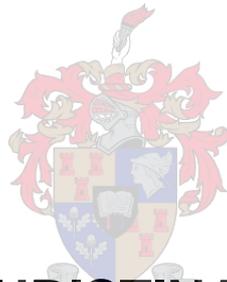


# **PATIENT EXPERIENCES AND PERCEPTIONS OF NON-COMPLIANCE WITH TB TREATMENT**



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**Thesis submitted in partial fulfilment  
of the requirements for the degree of  
Master of Nursing Science  
(Faculty of Health Sciences)  
at the  
University of Stellenbosch**

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March 2013

## DECLARATION

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## ABSTRACT

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Non-compliance with (tuberculosis) TB treatment is a problem at the Nyanga Clinic in the Western Cape Province. Non-compliance is defined as when a patient interrupted TB treatment for more than two months consecutively, at any time during the treatment period.

The aim of the study was to explore the patient experiences and perceptions of non-compliance regarding their TB treatment.

The following research question was posed by the researcher as a guide for this study: “What are the patient experiences and perceptions of non-compliance with TB treatment?”

The objectives of this study were to determine the:

- patients’ experiences and perceptions of non-compliance with TB treatment
- non-compliant patients’ knowledge regarding TB
- reasons why patients are not compliant with TB treatment.

A qualitative, explorative, descriptive and contextual design was applied. The target population included the 354 non-compliant with TB treatment patients from March 2010 until May 2011. A purposive, non-random sampling technique was used to select participants for the study. Every tenth participant who, according to the TB register, was colour-coded as non-compliant with TB treatment, was selected for interviewing until data saturation should occurred. A sample of fourteen (14) participants was realised. A semi-structured interview schedule was developed based on the objectives of the study, which was validated by experts in nursing and approved by the Human Resources Ethics Committee of the Faculty of Health Sciences of the University of Stellenbosch. Data was collected personally by the researcher. Informed written consent was obtained from the participants. One patient

who was not included in the main study was selected at random to pre-test the semi-structured interview. The pilot study revealed no pitfalls.

Trustworthiness of the research was enhanced by adhering to the principles of credibility, confirmability, transferability and dependability. Credibility was ensured by member checking, data saturation, triangulation and involvement of an experienced research supervisor. Confirmability was enhanced through member checking and the leaving of an audit trail. Transferability through keeping an intensive description of all the processes and dependability by using an interview schedule and by submitting the transcribed tape-recorded data and field notes to the research supervisor for verification.

The quantitative data was summarised in a table format to enhance clarity and facilitate a rapid overview of the results. The qualitative data was analysed manually with the findings coded and divided into subthemes and themes. Four themes emerged, namely: health system, client-related, social-economic and therapy factors. These themes identified the impeding factors regarding the non-compliance with TB treatment.

The main conclusion is that there is a need to educate the community regarding the lengthy duration of the TB treatment, its side-effects, its curability and the spread of the infection as well as the consequences of inadequate treatment to empower the community at large about the disease.

The National Department of Health framework of contributing to non-compliance with TB treatment was used as the conceptual framework for this study. The researcher applied the problem-solving approach of Faye Glen Abdellah's theory. According to this theory it is anticipated that by solving the problems or needs of patients, through appropriate and organised health strategies the client will be moved towards ultimate health.

## UITTREKSEL

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Onderbreking van tuberkulose (TB) behandeling is 'n probleem by die Nyangakliniek in die Wes-Kaap Provinsie. Onderbreking kan gedefinieer word wanneer'n pasiënt vir twee of drie opeenvolgende maande TB behandeling onderbreek het (Jaggarajamma, Sudha, Chandrasekaran, Nirupa, Thomas, Santha, Muniyandi & Narayanan, 2007:131).

Die doel van die studie is om die pasiënte se ervarings en persepsies betreffende die onderbreking in TB behandeling te ondersoek.

Die navorser het die volgende navorsingsvraag as riglyn vir hierdie studie gestel: "Wat is die pasiënte se ervarings en persepsies wat TB-behandeling onderbreek het?"

Die doelwitte van die studie was om te bepaal wat die:

- pasiëntervarings en persepsies is wat TB-behandeling onderbreek
- kennis van pasiënte is wat TB-behandeling onderbreek
- redes is waarom pasiënte TB-behandeling onderbreek.

'n Kwalitatiewe navorsingsontwerp met 'n ondersoekende, beskrywende en kontekstuele benadering is aangewend.

'n Doelbewuste, lukrake steekproef is gebruik om deelnemers te selekteer. 'n Steekproef van veertien (14) deelnemers uit 'n totale populasie van 354 hetrealiseer en sluit pasiënte in wat behandeling onderbreek het vanaf Maart 2010 tot en met Mei 2011. 'n Semi-gestruktureerde onderhoudsgids is ontwerp, gebaseer op die doelwitte van die studie en gevalideer deur kundiges in verpleegkunde en die Etiese Komitee van die Fakulteit van Gesondheidswetenskappe aan die Universiteit van Stellenbosch. Die data is persoonlik deur die navorser ingesamel. Ingeligte skriftelike toestemming is van die deelnemers verkry.

Een deelnemer wat nie ingesluit is by die hoofstudie nie, is lukraak gekies om die semi-gestruktureerde onderhoud te toets. Die loodsondersoek het geen tekortkominge aangedui nie.

Betroubaarheid van die studie is verseker deur die beginsels van objektiwiteit, bevestiging, veralgemening en neutraliteit te verseker. Getranskribeerde data is gekontroleer met die deelnemers, volledige beskrywings van alle prosesse is bygehou, 'n onderhoudsgids is gebruik om te verseker dat vir al die deelnemers dieselfde vrae gevra word, en 'n ervare navorsing toesighouers was deurgaans teenwoordig wat alle data gevalideer het.

Kwantitatiewe data is in 'n tabel opgesom ten einde goeie oorsig te bied. Kwalitatiewe data-analise is met die hand gedoen. Die data wat uit die analise na vore gekom het, is geënkodeer en in subtemas en temasgekategoriseer. Die vier temas wat hieruit voortspruit, is faktore betreffende die gesondheidsorgsisteem, kliënte, sosio-ekonomiese en terapie-verwante faktore. Die navorsers het 'n geskrewe verslag saamgestel betreffende die weergawe van die data-analise ten einde te verseker dat belangrike data nie verlore gaan.

Die belangrikste bevindinge van die studie dui daarop dat die gemeenskap 'n behoefte aan opleiding het betreffende die onderbreking in TB behandeling, die langdurige tydperk van behandeling, nuwe-effekte van die medikasie, geneesbaarheid daarvan, hoe die siekte versprei en die gevolge betreffende onvoldoende medikasie ten einde die gemeenskap te bemagtig betreffende die siekte.

Die raamwerk van die Nasionale Departement van Gesondheid (2009:45) betreffende die faktore wat bydra tot onderbreking in TB-behandeling is gebruik as konseptuele raamwerk vir die studie. Faye Abdallah se teorie (George, 2002:173-183) verduidelik verpleging as 'n omvattende diens wat insluit: identifisering van die pasiënt se verplegingsprobleme, die besluit van 'n toepaslike plan van aksie, sowel as die voortgesette sorg betreffende die individu se totale behoeftes.

## ACKNOWLEDGEMENTS

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- I thank my son, Simnikiwe Shasha for his encouragement, support and patience throughout my study. Without him, the research could not have succeeded.
- My sincere appreciation to all the patients of the Nyanga Clinic for sharing their feelings and for contributing to this study.

*I dedicate this thesis to my late mother, Nomalizo Ntunja, who died in 2008.  
A dedicated mother and educator, her example still inspires me.*

# CONTENTS

---

DECLARATION.....	ii
ABSTRACT .....	iii
UITTREKSEL .....	v
ACKNOWLEDGEMENTS.....	vii
LIST OF TABLES.....	xvi
LIST OF ACRONYMS .....	xvii
OPERATIONAL DEFINITIONS .....	xviii
CHAPTER 1: SCIENTIFIC FOUNDATION OF THE STUDY .....	1
1.1 INTRODUCTION.....	1
1.2 RATIONALE AND BACKGROUND LITERATURE.....	1
1.3 SIGNIFICANCE OF THE STUDY .....	2
1.4 PROBLEM STATEMENT.....	3
1.5 RESEARCH QUESTION.....	3
1.6 RESEARCH AIM.....	3
1.7 OBJECTIVES.....	3
1.8 METHODOLOGY.....	4
1.8.1 Research design .....	4
1.8.2 Population and sampling .....	4
1.8.2.1 Inclusion criteria.....	4
1.8.2.2 Exclusion criteria .....	4
1.8.3 Instrumentation.....	5
1.8.4 Pilot test .....	5
1.8.5 Validity and trustworthiness .....	5

1.8.5.1 Credibility.....	5
1.8.5.2 Confirmability .....	6
1.8.5.3 Transferability.....	6
1.8.5.4 Dependability.....	6
1.8.6 Data collection .....	7
1.8.7 Data management and analysis.....	7
1.8.8 Ethical consideration.....	7
1.8.8.1 Beneficence .....	8
1.8.8.2 Respect for human dignity .....	9
1.8.8.3 Principle of justice .....	9
1.9 CONCEPTUAL FRAMEWORK.....	10
1.10 DURATION OF STUDY .....	10
1.11 CHAPTER OUTLINE .....	10
1.12 CONCLUSION .....	11
CHAPTER 2: LITERATURE REVIEW .....	12
2.1 INTRODUCTION.....	12
2.2 SELECTING AND REVIEWING THE LITERATURE.....	12
2.3 FINDINGS FROM THE LITERATURE .....	13
2.3.1 Health system factors.....	13
2.3.1.1 Inadequate DOTS strategy.....	13
2.3.1.2 Long waiting time.....	14
2.3.1.3 Poor access to health centres.....	15

2.3.1.4 Inconvenient appointments .....	15
2.3.1.5 Poor management of TB programmes.....	16
2.3.1.6 Relationship between health care providers and patients .....	16
2.3.2 Client-related factors .....	17
2.3.2.1 Poor knowledge about TB and efficacy of treatment.....	17
2.3.2.2 Stigma .....	18
2.3.2.3 Depression.....	18
2.3.2.4 Disempowerment .....	19
2.3.3 Socio-economic factors .....	20
2.3.3.1 Extreme poverty .....	20
2.3.3.2 Poor support networks .....	21
2.3.3.3 Employment status .....	21
2.3.3.4 Migration .....	22
2.3.3.5 Sex and age .....	22
2.3.3.6 Alcohol dependency .....	23
2.3.3.7 Lower literacy rate.....	23
2.3.3.8 Perception and beliefs .....	24
2.3.3.9 Role of traditional healers.....	25
2.3.4 Therapy-related factors .....	26
2.3.4.1 Side-effects of TB drugs .....	26
2.3.4.2 Longer duration of treatment .....	27
2.3.4.3 Large pill burden .....	28
2.3.4.4 Complex treatment regimens .....	29
2.4 CONCEPTUAL FRAMEWORK.....	30

2.4.1	Faye Glenn Abdellah Theory.....	32
2.5	CONCLUSION .....	33
CHAPTER 3: RESEARCH METHODOLOGY.....		34
3.1	INTRODUCTION.....	34
3.2	RESEARCH DESIGN.....	35
3.3.	POPULATION AND SAMPLING.....	36
3.3.1	Inclusion criteria .....	38
3.3.2	Exclusion criteria .....	38
3.4	INSTRUMENTATION.....	38
3.5	PILOT TEST.....	40
3.6	TRUSTWORTHINESS .....	40
3.6.1	Credibility .....	40
3.6.2	Conformability .....	41
3.6.3	Transferability .....	42
3.6.4	Dependability .....	43
3.7	DATA COLLECTION .....	43
3.8	DATA ANALYSIS .....	44
3.9	CONCLUSION .....	46
CHAPTER 4: DATA ANALYSIS, INTERPRETATION ANDDISCUSSION .....		46
4.1.	INTRODUCTION.....	46
4.2	PRESENTATION OF THE STUDY FINDINGS.....	46
4.2.1	Demographic profile of the participants.....	46

<b>4.2.2</b>	<b>Codes, subthemes and themes that emerged from the qualitative data</b>	<b>47</b>
<b>4.2.3</b>	<b>Presentation, interpretation and discussion of the findings .....</b>	<b>49</b>
<b>4.2.3.1</b>	<b>Theme 1: Health-system factors.....</b>	<b>49</b>
<b>4.2.3.1.1</b>	<b>Subtheme: Inadequate management of waiting times.....</b>	<b>49</b>
	<b>Code: Long wait .....</b>	<b>49</b>
<b>4.2.3.1.2</b>	<b>Subtheme: Relationship with the clinic staff.....</b>	<b>50</b>
	<b>Code: Support and attitude .....</b>	<b>50</b>
<b>4.2.3.1.3</b>	<b>Subtheme: Improving services at the clinic .....</b>	<b>51</b>
	<b>Code: Extra staff.....</b>	<b>51</b>
	<b>Code: Service hours .....</b>	<b>51</b>
	<b>Code: Education of patients.....</b>	<b>52</b>
	<b>Code: Education of community members .....</b>	<b>53</b>
<b>4.2.3.1.4</b>	<b>Subtheme: Lack of DOTS strategy.....</b>	<b>54</b>
	<b>Code: Supply of education nearer home.....</b>	<b>54</b>
<b>4.2.3.2</b>	<b>Theme 2: Client-related factors.....</b>	<b>55</b>
<b>4.2.3.2.1</b>	<b>Subtheme: Stigma.....</b>	<b>55</b>
	<b>Code: TB/HIV hiding of diagnosis.....</b>	<b>55</b>
<b>4.2.3.2.2</b>	<b>Subtheme: Depression .....</b>	<b>55</b>
	<b>Code: Death .....</b>	<b>55</b>
<b>4.2.3.2.3</b>	<b>Subtheme: Knowledge of TB.....</b>	<b>56</b>
	<b>Code: What is TB? .....</b>	<b>56</b>
	<b>Code: Symptoms.....</b>	<b>57</b>
	<b>Code: Curability.....</b>	<b>57</b>

	<b>Code: Spread of TB infection .....</b>	<b>58</b>
	<b>Code: Consequences of inadequate treatment.....</b>	<b>59</b>
	<b>Code: Healthy lifestyle .....</b>	<b>60</b>
<b>4.2.3.3</b>	<b>Theme 3: Social and economic related factors .....</b>	<b>61</b>
<b>4.2.3.3.1</b>	<b>Subtheme: Presence of gangsters.....</b>	<b>61</b>
	<b>Code: Gangsters .....</b>	<b>61</b>
<b>4.2.3.3.2</b>	<b>Subtheme: Inadequate finances.....</b>	<b>62</b>
	<b>Code: Job, grant and food .....</b>	<b>62</b>
<b>4.2.3.3.3</b>	<b>Subtheme: Migration.....</b>	<b>62</b>
	<b>Code: Move to Eastern Cape .....</b>	<b>62</b>
<b>4.2.3.3.4</b>	<b>Subtheme: Alcohol abuse .....</b>	<b>63</b>
	<b>Code: Alcohol dependency .....</b>	<b>63</b>
<b>4.2.3.3.5</b>	<b>Subtheme: Role of traditional healers .....</b>	<b>63</b>
	<b>Code: Traditional healer .....</b>	<b>63</b>
<b>4.2.3.4</b>	<b>Theme 4: Therapy-related factors .....</b>	<b>64</b>
<b>4.2.3.4.1</b>	<b>Subtheme: Side-effects of medication.....</b>	<b>64</b>
	<b>Code: Urine colour changes.....</b>	<b>64</b>
	<b>Code: Painful injection.....</b>	<b>65</b>
	<b>Code: Dizziness.....</b>	<b>65</b>
	<b>Code: Deaf ears .....</b>	<b>65</b>
	<b>Code: Painful and swollen feet.....</b>	<b>65</b>
	<b>Code: Nausea .....</b>	<b>66</b>
	<b>Code: Skin rash.....</b>	<b>67</b>
<b>4.2.3.4.2</b>	<b>Subtheme: Heavy pill burden .....</b>	<b>67</b>

	<b>Code: Together with ARV treatment .....</b>	<b>67</b>
<b>4.2.3.4.3</b>	<b>Subtheme: Lengthy duration of treatment .....</b>	<b>68</b>
	<b>Code: Boredom .....</b>	<b>68</b>
<b>4.3</b>	<b>CONCLUSION .....</b>	<b>69</b>
	<b>CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS .....</b>	<b>70</b>
<b>5.1</b>	<b>INTRODUCTION .....</b>	<b>70</b>
<b>5.2</b>	<b>CONCLUSIONS .....</b>	<b>70</b>
	<b>5.2.1. Theme 1: Health-related factors .....</b>	<b>70</b>
	<b>5.2.2 Theme 2: Client-related factors .....</b>	<b>71</b>
	<b>5.2.3 Theme 3: Social and economic factors .....</b>	<b>71</b>
	<b>5.2.4 Theme 4: Therapy-related factors .....</b>	<b>72</b>
<b>5.3</b>	<b>OBJECTIVES REACHED .....</b>	<b>73</b>
<b>5.4</b>	<b>RECOMMENDATIONS .....</b>	<b>75</b>
	<b>5.4.1 Health-related factors .....</b>	<b>76</b>
	<b>5.4.2 Client-related factors .....</b>	<b>76</b>
	<b>5.4.3 Social and economic factors .....</b>	<b>77</b>
	<b>5.4.4 Therapy-related factors .....</b>	<b>78</b>
<b>5.5</b>	<b>LIMITATIONS .....</b>	<b>78</b>
<b>5.6</b>	<b>CONCLUSION .....</b>	<b>78</b>
	<b>BIBLIOGRAPHY .....</b>	<b>80</b>
	<b>ANNEXURES .....</b>	<b>93</b>
	<b>ANNEXURE 1: Interview Schedule .....</b>	<b>93</b>

<b>ANNEXURE 2: University of Stellenbosch Information and Assent form.....</b>	<b>98</b>
<b>ANNEXURE 3: University of Stellenbosch Ethical Approval.....</b>	<b>102</b>
<b>ANNEXURE 4: City of Cape Town Research Committee approval.....</b>	<b>103</b>
<b>ANNEXURE 5: Declaration by editors.....</b>	<b>104</b>
<b>FIELDNOTES .....</b>	<b>105</b>

## LIST OF TABLES

---

Table 2.1 Factors contributing to non-compliance with TB treatment	30
Table 4.2 Codes, subthemes and themes that emerged from the qualitative data	47
Table 5.1 Outcomes relating to each study objective	75

## LIST OF ACRONYMS

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DOTS	Directly Observed Treatment, Short-course
HIV	Human Immunodeficiency Virus
MDR	Multidrug-Resistant
WHO	World Health Organisation
XDR	Extensively Drug-Resistant

## OPERATIONAL DEFINITIONS

**Adherence:** Following the recommended course of treatment by taking all the medication as prescribed, for the entire length of time necessary (National Department of Health, 2011: 45).

**Directly Observed Treatment, Short-course (DOTS):**The process where an observer (treatment supporter) watches the patient swallowing the tablets, in a way that is sensitive and supportive to the client's needs (National Department of Health, 2011: 46).

**Experience:** Events or knowledge shared by all the members of a particular group in society that influences the way they think and behave (Oxford Advanced Learner's Dictionary, 2010: 514).

**Extensively drug-resistant (XDR-TB):** Refers to a situation in which there is resistance, *in vitro*, to: Isoniazid and rifampicin and any of the fluoroquinolones and one or more of the second-line injectable drugs (capreomycin, kanamycin, amikacin) (National Department of Health, 2009:85).

**Multidrug-resistant (MDR-TB):** Is defined as tuberculosis disease caused by strains of *Mycobacterium Tuberculosis* that are resistant, *in vitro*, to both rifampicin and isoniazid, with or without resistance to other drugs (National Department of Health, 2009:80).

**Non-compliance:** Is defined as when a patient who interrupted TB treatment for more than two months consecutively, at any time during the treatment period (Jaggarajamma, Sudha, Chandrasekaran, Nirupa, Thomas, Santha, Muniyandi & Narayanan, 2007:131).

**Perception:** The Oxford Advanced Learner's Dictionary (2010:1086) defines perception as "the way an individual notices things especially with the senses; the ability to understand the true nature; an idea, belief or an image individuals have as a result of how they see or understand".

**Tuberculosis (TB):**A disease caused by a bacterium belonging to the *Mycobacterium Tuberculosis* complex. The disease usually affects the lungs,

although in up to one third of cases other organs are also involved (Jetan, Jamaihah & Nissapatorn, 2010:378).

## CHAPTER 1

### SCIENTIFIC FOUNDATION OF THE STUDY

#### 1.1. INTRODUCTION

Chapter One describes the scientific foundation of the study referring to the rationale, research problem, research question, goal, as well as the objectives for the study. This is followed by a description of the research methodology. The chapter also outlines the conceptual framework, operational definitions and chapter outline.

#### 1.2. RATIONALE AND BACKGROUND LITERATURE

*Mycobacterium tuberculosis* (TB) was declared a worldwide emergency by the World Health Organisation (WHO) in 1993 and the burden of TB was shown in countries with larger populations such as China and India (Friedland, 2011:353). Sixteen years later, the WHO reported five countries with the largest number of new cases: India (1.6–2.4 million), China (1.1–1.5 million), South Africa (0.40–0.59 million), Nigeria (0.37–0.55 million) and Indonesia (0.35–0.52 million) (WHO, 2010:7). In South Africa, the National Department of Health reported that in 2006 the Western Cape Province had the highest TB incidence of 911 per 100 000 people, followed by KwaZulu-Natal with 907 TB cases per 100 000 people (National Department of Health: 2009:9). Cape Town, the largest city in the Western Cape with a population of 3.4 million people, is where the burden of both HIV and TB are high (Wood, Lawn, Caldwell, Kaplan, Middelkoop & Bekker, 2011:1-2). The Nyanga Clinic, situated in the Klipfontein sub-district in Cape Town, where the researcher is employed, has 922 patients on TB treatment (March 2010 to May 2011), of which 354 patients are non-compliant with their treatment. In addition, the cure rate is 63.7%, and the smear conversion rate (in two months) is 80% (Health Department, City of Cape Town, 2010:1).

South Africa is also ranked as the fifth highest Drug Resistant TB (DR-TB) high-burden country. In addition, the numbers of Multidrug-Resistant TB (MDR-TB) and Extensively Drug-resistant TB (XDR-TB) patients have increased due to the concurrent Human Immunodeficiency Virus (HIV) epidemic and inadequate management of TB (National Department of Health: 2011:5).

According to the Health Department, City of Cape Town (2010:1) non-compliance escalated from 6.7% to 11.2% between 2008 and 2010. Treatment default is one of the factors blamed for the low treatment success rate in the African region resulting in the development of MDR-TB (South African Family Practice, 2007:49).

Despite the implementation of the Directly Observed Treatment, Short-course strategy (DOTS), TB patients are still failing their treatment although they are monitored closely. The researcher could identify with this situation as in the Nyanga Clinic there were 354 non-compliant patients out of 922 TB cases, between March 2010 and May 2011, which could result in MDR-TB.

### **1.3 SIGNIFICANCE OF THE STUDY**

Non-compliance with TB treatment is a problem at the Nyanga Clinic (Health Department City of Cape Town, 2010:1).

The completion of this study should lead to, the experiences and perceptions of patients' referring to non-compliance with TB treatment becoming evident. These findings will enable the staff of the clinic to identify the problems, needs or challenges contributing to non-compliance with TB treatment, resulting in the formulation of action plans in order to address these challenges, whether it be health system-, socio-economic, client- or therapy-related, in order to improve on the number of patients who are compliant with their TB treatment.

#### **1.4 PROBLEM STATEMENT**

Compliance rates at the Nyanga clinic were sub-optimal, resulting in the situation where the statistics of patients non-compliant with TB treatment (interrupting treatment for more than two months consecutively) at the Nyanga Clinic are escalating every year (Health Department City of Cape Town, 2010:1).

Therefore it has become imperative for a scientific study to be undertaken in order to investigate the experiences and perceptions of non-compliance with TB treatment among patients at the Nyanga Clinic.

This study was conducted at the Nyanga Clinic where interventions such as the Directly Observed Treatment Short-course (DOTS) have not been implemented.

#### **1.5 RESEARCH QUESTION**

The researcher poses the following question as a guide for this study: "What are the experiences and perceptions of non-compliance with TB treatment among patients at the Nyanga Clinic?"

#### **1.6 RESEARCH AIM**

The aim of the study was to explore and describe the experiences and perceptions of non-compliance with TB treatment among patients at the Nyanga Clinic

#### **1.7 OBJECTIVES**

The objectives of the study were to determine the

- knowledge of non-compliant patients about TB treatment
- reasons why patients are non-compliant to TB treatment.

#### **1.8 METHODOLOGY**

In this chapter, a brief discussion is given about the research methodology applied in the study: a more in-depth discussion is described in Chapter 3.

### **1.8.1 Research design**

The researcher applied a qualitative, explorative, descriptive and contextual design for this study. The researcher preferred the qualitative design. It is an interactive and subjective approach to describe the experiences of the participants. It also describes the meaning they ascribe to their experiences in the context of the study regarding the patient experiences of non-compliance with TB treatment. Furthermore, in qualitative research the researcher could play an active role in order to identify, explore and describe the experiences of the participants (Burns and Grove, 2009: 35).

### **1.8.2 Population and sampling**

The target population for this study included the 354 non-compliant with TB treatment patients of the Nyanga Clinic from March 2010 to May 2011 as documented in the TB register. All non-compliant patients were colour-coded in the TB register for identification, irrespective of gender, age and race.

A purposive non-random sampling technique was used to select the participants for the study. Every tenth participant who, according to the TB register, was colour-coded as non-compliant with TB treatment was selected for interviewing until data saturation should occurred.

#### **1.8.2.1 Inclusion criteria**

Patients who were non-compliant (for two or more consecutive months) with TB treatment at the Nyanga Clinic for the period May 2010 to March 2011 as documented in the TB register were included in the study.

#### **1.8.2.2 Exclusion criteria**

The researcher excluded all patients who were very ill and could not take part, those who were compliant with their treatment and those who were not willing to take part.

### **1.8.3 Instrumentation**

An interview schedule (Appendix A) was developed based on the objectives of the study, the literature review and the researcher's own personal experiences for the

purpose of the study. The interview schedule was validated by the supervisor of the study, reviewed by a peer group during the scholarly tutorial session at the University of Stellenbosch, as well as approved by the Human Resource Ethical Committee (HREC).

The interview schedule consisted of Section A (Demographical data) and Section B (Patients' experiences and perceptions of non-compliance with TB treatment). Section A contained predetermined responses, where the participant could choose the most suitable response and could comment on these issues. Section B contained open-ended questions.

#### **1.8.4 Pilot test**

One patient, who was not included in the main study, was selected at random to pre-test whether the semi-structured interview schedule stimulated an in-depth discussion. The pilot test revealed no pitfalls.

#### **1.8.5 Validity and trustworthiness**

The researcher enhanced the quality of the research by ensuring trustworthiness of the research.

Lincoln and Guba (1985) suggested four criteria for developing the trustworthiness of a qualitative inquiry namely: truth value, applicability, consistency and neutrality (Lincoln & Guba, 1985: 290).

##### **1.8.5.1 Credibility**

According to Creswell (2009:191), credibility refers to whether the findings are accurate from the standpoint of the researcher, the participant, or the readers of an account.

The following strategies were used to ensure the truth of collected data and correct data interpretation: purposively sampling, data saturation; member checking and involvement of an experienced TB clinic supervisor. The researcher consulted with the TB clinic supervisor who has expert knowledge regarding the field of TB, and held impartial views of the study in order to ensure the collection of valid information.

### **1.8.5.2 Conformability**

Babbie and Mouton (2006:278) define conformability as the degree to which the findings are the product of the focus of the inquiry and not the biases of the researcher.

Objectivity, congruence and neutrality were ensured through member checking and leaving an audit trail to ensure that conclusions, interpretations and recommendations can be traced to their sources.

### **1.8.5.3 Transferability**

Transferability is the extent to which qualitative findings can be transferred to other settings or groups; it is analogous to generalizability (Polit & Beck, 2008:768).

Generalisation was not the aim of the findings of this study, as only the non-compliant TB patients of the Nyanga Clinic of the Cape Metropole district were included in the study.

Thick description regarding the collected data in context, data analysis and interpretation of the findings were done in order to enable the readers to compare with those in their situations.

### **1.8.5.4 Dependability**

Dependability refers to the techniques to show that, if the study were repeated, in the same context with the same methods and with the same participants, similar results would be obtained (Shenton, 2004:71).

Stability of data was ensured by using an interview schedule (Annexure 1) to ensure that all the interviews were done in the same manner. Member checking was done to ensure that participants were understood correctly. The tape-recorded data and field notes were transcribed and analysed by the researcher and submitted to the supervisor for verification of the coded data.

### **1.8.6 Data collection**

Semi-structured interviews and observations in the form of field notes were used as data collection procedures. The researcher collected the data personally at the homes of the participants to enhance the conduciveness towards the study. The interviews

were recorded with permission of the participants. Interviews were conducted according to an interview schedule(Annexure1) available in English and IsiXhosa, depending on the language of choice of the participants. The researcher confirmed that the participants understood the questions.

Interviews were carried out in a single session. The data was collected over a period of one month from 1 October 2011 to 30 October 2011.

#### **1.8.7 Data management and analysis**

The quantitative data (demographic data) was summarised in a table format using Microsoft Word to enhance clarity and facilitate a rapid overview of the results.

The audio tapes were labelled with an interview number and the date of the interview recorded on the tape before commencing with the recording of the interview.

The quality data reduction process was done in alignment with Tesch's (1990) open coding method of data analysis (Creswell, 2009:186).

The researcher analysed the data by listening to the tape recorded data and transcribing the recorded interviews of the participants. These interviews were captured then onto a master file on Microsoft Word, immediately after each interview.

The data were sorted into themes and these were then established into codes. A colour-coded index of the phrases was done to identify the different themes that evolved.

Data were sent to the research supervisor after being analysed in order to be validated.

#### **1.8.8 Ethical considerations**

The rights of study participants must be protected in all research studies (Nieswiadomy, 2011:19).

Permission to conduct this study was obtained from the Human Research Ethics Committee of the University of Stellenbosch(Annexure3); City of Cape Town(Annexure4); as well as from each participant or parent should the participant be a minor(Annexure 2).

Each participant was given a participant information leaflet concerning the purpose, procedure, risks and benefits, as well as the obligations and commitments of both the participants and the researcher were discussed (Annexure 2). Every participant had to give written consent to participate in the study. The permission was also obtained for the written and audio recordings of the interview session. Participants were assured of anonymity.

During the study, in cases where the participants could experience problems with the researcher, they were informed that they could notify the researcher's supervisor and the telephone number was provided. However, no problems were experienced by the participants.

The participants were informed of the following rights:

#### **1.8.8.1 Beneficence**

Beneficence imposes a duty on researchers to minimise harm and to maximise benefits (Polit & Beck, 2008:170-171).

The researcher is a clinical nurse practitioner in the Nyanga Clinic. The researcher is not directly involved with the daily treatment of TB patients as the service is rendered by professional nurses from the City of Cape Town, therefore bias was minimised as the researcher was unknown to the participants. Consequently the patients could talk freely because the researcher was not directly involved with them or in their treatment in any manner.

The researcher was constantly alert to any issues that may possibly harm the participants' physical or mental condition. The involvement of the participants throughout this research study did not put them at any disadvantage, nor did it expose them to any manipulation.

The interviews were conducted in the comfort of the participant's home. Participants were given a choice to answer the questions in English or Xhosa. During the study, should the participant be identified to be very ill, the interview would be cancelled and the participant would be referred for medical attention to the Nyanga Clinic. As mentioned in the exclusion criteria, sick participants would be excluded, if a participant

experienced any emotional distress they would be referred to a psychologist and a social worker at the Nyanga Clinic. However it was not necessary. Infection control measures such as open windows to allow for adequate ventilation, protective masks for both the researcher and participants were adhered to.

#### **1.8.8.2 Respect for human dignity**

This principle includes the right to self-determination and the right to full disclosure (Polit & Beck, 2008:171-172).

Each participant received an information leaflet where the purpose and objectives of the study, the roles of the participants and their rights were explained in a language with which they were comfortable (Annexure 2). Participants were encouraged to ask questions. The contact details of the researcher were included should there be any queries. Participation was voluntarily. They could choose to leave the study at any time.

#### **1.8.8.3 Principle of justice**

According to the principle of justice, participants have a right to fair treatment and their right to privacy (Polit & Beck, 2008:173-174).

Confidentiality, anonymity and privacy were ensured by using code numbers. Subjects were asked to sign consent forms which described the study, promise confidentiality and indicated that the subjects could withdraw participants at any given time. All data obtained were managed by the researcher and the research supervisor only. The name of the participant did not relate to the transcribed data, instead the participants were color-coded. The data were stored in a locked cupboard at the clinic, accessible to only the researcher and researcher's supervisor and will be destroyed within five years after the completion of the study.

### **1.9 CONCEPTUAL FRAMEWORK**

The researcher adopted the comprehensive framework of the National Department of Health (2009:45), dealing with the health system; client-related; social and economic; as well as therapy-related factors contributing to non-compliance with TB treatment.

According to the researcher this framework was suitable to describe the experiences and perceptions of the patients non-compliant with TB treatment, to identify the patients' knowledge regarding TB and identify the reasons why patients were not compliant with TB treatment.

Furthermore, the researcher applied the problem-solving approach of Faye Glenn Abdellah's theory (George, 2002:173-1830) to the study where it is reiterated that nurses should be able to recognise and identify the nursing problems or needs of their patients. From where the nurse has to decide on an appropriate course of action in order to manage the problems or needs as experienced by the patient. Therefore the patient could move in the direction of health.

#### **1.10 DURATION OF THE STUDY**

The empirical research study was undertaken from 2010 to 2012.

#### **1.11 CHAPTER OUTLINE**

**Chapter 1:** Scientific foundation of the study. This chapter describes the background, the focus and rationale of the study. A brief outline of the goals, objectives and methodology is given.

**Chapter 2:** The literature review as related to the experiences and perceptions of non-compliant TB patients is discussed.

**Chapter 3:** The research methodology – including the research design, population, sampling and data analysis are explained.

**Chapter 4:** The data analysis, interpretation and discussion applicable to the analysis are explained in this chapter.

**Chapter 5:** Recommendations and conclusions are described based on the scientific evidence obtained in the study.

## **1.12 CONCLUSION**

According to the TB register (from March 2010 to May 2011) there were a total of 922 TB patients at the Nyanga Clinic, with a cure rate of 63.7% (Health Department City of Cape Town, 2010: 1). At the time of the study there were 354 non-compliant patients. The statistics of non-compliance with TB treatment at the Nyanga Clinic is escalating every year (Health Department City of Cape Town, 2010: 1).

By completing this study, the patients' experiences and perceptions regarding the health system, client-related, social and economic as well as therapy-related factors which could result in non-compliance of TB treatment could be identified and addressed. Furthermore, the non-compliant patients' knowledge regarding TB as well as the reasons why patients are not compliant with TB treatment as stated in the objectives could be addressed.

In this chapter the researcher described the study that was conducted with specific reference to the rationale for the study, the problem statement, goal, objectives and research methodology applied. In chapter two the literature review will be discussed.

## CHAPTER 2

### LITERATURE REVIEW

#### 2.1 INTRODUCTION

This chapter reviews the relevant literature from previous studies on patients' experiences and perceptions of non-compliance with TB treatment. The conceptual, as well as the theoretical frameworks are described.

According to Burns and Grove (2007:545), the literature review is a summary of the theoretical and empirical sources to generate a picture of what is known and not known about a particular problem. The literature review enabled an appraisal and discussion of the findings of this study.

#### 2.2 SELECTING AND REVIEWING THE LITERATURE

According to Polit and Beck (2008:105), the purpose of a literature review in qualitative studies is to expand the researcher's understanding of the phenomenon from multiple perspectives. A literature review conveys what is currently known about a specific topic and the importance of obtaining an abroad background and understanding of what is already known about a particular problem (Burns and Grove 2009: 91).

The literature on patients' experiences and perceptions of non-compliance between 2001 and 2012 was reviewed. Several sources were consulted, including textbooks, the most current research journals(including: *The International Journal of Tuberculosis and Lung Disease*, *BioMed Central Public Health*, *Journal of Infectious Diseases and Immunity*, *PLoS ONE*, *Journal of Nepal Health Research Council*, *Journal of Advanced Nursing etc.*), TB policy guidelines(for example: all patients with positive sputum should be identified and treated with immediate effect), case studies, research reports, as well as electronic sources (EBSCOhost – Google, Medline, CINAHL and Health Source: Nursing).

## **2.3 FINDINGS FROM THE LITERATURE**

The findings from the literature review will be discussed according to the National Department of Health (2009: 45) framework as it is a comprehensive approach that succeeds in addressing the major issues that could have an effect on patients' experiences and perceptions of non-compliance of patients with TB treatment at the Nyanga Clinic namely:

1. Health system factors
2. Client-related factors
3. Social and economic factors
4. Therapy-related factors.

### **2.3.1 Health system factors**

#### **2.3.1.1 Inadequate DOTS strategy**

Hsieh, Kuo, Chaing, Su and Shih (2008:869-875) identified in their study conducted in Taiwan that non-compliance as the major problem in treating patients with TB and patients who are supported by the DOTS strategy had the best compliance rates.

On the other hand, Paliwal (2010:49) reported that a number of community-based studies in different parts of India have shown a significantly high defaulter rate even under the DOTS strategy. According to Paliwal "default" is a human behaviour. As a technical intervention, DOTS is less likely to improve treatment-seeking behaviour of patients, which could be better influenced by aggressive health education and sensitisation.

According to the study of Lwilla, Schellenberg, Masanja, Acosta, Galindo, Aponte, Egwaga, Njako, Ascaso, Tanner and Alonso (2003:208) conducted in Tanzania, it is not necessary that a health worker supervises the patient; a trained community observer can perform the task just as effectively and this could therefore result in health workers being able to perform other duties.

In an evaluation done in KwaZulu-Natal, South Africa showed poor implementation of DOTS where low coverage, low quality and high caseloads were associated with poorer outcomes (Finlay, Lancaster, Holtz, Weyer, Miranda & van der Walt, 2012:9).

There was no DOTS strategy in place at the Nyanga Clinic at the time of the study.

#### **2.3.1.2 Long waiting time**

Results in the study of Jittimane, Madigan, Jittimane and Nontasood (2007:359) undertaken in Thailand have shown that in spite of long waiting times, it did not differ between those with treatment default and those without and was therefore not significant in multivariate.

Being a daily paid worker was the only patient factor affecting treatment default and might be related to the lack of paid sick leave.

A study by Pandit and Choudhary (2006:241) conducted in India supported the fact that the traditional risk factors for non-compliance like timing, travelling and long waiting periods were not major hurdles for treatment adherence. However, the results in a case study done by Loveday, Thomson, Ndlela and Doodley (2007:10) in KwaZulu-Natal, South Africa showed that some participants defaulted because of the long waiting times.

#### **2.3.1.3 Poor access to health centres**

In the TB case study done by Loveday et al. (2007:77), in KwaZulu-Natal, it was reported that 60 (65%) of the respondents had to walk to their nearest clinic, whilst 29(32%) took either the taxi or bus.

According to Loveday et al. (2007:10) co-infected patients with TB and HIV/AIDS, because of their physical weaknesses, reported that they experienced difficulties in accessing clinics and then having to wait for attention.

#### **2.3.1.4 Inconvenient appointments**

Lafaiete, Da Motta and Villa (2011:512) reported that in Brazil it was shown that delay of office hours that are incompatible with a patient's work hours may lead a patient to abandon the health service and no longer seek diagnosis or treatment there.

In the studies of Finlay et al. (2011:5), conducted in South Africa, and the systematic review of Munro, Lewin, Smith, Engel, Fretheim and Volmink (2007:1236), findings shown that cases were more likely (than the controls) to report that clinic hours were inconvenient. Furthermore, in South Africa, in the case-control study done by the Medical Research Council (MRC) (2009:24), the cases were more likely to report that clinic hours were not convenient than the controls (UOR 3.2, 95% CI: 2.1-5.0).

A study by Bam, Chand and Shrestha (2005:56) illustrated that patients may default on treatment because of inconvenient opening hours of DOTS clinics situated far from their homes.

Based on the findings of Lamsal, Lewis, Smith and Jha (2009:29), a study conducted in Nepal, recommended that more DOTS centres with more flexible working hours are needed so that they are easily accessible to all patients.

#### **2.3.1.5 Poor management of TB programmes**

In a case control study done by Muture, Keraka, Kimuu, Ombeka and Oguya (2011:5) in Nairobi, Kenya it was found that unfavourable health system factors were cited as reasons for default. These included the unavailability of drugs as well as the failure of health providers to offer health education, to articulate the need for treatment compliance and to appropriately manage drug side-effects. This is supported by the findings of a systematic review done by Munro et al. (2007:1241) in which it was shown that programme failures such as: inadequate supplies of drugs; difficulties in consulting providers; long waiting times and inconvenient opening times all added to economic discomfort for patients, and therefore negatively influenced adherence.

#### **2.3.1.6 Relationship between health care providers and patients**

According to Jin, Sklar, Oh & Li (2008:277) the patient-provider relationship is a strong factor which affects patients' compliance. The qualitative review undertaken by a literature search of the Medline database from 1970 to 2005, numerous studies

conducted in the United States, United Kingdom, Australia, Canada and other countries have found that compliance is good when health care providers are emotionally supportive, give reassurance or respect and treat patients as equal partners. Lafaiete, Salvador, da Motta and Scatena Villa (2011:1) did a descriptive qualitative study in Brazil regarding satisfaction of TB patients. Positive evaluations resulted where patients were included in the TB control plan, and were cared for by a health team with whom they established bonds and received support for treatment adherence.

Poor understanding between primary care providers and patients as well as rigid task orientated care delivery is major reasons for non-adherence as identified by the study of Dick, Lewin, Rose, Zwarenstein and van der Walt (2004:441) conducted in Cape Town, South Africa. Furthermore, Finlay et al. (2012:5) identified that in South Africa certain health care workers had negative attitudes towards patients who had not treated them with respect; that patients often did not trust the health care workers and that they missed treatment because of negative attitudes shown by health care workers. The systematic review of Munro et al. (2007:1236) confirmed that a patient's relationship with the health care provider appeared to influence adherence.

Sagbakken, Frich and Bjune (2008:6) reported from their qualitative study conducted in Ethiopia that some nurses were more flexible than others, but there were examples from all three clinics under study of patients who were threatened, humiliated or treated angrily by staff for not adhering to the implicit rules of the system.

Results from the evaluation done by the MRC (2009:25) in South Africa, described the opinions about health services and health staff as unsatisfactory in terms of attitudes (UOR 3.6, 95% CI: 2.1 – 6.3). Furthermore, cases were more likely to report missing treatment because of the health care workers' attitudes (UOR 5.4, 95% CI: 2.8-10.5).

### **2.3.2 Client-related factors**

#### **2.3.2.1 Poor knowledge about TB and the efficacy of treatment**

Finlay et al. (2012:5) reported that cases in their study conducted in South Africa were more likely to report that they had not received enough education about TB at the

beginning of their treatment, that they were not told why treatment would take six or more months and lacked counsel and information about TB treatment in general. The study of Fatiregun, Ojo and Bamgboye (2009:100) confirmed that patients in Nigeria with a poor knowledge of TB had a higher risk of having a poor treatment outcome (RR=1.35; 95% CI: 1.25-1.62) compared to those with a good knowledge.

The analysis of Sardar, Jha, Roy, Roy, Guha and Bandyopadhyay (2010:471) revealed that in Kolkata, India a lack of proper counselling, knowledge about the correct method of TB transmission, patients visiting quacks and the urge to leave treatment once they started feeling better were the significant determinants of non-compliance.

The Nyanga Clinic, where the study was conducted, did not have counselling services to inform and advise TB patients about the duration and the different phases of the treatment. Therefore the researcher could relate to the study findings of Sardar et al.(2010:471).

#### **2.3.2.2 Stigma**

According to Dodor and Kelly (2009:170), in Ghana one major setback to the success of TB control globally is the stigma experienced by patients. Gebremariam, Bjune and Frich (2010:6) reported that in Ethiopia they found that many patients believed that they were susceptible to stigma because of TB. The stigma was mainly due to the fact that people associated TB with HIV. Stigma related to TB was supported by the study of Khan, Irfan, Zaki, Beg, Hussain and Rivi (2006:213), where almost half of the TB patients of the study undertaken in Pakistan were of the opinion that being infected with TB reduced their chances of getting married.

Xu, Lu, Zhou, Zhu, Shen and Wang (2009:169) reported from their research done in Jiangsu, China that the stigmatising attitudes and behaviours of the community members towards the disease may lead those with TB to hide the diagnosis from others and to default from treatment. Findings of Cramm, Finkenflugel, Moller and Nieboer (2010:3) in a study from the Eastern Cape brings to mind a high level of stigmatisation: a full 95% of respondents accepted it as true that people with TB tended to hide their TB status because they were scared of what others might say. Jin

et al. (2008:286) reported in their qualitative review that a negative attitude towards therapy should be seen as a strong predictor of poor compliance.

The researcher supports the findings of the above studies as in the Nyanga Clinic; she has experience of TB patients who do not attend the clinic regularly because they do not want people to know that they suffer from TB because of stigma from the disease.

### **2.3.2.3 Depression**

Sulehri, Dogar, Sohail, Mehdi, Azam, Niaz and Javed (2010:133) concluded their study in Faisalabad, Pakistan and the results shown that 80% of patients were suffering from depression. The frequency of depression was 86% among males, while 71% of the female patients were found to be depressed. The main causes of depression among the male TB patients were a changed social relationship and among female patients TB stigma. Depression had an adversative effect on drug compliance and TB treatment. The study by Mweemba, Haruzivishe, Sisiya, Peter, Kyllike and Johansson (2008:126) done in Lusaka, Zambia confirmed that TB was considered as a 'dirty' disease, with social stigmatisation leading to a delay in seeking medical advice and non-compliance. Many respondents described feelings of depression, anger and apathy associated with the disease process.

According to Issa, Yussuf and Kuranga (2009:133) TB is associated with psychiatric morbidity, particularly depressive disorder in Nigeria, and this has been recognised as a cause of poor compliance and a cause of increased morbidity and mortality from the disease.

In the study of Manoharam, John, Joseph and Jacob (2001:77) done in South India regarding psychiatric morbidity, the researcher reported that one fifth of the subjects had psychiatric morbidity, of which depression was the commonest condition.

In meta-analytic work, findings suggest that one of the strongest predictors of patient non-adherence to medical treatment is patient depression. Depression has long been known to predict poor health outcomes in the United States of America (Martin, Williams, Haskard & Matteo: 2005:189).

### **2.3.2.4 Disempowerment**

According to Zachariah, Harries, Srinath, Ram, Viney, Singogo, Lal, Mendoza-Ticona, Screenivas, Aung, Sharath, Kanyerere, van Soelen, Kirui, Ali, Hinderaker, Bissell, Enarson and Edginton (2012:714), the words 'defaulter', 'suspect' and 'control' have been part of the language of TB services for many decades in countries such as Africa, Asia, Latin America and the Pacific. From a patient-perspective, these terms are inappropriate, intimidating and disempowering, and at worst they could be perceived as judgmental and criminalising, tending to place the blame of the disease or responsibility for adverse treatment outcomes on the side of patients.

In addition Sagbakken et al. (2008:1) identified the daily TB treatment as time-consuming and physically demanding together with the rigid routines at health clinics, which could strengthen the feeling of disempowerment for TB patients in Ethiopia. Furthermore, patients with limited access to financial or practical help from relatives or friends experienced that the total costs of attending treatment exceeded their available resources. This was identified as a barrier to adherence already during early stages of treatment.

In the study of Sagbakken (2010:4) done in Ethiopia and Norway, it was found that people's interpretation and management of TB symptoms are influenced by cultural, social and economic factors. TB is viewed in both high-endemic and low-endemic settings associated with poverty, and subsequently as a disease that affects certain countries or certain segments of a population.

However, according to Burke (2011:47) acknowledging the dynamics of changing environments and recognising the role of biomedicine as a variable in controlling TB successfully, one saying has not faltered: that TB can and does flourish in social conditions defined by poverty, inequalities, disempowerment and injustice.

TB is a disease that is sometimes associated with poverty which means that these TB patients suffer from lack of financial help from friends or relatives to attend to the clinic to get their treatment and according to the researcher this could be a disempowering situation.

### **2.3.3 Socio-economic factors**

#### **2.3.3.1 Extreme poverty**

According to Lamsal et al. (2009:26), poverty and TB are closely connected. The poor have higher contact rates due to crowded homes, more active infection due to sub-optimal nutrition and working conditions, and they frequently have less access to diagnostic and treatment facilities. They may have less flexibility regarding work and clinic attendance and less ability to pay for medications and transport. Nurses who took part in the study of Sissolak, Marais and Mehtar (2011:7) conducted in Cape Town, South Africa, reported that their TB patients came from poor conditions and lived far from the hospital. Some of them did not have good housing, they stayed in shacks, their nutritional status was bad, and they had no work and no money to go to the hospital.

The researcher could relate to the above as about 70% of the houses in Nyanga (where she is employed) are in squatter camps and most of the patients come from those camps.

#### **2.3.3.2 Poor support networks**

The study results of Jin et al. (2008:280) confirmed that patients who had support from family members, friends or healthcare providers were more likely to be compliant to their treatment. Furthermore, the study of Munro et al. (2007:1239) supports previous studies in the sense that family support, including financial assistance, collecting medication and emotional support appear to be a strong influence on patient adherence to treatment. Study results of Gebremariam, Bjune and Frich(2010:6) revealed that social support was found to be crucial for patients' treatment.

Ayisi, van't Hoog, Agaya, Mchembere, Nyamthimba, Muhenje and Marston (2011:1) carried out a qualitative study in rural western Kenya and their study results showed that lack of family support might be a reason for non-compliance with TB treatment.

#### **2.3.3.3 Employment status**

Among employed patients, default was associated with patients missing treatment due to employment. Reasons mentioned by patients included that they were too busy and did not have enough time, work was too far from the TB clinic, their employer did not allow them to get TB treatment and some patients did not want other co-workers to know they had TB (Finlay et al., 2012:4-5).

Jittimanee et al. (2007:357) confirmed that treatment default was five times greater for patients who were daily paid workers, as they were not paid when they were absent from work, therefore they may choose to work, rather than to go to the clinic for treatment (OR=5.127).

The results of a prospective cohort study conducted by Okanurak, Kitayaporn and Akarasewi (2008:1160) in Bangkok showed that patients with regular earnings had twice the likelihood of success compared to the unemployed (OR=2.0, 95%CI 1.1-3.5).

In support of this, according to the Hasker, Khodjikhhanov, Usarova, Asamidinov, Yuldashova, van der Werf, Uzakova and Veen, (2008:1) study in Tashkent, Uzbekistan, being unemployed, being a pensioner, alcoholism and homelessness were all related to defaulting.

However, the cross-sectional study conducted by Pandit and Choudhar (2006:242) in India revealed that socio-economic status was not associated significantly with adherence.

#### **2.3.3.4 Migration**

In the national retrospective case control, which was conducted in eight out of nine provinces in South Africa the MRC (2009:22) reported that a higher proportion of cases (16%) than controls (7%) changed their residence during TB treatment. Among patients that had relocated, cases were more likely than controls to have missed treatment due to changing residence (UOR 11.5, 95% CI: 3.8-36). Finlay et al. (2012:5) confirmed that among new TB patients, cases were more likely than controls to have changed residence during TB treatment: they were often labourers and missed treatment due to work. Jaggarajamma, Muniyandi, Chandrasekaran, Sudha, Thomas, Gopi and Santha (2005:35) confirmed that their study results showed that migration was a significant factor for treatment default (24% of the defaulters had migrated) in Tamil Nadu. In their study, migration was mainly due to work-related reasons and the returning of the patient to his/her place of birth.

Although unemployment was confirmed as a statistically significant risk factor for default, migration according to the records accounted for only 16% of all default. The initial assumption that patients default mostly because they move around in search of job opportunities could not be substantiated (Hasker et al., 2008:5).

### **2.3.3.5 Sex and age**

According to the MRC et al. (2009:21), Hasker et al. (2008:3); Guzman-Montes, Ovalles and Laniado-Laborin (2009:779); Pandit and Choudhary (2006:241) it seemed to be that being male was significantly associated with TB treatment default.

Jin et al. (2008:272) reported a correlation between age and non-compliance. According to these researchers, the effect of age could be divided into three major groups: an elderly group (over 55 years old); a middle-aged group (40 to 54 years old) and a younger group (under 40 years old). However, in the study of Hasker et al. (2008:3) the median age was 37 years and according to the study of Guzman-Montes et al. (2009:779) the median age was 34 years. The studies of both Amoran, Osiyale and Lawal (2011:92) done in Nigeria, as well as the study of Pandit and Choudhary (2006:241) conducted in India showed that the mean age of the non-compliant TB patients was 36.6 years of age.

The majority of the patients in the TB register of the Nyanga Clinic were females, thus the opposite of the findings of the studies as described above.

### **2.3.3.6 Alcohol dependency**

Jin et al. (2008:278) reported several studies about compliance among asthma, hypertension and renal transplantation patients. They found that patients who smoked or drank alcohol were more likely to be non-compliant. Furthermore, Muture et al. (2011: 5) revealed that the recurrent use of alcohol and consequent forgetfulness to take drugs which led to defaulting was cited by 9 (7.5%) of cases.

Alcoholism was identified as a risk factor in the study by Jaggarajamma et al. (2007:134) conducted in Tamil Nadu. These researchers stressed alcohol was an important predictor of non-compliance in India and in different parts of the world. According to Finlay et al. (2012:9) alcohol was associated with default among new TB patients. Alcohol use or abuse has been frequently reported as a risk factor for default.

### **2.3.3.7 Lower literacy rate**

The results of the qualitative review undertaken by Jin et al. (2008:276) showed that educational levels may not be a good predictor of therapeutic compliance. Studies by Kaona, Tuba, Sisiya and Sikaona (2004:1) found similarly that age, marital status and educational levels were not significantly associated with compliance in Zambia.

In contrast, the study of Date and Okita (2005:680) demonstrated that educational levels of TB patients in Yemen were significant predictors of treatment compliance. Belo, Luiz, Teixeira, Hanson and Trajman (2011:979) conducted a prospective study in Brazil and found that educational background is among the most important determinants of socio-economic status and it is worthy of note that all deaths occurred in the group with a lower educational level.

#### **2.3.3.8 Perceptions and beliefs**

According to Ayisi et al. (2011:4), findings of a qualitative study done in Kenya showed that some participants thought that environmental factors such as inhaling smoke and hot air from burning charcoal or sharing a house with domestic animals were the cause of their TB symptoms. Other patients thought that TB was picked up from alcohol, water or sharing utensils.

In Ethiopia, some participants thought that 'evil spirits', sexual intercourse and 'the cold' were causes of TB, according to a qualitative study by Gebremariam, Bjune and Frich (2011:1). This report found among participants in Addis Ababa a predominant lay belief that TB was caused by contact with cold temperatures. In a further report, Ethiopian as well as Zambian participants were found to believe that a causal association existed between HIV and TB (Khan et al.:2006:213)). In Ethiopia, excessive sun exposure, exposure to mud, smoking, alcohol, chewing khat and inadequate food intake were also reported as causes for TB. (Gebremariam et al., 2011:1)

According to a study done by Khan et al. (2006: 211); patients considered separating dishes as an important means of preventing spread. Other patients discontinued their medications following relief of symptoms. Others thought that TB could lead to infertility and others believed that there were reduced chances of getting married following infection.

In their qualitative review, Jin et al. (2008:276) showed that patients' misconceptions or erroneous beliefs contributed to poor compliance. Patients' fears about treatment; their belief that the disease could not be controlled and their religious beliefs all contributed to the likelihood of non-compliance to therapy.

In South Africa's Limpopo province, the study by Promtussananon and Peltzer (2005:76) showed that the majority (63.8%) of the respondents perceived smoking to be the cause of TB. The second most important cause of TB, as seen especially by adults, was exposure to dust, dirty air and chemicals (30%).

### **2.3.3.9 Role of traditional healers**

Sissolak et al. (2011:7) conducted a qualitative study with a phenomenological approach using semi-structured interviews with 20 nurses employed in a large tertiary academic hospital in Cape Town regarding TB infection and control experiences. All participants were concerned about the role of traditional healers in TB care. Some felt that healers were often the first point of care for many patients. Many participants expressed strong opinions that patients accessed medical TB care after trying traditional treatment and when physically exceptionally unwell.

According to the evaluation done by Loveday et al. (2007:8), a quarter of the patients from KwaZulu-Natal regional/district hospital and three of its feeder clinics under study went to a traditional healer some time during their illness and 15% after they knew they had TB. Sixteen per cent of the patients went to a traditional healer as their first choice of care. Of those who went to a traditional healer, 72% were male.

According to Ayisi et al. (2011:5), their qualitative study in Kenya showed that those who attributed their TB to be caused by a curse or witchcraft contacted spiritual healers. More than half of the patients (17) sought the advice of a close relative, and most delayed seeking professional care because they were advised to seek help from herbal/spiritual healers.

A cross-sectional study done in Ethiopia by Wondimu, Michael, Kassahun and Getachew (2007:149-150) showed that in general 35.6% of patients reported first to drug shops, private clinics or private hospitals upon recognition of symptoms. Forty three per cent of patients reported first to either health centres or government hospitals. Patients reporting first to traditional/spiritual healers constituted 4.1% (n=8).

However, statistically significant difference was not observed upon comparing this group with patients who first consulted other health care providers.

According to Dodor and Kelly (2009:829-831), alternative treatment can contribute to the outcome: For example, the use of traditional medicine while taking the TB treatment may lead to the substitution of drugs which in turn may have a negative impact on treatment outcome.

### **2.3.4 Therapy-related factors**

#### **2.3.4.1 Side-effects of the TB drugs**

According to the WHO (2003:124) the number of tablets that need to be taken, as well as their toxicity and other side-effects associated with their use may act as a constraining factor for continuing the treatment. Side-effects were experienced by more than half of the participants, mainly at the beginning of TB treatment or upon initiation of concomitant treatment (Gebremariam et al., 2010: 4).

In contrast with Jin et al. (2008:278), compliance does not seem to correlate with the number of drugs described, but the number of dosing times every day of all prescribed medications. The rate of compliance decreased as the number of daily doses increased.

Bam et al. (2005:55) conducted a study regarding the factors responsible for non-compliance among TB patients in Nepal and the findings revealed that patients who did not know about potential side-effects of medicines were more likely to default.

In the study of Muture et al. (2011:6) and Kaona et al. (2004:5), the side-effects of TB medication were attributed to 13(10.8%) defaulters as cause for their default. Feeling better after medication for a while (and perceiving it as a cure) was cited by 14(11.7%) defaulters as a reason why they stopped taking drugs.

In some cases perceived side-effects resulting from chronic hunger could lead to defaulting treatment: "These drugs make one feel fatigue, improved appetite...when there is no food, it is not easy" (Ayisi et al., 2011:7).

Treatment default was significantly more likely if subjects had severe side-effects of medication. The severe side-effects of the medication caused the patient to require an

extra clinic visit because of physical discomfort, unnecessary patient distress or worsening symptoms. These reasons could increase the likelihood of treatment default (Jittimaneet et al., 2007:358).

Current prescribed medications have fewer adverse effects, but these do still occur in some patients. Some patients stop taking their medication when they encounter adverse effects such as nausea. Therefore, all new patients should be advised about potential adverse effects and the possibility of changing medication if these effects are severe (Okanurak et al., 2008:1163).

Munro et al. (2007:1239) reported from their study, that some patients said they had stopped medication because of adverse effects, while others reported that they were not informed about side-effects and what to do to counter them. In some cases patients had not communicated with their providers about the side-effects; in others, the health care worker had not given attention to the side-effects that patients reported, or had responded derisively to the patient's attempt to enquire about them. Few patients acknowledged that side-effects had influenced their decision to abandon treatment.

#### **2.3.4.2 Longer duration of treatment**

Bam et al. (2005:55) reported that studies done in Malawi and Vietnam showed that insufficient knowledge and duration of treatment were the main obstacles to compliance. Acute illnesses are associated with higher compliance than chronic illnesses. In addition, longer duration of the disease may adversely affect compliance. Similarly, a longer duration of the treatment period might also compromise patients' compliance. In one trial that compared six-month and nine-month treatment of TB, compliance rates were 60% and 50% for the two regimens, respectively. In another study comparing preventative regimens of three, six and 12 months, compliance rates were 87%, 78% and 68% for the three regimens respectively (Jin et al., 2008:279-280).

According to the study of Mwinga and Fourie (2004:827) effective treatment and management of TB cases tend to be limited by additional direct expenditure on drugs and also the long duration of treatment (six to eight months) that is required to cure patients. Patient adherence to the treatment regimen over such a long time is often

deficient, and requires considerable investment in human resources and laboratory monitoring to ensure successful treatment.

Patient default is a major problem encountered in the control of TB and the prevention of drug resistance to mycobacteria. About 50% of patients in Teheran, Iran fail to follow treatment regimens as described. The major causes of non-adherence to anti-TB drugs include multiple medications, unpleasant side-effects and long duration of treatment (Khalili, Dashti-khavidaki, Sajadi and Hajabolbaghi, 2008:48).

According to Anuwatnonthakate, Limsomboon, Nateniyom, Wattanaamorkiat, Komsakorn, Moolphate, Chiengsorn, Samroui Kaewsa-ard, Sombat, Siangphoe, Mock and Varma (2008:1), one barrier to global TB control is the long duration of TB treatment – a minimum of six months – which frequently results in patients taking their medication erratically or not at all.

TB patients have difficulty following a long-term treatment regimen. Efforts to improve treatment outcomes require better understanding of adherence as a complex behavioural issue and of the particular barriers to and facilitators of patient adherence (Xu et al., 2009:1).

In the systematic review conducted by Munro et al. (2007:1238), results showed that the long treatment period was poorly understood by patients and adherence appeared to be facilitated where patients understood the importance of completing the treatment.

#### **2.3.4.3 Large pill burden**

A study by Gebremariam et al. (2010:4) showed that patients attributed pill burden to be one of the major challenges of concomitant treatment: They used expressions such as “becoming a drug bag” and “becoming a pharmacy”. In addition to anti-TB drugs and antiretroviral drugs, patients were also taking co-trimoxazole prophylaxis and some in addition, had to take drugs for other diseases.

The studies of Padmapriyadarsini, Narendran and Swaminathan (2011:850) and Swaminathan, Padmapriyadarsini and Narendran (2010:1377) reported that where the treatment of HIV co-infected patients required anti-TB and antiretroviral drugs to be administered alongside, there were challenges of pill burden and patient compliance

as well as drug interactions, overlapping toxic effects and immune reconstitution inflammatory syndrome.

Adherence to therapy is difficult to achieve due to the large number of ART and anti-TB drugs administered simultaneously and their overlapping toxicities. The most decisive determinant for the success of TB treatment is a good drug adherence for the entire duration of therapy. When compliance is impaired, the development of drug resistance and relapses are common (Hoffman & Rockstroh, 2011:363).

#### **2.3.4.4 Complex treatment regimens**

Lienhardt, Vernon and Raviglione (2010:186) have shown that the current drug-based treatment of TB is more than 40 years old. Despite a demonstrated high efficacy in clinical trials, standardised short-course chemotherapy of active drug-susceptible TB requires direct supervision to assure good adherence and prevent drug resistance to all patients treated for TB. Drugs that are active against resistant forms of TB are less potent, more toxic and need to be taken for a long time ( $\geq 18$  months). The recent emergence of virtually untreatable XDR-TB poses a new threat to TB control worldwide. Furthermore, effective treatment of TB in persons co-infected with HIV is complicated due to drug-drug interactions. Shorter and simpler regimens that are safe, well tolerated, effective against drug-susceptible and drug-resistant TB, appropriate for joint HIV-TB treatment, and amenable to routine programmatic conditions are needed urgently.

Laurenzi, Ginsberg and Spigelman (2007:107) support the need to develop novel, better drugs and regimens for the treatment of TB and to improve TB treatment by focusing on achieving several goals, including:

- shortening the duration of treatment for active TB to improve compliance;
- lessening the burden on public health infrastructure;
- reducing the occurrence of MDR-TB;
- developing safe, tolerable drugs with novel mechanisms of action that will therefore be effective against resistant disease (MDR-TB and XDR-TB);
- developing TB drugs that lack cytochrome P450 enzyme induction and inhibition;

- avoiding drug interactions, especially with ART and facilitate treatment of patients co-infected with TB and HIV.

According to Laurenzi, Ginsberg and Spigelman (2007:107) a number of known drugs are being currently investigated by the British Medical Research Council for their contribution in the simplification or improvement of the current TB drug regimen. These include rifampicins and Fluor quinolones (Lienhardt et al., 2010:189). Furthermore, recent advances in TB drug research and development are encouraging, with nine compounds already in the clinical development pipeline, including five new chemical entities specifically developed against TB. However, this slender pipeline is not likely to be sufficient. New drugs are needed that have strong, synergistic and complementary activities against various TB subpopulations in order to shorten TB treatment, be effective against MDR TB/XDR TB and be easily administered in conjunction with ART.

## **2.4 CONCEPTUAL FRAMEWORK**

A conceptual framework starts with a set of ideas which may be vague or clearly formulated propositions, and which may determine an approach to a research topic and help determine which questions are to be answered by the research (De Vos, Strydom, Fouche & Delport, 200:34). According to Stommel and Wills (2004:15) conceptual frameworks are a type of intermediate theory that has the potential to connect to all aspects of inquiry, for example problem definition, purpose, literature review, methodology, data collection and analysis.

The researcher selected the National Department of Health(2009:45)framework, factors contributing to non-compliance with TB treatment as a conceptual framework as it is addressing the objectives for this study namely; patients' experiences and perceptions of non-compliance with TB treatment, non-compliant patients' knowledge regarding TB as well as reasons why patients are not-compliant with TB treatment.

**Table 2.1: Factors Contributing to Non-compliance with TB treatment**

(National Department of Health, 2009:45)

<p><b>Health System factors:</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Inadequate DOTS strategy</li> <li><input type="checkbox"/> Long waiting times</li> <li><input type="checkbox"/> Poor access to health services</li> <li><input type="checkbox"/> Inconvenient appointments</li> <li><input type="checkbox"/> Poor management of TB programs</li> <li><input type="checkbox"/> Relationship with health care providers</li> </ul>	<p><b>Client-related factors:</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Poor knowledge about TB treatment and the efficacy of treatment</li> <li><input type="checkbox"/> Stigma</li> <li><input type="checkbox"/> Depression</li> <li><input type="checkbox"/> Disempowerment</li> </ul>
<p><b>Social and economic factors:</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Extreme poverty</li> <li><input type="checkbox"/> Poor support networks</li> <li><input type="checkbox"/> Employment status</li> <li><input type="checkbox"/> Migration</li> <li><input type="checkbox"/> Sex and age</li> <li><input type="checkbox"/> Alcohol abuse</li> <li><input type="checkbox"/> Lower literacy rates</li> <li><input type="checkbox"/> Perception and beliefs</li> <li><input type="checkbox"/> Role of traditional healers</li> </ul>	<p><b>Therapy-related factors:</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Side-effects of TB drugs</li> <li><input type="checkbox"/> Longer duration of treatment</li> <li><input type="checkbox"/> Large pill burden</li> <li><input type="checkbox"/> Complex treatment regimens</li> </ul>

A theoretical framework is one that the researcher has developed through identifying and defining concepts and proposing relationships between the concepts (Brink, Van

der Walt & Van Rensburg, 2006:24). The Faye Glen Abdellah theory (George, 2002: 173-183) was used as the underpinning theoretical framework of the study.

#### **2.4.1 Faye Glenn Abdellah theory**

Faye Glenn Abdellah's theory mentions three major concepts, namely: health, nursing problems and problem-solving (George:2002:173-183).

Abdellah describes health as the continuous interaction with internal and external forces that results in the optimal use of necessary resources and results in wellness as a lifetime goal (op.cit.). Nursing problems are described by Abdellah as the patient's health needs which are emotional, sociological and interpersonal in nature. Problem-solving runs parallel to the steps of the nursing process, namely assessment and diagnosis, plan for the necessary action to ensure the desired outcomes, implementation and evaluation of the necessary action (op.cit.).

Abdellah explains nursing as a comprehensive service which includes:

- recognising the nursing problems of the patient;
- deciding on the appropriate course of action to take;
- providing continuous care of the individuals total needs;
- providing continuous care to relieve discomfort and provide immediate security for the individual;
- adjusting the total nursing care plan to meet the patient's individual needs;
- helping the individual to become more self-directing in attaining or maintenance of a healthy state of body and mind;
- instructing the nursing personnel and family to help the individual to do for himself that which he can within his limitations;
- helping the individual to adjust to his limitations and emotional problems;
- working with allied health professions in planning for optimum health on local, state, national and international level; and

- carrying out continuous evaluation and research to improve nursing techniques and to develop new techniques to meet the health needs of people.

The above theory provides a basis for determining and organising nursing care. It is anticipated that by solving the nursing problems through appropriate and organised nursing strategies, the client will be moved towards ultimate health (George, 2002:173-183).

According to this study, the analysis of the collected data as described in Chapter Four enabled the researcher to identify the 'nursing problems' influencing the TB treatment outcomes of the patients attending the Nyanga Clinic. Chapter Five describes the "problem solving" actions in the format of the study recommendations in order to address the "nursing problems" which will enable the patients to move in the direction of "health" meaning that patients will be adherent to their TB treatment.

## **2.5 CONCLUSION**

The findings from the literature review were discussed according to the National Department of Health (2009) framework regarding factors contributing to non-compliance with TB treatment, as it is a comprehensive approach that succeeds in addressing the major issues that could have an effect on the experiences and perceptions of non-compliance of patients with TB treatment at the Nyanga Clinic.

From the literature review it is clear that TB is a complex disease where patients have various experiences and perceptions of non-compliance with TB treatment in relation to themselves as clients; the health system; social and economic factors as well as factors related to therapy which could lead to non-compliance with TB treatment.

According to the theory of Faye Abdellah (George, 2002: 173-83), consideration should be given to the individual health problems or needs of TB patients by the health care providers. Furthermore, health care providers should support patients with their problem-solving skills to enable TB patients to be adherent to their treatment in order to reach a state of wellness or health.

In Chapter Three the research methodology is discussed in terms of what was implemented to explore the patient's experiences and perceptions of non-compliance with TB treatment.

## CHAPTER 3

### RESEARCH METHODOLOGY

#### 3.1 INTRODUCTION

The goal of this chapter is to provide an overview and rationale for the research methodology applied in the study to determine patients' experiences and perceptions of non-compliance to TB treatment. 'Research methodology' refers to the process or plan for conducting the specific steps of the study (Burns & Grove, 2009:719).

#### 3.2 RESEARCH DESIGN

According to Terre Blanche, Durrheim and Painter (2007:34) a research design is the overall plan that gives the exact instructions or guidelines on how to address the research problem or answers to the research question. The rationale of a research design is to plan and structure the research project in such a way that the eventual validity of the research findings is maximised through either minimising or, where possible, eliminating potential error (Mouton, 2009:108). For the purpose of this study, the researcher focuses on the subjective experiences or views of the participants.

The researcher adopted a qualitative, explorative, descriptive and contextual design for this study.

Burns and Grove (2009: 35) explain how a qualitative research uses inductive reasoning, starting with the detail of the experience while moving towards a more general picture. These aspects of the design are discussed in detail as follows:

##### Qualitative

Qualitative research is a systematic, subjective methodological approach where the researcher seeks to establish the meaning of a phenomenon from the views of the participants (Burns & Grove, 2007: 551). Nieswiadomy (2011:46) documented that qualitative research is concerned with in depth descriptions of

people or events where non-numerical data are collected through such methods as unstructured interviews and in particular observations.

In this study the focus is to describe the patients' experiences and perceptions of non-compliance with TB treatment. The researcher is actively involved through the conducting of interviews with the participants in order to collect the non-numerical data regarding the experiences and perceptions of the participants.

Explorative

An exploratory design was relevant for this study as the researcher intended to learn more about the experiences and perceptions of non-compliant patients with TB treatment in order to have a better understanding and insight regarding this phenomenon (Babbie & Mouton, 2004:79-80).

Descriptive

The main objective of descriptive research is to accurately describe the characteristics of persons, situations, or groups and the frequency with which certain phenomena occur (Polit & Beck, 2008:752). Once the researcher has explored the perceptions and experiences of non-compliant patients with TB treatment it was necessary to accurately describe what was discovered during the semi-structured interviews.

Contextual

Research findings need to be contextualised within the parameters of the phenomenon studied. According to Babbie and Mouton (2004: 272), the aim in qualitative research is to describe and understand events within the concrete, natural contexts in which they occur.

The focus of this study is regard for the experiences and perceptions of patients' non-compliance with TB treatment within the context of the Nyanga Clinic.

### 3.3 POPULATION AND SAMPLING

Brink et al. (2006:123) define a population as the entire group of persons or objects that are of interest for the researcher and meet the criteria which the researcher is interested in for the study. Population is all the elements that meet the sample criteria for inclusion in a study and can be referred to as a target population (Burns & Grove, 2007:549). The target population for this study was all the TB patients who are non-compliant with treatment for two or more consecutive months as from March 2010 to May 2011 as indicated in the TB register of Nyanga Clinic. There were 354 non-compliant TB patients according to the TB register.

A sample is a part or fraction of a whole or a subset of a larger set, selected by the researcher to participate in a research study (Brink et al., 2006:124). According to Burns and Grove (2007:554), sampling is a process of selecting a group of people, events, behaviours or other elements that are representative of the population being studied.

Sample size in a qualitative study is determined when saturation of data occurs. According to Burns and Grove (2007: 554), saturation of information is reached when the researcher begins to hear the same information repeatedly being reported and no longer learns anything new. An actual sample size of 20 participants was achieved. This was the stage where the data collected became repetitive and redundant, such that no new information was forthcoming.

However, according to the interviews, six of the twenty participants were identified as compliant; they were therefore excluded from the study.

The participants were purposely selected out of the TB register. For the sake of the interviews, every tenth patient was selected to be included, until data saturation occurred.

Purposive non-random sampling technique was used to select the participants for the study. According to Dewar, Woodgate-Jones, Wilmot, Betts and Hand (2005:15-16) with a purposive non-random sample the number of participants interviewed is less important than the criteria used to select them. The characteristics of individuals are used as the basis of selection.

Nieswiadomy (2011:48) states that sample sizes are often quite small in qualitative research. Saturation of data is the important concept regarding sampling. Saturation can occur after interviewing 10 people, or not until after 100 are interviewed. The researcher did not know in advance how many participants were needed.

The context of this study was bound to the Nyanga Clinic in the Cape Town Metropole district of the Western Cape Province. Working at the Nyanga Clinic, she observed that the statistics of non-compliant patients to TB treatment were escalating every year at the clinic.

### **3.3.1 Inclusion criteria**

Inclusion sampling criteria is defined as sampling requirements identified by the researcher that must be present for the element or subject to be included in the sample (Burns & Grove, 2009:703).

The inclusion criteria for this study was the non-compliant patients (for two or more consecutive months) with TB treatment of the Nyanga Clinic for the period March 2010 to May 2011 as documented in the TB register. Non-compliant patients with TB treatment were included irrespective of gender, age (in which consent from a parent or guardian was obtained) and language. A purposive non-probability sampling technique was used to select the participants for the study, in which every tenth participant who, according to the TB register, was colour-coded as non-compliant with TB treatment was selected for interviewing until data saturation occurred.

### **3.3.2 Exclusion criteria**

Exclusion criteria referred to the sampling requirements identified by the researcher that eliminates or exclude an element or subject from being in a sample (Burns & Grove, 2009: 699).

The researcher excluded all patients who were sick, compliant to their treatment and those who were not willing to take part in the study.

## **3.4 INSTRUMENTATION**

According to Burns and Grove (2009:704), instrumentation is a part of the measuring process where specific rules are applied in order to develop a data-collection tool.

An interview schedule (Appendix A) for the conduction of the semi-structured interviews was developed based on the objectives of the study, the literature review and the researcher's own personal experiences for the purpose of the study. Polit and Beck (2008:756) defined an interview schedule as the formal instrument that specifies the wording of all questions to be asked of participants in structured self-report studies. The interview schedule was validated by the research supervisor of the study, peer group reviewed during the scholarly tutorial session at the University of Stellenbosch, as well as approved by the Human Resource Ethical Committee (HREC). Furthermore, a pilot test was done and revealed no pitfalls. Therefore no changes were made to the interview schedule.

Section A of the interview schedule focuses on the demographical data referring to: age, gender, home language, marital status, educational level, employment status, access to financial support, access to the clinic and reasons for default. Participants could choose the most suitable response out of predetermined responses and could comment on these issues where applicable.

Section B of the interview schedule deals with testing the participants' knowledge of TB as a disease in order to gain a better understanding regarding the experiences and perceptions of non-compliance to TB treatment. Open-ended questions referred to:

- What is TB?
- How do you think a person gets infected with TB?
- What are the symptoms of TB?
- How do you think that TB could spread to other people?
- What are your thoughts regarding the lengthy duration?
- What do you think could be the consequences of inadequate treatment?
- Mention any side-effects that you experience while on TB treatment.

According to Nieswiadomy (2011:324), in semi-structured interviews the interviewer asks a certain number of specific questions.

### **3.5 PILOT TEST**

A pilot test involves conducting a preliminary test of data collection, tools and procedures to identify the eliminate problems allowing programmes to make corrective changes or adjustments before collecting data from the target population (Burns & Grove, 2007:549).

The researcher considered it as applicable to do a pilot test in order to test the semi-structured interview schedule before conducting the main study (De Vos et al., 2005:84). One patient, who was not included in the main study, was selected at random to pre-test whether the semi-structured interview schedule stimulated in-depth discussion. The pilot test revealed no pitfalls.

### **3.6 TRUSTWORTHINESS**

Trustworthiness is equivalent to the standards of validity and reliability in quantitative research (Polit & Beck, 2008:537).

Lincoln and Guba (1985) suggested four criteria for developing the trustworthiness of a qualitative inquiry namely: credibility, conformability, transferability and dependability (Polit & Beck, 2008:539).

#### **3.6.1 Credibility**

In qualitative research, credibility and authenticity refer to internal validity (Brink et al., 2006:118). Polit and Beck (2008:538) refer to credibility as “confidence in the truth.” Furthermore, De Vos et al. (2005:346) stated that, to reach the ultimate goal of credibility is to demonstrate that the investigation was conducted in such a manner as to ensure that the subject was correctly identified and described.

The following strategies were used to ensure the truthfulness of collected data and correct data interpretation:

- Purposive sampling was used as a non-probability method to ensure that participants were selected on personal judgment in order to include the most informative ones in the study (Polit & Beck, 2008:763). Therefore, according to the inclusion criteria participants had to be the non-compliant patients for two consecutive months or more with TB treatment as documented in the TB register in the identified time frame who could share their experiences and perceptions.
- Semi-structured interviews were conducted until data saturation occurred, that is when additional sampling provides no new information, only redundancy of previous collected data (Burns & Grove, 2009:721).
- Triangulation is where more than one data method is involved to gather data to ensure the truth (De Vos et al., 2005:362). In this study types of data collected sources included a literature review which provided insights into the topic under study, in depth semi-structured interviews which were tape recorded and transcribed, field notes in order to collect data.
- Member checking is a method of validating the credibility of data through discussions with the informants (Polit & Beck, 2008:758). Member checking was done at the end of each semi-structured interview in order to ensure that they showed understanding to the questions and agreed to the accuracy of the collected data as well as after transcribing the interviews.

An experienced research supervisor was involved throughout the whole study to ensure the feasibility, content and to evaluate the research process and outcome. The research supervisor and researcher analysed the transcriptions, the written field notes and results independently. These data were sent to the office of the research supervisor after the researcher had captured and documented the data. This enabled the research supervisor to do the co-coding and to reach consensus with the researcher on the identified themes, codes and sub-themes.

### **3.6.2 Conformability**

Babbie and Mouton (2006:278) defined conformability as the degree to which the findings are the product of the focus of the inquiry and not the biases of the researcher. According to Brink et al. (2006:119), when there is an internal agreement

or congruency between the investigator's understanding and the actual facts conformability is reached.

After the researcher transcribed each participant's data, the accuracy of the transcribed data was verified by an experienced TB clinic supervisor who holds an impartial view of the study to prevent incorrect or misinterpreted data.

Furthermore, member checking was done after the interviews and the participants confirming that the transcribed data was accurate. The TB clinic supervisor listened to the recorded interviews and confirmed that the data was accurately transcribed.

Conformability was attained through the involvement of an experienced research supervisor as well, who manually, analysed the transcriptions, the written field notes and results independently. Furthermore, the research supervisor did the coding independently and compared the coding with these of the researcher. After discussion between the researcher and the research supervisor consensus was reached on the identified themes, codes and sub-themes. There were no discrepancies.

Thus, an audit trail is available to ensure that conclusions, interpretations and recommendations can be traced to their sources and to confirm that such findings are supported by their sources (Babbie & Mouton, 2004: 278).

### **3.6.3 Transferability**

Transferability is the extent to which qualitative findings can be transferred to other settings or groups; analogous to generalizability (Polit & Beck, 2008:768). According to De Vos et al. (2005:346), transferability is the alternative to external validity or generalizability, in which the burden of demonstrating the applicability of one set of findings to another context rests more with the investigator who would make the transfer than with the original investigator.

Generalisation was not the aim of the findings of this study, as only the non-compliant TB patients of the Nyanga Clinic of the Cape Metropole district were included in the study.

The researcher enhanced transferability by applying the inclusion criteria when recruiting the sample to be included in the study. The researcher tried to describe the

collected data as accurately and detailed as possible, and by using the participants' own words in support of the researcher's interpretation of the data.

The researcher collected sufficient detailed descriptions of data in context and reported with sufficient detail and precision to allow judgment about transferability to be made by the reader (Babbie & Mouton, 2006:277).

#### **3.6.4 Dependability**

Dependability refers to the techniques to show that, if the study were repeated, in the same context with the same methods and with the same participants, similar results would be obtained (Babbie & Mouton, 2004:278).

Stability of data was ensured by using an interview schedule (Appendix A) to ensure that all the interviews were done in the same manner. The tape recorded data and field notes were transcribed and analysed by the researcher and submitted to the supervisor for scrutinising of the coded data. The researcher reviewed literature to verify the findings.

### **3.7 DATA COLLECTION**

Burns and Grove (2007:536) defined data collection as the precise, systematic gathering of information relevant to the research purpose or the specific objectives, questions, or hypothesis of a study.

Semi-structured interviews were conducted and observations in the format of field notes were used as data-collection procedures.

A semi-structured interview is the interaction between the interviewer and the participant according to a list of topics to cover rather than asking specific questions (Polit & Beck, 2008:766). Interviews were conducted on a one to one basis. An experienced TB clinic supervisor undertook to translate the semi-structured interview schedule into isiXhosa before it was conducted. The interviews were conducted according to a semi-structured interview schedule (Annexure A) available in English and IsiXhosa, depending on the language of choice of the participants. The researcher confirmed that participants understood the questions. The interviews were recorded

with permission of the participants ensuring that all the data was captured accurately. Interviews were carried out in a single session which lasted approximately 15 to 30 minutes.

In addition, interviewing enabled the researcher to observe the participants' non-verbal information, for example, their tone of voice, facial expression and body language while they were narrating their stories. According to Polit and Beck (2008:754), field notes is the documentation of the unstructured observations made in the field, and the interpretation of those observations. Field notes were used together with the transcribed interviews in the data analysis.

Data acquisition was through face to face, audio taped interviews. The field notes were recorded by the researcher in a separate book and filed in a locked cupboard. Field notes must be written with regards to regularity, intensity and duration of responses, while the ideal would be to write these observations during the interview (De Vos et al., 2005: 285)

The researcher collected the data personally at the homes of the participants to enhance the conduciveness towards the study. The data was collected over a period of one month from 1 October to 31 October 2011. Twenty (20) interviews were conducted until data saturation occurred.

The researcher is employed by the Day Hospital Organisation (DHO) and the research was conducted at the TB clinic which is under the City of Cape Town Health Department. Therefore the researcher was not directly involved with the TB patients, thus preventing bias.

### **3.8 DATA ANALYSIS**

According to Burns and Grove (2007:536), data analysis is the technique used to reduce, organise and give meaning to the data.

Data analysis of qualitative studies involves the integration and synthesis of narrative non-numeric (MS Word, videotapes, audiotapes) data that are reduced to themes and categories with the aid of a coding procedure (Brink et al. 2006:55).

The quantitative data was summarised in a table format on Microsoft Word to enhance clarity and facilitate a rapid overview of the results in terms of age, gender, marital status, employment status, educational level, access to financial support, availability of a fixed address, place of treatment and access to the clinic.

The researcher analysed the qualitative data from the table manually and as a result became familiar with the feelings and expressions of the participants as described by Van Heerden (2012: 43).

During this study the audio tapes were labelled with an interview number and the date of the interview recorded on the tape before commencing with the recording of the interview.

The researcher organised and prepared the data for analysis by transcribing the tape-recorded data, the verbal responses obtained from the interviews, as well as the observations of the non-verbal cues. Data was transcribed immediately after the interviews in order not to miss any important information. The transcribed interviews were captured onto a master file on a Microsoft Word document. The researcher read and re-read the notes and transcripts and a deeper understanding of the participant's responses developed.

Different colour highlighters were used to code all the data manually on the scripts and the emerging patterns were grouped together to form themes.

The data that was collected were compared by the researcher from one participant to another to determine the final themes.

The audio tapes were locked in a safe at the researcher supervisor's residence after all the interviews in order to obtain confidentiality of patients' identities.

The data analysis was done in alignment with Tesch's (1990) coding method as described in Creswell (2009:186). This included:

- The researcher read through all the transcripts to get a general impression of the collected data and wrote down short notes as they came to mind;

- One interview was selected to read through and the researcher started writing down margin thoughts or codes that emerged from the data;
- After the researcher had completed this task for several participants, a list was made of all the codes. Similar concepts or thoughts were clustered together as sub-themes.
- Related sub-themes were grouped together and themes emerged;
- Inductive analysis was employed as the data analysis was building from particular to general themes (Creswell, 2009:4).

### **3.9 CONCLUSION**

Chapter Three discussed the research methodology. A qualitative, explorative, descriptive and contextual design was applied for this study. The participants were purposive, non-random selected out of the TB register. Every 10<sup>th</sup> patient was selected to be included. An interview schedule was used to conduct one on one interview until data saturation occurred. Compliant patients with TB treatment were excluded.

Credibility was enhanced through purposive sampling, member checking, data saturation, triangulation and the involvement of an experience research supervisor. Furthermore conformability was promoted through member checking with the participants after transcription of the interviews, the involvement of an experienced TB clinic supervisor to ensure the collection of valid information, as part of peer debriefing and the involvement of the research supervisor throughout the study.

The quantitative data was summarised in table format to enhance clarity and facilitate a rapid overview of the results.

The qualitative data analysis was done in alignment with Tesch's (1990) coding method.

A list was made of all the codes. Similar concepts or thoughts were clustered together as sub-themes. Related sub-themes were grouped together and themes emerged.

Chapter Four will present an in depth description of data analysis and interpretation of the research finding.

## CHAPTER 4

### DATA ANALYSIS, INTERPRETATION AND DISCUSSION

#### 4.1 INTRODUCTION

In this chapter the findings of the research are presented, interpreted and discussed.

#### 4.2 PRESENTATION OF THE STUDY FINDINGS

The research findings will be presented as follows:

- Demographic profile of the participants
- Codes, sub-themes and themes that emerged from the qualitative data
- Presentation, interpretation and discussion of the study findings.

##### 4.2.1 Demographic profile of the participants

Demographic information was considered important as it provides the socio-cultural descriptive background of the participants regarding the experiences and perceptions of non-compliance to TB treatment.

The findings show that the participants (N=14) were between 19 and 62 years of age. Eleven of the participants were female and three were men. Only two participants were married. The majority of the participants were unemployed; six were employed as casual labourers. Most of the participants have attended school up to the secondary level. Twelve of the participants had access to financial support. All fourteen participants had fixed addresses. All the participants had to walk to the clinic to get their treatments as there were no DOTS in place at the time of the study.

Five of the fourteen participants were re-treatment TB cases. Seven of the participants stopped their medication in the intensive phase and seven stopped their

treatment in the continuation phase. According to these participants, their treatment was not documented at the clinic.

#### 4.2.2 Codes, sub-themes and themes that emerged from the qualitative data

In the interviews several concepts emerged in codes, sub-themes and four main themes, which are predetermined from the conceptual framework, are described below in Table 4.2.

**Table 4.2: Codes, sub-themes and themes that emerged from the qualitative data**

Code	Sub-themes	Themes
- Long waiting times	- Inadequate management of waiting times	Health-related factors
Support Attitude	- Relationship with clinic staff	
Service hours	- Improving services at the clinic	
- Education to patients - Education to community members		
- Supply of medication - Treatment nearer to home	- Lack of DOTS strategy	
- TB/HIV	- Stigma	
- Hiding of diagnosis - Death	- Depression	

<ul style="list-style-type: none"> <li>- What is TB</li> <li>- Symptoms</li> <li>- Curability</li> <li>- Spread</li> <li>- Consequences of inadequate treatment</li> <li>- Healthy lifestyle</li> </ul>	<ul style="list-style-type: none"> <li>- Knowledge of TB</li> </ul>	Client-related factors
<ul style="list-style-type: none"> <li>- Gangsters</li> </ul>	<ul style="list-style-type: none"> <li>- Presence of gangsters</li> </ul>	Social and economic factors
<ul style="list-style-type: none"> <li>- Job</li> <li>- Grant</li> <li>- Food</li> </ul>	<ul style="list-style-type: none"> <li>- Inadequate finances</li> </ul>	
<ul style="list-style-type: none"> <li>- Move to the Eastern Cape</li> </ul>	<ul style="list-style-type: none"> <li>- Migration</li> </ul>	
<ul style="list-style-type: none"> <li>- Alcohol</li> </ul>	<ul style="list-style-type: none"> <li>- Alcohol abuse</li> </ul>	
<ul style="list-style-type: none"> <li>- Traditional healer</li> </ul>	<ul style="list-style-type: none"> <li>- Role of traditional healers</li> </ul>	
<ul style="list-style-type: none"> <li>- Urine colour changes</li> <li>- Painful injection</li> <li>- Dizziness</li> <li>- Deaf ears</li> <li>- Painful feet</li> <li>- Nausea</li> <li>- Skin rash</li> </ul>	<ul style="list-style-type: none"> <li>- Side-effects of medication</li> </ul>	Therapy-related factors
<ul style="list-style-type: none"> <li>- Combination with ARV treatment</li> </ul>	<ul style="list-style-type: none"> <li>- Heavy pill burden</li> </ul>	
<ul style="list-style-type: none"> <li>- Bored</li> </ul>	<ul style="list-style-type: none"> <li>- Lengthy duration of treatment</li> </ul>	

### **4.2.3 Presentation, interpretation, and discussion of the findings**

Findings are presented and discussed according to the identified themes and codes that emerged from the analysis of the collected data summarized in table 4.2. All fourteen (14) of the participants were Xhosa speaking. The researcher used verbatim quotes and identifiers to maintain the accuracy of the participants' responses.

#### **4.2.3.1 Theme 1: Health system factors**

This theme is concerned regarding the health department. The researcher divided this theme into subthemes.

The purpose of this theme is to determine the experiences and perceptions encountered by participants regarding the health sector while taking their treatment. Each subtheme is discussed according to the codes, with regard to the responses by the participants.

##### **4.2.3.1.1 Subtheme: Inadequate management of waiting times**

- **Code: Long wait**

When the participants were probed regarding the reasons for defaulting, only two of the participants experienced and perceived waiting time as too long.

“Silinda ixesha elide. Andikwazi ukulinda ixesha elide ngoba ndinomntwana ekufuneka ndimse eChreche.”

[We wait a long time. I can't wait long because I have a child that I must take to the crèche (Participant 5)].

“Ndilinda ixesha elide eklinik ukuze ndifumane unyango. Ndixakeke kakhulu ukuya kulinda phaya ngoba kusoloko kugcwele ngabantu yaye andikwazi ukuya emva kwemini ngoba lixesha lezigulane ezine MDR, ndaxelelwa lonto.”

[I am waiting a long time in the clinic to get my treatment. I am very busy to go and wait there because it is always full and I cannot get there in the afternoon it is the time for all MDR patients that is what they told me. (Participant 12).]

These two participants experienced waiting time at the clinic as too long.

#### 4.2.3.1.2 Subtheme: Relationship with the clinic staff

- **Code: Support and attitude**

Almost all of the participants experience the support and attitude of the clinic staff as good. The following illustrates this:

“Uhoyo ngakubasebenzi eklinik alulubi kwaphela.”

[Support of the staff at the clinic is not bad at all. (Participant 1).]

“Uhoyo lwabo lulungile kakhulu, ngaphandle nje kokuba ndingxoliswa kuba ndingezi eklinik rhoqo.”

[Their support is good, except that they kept on shouting at me because I am not attending the clinic regularly. (Participant 4).]

According to the researcher, the behaviour of staff could also be experienced as disempowering at times when staff “shouted” at patients.

“Ndiyafumana uhoyo ekliniki kodwa ndisoloko ndixelelwa ukuba unyango lwam andiluthathi kakuhle.”

[I get support from the clinic but I’m always told I’m not taking treatment (Participant 9, line).]

This participant suggested that staff were confused about who was taking their treatment or not.

Studies have found that compliance is good when health care providers are emotionally supportive, give reassurance or respect and treat patients as equal partners (Jin et al., 2008:277). Furthermore, results of the study of Gebremariam et al. (2010:5) showed that the majority of patients were happy about the way health professionals received and treated them at the health centres. Some participants said that they were encouraged to go for treatment because health professionals received them with a “good face” and encouraged them to finish their treatment.

#### 4.2.3.1.3 Subtheme: Improving services at the clinic

- **Code: Extra staff**

During the interviews the participants were asked about how the clinic staff can improve their services at the clinic. Some of the responses were as follows:

“kunyanzeleke kufumaneke abanye abasebenzi ukunceda aba bangakwaziyo ukuziyela ekliniki.”

[Extra staff is needed to give us treatment at home for those who cannot walk to the clinic” (Participant 1).]

“kuzanywe kongezelelwe abasebenzi kwicala leTB.”

[To organise more staff at the TB side.(Participant 7).]

“kufuneka kongezwe abasebenzi ukuphelisa ukugcwala kwezigulane.”

[More staff is required to prevent overcrowding of patients (Participant 12).]

“kufuneka abasebenzi bongezwe ngoba inani lwabaguli lunyika ngenxa yeHIV.”

[There need to be more staff because the number of patients is increasing due to HIV (Participant 15).]

“makuzanywe abongikazi abaliqela”

[Try to get more nurses (Participant 17).]

Findings showed that there is a need for more staff, both to deliver treatment at the homes of patients and at the clinic to give better support to the TB patients.

- **Code: Service hours**

Research results of this study showed that several participants experienced problems with the hours of services at the clinic.

Participants claimed that the clinic opened at eight o'clock.

“Makwenziwe ngcono iinkonzo ngabasebenzi, umzekelo kuhlolwe amaxesha omsebenzi wabasebenzi ukuze isigulane zingabinazingxaki ngeenkonzo.”

Services must be improved, for example time off and on duty of staff must be evaluated so that patients cannot experience the problems regarding services times. (Participant 2).]

“iiyure zokusebenza ubuncikane ziqale ngentsimbi yesixhenxe kusasa kunokuba kusenzeka ngentsimbi yesibhozo ukuze ndikwazi ukudibana nogqirha ndihambe ndiye emsebenzini wam.”

[The hours of working: at least starting at 7 am instead of 8 am so that I can manage to see the doctor and go to work. (Participant 17).]

“iiyire mazandiswe.”

[By extending hours. (Participant 11, line 76).]

Participants identified that extending the hours of service at the clinic was a way of improving services.

- **Code: Education of patients**

Some of the participants had comments regarding the lack of health education of the patients:

Umongikazi makasinike ulwazi ngeTB.

[Nurse must give us education about TB. (Participant 4).]

“Xa ndithatha unyango lweTB ndiyagabha yaye umbala womchamo wam uyajika.”

[When I take the TB treatment, I vomit and my colour of urine changes, (Participant 4).]

“Eyona nto ndinokuxelela yona kukuba unyango lweTB lwenza iindlebe zam zingeva. Andazi nokuba lonto ngeyomzuzwana okanye ngumphelo.”

[The only thing I can tell you nurse is that the TB treatment makes my ears feel deaf. I am not sure if this is temporary or permanent. (Participation 16).]

A few participants identified that there is a lack of health education provided for patients of what to expect when taking the treatment.

The study of Muture et al. (2011:5) reported that unfavourable system factors were cited as reasons for default. These included the unavailability of drugs; failure by health care workers to offer health education and explain the need for treatment compliance as well as failure to appropriately manage drug side-effects. Some patients reportedly stopped medication because of adverse effects, while others reported that they were not informed about side-effects and how to counter them (Munro, 2007:1239).

- **Code: Education of community members**

Two participants reported having problems in the community.

“Abongikazi mabanike abahlali ulwazi malunga neTB.”

[They must give health education to the community members about TB.” (Participant 6).]

“zange ndixelelele mntu malunga nesisigulo ngoba abanye abantu abawazi umahluko phakathi kweTB neHIV.”

[I never told anyone about the disease because people do not know the difference between TB and HIV. (Participant 2).]

“Kungcono ndisifihle isigulo sam kuba abantu bathi ndineTB enkulu okanye ndi HIV positive.”

[I better hide my diagnosis because people are saying that I have a big TB and others say that I am HIV positive. (Participant 19).]

This is consistent with reported published findings. According to Courtwright and Turner (2010:125), TB is also stigmatized because of its associations with HIV. Where community members do not have the knowledge to differentiate between TB and HIV, there can be negative influences for TB patients, as expressed by participants in this study.

Xu et al. (2009:169) reported from their research that the attitude of the community members towards the disease may lead those with TB to hide the disease. Ayisi et al.

(2011:8) reported in their study that a small proportion of their participants expressed how they were treated as though they had HIV due to their cough and mass wasting.

#### **4.2.3.1.4 Subtheme: Lack of DOTS strategy**

- **Code: Supply of treatment nearer home**

Some of the participants preferred to receive their treatment nearer home.

“Ukuba ndinokufumana unyango lwam kufutshane nekhayaokanye udadobawo aye kundilandela, ndingaluthatha rhnoqo unyango.”

[If I can get my treatment near home or my aunt can fetch it for me then I would take it regular. (Participant 1).]

“kungu kungafumaneka umsebenzi wezempilo usinike unyango lwethu emakhaya sise siye kanye ngenyanga eklinik.”

[At least to get a health worker to give us the treatments at home then go to the clinic once a month. (Participant 19).]

Currently, all the participants walk to the clinic on a daily basis to collect their treatment. There is a lack of DOTS strategy at the clinic. A few participants identified the need of getting their treatment nearer to home instead of travelling to the clinic every day.

James and Watson (2010: 494) identified non-compliance was a major problem in treating patients with TB and stated that patients who are supported by the DOTS strategy had the best compliance rate. In an evaluation done in KwaZulu-Natal, South Africa the poor implementation of DOTS was associated with poorer TB outcomes (Finlay et al. 2012:9).

The overall conclusion of Theme 1 concerning the Health system factors develops from Abdellah's theory. For the total needs of the patients regarding the above mentioned codes, there is a need for an appropriate course of action to be taken to tackle them.

#### 4.2.3.2 Theme 2: Client-related factors

##### 4.2.3.2.1 Subtheme: Stigma

- **Code: TB/HIV hiding of diagnosis**

People suffering from TB are inclined to hide their diagnosis because people tend to associate TB with HIV.

Two participants reported this:

“Kungcono ndisifihle isigulo sam kuba abantu bathi ndineTB enkulu, abanye bathi ndineHIV.”

[I better hide my diagnosis because people are saying that I have a big TB and others say I am HIV positive. (Participant 19.)]

“Azange ndixelele mntu ngesigulo sam kuba abanye abantu abawazi umahluko phakathi kweTB kunye ne HIV.”

[I never told anyone about my disease because people do not know the difference between TB and HIV. (Participant 2).]

According to Dodor and Kelly (2009:170) one major setback to the success of TB control globally is the stigma attached to the disease. Stigma related to TB was supported by the study of Khan et al. (2006:213) stating that half of the participants were of the opinion that being infected with TB reduced their chances of getting married.

##### 4.23.2.2 Subtheme: Depression

- **Code: Death**

Patients become depressed because of the disease which could be a cause of poor compliance. One participant stressed this:

“Bathe kum imiphunga yam ayisebenzi kakuhle esibhedlele. Kubhetele ndingabisaluthatha unyango ngoba ndisakufa.”

[They told me that my lungs aren't functioning well at the clinic. I rather not take treatment because I'm going to die anyway." (Participant 4).]

In the study done by Issa et al. (2009:133) TB is associated with psychiatric morbidity, particularly a depressive disorder. Furthermore, Sulehri et al. (2010:133) concluded in their study that 80% of patients with TB were suffering from depression.

#### **4.2.3.2.3 Subtheme: Knowledge of TB**

- **Code: What is TB?**

During the interviews the participants were asked: What is TB? They reported as follows:

"iTB sisifo esonakalisa imiphunga"

[It is a disease that affects the lungs." (Participant 1).]

"iTB kukungcola okonakalisa imiphunga kunye namanye amalungu omzimba."

[It is a germ that affects the lungs and other parts of the body." (Participant 2).]

"Yintsholongwane esemoyeni eyosulelayo."

[It is a germ that is in the air and is infectious. (Participant 5).]

"Yintsholongwane engumbulali eyosulela imiphunga."

[It is a killer disease that affects the lungs. (Participant 6).]

Almost all the participants are knowledgeable regarding what is TB.

However, according to Maarmari (2008:543) it was shown that the main reason for a delay in seeking care was hoping that symptoms would resolve without treatment (30%). Long patient delay was significantly associated with inadequate knowledge regarding the disease, seeking care at non-specialised individuals (not a health care provider) initially and having more than one health care encounter before diagnosis.

- **Code: Symptoms**

During the interviews the participants were asked to identify the symptoms of TB. Their responses included:

“Ukukhohlela ngapha kweveki ezintathu, ukubila ebusuku nokungabina mdla wokutya.”

[Coughing more than three weeks, night sweating and loss of appetite.(Participant 8).]

“Iimpawu zeTB kukudinwa, ukuqaqanjelwa sisifuba, ukukhohlela kugqithe iiveki ezimbini, ukuphelelwa ngumdla kunye nokubila ebusuku.”

[Symptoms of TB are tiredness, chest pain, coughing for more than two weeks, loss of appetite and sweating at night.” (Participant 10).]

The overall finding was that the participants were able to identify the symptoms of the disease as night sweat, loss of appetite, loss of weight and coughing for more than three weeks.

Patients with a limited knowledge of TB were more likely to have severe TB disease, as well as limited knowledge regarding HIV. (Jittimane, Nateniyom, Kittikrasak,, Burapat, Akksilp, Chumpathat, Sirinak, Sattayawuthipong & Varma, 2009:1).

- **Code: Curability**

Participants were tested on the curability of TB during the interviews. Perceptions and views of the participants included:

“Iyanyangeka”

[It’s curable. (Participant 1).]

“Iyanyangeka”

[It’s curable.] (Participant 11).]

“Iyanyangeka xa usitya unyango”

[It’s curable when treatment is taken. (Participant 12).]

“Iyakwazi ukunyangeka xa unyango lutyiwa rhoqo”

[It can be cured when treatment is taken regularly. (Participant 17).]

“Andiqinisekanga’.”

[I am not sure. (Participant 10).]

“Andiyazi.Bendixelelwe ukuba manditye unyango iinganga ezintandathu eklinik.”

[I don't know, I was only told to take treatment for 6 months at the clinic.] (Participant 13).]

The majority of the participants were informed about the curability of TB, especially when taking their treatment regularly. A few of the participants were unsure about the curability of TB.

- **Code: Spread of TB infection**

The participants were asked how they think TB could spread to other people. Participants expressed their understanding as follows:

“Ngokungathathi unyango rhoqo, isifo sisakunaba.Ukuzamla nokukhohlela ungawugqumanga umlomo naxa iifestile zingavalwanga kungabangela esisigulo sinabe.”

[By not taking treatment regularly the disease could spread. Sneezing and coughing without covering your mouth and when the windows are not kept open the disease could spread.” (Participant 2).]

“Ukuba andiluthathi unyango, esisifo singanaba siphumele kwabanye abantu.”

[If I am not taking my treatment then it can spread to other people.” (Participant 13).]

“Ukuba ndiyakhohlela ndingawugqumi umlomo, ndingamsulela omnye umntu.”

[If I cough and not cover my mouth, I can infect someone. (Participant 17).]

From the respondents it was clear that the majority of participants were informed regarding the spread of TB as a disease.

However, according to Berger and Bratu (2006:100) it was shown that patients incorrectly identified the possible paths of TB transmission. For instance, 24% of patients incorrectly stated that TB could be transmitted by touch. Furthermore, when asked specifically how the patient contracted TB, more than half thought that they got it from a cold/flu. Less than half (46%) believed their TB was due to contact with a sick person.

- **Code: Consequences of inadequate treatment**

According to Muture et al. (2011:7) patients should on diagnosis receive: sufficient explanation of their disease and be made to understand the treatment requirements, the likely side-effects to be encountered when using anti-TB drugs and the need to comply with the treatment.

When participants were tested on the issue of what were their thoughts on the consequences of inadequate treatment, the following responses were given:

“Ndicinga ukuba ndingakhula iXDR neMDR.”

[I think I can also develop XDR and MDR. (Participant 2).]

“Andiyazi.”

[I do not know. (Participant 10).]

“Ukugula ngakumbi.”

[To get sicker.”(Participants 11).]

“Andisokunyangwa.”

[I will not be cured. (Participants 13).]

Overall, the responses showed that participants are aware that curability is related to adequate treatment. The majority of participants are aware that MDR and XDR could follow as a result of inadequate treatment. Only a few participants are unaware of the consequences of inadequate treatment.

- **Code: Healthy lifestyle**

According to the Primary Care Partnership Council (2009:2) the concept of a healthy lifestyle is about how people are able to become and stay healthy, rather than waiting to respond when people are already unwell.

Participants expressed their perceptions regarding a healthy lifestyle in the following ways:

“Impilo entle ingongeza uxabiseko ngokuthatha isiqhamo nemifuno ndingathathi utywala.”

[A healthy lifestyle could add value by taking fresh fruit and vegetables, a well-balanced diet and not to take alcohol. (Participant 2).]

“Ingongeza uxabiseko xa ndisitya ukutya okunempilo ndenze i-exercise ndiyeke ukutshaya.”

[It could add value if I eat healthy food, exercise and stop smoking. (Participant 3).]

“Impilo entle ilungile ivuselelela ukuphila ngokuthatha isiqhamo ezifresh phambi kokuthatha unyango.”

Healthy lifestyle is good; it promotes healing and taking fresh food before treatment. (Participant 7).]

“Andinalwazi.”

[I do not know. (Participant 10).]

“Inako ukongeza uxabiso xa ndinokuyeka ukutshaya nokusela utywala.”

[It can, especially when you stop drinking alcohol and smoking. (Participant 15).]

“Ngokuyeka ukutshaya xa ndithatha unyanga ingongeza uxabiseko.”

[By stop smoking while taking treatment can add value. (Participant 16).]

Most of the participants agreed that a healthy life style could add value while taking TB medications, although a few did not know. Participants described lifestyle in terms of healthy food, exercising and to stop smoking and drinking alcohol.

Abdellah's theory which recognises the nursing problems of the patient should be applied to the above codes since some participants have identified nursing problems such as the lack of health education and the consequences of inadequate treatment.

#### **4.2.3.3 Theme 3: Social and economic related factors**

##### **4.2.3.3.1 Subtheme: Presence of gangsters**

- **Code: Gangsters**

The Oxford Advanced Learner's Dictionary (2010:616) describes the concept gangster as a member of a group of violent criminals.

One of the participants described his reason for defaulting TB treatment as follows:

“Ndiyoyika ukuya eklinik ngoba ndiyiGangster.Ndifumana ingxaki ngokuya eklinik ngenxa ye-gangsters andiyi nasesikolweni, andazi ndisokuthini.Ndiyazi ukuba iTB iyosulela kodwa ingxaki zii-gangsters zisakundibulala kungcono ndihlale ekhaya.”

[I am scared of going to the clinic because I am a gangster. I am experiencing a problem going to the clinic due to the presence of gangsters. I do not attend even school. I do not know what I can do. I know that TB is an infectious disease but the problem is the gangsters will kill me. I would rather stay at home.” (Participant 1).]

According to this participant the presence of gangsters in the area of the Nyanga Clinic could lead to TB defaulting as the participant is too afraid to go to the clinic.

It is estimated that 150 000 people belong to 100 gangs on the Cape Flats. Some gangs date back to the 1940's. The culture and scale of gangs are unique to the Western Cape, which demands a unique approach to crime (Joubert, 2007:1). Furthermore, according to *Sowetan Live* (2012:2) at least 23 people, including seven children, have died in the area as a result of gang violence in recent months. Premier Helen Zille wrote a letter to President Jacob Zuma at the time of writing to ask for the army to be deployed to Lavender Hill and Hanover Park.

##### **4.2.3.3.2 Subtheme: Inadequate finances**

- **Code: Job, grant and food**

Most of the participants did not have employment. A few have work as casual labourers and the remaining participants survive on access to disability and child support grants in order to get food. Only one participant is self-employed.

“Ndisebenza manqapha-nqapha.Ndifumana inkamnkam.

[I am a casual labourer. I am getting financial support through disability grant. (Participant 3).]

“Andisebenzi, andinamali.”

[I am not working, no financial support. (Participant 7).]

“Ndiyazisebenzela, ndithengisa ukutya.”

[I am self-employed, selling groceries. (Participant 9).]

The results of a prospective cohort study conducted by Okanurak et al. (2008:1160) showed that patients with regular earnings had twice the likelihood of success of treatment compared to the unemployed. Being unemployed, a pensioner, an alcoholic and being homeless were related with default, according to Hasker et al. (2008:1).

#### **4.2.3.3.3 Subtheme: Migration**

- **Code: Move to Eastern Cape**

Changing of residence during TB treatment may lead patients to miss their treatment.

“Ndaswelekelwa ngumama emaxhoseni.Kwanyanzeleka ndiyokuhlala khona ndiyokujonga ikhaya. Khange ndikwazi ukuqhubekeka nonyango pha.”

[I lost my mother at the Eastern Cape. I had to migrate to the Eastern Cape to take care of her house. I couldn't continue with my treatment when I get there.” (Participant 8).]

The study of Jaggarajamma et al. (2005:35) showed that migration was a significant factor for treatment default.

#### **4.2.3.3.4 Subtheme: Alcohol dependency**

- **Code: Alcohol abuse**

Some TB patients are alcohol dependent. Three participants reported:

“Kutheni mongikazi uzihlupha ngokujongana nam?Ndim umntu ogula yiTB.Ndiyakucela undiyeke kuba ndim osela utywala.”

[Why,Nurse, do you bother looking after me? I am the one who is suffering from TB. Please leave me alone because I am the one who is taking alcohol.” (Participant 10)].

“Nam ndikhathazekile ngesisifo, ngoku ndisama ukuzinceda ngokusela utyala.”

[I am also stressed due to this disease, now I am trying to destress by taking alcohol.” (Participant 14).]

“Ndaziva ndiphelelwa ngamandla, ndikwasela notywala.Ngoku ndiphela ndilibala ukuthatha unyango lwam.”

[I felt weak and I am taking alcohol. So, I would forget to take treatment. (Participant 19).]

Jaggarajamma et al. (2007:134) showed that alcohol was an important predictor of non-compliance in India and in different parts of the world. According to Finlay et al. (2012:19), alcohol is associated with default among new TB patients. Several studies about compliance found that patients who smoked or drank alcohol were more likely to be non-compliant (Jin et al. 2008:278).

#### **4.2.3.3.5 Subtheme: Role of traditional healers**

- **Code: Traditional healer**

Traditional healers could influence TB adherence.

One participant reported:

“Utata wandithumela kwiXhwele ecinga ukuba lisoyinyanga leTB, ke ndaya ndahlala pha iiveki ezintathu ngaphandle konyango lwam.Azange ndibengcono.”

[My father referred me to a traditional healer whom he believed may cure my TB, so I went there and stayed three weeks without my treatment. I never get better. (Participant 14)]

According to Dodor and Kelly (2009: 829 - 831) alternative treatment can contribute to a negative impact on treatment outcomes, for example: the use of traditional medicine while taking the TB treatment leads to the substitution of drugs. Furthermore, results in a study by Ayisi et al. (2011:5) showed that those who attributed their TB to a curse or witchcraft contacted spiritual healers. A report by Haasnoot, Boeting, Kuney & van Roosmalen (2010:902), showed that the Maasi population believed TB was a punishment from god and was treatable with herbs, roots and bark. The report showed that traditional healers acted as family doctors and played a key role in TB treatment and adherence (Op.cit.).

Abdellah's theory provides continuous care to relieve discomfort and provide immediate security for the individual, for example the presence of gangsters in the area of the Nyanga Clinic may lead to TB defaulting to those individuals affected by gangsterism.

#### **4.2.3.4 Theme 4: Therapy-related factors**

##### **4.2.3.4.1 Subtheme: Side-effects of medication**

According to the WHO (2003:124), the number of tablets that need to be taken, as well as their toxicity and other side-effects associated with their use may act as constraining factors for the continuation of treatment.

Participants reported the following side-effects:

- **Code: Urine colour changes**

“Xa ndisitya unyango lwam ndiyagabha nomchamo ujike umbala.”

[When I take my treatment I vomit and my urine colour changes. (Participant 4).]

- **Code: Painful injection**

“Ndiyayoyika inaliti.Ibuhlungu kakhulu futhi indikhupha amaqhakuva ezimpundu.”

[I am scared of the injection. It is very painful and it makes lumps on my buttocks. (Participant 5).]

- **Code: Dizziness**

“Isiyezi namaqhakuva emzimbeni.”

[Dizziness, nausea and skin rash.(Participant 6).]

“Ukuqaqanjelwa ngamathambo, ukudinwa kunye nokuba nesiyezz.”

[Painful joints, tiredness and dizziness. (Participant 10).]

- **Code: Deaf ears**

“Ukungeva”.

[Loss of hearing (Participant 5).]

“Inye into endinokuxelela yona mongikazi: unyango lwam lweTB lwenza ndingeva. Andazi nokuba ikho okwexeshana okanye yinto ezokuhlala ikhona kum, ndikhathazekile ngalento”

[The only thing that I can tell you nurse is that the TB treatment makes my ears feel deaf. I am not sure if this is temporary or permanent, I am concerned about this. (Participant 16).]

- **Code: Painful and swollen feet**

Ndinenyawo ezibuhlungu.”

[I have painful feet. (Participant 1).]

“Ukudinwa neenyawo eziqaqambayo.”

[Tiredness, feeling weak and painful feet.(Participant 8).]

“Ndiyoyika ukuthatha unyango lwam lweTB ngoba iinyawo zam ziyadumba zibebuhlungu.”

[I am scared of taking TB treatment because my feet became swollen and painful. (Participant 15).]

“Ukuba neenwayo ezibuhlungu kunye nokuba nesiyezi.”

[Feet pains, nausea and loss of libido. (Participant 17).]

- **Code: Nausea**

“Amaqhakuva emzimbeni nesiyezi.”

[Skin rash and nausea.(Participant 2).]

“Andinalwazi oluninzi ngaphandle kokuba ndiyagabha xa ndigqiba ukutya unyango ngoba lunintsi.”

[No experience except vomiting after taking treatment, because it's a lot. (Participant 7,).]

“Ukuba nesiyezi namaqhakuva emzimbeni.”

[Nausea and skin rash.(Participant 15).]

“Isiyezi kunye nokungeva ngamanye amaxesha.”

[Nausea and temporary loss of hearing.(Participant 16).]

“Ukuqaqanjelwa ziinyawo nokuba nesiyezi”

[Feet pains, nausea and loss of libido. (Participant 17).]

“Isiyezi.”

[Nausea.(Participant 18).]

“Isiyezi, ukudinwa nokulamba.”

[Nausea, tired and hungry.(Participant 20).]

- **Code: Skin rash**

“Amaqhakuva emzimbeni kunye nesiyezi.”

[Skin rash and nausea.(Participant 2).]

“Isiyezi, ukugabha namaqhakuva.”

[Nausea, vomiting, skin rash and dizziness.(Participant 3).]

“Amaqhakuva omzimba.”

[Body rash.(Participant 4).]

“Isiyezi namaqhakuva omzimba.”

[Disziness, nausea and skin rash.(Participant 6).]

“Isiyezi namaqhakuva omzimba.”

[Nausea and skin rash.(Participant 15).]

The majority of participants experienced side-effects. Only two participants reported no side-effects. Nausea was the side-effect of which the majority of participants complained.

Side-effects of the drugs may act as a constraining factor for the continuation of treatment.

In the study of Muture et al. (2011:6) side-effects of medication were cited as the reason for default by 10.8% patients. Side-effects were experienced by more than half of the participants, mainly at the beginning of TB treatment or upon initiation of concomitant treatment (Gebremariam et al., 2010:4).

#### **4.2.3.4 Subtheme: Heavy pill burden**

- **Code: Together with ARV treatment**

Pill burden is also a major challenge of concomitant treatment.

One participant told the researcher that:

“Ndifikelele kwisigqibo sokuba ndiyeke ukuthatha olunyango lweTB ngoba ndisathatha neeARVs.Ziyandoyisa, ngamanye amaxesha ndiye ndigabhe ngokusela iipilisi ezinintsi.”

[I have decided to stop taking these drugs because I also take ARVs. They are too much for me. I sometimes vomit from taking lots of pills. (Participant 7).]

Gebremariam et al. (2010:4) have shown that patients refer to pill burden as being one of the major challenges of concomitant treatment and they used expressions such as “becoming a drug bag and becoming a pharmacy.” In addition, Padmapriyadarsini et

al. (2011:850); Swaminathan et al.(2010:1377) reported from their study that the treatment of co-infected patients requires anti-TB and anti-retro viral drugs to be administered alongside; challenges include pill burden and patient compliance.

#### **4.2.3.4.3 Subtheme: Lengthy duration of treatment**

- **Code: Boredom**

The lengthy duration of treatment remains one of the major obstacles to compliance.

At least three participants experienced a problem regarding the lengthy duration of treatment.

“lide kakhulu.”

[Too long(Participant 9).]

“Iinyanga ezintandathu zinintsi kakhulu, kodwa ndisokulithatha olunyango kude kuthiwe mandipheze.”

[Six months is too long, but I'll take my treatment until I am discharged. (Participant9).]

“Ndilutye unyango lwam rhoqo iinyanga ezimbini ndade ndadikwa emva kokuba umongikazi endixelele ukuba ndisokuqhubeka nolunyango iinyanga ezintandathu.”

[I took my treatment regularly for 2 months and I got bored after the health worker told me that I'll be taking my treatment for six months. (Participant 18).]

According to the study of Mwinga and Fourie (2004:827), effective treatment and management of TB cases tend to suffer, not only because of additional direct expenditure on drugs but also because of the long duration of treatment (six to eight months) that is required to cure patients. Bam et al. (2005:55) reported that studies done in Malawi and Vietnam showed that insufficient knowledge and duration of treatment were the main obstacles to compliance.

The overall conclusion of theme 4 concerning Therapy related factors is formed from Abdella's theory which recognises the nursing problems of the patients and providing continuous care of the individual's total needs for example the lack of health education regarding the side effects of the medication and the lengthy duration of the treatment were identified by the researcher as nursing problems.

### **4.3 CONCLUSION**

In this chapter the data collected during the interviews was analysed, interpreted and discussed. The data was transcribed and coded according to Tech's model. Subthemes and themes emerged from the interviews.

According to the experiences and perceptions of non-compliant TB patients with treatment, the reasons why they were non-compliant with their treatment was identified namely:

- poor management of TB programmes which leads to the lack of knowledge about side effects of the TB drugs,
- the lengthy duration of the TB treatment,
- the lack of DOTS strategy at the clinic,
- alcohol dependency of the patients,
- unemployment,
- migration of the patient from one province to another,
- the long waiting times of the patients to receive the treatment and
- the substitution of TB treatment with traditional medicine.

In Chapter Five certain limitations of the study will be described, the final conclusions drawn and recommendations will be made.

## CHAPTER 5

### CONCLUSIONS AND RECOMMENDATIONS

#### 5.1 INTRODUCTION

This chapter summarises the findings of the research based on the scientific evidence, obtained during this study. The limitations are briefly discussed in this chapter. Recommendations from the outcomes of this study are also presented.

#### 5.2 CONCLUSIONS

The conclusions derived from the study are based on the findings yielded from the interviews with participants at the Nyanga Clinic in the Cape Metropole district of the Western Cape Province regarding the experiences and perceptions of non-compliant patients to TB treatment. These include their attitudes about TB treatment and their knowledge and reasons why they are not compliant to treatment. A summary of the findings follows.

##### 5.2.1 Theme 1: Health-related factors

Almost all the participants were positive regarding the attitude and support from the staff. Some of the respondents highlighted that extra staff could improve the services. Incomplete documentation regarding the regular taking of treatment was identified as a shortcoming for the participants. Furthermore, results showed that the supply of treatment nearer to the homes of the TB patients could be of value, instead of receiving daily treatment at the clinic because this may lead them sometimes not to comply with their treatment. In addition, the results showed that educating the community was seen as a need to reduce the non-compliance rate. Only a few participants experienced the waiting time as too long. Currently all the patients have to walk to the clinic and most of them therefore become non-compliant when they are not willing to walk to fetch the treatment.

Health education about TB for patients on TB treatment is very important. The study of Fatiregun et al. (2009:100) confirmed that patients with a poor knowledge of TB had a higher risk of having poor treatment outcomes compared to those with a good knowledge thereof.

According to the report of the participants, there was no DOTS strategy for the patients to get their treatment nearer home; hence one participant reported that because of gangster activity he could not go to the clinic resulting in non-compliance.

### **5.2.2 Theme 2: Client-related factors**

According to the study by Xu et al. (2009:169), the findings showed that the stigmatising attitudes and behaviours of the community members towards the disease may lead those with TB to hide the diagnosis from others and to default from treatment.

Two of the participants indicated that despite having TB, they also experienced a problem of stigma attached to it. Community members could not always differentiate between TB and HIV. These two factors have caused these participants to be non-compliant with their treatment.

TB patients are well aware that the infection could spread due to treatment not being followed regularly. In addition, they are aware that by coughing and sneezing without covering their nose and mouth, and by not adhering to the open window policy. While the majority of the participants knew that TB is curable, a few participants did not know about the curability of the disease and that may affect their compliance with the treatment negatively.

The majority of the participants acknowledged the value of a healthy diet and the importance of stopping alcohol usage and tobacco smoking.

According to the findings in Chapter Four, community members lack knowledge about TB, resulting in patients suffering from stigma and refusing to take treatment because they do not want to be identified as TB sufferers. Consequently they became non-compliant with treatment.

### **5.2.3 Theme 3: Social and economic factors**

During this study, most of the participants were unemployed. A few participants worked as casual labourers. Most of them survived through access to child support and disability grants.

TB drugs should be taken with food to avoid nausea and other side effects. Due to high levels of unemployment among patients, many experienced difficulties with being able to buy food and many also had challenges with travelling to the clinics. These problems contributed to their non-compliance with the TB treatment.

Only one participant indicated that she had to migrate to another province to take care of her home and she discontinued her treatment because she was far from the clinic. Furthermore, one participant underwent traditional healing and did not comply with his medical TB treatment; after feeling physically unwell he accessed medical TB care again.

The use of traditional medicine as a substitute for the treatment causes non-compliance, as with participant 14, which is a social and economic factor.

### **5.2.4 Theme 4: Therapy-related factors**

One participant pointed out that he experienced the heavy pill burden as a challenge and as a result, he had stopped taking the treatment. The heavy pill burden is a challenge to patient compliance.

The majority of the participants experienced side-effects of the TB treatment.

During the study the researcher identified that the participants lacked a full knowledge of the side-effects of the drugs. Many side-effects of the TB treatment were not known to the participants. The lack of knowledge about the side-effects caused them to be non-compliant with their treatment.

Bam et al. (2005: 55) indicated in their study of the factors responsible for non-compliance among TB patients in Nepal that patients who did not know about potential side-effects of medicines were more likely to default. Severe side-effects of medication caused the patient to require an extra clinic visit to try and resolve physical discomfort,

unnecessary distress or worsening symptoms. These factors could increase the likelihood of treatment default (Jittimannee et al. 2007:358).

The long duration of treatment was also mentioned by participants because they were not aware of the duration of the TB treatment. Longer duration of the disease treatment may adversely affect compliance (Reyes-Guillen, Sanchez-Perez, Cruz-Burguete & Izaurieta-de Juan, 2008:255; Menzies, Jahdali & Otaibi, 2011:258). The major causes of non-compliance to anti-TB drugs include unpleasant side-effects of multiple medications (Joshi, Hussain, Hasan & Biswas, 2010:163-1640).

### 5.3 OBJECTIVES REACHED

The summarised details are presented alongside the specific objectives of this study.

**Table 5.1: Content concerning the outcomes according to each study objective**

OBJECTIVES	OUTCOME
To determine the experiences and perceptions of non-compliance with TB treatment among patients.	<p>Through the collected information, themes were identified according to patients' experiences and perceptions regarding health-, client-, socio- economic and therapy-related factors.</p> <p><input type="checkbox"/> Health system factors: Some participants experienced long waiting times at the clinic as a reason for their non-compliance with the treatment because they did not want to wait long [section4.2.3.1.1]. Since the clinic did not have a DOTS strategy in place at the time of the study, the participants had to walk to get to the clinic and those who were sick did not have money to take public transport [section 4.2.3.1.4]. The participants reported that their relationship with the health care workers was</p>

	<p>good [section 4.2.3.1.2].</p> <p><input type="checkbox"/> Client-related factors: Some participants reported that they lacked knowledge regarding TB [section 4.2.3.2.3]. The participants felt depressed about the disease and they became non-compliant with the treatment by not taking the treatment [section 4.2.3.2.2].</p> <p><input type="checkbox"/> Socio-economic factors: Most of the participants were unemployed, so they suffered from poverty and could not take their treatment without food. They also lacked financial support from their families [section 4.2.3.3.2]. Other participants were alcohol-dependent and did not take their treatment regularly because they were always drunk [section 4.2.3.3.4].</p> <p><input type="checkbox"/> Therapy-related factors: The participants experienced the duration of treatment as too long [section 4.2.3.4.3]. Some stopped taking their treatment after the symptoms have subsided.</p>
<p>To determine knowledge of non-compliant patients with TB treatment.</p>	<p><input type="checkbox"/> Participants had little knowledge regarding side-effects of the drugs and the longer duration of treatment [section 4.2.3.4.1].</p>
<p>To determine the reasons why patients are not compliant with TB treatment.</p>	<p><input type="checkbox"/> Some of the participants were alcohol dependent [section 4.2.3.3.4]</p> <p><input type="checkbox"/> Changing of residence during TB treatment may lead patients to miss their treatment. [section 4.2.3.3.3]</p>

	<input type="checkbox"/> The lengthy duration of treatment remains one of the major obstacles to compliance. (section 4.2.3.4.3)  <input type="checkbox"/> Traditional healers could influence TB adherence.  [section 4.2.3.3.5]  <input type="checkbox"/> People suffering from TB are inclined to hide their diagnosis because people tend to associate TB with HIV.  (section 4.2.3.2.1)  <input type="checkbox"/> Some of the participants had comments regarding the lack of health education of the patients(section 4.2.3.1.3).
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Through an in-depth research study, the above objectives were met to provide answers to the research question: “What are the experiences and perceptions of non-compliance with TB treatment at the Nyanga Clinic?”

#### **5.4 RECOMMENDATIONS**

Faye Abdellah’s theory explains nursing as a comprehensive service which includes: recognising the nursing problems of the patient, deciding on the appropriate course of action to take and provide continuous care of the individual’s total needs (George, 2002:173-183). During the analysis, the problems of the patients were identified and recommendations were presented by the researcher.

The recommendations are presented under headings, according to the themes that emerged from the data.

The following recommendations are proposed, based on the findings of this study and the themes identified:

#### **5.4.1 Health-related factors**

The Operational Manager of the clinic should organise a complaints and compliments mechanism in place at the clinic, so that the patients can express their views about the services.

The manager and head office of the City of Cape Town Health Department should be notified by the researcher about the incomplete documentation done by health workers because that can lead to wrong statistics of non-compliance. Furthermore, documentation audits and staff training regarding record-keeping should be done by the auditors employed by the department.

DOTS strategy at the Nyanga Clinic has been implemented only in January 2012. Patients and community members should be given health education regarding TB by the community health workers and the clinic staff from the Health Department, City of Cape Town.

The implementation of DOTS at patients' homes or near their work places will mean that it will not be necessary for the patients to walk to the clinic every day and they need not wait for long times at the clinic for treatment. Overcrowding in the clinic will be less, as well as workload of the clinic staff who will have more time available to do better documentation.

#### **5.4.2 Client-related factors**

The patients must be referred by the professional nurse at the TB clinic to social workers or clinical psychologists for counselling regarding depression where the need is identified.

The HIV/AIDS STI TB (HAST) programme coordinator should organise community outreach programmes and invite volunteers and community health workers in the community to teach the community members about TB, signs and symptoms, curability, spreading thereof, consequences of inadequate treatment and living a healthy lifestyle through the distribution of informational pamphlets about TB.

One of the aims of the TB programme is to organise TB services so that the client has treatment as close as possible to home or the workplace (National Department of Health, 2009:46).

Furthermore, the informational pamphlets should also include information about the consequences of inadequate treatment. Health care workers and clinic staff should encourage the community members to grow their own fresh vegetables to promote healthy living.

The majority of the participants knew that TB is curable. Only a few participants were unaware of the curability of the disease, therefore there is a need for health education, counselling and motivation by the healthcare workers to improve these statistics, so that more patients know about the curability of TB.

#### **5.4.3 Social and economic factors**

Soup kitchens, monitored by volunteering community members, for all TB patients could be introduced by the clinic supervisor.

Interdepartmental meetings with the police, social development, education and SASSA should be held about gangsters in order to strategise on reducing gangsterism. According to the *Sowetan Live* (2012:2), the Premier of the province, Helen Zille is aware of the gangsters and also the President of the country, Jacob Zuma has been notified. The clinic manager should report the matter to the police officers as soon as possible.

The nurses should advise the patients that when they are of intention to migrate to another area, they should report to the health workers so that they can get enough supplies for treatment and not miss their treatment due to the clinic being far away.

People have a freedom of choice regarding which type of treatment they want to use but health care workers should make it their responsibility to teach them about the risks of missing their TB treatment to take traditional medicine. The traditional healers should also be taught about TB and the importance of the patients taking their treatment. In this way traditional healers could enhance the TB programme.

It would be better that the clinic would open earlier so that they can go to the clinic and get their treatment on time and also if the clinic can close at 6pm instead of 4pm when they come from work to get their treatment from the clinic.

Alcohol-abusing patients should be admitted to a hospital during their treatment as their alcohol usage may disturb their treatment schedule.

#### **5.4.4 Therapy-related factors**

According to the findings, there is a lack of education of patients regarding the side-effects of TB treatment, the heavy pill burden and the lengthy duration of the treatment.

Every day, one of the professional nurses at the TB clinic should organise support group sessions where the health workers educate the patients about the side-effects of the treatment and everything they should know concerning the treatment, including the lengthy duration and combination of TB with other treatment.

All TB patients should be reassured by the health care worker regarding the side-effects of the TB drugs. Patients suffering from deafness should be referred to the doctor for audiometric tests.

### **5.5 LIMITATIONS**

As described by Burns and Grove (2007:545), a limitation is a theoretical and methodological restriction in a study that may decrease the generalisation of the findings. The study was limited to the context of the Nyanga Clinic in the Cape Metropole district of the Western Cape Province. The other districts were excluded due to geographical distribution therefore the results cannot be generalised to all six districts of the Western Cape.

The study only included 14 participants in Nyanga. The results would be more effective if the researcher could compare the results with other institutions.

### **5.6 CONCLUSION**

In this chapter the findings of the study were discussed in relation to the study objectives. The purpose of this study was to explore the patients' experiences and perceptions about non-compliance with TB treatment at the Nyanga Clinic.

The main conclusion is that there is a need for the community health care workers to educate the community members about TB, the lengthy duration of the treatment, its

side-effects, curability, the spreading of the disease and the consequences of inadequate treatment through the strategies discussed above to empower the community at large about the disease.

The objectives of the study are met, namely: the patient experiences and perceptions regarded non-compliance with TB treatment; the determining of the knowledge of non-compliant TB patients as well as the reasons why patients are non-compliant.

Recommendations resulting from the study;

- providing health education to patients and community by the health care workers;
- outreach campaigns in the community in order to teach the community about TB as a disease;
- interdepartmental meetings between the various state departments in order to prevent gangsters from keeping patients from accessing the clinic for their TB treatment;
- more support group sessions in the clinic regarding the lengthy treatment and managing of the medication side-effects.

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Further research regarding the patient experiences and perceptions of non-compliance with TB treatment is recommended to other institutions as this study was limited to the Nyanga Clinic only.

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**ANNEXURE 1 (QUESTIONNAIRE)**

**Interview Schedule**

PATIENTS' EXPERIENCES AND PERCEPTIONS ABOUT NON-COMPLIANCE WITH TUBERCULOSIS TREATMENT.

**Section A: Demographical data**

- Age (in years on your last birthday).....

- Gender

- <u>Male</u>	- <u>Female</u>
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- Home Language

- <u>English</u>	- <u>Afrikaans</u>	- <u>IsiXhosa</u>	- <u>Other</u>
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- Marital Status

<u>Married</u>	<u>Single</u>	<u>Widowed</u>	<u>Divorced</u>
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- Educational level

- <u>Never Literate</u>	- <u>Primary School</u>	- <u>Secondary School</u>	- <u>Tertiary Level</u>
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- Employment status

<u>Unemployed</u>	<u>Casual labourer</u>	<u>Unskilled labourer</u>	<u>Skilled labourer</u>	<u>Professional</u>
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- Access to financial support

<u>YES</u>	<u>NO</u>
------------	-----------

If yes, explain

.....  
 .....  
 .....

- Do you have a fixed address?

YES	NO
-----	----

If no, explain

.....

.....

.....

- Do you have Cultural or Spiritual beliefs regarding TB?

YES	NO
-----	----

If yes, explain

.....

.....

.....

- How do you get to the clinic?

Walking	Public Transport	Own Transport	Other
---------	------------------	---------------	-------

- Where do you get your TB treatment?

Clinic	DOTS strategy
--------	---------------

- When in your treatment schedule did you stop taking TB medication?

Intensive Phase	Continuation Phase
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- Share with me your reasons for defaulting

.....

.....

.....

.....

.....

- Are you a “new TB case” or a re-treatment?

New	Re-Treatment
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**Section B: Patient’s experiences and perceptions about non-compliance of Tuberculosis treatment**

What is TB?

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.....  
.....

How do you think a person gets infected with TB?

.....  
.....  
.....

What are the symptoms of TB?

.....  
.....  
.....

What do you know about the curability of TB?

.....  
.....  
.....

How do you think that TB could spread to other people?

.....  
.....  
.....

What are your thoughts regarding the lengthy duration of TB treatment (6 to 8 Months)?

.....  
.....  
.....

What do you think could be the consequences of inadequate treatment?

.....  
.....  
.....

How do you think a healthy lifestyle could add value while taking TB medication?

.....  
.....  
.....

Please mention any side effects which you experienced while on TB treatment.

.....  
.....  
.....

How do you experience the support of the staff at the clinic?

.....  
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.....  
.....

How do you experience the attitude of the health staff at the clinic?

.....  
.....  
.....

How do you think the clinic staff can improve their services at the clinic?

.....  
.....  
.....  
.....  
.....

**ANNEXURE 2**

**PARTICIPANT INFORMATION LEAFLET AND ASSENT FORM**

**TITLE OF THE RESEARCH PROJECT:**

PATIENTS' EXPERIENCES AND PERCEPTIONS ABOUT NON-COMPLIANCE  
WITH TUBERCULOSIS TREATMENT.

**RESEARCHERS NAME(S):** Mrs A. C. N Shasha

**ADDRESS:** NY 2 no 6<sub>A</sub> Gugulethu

**CONTACT NUMBER:** 083 9888 091

**What is RESEARCH?**

Research is something we do to find new knowledge about the way things (and people) work. We use research projects or studies to help us find out more about disease or illness. Research also helps us to find better ways of helping, or treating children who are sick.

**What is this research project all about?**

The Researcher would like to find out why TB patients are not adhering to their treatment.

**Why have I been invited to take part in this research project?**

You have been chosen because you meet the criteria and will be suitable to assist the Researcher by answering a few simple questions.

**Who is doing the research?**

I Mrs A. C. N. Shasha will be personally asking you some questions. I am a Clinic Sister who works in a TB Clinic at Nyanga.

**What will happen to me in this study?**

The researcher will ask you some questions regarding why you are not adhering to your treatment. You are expected to give honest and correct answers. You have the right not to answer a question if you do not wish to.

**Can anything bad happen to me?**

Nothing bad can happen to you. All answers that you give to the researcher will remain private, meaning that your name will not be mentioned to anyone.

**Can anything good happen to me?**

Yes, you will be helping the nurses and doctors to understand why TB patients are not adhering to their treatment.

**Will anyone know I am in the study?**

Your name will remain private. Only the people involved in the study will be able to see the information that you give us.

**Who can I talk to about the study?**

You can contact Dr E.L. Stellenberg at tel. (021) 938-9036 if you have any problems or questions.

You can contact the Committee for Human Research at (021) 938-9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.

**What if I do not want to do this?**

You can refuse to take part even your parents have agreed to their participation. You can stop being in the study at any time without getting in trouble.

**Do you understand this research study and are you willing to take part in it?**

YES

NO

**Has the researcher answered all your questions?**

YES

NO

**Do you understand that you can pull out of the study at any time?**

 YES NO

---

**Signature of Participant**

---

**Date**

Annexure 3  


Letter of permission from  
the university ethical  
Comm.

UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvenoot • your knowledge partner

05 June 2012

**MAILED**

Mrs A Shasha  
Department of Nursing  
2nd Floor  
Teaching Block

Dear Mrs Shasha

**Patients' experiences and perceptions of non-compliance of Tuberculosis treatment.**

**ETHICS REFERENCE NO: N11/03/098**

**RE : PROGRESS REPORT**

At a review panel meeting of the Health Research Ethics Committee that was held on 5 June 2012, the progress report for the abovementioned project has been approved and the study has been granted an extension for a period of one year from this date.

Please remember to submit progress reports in good time for annual renewal in the standard HREC format.

Approval Date: 5 June 2012

Expiry Date: 5 June 2013

Yours faithfully

**MRS MERTRUDE DAVIDS**

**RESEARCH DEVELOPMENT AND SUPPORT**

Tel: 021 938 9207 / E-mail: [mertrude@sun.ac.za](mailto:mertrude@sun.ac.za)

Fax: 021 931 3352

05 June 2012 14:06

Page 1 of 1



Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences



Verbind tot Optimale Gesondheid · Committed to Optimal Health

Afdeling Navorsingsontwikkeling en -steun · Division of Research Development and Support

Posbus/PO Box 19063 · Tygerberg 7505 · Suid-Afrika/South Africa  
Tel.: +27 21 938 9075 · Faks/Fax: +27 21 931 3352

*Annexure 4 letter from*



CITY OF CAPE TOWN | ISIXEKO SASEKAPA | STAD KAAPSTAD

Civic Centre  
12 Hertzog Boulevard  
Cape Town 8001  
P O Box 2815, Cape Town 8000  
Ask for: Dr G H Visser  
Tel: 021 400-3981  
Cell: 083 298 8718  
Fax: 021 421-4894

Iziko loLuntu  
12 Hertzog Boulevard  
Cape Town 8001  
P O Box 2815, Cape Town 8000  
Cell: Qrh G H Visser  
Umnxeba: 021 400-3981  
Cell: 083 298 8718  
Iveksi: 021 421-4894

Burgersentrum  
Hertzog-boulevard 12  
Kaapstad 8001  
Posbus 2815, Kaapstad 8000  
Vra vir: Dr G H Visser  
Tel: 021 400-3981  
Sel: 083 298 8718  
Faks: 021 421-4894

E-mail: [helena.visser@capetown.gov.za](mailto:helena.visser@capetown.gov.za)  
Website: <http://www.capetown.gov.za>  
Ref:  
Filename: G:\Research\2012\MdShasha10295.docx

CITY HEALTH — Specialised Health

2012-05-15

**re: Research Request: Patient's experiences and perceptions about non-compliance of Tuberculosis treatment (ID NO: 10295)**

Dear Ms Shasha

Permission has been granted to do your research as per your protocol at the following City Health Clinic only:

**Klipfontein Sub District:**  
Contact People

**Nyanga Clinic**  
Mr K Nkoko (Sub District Manager)  
Tel: (021) 630-1667/ 082 433 1332  
Mrs T Nojaholo (Head: PHC & Programmes)  
Tel: (021) 630-1626/ 084 220 0133

**Please note the following:**

1. All individual patient information obtained must be kept confidential.
2. Access to the clinic and its patients must be arranged with the relevant Manager such that normal activities are not disrupted.
3. A copy of the final report must be sent to the City Health Head Office, P O Box 2815 Cape Town 8001, within 3 months of its completion and feedback must also be given to the clinics involved.
4. Your project has been given an ID Number (10295). Please use this in any future correspondence with us.

Thank you for your co-operation and please contact me if you require any further information or assistance.

Yours sincerely

DR G H VISSER  
MANAGER: SPECIALISED HEALTH

cc. Mr Nkoko & Mrs Nojaholo  
Dr K Jennings  
Ms Caldwell

***ELIZABETH LE SUEUR***

Language practitioner

for expert wordwork

[editburo@gmail.com](mailto:editburo@gmail.com)

073-254-4995

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**AFFIDAVIT**

This is to certify that I, the undersigned, have completed the language and technical editing of the M.Health Sciences thesis of ALETHEA CHRISTINA N. SHASHA, titled:

PATIENT EXPERIENCES AND PERCEPTIONS OF NON-COMPLIANCE WITH  
TB TREATMENT.

I am satisfied that the academic style and language usage are of very high standard.

ELIZABETH LE SUEUR (BA Hons)

EDITBURO

25 February 2013

## FIELD NOTES

The following are transcriptions of notes taken by the researcher during interviews with patients explaining their non-compliance with TB medication.

### FIELD NOTES 1

#### DISABILITY GRANT

The participant is afraid of losing his disability grant when he completes the treatment, so he would rather stay sputum positive. The participant was given education about taking treatment regularly.

#### DISEMPOWERMENT – AFRAID OF STAFF

The participant is afraid of going to the clinic because she has lost her card and the health workers shout at her, because this is the third time she has lost her card.

#### JOB RESPONSIBILITY

The participant does not have a chance to go to the clinic because she recently got a job, but has not told her employer about the disease and has no-one to fetch her medicine for her.

#### ALCOHOL

The participant felt too weak in the morning to go to the clinic owing to alcohol abuse, but knows the consequences of defaulting on the treatment.

#### RECORD-KEEPING

1. The participant claims that she is taking her treatment regularly and is very surprised at the report that she is defaulting on the treatment.
2. The participant is taking the treatment, but the problem was that they (health care workers) do not record this on her clinic card.
3. The participant was very angry because he was taking his medication regularly. He also stressed that the nurses in the clinic did not record patients taking their medicine in the folders.

#### BEREAVEMENT

The participant was in tears and very emotional owing to the loss of her husband to the disease (TB), but is willing to take the treatment regularly to prevent herself from dying like her husband.

#### GANGSTERISM

The participant is experiencing a very large problem going to the clinic because of gangsterism. He is student at Oscar Mpeta High School, but is not attending school either. He understands the complications very well. His father's sister will try to fetch his medication at the clinic.

#### FIELD NOTES 2.

#### ANXIETY

The participant was very reluctant to talk during interviews, shaking and scared, but responds after 30 minutes

#### RECORDKEEPING

The participant explained that when the doctor did not come for their appointment, they were given another date and the nurses gave them the treatment, but when they came to the clinic for the second appointment they were told that they had defaulted on their treatment.

#### FAMILY RESPONSIBILITY (MIGRATION)

The mother of the participant reported that she told the health workers that the child was staying in a different area in Crossroads, so the child was taking his treatment at the Crossroads clinic.

#### UNEMPLOYMENT

The participant claims that when she goes looking for work, she does not take the treatment because it makes her feel tired, but she understands the disease very well.

#### LACK OF KNOWLEDGE

The participant was not sure about the disease and the importance of taking treatment. Education was given about taking treatment.

#### LONG WAIT AT CLINIC

The problem for the participant was the long wait at the clinic; she suggested that the clinic should be open till 6 pm.

#### SIDE-EFFECTS

The participant complained of the side-effects of the TB treatment. She specified that her legs were painful due to treatment, which is why she was defaulting on the treatment.

#### BULKINESS OF MEDICATION

The participant said that she could not swallow all the tablets for TB and HIV, so she wanted to take a break from the TB treatment. The participant was advised about the importance of taking regular treatment.