COMMUNITY CARE WORKERS’ EXPERIENCES OF SUPPORTING PATIENTS ON TUBERCULOSIS TREATMENT AT HLOGOTLOU AREA, LIMPOPO PROVINCE

by

MOTHOA PATRICK MASHILO

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DEDICATION

This mini-dissertation is dedicated to my mother, Masemola Monica Ramolokwane, and my beloved partner Tjie Hope and my daughter Chuene Keitumetse Ramolokwane, for their continuous support throughout my studies.
ACKNOWLEDGEMENTS

I thank God for giving me the strength and courage to complete my degree.

I would like to express my deepest appreciation to the following individuals and institutions that contributed and encouraged me to complete this study.

- Deepest thanks to my supervisor, Dr Sogo France Matlala: my sincere thanks for your skilful guidance, great support and encouragement during my studies.
- Ms Pam Mamogobo for co-coding the data.
- Hlogotlou Clinic Operational Manager, for the support.
- Community care workers, who participated in the interview sessions during their busy schedule of caring and supporting patients on TB treatment.
- Hlogotlou Home-Based Care, for granting me permission to interview the participants.
DECLARATION

I declare that COMMUNITY CARE WORKERS’ EXPERIENCES OF SUPPORTING PATIENTS ON TUBERCULOSIS TREATMENT AT HLOGOTLOU AREA, LIMPOPO PROVINCE, is my own work and that all the sources that I have used and quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

Mothoa Patrick Mashilo

Date………………………………..
DEFINITION OF CONCEPTS

Experiences
Experiences refer to the knowledge and skills that a person gained by doing something for a period of time (Oxford Advanced Learner’s Dictionary, 2010). In this study, experiences refer to the knowledge and skills acquired by community care workers who supported tuberculosis (TB) patients from four weeks of treatment initiation.

Community care worker
A community care worker is defined as any care worker delivering health care services and who is trained in the context of the intervention, but has no formal professional, tertiary education, certificate or degree (Languza, Lushaba, Magingxa, Masuku & Ngubo, 2011). A community care worker in this study refers to a person at Hlogotlou who belongs to a home-based care organisation and has been trained to support patients to take TB treatment as prescribed, and ensures that the patient eats first before taking treatment.

Supporting patients
Supporting patients refers to the act of enhancing self-management support to enable patients to have skills, knowledge and expertise to make positive choices about their health care, and to make long term positive changes to health behaviours, such as maintaining a healthy weight, staying active and managing the emotional impact of the condition on their day to day lives (Phillips, 2012). In this study, supporting patients refers to helping TB patients to take their medication as prescribed, making sure that the patients have nutritious diet and are eating healthy; ensure that they adhere to their check-up dates, and help them to live healthy lifestyles.

Tuberculosis treatment
Tuberculosis treatment refers to treatment that is used for TB in combination of the following drugs: Isoniazid (H), Rifampicin (R), Pyrazinamide (Z), Ethambutol (E) and Streptomycin (S) (National Department of Health, 2014). Tuberculosis treatment in this study refers to the medication that TB patients are taking through the intensive and continuation phase of the treatment.
**ABBREVIATIONS**

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>CCW</td>
<td>Community Care Worker</td>
</tr>
<tr>
<td>DOTS</td>
<td>Directly Observed Treatment Short-course</td>
</tr>
<tr>
<td>DR TB</td>
<td>Drug Resistant Tuberculosis</td>
</tr>
<tr>
<td>DST</td>
<td>Drug Susceptibility Testing</td>
</tr>
<tr>
<td>EPTB</td>
<td>Extra Pulmonary Tuberculosis</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>MDR TB</td>
<td>Multi Drug Resistant Tuberculosis</td>
</tr>
<tr>
<td>PTB</td>
<td>Pulmonary Tuberculosis</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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<tr>
<td>XDR TB</td>
<td>Extensively Drug Resistant Tuberculosis</td>
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ABSTRACT

Title: Community care workers’ experiences of supporting patients on tuberculosis treatment at Hlogotlou area, Limpopo Province

Background: Tuberculosis still continues to be a global public health problem and leads to many deaths. In an effective TB control strategy, TB patients are allocated to community care workers who provide care to these patients in their homes. It is important to understand the experiences of community care workers in order to strengthen TB control in the country.

Objective(s): The purpose of this study was to explore lived experiences of community care workers of supporting patients taking Tuberculosis treatment.

Methods: The design of the study was phenomenological, exploratory, descriptive, and contextual. The study site was Hlogotlou area in Limpopo Province. The target population was all community care workers supporting patients on Tuberculosis treatment. Purposive sampling was used with a sample of 13 participants, which was determined by the saturation of data. Semi-structured interviews were conducted using an interview guide and all sessions were audio recorded. The data were analysed using Interpretative Phenomenological Analysis.

Results: The results highlighted certain challenges met by community care workers. Patients thought that community care workers are there to kill them with treatment, they had mood swings during treatment and this caused them to use vulgar words and become aggressive to their community care workers. Most community care workers did not have enough information about Tuberculosis. This made it difficult for them to support patients on tuberculosis treatment.

Conclusions: A good relationship with patients enhances treatment compliance. The researcher recommends that intensive training about tuberculosis should be provided to community care workers.

Keywords: Community care workers; supporting; tuberculosis; Interpretative Phenomenological Analysis; DOTS.
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CHAPTER 1
OVERVIEW OF THE STUDY

1.1 INTRODUCTION AND BACKGROUND

It is important for community care workers (CCWs) to be resourceful in supporting patients on tuberculosis (TB) treatment as treatment defaulting has strong and complicated side effects. So if patients on TB treatment are fully supported by their CCWs, then they usually get motivated and tolerate some of the side effects of the treatment until they become resolved. Some CCWs undergo a traumatic experience of contracting communicable diseases while caring for sick patients. According to Mottiar and Lodge (2018), CCWs usually work in households of the poor, and render basic care and rehabilitation where necessary. CCWs sometimes give care without protective clothing. This leads them to improvise and use plastic bags for gloves and home-made clothes for dressings. Some are exposed to violent and sexual assault while rendering their services to desperate communities. CCWs visit households to provide care without any protection and local health facilities do not give sufficient support (Okeyo & Dowse, 2016).

Performance of CCWs is determined by the number of households visited by the CCWs, the quality of their knowledge and their supervision. High ratios of CCWs to households yield good results, and health problems are identified early before they could even complicate. This high ratio of CCWs to households can be attained by employing both full-time and part-time CCWs (Mottiar & Lodge, 2018). The ratio currently proposed in South Africa of one CCW to 270 households is extremely unlikely to have such an effect given South Africa’s very high burden of disease, and the large percentage of people requiring time-consuming home-based care. If South Africa were to adopt such a ‘two-tier’ approach of two CCWs per household, this would require a total of at least 500,000 CCWs, the majority of them are working part-time. In addition to rendering health care to be more accessible and equitable, this would create jobs, and indirectly improve health by reducing the prevalence and depth of poverty.
In South Africa, there is currently no standardised training or employment of CCWs (Okeyo & Dowse, 2016). Despite this, thousands of CCWs are working in vulnerable communities helping to address the need caused by South Africa’s burden of disease and the failure of an ailing health system. It is well established internationally that CCWs are the foundation of successful primary health care systems (Mottiar & Lodge, 2018).

Drug resistance and obstacles to a successful directly observed treatment short-course (DOTS) impede TB control. Drug resistance is common and a retreatment outcome is poor among patients because of initial treatment failure, default from initial treatment or relapse following initial treatment (Dooley, Lahlou, Ghali, Knudsen, Elmessaoud, Cherkaou & Aouad, 2011). Patients who had treatment failure after the completion of standard first-line TB treatment and present for retreatment were previously grouped together by the World Health Organization (WHO) as Category 2 cases. In settings where individual drug susceptibility testing (DST) was not universally accessible, these patients were often treated with a standard retreatment regimen of first-line agents, which is a regimen that adds a single drug to the standard initial TB treatment regimen. Retreatment outcomes are often poor, especially in patients with treatment failure. A high default rate leads to multiple drug resistance TB (MDR-TB), and therefore hampers the control of TB, and thus increases the morbidity and mortality rates (Boaten, Kodama, Tachibana & Hyoi, 2010). DST may help identify those patients with MDR-TB so that the appropriate treatment can be administered. Identifying patient characteristics that confer higher risk of relapse, failure or default from primary TB treatment may help inform country-specific prevention strategies aimed at reducing the need for retreatment, resulting in cost savings and diminished morbidity and transmission (Dooley et al, 2011).

CCWs play many roles when caring for a TB patient, including the assessment of adverse effects of medication, such as deafness, gastrointestinal upset, skin rashes, hypotension and many other health problems. In addition, the CCW should monitor the patient’s adherence to his or her treatment and should know how long the treatment will last until the next clinic appointment. CCWs should also support patients to plan their meals and to maintain their personal hygiene. CCWs should
also supervise the patient’s levels of activity and ensure that scheduled appointments with health care professionals are kept (Okeyo & Dowse, 2016). These roles pose challenges and exert pressure on CCWs who are caring for TB patients at home (Sukumani, Lebese, Khoza & Risenga, 2012).

1.2 PROBLEM STATEMENT
The researcher is a professional nurse working at a primary health care clinic in a village in Hlogotlou area under Elias Motswaledi Municipality. He has observed that some TB patients attending Hlogotlou clinic interrupt their treatment, with others interrupting for up to two months. As a result, they turn out to have poor treatment outcomes. According to TB management strategy (National Department of Health, 2014), every patient diagnosed TB positive should be put on Directly Observed Treatment Short-course (DOTS). At Hlogotlou clinic, every TB patient is put on DOTS, but still the treatment outcome remains poor. This poor treatment outcome sometimes leads to TB complications such as MDR-TB and XDR-TB. Hlogotlou clinic is currently experiencing an increasing number of MDR-TB patients. MDR-TB usually occurs when the patient is not taking TB treatment as prescribed. As a result, it becomes difficult to manage and contain TB. Some new TB cases get MDR-TB because of being infected by MDR strain directly. The researcher is interested in finding out experiences of CCWs of supporting TB patients at Hlogotlou area with the hope of discovering issues that may contribute to treatment interruption in the area.

1.3 LITERATURE REVIEW
The purpose of literature review is to compare findings of existing studies with those of the study at hand to inform or support a qualitative study, especially in conjunction with the collection and analysis of data (Brink, van der Walt & van Rensburg, 2012). The topics reviewed in the study are the following and are discussed in detail in Chapter 2, which is about causes and spread of TB, stigma related to TB, treatment defaulting, management of TB, and support of patients by CCWs.

1.4 AIM
The aim of the study was to explore the experiences of CCWs of supporting patients taking TB treatment at Hlogotlou area, Limpopo Province.
1.5 OBJECTIVES

The objective of the study was to explore and describe experiences of CCWs of supporting patients on TB treatment at Hlogotlou area, Limpopo Province.

1.6 RESEARCH QUESTION

What are the experiences of CCWs supporting patients on TB treatment at Hlogotlou area, Limpopo Province?

1.7 RESEARCH METHODOLOGY

The study used qualitative, exploratory, descriptive and phenomenological design to explore experiences of CCWs supporting patients on TB treatment at Hlogotlou area, Limpopo Province. The population consisted of 37 CCWs who were supporting patients on TB treatment from Hlogotlou area. Thirteen participants were purposively sampled and all of them were females who had experience of supporting TB patients on treatment from four weeks and above. The sample size was determined by data saturation. All CCWs who supported patients on TB treatment for less than four weeks were excluded, as the researcher believed that they would not provide sufficient information regarding the phenomenon studied.

The data was collected using semi-structured interviews. An audiotape recorder was used to capture interviews and was supplemented by field notes. Interpretative Phenomenological Analysis (IPA) was used to analyse data. Trustworthiness was ensured through the principles of credibility, conformability, dependability and transferability. Ethical clearance was obtained from Turfloop Research and Ethics Committee (TREC), and permission to collect data from the participants was obtained from Hlogotlou Home-Based Care. Informed consent was obtained from all the participants after explaining the purpose of the study to them. More information on the research methodology is discussed in Chapter 3.
1.8 SIGNIFICANCE OF THE STUDY

This study might assist in the prevention of MDR-TB emergent because full support by CCWs will enhance treatment compliance by patients and a good cure rate treatment outcome. The study might also assist in identifying skills gap from the available CCWs, therefore relevant training will be offered.

1.9 OUTLINE OF CHAPTERS

Chapter 1 briefly discusses the overview of the study, the research problem, the purpose, objective and the significance of the study.

Chapter 2 covers the literature review in the context of the research undertaken.

Chapter 3 describes the research methodology and study design used.

Chapter 4 discusses the findings in relation to the literature control.

Chapter 5 provides a summary of the results, limitations, recommendations and conclusions in the context of the aim and objectives of the study.

1.10 CONCLUSION

This chapter provided an overview of the study, with focus on the introduction, research problem, literature review, purpose of the study, research question and the objective, methodology, ethical considerations and significance of the study. Chapter 2 reviews literature from other studies that were relevant to the study.
CHAPTER 2
LITERATURE REVIEW

2.1 INTRODUCTION

In chapter 1, the overview of the study was discussed. Chapter 2 focuses on literature review, which helps the researcher to decide whether the topic can and should be researched. It also assists in obtaining clues to the methodology and instruments to be used in the study (Brink et al, 2012). A review of literature revealed the following issues discussed below: causes and spread of TB, management of TB, stigma related to TB and TB treatment defaulting.

2.2 CAUSES AND SPREAD OF TUBERCULOSIS

TB is caused by Mycobacterium tuberculosis bacteria that are spread in airborne droplets when people with active TB sneeze or cough (National Department of Health, 2014). Factors such as infection with HIV, poor nutritional status, smoking, age and increased virulence and/or increased dose of bacilli have been identified as substantial contributors for the development of the disease and its epidemiological burden. Poverty and lack of awareness about TB are considered the most important factors that increase the risk of acquiring TB. Poor access to health care, lack of financial source and lack of knowledge about the cause contribute to the spread of TB. In addition, poor adherence to TB treatment and sometimes long delay in diagnosis pose a formidable challenge in the control of the disease (Tolossa, Medhin & Legesse, 2014). Adherence refers to the fact of behaving according to a particular rule or a fixed way of doing something (Oxford Advanced Learner’s Dictionary, 2010). Tolossa et al (2014) suggest that the use of traditional medicine may delay health-seeking behaviour and provide time for the infection to spread to the healthy population.

2.3 MANAGEMENT OF TUBERCULOSIS

TB can be cured by taking treatment daily for at least six months, but many patients fail to complete the treatment. This is because the treatment is complicated and has unpleasant side-effects (Sukumani et al, 2012). For these reasons, creating general
awareness about TB among communities, and initiating community participation in the control of the disease make up one component of the six basic components of the *Stop TB Strategy* (WHO 2012; Tolossa et al, 2014). Making use of CCWs to support patients in the community is another management strategy.

CCWs promote adherence to TB treatment, identify defaulters, and provide information to TB patients. CCWs also assist with TB contact tracing, especially for children under five years, and assist with follow up and the monitoring of TB patients in line with the Stop TB Strategy. According to Tasnim, Rahman and Anamul-Hoque (2012), CCWs support awareness of TB, promote the reduced stigmatisation of TB and strengthen support groups.

Other roles of CCWs in the Stop TB Strategy are to create a link between the households and various services to community members, and referring members to other services. Furthermore, CCWs facilitate the entry of other health and social services professionals in households (National Department of Health and Social Development, 2009). CCWs are an important human resource for health with great potential for providing health care to the community as well as acting as advocates by helping them organise for health promoting environments (Okeyo & Dowse, 2016).

**2.4 STIGMA RELATED TO TUBERCULOSIS**

One major setback to the success of TB control globally is the stigma attached to the disease in most societies. According to Oxford Advanced Learner’s Dictionary (2010), stigma refers to feelings of disapproval that people have about particular illnesses or ways of behaving. In most communities, the fear of infection leads to imposition of the socio-physical distance and participatory restrictions on those suffering from TB (Krishnan, Akande, Shankar, McIntire, Gounder, Gupta & Yang, 2014). According to Dodor and Kelly (2009), some community members feel that TB patients should not be part of their society and say they will not marry a TB patient or encourage any family member to enter into such a relationship. They also point out that TB patients should not make business or other forms of earning a living in the
community and would not allow them at any public function because they can infect others.

Family members of TB patients were ostracised by their communities for staying with the patients. The extent of stigma on the family may also affect the way in which the family cares for their patient. In modern times families with a member diagnosed with TB are often stigmatised as being poor because TB is said to be a disease of the poor. Those diagnosed with TB have been regarded as dirty, as eating bad food and as having poor hygiene (WHO, 2012). Whenever it becomes unavoidable for community members to interact with someone with TB, they indicated that they would cover their mouths with a handkerchief, turn their head or sit in the opposite direction of the wind from the TB patient to avoid inhaling the air (Tasnim et al, 2012). When a TB patient joins community members at any function, he or she is expected to abide by certain codes of conduct. The stigmatising attitudes and behaviours of community members towards the disease and its sufferers may lead individuals with very obvious signs and symptoms of TB to attribute it to other non-stigmatising conditions, thus avoid or delay seeking treatment, or they may hide the diagnosis from others as well as default from treatment (Dodor & Kelly, 2009).

2.5 TREATMENT DEFAULTING

According to the National Department of Health (2014), treatment defaulting refers to an act of interrupting TB treatment for two consecutive months or more during the treatment period. TB patients often feel better soon after starting treatment, so they stop taking their medications before all the bacteria in their body are dead. Poor treatment adherence implies that people remain infectious for longer and are more likely to relapse and ultimately die. Poor treatment adherence also contributes to the emergence of DR-TB. To help people complete their treatment, WHO (2012) recommends a strategy known as Directly Observed Treatment Short-course (DOTS). As part of this strategy, CCWs support the patient while taking his or her treatment at home (Sukumani et al, 2012).

Default from TB treatment is driven both directly and indirectly by an interplay of individual, socio-demographic, economic, clinical and programmatic factors. In South Africa, attitudes, residing in the Eastern Cape or Western Cape provinces, alcohol
and substance abuse, previous treatment for DR-TB and economic instability have been identified as risk factors for default in various settings. An analysis of data from Khayelitsha has also shown that default occurs early in treatment and persists throughout the treatment period (Moyo & Cox, 2014).

2.6 CONCLUSION

In this chapter, different sources were consulted in order to gain insights into findings of the other authors on the topic under the study. TB patients are still faced with treatment challenges and stigmatisation by their communities. Literature showed that CCWs play a major role of supporting patients on TB treatment. They even go to an extent of assisting in the dissemination of information related to TB in general. Literature further showed that the role of CCWs included administering TB treatment, tracing TB defaulters and personal hygiene, feeding of TB patients who cannot feed themselves, and referring patients with severe treatment side effects to their local clinics for further management. The next chapter will discuss the research methodology in detail.
CHAPTER 3
RESEARCH METHODOLOGY

3.1 INTRODUCTION

In chapter 2, literature review in relation to the topic under study was discussed. Chapter 3 focuses on research methodology used in this study. Research methodology is the specific procedures or techniques that are used to identify, select, process and analyse information about a topic (Polit & Beck, 2012). In this chapter, the research design, study site, population, sampling method, data collection, data analysis, measures to ensure trustworthiness and ethical considerations are discussed in detail.

3.2 RESEARCH DESIGN

The design was phenomenological, exploratory, descriptive and contextual. A phenomenological design was used to explore and describe experiences of CCWs of supporting patients on TB treatment. The phenomenological design is an inductive approach to enquiry that attempts to describe experiences as they are lived by the participants (Grove et al, 2013).

Exploratory design was also used to gather detail data on experiences. The exploratory design gives light on the various ways in which a phenomenon manifests itself and on processes underlying it (Polit & Beck, 2012). The researcher has used an exploratory design to better understand the lived experiences of CCWs of supporting patients on TB treatment. Descriptive research design is meant to describe the phenomenon in detail (Grove et al, 2013). A contextual study was performed where the context was Hlogotlou area in Limpopo Province.

3.3 STUDY SITE

Study site refers to a specific place where the data are collected (Brink et al, 2012). The study was conducted at Hlogotlou area under Elias Motswaledi Local Municipality, Sekhukhune District. Hlogotlou area is comprises the following seven villages: Thabaleboto, Monsterlus, Selahlwe, Rondebosch, Hlogotlou, Jerusalem and Matsitsi. The languages spoken in these villages include Isindebele, Zulu and
Northern Sotho. Clinics under Hlogotlou area are Rossenakal, Zaaiplaas, Goedgedacht, Magukubjane and Hlogotlou. In this study the main focus was Hlogotlou clinic, which works with two Home-Based Care organisations: Jerusalem and Hlogotlou. There are 37 CCWs from both organisations, which serve the above mentioned villages. But the study focused on CCWs from Hlogotlou HBC. A map of Hlogotlou area is attached below as Figure 3.1.

![Map of Hlogotlou area showing local villages](image)

Figure 3.1: Map of Hlogotlou area showing local villages

The total cases of TB in Elias Motswanaedi Local Municipality in 2014 were 790 and 309 tested smear positive (Pulmonary Tuberculosis), while 481 were Extra-Pulmonary Tuberculosis. Out of 790 cases, 83 defaulted and 91 died. For 2015 there were 658 cases (Electronic record.net). Hlogotlou clinic contributes to the above mentioned figures for TB cases. Hlogotlou clinic admits many patients who are diagnosed with TB. Out of the total number of admissions, some had TB alone whereas others were co-infected, meaning they are diagnosed with TB and HIV positive at the same time. TB patients are being initiated on TB treatment after diagnosis, and they are supposed to take the treatment for a period of six months if they are diagnosed PTB. And for those who are diagnosed EPTB, they usually take the treatment for a period of nine months according to the guidelines (National Department of Health, 2014).
3.4 POPULATION

Population includes all members or units of some clearly defined group of people, objects or events (Grove et al, 2013). The population in this research was all 37 CCWs supporting patients on TB treatment at Hlogotlou area in Limpopo Province.

3.5 SAMPLING METHOD

Purposive sampling was used to select the study participants. In qualitative research, purposive sampling is used to recruit participants for whom the research topic is relevant, and the goal is to gather information about their experiences (Knudsen, Laplante-Levesque, Jones, Preminger, Nielsen, Lunner, Hickson, Naylor & Kramer, 2012). Purposive sampling was used because it enabled the researcher to select informative cases of CCWs who provided substantial information based on their personal experiences regarding supporting patients on TB treatment.

According to Polit and Beck (2012), qualitative research does not have a fixed sample size as it is driven by the information needs of the study. The sample size of this study was guided by the principle of data saturation. Saturation is a tool used for ensuring that adequate and quality data are collected to support the study (Grove et al, 2013). This point was reached when no new information was obtained from the participants during the stages of data collection, when subsequent interviews produced repetitions of information, indicating the completeness of the data gathered. All 13 CCWs who had supported patients on TB treatment were purposefully sampled and then interviewed until saturation of data was reached.

3.5.1 Inclusion criteria

Inclusion criteria are a set of conditions that must be met by participants in order to participate in the study (Brink et al, 2012). Inclusion criteria for this study were as follows: CCWs of any gender and age who had supported a TB patient on treatment from four weeks and above. The researcher believed that four weeks and above is a sufficient period to enable participants to provide enough information regarding the phenomenon being studied.
3.5.2 Exclusion criteria

Some CCWs who supported patients on TB treatment for less than four weeks were excluded as the researcher believed that those participants would not provide sufficient information regarding the phenomenon to be studied.

3.6 Data Collection

Data has been gathered by means of semi-structured interviews in a conducive environment. Semi-structured interviews lie between unstructured interviews where no specific questions but rather an area of interest is defined, and structured interviews, where all questions are listed and followed strictly during the interview. In semi-structured interviews, the researcher asks the participants to give accounts of their experiences of the phenomenon under study (Starks & Brown Trinidad, 2007). A semi-structured interview is a qualitative method of inquiry that combines a predetermined set of open questions with the opportunity for the interviewer to explore particular themes or responses further.

Interviews were held in a specific room within the CCWs office building. They were conducted individually for 30 to 50 minutes. An interview guide was used, which collected demographic information and had this main question that all participants responded to: “What are your experiences of supporting patients on TB treatment?” The interview guide was in English and translated in Sepedi as the common language which was used for interviewing. The Interview guide is attached as Annexure 1 in English and Annexure 2 in Sepedi.

An audiotape recorder was used to capture the interviews. This was supplemented by field notes, which refer to notes created by the researcher during the act of qualitative fieldwork to remember and record the behaviours, activities, events, and other features of an observation. Field notes are intended to be read by the researcher as evidence of producing meaning and understanding of the culture, social situation, or phenomenon being studied. The notes may constitute the whole data collected during an interview session or contribute to it, such as when field notes supplement conventional interview data (Schwandt, 2015).
3.7 DATA ANALYSIS

Data analysis involves organising the data that the researcher has collected, providing structure and eliciting meaning from it (Polit & Beck, 2012). All recorded data has been transcribed verbatim then those collected in Sepedi were translated into English (see Annexure 3 for transcripts).

The Interpretative Phenomenological Analysis (IPA) method has been used to analyse data. The aim of this method was to analyse the participant’s attempts to make sense of their experiences. The meaning is central, and the objective was to try to understand the content and complexity of those meanings rather than measuring their frequency. In order to do this, Smith, Flowers, and Larkin (2009) have suggested a flexible seven-step approach:

- **Step 1**: reading and re-reading the transcripts to immerse oneself in the data.
  The researcher has read all the transcripts over and over in order to get the message of the participants.

- **Step 2**: initial noting and writing notes in the margin.
  Phrases that attracted the researcher were noted in the form of underlining them and notes were written to summarise each transcript.

- **Step 3**: developing emergent themes from notes and chunks of transcripts.
  The researcher developed themes from each transcript.

- **Step 4**: abstracting and integrating emergent themes.
  Themes that emerged from Step 3 were grouped and summarised in order to avoid a long list of repetition of themes.

- **Step 5**: bracketing previous themes and remaining open-minded in each case.
  This simply means that the researcher can change or re-shape emerged themes throughout the data analysis stage.

- **Step 6**: finding patterns of shared qualities across cases. Comparing participants’ responses for similarities from their interviews.

- **Step 7**: taking interpretations to deeper levels by utilising metaphors and temporal referents in developing final themes and sub-themes.
An independent coder was given transcripts and field notes to code them independently. The coder had a Diploma in Nursing Education, specialised in Primary Health Care, and had a Master of Public Health and sufficient experience in qualitative research methodology. The coder and the researcher compared the findings to establish if they yielded the same results. The findings were the same but written in different ways. The researcher and the coder agreed on the wording to be used in formulating the final themes and sub-themes that emerged from the interview.

3.8 MEASURES TO ENSURE TRUSTWORTHINESS

According to Grove et al (2013), trustworthiness can be defined as a demonstration that the evidence for the results reported is sound, and the argument made based on the results is strong. Trustworthiness is measured by the following criteria: credibility, dependability, confirmability and transferability (Brink et al, 2012).

3.8.1 Credibility

Credibility is a criterion for evaluating the quality of qualitative data, referring to confidence in the truth of the data (Brink et al, 2012). Credibility was ensured by prolonged engagement with the participants through face-to-face interviews, triangulation, peer debriefing and member checking.

- **Prolonged engagement**
  
Prolong engagement refers to spending extended time with the participants in their culture and everyday world in order to gain a better understanding of their behaviour, values and social relationship in a social context (Brink et al, 2012). The researcher spent three months in the field with participants during interview sessions. This was done in order to be fully engaged with them in order to get rich data during data collection. During data analysis audio tape recordings were replayed for purposes of transcribing the data verbatim. The researcher read the transcripts many times to immerse oneself in the data.

- **Triangulation**
  
Triangulation refers to the application and combination of several research methods in the study of the same phenomenon (Polit and Beck, 2010). The
researcher used methodological triangulation to gather data by means of different data collection methods where in-depth interviews and field notes of observations were used. The independent coder was used to ascertain that the believability of the findings was enhanced and credibility demonstrated.

- **Peer debriefing**
  Peer debriefing is the process whereby a researcher calls upon a peer who is not involved in the research project to aid in probing the researcher’s thinking around all or part of the research process (Brink et al, 2012). In this study, the researcher used experienced colleagues in qualitative research methodology and TB management for inputs. The supervisor also gave the researcher inputs on how to conduct the study.

- **Member checking**
  According to Brink et al (2012), member checking is a qualitative research technique wherein the researcher compares understanding of what an interview participant said or meant with the participant to ensure that the researcher’s interpretation is accurate. The researcher interviewed the participants until data saturation was reached. Probing questions were asked deliberately during interviews to ensure that the participants’ experiences were well understood.

### 3.8.2 Transferability
Transferability is a criterion for evaluating the quality of qualitative data, referring to the extent to which the findings from the data can be transferred or applied to other settings or groups (Brink et al, 2012). Transferability has been obtained by creating a dense description of the methodology so that other researchers can see it and decide if they can follow and apply the process in other settings. The findings of the study were supported by direct quotations from the interviews as a way of showing authenticity of the findings.

### 3.8.3 Dependability
Dependability is a criterion for evaluating the quality of qualitative data, referring to the stability of data over time and over conditions (Polit & Beck, 2010; Brink et al,
2012). Dependability considers the consistency of the data whether the findings will be consistent if the study will be replicated with the same participants or in similar contexts. The independent coder developed the same themes as the researcher though the wording differed. This demonstrated the consistency of the data. All materials used and audio-tape recorder will be kept for a period of five years so that others would be able to confirm the findings of the study.

3.8.4 Confirmability

Confirmability is a criterion for evaluating the quality of qualitative data, referring to its objectivity or neutrality (Brink et al, 2012). The independent coder was given copies of transcripts and field notes for data analysis purposes. An audit trail was maintained by keeping voice recordings, transcripts and field notes. Auditing was done not only at the end of the process, but throughout the research by the supervisor.

3.9 ETHICAL CONSIDERATIONS

The ethical principles that guide the researcher are respect for persons, beneficences and justice; and they have been considered throughout the study (Grove et al, 2013). Ethical clearance was requested and obtained from Turfloop Research and Ethics Committee (TREC). The ethical clearance certificate is attached as Annexure 4. The following has been discussed: seeking permission to conduct the study, anonymity and confidentiality, protection of emotional harm to participants and informed consent.

3.9.1 Seeking permission to conduct the research

The researcher submitted the proposal to the Senior Degrees Committee of the University of Limpopo for approval. After approval, permission to collect data from the participants was requested and obtained from management of Hlogotlou Home-Based Care. A letter requesting permission from management of Hlogotlou Home-Based Care is attached as Annexure 5, and on granting permission from Hlogotlou Home-Based Care is attached as Annexure 6.
3.9.2 Anonymity and confidentiality

Anonymity is the situation in which someone’s personal details are never passed on to the third parties (Oxford Advanced Learner’s Dictionary, 2010). According to the Oxford Advanced Learner’s Dictionary (2010), confidentiality refers to a condition in which the researcher knows the identity of a research subject, but takes steps to protect that identity from being discovered by others. Anonymity was ensured as the participants were numbered sequentially without any identification of the person. Participants were advised not to mention any names during interviews. The door of the room was always under lock, so there was no interruption during the interview, and the confidentiality and privacy of the participants was well ensured or adhered to. Confidentiality was also ensured by not discussing the result with anyone but the supervisor and relevant stakeholders.

3.9.3 Protection of emotional harm to participants

The participants were informed beforehand about the reason for the study and that they have full right to withdraw from it at any time. An information leaflet is attached as Annexure 7 in English and Annexure 8 in Sepedi. During the study, the researcher did not have any participant who wished to withdraw from the study and there was no one who needed any emotional support. A psychiatric nurse and a social worker were available for counselling if was needed.

3.9.4 Informed consent

Written and verbal informed consent in the case of illiterate participants was obtained from the participants before participation in the study. The consent form is attached as Annexure 9 in English and Annexure 10 in Sepedi. The researcher requested permission from participants to record the interviews.

3.10 CONCLUSION

This chapter explored the research methodology that was followed when conducting this study, the research design, study site, population, sampling method, data collection, data analysis, measures to ensure trustworthiness, and ethical considerations. Chapter 4 will discuss the research findings and literature control.
CHAPTER 4
FINDINGS AND LITERATURE CONTROL

4.1 INTRODUCTION

The research methodology used in this study was fully discussed in Chapter 3. This chapter will dwell on the findings of the study and the literature control in substantiating the findings. The demographic profile of the participants will also be discussed in this chapter. The following themes and sub-themes emerged: exciting and fulfilling work; training is empowering; CCWs have lack of special skills; and TB stigma as a challenge in the work of CCWs.

4.2 THE DEMOGRAPHIC PROFILE OF THE PARTICIPANTS

The sample included 13 CCWs who had supported patients on TB treatment from four weeks of treatment and over. All of them were female above 27 years of age. Seven of them were married and six were single. All of them were literate, four passed grade nine, three passed grade ten, two passed grade 11, and only four passed grade 12. They all spoke Sepedi and other languages: eight spoke Sepedi; three were Zulu-speaking; and two were Isindebele-speaking. But during interviews, all of them used Sepedi as it was a common language and they could understand it better than English. There were seven CCWs who had two to six years of experience; and six had seven to 12 years of experience.

According to Asuquo, Etowa and Akpan (2017) and Mottiar and Lodge (2018), most CCWs in Nigeria started caring for patients at their early thirties, maintained this role as they grew older and were generally secondary educated. In this study, it was revealed that the youngest CCW was 28 years old and most of the CCWs were elders. The study again revealed that all CCWs who participated did not have tertiary education, only secondary education with grade 12 as the highest qualification.

CCWs that once took care of their sick relatives reported that their experience had made them to know how to care for sick patients, and this prompted the will to assist patients who did not have others to care for them (Okeyo & Dowse, 2016). In this
study, 12 of the CCWs had long years of service. This made it easy for them to care for their TB patients.

Generally, care-giving is known to be a female role in many countries (Rice, Walker & Main, 2008; Hurd, 2017; Loveday, Sunkari, Master, Daftary, Mehlomakulu, Hlangu & Marais, 2018). In this study, all CCWs were females. This indeed supports the view that caring is a female role. Table 4.1 summarises the demographic profile of the participants.

Table 4.1: Demographic profile

<table>
<thead>
<tr>
<th>GENDER</th>
<th>AGE</th>
<th>MARITAL STATUS</th>
<th>LANGUAGE</th>
<th>HIGHEST GRADE</th>
<th>YEARS OF EXPERIENCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>28years</td>
<td>Married</td>
<td>Sepedi</td>
<td>Grade 10</td>
<td>3years</td>
</tr>
<tr>
<td>Female</td>
<td>33years</td>
<td>Single</td>
<td>Isindebele</td>
<td>Grade 10</td>
<td>5years</td>
</tr>
<tr>
<td>Female</td>
<td>34years</td>
<td>Married</td>
<td>Sepedi</td>
<td>Grade 11</td>
<td>4years</td>
</tr>
<tr>
<td>Female</td>
<td>38years</td>
<td>Single</td>
<td>Sepedi</td>
<td>Grade 9</td>
<td>5years</td>
</tr>
<tr>
<td>Female</td>
<td>42years</td>
<td>Single</td>
<td>Isindebele</td>
<td>Grade 10</td>
<td>6years</td>
</tr>
<tr>
<td>Female</td>
<td>44years</td>
<td>Married</td>
<td>Sepedi</td>
<td>Grade 12</td>
<td>3years</td>
</tr>
<tr>
<td>Female</td>
<td>45years</td>
<td>Single</td>
<td>Sepedi</td>
<td>Grade 12</td>
<td>7years</td>
</tr>
<tr>
<td>Female</td>
<td>45years</td>
<td>Married</td>
<td>Sepedi</td>
<td>Grade 12</td>
<td>2years</td>
</tr>
<tr>
<td>Female</td>
<td>47years</td>
<td>Married</td>
<td>Zulu</td>
<td>Grade 12</td>
<td>8years</td>
</tr>
<tr>
<td>Female</td>
<td>48years</td>
<td>Married</td>
<td>Zulu</td>
<td>Grade 9</td>
<td>12years</td>
</tr>
<tr>
<td>Female</td>
<td>48years</td>
<td>Married</td>
<td>Zulu</td>
<td>Grade 11</td>
<td>12years</td>
</tr>
<tr>
<td>Female</td>
<td>55years</td>
<td>Single</td>
<td>Sepedi</td>
<td>Grade 9</td>
<td>11years</td>
</tr>
</tbody>
</table>

4.3 THEMES AND SUB-THEMES

During data analysis, four themes and eight sub-themes emerged and are summarised in Table 4.2 below, and then discussed in detail.
### Table 4.2: Themes and sub-themes

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
</table>
| 1. Exciting and fulfilling work. | 1.1 CCWs monitor the taking of TB treatment.  
1.2 Patients appreciate the support given by CCWs.  
1.3 Patients regard CCWs as friends and part of extended family members. |
| 2. Training is empowering. | 2.1 CCWs have TB screening skills.  
2.2 CCWs are aware that side-effects may lead to treatment defaulting.  
2.3 CCWs are aware that alcohol abuse leads to treatment defaulting. |
| 3. CCWs have lack of special skills. | 3.1 Failure to recall training sessions.  
3.2 Inability to offer comprehensive support. |
| 4. TB stigma as a challenge on the work of CCWs. | |

#### 4.3.1 Theme 1: Exciting and fulfilling work

These findings show the excitement of CCWs and their value towards TB patients. Under this theme three subthemes emerged.

##### 4.3.1.1 Sub-theme 1.1: CCWs monitor the taking of TB treatment

This study revealed that CCWs play a major role in supervising patients on TB treatment, encouraging them in treatment compliance. They also observe patients while swallowing their treatment. According to CCWs experiences, it has never been easy for TB patients to take their treatment without any support. As a result CCWs become positive support to patients.

Participant 8 said: “I check whether the tablets that he is taking are the correct one, and the correct dosage; when he is done taking the tablets then I create a small conversation to establish if he has swallowed all the tablets”.

Participant 11 added: “Yes, and to ensure that he has taken his treatment well I create a conversation to establish that he has swallowed everything”.

Patients received daily treatment support from CCWs and from their family members, as well as monthly reinforcement by the clinic staff. CCWs cooked and fed helpless patients, bathed them, and did some passive exercises for bed-ridden
patients (Mottiar & Lodge, 2018). Similarly, in this study, it was found that CCWs assisted patients who were helpless in bathing themselves and feeding them before they could take their treatment.

Participant 7 said: “To give treatment, to feed patients, to help those who cannot help themselves”.

According to Cataldo et al (2015), CCWs are supposed to observe patients when they take their treatment, then they have to talk to the patients to make sure that the mouths are clear and the medicine has been swallowed. Some patients pretended to have swallowed tablets while they did not; they kept tablets under their tongue and waited for the CCWs to leave so that they could spit them out. That is why CCWs use a technique of conversing with the client immediately after taking their medicine to check whether they have swallowed the treatment completely (Cataldo et al, 2015).

4.3.1.2 Sub-theme 1.2: Patients appreciate the support given by CCWs

This study also showed that most TB patients appreciate the support given throughout their course of treatment, and acknowledge the importance of CCWs in treatment. Patients were thankful when they realised that they could finish their treatment without defaulting and become cured from TB.

Participant 5 said: “…our patients when we support them we become useful to them, and in future they appreciate our help”.

Participant 6 added: “others were very much thankful saying that if it was not us they would not become cured, they did not have knowledge about TB. I remember one of my patients I once had, he thanked us and he was grateful for our support”.

Participant 10 also added: “Good thing is that when patients are cured they come back to us and thank us”.

The role of CCWs were recognised in clinics and their communities. This built respect and trusting relationships. Patients were able to confide information that they would not normally disclose to other healthcare professionals, such as skipping their dose (Okeyo & Dowse, 2016). Patients feel grateful for the support offered by the CCWs as it impacts their lives in a positive way (Orr, 2011).
In this study it was revealed that patients became open to CCWs once they got used to their visits. They ended up sharing their secrets with their CCWs. Eventually, patients appreciated the CCWs’ presence in their treatment journey, and were grateful for the impact yielded by this.

Participant 2 said: “You find there are some things that patients want to share with you... The patient’s family thought he was brought home due to his illness but only to find out that is the illness and divorce, but his sisters could see that their brother had his personal problems, and the brother could open up to me instead of his sisters and the mother”.

Participant 7 also shared her experience: “Mm..., we engage in many conversations together, we even engage in telephone conversations very often”.

4.3.1.3 Sub-theme 1.3: Patients regard CCWs as friends and part of the extended family

It was highlighted in this study that TB patients end up being alone because of the stigma from family and community; so they end up perceiving CCWs as a pillar to lean on. Even after the completion of treatment, they still preserve contact with their CCWs, and the friendship between them become extended to a family relationship.

Participant 1 said: “When I get to their homes, they see me as one of their children because I can communicate and laugh with them then when they have trips they inform me before they leave and even when they come back they inform me, and when we meet again we become happy as if we are family”.

Participant 5 added: “We are friends, it is all good, others will just call you even if they are away from you, somewhere around Cape Town, Mamelodi, wherever, they always send us some regards”

Participant 6 said: “the relationship with my patients is like they are my family and I am like their sister... it is like we are friends or relatives”.

Similarly, according to Fiseha and Demissie (2016), most patients reported that the advice they got from their CCWs helped them to comply with their treatment, describing the relationship they had with their CCWs as positive.
4.3.2 Theme 2: Training is empowering

Skills and proper training offered to CCWs by healthcare professionals could have good outcome in patients’ treatment, and therefore comprehensive TB support will be given. If CCWs are provided with the support, job descriptions, clear lines of responsibility and authority that allow them to act as educators and advocates, then they will play a major role in the promotion of TB adherence (Orr, 2011). The following sub-themes will be discussed: CCWs have TB screening skills, they are aware that side-effects may lead to treatment defaulting, and are aware that alcohol abuse leads to treatment defaulting.

4.3.2.1 Sub-theme 2.1: CCWs have TB screening skills

This study revealed that CCWs have competencies in screening patients for TB and identifying TB suspects. They can also trace contacts from families that have a member suffering from TB, and therefore refer them to clinics for further screening. Participant 12 said: “...and then I will also tell my patient that all the contacts or people he is staying with should be screened for TB, even kids”.

In Kwa-Zulu Natal, CCWs participate in TB screening and the provision of basic health education at clinics and by means of door to door (Mottiar & Lodge, 2018). According to study conducted in Grahamstown and Kwa-Zulu Natal, CCWs conduct door to door campaigns to detect TB cases through health education and tracing contacts of the person who is suffering from TB (Datiko & Lindtjorn, 2009; Okeyo & Dowse, 2016). Similarly, in this study CCWs give health education to TB patients and their relatives about the importance of adhering to the prevention of cross transmission through cough, tracing and screening contacts.

4.3.2.2 Sub-theme 2.2: CCWs are aware that side-effects may lead to treatment defaulting

In this study, it was highlighted that some patients default treatment at early stages of treatment due to unbearable treatment side-effects. This is caused by lack of knowledge. Immediately when side effects occur, patients stop treatment without consulting their CCWs.
Participant 2 said: “…women are not troublesome, it’s just that their problem…. they like running away especially when they start experiencing side effects”.

Participant 4 added: “Side effects differ so you need to assess, if you think there are those that the patient cannot tolerate, then you refer her to the clinic”.

TB patients reporting more serious side effects are brought to clinics by CCWs for immediate medical evaluation (Brust et al, 2012). Sometimes perceived side effects resulting from chronic hunger could lead to defaulting treatment (Ayisi, van’t Hoog, Agaya, Mchembere, Nyamthimba, Muhenje & Marston, 2011).

According to Ayisi et al (2011), some patients default treatment when they start feeling better after few months of treatment initiation. Similarly, in this study some patients stop TB treatment on their own account when they feel better after taking treatment for the first few months.

Participant 4 said: “…immediately when she feels better, then they leave home and relocate to other places”.

Participant 5 added: “Others end up running away from us, when you do routine home visits you do not find them because when the treatment start working they feel better and think they should stop taking treatment”.

Sometimes patients fail to complete their treatment if they feel that it lasts too long, particularly after the symptoms have disappeared. Most of the time patients stop taking their treatment because they feel better as a result of the early stages (intensive phase) of treatment. This is associated with a poor understanding of the need to continue with the treatment even after the patient’s condition has subsided (Ayisi et al, 2011).

4.3.2.3 Sub-theme 2.3: CCWs are aware that alcohol abuse leads to treatment defaulting

This study reveals that some patients drink alcohol while on TB treatment. This makes them to forget to take their treatment in time, or may influence their judgement. As a result, they forget to take the treatment at all.
Participant 5 said: “…others start to consume liquor when they feel better and they go to taverns, they feel as if you waste their time with your home visits”.

Participant 7 added by sharing her experiences with a particular patient: “He was drinking alcohol while on TB treatment, sometimes you find him being under the influence of alcohol before taking his treatment”.

Alcohol abuse by patients makes them to forget to take treatment. This may lead to treatment defaulting (Mature, Keraka, Kimuu, Kabiru, Ombeka & Oguya, 2011).

4.3.3 Theme 3: CCWs have lack of special skills

CCWs have shown better performance of supporting patients on TB, but they have challenges in integrating TB with other non-communicable diseases such as hypertension and diabetes mellitus, which might co-exist with TB. Some CCWs were not trained about TB at all. The following sub-themes will be discussed: failure to recall training sessions and inability to offer comprehensive support.

4.3.3.1 Sub-theme 3.1: Failure to recall training sessions

In this study, CCWs reported that they were offered training on the following: ancillary, which involves basic care such as bathing patients; HIV/AIDS; diabetes mellitus; hypertension; sexually transmitted infections; nutrition; epilepsy; asthma; teenage pregnancy; breastfeeding; prevention of mother-to-child transmission; family planning services; pregnant women; and post delivered women. Most of them could not remember the type of training offered to them other than DOT supporting session.

Participant 6 said: “I do not remember the names of the training. So I also remember one training that contained a lesson about using a bucket with soil inside that bucket to cover up the produced sputum but I do not remember the training well”.

Participant 8 added: “And what else? It’s been long I do not remember well”.

Participant 11 also added: “Eish, mm, I do not remember the names of the training”.
4.3.3.2 Sub-theme 3.2: Inability to offer comprehensive support

In this study, comprehensive support is to help TB patients to take their treatment; answering questions pertaining TB as a whole; encouraging health promotion; and giving health education about TB and its complications. Even though training is empowering, this study showed that some CCWs lacked information pertaining to TB guidelines. As a result, this made it difficult for them to offer health education and health promotion to TB patients and their contacts.

Participant 3 said: “I did not do TB training. I know TB from the radio station. To tell you the truth I did not read the guidelines”.

Participant 11 shared her experience: “Eh, the one I once experience was when I went to the patient who was suffering from TB of the bones, while I was used to pulmonary TB. So that’s where I realised that there are different types of TB”.

Participant 13 also said: “…we have TB of the bones, but I forgot where it falls”.

According to Okeyo and Dowse (2016), some CCWs felt that the training received was not enough as they lacked understanding of how to deal with certain issues. For example, explaining to patients how to produce sputum as opposed to saliva, and how to respond to patients when they reported lack of food as an excuse for defaulting treatment. They felt that single a training session without subsequent follow-up training was not enough, as they needed to both reinforce certain topics and expand their knowledge. They identified a need for being informed about frequent changes in TB policy or treatment guidelines (Okeyo & Dowse, 2016). This study revealed that some CCWs had little or no information pertaining to MDR-TB and XDR TB and with regard to changes in TB guidelines.

According to Okeyo and Dowse (2016), CCWs realised that drug-resistant TB became common in their communities. So they needed more information on the management of MDR-TB and XDR-TB patients, and advised patients on the importance of treatment compliance to prevent resistance. CCWs felt that ongoing training would assist them to educate and empower both patients and fellow community members (Okeyo & Dowse, 2016).
4.3.4 Theme 4: TB stigma as a challenge on the work of CCWs

Good communication between CCWs and TB patients enhances good relationship, and therefore, this will result in treatment compliance. It was highlighted that some patients deny the diagnosis of TB due to perceive stigma about the condition from their community. The fact of having CCWs attached to a TB patient was still a challenge to patients as it presented many preconceived ideas of stigmatisation.

Participant 1 said: “…others will not appreciate our visits at first saying that we are here to force them to drink their medications and force them to do this and that”.

Participant 6 added: “When you start supporting him and helping him to take treatment, sometimes when you knock you find that he does not want you to come”.

TB stigmatisation is still a problem and is an important factor which not only delays the initiation of treatment, but is also hinders treatment adherence (Courtwright & Turner, 2010). Patients often try to hide their diseases from others due to stigma. This results in further delay in diagnosis and treatment, and thus increases chances of transmission to a healthy community.

When they are diagnosed with TB and on TB treatment, some patients start isolating themselves from community gatherings, and socialising becomes minimal.

Participant 8 said: “…so because they are suffering from TB, they start isolating themselves and having the thought of dying from TB. They know that TB is very infectious so they afraid to go to the clinic because they think people will laugh at them”.

The utilisation of isolation wards in most hospitals, and the observation that some doctors and nurses use protective equipment such as masks and gloves when dealing with TB patients can lead to stigmatisation of TB in the eyes of community members (Dhingra & Khan, 2009). Fear of infection had been identified as the main reason for the stigmatisation attitudes and behaviour of both health professionals and community members towards TB patients (Dhingra & Khan, 2009). The stigmatisation of TB may occur because the community of TB patients believes he or she must have done something wrong deserving the infection. This judgement may reflect the belief that TB is divine punishment for a moral or personal failing, which
then licenses stigmatisation. The stigma also results in a sense of shame or guilt, leading to self-isolation as TB patients internalise their community’s negative judgements about the disease (Courtwright & Turner, 2010).

4.4 CONCLUSION

This chapter discussed the research findings and the literature control. The findings were arranged according to the main themes and sub-themes, and are as follows: exciting and fulfilling work; training is empowering; CCWs have lack of special skills; and TB stigma as a challenge on the work of CCWs. Chapter 5 will focus on the summary, limitations, conclusions and recommendations of the study.
CHAPTER 5
SUMMARY, RECOMMENDATIONS, LIMITATIONS AND CONCLUSION

5.1 INTRODUCTION
The previous chapter focused on the research findings and literature control where a number of themes and sub-themes were discussed. The first theme focused on the exciting and fulfilling work of CCWs. Under this theme, the following sub-themes were discussed: CCWs monitor the taking of TB treatment; patients appreciate the support given by CCWs, and regard CCWs as friends and extended family members. The second theme looked at training as empowering to CCWs. Under this theme, the following sub-themes emerged: CCWs have TB screening skills; they are aware that side effects may lead to treatment defaulting; and are aware that alcohol abuse leads to treatment defaulting. The third theme focused on CCWs having lack of special skills. Under this theme, the following sub-themes emerged: failure to recall training sessions and inability to offer comprehensive support. The last theme looked at TB stigma as a challenge on the work of CCWs.

In this chapter, the conclusion of the study, its limitations, and the recommendations based on the research objectives are made. The main aim of the study was to explore lived experiences of CCWs of supporting patients taking TB treatment at Hlogotlou area, Limpopo Province. The qualitative research method employing the phenomenological approach was used.

The objective of the study was as follows:
• To explore and describe the lived experiences of CCWs of supporting patients on TB treatment at Hlogotlou area, Limpopo Province. In order to ensure that this objective was met, the researcher asked the main question and probing questions. CCWs were able to answer both the main question and the probing questions. CCWs were able to describe their experiences in the findings, themes and sub-themes in chapter 4. In the findings, CCWs described the empowerment gained through training, and highlighted how lack of special skills affects competence and performance in treatment support.
5.2 SUMMARY

This chapter focused on making conclusions on the objectives of the study and recommendations on the findings of the analysis of qualitative data. The researcher summarised the findings of the study. Four themes were generated from data because of the similarities displayed in the transcriptions. The themes were discussed through literature control. The work of CCWs was exciting and fulfilling. This was reflected on the emergent themes.

Despite the exciting work, CCWs played a major role in the administration of TB treatment. They highlighted that patients appreciated their support and regarded them as extended family members. They raised a worrying concern of having lack of special skills, but they were still able to screen people for TB, and referred complicated cases to clinics for further management by healthcare professionals.

CCWs showed that patients were defaulting TB treatment due to stigma, alcohol abuse, and treatment side effects. Good communication skills by CCWs enhance treatment compliance and, create assurance to patients. Refresher courses for CCWs and support by other healthcare professionals boost their self-confidence and enable them to offer comprehensive support.

5.3 RECOMMENDATIONS

The following recommendations are made:

Practice

- CCWs should conduct frequent TB and door to door campaigns in order to avoid delays in diagnosis, and enhance early treatment initiation.
- Health education and health promotion should be emphasised during TB campaigns in order to equip both patients and society on TB matters.
- It is highly recommended that the Department of Health provide social support and counselling to CCWs before role assumption to alleviate the burden of support giving and enhance willingness to continue with the role.
- Government should offer consistent support to CCWs as it is recognised that their role is effective in TB management.
• CCWs should acknowledge privacy and confidentiality pledge in relation to patients’ diagnosis and treatment.

Education
• The Department of Health should standardise basic training for CCWs.
• It should provide further training and access to additional information about TB in order to reinforce knowledge in a form of workshops.
• TB guidelines and standard operating procedures (SOPs) should be incorporated in training.

Research
• Further research is needed in order to establish how to overcome TB stigma in the work of CCWs in order to enhance long term patient support and, as a result, adherence to treatment will be good.

5.4 STRENGTHS AND LIMITATIONS OF THE STUDY

• Strengths
  The researcher interviewed all participants who took part in the study in their common language, which allowed the researcher to probe more, and the participants were able to give all the information needed.

• Limitations
  Only females participated in this study; therefore, there were no male experiences pertaining the study.

5.5 CONCLUSION
This chapter outlined the summary, conclusion, limitations and recommendations of the study. Key findings were presented on the lived experiences of the participants as emerged from the study. Recommendations highlighted by the researcher will have an implication for the improvement of TB management and the role of CCWs in PHC facilities.
List of References


ANNEXURE 1: INTERVIEW GUIDE IN ENGLISH

Section A: Demographic Data

1. Age: ........................................
2. Gender: Male........... Female:.........
3. Nationality:........................................
4. Home Language:........................................
5. Educational Level:........................................
6. Marital Status:

<table>
<thead>
<tr>
<th>Married</th>
<th>Single</th>
<th>Widowed</th>
<th>Divorced</th>
</tr>
</thead>
</table>

7. Duration of being a community care workers:........................................

Section B

Main question: What are your experiences of supporting patients on TB treatment?

Probing or follow-up questions

1. Tell me about your involvement with patient support on TB treatment?
2. Tell me what you understand about supporting TB patients?
3. What does TB guidelines or protocols say about TB control/management?
4. What kind of training regarding supporting patients on TB treatment did you have?
5. What are your typical experiences of supporting patients on TB treatment?
6. Can you recall any specific experiences you have for supporting patients on TB treatment?
7. What is the current relationship between you and your patient/s?
ANNEXURE 2: INTERVIEW GUIDE IN SEPEDI

TLHAHLO YA POLEDIŠANO

Karoloya Pele: Data yaBoitsibišo
1. Bogolo:..............................
2. Bong: Monna:....................Mosadi:..........................
3. Morafe:..............................
4. Leleme la Segageno:..........................
5. Maemo a Thuto:..........................
6. SeemosaLenyalo:

<table>
<thead>
<tr>
<th>Nyetše</th>
<th>Noši</th>
<th>Mohlologadi/Mohlolo</th>
<th>Hladile</th>
</tr>
</thead>
</table>

7. Lebaka le o bilengmodirediwa go hlokomelasetšhaba:..........................

Karolo ya Bobedi

Potšišo-kgolo: O kampotšakamaitemogelo a ggomabapi le go thekgabalwetšikakalafoyasehuba se segolo?

Dipotšišotšagolatela:
1. Mpotšekakamanoyagagomabapi le go thekgabalwetšikakalafoyasehuba se segolo?
2. Mpotše se o se kwešišangmabapi le go thekgabalwetšibasehuba se segolo?
3. Keeng se sebolelwagokamethalohlahliya go laolasehuba se segolo?
4. Ketlhahloefe e o etšeregomabapi le go thekgabalwetšikakalafoyasehuba se segolo?
5. Kemaiitemogeloafe a gagoa we a twaelegilegomabapi le go thekgabalwetšikakalafoyasehuba se segolo?
6. O kagopolamaitemogelo a gago a aitšegomabapi le go thekgabalwetšikakalafoyasehuba se segolo?
7. Setswallesabjalemagarenggagago le molwetši/balwetšibagago se bjang?
ANNEXURE 3: INTERVIEW TRANSCRIPTS OF THE CCWs IN HLOGOTLOU AREA

Transcripts of semi-structured interview of Participant 1

<table>
<thead>
<tr>
<th>Researcher</th>
<th>What are your experiences of supporting patients on TB treatment?</th>
<th>Coding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant</td>
<td>What I have observed throughout my experience of supporting patients on TB is that many people do not have knowledge about TB, an individual will think that when is infected by the disease then all other relatives in the home will not get it, that is why when I support them I also help them to prevent the disease from walking in the street to make sure that, individual protects themselves in order to prevent the disease from spreading to other people.</td>
<td></td>
</tr>
<tr>
<td>Researcher</td>
<td>When you say you may find that they may not know how the disease spread, what gave you this idea, or what have you observed?</td>
<td></td>
</tr>
<tr>
<td>Participant</td>
<td>What gave me an idea is that when we go for home visits to the houses that are allocated for me to support, you find that the patient just got up and all the windows and doors are still closed maybe somewhere around 08H00 am, whereas the whole night, the client spent it coughing and no adequate ventilation therefore the</td>
<td></td>
</tr>
</tbody>
</table>
mycobacterium is all over in the house, others when we get to their houses we find that they were using buckets for their sputum’s and cloths then kids come and they just touch the contaminated cloths with their bare hands. I usually advise them on how to prevent them from spreading the disease, advise them on cough etiquettes and advise them to throw away the used bucked and used cloths during coughing-throw the cloths in the toilets or burn them. Advise them on the importance of opening windows and doors, because the mycobacterium multiply in the dark, no ventilation room and it will make it easy for other family members to contract the disease.

<table>
<thead>
<tr>
<th>Researcher</th>
<th>Tell me about your involvement with patient support on TB treatment?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant</td>
<td>My involvement with patient support is that I do care, I like seeing my community and the whole public living a healthy life, without any illness. I do not want to see myself in a situation where we are all sick and there is no one to take care of the other, if I do not support them people will stay home without seeking help, whereas the disease progress and complicate and ending up with nothing to eat because people</td>
</tr>
</tbody>
</table>
are too sick to work, that is why I volunteered to help in supporting TB patients.

<table>
<thead>
<tr>
<th>Researcher</th>
<th>Tell me what you understand about supporting TB patients?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant</td>
<td>What I understand with this disease is that it is curable, when a patient is being assigned one of us in terms of TB treatment support, and giving myself time to understand the client and for the client to eat healthy normal diet, that what I think will help the client to win and become healed, because TB is curable and can be healed only if you comply to treatment.</td>
</tr>
<tr>
<td>Researcher</td>
<td>What does TB guidelines or protocols say about TB control/management?</td>
</tr>
<tr>
<td>Participant</td>
<td>First thing I do is to screen people for TB, then during screening there are few questions on the screening tool to ask each client such as signs and symptoms of TB, then you will have some of the positive TB signs…</td>
</tr>
<tr>
<td>Researcher</td>
<td>Then?</td>
</tr>
</tbody>
</table>
| Participant  | …then I will take sputum bottle and give it to the client so that they can produce sputum, after sputum collection, I will send the specimen to the clinic, then at the clinic they know what they supposed to do with the specimen. Then when the results are back I will go again to the clinic and check them,
and wait to be told on what should I tell the client in relation to the results.

<table>
<thead>
<tr>
<th>Researcher</th>
<th>Eh, then from there what do you do?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant</td>
<td>From there when they have told me the status of the results, now is me and my patient, I will go to my patient and tell them that I am being send to inform about the results status, I got them and they said I must come and support you with TB treatment.</td>
</tr>
<tr>
<td>Researcher</td>
<td>How will the result look like?</td>
</tr>
<tr>
<td>Participant</td>
<td>The results will be showing TB smear positive. Then I will have to sit down with the client and greet each other, and start negotiating on the plans on how are we going about treatment support, I will tell the client that I am back with results as I have collected the sputum for investigations and the results showed that there is TB disease, and first thing that I will ask from the client is time.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Mmm..</td>
</tr>
<tr>
<td>Participant</td>
<td>Yes I will ask the client to tell me the time that will be suitable for her in order for me to give treatment but it must not be above 10h00 am because you may find things clashing so we have to have an agreement.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Mmm..</td>
</tr>
<tr>
<td>Participant</td>
<td>Then after having an agreement, I will tell the client that okay, I am going to go back</td>
</tr>
</tbody>
</table>
to the clinic and do not be surprised when I come back with someone new, coming to check or see what is happening or what have we agreed on, then when I go back, I will go back where they have sent me to support you and back to the person who comes to see the client, the client should not be surprised and see me coming with a new person, someone that he does not know. I will come and tell the client that this person is my supervisor and suppose to see how I support you.

<table>
<thead>
<tr>
<th>Researcher</th>
<th>You were speaking about ten, which one were you referring? Morning or at night?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant</td>
<td>Ten I am referring to 10:00 in the morning.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Researcher</th>
<th>What kind of training regarding supporting patients on TB treatment did you have?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant</td>
<td>We have done TB DOTS.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Researcher</th>
<th>You have done TB DOTS, what was that? Was it a training or what…?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant</td>
<td>It was training, and then we also did ancillary.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Researcher</th>
<th>What is ancillary?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant</td>
<td>It embraces home base care as a whole, all the illnesses, and we did TB on 59 days.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Researcher</th>
<th>Can you explain TB on 59 days what it entails?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant</td>
<td>This 59 days it is called like that because we will be receiving training for 59 days being</td>
</tr>
</tbody>
</table>
trained on duties and responsibilities of a community care worker, and it also includes TB and other diseases.

<table>
<thead>
<tr>
<th>Researcher</th>
<th>Ooh...and other diseases?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant</td>
<td>Yes.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Diseases like what?</td>
</tr>
<tr>
<td>Participant</td>
<td>Diseases like HIV and AIDS.</td>
</tr>
<tr>
<td>Researcher</td>
<td>What are your typical experiences of supporting patients on TB treatment?</td>
</tr>
<tr>
<td>Participant</td>
<td>I have experienced that many people in our community they do understand, I have realised that the way we were trained in supporting patients, if we adhere to the skills we have acquired, our clients end up being cured. I have already made many people to be well and healed from TB disease.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Mmm..</td>
</tr>
<tr>
<td>Participant</td>
<td>Yes, there are many people who are healed from TB disease when I have supported them and using what I was taught during my training on how to communicate with them.</td>
</tr>
<tr>
<td>Researcher</td>
<td>In other words you do not meet challenges?</td>
</tr>
<tr>
<td>Participant</td>
<td>Challenges..?</td>
</tr>
<tr>
<td>Researcher</td>
<td>We also want them because they fall under experiences.</td>
</tr>
<tr>
<td>Participant</td>
<td>Yes, some of the challenges are that many people did not want to take TB treatment alone; you will find one having a small bottle during home visit for treatment support.</td>
</tr>
<tr>
<td>Researcher</td>
<td>What kind of small bottle are</td>
</tr>
<tr>
<td>Participant</td>
<td>The client will be telling us that this small bottle is from traditional healer, maybe according to the traditional healer, the client will be having poison, consumed poison.</td>
</tr>
<tr>
<td>------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Researcher</td>
<td>Ooh, you speaking of traditional herbs that are not tested in the laboratory before use?</td>
</tr>
<tr>
<td>Participant</td>
<td>Yes, then you find the small bottle being put there, and when we ask how can this happen, the client will tell us that he is not suffering from TB disease, maybe is witchcraft, I am being bewitched that is why I am coughing is because of the poison that I have consumed.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Ooh, is that what they usually do?</td>
</tr>
<tr>
<td>Participant</td>
<td>Yes.</td>
</tr>
<tr>
<td>Researcher</td>
<td>So how do you convince them?</td>
</tr>
<tr>
<td>Participant</td>
<td>I ask the client, since well I am the one who has screened you, and collected your sputum sent it to the laboratory. And since I am the one who gave you the sputum results which were positive and you run to the traditional healer after I told you the sputum results, so I will ask the client to give me only a period of 6 months to give him TB treatment and maybe after 2 months of treatment initiation, he will start feeling better and feel the progress of the ingested poison. But because of good communication and the manner</td>
</tr>
</tbody>
</table>
of communicating, we end up having an agreement, and the client will stop using herbal treatment instead continue with TB treatment, and after 2 months will tell you that he is feeling better.

<table>
<thead>
<tr>
<th>Researcher</th>
<th>Okay, is there any patient(s) that you are currently supporting?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant</td>
<td>Yes I do have them.</td>
</tr>
<tr>
<td>Researcher</td>
<td>What is the current relationship between you and your patient(s)?</td>
</tr>
<tr>
<td>Participant</td>
<td>I have big relationship with my clients, especially the elders; to me they are my elders.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Mm.</td>
</tr>
<tr>
<td>Participant</td>
<td>When I get to their homes, they see me as one of their child because I can communicate and laugh with them then when they have trips they inform me before they leave and even when they come back they inform me, and when we meet again we become happy as if we are family.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Mmm..</td>
</tr>
<tr>
<td>Participant</td>
<td>Yes, we have already built a strong relationship.</td>
</tr>
<tr>
<td>Researcher</td>
<td>This relationship started being like this from the beginning or it became like that when due course?</td>
</tr>
<tr>
<td>Participant</td>
<td>It became like this with time, when I started with my visits at first they were having some doubts, but because facial expressions are different, others</td>
</tr>
</tbody>
</table>
will judge you by the mere looking at your face and think that they will not tolerate me, but when we continuously engage, the client will gradually realise that she can actually be open to you. Others will not appreciate our visits at first saying that we are here to force them to drink their medications and force them to do this and that. But when you communicate with them well trying to show them reasons they end up understanding as communication is the key.

Researcher

Mmm...

Participant

The client end up getting much better because of good communication between you and her, and as a result, a good relationship emanates from that.

Researcher

What do you think causes the hesitant of client towards community care workers at the beginning of first contact?

Participant

In elders, they become hesitant thinking that you are just there to kill them with your medication, but later on they start realising that actually this medication is there to help them contain the disease and conserve their lives. During home visits you will find them being ready, and well groomed, just waiting for the community care worker so that they can go together to the clinic in order to collect their treatment. This
thing of hesitant has started long time ago with the myth of saying hospitals kill people and people get worse in hospital as compared to being ill and taken care at home. It only emanates from peer pressure.

Researcher

Thank you.

Transcripts of semi-structured interview of Participant 2

<table>
<thead>
<tr>
<th>Researcher</th>
<th>What are your experiences of supporting patients on TB treatment?</th>
<th>Coding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant</td>
<td>We learn many things about TB patients, they do not want to take their treatment, and they feel shy to take their treatment maybe because of the community care worker that is allocated to them. Patients know them so it becomes difficult for them to comment, others will shout at you and become aggressive.</td>
<td></td>
</tr>
<tr>
<td>Researcher</td>
<td>They shout at you and become aggressive, so what do you do in response to that?</td>
<td></td>
</tr>
<tr>
<td>Participant</td>
<td>You just have to be down and calm, it is not helpful for you to shout back at the patient because if you do you will end up dropping the patient mean while the disease will progress more and the patient will spread it more. So when the patient keeps on shouting at you, yours is just to become calm and understand their situation and do not give up on your patient instead continue with your home visits and DOT supporting. One day you will find the patient in own normal senses.</td>
<td></td>
</tr>
<tr>
<td>Researcher</td>
<td>What do you mean when you say you have to be down when the patient is busy shouting at you?</td>
<td></td>
</tr>
<tr>
<td>Participant</td>
<td>It means when the patient shout at you, do not shout back at the patient and when they</td>
<td></td>
</tr>
</tbody>
</table>
fight you do not fight back, when they do all those things just keep calm but telling them the truth of the matter.

<table>
<thead>
<tr>
<th>Researcher</th>
<th>Tell me about your involvement with patient support on TB treatment?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant</td>
<td>My involvement is to help the patient take treatment on time every day.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Mmm….</td>
</tr>
<tr>
<td>Participant</td>
<td>She must attend clinic for her follow up visits and befriend her.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Befriend her? Why are you supposed to become their friend?</td>
</tr>
<tr>
<td>Participant</td>
<td>Our patients are not supposed to be scared from us, they do fight the first month after initiation of treatment, they lose their temper, they just want to see you in giving them treatment and leave very fast.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Mmm.</td>
</tr>
<tr>
<td>Participant</td>
<td>But somewhere around 3-4 months,</td>
</tr>
<tr>
<td>Researcher</td>
<td>Mmm.</td>
</tr>
<tr>
<td>Participant</td>
<td>….the patient does not want treatment only,</td>
</tr>
<tr>
<td>Researcher</td>
<td>Mmm.</td>
</tr>
<tr>
<td>Participant</td>
<td>….because they know that you are no longer going to come every day, you will come occasionally.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Mmm.</td>
</tr>
<tr>
<td>Participant</td>
<td>You find there are some things that they want to share with you.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Mmm…</td>
</tr>
<tr>
<td>Participant</td>
<td>The patient should not be scared of you instead she must be open to you in order to verbalise things that bothers her.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Things that she wants to say, you mean the patient?</td>
</tr>
<tr>
<td>Participant</td>
<td>Yes.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Like what?</td>
</tr>
</tbody>
</table>
| Participant | It is not, not taking TB treatment only, at home he does not have anyone whom he can open up to, at the end you find yourself
being their friend, the patient can open up and tell you everything that he cannot tell his family.

<table>
<thead>
<tr>
<th>Researcher</th>
<th>Now what are the things that you encountered that the patient cannot tell his family instead he told you?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant</td>
<td>Something that amused me was a certain man, an old man staying at his home.</td>
</tr>
<tr>
<td>Research</td>
<td>Mmm..</td>
</tr>
<tr>
<td>Participant</td>
<td>They were surprised to see him in the house because he was residing at Gauteng province and they were just surprised to see him home. They thought he was brought home due to his illness but only to find out that is the illness and divorce, but his sisters could see that their brother had his personal problems, and the brother could open up to me instead of his sisters and the mother.</td>
</tr>
<tr>
<td>Research</td>
<td>Mmm..</td>
</tr>
<tr>
<td>Participant</td>
<td>Meanwhile I am young.</td>
</tr>
<tr>
<td>Research</td>
<td>Mmm, tell me what you understand about supporting TB patients?</td>
</tr>
<tr>
<td>Participant</td>
<td>I understand that to support patient on TB treatment is to make sure that they drink their medication.</td>
</tr>
<tr>
<td>Research</td>
<td>Is to make sure that they drink their medication, whether they like it or not?</td>
</tr>
<tr>
<td>Participant</td>
<td>Yes, no he will take his medication willingly so, yes at first they start by being difficult but due to my persuasion and emphasis on importance of treatment compliance.</td>
</tr>
<tr>
<td>Research</td>
<td>Mmm..</td>
</tr>
<tr>
<td>Participant</td>
<td>Importance of drinking his treatment, yes he will shout at me and try to become a delinquent but when he is alone he will come into his normal senses of taking treatment well. He will be remembering that if he does not take his treatment the result thereof will be spreading the disease more and maybe end up being dead due to tremendous</td>
</tr>
</tbody>
</table>
complications from the disease. The following day when I come back for home visits he will become more understanding, when time goes he will be taking his treatment well. Usually others develop problems when they take their treatment, they develop side effects and when they do, they start hating you thinking that you are the one who is causing all what is happening to them.

| Researcher | Mmm.. |
| Participant | But when all side effects disappear both of you, end up being friends. |
| Researcher | Yes, so about how long do the side effects last? |
| Participant | Around 2 months. |
| Researcher | Around 2 months? |
| Participant | Mmm.. |
| Researcher | So in other words after 2 months you become friends? |
| Participant | Yes we become friends, when you want to leave they will tell you is too early to leave simply because the patient still enjoying your company. |
| Researcher | Mmm, okay, what does TB guidelines or protocols say about TB control/management? |
| Participant | Mmm. It says people should take their TB treatment for 6 months if is pulmonary tuberculosis. Pulmonary tuberculosis treated for 6 months. |
| Researcher | Mmm.. |
| Participant | They should drink water. |
| Researcher | It talks about those you have mentioned only? |
| Participant | Yes it talks about those and even to care for yourself, and their lifestyle. |
| Researcher | What do you mean when you say they have to take care of themselves? |
| Participant | They must not cough anyhow and spit their
sputum on an open place. When you see signs and symptoms of TB you must quickly go to the clinic and be screened for TB.

<table>
<thead>
<tr>
<th>Researcher</th>
<th>What are those signs and symptoms?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant</td>
<td>When you cough more than 2 weeks, blood stained sputum, night sweats, loss of appetite, and loss of weight.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Mm, I heard you talking of pulmonary tuberculosis only.</td>
</tr>
<tr>
<td>Participant</td>
<td>Yes, that’s because most of patients that we are supporting are suffering from pulmonary tuberculosis (PTB), I have never seen any patient suffering from TB of bones here home.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Okay, so what kind of training regarding supporting patients on TB treatment do you have?</td>
</tr>
<tr>
<td>Participant</td>
<td>I did a training of NQF level 3.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Can you explain what it means? What does it entails?</td>
</tr>
<tr>
<td>Participant</td>
<td>I also did fundamental and also attended other workshops that we normally go to while working as a community care worker and we were being trained on TB, especially for PTB because other TB are not common in our area.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Mmm..</td>
</tr>
<tr>
<td>Participant</td>
<td>They only teach us about PTB only unless someone raises a question concerning TB of bones that will be the time where they will start explaining what it is.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Okay, what are your typical experiences of supporting patients on TB treatment?</td>
</tr>
<tr>
<td>Participant</td>
<td>What I have experienced with patients especially male patients, you support them…</td>
</tr>
<tr>
<td>Researcher</td>
<td>Mmm..</td>
</tr>
<tr>
<td>Participant</td>
<td>…when you go at the end of supporting session you are no longer a friend instead you have to become his girlfriend.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Ooh they see wife in you guys?</td>
</tr>
<tr>
<td>------------</td>
<td>--------------------------------</td>
</tr>
<tr>
<td>Participant</td>
<td>Yes, most of male patients are like that, I do not know if ever their wives runaway after initiation of treatment, you start by fighting, then become friends, and you have given them your number to call you when there is a problem, one day you get a call at eight during the night just reminding you that the following day do not forget to come and DOT support him, when you get to his place and asking them what was he saying on phone then while you still listening he start proposing, that is a problem we encounter with male patients.</td>
</tr>
<tr>
<td>Researcher</td>
<td>So is it all male patients?</td>
</tr>
<tr>
<td>Participant</td>
<td>No it’s not all of them but most of them, especially when you find the man in his home there is no woman, maybe the woman left immediately after the man was diagnosed TB.</td>
</tr>
<tr>
<td>Researcher</td>
<td>So women are not troublesome?</td>
</tr>
<tr>
<td>Participant</td>
<td>No, women are not troublesome, it’s just that their problem they like running away especially when they start experiencing side effects.</td>
</tr>
<tr>
<td>Researcher</td>
<td>So you end up doing what? How do you deal with them?</td>
</tr>
<tr>
<td>Participant</td>
<td>We report them, call them, some will come back when they feel they are getting worse and become helpless, then that means we going to start afresh with them.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Yes, that’s true; so do you have patients that you are currently supporting?</td>
</tr>
<tr>
<td>Participant</td>
<td>Yes.</td>
</tr>
<tr>
<td>Researcher</td>
<td>What is the current relationship between you and your patient/s?</td>
</tr>
<tr>
<td>Participant</td>
<td>You mean TB patients?</td>
</tr>
<tr>
<td>Researcher</td>
<td>Yes TB patients.</td>
</tr>
<tr>
<td>Participant</td>
<td>Eish mine is a problem; I was still telling my</td>
</tr>
<tr>
<td>Researcher</td>
<td>Mmm, what is the problem? Why are you saying that?</td>
</tr>
<tr>
<td>------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td>Participant</td>
<td>They allocated me for him mean while I know his behaviour, he is disrespectful, and I know him from somewhere else.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Mmm..</td>
</tr>
<tr>
<td>Participant</td>
<td>I went to his place, he is disrespectful and he only disrespects me because he knows me and I know him too. When you call him, first time when I started supporting him I did not know his name, when I called him, he then said vulgar words to me, and I called him with the knowledge that he will respond with vulgar words on phone. So his moods just changes, today he will say vulgar words but the following day he will become the nicest person as if the previous day nothing happened, and he will be laughing with you.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Mmm. Okay.</td>
</tr>
<tr>
<td>Participant</td>
<td>Sometimes when you go to him instead of drinking his medication, he will tell you that he did not eat so he cannot take treatment; he is doing this as if by drinking his medication he is doing me a favour.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Mmm.. Okay, is that all? So how do you handle him?</td>
</tr>
<tr>
<td>Participant</td>
<td>When he drinks his treatment, at least he becomes better.</td>
</tr>
<tr>
<td>Researcher</td>
<td>He becomes better?</td>
</tr>
<tr>
<td>Participant</td>
<td>Mm, his problem before supporting him, we going according to section for DOT support, so while we were busy tracing, we have found an old man from Hlogotlou registered his son’s name and we did not find him.</td>
</tr>
<tr>
<td>Researcher</td>
<td>Mmm.</td>
</tr>
<tr>
<td>Participant</td>
<td>He is a traditional healer, there is no kraal for his cattle, they just roam around the yard, and when he coughs up he spits his sputum</td>
</tr>
</tbody>
</table>
Researcher | Mmm.
---|---
Participant | It's his friend.
Researcher | Friend of the troublesome one.
Participant | Yes, so we ended up with disagreement and he brought back the treatment to the clinic saying that we want to kill him.
Researcher | Mmm..
Participant | Then I walked with him to the clinic and on our way he told me about the traditional healer guy who has stopped the treatment, so he thought I do not know him and I did not tell him that I once supported him, then I concluded that he is troublesome because of the guy, they are both friends and influences each other hence they behave the same.
Researcher | Mmm…
Participant | So he wanted to hear my opinions about everything he was telling me. He wanted to find out what his friend was doing was it the right thing or not? So the plan was to do the same thing and stop treatment like his friend did.
Researcher | Ooh, eish ….
Participant | So I did not tell him that I know the guy he is been talking about.
Researcher | Mm, alright my friend, thank you that will be all for now.
ANNEXURE 4: ETHICAL CLEARANCE CERTIFICATE

University of Limpopo
Department of Research Administration and Development
Private Bag X1106, Sovenga, 0727, South Africa
Tel: (015) 268 2212, Fax: (015) 268 2306, Email:noko.monene@ul.ac.za

TURFLOOP RESEARCH ETHICS COMMITTEE CLEARANCE CERTIFICATE

MEETING: 05 July 2016
PROJECT NUMBER: TREC/122/2016: PG

PROJECT:
Title: Community care workers' experiences of supporting patients on tuberculosis treatment at Hlogotlou Area, Limpopo Province
Researcher: Mr P Phahlane
Supervisor: Mr SF Matlala
Co-Supervisor: N/A
School: Health Care Sciences
Degree: Masters in Public Health

PROF TAB MASHEGO
CHAIRPERSON: TURFLOOP RESEARCH ETHICS COMMITTEE

The Turfloop Research Ethics Committee (TREC) is registered with the National Health Research Ethics Council, Registration Number: REC-0310111-031

Note:

i) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.
ii) The budget for the research will be considered separately from the protocol. PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.
ANNEXURE 5: LETTER REQUESTING PERMISSION FROM MANAGEMENT OF HLOGOTLOU HOME-BASED CARE

Mr Mothoa Patrick Mashilo
P O Box 1603
Siyabuswa
0472
18 May 2016

The Manager
Hlogotlou Home-Based Care
Dear sir/madam

Permission to conduct research
I (University of Limpopo MPH student) would like to be granted permission to collect data on the following research title: Community care workers’ experiences of supporting patients on tuberculosis treatment at Hlogotlou area in Limpopo Province, South Africa.

Data will be collected from all community care workers of any gender and age who have supported patient/s on tuberculosis treatment from four (4) weeks and above. The study will provide information about community care workers’ experiences of supporting patients on tuberculosis treatment.

Researcher’s signature .................................. Date 18/05/2016
Contact number: 079 549 8001
ANNEXURE 6: LETTER GRANTING PERMISSION FROM HLOGOTLOU HOME-BASED CARE

ENQ: CAIPHUS 076 238 1123
EMELINA 082 046 9385
CARLOS 079 968 4956

P.O. BOX 50426
MPUDULLE
1057
STAND 669 A
MONSTERLIJS

PERMISSION LETIER TO MADE RESEARCH BY MR P PHAHLANE

THE ABOVE MENTIONED ORGANISATION PERMITED, YOUR SELF TO CONDUCT A RESEARCH ON THE ACTIVITIES OF TB MANAGEMENT AND OTHER RELATED MATIERS CONCERNING TB, INCLUDING INTERVIEWING COMMUNITY CARE WORKERS ABOUT TB.

YOURS IN COMMUNITY

DEVELOPMENT PROJECT MANAGER

SIGNATURE: ..................................

........................................DATE: 10/10/2016
ANNEXURE 7: INFORMATION LEAFLET

I am Patrick Mashilo Mothoa, a student at University of Limpopo doing MPH; I am conducting a study on: Community care workers experiences of supporting patients on tuberculosis treatment at Hlogotlou area in Limpopo Province.

Together with my supervisor, we will be investigating CCWs experiences of supporting patients on TB treatment; we are inviting you to participate in this study because the results will improve the disease trend.

Kindly avail yourself and if you want you can sign a consent form attached. If you have any questions or clarity seeking questions contact me on this number 079 549 8001 and my supervisor Dr SF Matlala, contact number 015 268 3404. Your refusal to participate will not disadvantage you in any way.
ANNEXURE 8: LETLAKALA LA TSHEDIMOŠO

Kenna Patrick Mashilo Mothoa, moithutiwa Yunibesithiya Limpopo keithutelatsamaphelo a setšhaba; kehlahlathutoka: Maitemogelo a badirediba go hlokomelasetšhabamabapi le go thekgabalwetšikakalafoyasehuba se segololefelong la Hlogotloumo Limpopo.

Nnagammogo le molaodiwaka, retlonyakišišamaitemogelo a badirediba go hlokomelasetšhabamabapi le go thekgabalwetšikakalafoyasehuba se segolo; re le laletšagotla go kgathatemamo go thuto ye kabaka la gore dipoeletšagonaditlokaonafatšamalebiša a bolwetši.

Kaboleta re kgopela le e ponagatše go thuto ye gape ge o nyaka o kakgona go saenaforomoyatumello yeo e kgomagantšwego. Ge o na le dipotšišogobaponagalo, kgokagana le nnamonomorong ye e latelang 079 549 8001 le molaodiwaka Morena S.F Matlala, nomoroya gage yamogalake 015 268 3404. Kganoyagagoya go kgathatemama e ka se be bothatakaholegoyagago.
ANNEXURE 9: UNIVERSITY OF LIMPOPO CONSENT FORM

Statement concerning participation in a research project

Name of research project: Community care workers’ experiences of supporting patients on tuberculosis treatment.

I have read the information on/heard the aims and objectives of the proposed study and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aims and objectives of the study are sufficiently clear to me. I have not been pressurised to participate in any way.

I understand that participation in this research project is completely voluntarily and that I may withdraw from it at any time and without supplying reasons. This will have no influence on the regular treatment that holds for my condition neither will it influence the care that I receive from my regular doctor.

I know that this research project has been approved by the Research, Ethics and Publications Committee of Faculty of Health Sciences, University of Limpopo (Turfloop Campus)/Hlogotlou Home-Based Care. I am fully aware that the results of this research project will be used to scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

............................................................................................
............................................................................................
Name of volunteer  Signature of volunteer
............................................................................................
............................................................................................
Place................................................. Date............................ Witness..........................

Statement by researcher

I provided verbal and/or written information regarding this study. I agreed to answer any future questions concerning the study as best as I am able. I will adhere to approved protocol.

MOTHOA PM ..................................................
Name of researcher  Signature  Date  Place
ANNEXURE 10: YUNIBESITHI YA LIMPOPO FOROMO YA TUMELLO

Setatamentemabapi le go kgathatemakaprojekeyanyakišišo.

Leina la projekeyanyakišišo

Maitemogelo a badirediba go hlokomelasetšhabamabapi le go thekgalwetšikakalafoyasehuba se segolo. Kebadiletshedimošebilekekwelekamaikemisetšo a šišinyoyathuto le gonakefiwelwesbakasa go botšišadipotšišo gape kefiwenakoya go lekanela go kanangantšišakataba ye. Maikemisetšo a thuto ye a tloga a le molalengebile a lekanetše kudu gonna. Ga se kagatelelwa go kagathatemakamokgwana omongwe. Kea kwešiša gore go kgathatemamoprojekenganyakišišo ye e tlogaelekaithaopiaafeleletšegogommenkaikgogelamoragokanakoengwe le engwentle le gofamabaka. Se sekasebe le khuetsyo go kalafoyakayamehlebile se kasebe le khetšonyathhokomeloyeweke e amogelanggotšwa go ngakayakayamehleng.

Kea tseba gore projeke ye yanyakišišo e dumeleletšwekebaNyakišišo, Maitshwaro le baKomitiyaKgatišoyaLefapha la tšaSaenseyaMaphelo, Yunibesithiya Limpopo (Turfloop Campus). Kena le temogo e tletšeng gore dipovelotšaprojekeyanyakišišo e tlošomišawamalebagommeyagatišwa. Nedumellana le se gefelagona le bonnetebja gore lebitšolaka e tlabasephiri.

............................
...........................................................................................................
...........................................................................................................................
Leina la moithaopi Gosaena
........................................🌠........................................
Lefelo.........................................Letšatšikgwedi.........................Hlatse....................

Setatamentekamonyakišiši

Ke file tshedimošokamokgwawapolelo le go ngwalambapi le go tšeathuto ye. Kedumetše go arabadipotšišotšewe di katšwelelagomabapi le thuto ye kabokaonebjoonkabokgonago. Ketlagomarela go tlahlo yeo ke e dumeleletšego.

MOTHOA PM .......................................................... .............................................................
Leina la monyakišišiGosaena Letšatšikgwedi Lefelo

62
15 October 2018

Dear Sir/Madam

SUBJECT: EDITING OF MINI-DISSERTATION

This is to certify that the mini-dissertation in Public Health entitled ‘Community care workers’ experiences of supporting patients on tuberculosis treatment at Hlogotlou area, Limpopo Province’ by Mothoa Patrick Mashilo has been proofread and edited, and that unless further tampered with, I am satisfied that all editorial issues have been dealt with.

Kind regards

Dr SJ Kubayi (DLitt et Phil - Unisa)
Senior Lecturer (Department of Translation Studies and Linguistics – UL)
SATI Membership No. 1002606