor and vulnerable people can result in people not seeking health care at all for TB. Accessibility to Health care facilities and Geographical factors are also social factors, which contribute to patients' delays in seeking treatment of TB.

Health care factors include interpersonal relationships between health service providers and patients. Interpersonal relationships include poor interpersonal communication over-sights by health care providers and neglect coupled with the lack of attention and support to patients. These factors accounted for delays in treatment of TB. Inadequate attitudes of staff contribute to patients' delays in seeking treatment for TB. Staff attitudes were described by the participants as not always corresponding to people's expectations of appropriate health services.

Poor quality health care is another health service factor which contributes to delays. It was found that in order to rectify health care factors contributing to delays it is necessary to do quality control and setting standards for health services. Infrastructural deficits include lack of flexibility for treatment supervisors, inadequate supplies for treatment centers and centralized treatment delivery. These are the health care system factors that contribute to case finding and treatment delays. Other health care system factors that contribute to case finding and treatment delays include poor training and supervision of health community workers.

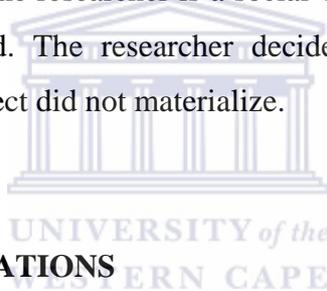
#### **5.4 LIMITATIONS OF THE STUDY**

The fact that data was collected at one site limits the study, although other larger medical centers with similar socio-demographics may find similarities to their patients' populations. Human error can occur during analysis. The accuracy of data codes depends on the perceptiveness of the

coder, who summarizes them. Accuracy was checked by looking for data on a particular issue by going back to the original document to ensure that the issue had been examined exhaustively.

This study started out to be as part of a superior study initiated by the Human Science Research Council (MRC), under the management of Professor N. Phaswana-Mafuya. Professor Phaswana-Mafuya could not continue to be the supervisor of the researcher due to logistical reasons and Dr. Beytell the current supervisor had been assigned to the researcher. This had been one of the major challenges and limitation for the study. The incentives of the project were funds for research, but it did not realize.

The study was difficult to conduct since it has been from a medical background and the researcher is a social worker and work in the forensic social work field. The researcher decided to continue with the topic although the project did not materialize.



## **5.5 RECOMMENDATIONS**

### **5.5.1 Recommendations for practice**

- Establishing case finding is of utmost importance in the treatment of TB. Finding, diagnosing and curing more patients will accelerate the decline in prevalence. The delay between first health care seeking action and receiving an accurate diagnosis of TB should be reduced.
- South Africa's health care program will have to make substantial provision in the short term to achieve some measure of control over TB. This is specifically of importance because of the co-diagnosis TB/HIV/Aids, as well as the seriousness of

MDR and especially XDR-TB, which is at present a serious problem. Conditions should be made favourable for the patients to adhere to treatment. Treatment should be adequate in order to achieve permanent cure, to prevent development of a resistance and to prevent failure of treatment. The variable efficacy of the BCG vaccine, combined with alarming increases in the levels of resistance to existing anti-TB drugs, has underscored the need to develop new tools for the prevention and treatment of this devastating disease.

- New means of delivering care, which emphasize the person with TB as co-partner in the delivery process should be advocated to replace approaches, which view these individuals as inexperienced and passive recipients of medical care.
- There is a need to attend to TB in a holistic manner, and that it should be dealt with in a multi-disciplinary manner. There is also a need for social workers to become engaged with the management of this disease. Social conditions that increase the risk of becoming infected with TB, such as overcrowding, large communities living in informal settlements, rapid urbanization, unemployment, poverty, malnutrition, fatigue and the rising of HIV infection should be reduced or eliminated. Delays seem to be related to unemployment and general attitudes towards health.
- There is a need for improved health educational programmes, which could be utilized and modified to eliminate these social factors which could be a barrier to seeking treatment. TB programmes should focus on the eradication of stigma and the lack of knowledge. More specific and effective health education of the general public on tuberculosis and seeking of appropriate medical consultation are likely to improve case

detection. The public should be educated on the mode of spread and methods of control and the importance of early diagnosis. The goal of educational programmes should be to raise public awareness of TB and how to access diagnostic and treatment services. It is also important that cultural diversity will be acknowledged in the presentation of health education programmes.

### **5.5.2 Recommendations for future research:**

- The researcher would like to recommend that the same research should be done on a bigger scale, since this one had been limited.
- Gender aspects of health seeking and diagnosis of potential tuberculosis patients, should be further studied. It had been discovered during the literature study that gender is one of the social factors contributing mostly to patients' delays in seeking treatment for TB, but the researcher did not obtain enough information during the interviews to justify her claim. Interventions are needed in order to reduce delay to TB diagnosis especially for women and the current TB control strategy, (DOTS), needs to be examined from an equity perspective.
- More extensive research should be conducted into the health care-seeking chain in order to identify the specific steps where TB diagnosis of patients may be delayed.
- It is recommended that further research should be done with regards to the role of the social worker in TB. It is evident that the social worker has indeed a pertinent role to play if the social factors, which contribute to patient delays in seeking treatment for TB, should be taken into consideration.

## 5.6 CONCLUDING REMARKS

One of the concluding remarks is that of the role of the social worker and TB.

A holistic approach in treatment of TB is the best option to a better success rate in treatment and cure. The literature review, as well as the results of this study clearly indicated the social factors associated with TB and the treatment thereof. There is however not much clarity about the role, which the social worker plays with regard to the fight against the TB epidemic in the Western Cape and South Africa on the whole. The researcher, being a social worker, trusts that intervention by social workers with relation to TB will be emphasized. The needs of patients/clients/ infected persons, as well as the affected people in their lives should be included in such a service. Social workers and the Department of Social Development are very much involved with the plight of HIV/AIDS sufferers, but have not yet assisted TB sufferers. It seems as if people consider TB to be only a health care problem, but the social circumstances that largely contribute to the spread of the illness, is making TB a social, housing and economical problem, and this called for a holistic and multi-disciplinary effort in the prevention, diagnosis and treatment of TB.

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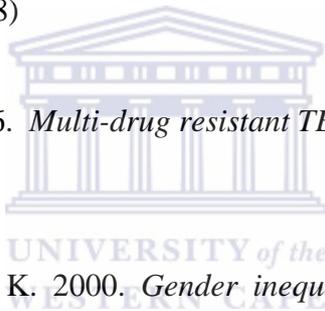
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### **Personal communications**

Beyers, N. 2007. TB coordinator at Karl Bremer Hospital. She is also working at the Desmond Tutu Centre at Stellenbosch University. Interview took place at Karl Bremer hospital on 03 September 2007 about TB control in the Western Cape.

Daniels, F. 2007. Facility manager. St. Vincent Drive clinic in Belhar. Interview on 07 August 2007 about the research study and patients who has presented with delays with regard to seeking treatment for TB.

Feigin, R. 2007. Ph.D. at Bob Shapell School of Social Work. Tel Aviv University, Ramat Aviv, Israel. The interview took place at the University of the Western Cape on 12 September 2007 about social and health factors contributing to delays when patients seek treatment for TB.

Groenewald, C. 2007. Social worker. Brewelskloof TB Hospital in Worcester. Interview on 10 August 2007 about the research study as well as the treatment of Tuberculosis.

Swartz, A. 2007. Assistant Director. TB control, at the Department of Health, Provincial office, Cape Town. Interview on 13 August 2007 about primary health care within the Western Cape Province.



**ADDENDUM 1**  
**INFORMATION SHEET**  
**CONSENT FORMS**



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# ANNEXURE 1





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## **ANNEXURE 2**



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# ANNEXURE 3



**ADDENDUM 2**  
**QUESTIONNAIRES**



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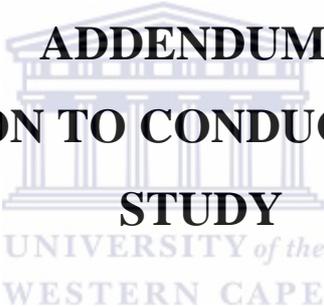
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**ADDENDUM 3**  
**PERMISSION TO CONDUCT RESEARCH**  
**STUDY**  
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