AN EXPLORATION OF HOW TREATMENT INTERRUPTION AND DEFAULT AFFECTS TUBERCULOSIS (TB) PATIENTS IN OSHAKATI DISTRICT, OSHANA REGION, NAMIBIA

A THESIS SUBMITTED IN PARTIAL FULFILMENT

OF THE REQUIREMENT FOR THE DEGREE OF

MASTER OF ARTS IN SOCIAL WORK

OF

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BY

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ABSTRACT

The main aim of the study was to explore and study, in order to understand the lived experience of TB patients whose treatment was interrupted and those who default the TB treatment. Tuberculosis is an infectious disease caused by a *Mycobacterium tuberculosis* bacterium. The research project explored the treatment interruption and default among the TB patients in Oshakati District, Oshana Region in Namibia. A person can become infected with tuberculosis bacteria when he/she inhales particles of infected sputum from the air. The bacteria get into the air when an infected person coughs, sneezes, shouts or spits. Therefore, a person who is nearby an infected person can then possibly inhale the bacteria into the lungs. The treatment of TB can last from 6 to 24 months. Due to the length of the treatment, people might be tempted to stop taking medication as soon as they start feeling better, and may therefore defaults from treatment.

In the current study, ten (10) respondents both male and female were interviewed by the researcher with the use of semi-structured interview schedule. Purposive sampling technique was used in this qualitative study which utilised a phenomenological research design. By providing an in-depth exploration of the experience of being a TB patient, the study contributes to knowledge that can be used to establish a patient centred intervention to improve treatment adherence and reduce global disease burden that is attributed to TB. Furthermore, the findings of this study will be used by health care providers and policy makers to design and deliver
services to TB patients in Namibia. The findings can be used to broaden people’s understanding on the importance of completion of the TB treatment as well.

Key words: treatment default, tuberculosis, treatment adherence
TABLE OF CONTENTS

TITLE PAGE

ABSTRACT

TABLE OF CONTENTS

LIST OF ANNEXURES

LIST OF GRAPHS

LIST OF FIGURES

LIST OF TABLES

LIST OF ABBREVIATIONS

ACKNOWLEDGEMENTS

DECLARATION

CHAPTER 1: ORIENTATION TO THE STUDY

1.1 INTRODUCTION

1.2 BACKGROUND TO THE PROBLEM

1.3 PROBLEM STATEMENT

1.4 RESEARCH QUESTIONS GUIDING THE INQUIRY
1.5 SIGNIFICANCE OF THE STUDY .............................................................................10

1.6 DEFINITION OF KEY CONCEPTS ..................................................................11

1.7 FOUNDATION OF THE STUDY .........................................................................13

1.8 SUMMARY ...........................................................................................................15

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION ...................................................................................................17

2.2 CONCEPTUAL FRAMEWORK .........................................................................18

2.2.1 The Trans-theoretical Model (TTM) (Stages of change) .........................19

2.2.2 Understanding change .................................................................................21

2.2.2.1 Pre-Contemplation stage .................................................................22

2.2.2.2 Contemplation Stage ...........................................................................22

2.2.2.3 Preparation / Determination stage .....................................................22

2.2.2.4 Action stage .......................................................................................23

2.2.2.5 Relapse from the changed behaviour .................................................23

2.2.2.6 Maintenance and relapse prevention ..................................................24

2.2.2.6.1 Involving others ..........................................................24
2.3 NATIONAL GUIDELINES FOR THE MANAGEMENT OF TUBERCULOSIS IN NAMIBIA...............................................................................26

2.3.1 ADVOCACY, COMMUNICATION AND SOCIAL MOBILISATION...........................................................................................................30

2.4 WHAT IS TUBERCULOSIS?..................................................................................................................................................................................32

2.5 HOW DOES A PERSON GET TB?.................................................................32

2.6 HOW CAN TB BE PREVENTED?.................................................................................................................................33

2.7 THE GLOBAL CONTEXT FOR TB.................................................................34

2.8 FACTORS INFLUENCING THE GLOBAL INCREASE OF TB.................37

2.9 FACTORS THAT AFFECTS TB TREATMENT NON-ADHERENCE........38

2.9.1. Applications of common interruption and default factors to the current study..................................................................................................................................................38
2.9.1.1 Social and economic related factors.........................................................39

29.1.2 Health care system related factors.............................................................41

2.9.1.3 Condition related factors...........................................................................42

2.9.1.4 Therapy related factors...............................................................................43

2.9.1.5 Patient related factors..................................................................................44

2.10 POTENTIAL INTERVENTIONS TO ADDRESS TB TREATMENT ADHERENCE..............................................................................................................47

2.11 STRATEGIES IMPLEMENTED TO CONTROL TB...........................................48

2.11.1 Patients receiving other medical treatment together with TB treatment.........................................................................................................................48

2.12 SUMMARY........................................................................................................49

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION..................................................................................................51

3.2 RATIONALE FOR THE DESIGN OF THE STUDY...........................................51

3.3 CONTEXT............................................................................................................54
CHAPTER 4: FINDINGS

4.1 INTRODUCTION

4.2 IMPORTANT CHARACTERISTICS OF THE SAMPLE

4.3 MAIN CATEGORIES AND SUB-CATEGORIES
4.3.1 Support available for TB patients .......................................................... 76
4.3.2 How was the TB diagnosis communicated to the patient? ...................... 77
4.3.3 Family and professional support ................................................................ 79
4.3.4 Employment situation and income sources of participants ...................... 84
4.4. UNDERSTANDING OF TB AND ITS TREATMENT .................................... 88
  4.4.1 The TB diagnosis communication .......................................................... 89
  4.4.2 Duration of treatment ........................................................................... 92
  4.4.3 The TB transmission and symptoms ..................................................... 93
  4.4.4 Patients experiences of TB treatment .................................................... 95
  4.4.5 Feeling better ....................................................................................... 96
  4.4.6 Other treatment apart from TB treatment ............................................ 96
  4.4.7 Procedure of treatment ........................................................................ 97
  4.4.8 Distance to health facility ...................................................................... 98
  4.4.9 Life style interference ........................................................................... 99
  4.4.10 Alcohol use ........................................................................................ 99
  4.4.11 Tobacco smoking ............................................................................... 101
  4.4.12 Lived experience of TB patient on treatment ...................................... 101
4.5 PARTICIPANTS’ PERCEPTIONS ABOUT TREATMENT INTERRUPTION
  AND DEFAULT .................................................................................................. 103
  4.5.1 Thoughts about treatment interruption and default .............................. 103
4.5.2 Opinions to improve treatment compliance

4.6 STIGMA AND DISCRIMINATION

4.6.1 Negative remarks/labelling/gossip

4.7 SUMMARY

CHAPTER 5: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 INTRODUCTION

5.2 DISCUSSION OF FINDINGS

5.2.1 Demographic information

5.2.2 Support available for TB patients

5.2.3 Participant’s understanding of TB and its treatment

5.2.4 Participant’s perceptions about treatment interruption and default

5.2.5 Stigma and discrimination

5.3 LIMITATIONS OF THE STUDY

5.4 RECOMMENDATIONS

5.4.1 Recommendations for future research

5.4.2 Recommendation for policymakers

5.4.3 Recommendations for Clinicians working with TB population

5.5 SUMMARY AND CONCLUSION

REFERENCES
LIST OF ANNEXURES

ANNEXURE I: PARTICIPANTS’ CONSENT FORM.................................................137
ANNEXURE II: INFORMED CONSENT (OSHIWAMBO TRANSLATED)…139
ANNEXURE III: SEMI STRUCTURED INTERVIEW SCHEDULE ..................142
ANNEXURE IV: INTERVIEW TRANSCRIPTS......................................................146
ANNEXURE V: APPROVAL LETTER FROM UNAM POSTGRADUATE STUDIES COMMITTEE..............................................................................................................205
ANNEXURE VI: PERMISSION LETTER FROM MINISTRY OF HEALTH AND SOCIAL SERVICES.................................................................206
LIST OF GRAPHS

Graph 2.1: The Trans-theoretical Model (TTM) ............................................. 20

LIST OF FIGURES

Figure 3.3.1. The map of Namibia .................................................................. 55

Figure 3.4.1: The Map of Oshana Region, Namibia ........................................ 56
<table>
<thead>
<tr>
<th>Table</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1</td>
<td>TB situation in Namibia: 2007-2011</td>
<td>4</td>
</tr>
<tr>
<td>2.1</td>
<td>Potential interventions to address TB treatment adherence</td>
<td>47</td>
</tr>
<tr>
<td>4.1</td>
<td>A summary table of the important characteristics of the sample</td>
<td>72</td>
</tr>
<tr>
<td>4.2</td>
<td>The main categories and sub-categories</td>
<td>75</td>
</tr>
<tr>
<td>4.3</td>
<td>Assessment of participants’ survival needs</td>
<td>85</td>
</tr>
<tr>
<td>4.4</td>
<td>Procedure of treatment</td>
<td>97</td>
</tr>
<tr>
<td>4.5</td>
<td>Alcohol use</td>
<td>100</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Description</td>
<td></td>
</tr>
<tr>
<td>--------------</td>
<td>-------------</td>
<td></td>
</tr>
<tr>
<td>AFB</td>
<td>acid-fast bacilli</td>
<td></td>
</tr>
<tr>
<td>ANC</td>
<td>Antenatal Clinics</td>
<td></td>
</tr>
<tr>
<td>ART</td>
<td>Anti-retroviral therapy</td>
<td></td>
</tr>
<tr>
<td>ARVs</td>
<td>Antiretroviral</td>
<td></td>
</tr>
<tr>
<td>BCG</td>
<td>Bacille Calmette Guerin also known as vaccine for Tuberculosis</td>
<td></td>
</tr>
<tr>
<td>CHPA</td>
<td>Chief Health Programme Administrator</td>
<td></td>
</tr>
<tr>
<td>CMO</td>
<td>Chief Medical Officer</td>
<td></td>
</tr>
<tr>
<td>CNR</td>
<td>case notification rate</td>
<td></td>
</tr>
<tr>
<td>CPT</td>
<td>co-trimoxazole prevention therapy</td>
<td></td>
</tr>
<tr>
<td>DOTS</td>
<td>Directly Observed Treatment Short Course</td>
<td></td>
</tr>
<tr>
<td>DOT</td>
<td>Direct Observed Treatment</td>
<td></td>
</tr>
<tr>
<td>DR-TB</td>
<td>Drug Resistance - Tuberculosis</td>
<td></td>
</tr>
<tr>
<td>DSP</td>
<td>Directorate of Special Programmes</td>
<td></td>
</tr>
<tr>
<td>DTLC</td>
<td>District Tuberculosis and Leprosy Coordinator</td>
<td></td>
</tr>
<tr>
<td>EPTB</td>
<td>extra-pulmonary Tuberculosis</td>
<td></td>
</tr>
<tr>
<td>HAART</td>
<td>Highly Active Anti-Retroviral Therapy</td>
<td></td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>Human Immunodeficiency virus/ Acquired Immunodeficiency Syndrome</td>
<td></td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
<td></td>
</tr>
<tr>
<td>IEC</td>
<td>Information Education and Communication</td>
<td></td>
</tr>
<tr>
<td>IHO</td>
<td>Intermediate Hospital Oshakati</td>
<td></td>
</tr>
<tr>
<td>LTBI</td>
<td>Latent TB infection</td>
<td></td>
</tr>
<tr>
<td>MDGs</td>
<td>Millennium Development Goals</td>
<td></td>
</tr>
<tr>
<td>MDR-TB</td>
<td>Multidrug resistance tuberculosis</td>
<td></td>
</tr>
<tr>
<td>Acronym</td>
<td>Full Form</td>
<td></td>
</tr>
<tr>
<td>---------</td>
<td>-----------</td>
<td></td>
</tr>
<tr>
<td>MoHSS</td>
<td>Ministry of Health and Social Services</td>
<td></td>
</tr>
<tr>
<td>NGOs</td>
<td>Non-Governmental Organisations</td>
<td></td>
</tr>
<tr>
<td>NTPs</td>
<td>National Tuberculosis Control Programmes</td>
<td></td>
</tr>
<tr>
<td>NTLP</td>
<td>National Tuberculosis and Leprosy Programme</td>
<td></td>
</tr>
<tr>
<td>NVDCP</td>
<td>National Vector-borne Disease Control Programme</td>
<td></td>
</tr>
<tr>
<td>PHC</td>
<td>Primary Health Care</td>
<td></td>
</tr>
<tr>
<td>PLHIV</td>
<td>people living with Human Immunodeficiency Virus</td>
<td></td>
</tr>
<tr>
<td>PTB</td>
<td>Pulmonary tuberculosis</td>
<td></td>
</tr>
<tr>
<td>RDMT</td>
<td>Regional Directorate Management Teams</td>
<td></td>
</tr>
<tr>
<td>SHPA</td>
<td>Senior Health Programme Administrators</td>
<td></td>
</tr>
<tr>
<td>STI</td>
<td>Sexual transmitted infections</td>
<td></td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
<td></td>
</tr>
<tr>
<td>TB/HIV</td>
<td>Tuberculosis/Human Immunodeficiency Virus</td>
<td></td>
</tr>
<tr>
<td>TTM</td>
<td>Trans-theoretical Model</td>
<td></td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
<td></td>
</tr>
<tr>
<td>XDR-TB</td>
<td>Extensively Drug Resistant Tuberculosis</td>
<td></td>
</tr>
</tbody>
</table>
ACKNOWLEDGEMENTS

First and foremost I would like to thank the almighty God for having granted me an opportunity to accomplish this task.

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I want to thank the participants in this study for their willingness to participate in this study.
Finally, I want to thank everyone who supported and contributed to the success of this study.
DECLARATION

I, Tabita Tuwilika Kalunduka, declare hereby that this study is a true reflection of my own research and that this work or part thereof has not been submitted for a degree in any other institution of higher education.

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.........................................................(signature)                 Date........................................

Tabita Tuwilika Kalunduka
CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

Tuberculosis (TB) is an infectious disease caused by *Mycobacterium tuberculosis*. Typically, it affects the lungs and is diagnosed as pulmonary TB. In addition, TB can affect other organs as well when it is diagnosed as extra pulmonary TB (World Health Organisation [WHO], 2012). The Ministry of Health and Social Services [MoHSS] (2012) has reported that in Namibia, TB is usually caused by *Mycobacterium tuberculosis*. Therefore, infections caused by other mycobacteria are rare. It further states that pulmonary tuberculosis (PTB) is the most frequent form, which accounts for 80% of TB disease in Namibia. This is also the most important form in public health issue due to its infectiousness. It is transmitted through the air when an infected person coughs, sneezes, laughs or speaks. In most cases, the infection is transferred when a susceptible person inhales one or more droplets containing *mycobacteria* into their lungs.

According to MoHSS (2012), the common symptoms of TB include; night sweat, fever, chest pains and cough that lasts for more than two weeks. Other symptoms can be investigated to confirm the TB diagnosis. In addition, people with TB of the lungs usually have a cough that may be productive or have some blood in the sputum. Moreover, the MoHSS (2012) further explained that TB infection in people living with HIV (PLHIV) can rapidly progress to active TB. Therefore, a person with both TB and HIV has approximately 5-10% risk of developing an active
TB. An active TB refers to the TB associated with symptoms or signs of the TB (MoHSS, 2009). As a result, the MoHSS (2012) has reported that in 2010, the rate of HIV among patients with all forms of TB was 55%. This could happen as HIV is suppressing the person’s immunity against opportunistic infections. Because of this, a person becomes susceptible to many diseases, including TB. According to the MoHSS (2009), the treatment of TB is curable with standard treatment in over 95% of cases, even in people living with HIV (PLHIV) if there is no drug resistance. This is confirmed by recent research conducted by Cramm, Finkenflugel, Moller, and Nieboer (2010), which confirmed that TB has become a health concern and a major cause of illness and death worldwide especially, when it goes hand in hand with HIV/AIDS.

According to Muture et al. (2011), successful treatment of TB involves taking anti-TB drugs for at least six months. It was further explained that poor adherence to treatment may mean that patients will remain infectious for a longer period of time. These patients are more likely to relapse, could result in treatment failure and may develop a form of drug resistant TB. This can result in a public health problem since many people who come into close contact with an infected person may potentially become infected as well. Therefore, it is very important that people who are diagnosed with TB should be given treatment as soon as possible so that they cannot infect others. If TB is not treated, the person can die because of it.
According to the WHO (2011), Namibia has one of the highest HIV prevalence rates in the world. It is also one of the Sub-Saharan countries that are highly affected by the dual epidemic of HIV and TB. In Namibia, TB patients with known HIV status who are HIV positive in the year 2011 were 50% which is a decrease from 59% in 2008. Furthermore, the WHO (2012) highlighted the situation of TB diagnosed patients. It stated that in 2011, 11,981 patients in Namibia were diagnosed with TB compared to 12,625 patients diagnosed in 2010. However, the cases of MDR-TB were reported to have been decreased from 214 patients in 2010 to 195 in 2011.

The MoHSS (2008) has also confirmed that TB was a major public health problem in Namibia, which is further compounded by the HIV pandemic. Pulmonary TB was rated the third leading cause of death in Namibian hospitals during 2007, which are the most current statistics available on this issue. The most affected groups were those between the ages of 24 to 34 years. Coincidentally, this is the same age group mostly affected by HIV/AIDS. It further stated that the monitoring of Multi-Drug Resistant Tuberculosis (MDR-TB) and Extensively Drug Resistant TB (XDR-TB) in the country have resulted in the discovery of eight cases of XDR-TB. Therefore, this discovery has imposed additional challenges for improved infection control in health care facilities. This has included the provision of isolation wards, improved capacity for the management of identified cases, strengthened surveillance and reporting.
The Namibia TB and Leprosy Control Programme highlighted the situation of TB in Namibia as from 2007-2011 in the following table (Table 1.1) (as cited in WHO, 2012, p. 9).

**Table 1.1: TB situation in Namibia: 2007-2011**

<table>
<thead>
<tr>
<th>Indicator</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of notified cases for all forms of TB</td>
<td>15,244</td>
<td>13,737</td>
<td>13,332</td>
<td>12,625</td>
<td>11,937</td>
</tr>
<tr>
<td>TB case notification rate for all forms of TB per 100 000</td>
<td>722</td>
<td>665</td>
<td>634</td>
<td>589</td>
<td>556</td>
</tr>
<tr>
<td>Number of new smear positive TB cases</td>
<td>5114</td>
<td>4928</td>
<td>4608</td>
<td>4464</td>
<td>4608</td>
</tr>
<tr>
<td>TB patients with known HIV status</td>
<td>8186</td>
<td>9188</td>
<td>9849</td>
<td>9534</td>
<td>10039</td>
</tr>
<tr>
<td>54%</td>
<td>67%</td>
<td>74%</td>
<td>78%</td>
<td>84%</td>
<td></td>
</tr>
<tr>
<td>TB patients</td>
<td>4358</td>
<td>5425</td>
<td>5676</td>
<td>5227</td>
<td>4980</td>
</tr>
</tbody>
</table>
with known HIV status who are HIV positive

<table>
<thead>
<tr>
<th></th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV positive TB patients on CPT</td>
<td>59%</td>
<td>59%</td>
<td>58%</td>
<td>55%</td>
<td>50%</td>
</tr>
<tr>
<td></td>
<td>1495</td>
<td>5289</td>
<td>4434</td>
<td>4869</td>
<td>4995</td>
</tr>
<tr>
<td></td>
<td>34%</td>
<td>98%</td>
<td>78%</td>
<td>92%</td>
<td>98%</td>
</tr>
<tr>
<td>HIV positive TB patients on ART</td>
<td>749</td>
<td>2019</td>
<td>1995</td>
<td>2294</td>
<td>2700</td>
</tr>
<tr>
<td></td>
<td>17%</td>
<td>37%</td>
<td>35%</td>
<td>43%</td>
<td>54%</td>
</tr>
<tr>
<td>Treatment success rate for new smear positive TB cases</td>
<td>76%</td>
<td>83%</td>
<td>82%</td>
<td>85%</td>
<td>85%</td>
</tr>
</tbody>
</table>

Number of cases of MDR-TB

<table>
<thead>
<tr>
<th></th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
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<tr>
<td></td>
<td>116</td>
<td>201</td>
<td>275</td>
<td>214</td>
<td>192</td>
</tr>
</tbody>
</table>

Number of cases of XDR-TB

<table>
<thead>
<tr>
<th></th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
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</thead>
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<tr>
<td></td>
<td>3</td>
<td>20</td>
<td>17</td>
<td>8</td>
<td>2</td>
</tr>
</tbody>
</table>
1.2 BACKGROUND TO THE PROBLEM

According to Kaumbi (2004), starting in 1999, an increase in TB notification was reported from large urban districts such as Oshakati, Windhoek, WalvisBay, Katima Mulilo and Rundu. It was further reported that in Oshana Region and Komas Region, cases of TB were high as well. This was explained that higher rates were reported in these regions as they are home to referral hospitals such as Windhoek Central Hospital, Katutura Intermediate Hospital and Intermediate Hospital Oshakati (IHO).

According to the MoHSS (2008), Namibia reported 15,244 of all forms of TB in 2007, which translated to 722 cases notified per 100,000 populations. It was further reported that the treatment success rate in new sputum smear positive in pulmonary TB (PTB) was 76%. This was lower than the National and Global target of 85%. The treatment success was negatively affected by significant number of defaulters, deaths, transfers and treatment failures. In addition, the Ministry also experienced a problem of MDR-TB that posed additional challenges to the rate of treatment success. Furthermore, Namibia experienced three cases of XDR-TB during the same period (WHO, 2012).

Therefore, the National TB Programme has planned the strategies for implementation such as; advocacy and social mobilization and the launching of TB-Combi Strategy. This has included an expansion of the laboratory network for TB diagnosis and maintenance of an uninterrupted supply of anti TB medicines. At this
point, the World Health Organisation (WHO) recommended the Directly Observed Treatment Short Course (DOTS) strategy. This is a strategy that is when a trained and supervised individual observe the patient swallowing the medication. This strategy has been introduced in Namibia since 1995. According to MoHSS (2012), the Direct Observed Treatment (DOT) is the most reliable measure to ensure that patients take their medicines as prescribed. It further explained that DOT means that TB patients swallow their medicines in the presence of another person who is observing them swallowing medicines. The person who is the observer is called a DOT supporter because the psychological support is a crucial issue for DOT. This supporter can be a health care worker or any other person who has assumed the co-responsibility for the treatment of the patient during the entire treatment period. This DOT should be provided in a patient friendly and supportive manner, preferably by the same person throughout the treatment.

According to Tessema, Muche, Bekele, Reissig & Sack (as cited in Chani, 2010, p. 4), compliance with TB treatment protocols has been one of the major obstacles that TB control programmes worldwide have to tackle, especially in developing countries. Therefore, when trying to understand how TB treatment interruption and default affect patients in Oshakati district, this study helps in identifying potential interventions. These interventions help to improve patient adherence to treatment and improve TB treatment compliance. According to Caminero (as cited in Chani, 2010, p. 4), the main objective of TB programmes in all
countries is to interrupt the chain of transmission by acting on the human reservoir of TB bacilli.

Therefore, the correct management of patients with TB is crucial. This has become crucial; since most patients come for TB treatment with treatable or drug-susceptible *mycobacterium*. At many times they developed resistance to treatment after a health worker has introduced TB medicines. This medicine may have been administered in incorrect doses and could have been taken incorrectly for an insufficient duration. In addition, this study explored how TB treatment interruption and default affect TB patients in Oshakati district in order to help the health workers to understand the TB patients better. The policy makers will gain relevant skills from this study which will help them to develop policies that aimed at addressing the problem of treatment interruption and default among all TB patients.

1.3 PROBLEM STATEMENT

In the problem statement, the researcher indicated the issues to be investigated in the study as well as the purpose of the study. The research problem under investigation is centred on the exploration of how treatment interruption and default affects TB patients in Oshakati District. The research issues that were investigated in this study included patients’ understanding of TB and its treatment, support available for TB patients, participants’ perceptions about TB treatment interruption and default as well as stigma and discrimination.
According to MoHSS (2008), DOT is the policy for treatment of all patients. Its implementation is challenging due to difficulties experienced by patients in accessing health care facilities on a daily basis. A community-based DOT programme has been commenced to address this challenge. To address these challenges, the MoHSS (2012) reported that an expansion of the community TB care contributed to the reduction of default rates from 17% in 2000 to 4% in 2009. This Ministry further continued to explain that the recruitment of field promoters has become a success. The field promoters are complementing the role of nurses and ensure the continuum of care from TB diagnosis to cure or to treatment completion. Field promoters are lay persons from the community who can be attached to a health facility or to other TB treatment points in the community. They were trained in TB-DOT and TB case-finding. They provide support to the TB nurses regarding Information, Education and Communication (IEC), observing the treatment, recording and tracing patients who interrupt treatment. They also support community education in both TB and HIV.

Furthermore, the MoHSS (2008) has stated that the treatment of TB is free of charge in all public health care facilities in Namibia. However, many factors contributed to high burden of TB in the country. This includes; overcrowding and poor ventilation, poor nutrition, alcoholism, the HIV-TB co-infection rate (59%) and inadequate infection control/prevention. As a result, the default rates that have been observed and reported in Namibia, has included statistics of Oshakati district. The Intermediate Hospital Oshakati (IHO) reported an approximate 10, 9% TB default rate (Kakungulu, 2012). These rates have been a concern especially, when it is known
that interrupting and defaulting TB treatment has been the primary contributors of the increasing rate of drug resistant TB (DR-TB) (Chani, 2010).

1.4 RESEARCH QUESTIONS GUIDING THE INQUIRY

Research questions are a basis for the study as they act as a guide on the topic that will be studied. According to Mouton (2001), the problem statement is sometimes formulated as a specific research questions.

The main research question for the study is:

*How does treatment interruption and default affects TB treatment among patients in Oshakati district?*

The sub questions of the study are:

- How do patients understand TB and its treatment?
- What is the cause that some TB patients in Oshakati district interrupt or default their treatment?
- What are patients’ suggestions to increase successful treatment outcome and minimize default?
- What support systems exist for TB patients in Oshakati District?

1.5 SIGNIFICANCE OF THE STUDY

The study explored how treatment interruption and default affect TB patients at Oshakati district in Namibia. However, the knowledge gained from the study will be valuable in Oshakati district as well as in other regions given the highly infectious nature of TB disease. The study provides exploratory insight into the reasons for
interruption and default. It will provide first-hand information and suggestions from patients that may be useful to minimize default. In addition, this study will provide an in depth exploration of the experience of being a TB patient on treatment. The WHO (2008) has provided useful information stating that some of the drivers of the TB epidemic included poverty, equity, illiteracy and poor housing. These drivers of the TB epidemic need to be tackled mainly by actors outside the health sector, such as social workers. Therefore, these actors could advocate for interventions relevant to decision-makers. As a result, this study provides useful information to health care providers. Health care providers are responsible for designing and delivering services to TB patients in Namibia. Furthermore, the study can contribute to what Munro, Lewin, Smith, Engel, and Volmink, (2007) describes as a development of a patient centred intervention. The patient centred interventions improves treatment adherence and reduce global disease burden attributed to TB. Therefore, the MoHSS may also benefit as they will have a document containing updated information on treatment interruption and default. This information can be used as an information source. In this regard, this document may also assist health care professionals and social workers, especially those who work closely with TB patients on a daily basis to understand the challenges experienced by TB patients.

1.6 DEFINITION OF KEY CONCEPTS

The following concepts are explained and will be used in guiding the study:
Adherence – Adherence to treatment is generally defined as the extent to which a patient follows the prescribed treatment regimen (Boogaard, Boeree, Kibiki & Aarnoutse, 2011).

Tuberculosis – Tuberculosis is an infectious disease caused by bacteria whose scientific name is *Mycobacterium tuberculosis* (Schiffman, 2012).

Defaulter – A patient whose treatment has been interrupted for a period of at least eight consecutive weeks and all efforts to put the patient back on treatment have failed (MoHSS, 2012).

Relapse - A patient who presents with bacteriologically (smear or culture) positive TB after previous treatment with a successful outcome (cured or completed treatment) (MoHSS, 2012).

Drug-resistant TB (DR-TB) – The TB caused by *Mycobacterium tuberculosis* strains which are resistant to at least one TB medicine (MoHSS, 2009).

Extensively drug resistant TB (XDR-TB) – The TB caused by strains of *Mycobacterium tuberculosis* that are resistant to isoniazid and rifampicin and to any of the fluoroquinolones. This form of TB drug resistance may also be resistant to at least one of the injectable second-line anti-TB medicine (MoHSS, 2009).

Extra-pulmonary tuberculosis – TB of organs rather than the lungs: e. g. Pleura, lymph nodes, abdomen, genitor-urinary tract, skin, joints and bones, meninges etc. (MoHSS, 2009).

First-line TB medicine – Anti TB medicine used for treatment of TB in a patient who has not been treated for TB before and who has no evidence of resistance to these medicines (e. g. Rifampicin, streptomycin, ethambutol). Some of the first-line
medicines can be incorporated into regimens for drug resistant TB if there is evidence of susceptibility to them (MoHSS, 2009).

Multidrug-resistant Tuberculosis (MDR-TB) – The TB caused by strains of mycobacteria of the M. tuberculosis complex that are resistant to at least isoniazid and rifampicin (MoHSS, 2009).

1.7 THE FOUNDATION OF THE STUDY

The publicly reported statistical information on TB default rate in Intermediate Hospital Oshakati (IHO) was the foundation of the study. The study was guided by the stages of change trans-theoretical model (TTM) to help patients change their behaviour. Helping patients change behaviour is according to Zimmerman, et.al. (2000), a very important role the family physicians and other professionals may play. These professionals included social workers and other members of the multi-disciplinary team who are involved with TB treatment. These authors further explained that change interventions can be useful. In addition, these could be useful in addressing lifestyle modification for disease prevention, long-term disease management and addictions. Furthermore, it understands patient’s readiness to change, appreciate barriers to change and help patients to anticipate relapse. As a result, this can improve patient satisfaction and lower physician frustration during the change process.

The MoHSS currently implemented an advocacy, communication and social mobilisation campaign to address the TB in Namibia. According to the MoHSS
advocacy is the process of ensuring that adequate financial and material resources are available for TB control. It ensures that the TB disease is accorded its status among the country’s priorities. Behaviour-change communication aims to change knowledge, attitudes and practices among various groups of people. Through behaviour-change communication, the public is informed about the services that exist for diagnosis and treatment. It relay series of messages about the disease such as “get tested for TB if you have a cough for more than two weeks” or “if you are on TB treatment, complete it”. Social mobilisation brings together people such as community members and other stakeholders in the TB management to strengthen community participation for sustainability and self-reliance. Social mobilisations generate dialogue and negotiate for all players to reach consensus in the treatment of the TB. These players include; decision makers, media, NGOs, opinion leaders, policy makers, the private sector, professional associations, TB-patients networks and religious groups.

According to Zimmerman, et al. (2000), the primary focus in the stages of change approach is to help patients change including the following stages such as pre-contemplation stage, contemplation stage, preparation stage, action stage, and maintenance and relapse prevention as well as other interventions.

In conclusion, the target population in this study was the TB patients whose treatment had been interrupted for a period of at least four to eight consecutive weeks and more. The behaviour that needs to be understood and changed is TB treatment
interruption and default. The Trans Theoretical Model will guide the process of understanding behaviour. It was discussed to facilitate in helping the change of behaviour. Therefore, through identification, understanding patients’ needs and interventions, the change in TB patient’s behaviour might be possible.

Chani (2010) mentioned that if patients know someone with whom they can identify themselves who is cured of TB; self-efficacy could be enhanced. Again, it has been felt that health care professionals and social workers would play a very important role in TB treatment. These health professionals possess expert information on the TB as well as in counselling, and can however encourage patients to complete their treatment.

One important role of family physician is to assist patients in understanding their health. Physicians can involve social worker, field promoters as well as the DOT supporters in the treatment of TB patients. These people will help patients to make the change necessary for health improvement. Therefore, a change in patient lifestyle is necessary for successful management of long-term illness and relapses and can be attributed to lapses in healthy behaviour by the patient (Zimmermann, et al. 2000). This model will be discussed further in detail in the second chapter.

1.8 SUMMARY

This chapter has provided introduction, background to the problem, research questions and significance of the study as well as the foundation of the study. In the next chapter the researcher provided a detailed related literature review and explored
more on TB treatment interruption and default which is the main problem that is being investigated. The research design, methodology and procedures that were used to collect data for the study are presented in Chapter 3. The findings from the study were analysed in Chapter 4 while Chapter 5 contained discussion, conclusion drawn from the findings and recommendations for future interventions.
CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The researcher is a social worker working in the hospital who has seen many patients interrupt and default their TB treatment. Since tuberculosis is a public health issue, the researcher wants to explore more about the disease. However, the researcher went into the literature review without any knowledge about why these patients interrupt or default their treatment. The phenomenological approach looks at how people view themselves. This approach supports the faith in the person’s ability to fulfil own ultimate capacity. The researcher has chosen this approach because it is a client-centred approach in problem solving and it also fit to guide in this research because it involves people’s problems that need to be addressed.

This chapter provided a summary and synthesis of the existing professional literature related to the treatment of the tuberculosis. The topics included in this review of the literature aimed on review of the literature to explore more on tuberculosis treatment interruption and default. The conceptual framework was presented to provide the context to the issue of behaviour change. Furthermore, the researcher continued to explore and study what TB is, how it is transmitted and how it can be prevented. The situation of TB locally and globally was also explored to get a better understanding of the tuberculosis. Finally, the National Guidelines for the Management of tuberculosis in Namibia and the exploration of the treatment interruption and default were also discussed. The chapter also included potential
interventions to address tuberculosis, treatment adherence as well as the strategies implemented to tuberculosis control.

The aim of the study was to explore how TB treatment interruption and default affect TB patients in Oshakati district of Oshana Region. The study tentatively explored more on TB treatment interruption and default by examining significant professional literature. The study of the literature focussed on studying and exploring TB treatment interruption and default as well as how it contributes to treatment adherence, including TB medication protocols. The literature review identified a model relevant to behaviour change. This model seems to be helpful in understanding and preventing treatment interruption and default. It also clarified the global review of the problem as well as the current situation of the problem in a Namibian context. The sources where the literature information was obtained included scholarly journal articles, published research reports, policy materials from the Ministry of Health and Social Services as well as other relevant international reports. This information sources highlighted what is known in the literature concerning TB treatment interruption and default, as well as what is known on medication adherence and compliance.

2.2 CONCEPTUAL FRAMEWORK

According to de Vos et al (2005), the phenomenological approach aims to understand and interpret the meaning that subjects give to their everyday life. Therefore, the product of the study is a description of the essence of the experience being studied.
However, Del Siegle (n.d) further explained that the process of qualitative research is inductive in the sense that the researcher builds abstractions, concepts, hypotheses and theories from details. As a result, this TTM was discussed to guide the study.

2.2.1 The Trans-theoretical Model (TTM) (Stages of Change)

The Trans-Theoretical Model (TTM) was used to guide the study. This theory was used as an intervention to change any type of behaviour. It was used in this study to explain the study’s focus on the problem of treatment interruption or default. However, the theory studied the experience of clients with the aim to change the risky behaviour. Therefore, it can be used as an intervention to change any type of risky behaviour.

According to the Boston University School of Public Health (2013), the TTM was developed by Prochaska and DiClemente in the late 1970s. It evolved studies of examining the experience of smokers who quit on their own comparing them with those requiring further treatment. This comparison was made to understand why some people were capable to quit on their own. It was found that those who quit smoking on their own were ready to do so. Therefore, this model has been focusing on the decision making of individuals and was identified as a model of intentional change.
The TTM explained that individuals move through six stages of change such as pre-contemplation, contemplation, preparation, action, maintenance and termination stages.

In the next graph (Graph 2.1) this Stages of Change Model illustrated how these stages circulate as it is cited from the Boston University School of Public Health (2013).

**Graph 2.1: The Trans-theoretical Model (TTM)**
In addition, this TTM suggested strategies for public health interventions that helps in addressing people at various stages of the decision making process. This can result in interventions that were tailored for instance, to a message or program component. This can be a program that has been specifically created to effectively suit the target population’s level of knowledge and motivation. It involved an assessment of an individual’s current stage of change and accounts for relapse in a person’s decision-making process.

2.2.2 Understanding change

Zimmerman, Olsen and Bosworth (2000) explained that the Stages of Change approach has been used in variety of behaviours includes smoking cessation, exercise behaviour, contraceptive use as well as in dietary behaviour. Furthermore, a brief counselling session of five to fifteen minutes has been effective in providing support counselling to patients. Thus, physicians need to be reminded that behaviour change is rarely a discrete and a single event. Sometimes patients experiencing medical crisis are advised to change and comply readily. More often, physician encounters patients who seem unable or unwillingly to change. In the past, behaviour change has come to be understood as a process of identifiable stages through which patients pass.

Physicians and other health care professionals including social workers can enhance those stages by taking specific actions. If all health care providers understand this process, it could provide them with additional tools to assist patients
who were often feeling discouraged. These individuals may need support to enhance behaviour change.

These stages of change were discussed as follows:

2.2.2.1. Pre-contemplation stage

According to Zimmermann et al. (2000), in this stage the patient might seem uninterested, unaware or unwilling to make a change, and does not consider changing. Patients for example, smokers might not see that this advice applies to them personally since they are in denial. Patients may appear argumentative or hopeless therefore, the physician may try several times to convince them to change.

2.2.2.2 Contemplation stage

This is the stage where the person becomes aware that there are no benefits in the situation where he is, but still does not consider changing risky behaviour. Zimmermann et al. (2000) further continued discussing these stages by explaining that during the contemplation stage, patients are ambivalent about changing the risky behaviour. They give up any enjoyed behaviour that caused them to feel a sense of loss despite the perceived gain. During this stage, patients assess the barrier in the process of change such as time, expenses, fear as well as the benefits of change.

2.2.2.3 Preparation / Determination stage

At this stage, the patient prepares to change for instance, within the next 30 days. A patient may experiment with small changes as the determination to change increases. For instance, an alcoholic client who came for a follow up counselling session can be
requested to give feedback about what has happened in the past week with regards to his attempts to stop drinking. The client can give a positive feedback and report that, instead of going to the bar for a drink he has joined a church choir. Through this stage, the client can be praised and be encouraged to continue keeping up the changed behaviour.

2.2 2.4 Action stage

For Boston University School of Public Health (2013), this is the stage where people who have changed their behaviour and intends to keep moving forward with the behaviour change. People may exhibit this by modifying the risky behaviour and start with the healthy behaviour. For instance, the client can be assisted in drawing up a plan of activities that can keep him busy in order to draw his attention away from the risky behaviour.

2.2.2 5 Relapse from changed behaviour

Relapse is common during lifestyle changes. The therapist can explain to patients that even though a relapse has occurred, the person has learned something new about self and about the process of changing behaviour. The aim is to support patients to re-engage their efforts into the change process. Social worker can also add some tools to encourage behaviour change such as setting up the agenda for next discussion or give patient homework to do. The field promoters, community counsellors and DOTS supporters can also be involved as well. These groups of supporters represent the TB patients in the community and at home. They provide support to encourage individuals to complete the TB treatment.
According to Boston University School of Public Health (2013), in order to progress through these stages of change, people apply cognitive, affective and evaluative processes. These processes result in strategies that can help people make and maintain change. The processes mentioned above, include interventions that explain how to involve other people in the helping process.

2.2.2.6 Maintenance and relapse prevention

This stage involved the incorporation of new behaviour over a long period of time. The person needs to work on the changed behaviour to prevent relapse to earlier stages. However, patients may find themselves cycling through these stages of change several times before the change truly is established.

2.2.2.6.1 Involving others

The doctors and other health professionals can train family members on how to intervene with their loved one’s risky health behaviour. They can consult with other professionals such as social workers, to reinforce the message that a change in behaviour is needed. Social workers provide additional education and skill to the patient to strengthen the patient’s coping capacity. Referral to other health professionals can help to reduce the patient care burden for physicians. The helping professional needs to document the content and outcome of patient conversations, including specific tasks and plans for follow up session (Zimmermann, et.al. 2000).

According to Liefooghe, Suetens, Meulemans, Moran and De Muynck, (2009), intensive counselling by social workers, can improve treatment adherence.
This intervention includes counselling at the beginning of the treatment, throughout the treatment as well as at the completion of the treatment. Counselling can be combined with health education and can include strategies to strengthen patients’ self-efficacy. This can be done through group therapy that can be conducted jointly by occupational therapist, social worker and nurses. These authors defined counselling as a process that consists of improving patients’ knowledge about TB. It also includes its curability, in enhancing patients’ belief in their ability to complete treatment. Through the process, patients develop problem-solving skills to overcome non-supportive family and community environment. During the counselling process, patients receive permanent support to continue with the treatment in order to overcome problems that may jeopardise adherence. It was therefore concluded that intensive counselling is significant, although limited and impacted on the treatment adherence.

For the researcher, the social work intervention can be done with TB patients to identify problems and provide psycho-social support as well as support counselling.

Hence, the network for patients involving TB medical staff, social workers, psychologist, family members and friends, need to be developed and institutionalised at country level to enhance successful treatment outcomes.
2.3 NATIONAL GUIDELINES FOR THE MANAGEMENT OF TUBERCULOSIS IN NAMIBIA

According to the MoHSS (2012), TB is the commonest cause of death among all infectious and curable diseases worldwide. It stated that Namibia still has an alarmingly high TB burden, when it reported 12,625 TB patients in the year 2010. It further reported that in 2009 alone, 1,044 people were reported to have died while they were on TB treatment. However, the report revealed that there has been a significant progress in ensuring that TB patients completed their treatment successfully. Despite that, an increasing number of patients have become difficult to be cured because they developed multi-drug resistant tuberculosis (MDR-TB). As a result, this form of TB has become the greatest threat to achieve the global and national TB control targets.

According to James et al. (2011), treatment interruption is a significant cause for resistance. Therefore, treatment programmes should have resources to track and prevent defaults. Again, it was explained that in order to reduce MDR-TB default, decentralisation of MDR-TB treatment should be considered either by creating community-based treatment programs or satellite in-patient centres. Moreover, the WHO (2008) clarified the duration of treatment and stated that the recommended duration of MDR-TB treatment is guided by smear culture conversion. The minimal recommendation is that MDR-TB treatment last for at least 18 months after culture conversion. It can be extended to 24 months in chronic cases with extensive pulmonary damage.
According to MoHSS (2012), the MoHSS through the Directorate of Special Programmes (DSP) is responsible for the overall co-ordination, implementation, monitoring and evaluation of TB and Leprosy. This directorate is headed by a director and its two divisions namely; Health Sector Response and National AIDS Coordination Programme Secretariat. These divisions are headed each by a deputy director respectively. The Health Sector Response division comprises of three sub-divisions namely; National HIV/AIDS and STI Programme, National Tuberculosis and Leprosy Programme (NTLP) and National Vector-borne Disease Control Programme (NVDCP). Each of these sub-divisions is headed by a Chief Medical Officer (CMO) assisted by a Chief Health Programme Administrator (CHPA) and Senior Health Programme Administrators (SHPA). It has been reported that in the regions, all Regional Directorate Management Teams (RDMT) are responsible for coordinating TB control at regional level. The RDMT support and oversee TB control activities at district level. Medical doctors are responsible for diagnosing complicated forms of TB including sputum-smear negative and extra-pulmonary TB (EPTB). Extra-pulmonary TB refers to a case where TB involve organs other than the lungs e.g. pleura, lymph nodes, abdomen, genitor-urinary tract, skin, joints, bones and meninges.

Sputum smear negative means when a patient with clinical feature of PTB and either:
- Have sputum that is smear negative but culture positive for *Mycobacterium tuberculosis*. Or

- Have at least two sputum specimens at the start of treatment that are negative for acid-fast bacilli (AFB) and clinicians decided to treat with a full course of anti-TB therapy (MoHSS 2012).

Medical Officers provide leadership to the clinical team in case management as well as in providing technical support to the District TB and Leprosy Coordinator (DTLC). Social workers provide psycho-social counselling and support counselling to patients who are experiencing social problems in the hospitals. They are involved in individual counselling and conduct group work with patients. The TB patients can be engaged in discussing issues affecting their lives for instance, discussion of social problems that they experience as TB patients. The social worker facilitates group work sessions as well. Through these group work sessions, patients can learn from each other. This will help them to find solutions for problems that they are experiencing.

The MoHSS (2009) reported that Namibia has one of the world’s highest incidences rates of TB infections. Its case notification rate (CNR) in the year 2007 was 722 per 100,000. The TB CNR is according to Chani, (2010) the number of TB patients diagnosed and notified per 100,000 populations during the specified period.

According to the MoHSS (2011), the DOTS has been the most cost effective public health approach to fight TB in Namibia especially in Oshakati district. The DOT is a process whereby TB patient swallow TB medicines in the presence of
another person who is observing the patient swallowing the medicines (MOHSS, 2012). Namibia adopted this strategy in the year 1995. Presently, this strategy has been implemented countrywide.

The targets for DOTS strategy are:

To achieve treatment success rate of more than 85% among smear positive TB cases detected.

To detect more than 70% of the estimated sputum smear positive TB cases.

The MoHSS (2008) has reported that in 2006, there were 15,771 TB cases in Namibia with a case notification rate (CNR) of 765 per 100,000 people. Again, MoHSS (2011) reported the reduction in CNR of 13,332 TB cases in 2009, which was equivalent to a CNR of 634 per 100,000 people.

According to Namhando (2012), in Intermediate Hospital Oshakati (IHO), TB was rated fourth among the top ten diseases that have caused mortality in 2009/2010 after it claimed 169 lives. In 2010/2011, it was rated third after it claimed lives of 172 people while in the year 2011/2012 it was again rated fourth after it claimed 147 lives. Again, Kakungulu (2012) reported that the TB defaulter rate for the year 2011/2012 was approximately 10.9% while the treatment success rate was approximately 86%. According to Kruk, Schwalbe and Aguiar (2008), default has been linked to the length and complexity of treatment as well as to the fact that most patients felt better after the first or second month of treatment. The DOTS strategy has been implemented in Oshakati District with the help of field promoters, community counsellors, family DOTS supporters as well as DOTS supporters at the
workplace. For example, in the Namibian Defence Force, patients who are receiving TB treatment are supported at workplace. These supporters help in strengthening relationships and encourage TB patients to complete their treatment.

2.3.1. ADVOCACY, COMMUNICATION AND SOCIAL MOBILISATION

According to MoHSS (2012), it is implementing an advocacy, communication and social mobilisation campaign throughout the country.

Advocacy

According to MoHSS (2012), advocacy seeks to ensure that national and local governments remain strong and committed to the implementation of TB control policies. It focuses on influencing policy-makers funders and international decision-making bodies through variety of channels. Different types of advocacy include; policy advocacy, programme advocacy, and media advocacy. Policy advocacy informs politicians and administrators on how the issue affects the country. In order to respond, the policy makers outline actions to take and improve laws and policies. Programme advocacy targets opinion leaders on the need of local action. Media advocacy validates the relevance of the subject. It puts the issue on the public agenda, encourage the media to cover TB-related topics regularly in the responsible manner and raise awareness on possible solutions to problems.
Communication

In addition to advocacy, the MoHSS has also included Behaviour-Change Communication as an approach in implementing the TB programme. According to MoHSS (2012), behaviour change aims to change knowledge, attitudes and practices among various groups of people. It frequently informs the public on different health services and the latest medical interventions available. This is done with the aim to hear from individual people about their suggestions on how to improve the situation. These suggestions include the required information; the recommended strategy to improve communication in order to make sure that the message is implemented by all people involved. Behaviour change communication aims to change behaviour and persuade people to seek treatment as soon as they start to show symptoms of the TB.

Social mobilisation

According to the MoHSS (2012), social mobilisation brings together community members and other stakeholders to strengthen community participation for sustainability and self-reliance. As a result, empowerment of TB patients and affected community helps to achieve timely diagnosis and treatment completion, especially among families of TB patients. Through social mobilisation, all stakeholders in TB are trained to build their capacity so that they can continue to support all TB patients. The stakeholders should encourage patients to complete treatment, provide counselling and monitor the treatment progress and patient wellbeing.
2.4 WHAT IS TUBERCULOSIS?

Tuberculosis (TB) is an infectious disease caused by bacteria called *Mycobacterium tuberculosis*. The disease most commonly affects the lungs but can involve almost any organ of the body such as kidneys, bones, the lining of the brain and spinal cord.

Today, TB can be treated successfully with antibiotics (Schiffman, 2011). In addition, treatment for new cases of drug susceptible TB consist of a six month regimen of four first-line drugs; isoniazid, rifampicin, ethambutol and pyrazinamide.

Treatment for multidrug-resistant TB (MDR-TB) is defined as resistance to isoniazid and rifampicin (the two most powerful anti-TB drugs). This treatment is longer and requires more expensive and toxic drugs. For most patients with MDR-TB, the current regimen recommended by the WHO lasts for 20 months. It further states that no effective vaccine existed to prevent TB in adults. In the past decade, it was mentioned that it might be possible that at least one new vaccine could be licensed by 2020 (WHO, 2012).

2.5 HOW DOES A PERSON GET TB?

A person can become infected with the TB bacteria when he/she inhales particles of infected sputum from the air. The bacteria can get into the air when someone who has TB lung infection coughs, sneezes, shouts, or spits. A person who is nearby the infected person can possibly breathe the bacteria into the lungs. However, the person will not get TB just by touching the clothes or shaking the hand of someone who is
infected. Tuberculosis is primarily transmitted from person to person by breathing infected air during close contact (Schiffman, 2011).

Furthermore, anyone can get TB but certain people are at high risk. These people include people who live with individuals who have active TB infection as well as poor or homeless people. The people from countries that have high prevalence of TB, nursing home residents or prison inmates are also at high risk of infection. Again, alcoholics and intravenous drug users, people with diabetes, people suffer from certain cancers and HIV infected persons as well as health care workers are also at high risk.

The usual symptoms that occur with an active TB infection are a generalized tiredness or weakness, weight loss, fever and night sweats. There is no strong evidence for a genetically determined inherited susceptibility for TB (Schiffman, 2011).

2.6 HOW CAN TB BE PREVENTED?

According to the WHO (2008), prevention of TB includes interventions to reduce transmission and to reduce the risk of TB in infected persons. Some of the interventions result in specific activities of TB control programmes. These activities are such as contact tracing, detection of sources, infection control, preventive therapy, BCG Vaccine and treatment of HIV infected persons with ARV.
2.7 THE GLOBAL CONTEXT FOR TB

The WHO (2012) presented the key findings of the latest information and analysis about TB epidemic and progress in TB care and control at global, regional and country level. However, the global burden of TB remains enormous. In 2012, there was an estimated 8.7 million new cases of TB (13% co-infected with HIV). The number of 1.4 million people died from TB. These number included almost one million deaths among HIV negative individuals and 430 000 among people who were HIV positive. It was discovered from this report that TB has become one of the top killers of women, with 300 000 deaths among HIV negative women and 200 000 deaths among HIV positive women in 2011.

Geographically, the burden of TB is highest in Asia and in Africa. The African Region has 24% of the world’s cases, and the highest cases and deaths per capita. Worldwide, 3, 7% of new cases and 20% of previously treated were estimated to have MDR-TB. The highest proportions of TB patients with MDR-TB are in Eastern Europe and Central Africa. Almost 80% of TB cases among people living with HIV reside in Africa. In addition, TB remains a major global health problem which causes ill health among millions of people each year. This disease ranks as the second leading cause of death from an infectious disease worldwide, after the Human Immuno-deficiency virus (HIV). It was also reported that there were 9 million new cases in 2011. Again, there were 1.4 million TB deaths despite the availability of treatment that will cure most cases of TB.
The World Health Organization (WHO) declared TB a global public health emergency in 1993. Since the mid-1990, many efforts to improve TB care and control were intensified at national and international levels. The WHO developed the DOTS strategy, which is a five component package. This package comprised of the political commitment. It diagnosed the disease using sputum smear microscopy and a regular supply of first line anti-TB drugs. The package further consisted of short course chemotherapy and a standard system for recording and reporting the number of cases detected by the National TB Control Programmes (NTPs) as well as the treatment outcomes.

Within a decade, almost all countries adopted the strategy. There has been a considerably progress towards global targets that was established in 2005. In 2005, the numbers of cases reported by NTPs grew to over 5 million and treatment success rates reached 85%. The WHO’s recommended an approach to TB care and control that is the “Stop TB Strategy”. This strategy was launched in 2006. It was linked to the new global targets for reductions in TB cases and deaths. These targets were set for 2015 as part of the Millennium Development Goals (MDGs) by the Stop TB Partnership. The targets involved plans that TB incidence need to be falling by 2015. Its prevalence and death rates should be halved in comparison with their levels in 1990 (WHO, 2012). According to Jakubowiak et al. (2001), NTP is a tool for TB control strategy implementation within the national health system. It is a vehicle for DOTS strategy which plans that activities are designed to achieve efficient case finding and treatment of TB patients. For the patients, the purpose of the NTP is to
cure the disease by quickly restoring their capacity for activities of daily living and to allow them to remain within their families and communities. For the community, the purpose of the NTP is to stop the spread of TB infection in the community in order to prevent costly public health crisis.

Further, Cramm, Finkelflugel, Moller and Nieboer (2010) also agreed that TB is a global health concern and a major cause of death worldwide. This was resulted by the fact that it is accompanied by Human Immunodeficiency virus / acquired immune deficiency syndrome (HIV/AIDS) by population increase. However, TB is most prevalent and has been increased by the poverty situation. Furthermore, Garada, Penna, Perez-Porcuna, Souza and Marreiro (2012), explained that mortality rates were among TB patients who discontinued treatment, especially when associated with HIV infection. Therefore, receiving sufficient explanation on TB make patients to understand treatment requirements, explain likely side effects to be encountered when using anti-TB drugs and propose for the need to comply with treatment.

In 2011, Pardesi conducted a study that explained that default was one of the unfavourable outcomes for patients on DOTS that represent an important challenge for TB control programme. Furthermore, this study reported that inadequate treatment adherence was considered as a potential cause of drug resistance. In 2005, Waisbord conducted a study that concluded by saying that
understanding patient’s behaviour is fundamental. This is important in designing interventions that help in strengthening TB control programs which includes communication interventions. The author further suggested that communication interventions should identify key problems, reasons for adherence and intended audience. As a result, this study concluded that a wider perspective is needed. These perspectives were needed to understand how they can contribute to minimize behavioural barriers. The behavioural barriers improve case finding and treatment adherence rate particularly amongst the at risk populations.

According to the WHO (2008), the NTPs can play a role in attempting to alleviate the impact of overcrowding, HIV infections, poor nutrition, smoking, diabetes and alcohol abuse which are risk factors of TB infections.

2.8 FACTORS INFLUENCING THE GLOBAL INCREASE OF TB

According to Gebre-Mariam (2009), many factors might play a role in the increase of TB worldwide. This may include socio-demographic factors such as the increase in population worldwide. In addition, this occurs to a higher extent in populations where the prevalence of TB is already high and an increase in poverty is experienced worldwide. Therefore, an increase in poverty may result in overcrowding, under nutrition as well as in an increased susceptibility and transmission of the TB. Similarly, the HIV epidemic has been occurring mainly in areas that were already affected by TB and has resulted in significant increase in case rates.
2.9 FACTORS THAT AFFECTS TREATMENT NON-ADHERENCE

The literature has indicated many factors that affect treatment interruption and default as well as non-adherence. These factors were grouped into related factors that included socio-economic factors. Other factors involved health care, the condition in which patients find themselves, the factors with regards to treatment as well as factors related to the patient as a person.

2.9.1 Application of common interruption and default factors to the current study

According to Franke et al. (2008), the implementation for intervention is designed to facilitate the treatment completion for vulnerable groups that are crucial to the success of programmes to provide long-term therapies. Dias et al. (2013) stated that emotional support that has been provided by family and health care professionals is considered essential to treatment adherence and completion. As a result, participants in this study revealed that friends and colleagues sometimes distanced themselves from patients for fear of being infected with TB. According to Pachi, Bratis, Moussas, and Tselebis (2013), studies have reported high rates of depression and anxiety among TB patients. These were most likely related to stigma, inadequate social support as well as the psychological impact of chronic diseases.

The American Society on Aging and American Society of Consultant Pharmacists Foundation (2006) grouped the factors affecting medication adherence in five groups as follows:
Social and economic factors
Health care related factors
Condition related factors
Therapy related factors
Patient related factors

In addition, the American Society on Aging and American Society of Consultant Pharmacists Foundation (2006) states that medication adherence was related to people’s knowledge and beliefs about their illness. People’s motivation and confidence in their ability to manage illnesses, their expectation towards treatment outcome and consequences of poor adherence also boost people’s morale to adhere to treatment. The factors mentioned above have been discussed as follows:

2.9.1.1 Social and economic related factors

This includes circumstances such as family environment and support, other social networks, cultural aspects, economic situation, income and financial issues of patients. According to Hayden (2010), patients need to have knowledge, positive attitude and skills to follow the appropriate treatment. The RX Canada (2007) suggested that in order for the treatment to be successful, patients need to learn about medication, stick to the treatment schedule, and follow directions provided by health care providers. Furthermore, Behera & Balamungesh (2006) revealed that default has been found to be common in joint family, perhaps due to the lack of individual care when many members share a common economy. According to Endjala (2011), patients with little or no family support tend to interrupt or default from the treatment
and get sick often. It is therefore suggested that family members should support patients by reminding them to take medicine and ensure that it is taken correctly and at the right time. Najera-Ortiz, Sanchez-Perez, Ochoa-Diaz-Lopez, Leal-Fernandez and Navorro-Gine (2012) explained that the high attrition rate of follow up patients was caused by population movements. They further explained that migration of patients was mainly due to economic factors e.g. patient migrate to another town. In some instances, patients have been accompanying their relatives to look for job opportunities or some rural patients move to urban areas looking for better health care.

According to Cummings, Mohle-Boetani, Royce, and Chin (1998), patients who moved defaulted more often than those who did not move. Thus, failure to complete treatment prolongs the mobility of individual patient and facilitates transmission of TB.

Shargie and Lindtjorn (2007) indicated that distance goes hand in hand with other factors such as feeling better; loss of hope, unaffordable transportation cost and drug side effects. However, the MoHSS (2012) stated that the health services and social welfare professions have a collective responsibility of ensuring that patients started on TB treatment take all their medicines as prescribed. This is very important as TB treatment is quite demanding for the patient. It further explained that the daily intake of medicines for a period of 6 to 8 months can be very difficult for most patients. It has been commonly observed that patient without strong and continuous psychological support from nurses, social workers, physicians, close relatives and the community tend to interrupt or default the treatment. It is therefore important to
support each TB patients in such a way that this treatment becomes more attractive. This will make it easier for patients to complete TB treatment rather than stop it before they are cured.

2.9.1.2 Health care system related factors

These factors explained the relationship between patients and health care providers. The MoHSS (2012) has put established gold standards for managing TB by encouraging nurses and clinicians to create a patient-centred service delivery system. This system should be well accessible (geographically, culturally and financially) patient-friendly, compassionate, creative, and convenient for each patient. According to Hayden (2010), health care providers need to follow an established guideline in the prescribed regimen to ensure that patients understand reasons for taking the prescribed medication. Service providers should explain possible side effects, how medicines are taken, and ensure that treatment is as simple as possible. Nackers et al. (2012) suggested for an introduction of tools that may assist in supporting and monitoring adherence to TB treatment. These tools include communication devices such as mobile phones that can be used to call or send short messages to patients to remind them to take medication.

Further, the MoHSS (2012) has set up a program for tracing of patients interrupting treatment. This program is also implemented in Oshakati district. The procedure is explained that, when a patient did not turn up for daily DOT appointment or for collection of a weekly or 2-weekly medicine supply, efforts to
trace the patient starts as soon as possible. This is implemented because the patient who interrupts the treatment can be regarded as a potential defaulter. After the patient has been traced, the reason for treatment interruption is established and treatment can be continued as before.

However, Osterberg and Blaschke (2005) further proposed that addressing the long waiting time, may involve health care providers to make follow up visits convenient and efficient to patients. Lack of communication in local languages comes across as an issue of health care provider attitudes towards minority people in Zambezi Region. This has taken place because most health workers were from other ethnic groups and do not speak local languages or understand the local cultures well (Van Rooy et al. (2012). The Medical Research Council (2009) also agreed that some studies have reported communication barrier or poor communication between patients and providers as being linked to non-adherence.

The WHO (2008) has placed an emphasis that services providing TB care should offer full support to patients to ensure that treatment is completed. Therefore, staff members should identify and address situations that may make patients to interrupt or stop treatment.

### 2.9.1.3 Condition related factors

This may include chronic medical conditions, lack of symptoms and mental health problems. According to Kaliakbarova et al (2013), the availability of psychological counselling to patients was support modalities for improving adherence to treatment.
In addition, Behera and Balamungesh (2006) have found that the most important cause of failure for anti-TB therapy is that patients fail to take medication as prescribed. Therefore, Hasker et al. (2008) emphasised that default should be reduced by shortening the duration of in-patient treatment and improving the referral between in-patient facilities and the Primary Health Care (PHC) services.

2.9.1.4 Therapy related factors

These include issues such as that the TB treatment may require certain procedures such as injection or inhalers, the duration of treatment, unpleasant side effects and that treatment may interfere with patient’s lifestyle. According to Slama, Tachfouti, Obtel, and Nejjari (2012), adherence to the long course of treatment is a complex dynamic phenomenon with a wide range of factors impacting on patient’s treatment taking behaviour.

Osterberg and Blaschke (2005) disagreed and pointed out that some physicians also contribute to patient’s poor adherence. These physicians prescribed complex regimens, fails to explain benefits and side effects of medication adequately. However it was stated further that they seem not consider patient’s lifestyle, and seem to have poor communication skills or relationships with patients. The study suggested that methods to improve adherence should include patient education and improved dosing schedule. Again, this can introduce increased hours when clinic is open which includes evening hours, shorter waiting times, and improved communication between physicians and patients.
According to Dooley et al. (2011), default patients may require intensified case management and education rather than more intensive treatment. Therefore, preventing the need for retreatment is the best strategy that social workers can do through individual counselling. This can be done by looking into specific situation where the patient finds himself in order to address those challenges that the patient is faced with. As a result, strategies to identify and address country-specific risk factors were warranted to maximise treatment success.

2.9.1.5. Patient related factors

These factors include knowledge of the disease, patient’s motivation and ability to take medication, stigma as well as alcohol and substance abuse. According to Chani (2010), when one is under the influence of alcohol, one is likely to forget to take medication. Physicians should always explore alcohol and substance use in all the patients and any indications of such behaviour would enable them to focus their treatment literacy on such patient. According to Garrido et al (2012), alcoholism has been identified as an important predictor of treatment default in several continents. This study revealed that people who use alcohol have a greater risk of treatment default. Therefore, Gelmanova et al. (2007) have suggested that systematic studies using standardised and validated alcohol assessment instruments are needed. These assessment instruments have to ascertain the full impact of alcohol disorders on patient’s ability to comply with TB treatment.
The American Society on Aging and American Society of Consultant Pharmacists Foundation (2006) argued that the common belief that patients are responsible for taking medication reflects a misunderstanding of how factors affect people’s medication-taking behaviour and capacity to adhere to treatment regimens. Elbreer, Guwatude, Mudiope, Nabbuye-Sekandi and Manabe (2011) have concluded that counselling of patients is required to reduce TB treatment default. According to Dias et al. (2013), health care professionals should be aware of ways TB treatment affects patients’ psychosocial life. The health care professionals need to develop strategies to mitigate the effects and provide opportunities for patients to share their anxiety and sufferings. However, Endjala (2011) argued that some patients might stop going to the treatment centre because of the fear for daily injection.

Again, Liefooghe et al. (2009) are of the opinion that informational and motivational impact of counselling has the potential to unleash mechanism. This mechanism can in the long run, reduce the stigmatisation of TB. The presence of stigma and discrimination in a community may act as barriers to patients disclosing their disease to family or community members. These family or community members might be needed to provide psychosocial support to the patient. Stigma therefore may result in delay in seeking treatment or taking treatment inconsistently or incorrectly (Chani, 2010). According to the Medical Research Council (2009), additional qualitative studies among patients and providers have identified stigma as a likely barrier to adherence to treatment. According to Dias et al. (2013), although TB is curable, it was still stigmatised. This study understands meanings provided by
participants themselves since it has found that TB still cause patients to suffer from fear of transmission, social prejudice and death.

According to Gelmanova et al. (2013), counselling and education should involve psychosocial support, group therapy, patient education with or without family involvement. Again, it can include peer support groups, provision of psychiatric care with regular psychiatric assessment and substance abuse as well as any specialist support. The study by Liefooghe et al. (2009) has found that patients who received TB adherence counselling right from the start of the treatment adhere better than those who were not counselled. Therefore, counselling was regarded to be an effective tool for enhancing adherence to TB treatment.

Najera-Ortiz, Sanchez-Perez, Ochoa-Diaz-Lopez, Leal-Fernandez and Navorro-Gine (2012) presented results on factors related to survival from TB treatment. They argued that patients of 45 years and over have poor survival of TB and concluded that their poor survival is associated with their age. On the contrary, The American Society on Aging and American Society of Consultant Pharmacists Foundation (2006) disagreed by stating that age by itself is not a determining factor in medication adherence. It stated that many factors can combine to render older persons to adhere to treatment.
2.10 POTENTIAL INTERVENTIONS TO ADDRESS TB TREATMENT ADHERENCE

According to Hasker et al. (2008) certain groups may require special attention. These include the jobless, pensioners, homeless and alcoholics. Therefore, pensioners and unemployed need specific measures such as systems of social support including the use of incentives and enablers. Torzek, Cox, Ducres, Cooke, and Ford, (2012) reviewed and identified several simple inexpensive interventions that have potential to reduce default. These interventions included decentralisation of service, providing patient education and packages of adherence intervention.

The Medical Research Council (2009) summarised potential interventions to address TB treatment adherence in the table as follows:

**Table 2.1: Potential interventions to address TB treatment adherence**

<table>
<thead>
<tr>
<th>Default factor</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social and economic related factors</td>
<td>Assess social needs of each patient</td>
</tr>
<tr>
<td></td>
<td>Tracing of those who missed their appointments</td>
</tr>
<tr>
<td></td>
<td>Provide incentives e.g. temporary disability grant</td>
</tr>
<tr>
<td>Health care related factor</td>
<td>Continuous training of staff to improve communication between staff and patients</td>
</tr>
<tr>
<td>Condition related factors</td>
<td>Provide education on the use of medication</td>
</tr>
<tr>
<td></td>
<td>Provide effective counselling</td>
</tr>
<tr>
<td></td>
<td>Develop and use educational tools that are suitable</td>
</tr>
</tbody>
</table>
| Therapy related factors | Involve DOT supporter and family members in education and counselling about TB  
| Carefully monitors patients who previously interrupted or defaulted and motivate them to complete treatment  
| Educate patients on the duration of treatment |
|-------------------------|--------------------------------------------------------------------------------------------------------|
| Patient related factors | Screen patients for alcohol abuse and dependency  
| Incorporate behaviour change interventions  
| Use prompts to encourage adherence  
| Provide incentives and peer support |

2.11 STRATEGIES IMPLEMENTED TO CONTROL TB

2.11.1 Patients receiving other medical treatment together with TB treatment.

An HIV infection is the highest risk factor for progression from latent TB infection (LTBI) to TB. The LTBI is the state of having a small number of live TB bacilli in the body which are unable to grow due to control by immune system. These bacteria are inactive, but can become active later. It does not cause a person to become sick and there are no symptoms of the TB (MOHSS, 2009). People living with HIV (PLHIV) may become infected or re-infected with *Mycobacterium tuberculosis* when exposed to someone with infectious TB. Persons infected with TB/HIV co-infection have approximately 10% risk per year of developing active TB. Other medical conditions which lead to increased risk of developing TB from LTBI include
silicosis, diabetes mellitus, malignancies, chronic renal failure, and all other diseases which compromise the immune system. According to Shastri, et al. (2013), co-infected patients who were already on ART demonstrated better outcomes than those not on ART. These authors further explained that if you compare those patients with TB only and those who are co-infected patients, they will have similar TB treatment success rate of treatment default and failure. Therefore, it was concluded that integration of TB/HIV collaborative activities will strengthen the battle to control TB and HIV globally.

2.12 SUMMARY
The TB disease is a major global health concern. It can be cured if patients take their treatment correctly for a minimum of six months and a maximum of twenty four months. The WHO developed a DOTS strategy that advocates for the monitoring of patients by administering treatment in the presence of a treatment supporter. This strategy was almost adopted by all countries. Namibia adopted the DOTS strategy in 1995. The TB is also a major cause of death in Namibian Hospitals. At IHO, TB was rated fourth among the top ten causes of death in the year 2011/2012 with the default rate of approximately 10.9% and the treatment success rate of approximately 86%. A conceptual framework with a TTM has been discussed to address the issue of behaviour change in patients. The factors that effects treatment interruption and default were discussed. Since TB treatment takes long to be cured, patients need support from health care providers in order to help them adhere to treatment.
The researcher is of the opinion that more qualitative studies need to be done on the effects of medication to explore more on the side effects as well as on the coping capacities of those patients who were cured from TB.

In the third chapter, the research design and methodology guiding the study are discussed.
CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

Chapter 2 included a literature review of existing literature related to the topic under discussion. In this chapter, the research design and methodology was discussed in detail covering population, sample, instrumentation, data collection and analysis, ethical considerations as well as credibility and trustworthiness of the study.

3.2 RATIONALE FOR THE DESIGN OF THE STUDY

De Vos, Strydom, Fouche and Delport, (2005) described a research design as the option available to qualitative researchers to study certain phenomena according to certain “formulas” suitable for their specific research goal. The researcher have chosen to conduct a qualitative study because the topic selected needed to be explored more in order to get a detailed description of the problem. According to Creswell (1998), undertaking a qualitative research requires a strong commitment to study a problem and demands more time and resources. Moreover, the researcher may select to conduct a qualitative study because the topic needs to be explored and be understood in depth.

The current study utilises a phenomenological research design. Neill (2006) explained that phenomenological research design described the structure of experience that presented itself to consciousness without recourse to theory, deduction or assumption from other disciplines. For Sarantakos (1997), phenomenology stems from philosophy and Husserl’s work. It is a methodology that
aims at understanding everyday life by means of unravelling taken for granted assumptions. This is an exploratory study of patients who interrupted or defaulted from the TB treatment. The treatment may have been interrupted for four weeks or eight months and more between January 2012 and March 2013 in Oshakati District. According to Del Siegle (n.d.), one cannot understand human behaviour without understanding the framework within which the subjects interprets their thoughts, feelings and actions. However, qualitative researchers are concerned primarily with the process rather than outcomes or products. Therefore, they are interested in understanding how people make sense of their lives.

In this study, the researcher created a research strategy that was best suited to the research, and then designed the research project around the selected strategy (De Vos, et.al, 2005). This study aimed at understanding and interpreting the essence of the meaning that the subjects gave to their daily lives. It therefore, explores how treatment interruption and default affect TB patients in Oshakati district.

According to Paul (2010), in a phenomenological study, the participants need to be carefully chosen to be individuals who have experience in the phenomenon. The phenomenon is according to Cresswell (1998), a central concept that is being examined by a phenomenologist. It is the concept that is being experienced by the subjects in the study, for instance, a psychological concept such as grief, anger or love. Therefore, the researcher needs to decide how and in what way his or her personal experiences will be introduced into the study. According to
De Vos et al. (2005), phenomenological studies are mainly conducted by means of naturalistic methods of study, analysing the conversations and interactions that researchers have with the subjects. They further states that researchers who utilise this strategy of interpretive enquiry will mainly use participant observation and long interviews (with up to ten people) as a method of data collection. Therefore, this study was conducted to gain a better understanding of the lived experience of TB patients. The data was collected from ten TB patients using semi-structured interviews.

According to Sarantakos (1997), qualitative research has strengths and weaknesses. **The following are the strengths of qualitative research:**

- It is researching people in the natural setting, which means that participants are interviewed at the place where they live.
- It is stressing interpretations and meanings because the researcher seeks to understand meaning in event and in human interactions.
- It is achieving a deeper understanding of respondent’s world.
- It allows a higher flexibility.
- It presents a more realistic view of the participant’s world.

**The weaknesses of the qualitative research are as follows:**

- There is a risk of collecting meaningless and useless information
- It is time consuming.
- Findings cannot be the representation and the generalization of the whole population.
There might be problems with objectivity.

3.3 CONTEXT

The context of this study was to examine the lived experiences of TB patients in Oshakati District in Oshana Region in Namibia (see Figure 3.3.1. The Map of Namibia). According to Moustakas, (1994) (as cited in Creswell, 1998), the term ‘lived experience’ is used in phenomenological studies to emphasise the importance of individual experiences of people as conscious human beings. The researcher wants to explore and discuss issues that have influenced TB patients to stop taking their medication. These issues need to be identified so that strategies can be developed to address them in future. The next Figure 3.3.1 will show the Map of the Namibian Country showing all the regions in Namibia including Oshana Region where Oshakati district is situated.
Figure 3.3.1: The Namibian Map
3.4 OSHANA REGION

The Oshana region is a region in the north-western part of Namibia. It shares boundaries with Omusati, Ohangwena, Kunene and Oshikoto. The next figure on the following page (Figure 3.4.1) will show the Map of Oshana Region, Namibia.

Figure 3.4.1: The Map of Oshana Region, Namibia.

According to the National Planning Commission (2012), the population of the Oshana region is approximately 174,900 people. Its area is 8647 square kilometres. Intermediate Hospital Oshakati is a 750-bed hospital with a catchment population of almost
200,000 people. The researcher conducted the study at Oshakati District in Oshana Region. Oshakati District has only one hospital that is a District hospital as well as a Regional Referral Hospital for Oshana, Omusati, Ohangwena, Oshikoto and Kunene Regions respectively. Intermediate Hospital Oshakati (IHO) as a Referral Hospital in Oshana Region, is receiving patients from five health centres, eleven PHC clinics, forty seven outreach points, eleven Constituencies and three Towns. The hospital is currently undergoing major renovations and it is believed that after its completion, it will have more than 1000 beds.

Patients who presents with symptoms of TB are investigated at the health centres and clinics and are referred to district hospital for the initiation of treatment. Once the diagnosis of TB is confirmed, their names and details are entered in the District TB Register and a treatment card is opened. Follow up of TB treatment with patients who are stable is done at the nearest health facility. The very sick patients and those who live far from the health facilities are admitted in the TB Unit where male and female are admitted in separate wards for treatment.

In a 2010 study conducted by Amoomo, it was reported that IHO had a catchment population of approximately 186,754 in the year 2010. According to the most recent HIV sentinel survey the HIV prevalence rate in Oshana Region is 25,1% among pregnant receiving services at public Antenatal Clinics (ANC) (MoHSS 2012). In 2012, the TB default rate for IHO was approximately 10,9% while the TB success rate was
approximately 86% (Kakungulu, 2012). Thus, Oshakati district where IHO is situated as a district hospital was chosen for the study because of the need to find out why 1 in 10 patients interrupt or default from their treatment regimen. Tuberculosis is an infectious public health disease, therefore the public need to be protected from it hence the need for this study.

3.5 POPULATION AND SAMPLE

The study population and sampling will be covered in this sub-section. A target population is “the concretely specified large group of many cases from which a researcher draws a sample” (Newmann, 2011, p. 246). The target population for this study consists of TB patients (Pulmonary, and MDR-TB) adults whose treatment was interrupted for four weeks as well as those who defaulted from their treatment. Patients whose treatment was interrupted were included in the study because they were seen as potential defaulters. The researcher has included them for future development of prevention strategies that may help TB patients to adhere and complete their treatment.

3.5.1 Population

Population refers to individuals in the universe who possess specific characteristics, or to a set of entities that represent all the measurements of interest to the practitioner or researcher. These entities may be people, such as all clients comprising a particular worker’s case-load, or things such as all the research books housed in a specific library (De Vos et al. 2005, p. 193). The study population for the current study is the TB patients whose treatment was interrupted for a period of at least four to eight and more consecutive
weeks. (MoHSS, 2012). The researcher conducted the study at IHO which is a central point in the region where all TB patients who have been classified as treatment interrupts and defaults were admitted for treatment.

3.5.2 Sample

A sample is “a small representation of a whole” (De Vos, et al. (2005), p. 82). The sampling frame is “a list of cases in population or in best approximation of them” (Newmann, 2011, p. 246). According to Gebre-Mariam (2009), sampling in qualitative research is done to enhance and saturate theoretical sensitivity through strategic sampling, and not random sampling, as is the case with quantitative studies. This should result in adequate diversity and breadth of the matter that researcher wants to analyze.

Before the researcher started with data collection, permission to conduct research in Oshakati district was sought from the MoHSS through Oshana Regional Health and Social Services Director. After permission was granted, the researcher contacted the Registered Nurse in charge of the TB Clinic to provide information on the study and started with the preparations to collect data.

The researcher obtained primary information on patients whose treatment was interrupted for four weeks and those who default treatment from the Registered Nurse in charge of the TB Clinic and TB wards (male and female wards). All patients who were admitted in the TB Wards or recorded to have their treatment interrupted for four weeks and those who default treatment in Oshakati district were included in the sample. Most participants were interviewed in the TB wards where they were admitted for treatment. Only one participant was traced by the researcher and was interviewed at the workplace.
The sampling frame for the study consisted of ten patients whose treatment was interrupted for four to eight and more weeks during the period January 2012 to April 2013 in Oshakati district. The researcher used non-probability sampling techniques, specifically purposive sampling. Purposive sampling is a non-random sampling technique in which the researcher uses a wide range of methods to locate all possible cases of highly specific and difficult to reach population (Newmann, 2011). Ten patients were interviewed for the current study. In this study, the sampling frame consisted of all TB patient who interrupted and those who default their treatment. The researcher obtained information from the patient files. This information recorded patient’s names, hospital registration number, date treatment started, approximate time defaulted and date readmitted as well as date treatment restarted, demographic details, residential address and diagnosis. The researcher went first to the TB Clinic, which is situated in IHO to inform the Registered Nurse in charge about the intention to do the study. Only one patient reported at the TB Clinic and was admitted as a return after default. Thereafter, the researcher interviewed him.

Because of the low turn up of treatment interrupts and defaulters, the researcher went to other health centres in the district to check if there were patients who interrupted or default from their treatment. The researcher only found one patient at the alternative site, but this one needed to be traced as he was no longer receiving treatment at that specific health centre. This patient was categorised as a defaulter from the State facility. Thereafter, the researcher went to the TB wards to check if there were patient who interrupted or who defaults from their TB treatment who were admitted in the ward for treatment. The majority of treatment interrupters and defaulters were admitted in the TB ward in IHO where the researcher continued to interview them. In the TB Ward, information was
obtained from the admission book as well as from the patient’s files with the help of the Registered Nurse in charge.

3.6 RESEARCH INSTRUMENTS

The researcher used an interview schedule to direct and guide the semi-structured interviews during the data collection process. An interview schedule is a document used to guide interviews (De Vos, 2007). The interview schedule had 36 questions and was purposefully constructed to fully explore all possibilities of treatment interruptions and default. The interview schedule covered biographical data, information about the support available for TB patients. During the interview, the researcher explored on how patients understands TB and its treatment and their’ perceptions about interrupting or defaulting the TB treatment. The last part of the interview schedule explored more on patients’ suggestions to help increase positive treatment outcomes and minimise default. Further, exploration about the issues related to stigma and discrimination were also done to collect related data.

Participants were expected to provide insight on their experiences of being TB patients and to explain how they understood and coped with TB. The researcher conducted a pilot study with two male TB patients in the ward who were not included in the sample. These participants were interviewed to do the pilot test in order to see where further refinements were needed. After the pilot test, questions were modified and prepared for use in the semi structured interviews with study participants. The researcher interviewed all ten
participants alone and no any other person was used to assist the researcher to collect data. A copy of interview schedule can be found as Annex III.

3.7 DATA COLLECTION

Data collection is a process of collecting information from participants. After the sample was established, the researcher interviewed the participants in the TB Ward and at the Health Centre. The researcher collected data using an interview schedule which was semi-structured and consisted of open-ended questions. The biographical information was filled in by the researcher. The researcher tried to explore knowledge from participants on the support available to TB patients. Information on how patients understood disease and its treatment, their perception about TB treatment interruption and default as well as on stigma and discrimination were included. Although all these information were already part of the interview schedule, some issues that came up during the interview were explored to obtain a rich description of the issues under investigation. This has resulted in the interview schedule to contain 36 questions.

Informed consent was obtained from all participants before conducting in-depth interviews. The researcher also asked permission from participants to take notes while interviewing them. The interviews lasted for thirty to forty five minutes and the researcher took some notes for more clarity during the data analysis process. All these collected information has been stored for the study purposes only and cannot be shared among other people who are not part of this study. The researcher sampled until started hearing
repetition from participants. Padgett (1998) highlighted on the emphasis in a qualitative research explaining that it is on quality rather than quantity. It was further explained that qualitative researcher’s samples should not focus on fixed numbers. The researcher should know when to cease data collection once started to hear repetition from participants and no new information is being uncovered.

3.8 DATA ANALYSIS

During the data collection, and after all data were collected, the researcher transcribed the data to create a written record of interviews. This assisted the researcher in recalling important aspects of the interviews. The notes that were taken contained detailed information on the responses from participants. This was helpful as the researcher did the interviews in Oshiwambo. While interviewing the participants, the researcher was simultaneously translating the responses in English at the same time. This process was made easier because the researcher could fluently speak Oshiwambo and English. The researcher checked in with participants to make sure if their ideas that were translated in Oshiwambo have appropriately captured what they have said.

The analysis procedure which is a constant comparison approach contained four processes. First, the researcher read the entire volume of materials to understand their meaning. Next, an initial identification of key categories of data was developed based on initial understanding of the phenomenon. Thirdly, the researcher refined the classification system using categories, broke down transcribed data into meaningful units. The data was
further examined and put back together to make new connections between categories. Finally, the researcher analysed each category systematically, examined how it related to other categories, in order to validate relationships between categories. Further, the categories that needed further refinements and developments were identified (Cohen and Crabtree, 2006).

3.9 INSPIRATION FOR THE STUDY

Because of the researcher’s understanding of the literature review on this specific topic, it is understood that treatment interruption and default was influenced by several situations. These situations were patient related, therapy related, health care provider related, condition related and socio-economic related. Given that, these issues were explored and understood to explain how the study was committed to TB treatment interruption and default. These issues were analysed in the next chapter and further discussed in the last chapter.

3.10 TRUSTWORTHINESS AND CREDIBILITY

According to Padgett (1998), in qualitative research, these terms refers to the quality of a study in terms of trustworthiness of the findings. A study is trustworthy when it is conducted in a fair and ethical way. The findings of the study should closely represent the experience of participants.
The three main threats to trustworthiness are; reactivity, researcher bias and respondent bias. De Vos et al (2005) explained reactivity as unnatural reactions in the behaviour of respondents when they are observed. Researcher bias is according to Mouton, (2001) a very common problem in research because many methods involve choices on the part of the researcher about which data to observe or select and which data to ignore. Respondent bias is explained as the way the respondents behave in the data collection process for instance, participant may try to hide the truth or try to do everything or be helpful.

According to Newmann (2011), a researcher considers a range of data sources and employs multiple measurement methods. Therefore, Chani (2010), states that, if the same questions were administered to the same study participants at different times, the chances are very high that one would get the same responses. In this way, introduction of biases is reduced.

Padgett (1998) identified six strategies that can be used to enhance trustworthiness of qualitative research. They are; prolonged engagement, triangulation, peer debriefing and support, member checking, negative case analysis and audit trial. A discussion of the strategies applied by the researcher is as follows:

The researcher collected data until hearing the same information from study participants. In addition, the researcher gained insight into the context where participants understood and coped with the TB treatment. Triangulation was done by using multiple sources to understand a phenomenon. For theoretical triangulation, the researcher verified data with the use of literature control. Peer debriefing support has been called a “lifeline”
for qualitative researchers. During the process of data collection, the researcher received support from other researchers and make regular contacts with the supervisor to evaluate the progress in the research. The researcher went back to participants for follow up interviews to clarify some responses. Again, during data collection process, the researcher consulted patient’s files to find more information on the characteristics of the sample.

Audit trial means the creation of opportunities for others to understand how the researcher has come to the conclusion. The researcher went back to the field notes and transcripts, to create a record of the researcher’s conclusions to analyse the data.

3.11 ETHICAL CONSIDERATION

According to Padgett (1998), institutional requirements for protecting human ”subjects” are a necessary mechanism for ensuring that ethical qualitative research is carried out. The researcher is, however, of the opinion that it is very important that one should comply with professional ethics and research ethics when conducting the study. Before the study was conducted, approval was obtained from the Postgraduate Studies Committee of the University of Namibia. Permission was also obtained from the Ministry of Health and Social Services through the Oshana Regional Health and Social Services Directorate to conduct the study in Oshakati district. The researcher developed a consent form that the participants signed indicating that they voluntarily agreed to participate in the study, and were aware of their rights as participants. A copy of the consent form can be found as Annex I (an Oshiwambo translated consent form is also attached as Annexure II). The researcher used names that were made up in this study to protect the participant identities.
3.11.1 Informed consent

All ten participants read the consent form and signed it before they were interviewed. They were given an explanation of the content of the consent form. The aim of the study was also explained to them. Thereafter, all of them signed the consent form as an indication that they have agreed to participate in the study. The informed consent document was prepared in Oshiwambo, which was the primary language of participants.

3.11.2 Avoidance of harm to the respondents

To avoid harm to any participant, all participants were informed about their right to refuse to participate in the study without negative consequences. They were reassured that no treatment due will be withheld from them if they refuse to participate. The researcher was fully aware that some participants might become emotional or become tired especially those who are very sick. Participants were informed that once they become too emotional or become tired, they will be allowed to take a break or stop the interviewing session until they are ready to continue with the interview.

3.11.3 Violation of privacy

The researcher considered the issue of confidentiality and anonymity to ensure privacy. Participants were informed that no identifying information would be written on the interview schedule. While the researcher used names in the findings, this was done to increase the readability and personalisation of the findings. All of the names presented in the study were pseudonyms.
3.11.4 Deception of respondents

The researcher explained to all participants about the purpose of the study, the data collection procedure and how their information would be used. Thereafter, they were requested to sign a consent form as a way of accepting responsibility to participate in the study. Participants participated out of their own free will and were not compensated for participating in the study.

3.12 SUMMARY

This chapter discussed the rationale for the design of the study, with a specific focus on the population of the study, the sample and sampling method. It further concentrated on the research instruments, data collection, data analysis, credibility and trustworthiness as well as on ethical issues. The findings of the study are presented in the next chapter.
CHAPTER 4

FINDINGS

4.1 INTRODUCTION

The previous chapter explained methodology used in this study. In this chapter, the data was analysed and interpreted as it is. Before the data analysis process, the researcher introduced the characteristic of the sample. The categories were also identified and divided into sub-categories, which were explained and supported by quotes from participants.

The main research question for the study was: *How does treatment interruption and default affects TB treatment among patients in Oshakati district?*

The sub-questions of the study were:

- How do patients understand TB and its treatment?
- What leads that some TB patients in Oshakati District still interrupt and default from treatment?
- What suggestions do participants have to increase successful treatment outcomes and minimize default?
- What support systems for TB patients exist in Oshakati district?

The interview schedule was divided into five headings, which guided the researcher in the data analysis process.

- Demographic information
- Support available for TB patients
- Patients’ understanding of TB and its treatment
• Patients’ perceptions about interrupting and defaulting treatment

• Stigma and discrimination

Only ten patients were found to have their treatment interrupted for 1-2 and more months after they presented themselves back at the treatment centres. When they came back to the treatment centre their treatment cards were assessed for more information and clarity about the progress in their treatment schedule. Thereafter, they were assisted and treated according the National Guidelines for the Management of Tuberculosis in Namibia. Six patients were already being retreated for Pulmonary TB (PTB) as return after default. However, the three MDR patients were not yet placed back on TB treatment because the doctor was waiting for their sputum sample results.

According to MoHSS (2012) when a patient interrupt his treatment for 1-2 months two sputum samples should be collected for investigation which is called smear microscopy. In this case, the treatment will continue while waiting for results. When the patient interrupts the treatment for 2 months or more (defaulter) 2-3 sputum smears has to be obtained from the patient. A TB treatment defaulter will not receive treatment while waiting for sputum smear results. Therefore, the second option concerning the treatment of someone who defaults the TB treatment is that the clinical decision has to be done on individual basis. This will be done to decide as to whether the patient can be restarted on treatment, continue treatment, or receive no further treatment.
As a result, only three patients were admitted in the TB wards that were waiting to be treated for Multi-Drug Resistant Tuberculosis (MDR-TB). However, the MoHSS (2009) revealed that patients with drug resistant tuberculosis (DR-TB) require specialised management at a referral centre for some period. These patients are regarded as infectious for a longer period with resultant increased risk for nosocomial transmission. Nosocomial transmission is a result of treatment in a hospital or hospital-like setting, but secondary to the patient’s original condition. Therefore, patients suspected or confirmed to be DR-TB should be placed in a separate area or building in a facility. This facility should preferably be a well-ventilated individual patient room where the possibility of contact with other patients without TB or with presumed drug sensitive TB is not possible.

Only one patient who was identified as a defaulter by the State was traced and was interviewed at workplace. The researcher discovered that this patient was still receiving TB treatment at the Private Hospital. However, the researcher decided to include this patient in the sample because the State Facility identified him as a defaulter. Therefore, the researcher interviewed him as a defaulter who default his treatment from the State facility. Presently, it seems that there is a gap between the reporting and co-ordination of TB service between private and state facilities with regards to the management of TB patients. This patient was still receiving his TB treatment and was reported to have been a defaulter. None of the participants refused to participate in the study.
4.2 IMPORTANT CHARACTERISTICS OF THE SAMPLE

In the table below (Table 4.1) the important characteristics of the sample is presented.

It is however important to note that all the names used in this document are not real names of participants, these names were made up in order to protect the identity of the participants.

**TABLE 4.1: A SUMMARY TABLE OF THE IMPORTANT CHARACTERISTICS OF THE SAMPLE**

<table>
<thead>
<tr>
<th>Participant name</th>
<th>Age</th>
<th>Sex</th>
<th>Educational level</th>
<th>Marital status</th>
<th>Employment status</th>
<th>Medical diagnosis</th>
<th>Time defaulted/treated interrupted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sam</td>
<td>Above 60 years</td>
<td>Male</td>
<td>Primary Education</td>
<td>Single</td>
<td>Pensioner</td>
<td>MD TB</td>
<td>Default for more than 12 months</td>
</tr>
<tr>
<td>Tina</td>
<td>Between 31-40 years</td>
<td>Female</td>
<td>Secondary Education</td>
<td>Single</td>
<td>Unemployed</td>
<td>PTB</td>
<td>Default for 3 months</td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>Sex</td>
<td>Education</td>
<td>Marital Status</td>
<td>Occupation</td>
<td>Disease</td>
<td>Defaulted for Months</td>
</tr>
<tr>
<td>------</td>
<td>-----</td>
<td>-----</td>
<td>-----------</td>
<td>----------------</td>
<td>------------</td>
<td>---------</td>
<td>---------------------</td>
</tr>
<tr>
<td>Ina</td>
<td>Above 60 years</td>
<td>Female</td>
<td>Never attended school</td>
<td>Single</td>
<td>Pensioner</td>
<td>PTB</td>
<td>9 months</td>
</tr>
<tr>
<td>Miina</td>
<td>Between 31-40 years old</td>
<td>Female</td>
<td>Primary Education</td>
<td>Single</td>
<td>Unemployed</td>
<td>PTB</td>
<td>6 months</td>
</tr>
<tr>
<td>Anne</td>
<td>Between 31-40 years old</td>
<td>Female</td>
<td>Primary Education</td>
<td>Single</td>
<td>Unemployed</td>
<td>MD R TB</td>
<td>15 months</td>
</tr>
<tr>
<td>Leo</td>
<td>Between 41-50 years old</td>
<td>Male</td>
<td>Never attended school</td>
<td>Single</td>
<td>Plumber</td>
<td>PTB</td>
<td>More than 2 months</td>
</tr>
<tr>
<td>Tim</td>
<td>Between 18-30 years old</td>
<td>Male</td>
<td>Secondary Education</td>
<td>Single</td>
<td>Unemployed</td>
<td>PTB</td>
<td>11 months</td>
</tr>
</tbody>
</table>
### 4.3 MAIN CATEGORIES AND SUB-CATEGORIES

The main categories for the study were developed as well as the sub-categories. The main categories were:

- Support available for TB patient
- Participants’ understanding of TB and its treatment
➢ Participants’ perceptions about TB treatment interruption and default
➢ Stigma and discrimination.

In the next table (Table 4.2), the main categories were presented together with sub-categories.

Table 4.2: The main categories and sub-categories

<table>
<thead>
<tr>
<th>Main categories</th>
<th>Sub-categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support available for TB patients</td>
<td>Finding out about TB diagnosis</td>
</tr>
<tr>
<td></td>
<td>Family and professional support</td>
</tr>
<tr>
<td></td>
<td>Employment situation and income source of participants</td>
</tr>
<tr>
<td>Participants’ understanding of TB and its treatment</td>
<td>How was the TB diagnosis communicated to patient?</td>
</tr>
<tr>
<td></td>
<td>Duration of treatment</td>
</tr>
<tr>
<td></td>
<td>How is TB transmitted?</td>
</tr>
<tr>
<td></td>
<td>Participants’ experience of treatment</td>
</tr>
<tr>
<td></td>
<td>Feeling better after taking medication for few weeks</td>
</tr>
<tr>
<td></td>
<td>Patients receiving other treatments apart from TB treatment</td>
</tr>
<tr>
<td></td>
<td>Procedure of administering treatment</td>
</tr>
<tr>
<td></td>
<td>Distance to health facility</td>
</tr>
<tr>
<td></td>
<td>Life style interferences</td>
</tr>
</tbody>
</table>

4.3.1 Support available for TB patients

The first main category of the data collected was labelled support available for TB patient. This category contained data that were related as to whether TB patients received any support. The data in this category was divided into two sub-categories. The first sub-category, which is finding out about TB diagnosis contained data with regards to how participants found out that they have TB. The second sub-category was labelled family and professional support. The data contained in this sub-category, spoke about who supported the participant when the diagnosis of TB was made known to them, how participants were supported as well as participants’ concern about the lack of family support.
The third sub-category was labelled employment situation and income source of participant. The data contained in this sub-category asked about what participant does to make a living. It probed further to ask about what the source of income for the participant were, if participant were not employed. The data further explored to find out whether the source of income mentioned was sufficient to meet the basic needs, and continued to ask about who the participant was responsible for supporting. It probed further for an explanation on how participant survive if the source of income was not sufficient to meet the basic needs.

4.3.2 How was the TB diagnosis communicated to the patient?

During the interviews, participants discussed and explained how they find out that they were having TB. Sam has noted the following: “I became sick and I went to the hospital where I was diagnosed with TB. I have been treated for TB previously and was discharged so that I can go home and continue with my treatment at home. I have been receiving treatment at the clinic” (P1, I 2.1, P130). Other participants have expressed their experiences differently as they noted as follows: Tina has noted the following: ”I started coughing and become feverish. Then I went to the hospital for check-up. Later, I was diagnosed with the TB disease” (P2, I 2.1, P134). Again, Ina had this to say: “I was admitted three times. This time I started having joint pains, coughing and stabbing pains. I was diagnosed with TB and was admitted” (P3, I 2.1, P138). Miina also felt the same way as she recalled what happened and said: “I started coughing and went to the clinic. They requested my sputum for laboratory investigation and the results came out positive for TB” (P4, I 2.1, P143).
For Leo, it was different from other participants as he noted: “I went to the hospital because of the cough I was having for a long time. I was admitted three times now. The situation that has contributed to the fact that I am still not yet cured” (P6, I 2.1, P151). Again, what lead to Tim to know that he was having TB is as follows: “I started experiencing stabbing pains in the ribs. After I went to the clinic I was examined and was informed that I have TB” (P7, I 2.1, P154). Tobby also had different symptoms as other participant and said the following: “I started coughing, feeling dizziness, fever and cold. I was examined at the clinic and was informed that I have TB” (P8, I 2.1, P158). Nick said: “I started coughing four years ago. I was examined at the clinic and I was given results that I have TB” (P9, I 2.1, P163). Paul also came to the same conclusion and said this: “I was sick and went for general check-up and the results came out positive for TB” (P10, I 2.1, P167). Finally, Anne expressed her situation as she did not come herself to the hospital for admission and concluded by saying that:

“I started coughing, experiencing stabbing pains in the ribs, feeling feverish and sometimes cold and went to the clinic. My sputum was sent for Laboratory investigation and I went home to wait for my results. Later, the nurses came to collect me from home and took me to the hospital where I was admitted. I have stayed in the hospital for two months now” (P5, I 2.1, P149). The findings of this study revealed that all participants fell ill and went to the health facilities to seek medical help. Because the majority of patients presented them with the symptoms of cough that lasted for a long period, their sputum was examined and thereafter a TB bacteria was discovered in their sputum.
4.3.3 Family and professional support

The participants discussed further to answer about who supported them when they were diagnosed with TB. They further continued to discuss how they were supported as well as their concern about the lack of family support. On the discussion about who supported them and how they were supported, participants also gave their responses. Those who received support from the nurses and family members have noted the following:

For Sam, it was a feeling of reassurance and said: “The nurses, my mother and my sister supported me during the process of admission and hospitalization”. He further continued to discuss how they supported him by saying this: “My mother and my sister always visited me in the hospital. My sister gives me food and administer my medication” (P1, I 2.2-2.3, P132). Tina’s reply also sounded familiar and noted: “I was supported by Nurses and by my mother” and continued by saying that: “The nurses assisted and encouraged me to go for admission in the TB Ward. My mother is taking care of my son and is always visiting me in the hospital” (P3, I 2.2-2.3, P135-136). Miina has this to say: “I was sent to the hospital supported by nurses and my relative“. About the type of support she received she answered and said: “The nurses encouraged me and reassured me that TB is curable. My relatives are visiting and bringing food for me at the hospital” (P4, I 22-2.3, P144). Leo also gave almost the same answer and said: “The nurses and my relatives supported me”. “The nurses gave me counselling and encouraged me to continue with treatment. My relatives are visiting me regularly in the hospital” (P6, I 2.2-2.3, P152-153).
Tim noted the following: “The Nurses and Community Counsellor supported me”. “The community counsellor gave me counselling and encouraged me to take my treatment while the nurses gave me information about TB” (P7, 2.2-2.3, P155). Tobby also showed appreciation for the support and said: “The nurses and my brother supported me”. “They both encouraged me to take my medication as prescribed by the Doctor” (P8, 2.2-2.3, P160). Nick also had this to say: “The nurses and my wife supported me”. “The nurses and my wife have been encouraging me to take my treatment” (P9, 2.2-2.3, P165). Some participants replied that they were only supported by the Nurses and noted the following: For Ina, her reply was different, as she sounded neglected. Here she noted: “The nurses supported me”. “They explained to me how TB is transmitted and that I should never go home without medication as I did. They were very helpful to me and accepted me back for readmission” (P3, 2.2-2.3, P139-140).

Again, Anne noted: “The nurses supported me”. “They encouraged me to take my treatment as prescribed by doctor” (P5, 2.2-2.3, P149). Finally, Paul concluded by saying that: “The nurses and my colleagues at work supported me”. “The nurses and my colleagues gave me information about TB and encouraged me to take treatment as prescribed” (P10, 2.3-2.3, P169). The findings from the study shows that the majority of participants received support from both nurses and relatives, three participants received support from the nurses only while one participant who lives alone received the support from nurses and colleagues at work. This support from relatives and nurses has been categorised under the DOT support where a relative and
a nurse observe a patient taking medication. Through this process, patients were encouraged to take and complete the treatment. Despite the fact that they received support, participants explained how they were supported.

It is evident from the above responses that the nurses, family members and colleagues were the main supporters of TB patients. Many patients are relying from this support. Poor family relations have also resulted in some patients only relying on the support from the nurses. A number of participants reported to have no relatives that visited them. For the researcher, these findings indicated that most participants feel more secure when receiving support from a professional person whom they trust to protect their well-being.

Participants who did not receive support from their relatives felt neglected and have expressed their concerns. Their responses showed clearly that participants presented their concerns as a result of different situations where they live in. One can see that some people felt neglected although there are also some who were receiving proper support from nurses and relatives. One participant stated that their parents died and this has created a gap amongst them because instead of supporting each other some siblings are rejecting them.

According to Nghonyama, (2005), the need for social support can never be over emphasized because previously, there was less information on social support and its impact on people who are terminally ill. Recently, more researches have been
done in that area. The researcher showed that social support plays an important role in helping the concerned people to cope with their illnesses. However, it was further emphasized that the kind of social support that participants received from their families depended on their needs, economic situation, and the illness they are suffering from as well as on their relationship with other people. People who are unemployed are more likely to need financial support than those who are employed.

According to Nghonyama (2005), we all need to have support networks at one stage in our lives which we often get and sometimes may even go to the extent of taking it for granted. However, there were some people who lack this support from their relatives. In this study, three participants did not receive support from their relatives during their hospital admission.

Ina has brought out some of the emotions such as: “My daughter did not do well because I was supposed to be cured but now I am back in the hospital very sick” (P3 I 2.4, P140). Anne also felt the same and expressed her feeling as follows: “...............My mother needs to be encouraged to support me” (P5, I 2.4, P149). Tim also noted: “My parents passed away. We were left with no sufficient income and are struggling to survive” (P7, I 2.4, P156). Paul had this to say: “I am staying alone. My colleagues encouraged to take my medication and supported me to eat well” (P10, I 2.4, P169).
It was however not easy for the researcher to establish whether those participants who did not receive support from their relatives did not receive it because they were unsupportive, or because of the fact that they were not aware of their illnesses.

Nghonyama (2005) stated that in HIV infection; understanding barriers to social support in the form of network density, disclosure or relationship satisfaction is especially important for the person to benefit from social support to the overall health and well-being of HIV positive person. In comparison to TB, the researcher feels that this disease involved a long-term treatment regime therefore; it is also necessary for all TB patients to be supported by their relatives. This will help them to cope with the illness, complete treatment and prevent treatment interruption and defaults.

The researcher is of the opinion that since TB patients rely mostly on both informal and formal social support services, social work intervention is necessary to involve them in the development and the maintenance of the support network. Nghonyama (2005) stated that social work intervention could play important roles such as advocates, brokers, mediators and planners.

By having said that, it does not necessarily mean that social workers must work in isolation in helping people instead, they must also involve other relevant professionals to ensure proper and efficient support. In addition, all these interventions can assist people to identify alternative support network, which in turn will enable them to cope. The study revealed that three participants received their
formal social support from the nurses and one participant worked closely with his private doctor. This form of support includes medical treatment, health talks as well as the support by treating them in a way that will ensure that they have faith and confidence to believe that they can be cured with TB.

4.3.4 Employment situation and income sources of participants

Throughout the interview, the participants discussed about what they do to make a living. The TB patients also have basic needs like any other people and should have sources of income, if they are not employed. The findings in this study revealed how participants fulfil their basic needs.

Sam noted: “I am receiving old age pension” (P1, I 2.5, P132,) while Tina revealed that: “I am receiving financial support from my mother” (P2, I 2.5, P136). Ina continued to say: “I am receiving old age pension” (P3, I 2.5, P140). For Miina, it was the same response as others and noted: “I am receiving disability grant” (P4, I 2.5, P144). Leo had a different response and said: “I am a Plumber. ...because I am self-employed ...I am now in the hospital with no income” (P6, I 2.5, P153). Anne sounded neglected as she said: “I am unemployed. My sister is giving me pocket money...” (P5, I 2.5, P149). Tobby responded and said: “I am a Barber. I am self-employed but now that I am in the hospital, I have no income” (P6, I 2.5, P160). Paul who has a secure job felt reassured and noted the following: “I am a Driver. ...I do receive my salary every month” (P10, I 2.5, P169). This study indicated that participants live in different situations when it comes to sources of income. Three participants were recipients of old age pension which is a source of income for the
family, three participants depend on extended family members for financial support. The other two participants were self-employed but have lost income due to hospitalisation, one participant was receiving temporary disability grant due to TB since this patient is on TB treatment for a longer period. Presently, the patient cannot do formal job and was categorised under temporary disability grant. Once this patient has recovered fully, the temporary grant will be stopped. Another patient has a formal employment and uses his salary to meet his basic needs.

However, participants continued to discuss whether the sources of income mentioned were sufficient to meet basic needs and who are they responsible for supporting. They further explained how they were surviving if the basic needs were not met. The following Table (Table 4.3) provided an assessment on the participants’ survival.

**Table 4.3: Assessment of participants’ survival needs**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Is income sufficient?</th>
<th>Who are you providing support?</th>
<th>How are you surviving with no income?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sam</td>
<td>Yes. I am receiving old age pension</td>
<td>Support the household.</td>
<td>N/A</td>
</tr>
<tr>
<td>Tina</td>
<td>Yes.</td>
<td>One child.</td>
<td>I am receiving</td>
</tr>
<tr>
<td>Name</td>
<td>Income Source</td>
<td>Family Member(s)</td>
<td>Financial Support Details</td>
</tr>
<tr>
<td>-------</td>
<td>---------------</td>
<td>------------------</td>
<td>--------------------------</td>
</tr>
<tr>
<td>Mother and sister provide for the household.</td>
<td>financial support from my mother.</td>
<td>Ina Yes. I am receiving old age pension</td>
<td>Daughter and two grandchildren.</td>
</tr>
<tr>
<td>Miina Yes. I am receiving disability grant.</td>
<td>N/A</td>
<td>Aunt and five children.</td>
<td></td>
</tr>
<tr>
<td>Anne No income.</td>
<td>......When I am at home, I depend on my sister for financial support.</td>
<td>Need to support three children.</td>
<td></td>
</tr>
<tr>
<td>Leo No.</td>
<td>Relying on financial support from relatives.</td>
<td>Parents and children.</td>
<td></td>
</tr>
<tr>
<td>Tim No.</td>
<td>My sister is giving me pocket</td>
<td>None</td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Tobby</td>
<td>No.</td>
<td>Three children</td>
<td>I am relying on relatives for financial support.</td>
</tr>
<tr>
<td>Nick</td>
<td>Yes. I am receiving pension.</td>
<td>I am the head of the household.</td>
<td>N/A</td>
</tr>
<tr>
<td>Paul</td>
<td>Yes. I receive my salary every month.</td>
<td>Parents</td>
<td>N/A</td>
</tr>
</tbody>
</table>

For Sam, Ina, Miina and Nick who were recipients of old age pension and the disability grant respectively, the situation looks better because there is reliable source of income that they could expect every month. This was a form of assurance that they will have income every month. Paul, who is a public servant, expected his salary every month while the rest of participants (n=5) continued to struggle and relied on family members for financial support.
4.4. UNDERSTANDING OF TB AND ITS TREATMENT

The second main category of data was labelled understanding of TB and its treatment. This category contained data that were related as to how the TB diagnosis was explained to patients. The data contained in this category were divided into twelve sub-categories. The first sub-category TB diagnosis communication contained data about how participants were told that they were having TB and what they were told. The second sub-category is duration of treatment. The data presented in this sub-category included information on whether participants were told about the duration of treatment and probed to find out what they were told. The next sub-category was labelled TB transmission. These data were centred on what participants knew about how TB is transmitted.

The fourth sub-category was labelled patients experience of TB treatment. These data contained the participants’ description of experience of receiving treatment and information that explained whether TB is a chronic medical condition or not. The fifth sub-category was about feeling better. The data contained information whether the participants were still feeling sick after taking treatment. The sixth sub-category was about other treatment apart from TB treatment. The data contained information whether participants received treatment for any other medical condition together with the TB treatment. It further probed to find out how participants cope when they are taking both treatments at the same time.

The seventh sub-category was about the procedure of treatment. The data in this sub-category contained information whether the participant received pills or
injection as well as to whether the participants experienced side effects of medication. The eighth sub-category was about the distance to the health facility. The data contained information whether participants walks long distance to health facility. The ninth sub-category was about life style interference. These data contained information about whether the treatment interferes with participants’ life style and probed to find more on how they managed. The tenth sub-category was labelled alcohol use. These data included the questions if participants drink alcohol and probed to find more on which type of alcohol beverages and how often participant drinks. The eleventh sub-category was labelled smoking of tobacco. These data contained information whether the participant smoked tobacco and continued to probe which type of tobacco and how often. The last sub-category was about the lived experience of TB patient on treatment. These data included information on what it has been like to be a patient on treatment.

4.4. 1 TB diagnosis communication

As the interviews continued, the participants were engaged in the discussions about how the nurses gave explanation to inform them that they had TB. Some participants expressed guilty feeling.

As Nick has noted: “I was first admitted in ........... (Name of the hospital) Hospital where I was informed that I have TB and need to be admitted for treatment. I made a mistake by not completing my treatment. Now, I got a relapse and in pain because of that” (P9, I 3.1, P132). Sam has remembered all information because he
was told to do what was expected in his case when someone is being diagnosed with TB. He noted: “They informed me that I have TB and need to be admitted for treatment because I am staying far from the hospital” (P1, I 3.1, P136). For Tina, Ina and Tobby the responses were almost the same. They recalled that they were told that their sputum were examined and it was found that they have TB and needed to be admitted in the TB ward for treatment” (P2, I 3.1, P136, P3, I 3.1, P140, P8, I 3.1, P160). Paul has concluded as other participants. According to him, it was a word of encouragement as he noted: “They first informed me that I have TB and encouraged me to adhere to my treatment. I should not skip follow up and should take treatment everyday as prescribed” (P10, I 3.1, P169). Finally, Anne concluded by revealing what was said by the nurses and said: “They explained to me that I have TB and need to take medications if I want to get cured” (P5, I 3.1, P149).

All the participants (N=10) were informed that they were diagnosed with TB. However, the nurses continued to explain to them that once they were diagnosed with TB they needed to be admitted in the hospital for treatment.

Throughout the interview, participants discussed what they were told about TB. Sam recalled what he was told and noted: “The nurses informed me that I am suffering from TB of the lungs which is infectious but curable if I take my medication well” (P1, I 3.2, P132). Tina also remembered what was said about TB and says:”I was informed that TB is a disease that can be cured. I need to follow instructions by nurses and doctors in order to get cured. They encouraged me to take medication” (P2, I. 3.2, P136). For Ina, she
also received the same information and said: “They told me that TB is a disease of the lungs which is infectious when it is not treated” (P3, I 3.2, P140). Anne also received information and noted: “They said that TB is a lung disease and I should not take alcohol” (P5, I 3.2, P149). Leo was also given information as he recalled: “They told me that I have TB of the lungs” (P6, I 3.2, P153). Tim recalled and said this: “They said that TB treatment needs to be completed; it needs to be taken on time with food” (P7, I 3.2, P157). Tobby could remember what he was told and noted that: “They said that TB is transmitted through alcohol abuse. When a person is only drinking alcohol and does not eat and when too many people stays in a room with no ventilation, if there is someone with TB among them they may all get TB” (P8, I 3.2, P160). Nick concluded and noted the following: “They told me that I have TB of the lungs and its treatment need to be completed otherwise my body will become resistant to treatment” (P9, I 3.2, P165).

Finally, Paul could also recall what he was told and said: “TB is a disease of lungs. Its treatment need to be completed. If I do not complete my treatment my body may become resistant to medication and the treatment may last longer” (P10, I 3.2, P169). All the participants (N=10) were informed about the type of TB they were infected with. However, the nurses continued to give health education with regards to TB by informing them to adhere to the treatment, to stop drinking alcohol, stop smoking and prevent that their body become resistant to medication.
4.4.2 Duration of treatment

As the interviews continued, participants revealed what they were told about the duration of the treatment. Half of the participants said that they were not given information about the duration of their treatment. Participants who were informed about the duration of their treatment revealed the following information:

As Tina remembered what she was told about the duration of treatment and said: “They informed me that the duration of treatment will depend on my motivation and willingness to take treatment for 6 – 8 months. If I do not adhere the duration of treatment will become longer” (P2, I 3.3, P136). For Miina, the information she received from other participants differ a little bit as she noted: “I received no information about the duration of my treatment. I heard from other patients that treatment may be for two to eight months” (P4, I 3.3, P144). Anne has remembered what the nurses had told her and said this: “The duration of treatment is 8 to 24 months” (P5, I 3.3, P149). Leo also received the same information as other participants and said: “The duration of treatment can take 6-24 months if not improving” (P6, I 3.3, P153). Nick concluded as he has regretted that he did not followed what he was told about his treatment and expressed himself as follow: “The duration of treatment may take more than eight months. Now that I have defaulted I do not know how long the treatment will take” (P9, I 3.3, P165). Finally, Paul concluded on the information he received about his treatment and said: “My private doctor informed me that the duration of my treatment is six months” (P10, I 3.3, P169).
Information that was provided to participant on the duration of treatment differs. Half of the participants (n=5) reported that they were not informed about how long their treatment will take. Those who received information were also not given the same information. For instance, some participants were saying that the treatment will take 6-24 months while others are saying treatment will take 8-24 months.

### 4.4.3 Tuberculosis transmission and symptoms

Throughout the interviews, the participants continued to discuss how TB is transmitted and mentioned symptoms they have experienced when they were diagnosed with the TB. Here follows their expressions: Sam has reported on what he knew about how TB is transmitted and said: “The nurses told me that TB spreads through the air when a person who has a cough coughs without covering the mouth” (P1, I 3.4, P132). Tina noted this: “The TB is transmitted when a person is coughing while he/she has not covering his/her mouth” (P1, I 3.4, P137). The majority (n=8) of participants discussed TB transmission as Ina noted: “Tuberculosis is transmitted through the air and when a TB patient is coughing or sneezing while he did not cover his mouth. It is contagious. A person should not eat or drink from the same cup; he should sleep alone and should cover the mouth when coughing” (P3, I 3.4, P141). For Miina, “Tuberculosis is spreading when an infected person is coughing without covering the mouth” (P4, I 3.4, P144). Anne replied by saying: “This disease is transmitted through the air and by drinking from the same cup” (P5, I 3.4, P149). Leo had this to say about his knowledge on how TB is transmitted: “If a person is taking excessive alcohol, he can get infected with TB as well as when coughing without covering the mouth. The disease can also be inherited from the person’s parents” (P6, I 3.4, P153). Tim also had this to say: “The TB is an airborne disease. A person can catch TB
through the air”. For Tobby, “The TB is transmitted through the family, when a family member has the TB, he can spread it to others when he is coughing without covering his mouth or when he sleeps with other people in the room where there is no enough ventilation. The disease is also caused by alcohol abuse and tobacco smoking” (P8, I 3.4, P161).

Nick tried to tell what he knew about how TB is transmitted and said: “The disease is spreading through the air. A person can get infected if he is drinking alcohol too much and do not eat well” (P9, I 3.4, P166). Paul concluded to share his knowledge about TB transmission and said: “The TB is spreading through the air. It can spread quickly in a congested place where there is no ventilation” (P10, I 3.4, P169). All participants (N=10) were aware on how TB is transmitted and everyone could tell about how it feels when a person has TB. These symptoms varied from person to person.

On the question as to how the body feels when a person has TB all participants shared the symptoms they experienced. These symptoms were summarised as follows; body weakness, tiredness, lack of appetite, burning chest pain, cough, feeling sick, chest pains, and joint pains, stabbing pains in the chest or in the ribs, feeling dizziness as well as coldness and fever. To conclude on how the body with TB infection feels, two participants have approached the question differently. Miina had this to say: “Tuberculosis is a bad disease because it can make a person to feel sick, coughing too much even when you are taking treatment for a long time” (P4, I 3.5, P145). Anne concluded and said that: “The body feels weak. The disease takes long to get cured. The person might not get employment or get
light work” (P5, I 3.5, P149). All (N=10) participants also explained how TB is transmitted as well as how it could be prevented.

4.4.4 Patients’ experiences of TB treatment

Throughout the interviews, the participants continued to discuss their experiences of the TB treatment. Here follows how they have been experiencing the TB treatment:

For Sam, the response included mixed feelings as he noted: “The treatment is fine but is very long and you spend a lot of time in the hospital” (P1 I 3.6, P133). Tina sounds very satisfied with the treatment she is receiving and said: “I am fine with the treatment” (P2, I 3.6, P. 137). Ina also felt good with the treatment as she expresses her satisfaction and said: “When a person is on TB treatment, you are treated well and are well cared for” (P3, I 3.6, P141). Miina was also satisfied and hopeful with the treatment she receives as she noted: “I feel the treatment is good because if a person adheres to take medication correctly, he can get cured” (P4, I 3.6, P145). Anne does not seem to have complaints concerning the treatment as she noted: “The treatment is fine” (P5, I 3.6, P150). For Leo, the treatment was accepted with mixed feelings as he replied: “The treatment is fine but you cannot do your work. If I work, I cough up blood” (P6, I 3.6, P153). Tim was also hopeful and said the following: “I do not have problem with the treatment what is needed is that the person should adhere to this treatment to get cured” (P7, I 3.6, P157). Tobby does not sound happy with the duration of treatment as he noted: “When you are on treatment you get admitted which means that you cannot work and you will stay long in the hospital” (P8, I 3.6, P161). Nick was hopeful and satisfied with the treatment. He noted: “The treatment is fine. A person can just get pills and injection for four months and you will feel better” (P9, I 3.6, P165). Paul has however, concluded and shared his experience with the treatment and said this: “I feel good. I did not experience any problem with regards to receiving treatment” (P9, I 3.6, P170).
On the question if TB is a chronic medical condition or not, the majority admitted that TB is a chronic medical condition. However, they showed their hope by saying that even though it is a chronic illness, it can be cured. Findings of the study however, showed that the majority of participants (n=8) were satisfied with the treatment. The minority (n=2) have accepted the treatment with mixed feelings and had negative feelings towards the long duration of treatment as well as their inability to work.

4.4.5 Feeling better

The interviews continued to explore more in order to find out if participants were still feeling sick after they have taken treatment. The majority of participants (n=7) have reported that they were still sick even though they have taken treatment. They mentioned physical symptoms such as cough, leg pains chest pains while the minority (n=3) were not feeling any pain.

4.4.6 Other treatment apart from TB treatment

Participants were also asked if they were taking other treatment for other medical conditions apart from the TB treatment. The majority (n=6) of participants have been only diagnosed with TB while four participants were diagnosed with HIV as well. These patients were receiving HAART or ARVs. All participants who indicated that they were on HAART have reported that they did not experience any problem with taking both treatments.
4.4.7 Procedure of treatment

The table below (Table 4.6) is showed the procedure of treatment. It will include participants who are receiving pills an injection, those who are receiving pills as well as those who are not yet on treatment.

**Table 4.4: Procedure of treatment**

<table>
<thead>
<tr>
<th>Participants receiving both pills and injection</th>
<th>Participants receiving pills only</th>
<th>Participants not yet on treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>

The findings indicated that the majority of participants (n=4) were receiving both pills and injection, while the other participants receive pills only (n=3) and the rest (n=3) were not yet put on TB treatment. Again, the participants continued discussed whether they have experienced side effects of medications. The majority of participants (n=8) did not experienced side effects of their treatment. Participants who experienced side effects have responded and their responses were noted as follows: For Tina, she has been forcing herself to take medication as she noted: “The medications make me to feel like vomiting. I do not feel good about this but I am forcing myself to take medication. I want to be cured” (P2, I 3.12, P137). Nick also had the same experience, but is now over it. Here is his response: “Yes. I had some medications that make me to feel like vomiting then I told the doctor and he changed it” (P9, I 3.12, P166).
4.4.8 Distance to health facility

As the interviews continued, participants were discussing about the distances to health facilities. The majority of participants (n=6) claimed that they live far from the health facility. Participants have responded and their responses have been noted as follows:

Sam claims that he was staying far from the clinic as he noted: “Yes it is a long distance. When I was sick and weak I did not go to the clinic” (P1, I 3.13, P133). Tina has also admitted that the long distance is a problem said: “Yes, I walk long distance. This has contributed to me having skipped my follow up medication for weeks” (P2, I 3.13, P137). Anne agreed that the clinic is far and said: “Yes. It is a long distance, I need money for transport” (P5, 3.13, P142). Leo also felt the same and noted: “Yes. It is a long distance. I need transport money to reach the hospital” (P6, 3.13, P145). Tim has also the same experience as others and said: “Yes, it is a long distance. I always need money for transport” (P7, 3.13, P157). For Nick, it was a different response as he concluded and said: “I did not collect medications from the clinic because I refused to go and collect it there. I will now receive medication in the hospital. The clinic is far. It is a long distance for a sick person although it is stationned near the Church. Almost all people do receive their treatment there” (P9, I 3.13, P166). The majority (n=5) have indicated that they walk long distance to the nearest health facility. They indicated the lack of transport money as the main contributing factor and indicated that when they cannot walk because of ill health they do not go to collect medication. Those who live near the health facility (N=4) were always walking to the health facility for treatment.
4.4.9 Life style interference

Participants were asked about whether the treatment interfered with their life styles. Those participants who felt that the treatment was interfering with their lifestyle have this to say: Miina does not sound happy and noted: “Yes. When I was healthy I was making traditional baskets and did many household activities but now I cannot do that because I am sick” (P4, I 3.14, P145). Leo sounds negative about the whole issue that he could not do his usual job and said: “Yes. If I work, I cough up blood. When I came back I was very sick. I started working while at home, then I became sick coughing up blood” (P6, I 3.14, P154). Tobby also feel the same because of the lack of income and noted: “Yes. I was working as a Barber in Windhoek and had many customers. Now I am in the hospital with no income” (P8, I 3.14, P161). For Paul, it is another opportunity, as he does not experience any problems. He concluded and said: “No. I can take my medicine and do my work. Like now I am at work taking my medication at workplace” (P10, I 3.14, P170). The majority of participants (n=5) indicated that the treatment does not interfere with their lifestyle. Those who reported interference seem to be frustrated because of the fact that they could no longer do their work. However, some (n=2) have indicated that they were old and weak and cannot work anymore.

4.4.10 Alcohol use

Participants continued to discuss the issues of their lives. They were asked if they were drinking alcohol. The findings are presented in the next table.
Table 4.5: Alcohol use

<table>
<thead>
<tr>
<th>Participant name</th>
<th>Alcohol</th>
<th>Type</th>
<th>How often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sam</td>
<td>No</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Tina</td>
<td>Yes</td>
<td>Beer</td>
<td>Any time being offered</td>
</tr>
<tr>
<td>Ina</td>
<td>No</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Miina</td>
<td>No</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Anne</td>
<td>Yes</td>
<td>Beer, Otombo or any type</td>
<td>Any time available</td>
</tr>
<tr>
<td>Leo</td>
<td>Yes</td>
<td>All types</td>
<td>Almost every day</td>
</tr>
<tr>
<td>Tim</td>
<td>No</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Tobby</td>
<td>Yes</td>
<td>Beer</td>
<td>Every day</td>
</tr>
<tr>
<td>Nick</td>
<td>No</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Paul</td>
<td>No</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Findings revealed that the majority of participants (n=6) does not drink. Participants who admitted that they drink alcohol, some of them (n=2) admitted that they can take any type of an alcoholic beverages. These participants responded that
they drink any time they are being offered with less control while the rest (n=2) indicated only to have been taking beer.

4.4.11 Tobacco smoking

Participants continued to discuss if they do smoke tobacco. The majority of participants (n=9) do not smoke tobacco. Only one participant admitted to have been smoking pipe, which he started smoked since his early years for his personal medicinal use.

4.4.12 Lived experience of TB patient on treatment

During the interviews, participants were asked to explain about what has been like to be a patient on TB treatment. Sam seems as if he has lost hope and decided on accepting the disease as he noted: “I think that being a TB patient is just like being treated for any other disease” (P1, I 3.22, P134). Again, Tina seems like she is frustrated because of the duration of treatment as she said: “Being a TB patient does not make me feel good. The treatment takes too long which is a waste of time. I am just lying and hanging around doing nothing” (P2, I 3.22, P139). Ina also has accepted to live with the disease as she said: “I do not have any choice I just have to accept and live with the TB” (P3, I 3.22, P143). Miina also does not feel good as she noted: “I feel bad because I have TB and HIV (all the big diseases are in my body)” (P4, I 3.22, P147). Anne also expressed her unhappiness with the duration and said: “I feel bad because TB treatment takes long 8-24 months as well as HIV which I will carry for the rest of my life” (P5, I 3.22, P152).
Leo expressed his fear of the disease and noted: “The TB is a bad disease because it can kill you. It prevents you from doing you to work. Some people cannot walk, see or hear and some are in wheelchairs because of TB. As a TB patient, I need to take treatment as prescribed otherwise I will not get cured” (P6, I 3.22, P155). Tim has learnt a lot in being a patient on TB treatment and has this to say: “Being a TB patient on treatment requires a lot of motivation so that you can adhere. If you do not adhere to the treatment, your body become resistant to treatment and it will take long to be cured. In my situation, I was receiving treatment from the Health Centre and stayed away for two months. I was traced by the Nurses and was brought back in the hospital on the 18 July 2013” (P7, I 3.22, P159). Tobby also sounded frustrated and said: “This TB treatment is taking long. As a bread winner for my children it is difficult because I cannot do my work to provide for them” (P8, I 3.22, P163). Nick noted: “The TB treatment has been taking too long and I have been tempted to stop on my own. I am now admitted in the hospital and will try to adhere to the treatment” (P9, I 3.22, P167). Paul has also learnt a lesson with TB and concluded to say: ‘Being a patient on TB treatment was not easy. I was first on denial trying to justify how I got infected with TB and later I accepted it” (P10, I 3.22, P172). All (N=10) patients admitted that it was not easy to be a TB patient on treatment and indicated the long time spent in the hospital as well as the problem that some of them have lost their income as a result of being admitted in the hospital.
4.5 PARTICIPANTS’ PERCEPTIONS ABOUT TREATMENT INTERRUPTION AND DEFAULT

The third main category was labelled participants’ perceptions about treatment interruption and default. This category contained information about what participants think about treatment interruption and default as well as their suggestions to minimise treatment interruption and default. The data contained in this category were divided among two sub-categories. The first sub-category that is thoughts about treatment default; contained data about what the participants think about treatment interruption and default. The second sub-category was labelled suggestions / opinions for further improvement on treatment adherence. The data contained in this sub-category, was the participants’ suggestions or opinions to minimise treatment interruption and defaults among TB patients.

4.5.1 Thoughts about treatment interruption and default

As the interviews progressing, participants discussed what they think about treatment interruption and default. The majority (n=9) have responded to justify their actions as they noted:

Sam had this to say: “I stopped collecting and taking medication because I live far from the treatment centre where I collect medication. I walk a long distance to the clinic. When I was sick, I became tired very easy and experienced a lack of energy” (P1, I 4.1, P135). Tina also thought the same and said: “I walk long distance to and from the clinic, and become tired and weak and there was no transport money”
Ina has thought differently and said: “I think that it is because I was not given the necessary information on the way forward when I was discharged. I went home without medication because I was not told to wait for it on the day I was discharged. I stopped taking medication since August 2012 until June 2013. I stopped taking medication because I did not get information on the disease” (P3, I 4.1, P143).

Miina also noted the following: “I stopped my treatment because I was not given enough information. I was not having transport money to the health facility. I lost hope and had no motivation to go to collect and take my medication” (P4, I 4.1, P147).

For Anne, it is a matter of discouragement as she noted: “I have defaulted from TB treatment as a result of the lack of motivation to take medication, tiredness due to walking long distance to collect medication from the clinic, weakness as a result of ill health and lack of transport money” (P5, I 4.1, P152). Again, Leo acted as if he was unaware of this and said: “I do not know. Maybe the person who default the treatment does not want to be cured. Or maybe they want to live with the disease” (P6, I 4.1, P155). For Tim, it was a matter of non-adherence as he noted: “It is not good to stop taking medication because your body can become resistant to treatment. Like in my case, I stopped taking treatment because I was not having money for transport to the clinic. As a result, I will have to stay longer in the hospital” (P7, I 4.1, P159). Tobby had this to say: “I stopped taking treatment because of ignorance. I did not listen to nurses and doctors when I was told to take medication” (P8, I 4.1, P163).
Nick noted this: “When I feel better I stop taking treatment. When I was not having any motivation to continue taking medication, I refused to collect my medication and defaulted” (P9, I 4.1, P167). Paul has concluded by saying: “I did not default. I am still on treatment. People do default their treatment because they lack motivation to take the treatment. All these problems depend from the person’s self-motivation” (P10, I 4.1, P172). All participants (N=10) felt that patients should adhere to the treatment. Participants have mentioned few points that they think were the leading causes of treatment interruption and default. They were summarised as follows:

- Long distance to health facility
- Ill health, body weakness, tiredness
- Lack of transport money
- Lack of information
- Lack of motivation
- Person does not want to be cured
- Lack of respect of one’s health
- Not listening to health workers
- Feeling better

### 4.5.2 Opinions to improve treatment compliance

Participants were further asked to give their opinions to improve compliance. For Ina, the issue of lack of information need to be addressed as she noted: “I think nurses should tell us beforehand to come back to them to collect medication before we leave the hospital” (P3, I 4.2, P143). Tim also had this to say: “We need to be given
information continuously about the need to finish medication. Those who abuse alcohol should be given counselling to help them stop abusing alcohol” (P7, I 4.2, P159). Tobby has advised others and said: “People should finish their treatment schedule. They should be encouraged to finish the TB treatment” (P8, I 4.2, P163). For Nick, it was a matter of personality as he noted: “Treatment compliance depends from the person’s motivation. People are difficult to convince some of them always do what they want” (P9, I 4.2, P168). Paul has concluded as he noted on the importance of communication between patient and health worker and said: “Patients need to be continuously encouraged to take their medication until they complete treatment” (P10, I 4.2, P172). Findings in this study on participants’ suggestions to improve compliance to treatment were summarised as follows:

The majority of participants (n=4) have requested the health workers to continuously encourage all patients to finish and complete their treatment schedule as well as to tell them the reasons why they need to complete treatment. Three participants have advised others to take treatment as prescribed and not stop on their own. One participant suggested that Nurses should provide information to patients about what the next step will be to prevent that patients go home without medication. Again, one participant mentioned that there are difficult people who do what they want. For the researcher a question was raised by that statement as to; what should be done to convince these patients to complete their treatment?
4.6 STIGMA AND DISCRIMINATION

The fourth main category was stigma and discrimination. This category contained information that was related to find out if participants have heard people making bad remarks to them. The sub-category was labelled negative remarks/ labelling/ gossip. The data in this sub-category contained remarks made in their presence that indicate that they were aware of the participant suffering from TB. The data further probed to find what kind of remarks as well as how participants felt about those remarks.

4.6.1 Negative remarks/labelling/gossip

Participants continued to discuss to tell if they heard people making remarks in their presence that indicates that they were aware that they were suffering from TB. Findings in this study showed that half of the participants did not experienced stigma and discrimination. Those participants who experienced that had this to say: For Sam, he has accepted the TB as he noted: “I did not hear them. If they are talking about me, I think TB is just a disease like other diseases. Anyone can get infected with TB” (P1, I 5, I 1, P135). Miina admitted that she has been discriminated against and said the following: “Yes. My relatives do not treat me well”. She continued to tell what they do to her and said: “They are saying that I went to look for my diseases myself. My aunt who lives with my children does not even visit me. I am only being visited by my first-born daughter. Other relatives do not even bother to come visit me in the hospital”. She continued to express how she feels about those remarks and said: “I am feeling sad and cry often about that but I have courage and faith that I will be cured” (P4, I 5.1-3, P139).
Anne also has experienced stigmatisation and noted the following: “Yes. Some are discriminating against me and try to isolate me”. She continued to explain what they do to her and said: “They tell me in my face that they are not sick with TB”. Anne does not feel happy about that and said: “I feel bad because they are making me to feel bad. Tuberculosis can infect anyone. I just ignore them and make as if I do not care” (P5, I 5.1-3, P152). Tim is also being discriminated and stigmatised by the brother and has this to say: “Yes. My brother is talking bad about me”. Tim continued to tell what the brother says to him and said: “He is saying that he sees me as a dead person because he knows that I have TB and HIV”. These remarks made Tim to feel bad as he noted: “I feel bad about that. How can he say something like that to me?” (P7, I 5.1-3, P159). Tobby is also being isolated from his friends as he noted: “Yes”. He further discussed to explain how they do this and said: “Some of my friends have been chased me away saying that they are afraid of me to infect them with TB”, and concluded to say how he feels by saying this: “It makes me to feel bad. I just have to go back home because I feel people are rejecting me” (P8, I 5.1-3, P163-164).

Finally, Nick also experienced this social isolation as he noted: “Yes” and continued to explain how people are treating him and said: “People are chasing me away telling me straight that they are afraid that I will infect them with TB. Some does not even talk to me”. About his feelings, Nick has this to say: ”I feel bad but I have accepted it and only put my trust in God” (P9, I 5.1-3, P168). It has come out of this study that people with TB were still stigmatised and discriminated against. All
five participants have admitted feeling very bad because they were treated badly by others. The summary of the way they were treated is presented as follows: Participants (n=2) were chased away from public places in the villages and were isolated because they have TB. Some were teased because they have TB (n=1), some (n=1) were scolded or given bad remarks by telling them that they went to look for the illness themselves or some (n=1) were regarded as dead already because of TB/HIV co-infection.

4.7 SUMMARY

This chapter focussed on analysis and interpretation of the data. The study revealed that the majority of participants had their treatment interrupted and defaulted due to lack of information about treatment. The issues that contributed to treatment interruption and default were listed such as long distance to health facilities, ill-health, lack of transport money, lack of motivation to take treatment and ignorance. The lack of respect of own body or health and feeling better after taking treatment for a few weeks were also identified as some of the issues that contributed to treatment interruption and default. It also came out clearly that people with TB and TB/HIV co-infection were still stigmatised and discriminated against because of their illnesses. The next chapter will discuss the findings; make conclusions as well as recommendations.
CHAPTER 5
DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 INTRODUCTION

This chapter will present the discussion, conclusion and recommendations made by the researcher. The discussion provided an in-depth analysis of how the collected data related to the research questions, as well as the comparison of the research findings with existing literature.

The main research question was: *How does treatment interruption and default affect TB treatment among patients in Oshakati district?*

The sub questions of the study were:

- How do patients understand TB and its treatment?
- What factors lead to the fact that some TB patients interrupt and default from treatment?
- What support systems for TB patients exist in Oshakati district?
- What are the patients’ suggestions to increase successful treatment outcomes and minimise treatment interruption and default?

5.2 DISCUSSION OF FINDINGS

The discussion is organised around the following categories:

- Demographic information
- Support available for TB patients
- Participants’ understanding of TB and its treatment
Participants’ perceptions about treatment interruption and default

Stigma and discrimination

During this project, the researcher explored how treatment interruption and default affect the TB patients in Oshakati District. Data were collected from participants through semi-structured interviews with the use of an interview schedule. The following are discussions of the findings in line with the research questions of the study.

5.2.1 Demographic information

The demographic information included the participant ages, marital status, gender and educational level. The majority of the participants (n=4) in the current study were among the age group of 31-40 years old while the minority (n=1) was among the age group of 18-30. These findings correlate with the literature as the MoHSS (2008) has also indicated that TB mostly affected those who were in the age group between the ages of 24 to 34 years. Coincidentally, this is the same age group mostly affected by HIV/AIDS. The findings also showed that there was no participant in the age group of 41-50 who was identified as a treatment interrupter or defaulter. Findings from this study showed a significant number of single people (n=9) who were identified to have interrupted and defaults their treatment. Only one participant indicated to have been married.

The majority of participants who were identified as treatment interrupters and defaulters in this study were males (n=6) while the females were four
participants. Norgbe, Smith and Du Toit (2011) have indicated that males were unwillingly to access health facilities. Therefore, the findings have been based on the review of the existing literature on barriers to accessing health services. The study showed that, the majority of study participants (n=4) have formal education up to the primary school level, three participants went to school up to secondary level while three participants did not go to school at all.

5.2.2 Support available for TB patients

This category is centred on the social and economic related factors which included family environment and support, economic situation, income and financial issues of patients. The majority of participants (n=6) have indicated being supported by nurses and relatives. However, a significant number of participants (n=4) have reported that they were only supported by nurses. It is evident from the findings that the nurses, family members and colleagues were the main supporters of TB patients. Many patients were relying heavily on this support. Poor family relations have also resulted in some patients only relying on the support from the nurses. A number of participants (n=3) reported to have no relatives visiting them. For the researcher, these findings means that most participants feel more secure when receiving support from a professional person whom they trust to protect their well-being.

According to Nghonyama, (2005), it must be taken into consideration that there is no confidentiality when one’s action and behaviour is putting other people’s lives in danger. Therefore, professional people need to keep confidentiality when
dealing with their patients. Participants who did not receive support from their relatives felt neglected and have expressed their concerns on the lack of family support. Their responses showed clearly that participants presented their concerns from different situations where they were living in. One can see that some people felt neglected although there were also some who were receiving proper support from nurses and relatives. One participant stated that their parents died and this has created a gap amongst them because instead of supporting each other some siblings were rejecting them.

On the issue of financial support, the findings showed that the majority of participants were recipients of old age pension and disability grant (n=4), three participants were unemployed, and two participants were self-employed but have lost their income due to hospitalisation. Finally, one participant was employed as a public servant. Participants who reported that they have no income were highly dependants on relatives for financial support. The data presented in this study revealed that all participants have either received support from their relatives or from the nurses during their admission in the hospital. One participant reported to have no income and said that being in the hospital she has been eating, washing herself, sleeping in the hospital and is completely depending on this support. The study conducted by Yahaya and Aquah (2013) have also found that many TB patients were burdened with the wide range of social and medical problems. These authors revealed that many TB patients were unemployed while some were living in serious poverty.
5.2.3 Participant’s understanding of TB and its treatment

This category is centred on therapy related factors which include patient education, the duration of treatment, treatment procedure, unpleasant side-effects as well as when treatment interferes with patient’s lifestyle. Other factors such as condition related factors were also included and discussed under this category. The condition related factors were related to the issues such as feeling better (lack of symptoms), taking other treatments apart from TB treatment and distance to health facility. Health care system related factors which included relationship between patients and health care providers were also discussed under this category. However, findings from this study has found that the all participants (N=10) reported that they received support from nurses. According to Hayden (2010), health care workers should follow prescribed guidelines to ensure that patients understood the reason for being given those medications. This author is also of the opinion that more emphasis should be placed on the relationship between patient and the health care workers. The patient related factors were also included under this category. This included knowledge about the disease, information on the duration of treatment, strengthening and motivating patients to take and complete medication as well as alcohol and tobacco use.

All participants (N=10) knew the symptoms of TB, they knew what TB is and that it is infectious, curable and can kill if it is not treated. However, half of the participants (n=5) did not knew the duration of their treatment while the other half (n=5) that could say more about the duration of the treatment had differences in their responses to tell how long the treatment will take.
All the participants (N=10) have knowledge of how TB is transmitted. Therefore, they explained their experiences of the TB transmission, infection and treatment. The majority of participants (n=6) have expressed their satisfaction with their experience of TB treatment and have admitted their desire to adhere to the treatment. One participant was satisfied with the treatment while the rest (n=2) complained that it was too long as well as the fact that they cannot work.

Only one participant responded that when felt well, he stopped treatment. The majority of participants (n=7) were still feeling sick while three participants did not have any pain. Many participants (n=4) were receiving injection and pills, three participants were receiving pills only while the rest of the participants (n=3) were still waiting for the decision as per their treatment protocol. According to Yone, Kengne and Kuaban (2011), it was possible that patients who feel clinically better were less motivated to continue treatment as they do not feel the need to do so. Their study has found that during the follow up, probability of treatment discontinuation was lower in patients who were hospitalised during the intensive phase of treatment than in those treated as outpatients during the intensive phase.

With regards to the procedure of treatment the majority of participants (n=4) are receiving both pills and injection while three participants are receiving pills only and the rest of participants (n=3) were not yet on treatment. However, findings from this study showed that being on injection for six days per week was not related with treatment interruption and default because the majority of participants (n=6) felt that the treatment was fine, one participant was satisfied with the treatment while the rest
(n=2) participants complained that the treatment was long as well as the fact that they could not work to provide for their families.

Participants were asked if they were receiving treatment for any other medical condition. Six participants responded that they were not receiving other treatments apart from TB treatment while four participants responded that they were on other treatment as well. These participants revealed that they were receiving ARTs. The study conducted by Shastri, Naik, Shet, and De Costa (2013) found that co-infected patients already on ART demonstrated better outcomes in treatment than those who were not on ART. In comparison with those with TB only, co-infected patients had similar TB treatment success rates of treatment default and failure. However, the findings of this study showed that taking other medicine was not associated with treatment interruption and default. The participants responded that they did not experienced problems with taking both treatments at the same time.

Participants were requested to assess different diseases and medicine related factors that contributed to TB treatment default. They were asked whether they experienced side effects from medicine, the procedure of administering treatment as well as to whether the treatment did interfere with their lifestyle. From data collected, it was established that the majority of participants (n=8) did not experienced any side effects of the medicine while a few (n=2) admitted to have felt like vomiting after they took medication. Regarding the treatment protocols, four participants revealed that they are taking pills only; four participants were taking both pills and injection and three have not yet been placed back on treatment. Five participants reported that the treatment did not interfere with their life-style, while; three participants who were
self-employed revealed that the treatment was interfering with their lifestyle because they can no longer earn income. Finally, two participants who were elderly persons reported being too weak to do any work.

The participants were asked about what other medicine they were taking. Four participants were HIV positive and were taking Highly Active Anti-Retroviral Therapy (HAART). While these four participants have defaulted TB treatment, it was not established whether they also have defaulted their HAART treatment. The majority (n=6) of participants reported that they walk long distances to the health facilities to collect medication. They indicated that they needed transport money. Four of the participants reported living close to health facilities and were able to walk to the health facility to receive treatment.

The majority of participants (n=6) indicated that they did not drink alcohol while the rest of participants (n=4) were casual drinkers. Two of them drink beer only while other two reported drinking all types of alcoholic beverages. Of the participants who drink alcohol, two of them drink any-time alcohol was available. The other two drink almost every day. Only one participant indicated that he smoked pipe which he started in his early years for his personal medicinal use. The majority of participants (n=9) were non-smokers. All participants (N=10) indicated that TB is a difficult illness to live with. For them, it was not possible to continue working during treatment; as the treatment resulted in a patient staying for many months in the hospital. Further, being in hospital could cause fear as they typically encountered other patients who lost their hearing, lost their eyesight, become wheelchair bound due to side effects of medication or died during treatment.
5.2.4 Participant’s perceptions about treatment interruption and default

This category was centred on participants’ perceptions of the most common reasons for treatment interruption and default. The findings of this study included; long walking distance to health facility, ill-health (e.g. body weakness and tiredness). The lack of transport money, lack of information, lack of self-motivation, lack of desire for a cure and ignorance were also listed as causes for treatment interruption and default. Again, unwillingness to listen to health workers and feeling better because of treatment were also included in the list of contributing factors. In the 2002 study by Van der Walt, Lancaster, and Holtz, (2002) they investigated about the significant risks factors that affects default among both new and retreatment patients. These factors included poor health care worker attitude and changed residence during TB treatment. Other factors were; not receiving adequate counselling about treatment, feeling ashamed to have TB, seeking care from traditional healer, stopping treatment because one felt better and having a previous history of TB treatment non-adherence. Comparing this finding with the study findings, only three factors were correlating with these findings such as; feeling better because of treatment and lack of information and lack of self-motivation. The other factors were found by Elbreer, Guwatudde, Mudiope, Nabbuye-Sekandi and Manabe (2011) in the study which identified factors associated with defaulting from TB treatment. The similar factors they have found were; distance from home to the clinic, lack of health education (not being aware of the duration of treatment and the risk of discontinuing it), length of TB treatment and side effects of treatment.
Similarly, Muture et al. (2011) reported some of the factors associated with default such as: low income, lack of social support, low education, financial problem and inability to afford services. The other factors included were; older age, the male sex, inadequate knowledge, importance on need for treatment compliance, alcoholism and stigma.

Participants have suggested the following points that may help to improve treatment compliances.

From the data collected, it has come out that the majority of participants (n=4) felt that patients should be encouraged continuously to finish their treatment schedule. Three participants felt that patients should take their treatment as prescribed, while the rest (n=3) had different opinions as expressed above.

One participant raised a very important point that: “Treatment compliance depends from persons’ motivation. People are difficult to convince, some of them always do as they want”. This participant raised an important point for health care providers to be aware that there are some people who are difficult to convince. These people need specialised intervention where they can be made to understand the importance of completing TB treatment. This may include referring these patients for social work intervention of for psychosocial assessment.

According to Prager (2011), this is a pre-contemplation stage of ‘Stages of Change’ when a patient behaves like this. In this stage, the patient might seem uninterested, unaware or unwilling to make a change, and does not consider changing. Patients may appear argumentative or hopeless and the helping
professional such as social workers, nurses, or physicians may try to convince them to change. According to Nghonyama (2005), social workers play an important role in providing formal social support to clients infected with TB/HIV/AIDS. They also refer clients to other professionals for further service and link them with available resources in their communities.

5.2.5 Stigma and discrimination

This category was centred on patient related factor that leads to treatment default. The category involved stigma and discrimination as well as feelings about negative remarks regarding TB and HIV. Participants reported that they were discriminated against and also stigmatised because they have TB. About half of the participants (n=5) did not experience that. The other half of the participants reported bad experiences such as; hearing bad remarks saying that they went to look for the disease (n=1). One participant was being regarded as dead already because of TB/HIV co-infection. One participant has been teased by people saying that they do not have TB like her. The other two participants reported that their friend have been chasing them away from public places saying that they were afraid that they will be infected by them with TB.

According to Nghonyama (2005), HIV/AIDS has been linked with stigma which is one of the reasons that prevents people who are infected from disclosing their status. Sometimes people can be insensitive to those who are HIV positive by making hurtful remarks. Such remarks may have negative impact on those who are infected. As a result, they are likely to feel isolated, rejected and socially withdrawn.
Regarding how participants feel about negative remarks with regards to TB/HIV co-infection participant reported to ignore them, some has been crying, some has been isolating them self because they know that others were rejecting them. Nghonyama (2005) stated that it is apparent that being subjected to negative remarks can do more harm than good for those who are infected.

5.3 LIMITATIONS OF THE STUDY

All studies have inherent limitations; and this current study was no exception. First, the findings of this study cannot be generalised to the whole country because the study was only done in one district. Due to time and financial issues, the researcher could only focus on the patients who were admitted in Oshakati Hospital which is a district hospital for Oshana Region as well. The study only focussed on patients whose treatment was interrupted for four weeks and those who defaults their TB treatment. This study did not include patients suffering from all types of TB such as TB of spine and other TB conditions. This study has been conducted by a first time researcher with limited skills in research therefore; a small sample was selected for this study limited to Oshakati District only.

5.4 RECOMMENDATIONS

5.4.1 Recommendations for future research

- Similar studies should be done in other districts to find out about how TB treatment interruption and default affect the TB patients.
Studies comparing reasons for treatment interruption and default among private and state patients are also important in order to understand the treatment experiences in different types of health care setting.

More qualitative studies need to be done to explore on how medication side effects affects patients as well as on the coping capacities of patients who were cured from the TB disease.

5.4.2 Recommendation for policymakers

- Sensitivity training for health care providers working with TB patients to equip them with knowledge and skills on how to improve the patient centred approach when working with TB patients.
- Continuous training of professionals and stakeholders involved in working with TB patients to help strengthen the Advocacy, Communication and Social Mobilisation approach to TB treatment.

5.4.3 Recommendations for Clinicians working with TB population

- Outreach services need to be strengthened with the aim of taking service closer to people to ensure that patients who are living far from health facilities are catered for.
- Strengthen the referral of potential TB interrupters and defaulters for social work intervention to help identify problems and work on addressing these problems.
5.5 SUMMARY AND CONCLUSION

This was a small qualitative research study in which the researcher focussed the findings of the study on patients whose treatment was interrupted for four weeks and those who default treatment. This study looked at the support available for TB patients in Oshakati District, and explored on issues such as; who supported participants, their concern about lack of support, and their income as well as how participants survive without income. Secondly, it examined how patients understands TB and its treatment examining their understanding specifically on issues such as; what TB is, how it is transmitted, how it is prevented, its duration, as well as the lived experiences of TB patients.

Thirdly, the study explored on the perceptions of participants with regards to treatment interruption and default. This included issues such as what participants think about treatment interruption and default as well as their opinions and suggestions to minimise treatment interruption and default. Finally, it looked at stigma and discrimination exploring on bad remarks as well as on participants feelings about those bad remarks. Furthermore, the study looked on the importance of available literature. Lastly, the researcher’s experience of working with TB patients was a lesson learnt.

Previously, the researcher was anxious in working with TB patient in fear of infection with TB. This was a learning opportunity since the researcher has been equipped with knowledge and skills. Through this study, the researcher has been
enabled to guide other social workers who are still in fear of TB patients and will ensure that all TB patients receive improved social services.

In conclusion, the study have explored on how treatment interruption and default affects patients in Oshakati District and revealed the following issues such as; long walking distance to health facility and ill-health (including body weakness and tiredness). Other issues that came out in the findings of the study were; lack of transport money, lack of information, lack of self-motivation, lacks of desire for a cure and ignorance. An unwillingness to listen to health workers, and feeling better because of the treatment were also among the findings of the study.
REFERENCES


associated with treatment default from treatment among tuberculosis patients in
Nairobi province Kenya


RX Canada. (2007). Patients. *What is medication adherence and why is it important for me?* Retrieved from file://G:TB\ADHERENCE\what is medication adherence and why is it important for me


Tachoufi, N., Slama, K., Berraho, M., & Nejjari, C. (2012). *The impact of knowledge and attitudes on adherence to tuberculosis treatment: A case-control study in a*


LIST OF ANNEXURES

ANNEXURE I: PARTICIPANTS’ CONSENT FORM

CONSENT FORM

Participant No: ………………………Date: ………………………………………

Investigator: Tabita T. Kalunduka, University of Namibia, Private Bag 13301, Windhoek / Ministry of Health and Social Services, Private bag 5501, Oshakati

Informed consent

Title of study: An exploration of how treatment interruption and default affects tuberculosis (TB) patients in Oshakati District, Oshana Region, Namibia.

Purpose of the study: To explore how treatment interruption and default affect TB patients in Oshakati District.

Procedure: I will be asked to answer/ respond to questions about the study. The interviewing process will be scheduled at my convenience and will be conducted at the Health Centre/Hospital TB ward/at home to collect information.

Risk and discomforts: There are no medical risks or discomforts associated with this project, although I may experience fatigue and or stress when responding to these questions. I will be given as many breaks as I need during the interviewing session.

Benefits: I understand that there are no known direct medical benefits to me for participating in this study. However, the results of the study may help the researcher to gain better understanding of the exploration of TB treatment interruption and default among patients.

Participant’s rights: I may withdraw from participating in the study at any time.
Financial compensation: I will not be compensated for my participation and any travel expenses.

Confidentiality: The researcher will take notes of my responses enable her to have valid and reliable data. The transcript will only be read by investigator and authorized members of the research team at University of Namibia. I understand that the results of this study will be kept confidential unless I ask that they be released to public. The result of this study may be published in Professional Journals or presented at Professional Conferences but my record or identity will not be released unless required by law.

If I have any questions or concerns I can call Tabitha Kalunduka, the investigator at 0812771161 or 065-2233054 or Professor JD Matthews, Supervisor at + 264 61 2063713.

I understand my rights as research subject, and I voluntarily give consent to participate in this study. I understand what the study is about, how and why it is being done. I will receive a signed copy of this consent form.

__________________________  _______________________
SUBJECT’S SIGNATURE  DATE

CONTACT DETAILS: ______________________

__________________________  _______________________
SIGNATURE OF INVESTIGATOR  DATE
ANNEXURE II: OSHIWAMBO TRANSLATED INFORMED CONSENT

OFOLOMA YOKUYANDJA EPITIKILO MOKUKUFA OMBINGA
MOMAPEKAAPEKO

Onomola yomukifimbinga:........................................ Efiku:..............................
Onupekaapeki:..........................................................

Edina lomapekaapeko: Ekonaakono nghee eefepo lokunwa omiti domukifi wo”TB”
lakuma ovanaudu vomukifi wo”TB” moshitukulwa sha Shana moNamibia.

Elalakano lomapekaapeko: Okukonaakona nghee eefepo lokunwa omiti domukifi
wo”TB” lakuma eenghalo dovanaudu vomukifi wo”TB” moshitukulwa sha Shana
moNamibia.

Nghee omapekaapeko taa ka enda: Ohandi ka pulwa ndi nyamukule omapulo e na
sha nomapekaapeko. Omhito yomapekaapeko otai ka ningwa ikale ya wapalela
onghalo yange. Omapekaapeko otaa ningilwa meenhele douhaku nomoshipangelo
mOshakati momukunda woTB.

Omaupyakadi aa taa dulu okuholoka po: Kape na naanaa omaupyakadi
opaunamiti e likwatelela komapekaapeko aa, nande ame otashi dulika ngoo ndi ka
kale ndi udite eloloko, ile ndi lulilwe mokunyamukula omapulo. Ohandi ka pewa
oufudo va wana pefimbo lokunyamukula omapulo opo shi keelele eloloko.

Omauwa: Onda fatululilwa nokutya kapena nande omauwa opaunamiti handi ke a
pewa eshi nda kufa ombinga momapulaapulo aa. Ashike oidjemo yomapekaapeko
otai ka kwafela omupekaapeki novanailonga vopaunamiti opo va mone eudeko li
mondjila li na sha nomatomhelo kutya omolwashike ovanaudu vomukifi woTB hava
efa po okukatala nokunwa omiti davo.

**Oufemba wange:** Onda manguluka okuefa po okukufa ombinga momapekaapeko aa
efimbo keshe.

**Ofuto yopaimaliwa:** Itandi ka futwa sha nande eshi handi kufa ombinga
momapekaapeko aa, ame itandi ka pewa sha nande ongolupandu eshi nda kufa
ombinga momapekaapeko aa.

**Okukaleka po oiholekwa:** Omupekaapeki ota ka shanga eshi hatu kundafana. Eshi
handi nyamukula omapulo ota ka kala ta shange opo a ha dimbwe eenghundafana
detu. Oikundafanwa yetu otai ka lesha ashike komupekaapeki nokwaava yo va kufa
ombinga momapekaapeko aa nosho yo kovadeuli vomoupekaapeki vokoshiputudilo
shelongo lopombada shaUNAM. Onda fatululilwa yo kutya oijdemo yomapekaapeko
otai ka kala oshiholekwa kakele ngeenge aame nda yandje epitikilo opo ouyelele ou u
uyandjwe moshiwana. Oijdemo yomapekaapeko aa otai dulu okukayandjwa
momishangwa dopapangelo, momambo ehongo ile tai yandjwa moiongalele
yomapukululo opamadeulo, ashike ehokololo lange ile omaukwatya ange itaa ka
andjakanekwa nande, shapo pamwe ongee a pulwa paveta.

Ngee ondina omapulo a wedwa po ohandi dulu okupula Tabitha Kalunduka,
omupekaapeki kongodi e 0812771161 ile 065-2233054 ile omudeuli Professor JD
Matthews kongodi e 061-2063713.

Onda fatululilwa nee omaufemba ange ongomukufumbainga momapekaapeko aa
nohandi liyambe ndi yandje epitikilo lange opo ndi kufe ombinga momapekaapeko
aa. Onda fatululwa kutya oshike tashi ningwa notashi ka ningwa ngahelipinomolwashike. Ohandi pewa yo okopi oyo nda shaina yokuyandja epitikilo elilokukufa ombinga momapekaapeko aa.

__________________________________ ______________________

ESHAINO LOMUKUFIMBINGA EFIKU

ONGODI YOMUKUFIMBINGA:_______________________________

__________________________________ ______________________

ESHAINO LOMUPEKAPEKI EFIKU
ANNEXURE III: SEMI STRUCTURED INTERVIEW SCHEDULE

INTERVIEW SCHEDULE

PARTICIPANT NO: ...

1. BIOGRAPHICAL DATA

1.1 Age

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1.2 Sex

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<td>Female</td>
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1.3 Educational level

<table>
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</tr>
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<td>University</td>
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<td>Other (specify)</td>
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</table>

2. SUPPORT AVAILABLE FOR TB PATIENTS
2.1 How did you find out that you have TB?
2.2 Who supported you when you were diagnosed with TB?
2.3 Please explain how you were supported.
2.4 If you did not get support from your family members, what are your concerns about the lack of support?
2.5 What do you do to make a living?
2.6 If you are not employed, what is your source of income?
2.7 Is the source of income mentioned above sufficient to meet your basic needs and those of your family members?
2.8 Who are you responsible for supporting?
2.9 If you answered no to 2.7, please explain how you survive.

3. PATIENT’S UNDERSTANDING OF TB AND ITS TREATMENT
3.1 How did the nurse and doctors explain to you that you have TB?
3.2 What did they tell you about TB?
3.3 What did they say about the duration of your treatment?
3.4 How is TB transmitted? Please explain.
3.5 How does your body feel when you have TB?
3.6 What would you say about your experience of the TB treatment?
3.7 Do you think that TB is a chronic medical condition? Please explain.
3.8 Do you still feel sick after you have taken TB treatment?
3.9 Do you receive treatment for any other medical condition together with TB treatment?
3.10 If you answered yes to 3.9, how do you cope taking both treatments at the same time?

3.11 Do you take pills or injection?

3.12 Did you experienced side effects of the medications?

3.13 Do you walk long distance to the clinic to collect medication?

3.14 Does the treatment interfere with your lifestyle?

3.15 If answered yes to 3.14, please explain how you manage.

3.16 Do you drink alcohol?

3.17 If answered yes to 3.16, which type of alcohol beverage?

3.18 How often?

3.19 Do you smoke tobacco?

3.20 If answered yes to 3.19, which type of tobacco.

3.21 How much/ how frequent?

3.22 What has it been like to be a TB patient on treatment?

4. PATIENT’S PERCEPTIONS ABOUT TB TREATMENT INTERRUPTION AND DEFAULTING

4.1 What do you think about interrupting and defaulting TB treatment?

4.2 What is your opinion about improving TB treatment compliance?
5. STIGMA AND DISCRIMINATION

5.1 Do people make remarks in your presence that indicates that they are aware of you suffering from TB?

5.2 If answered yes to 5.1 what kind of remarks?

5.3 Please explain how you feel about those remarks.

Thank you for your co-operation.
### 1. DEMOGRAPHIC INFORMATION

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2. SUPPORT AVAILABLE FOR TB PATIENTS

2.1 How did you find out that you have TB?

I became sick and went to the hospital and was diagnosed with TB. I have been treated for TB previously and was discharged so that I can go home to continue with my treatment at home. I was receiving my follow up treatment at the clinic.

2.2 Who supported you when you were diagnosed with TB?

The nurses, my mother and my sister supported me during the process of admission and hospitalization.

2.3 Please explain how they supported you.

My mother and my sister always visited me in the hospital. My sister gives me food and administers my medication.

2.4 If you did not get support from your family members, what are your concerns about the lack of support?

N/A

2.5 What do you do to make a living?

I am receiving pension.
2.6 If you are not employed, what is your source of income?
N/A

2.7 Is the source of income mentioned above sufficient to meet your basic needs and those of your family members?
I am buying maize meal every month and other things in the house. My mother also provides for the household.

2.8 Who are you responsible for supporting?
I do only support the household because my children are all grownups.

2.9 If you answered no to 2.7, please explain how you survive.
N/A

3. PATIENT'S UNDERSTANDING OF TB AND ITS TREATMENT

3.1 How did the nurse and doctors explain to you that you have TB?
They informed me that I have TB and need to be admitted in hospital for treatment, because I am staying far from the hospital.

3.2 What did they tell you about TB?
The nurses informed me that I am suffering from TB of the lungs which is infectious but curable if I take my medication well.

3.3 Did they explain to you the duration of your treatment? What did they say?
They did not tell me about how long my treatment will be.

3.4 How is TB transmitted? Please explain.
The nurses told me that TB spreads through the air when a person who has a cough coughs without covering the mouth.

3.5 How does your body feel when you have TB?
The person will cough too much and feel weak.

3.6 What would you say about your experience of the TB treatment?
The treatment is fine but is very long and you spend a lot of time in the hospital.

3.7 Do you think that TB is a chronic medical condition? Please explain.

It is a chronic medical condition. TB is curable except the TB of the spine.

3.8 Do you still feel sick after you have taken TB treatment?

Yes I am still coughing; I have pains in the stomach and below the ribs.

3.9 Do you receive treatment for any other medical condition together with TB treatment?

No. I am receiving TB treatment only.

3.10 If you answered yes to 3.9, how do you cope taking both treatments at the same time?

N/A

3.11 Do you take pills or injection?

I take pills only.

3.12 Did you experience any side effects from medication?

No, I did not.

3.13 Do you walk long distance to collect your medication at the clinic?

Yes it is a long distance. When I feel weak I do not go to the clinic.

3.14 Do the treatment interfere with your lifestyle?

No. I do not work.

3.15 If answered yes to 3.14, explain how you manage.

N/A

3.16 Do you drink alcohol?

No

3.17 If answered yes to 3.16, which type of alcohol beverage?

N/A

3.18 How often?

N/A

3.19 Do you smoke tobacco?
No

3.20 If answered yes to 3.20, explain which type of tobacco.

N/A

3.21 How much/ how frequent?

N/A

3.22 What has it been like to be a TB patient on treatment?

I think that being a TB patient is just like being treated for any other disease.

4. PATIENT’S PERCEPTIONS ABOUT DEFAULTING TREATMENT

4.1 What do you think about defaulting TB treatment?

I stopped collecting and taking medication because I live far from the treatment centre where I collect medication. I walk a long distance. When I am sick, I become tired very easily and experienced a lack of energy.

4.2 What is your opinion about improving TB treatment compliance?

I think that people should take their treatment as prescribed by the doctor.

5. STIGMA AND DISCRIMINATION

5.1 Do people make remarks in your presence that indicates that they are aware of you suffering from TB?

I did not hear them. If they are talking about me I think TB is just a disease like other diseases. Anyone can get infected with TB.

5.2 If answered yes to 5.1 what kind of remarks?

N/A

5.3 Explain how you feel about those remarks.

N/A

Thank you for your co-operation.
SEMI STRUCTURED INTERVIEW SCHEDULE

PARTICIPANT: 2 (Tina)

1. DEMOGRAPHIC INFORMATION

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2. SUPPORT AVAILABLE FOR TB PATIENTS

2.1 How did you find out that you have TB?

I started coughing and feverish. Then I went to the hospital for check-up and was diagnosed with TB.

2.2 Who supported you when you were diagnosed with TB?

I was supported by Nurses and my mother.

2.3 Please explain how they supported you.

The nurses assisted and encouraged me to go for admission in the TB Ward. My mother is taking care of my son and is always visiting me in the hospital.

2.4 If you did not get support from your family members, what are your concerns about the lack of support?

N/A

2.5 What do you do to make a living?

I am not employed.

2.6 If you are not employed, what is your source of income?
I am receiving financial support from my mother.

2.7 Is the source of income mentioned above sufficient to meet your basic needs and those of your family members?

My mother and one of my sister provides for the house through buying food and other household goods.

2.8 Who are you responsible for supporting?

I have a son whom I am responsible for support. He is now under the care of my mother.

2.9 If you answered no to 2.7, please explain how you survive.

I am relying on my mother for support.

3. PATIENT’S UNDERSTANDING OF TB AND ITS TREATMENT

3.1 How did the nurse and doctors explain to you that you have TB?

I was informed that my sputum was examined and was found to have TB bacteria.

3.2 What did they tell you about TB?

I was informed that TB is a disease that can be cured. I need to follow the instructions by nurses and doctors in order to get cured. They also encouraged me to take my medication.

3.3 What did they say about the duration of your treatment?

They informed me that the duration of treatment will depend on my motivation and willingness to take treatment for 6 – 8 months. If I do not adhere to treatment then my treatment will be longer.

3.4 How is TB transmitted? Please explain.
The TB disease is transmitted when a person is coughing while he/she has not covering his/her mouth.

3.5 How does your body feel when you have TB?

The person starts coughing, has chest pains and becomes weak.

3.6 What would you say about your experience of the TB treatment?

I am fine with the treatment.

3.7 Do you think that TB is a chronic medical condition? Please explain.

Tuberculosis can be cured no matter what they are saying or complaining.

3.8 Do you feel sick after you have taken TB treatment?

I am still coughing.

3.9 Do you receive treatment for any other medical condition together with TB treatment?

No. I am only on TB treatment.

3.10 If you answered yes to 3.9, how do you cope taking both treatments at the same time?

N/A

3.11 Do you take pills or injection?

I am on injection and also take pills.

3.12 Did you experience side effects from treatment?

The medications make me to feel like vomiting. I do not feel good about this but I am forcing myself to take medication. I want to get cured.

3.13 Do you walk long distance to the clinic to collect medication?
Yes, I walk long distance. This has contributed to me having skipped collecting my medication for weeks.

3.14 Does the treatment interfere with your lifestyle?

No. I can still do my normal work while taking my treatment.

3.15 If answered yes to 3.14, explain how you manage.

N/A

3.16 Do you drink alcohol?

Yes

3.17 If answered yes to 3.16, which type of alcohol beverage?

I drink the Tafel Laager Beer.

3.18 How often?

I drink every time when I am being offered.

3.19 Do you smoke tobacco?

No.

3.20 If answered yes to 3.19, explain which type of tobacco.

N/A

3.21 How much/ how frequent?

N/A

3.22 What has it been like to be a TB patient on treatment?
Being a TB patient does not make me feel good. The treatment takes too long which is a waste of time. I am just lying and hanging around doing nothing.

4. PATIENT’S PERCEPTIONS ABOUT TREATMENT INTERRUPTION AND DEFAULT

4.1 What do you think about treatment interruption and default TB treatment?
I walk long distance to and from the clinic, and become tired and weak. I have no transport money.

4.2 What is your opinion about improving TB treatment compliance?
I think that people should just take their medication as they are told by the nurses.

5. STIGMA AND DISCRIMINATION

5.1 Do people make remarks in your presence that indicates that they are aware of you suffering from TB?

No.

5.2 If answered yes to 5.1 what kind of remarks?
N/A

5.3 Explain how you feel about those remarks.
N/A

Thank you for your co-operation.
**SEMI STRUCTURED INTERVIEW SCHEDULE**

**PARTICIPANT: 3 (Ina)**

**DEMOGRAPHIC INFORMATION**

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2. SUPPORT AVAILABLE FOR TB PATIENTS

2.1 How did you find out that you have TB?

I was admitted three times. This time I started having joint pains, coughing and stabbing pains. I was diagnosed with TB and was admitted.

2.2 Who supported you when you were diagnosed with TB?

The nurses supported me.

2.3 Please explain how they supported you.

They explained to me how TB is transmitted and that I should never go home without medication like what I did. They were very helpful to me; they accepted me back and readmitted me.

2.4 If you did not get support from your family members, what are your concerns about the lack of support?

My relative did not do well because I was supposed to be cured but now I am here back in the hospital feeling sick.
2.5 What do you do to make a living?
I am receiving pension.

2.6 If you are not employed, what is your source of income?
N/A

2.7 Is the source of income mentioned above sufficient to meet your basic needs and those of your family members?
Yes. We are surviving with this pension money.

2.8 Who are you responsible for supporting?
I am staying with my daughter and my two grandchildren whom I am supporting.

2.9 If you answered no to 2.7, please explain how you survive.
We are surviving with the pension money.

3. **PATIENT’S UNDERSTANDING OF TB AND ITS TREATMENT**

3.1 How did the nurse and doctors explain to you that you have TB?
They explained to me that when they examined my sputum they discovered that I was suffering from TB.

3.2 What did they tell you about TB?
They told me that TB is a disease of the lungs which is infectious when it is not treated.

3.3 What did they say about the duration of your treatment?
No. They did not tell me.

3.4 How is TB transmitted? Please explain.
TB is transmitted through the air and when a TB patient is coughing or sneezing while he did not cover his mouth. It is contagious. A person should not eat or drink from the same cup, he should sleep alone and should cover ye mouth when coughing.

3.5 How does your body feel when you have TB?
You feel sick, coughing too much and sometimes feels weak.

3.6 What would you say about your experience of the TB treatment?
When a person is on TB treatment, you are treated well and are well taken care of.

3.7 Do you think that TB is a chronic medical condition?
TB is a difficult disease; it takes long to get cured.

3.8 Do you still feel sick after you have taken TB treatment?
I still have pain on my left side in the chest.

3.9 Do you receive treatment for any other medical condition together with TB treatment?
No. I am only on TB treatment.

3.10 If you answered yes to 3.9, how do you cope taking both treatments at the same time?
N/A

3.11 Do you take pills or injection?
I am on injections and also take tablets.

3.12 Did you experience side effects from medication?
No.

3.13 Do you walk long distance to the clinic to collect medication?
No. The distance is not too long.
3.14 Does the treatment interfere with your lifestyle?
I do not do any work because I am weak.
3.15 If answered yes to 3.14, explain how you manage.
N/A
3.16 Do you drink alcohol?
No.
3.17 If answered yes to 3.16, which type of alcohol beverage?
N/A
3.18 How often?
N/A
3.19 Do you smoke tobacco?
N/A
3.20 If answered yes to 3.19, explain which type of tobacco.
N/A
3.21 How much/ how frequent?
N/A
3.22 What has it been like to be a TB patient on treatment?
I do not have any choice I just have to accept and live with TB.

4. PATIENT’S PERCEPTIONS ABOUT TREATMENT INTERRUPTION AND DEFAULT

4.1 What do you think about defaulting TB treatment?
I think that it is because of a lack of information. Like me I went home without medication because I was not told to wait for it on the day I was discharged then I stopped taking medication since August 2012 until June 2013. I stopped taking medication because of the lack of information.

4.2 What is your opinion about improving TB treatment compliance?
I think nurses should tell us beforehand to come back to them to collect medication before we leave the hospital.

5. STIGMA AND DISCRIMINATION

5.1 Do people make remarks in your presence that indicates that they are aware of you suffering from TB?

No.

5.2 If answered yes to 5.1 what kind of remarks?

N/A

5.3 Explain how you feel about those remarks.

N/A

Thank you for your co-operation.
SEMI STRUCTURED INTERVIEW SCHEDULE

PARTICIPANT: 4 (Miina)

1. DEMOGRAPHIC INFORMATION

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2. SUPPORT AVAILABLE FOR TB PATIENTS

2.1 How did you find out that you have TB?

I started coughing and went to the clinic. They requested my sputum for laboratory investigation and the results came out positive for TB.

2.2 Who supported you when you were diagnosed with TB?

I was sent to the hospital supported by nurses and my relative.

2.3 Please explain how they supported you.

The nurses encouraged me and reassured me that TB is curable. My relatives are visiting me and bring me food at the hospital.

2.4 If you did not get support from your family members, what are your concerns about the lack of support?

N/A

2.5 What do you do to make a living?

I am receiving disability grant.
2.6 If you are not employed, what is your source of income?
N/A

2.7 Is the source of income mentioned above sufficient to meet your basic needs and those of your family members?
I am supporting my family with this disability grant.

2.8 Who are you responsible for supporting?
My aunt is taking care of my 5 children 1 boy and four girls and they all depend on me for support.

2.9 If you answered no to 2.7, please explain how you survive.
N/A.

3. PATIENT’S UNDERSTANDING OF TB AND ITS TREATMENT

3.1 How did the nurse and doctors explain to you that you have TB?
They told me that I was diagnosed with TB and need to be admitted for treatment.

3.2 What did they tell you about TB?
I cannot remember if they have told me anything about TB.

3.3 What did they say about the duration of your treatment?
I received no information about the duration of my treatment. I heard from other patients that treatment may be for two to eight months.

3.4 How is TB transmitted? Please explain.
Tuberculosis is spreading when an infected person is coughing without covering the mouth.

3.5 How does your body feel when you have TB?
Tuberculosis is a bad disease because it can make a person to feel sick, coughing too much even when you are taking treatment for a long time.

3.6 What would you say about your experience of the TB treatment?
I feel the treatment is good because if a person adheres to take medication correctly, he can get cured.

3.7 Do you think that TB is a chronic medical condition?
Yes. Tuberculosis is a chronic medical condition because you take treatment for a long time.

3.8 Do you still feel sick after you have taken TB treatment?
Yes. I still have leg pains.

3.9 Do you receive treatment for any other medical condition together with TB treatment?
Yes. I am taking ARV’s as well.

3.10 If you answered yes to 3.9, how do you cope taking both treatments at the same time?
I do not have any problem taking both.

3.11 Do you take pills or injection?
I am getting injection five days a week and pills every day.

3.12 Do you feel like vomiting after you have taken treatment or did you experienced some other side effects?
No. I have not experienced any side effects.

3.13 Do you walk long distance to collect your medication from the clinic?
No. The clinic is near our house.
3.14 Does the treatment interfere with your lifestyle?
Yes. When I was healthy I was making traditional baskets and do many household activities but now I cannot do it because I am sick.

3.15 If answered yes to 3.14 explain how you manage.
I am relying on the support from the nurse, my aunt and my children. I cannot do anything to change the situation.

3.16 Do you drink alcohol?
No.

3.17 If answered yes to 3.16, which type of alcohol beverage?
N/A

3.18 How often?
N/A

3.19 Do you smoke tobacco?
N/A

3.20 If answered yes to 3.19, explain which type of tobacco.
N/A

3.21 How much/ how frequent?
N/A

3.22 What has it been like to be a TB patient on treatment?
I feel bad because I have TB and HIV (all the big diseases are in my body).

4. PATIENT’S PERCEPTIONS ABOUT TREATMENT INTERRUPTION AND DEFAULT

4.1 What do you think about defaulting TB treatment?
I have default the treatment because of the lack of information, lack of transport money, lack of motivation to collect and take medication.

4.2 What is your opinion about improving TB treatment compliance?

Patients need encouragement to continuously taking their medication until they complete treatment

5. STIGMA AND DISCRIMINATION

5.1 Do people make remarks in your presence that indicates that they are aware of you suffering from TB?

Yes. My relatives do not treat me well.

5.2 If answered yes to 5.1 what kind of remarks?

They are saying that I went to look for my diseases myself. My aunt who lives with my children does not even visit me. I am only visited by my first born daughter. Other relatives do not even bother to come visit me in the hospital.

5.3 Explain how you feel about those remarks.

I am feeling bad and crying but I have courage and faith that I will be cured.

Thank you for your co-operation.
SEMI STRUCTURED INTERVIEW SCHEDULE

PARTICIPANT NO: 5 (Anne)

1. DEMOGRAPHIC INFORMATION

1.1 Age

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2. SUPPORT AVAILABLE FOR TB PATIENTS

2.1 How did you find out that you have TB?

“I started coughing, experiencing stabbing pains in the ribs, feeling feverish and sometimes cold and went to the clinic. My sputum was sent for Laboratory investigation and I went home to wait for my results. Later, the nurses came to collect me from home and take me to the hospital where I was admitted. I have stayed in the hospital for two months now”.

2.2 Who supported you when you were diagnosed with TB?

The nurses supported me.

2.3 Please explain how they supported you.

They encouraged me to take my treatment as prescribed by doctor.

2.4 If you did not get support from your family members, what are your concerns about the lack of support?
I did not receive any support from my mother. I do not receive visitors. I have three children who stay with my sister, my paternal grandmother and uncle. My mother needs to be encouraged to support me.

2.5 What do you do to make a living?
I am not employed.

2.6 If you are not employed, what is your source of income?
I have no income, my sister was always supporting me but now that I am in the hospital I have no income.

2.7 Is the source of income mentioned above sufficient to meet your basic needs and those of your family members?
N/A

2.8 Who are you responsible for supporting?
I have to support my three children but have no income.

2.9 If you answered no to 2.7, please explain how you survive.
I am now in the hospital. I am eating food from the hospital and depend on their care. When I am at home I am also depend from my sister.

3. PATIENT’S UNDERSTANDING OF TB AND ITS TREATMENT

3.1 How did the nurse and doctors explain to you that you have TB?
They explained to me that I have TB and need to take medication if I want to get cured.

3.2 What did they tell you about TB?
They said that TB is a lung disease and I should not take alcohol.

3.3 What did they say about the duration of your treatment?
The duration of treatment is 8 to 24 months.

3.4 How is TB transmitted? Please explain.

TB is transmitted through the air and by drinking from the same cup.

3.5 How does your body feel when you have TB?

The body feels weak. The disease takes long to get cured. The person might not get employment or get light work.

3.6 What would you say about your experience of the TB treatment?

The treatment is fine.

3.7 Do you think that TB is a chronic medical condition?

It is a chronic illness but the good thing is that TB can be cured. I have accepted it and will take treatment.

3.8 Do you still feel sick after you have taken TB treatment?

I do not have any pain.

3.9 Do you receive treatment for any other medical condition together with TB treatment?

Yes. I am on ARV’s as well.

3.10 If you answered yes to 3.9, how do you cope taking both treatments at the same time?

I am not yet on TB treatment; my treatment will start soon with both pills and injection.

3.11 Do you take pills or injection?

N/A
3.12 Do you feel like vomiting after you have taken treatment or did you experienced some other side effects?
No.

3.13 Do you walk long distance to collect your medication from the clinic?
Yes. It is a long distance, I need money for transport.

3.14 Does the treatment interfere with your lifestyle?
No.

3.15 If answered yes to 3.14, explain how you manage.
N/A

3.16 Do you drink alcohol?
Yes.

3.17 If answered yes to 3.16, which type of alcohol beverage?
I can take any alcohol beverage, like Beer, Otombo and other light and hard liquor.

3.18 How often?
I can take any time I am being offered.

3.19 Do you smoke tobacco?
No.

3.20 If answered yes to 3.19, explain which type of tobacco.
N/A

3.21 How much/ how frequent?
N/A

3.22 What has it been like to be a TB patient on treatment?
I feel bad because TB treatment takes long 8-24 months as well as HIV which I will carry for the rest of my life.

4. PATIENT’S PERCEPTIONS OF DEFAULTING TREATMENT

4.1 What do you think about defaulting TB treatment?

I stopped TB treatment as a result of the lack of motivation to take medication, tiredness, walking long distance to collect medication from the clinic, weakness as a result of ill health and lack of transport money.

4.2 What is your opinion about improving TB treatment compliance?

The Nurses should encourage patients to continue taking medication until they are cured.

5. STIGMA AND DISCRIMINATION

5.1 Do people make remarks in your presence that indicates that they are aware of you suffering from TB?

Yes. Some are discriminating against me and try to isolate me.

5.2 If answered yes to 5.1, what kind of remarks?

They can tell me straight in me face saying that they are not sick with TB.

5.3 Explain how you feel about those remarks.

I feel bad because they are making me to feel bad. TB can infect anyone. I just ignore them and make as if I do not care.

Thank you for your co-operation.
SEMI STRUCTURED INTERVIEW SCHEDULE

PARTICIPANT NO: 6 (Leo)

1. DEMOGRAPHIC INFORMATION

1.1 Age

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2. SUPPORT AVAILABLE FOR TB PATIENTS

2.1 How did you find out that you have TB?

I went to the hospital because of the cough I was having for a long time. I was admitted for three times now. This has contributed to the fact that I am still not yet cured.

2.2 Who supported you when you were diagnosed with TB?

The nurses and my relatives supported me.

2.3 Please explain how they supported you.

The nurses gave me counselling to continue with treatment. My relatives are visiting me regularly in the hospital.

2.4 If you did not get support from your family members, what are your concerns about the lack of support?

N/A

2.5 What do you do to make a living?
I am a Plumber.

2.6 If you are not employed, what is your source of income?

N/A

2.7 Is the source of income mentioned above sufficient to meet your basic needs and those of your family members?

The money was always enough for the family.

2.7 Who are you responsible for supporting?

I support my children and my parents.

2.8 If you answered no to 2.7, please explain how you survive.

I am now in the hospital with no income.

3. PATIENT’S UNDERSTANDING OF TB AND ITS TREATMENT

3.1 How did the nurse and doctors explain to you that you have TB?

They informed me that I have TB and need to be admitted for treatment.

3.2 What did they tell you about TB?

They told me that I have TB of the lungs.

3.3 What did they say about the duration of your treatment?

The duration of treatment can take 6-24 months if not improving.

3.4 How is TB transmitted? Please explain.

If a person is taking excessive alcohol, you can get infected with TB as well as when coughing without covering the mouth. TB can also be inherited from ones parents.

3.5 How does your body feel when you have TB?

I feel chest pains, tiredness, cold, fever.

3.6 How would you describe your experiences receiving treatment?
The treatment is fine but you cannot do your work. If you work, you cough up blood.

3.7 Do you think that TB is a chronic medical condition?

TB is a chronic illness but can be cured.

3.8 Do you still feel sick after you have taken TB treatment?

I only have cough.

3.9 Do you receive treatment for any other medical condition together with TB treatment?

Yes. I am on ARV’s as well.

3.10 If you answered yes to 3.9, how do you cope taking both treatments at the same time?

I have no problem with taking both treatments.

3.11 Do you take pills or injection?

I take pills.

3.12 Do you feel like vomiting after you have taken treatment or did you experienced some other side effects?

No.

3.13 Do you walk long distance to the clinic to collect medication?

Yes. It is a long distance. You need to have transport money to reach the hospital.

3.14 Does the treatment interfere with your lifestyle?

Yes. If I work I cough up blood. When I came back very sick I started working then I became sick coughing up blood.

3.15 If answered yes to 3.14, explain how you manage.

I do not do anything.
3.16 Do you drink alcohol?
Yes. I was drinking and have stopped since February 2013.

3.17 If answered yes to 3.16, which type of alcohol beverage?
I can drink all types of alcoholic beverages.

3.18 How often?
I was drinking almost after every day’s work.

3.19 Do you smoke tobacco?
Yes. I started smoking when I was very young because of stomach pains.

3.20 If answered yes to 3.19, explain which type of tobacco.
I was smoking pipe.

3.21 How much/ how frequent?
3.22 More than three times a day.

2.23 What has it been like to be a TB patient on treatment?
TB is a bad disease because it can kill you. It prevents you from doing you to work. Some people cannot walk, see or hear and some are in wheelchairs because of TB. As a TB patient one need to take treatment as prescribed otherwise you will not get cured.

4. PATIENT’S PERCEPTIONS ABOUT TREATMENTINTERRUPTION AND DEFAULT

4/1 What do you think about interrupting and defaulting TB treatment?
I do not know. Maybe the person who is interrupt or default the treatment does not want to be cured. Or maybe that is what they want

4.2 What is your opinion about improving TB treatment compliance?
All TB patients should be encouraged to take their medication as prescribed by the doctor.

5. STIGMA AND DISCRIMINATION

5.1 Do people make remarks in your presence that indicates that they are aware of you suffering from TB?

No. I did not experience that.

5.2 If answered yes to 5.1 what kind of remarks?

N/A

5.3 Explain how you feel about those remarks.

N/A

Thank you for your co-operation.
SEMI STRUCTURED INTERVIEW SCHEDULE

PARTICIPANT NO: 7 (Tim)

1. DEMOGRAPHIC INFORMATION

1.1 Age

| Age Range          |  
|--------------------|---
| 18-30 years       | X |
| 31- 40 years      |   |
| 41- 50 years      |   |
| 51- 60 years      |   |
| 61 years and above|   |

1.2 Gender

| Gender  |  
|---------|---
| Male    | X |
| Female  |   |

1.3 Marital status

| Marital Status   |  
|------------------|---
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| Married          |   |
| Divorced         |   |
| Separated        |   |
| Widowed          |   |
1.4 Educational level

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2. SUPPORT AVAILABLE FOR TB PATIENTS

2.1 How did you find out that you have TB?

I started experiencing stabbing pains in the ribs. After I went to the clinic I was examined and I was informed that I have TB.

2.2 Who supported you when you were diagnosed with TB?

The Nurses and Community Counsellor supported me.

2.3 Please explain how they supported you.

The community counsellor gave me counselling to take my treatment while the nurses gave me information on what is TB.

2.4 If you did not get support from your family members, what are your concerns about the lack of support?

My parents passed away. We were left with no sufficient income and are struggling to survive. I was collecting my medication from the nearest facility and defaulted for two months. I was traced and was brought back to the hospital.

2.5 What do you do to make a living?
I am not employed

2.6 If you are not employed, what is your source of income?

My sister is giving me pocket money because our parents died and we are only four people in the house.

2.7 Is the source of income mentioned above sufficient to meet your basic needs and those of your family members?

It is not sufficient.

2.8 Who are you responsible for supporting?

None

2.9 If you answered no to 2.7, please explain how you survive.

My sister provides me with pocket money. I stopped collecting my medication from the health centre because I had no transport money.

3. PATIENT’S UNDERSTANDING OF TB AND ITS TREATMENT

3.1 How did the nurse and doctors explain to you that you have TB?

They informed me that I have TB and need to be admitted in the hospital for treatment.

3.2 What did they tell you about TB?

They said that TB treatment needs to be completed, it need to be taken on time with food.

3.3 What did they say about the duration of your treatment?

No they did not tell me.

3.4 How is TB transmitted? Please explain.

Tuberculosis is an airborne disease. You can catch TB through the air.
3.5 How does your body feel when you have TB?
A person will feel sick, coughing and experiencing chest pains.

3.6 What would you say about your experience of the TB treatment?
I do not have problem with the treatment what is needed is that the person should adhere to this treatment to get cured.

3.7 Do you think that TB is a chronic medical condition?
Tuberculosis can be cured.

3.8 Do you still feel sick after you have taken TB treatment?
Yes. I am still having chest pains and cough.

3.9 Do you receive treatment for any other medical condition together with TB treatment?
Yes. I am on ARV’s as well.

3.10 If you answered yes to 3.9, how do you cope taking both treatments at the same time?
No. I do not have problems taking both treatments.

3.11 Do you take pills or injection?
I am taking pills.

3.12 Do you feel like vomiting after you have taken treatment or did you experienced some other side effects?
No. I am fine with the treatment.

3.13 Do you walk long distance to the clinic to collect medications?
Yes, it is a long distance. I always need money for transport.

3.14 Does the treatment interfere with your lifestyle?
No. I can take my medicine and do what I have to do.

3.15 If answered yes to 3.14, explain how you manage.

N/A

3.16 Do you drink alcohol?

No.

3.17 If answered yes to 3.16, which type of alcohol beverage?

N/A

3.18 How often?

N/A

3.19 Do you smoke tobacco?

No

3.20 If answered yes to 3.19, explain which type of tobacco.

N/A

3.21 How much/ how frequent?

N/A

3.22 What has it been like to be a TB patient on treatment?

Being a TB patient on treatment requires a lot of motivation so that you can adhere. If you do not adhere to the treatment your body become resistant to treatment and it will take long to get cured. In my situation I was receiving treatment from ..... Health Centre and stayed away for two months. I was traced by the Nurses and was brought back in the hospital on the 18 July 2013.

4. PATIENT’S PERCEPTIONS ABOUT INTERRUPTING AND DEFAULT

4.1 What do you think about defaulting TB treatment?
It is not good to stop taking medication because your body can become resistant to treatment. Like in my case I stopped taking treatment because I was not having money for transport to the clinic. Now I will stay long in the hospital.

4.2 What is your opinion about improving TB treatment compliance?
People need to be given information continuously about the need to finish their medication. Those who abuse alcohol need to be counselled to help them to stop abusing alcohol.

5. STIGMA AND DISCRIMINATION

5.1 Do people make remarks in your presence that indicates that they are aware of you suffering from TB?

Yes. My brother is talking bad about me.

5.2 If answered yes to 5.1 what kind of remarks?
He is saying that he sees me as a dead person because he knows that I have TB and HIV.

5.3 Explain how you feel about those remarks.

I feel bad about that. How can he say something like that to me?

Thank you for your co-operation.
SEMI STRUCTURED INTERVIEW SCHEDULE

PARTICIPANT NO: 8 (Tobby)

1. DEMOGRAPHIC INFORMATION

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2. SUPPORT AVAILABLE FOR TB PATIENTS

2.1 How did you find out that you have TB?

I started coughing, feeling dizziness, fever and cold. I was examined at the clinic and was informed that I have TB.

2.2 Who supported you when you were diagnosed with TB?

The nurses and my brother supported me.

2.3 Please explain how they supported you.

They both encouraged me to take my medication as prescribed by the Doctor.

2.4 If you did not get support from your family members, what are your concerns about the lack of support?

N/A

2.5 What do you do to make a living?

I am a Barber.

2.6 If you are not employed, what is your source of income?

N/A
2.7 Is the source of income mentioned above sufficient to meet your basic needs and those of your family members?
Yes. The money was enough but now I have no income because I am in the hospital.

2.8 Who are you responsible for supporting?
My three children depend on me.

2.9 If you answered no to 2.7, please explain how you survive.
N/A

3. PATIENT’S UNDERSTANDING OF TB AND ITS TREATMENT

3.1 How did the nurse and doctors explain to you that you have TB?
They told me that they have examined my sputum and found that I have TB and need to be admitted in the TB Ward for treatment.

3.2 What did they tell you about TB?
They said that TB transmitted through alcohol abuse, when a person is only drinking alcohol and does not eat and when too many people stays in a room with no ventilation if there is someone with TB among them they may all get TB

3.3 What did they say about the duration of your treatment?
They did not tell me about the duration of my treatment.

3.4 How is TB transmitted? Please explain.
Tuberculosis is transmitted through the family, when a family member has TB he can spread it to others when he is coughing without covering his mouth or when he sleeps with other people in the room where there is no enough ventilation. TB is also caused by alcohol abuse and tobacco smoking.

3.5 How does your body feel when you have TB?
The person will cough too much and feel weak.

3.6 What would you say about your experience of the TB treatment?

When you are on treatment you get admitted which means that you cannot go to work and you will stay long in the hospital.

3.7 Do you think that TB is a chronic medical condition?

Tuberculosis is curable. If one adheres to take treatment he will get cured.

3.8 Do you still feel sick after you have taken TB treatment?

No. I do not have pain anymore.

3.9 Do you receive treatment for any other medical condition together with TB treatment?

No. I am only receiving TB treatment.

3.10 If you answered yes to 3.9, how do you cope taking both treatments at the same time?

N/A

3.11 Do you take pills or injection?

I get pills and injection.

3.12 Do you feel like vomiting after you have taken treatment or did you experienced some other side effects?

No.

3.13 Do you walk long distance to the clinic to collect medication?

No. I walk to the clinic and to the hospital I do not need transport money.

3.14 Does the treatment interfere with your lifestyle?
Yes. I was working as a Barber in Windhoek and had many customers. Now I am here in the hospital with no income.

3.15 If answered yes to 3.14, explain how you manage.

What can I do? I have to finish this treatment.

3.16 Do you drink alcohol?

Yes.

3.17 If answered yes to 3.16, which type of alcohol beverage?

I was taking Beers.

3.18 How often?

I drink almost after each working day.

3.19 Do you smoke tobacco?

No.

3.20 If answered yes to 3.19, explain which type of tobacco.

N/A

3.21 How much/ how frequent?

N/A

3.22 What has it been like to be a TB patient on treatment?

This TB treatment is taking long. As a bread winner for my children it is difficult because I cannot do my work to provide for them.
4. PATIENT’S PERCEPTIONS ABOUT TREATMENT INTERRUPTION AND DEFAULT

4.1 What do you think about defaulting TB treatment?
I stopped the treatment because of ignorance. I did not listen to nurses and doctors when told me to take medication.

4.2 What is your opinion about improving TB treatment compliance?
People should finish their treatment schedule and need to be encouraged to finish the course of treatment.

5. STIGMA AND DISCRIMINATION

5.1 Do people make remarks in your presence that indicates that they are aware of you suffering from TB?
Yes.

5.2 If answered yes to 5.1, what kind of remarks?
Some of my friends always chase me away saying that they are afraid of me to infect them with TB.

5.3 Explain how you feel about those remarks.
It makes me to feel bad. I just have to go back home because I feel people are rejecting me.

Thank you for your co-operation.
# SEMI STRUCTURED INTERVIEW SCHEDULE

**PARTICIPANT NO: 9 (Nick)**

## DEMOGRAPHIC INFORMATION

### 1.1 Age

<table>
<thead>
<tr>
<th>Age Range</th>
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<tbody>
<tr>
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### 1.2 Gender

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### 1.3 Marital status

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1.4 Educational level

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<tr>
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<tr>
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2. SUPPORT AVAILABLE FOR TB PATIENTS

2.1 How did you find out that you have TB?

I started coughing four years ago. I was examined at the clinic and I was given results that I have TB.

2.2 Who supported you when you were diagnosed with TB?

The nurses and my wife supported me.

2.3 Please explain how they supported you.

The nurses and my wife have been encouraging me to take my treatment.

2.4 If you did not get support from your family members, what are your concerns about the lack of support?

N/A

2.5 What do you do to make a living?

I am receiving pension.

2.6 If you are not employed, what is your source of income?
2.7 Is the source of income mentioned above sufficient to meet your basic needs and those of your family members?
Yes. We also live with one of our child who lives with disability and receive disability grant.

2.8 Who are you responsible for supporting?
I am the main provider for the family.

2.9 If you answered no to 2.7, please explain how you survive.
N/A

3. PATIENT’S UNDERSTANDING OF TB AND ITS TREATMENT

3.1 How did the nurse and doctors explain to you that you have TB?
I was first admitted in Onandjokwe Hospital where they informed me that I have TB and need to be treated. I made a mistake by not completing my treatment. Now I am sick again feeling pain because of that.

3.2 What did they tell you about TB?
They told me that I have TB of the lungs and its treatment need to be completed otherwise my body will become resistant to treatment.

3.3 What did they say about the duration of your treatment?
The duration of treatment may take more than eight months. Now that I have defaulted I do not know how long the treatment will take.

3.4 How is TB transmitted? Please explain.
Tuberculosis is spreading through the air. One can get infected if you are drinking alcohol too much and do not eat well.
3.5 How does your body feel when you have TB?
I have burning chest pains and feel tired.

3.6 What would you say about your experience of the TB treatment?
The treatment is fine. A person can just get pills and injection for four months and you will feel better.

3.7 Do you think that TB is a chronic medical condition?
Tuberculosis is a chronic illness but it can be cured.

3.8 Do you still feel sick after you have taken TB treatment?
I only came today and not yet on treatment. I am in pain.

3.9 Do you receive treatment for any other medical condition together with TB treatment?
So far I was only diagnosed with TB.

3.10 If you answered yes to 3.9, how do you cope taking both treatments at the same time?
N/A

3.11 Do you take pills or injection?
I am still not yet back on TB treatment. Before I stopped taking medications I was only taking pills.

3.12 Do you feel like vomiting after you have taken treatment or did you experienced some other side effects?
Yes. I had some medications that make me to feel like vomiting then I told the doctor and he changed it.

3.13 Do you walk long distance to the clinic to collect medication?
I did not collect medications from the clinic because I refused to go and collect it there. I will now receive medication in the hospital. The clinic is far. It is a long distance for a sick person but it is stationed near the Church. Almost all people get treatment there.

3.14 Does the treatment interfere with your lifestyle?

No. I can do my work while on treatment.

3.15 If answered yes to 3.14, explain how you manage.

N/A

3.16 Do you drink alcohol?

No.

3.17 If answered yes to 3.16, which type of alcohol beverage?

N/A

3.18 How often?

N/A

3.19 Do you smoke tobacco?

No.

3.20 If answered yes to 3.19, explain which type of tobacco.

N/A

3.21 How much/ how frequent?

N/A

3.22 What has it been like to be a TB patient on treatment?
The treatment is taking too long and I get tempted to stop on my own. I am now admitted in the hospital and will try to adhere to the treatment.

4. PATIENT’S PERCEPTIONS ABOUT TREATMENT INTERRUPTION AND DEFAULT

4.1 What do you think about defaulting TB treatment?

When I feel better I stop taking treatment. When I have no motivation to continue taking treatment I stop taking treatment.

4.2 What is your opinion about improving TB treatment compliance?

Treatment compliance depends from the person’s motivation. People are difficult to convince some of them always do what they want.

5. STIGMA AND DISCRIMINATION

5.1 Do people make remarks in your presence that indicates that they are aware of you suffering from TB?

Yes.

5.2 If answered yes to 5.1 what kind of remarks?

People are chasing me away telling me straight that they are afraid that I will infect them with TB. Some does not even talk to me.

5.3 Explain how you feel about those remarks.

I feel bad but I have accepted it and only put my trust in God.

Thank you for your co-operation.
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2. SUPPORT AVAILABLE FOR TB PATIENTS

2.1 How did you find out that you have TB?

I was sick and went for general check-up and the results came out positive for TB.

2.2 Who supported you when you were diagnosed with TB?

The nurses and my colleagues at work supported me.

2.3 Please explain how they supported you.

The nurses and my colleagues gave me information about TB and encouraged me to take treatment as prescribed.

2.4 If you did not get support from your family members, what are your concerns about the lack of support?

I am staying alone. My colleagues encouraged to take my medication and supported me to eat well.

2.5 What do you do to make a living?

I am a Driver employed in the government.

2.6 If you are not employed, what is your source of income?
2.7 Is the source of income mentioned above sufficient to meet your basic needs and those of your family members?

Yes.

2.8 Who are you responsible for supporting?

I am responsible for supporting my parents.

2.9 If you answered no to 2.7, please explain how you survive.

N/A

3. PATIENT’S UNDERSTANDING OF TB AND ITS TREATMENT

3.1 How did the nurse and doctors explain to you that you have TB?

They first informed me that I have TB and encouraged me to adhere to my treatment. I should not skip follow up and should take treatment everyday as prescribed.

3.2 What did they tell you about TB?

Tuberculosis is a disease of lungs. Its treatment need to be completed. If I do not complete my treatment my body may become resistant to treatment and the treatment may last longer.

3.3 What did they say about the duration of your treatment?

My private doctor informed me that the duration of treatment is six months.

3.4 How is TB transmitted? Please explain.

Tuberculosis is spreading through the air. It can spread quickly in a congested place where there is no ventilation.

3.5 How does your body feel when you have TB?

The body feels weak, tired and lacks appetite.
3.6 How would you describe your experiences receiving treatment?
I feel good. I did not experience any problem with regards to receiving treatment.

3.7 Do you think that TB is a chronic medical condition?
Tuberculosis is a chronic condition but it can be cured.

3.8 Do you still feel sick after you have taken TB treatment?
No. I do not have any pain.

3.9 Do you receive treatment for any other medical condition together with TB treatment?
No. I am only on TB treatment.

3.10 If you answered yes to 3.9, how do you cope taking both treatments at the same time?
N/A

3.11 Do you take pills or injection?
I am taking pills.

3.12 Do you feel like vomiting after you have taken treatment or did you experienced some other side effects?
No.

3.13 Do you walk long distance to the clinic to collect medication?
No. It is a walking distance.

3.14 Does the treatment interfere with your lifestyle?
No. I can take my medicine and do my work. Like now I am at work, I took my medication at workplace.

3.15 If answered yes to 3.14, explain how you manage.
N/A

3.16 Do you drink alcohol?
No.

3.17 If answered yes to 3.16, which type of alcohol beverage?
N/A

3.18 How often?
N/A

3.19 Do you smoke tobacco?
No.

3.20 If answered yes to 3.19, explain which type of tobacco.
N/A

3.21 How much/ how frequent?
N/A

3.22 What has it been like to be a TB patient on treatment?
Being a patient on TB treatment was not easy. I was first on denial trying to justify how I got infected with TB and later I accepted it.

4. PATIENT’S PERCEPTIONS ABOUT TREATMENT INTERRUPTION AND DEFAULT

4.1 What do you think about defaulting TB treatment?
People do default their treatment because they lack motivation to take the treatment. All these depend from the person’s self-motivation. I am still taking my medication.

4.2 What is your opinion about improving TB treatment compliance?
Patients need to be continuously encouraged to take their medication until they complete treatment.

5. STIGMA AND DISCRIMINATION

5.1 Do people make remarks in your presence that indicates that they are aware of you suffering from TB?

No. I did not experience that

5.2 If answered yes to 5.1 what kind of remarks?

N/A

5.3 Explain how you feel about those remarks.

N/A

Thank you for your co-operation.
ANNEXURE V: APPROVAL LETTER FROM THE POSTGRADUATE
STUDIES COMMITTEE OF THE UNIVERSITY OF NAMIBIA
ANNEXURE VI: PERMISSION LETTER FROM THE MINISTRY OF HEALTH AND SOCIAL SERVICES