EXPERIENCES OF DIRECT OBSERVATION TREATMENT SUPPORTERS
MANAGING TB PATIENTS IN THE INFORMAL SETTLEMENT OF
JOHANNESBURG (ORANGE FARM)

REGINA MOITSHEKI MAITHUFI

Student Number: 201216669

Submitted in partial fulfilment of the requirements for the degree

MASTER OF PUBLIC HEALTH

DEPARTMENT OF PUBLIC HEALTH

Sefako Makgatho Health Science University

Supervisor: Ms Busi Ntuli

November 2015
DECLARATION AND COPYRIGHT

I certify that the ideas, case study work, results, analysis, computer software used and conclusions reported in this dissertation were achieved entirely by my own efforts and have not previously been submitted to any other institution of higher education. I further declare that all sources cited or quoted are indicated and acknowledged by means of a comprehensive list of references.

I hereby declare that all of the information in this document was obtained and presented in accordance with standard academic rules and ethical conduct. I also declare that, as required by these rules and conduct, I have fully cited and referenced all material and results that are not original to this work.

Name:

___________________
Signature of candidate

Date: November 2015
DEDICATION

This work is dedicated to the following individuals who have supported, cared and trusted that I will make it in my career:

My late mother, grandfather & grand mother (Mr Jacob Thipe and Johanna Thipe).
My dear son, Kitso Maithufi for your motivation and trust in your mom.
My dear daughter, Oreneile Thipe.
My sister, Ms Miriam Thipe and my brothers Japhta Thipe, Thabo Thipe and all my friends and other family members who supported me. Thank you very much for your remarkable role played in my life.
ACKNOWLEDGEMENTS

I thank God, the Almighty, for providing me with the talent and perseverance to complete this dissertation.

My sincere appreciation goes to the following individuals and organisations:

- My study supervisor, Ms Busi Ntuli-Nqobo, for her encouragement and guidance.
- To all DOTS Supporters for their participation in this study.
- The Department of Health (Region G, City of Johannesburg Metropolitan Municipality).
- Vumani Project
- Inkanyiso HIV and AIDS Care Initiative
- Thalithakhumi Primary Health Care.
- Sefako Makgatho Health Science University.
- Johannesburg Research and Ethics Committee for granting me permission to conduct this research activity.
ABSTRACT

Background: The current global tuberculosis (TB) epidemic has pressurised health care managers, particularly in developing countries, to seek for alternative and innovative means of delivering effective treatment to the high number of TB patients diagnosed annually. One strategy employed is the direct observation short-course strategy (DOTS) for all patients. This strategy is characterised by the employment of lay community members or so-called DOTS Supporters who supervise TB patients for the duration of their treatment. Mostly these health workers are faced with several challenges including poor working conditions which sometimes impact negatively on TB programmes in such communities.

Aim: The aim of this study was to explore the experiences and challenges of DOTS supporters working in the Orange Farm informal settlement

Methodology: This was a qualitative exploratory descriptive study, where six focus group discussions (FGDs) were conducted with TB DOT supporters, each FGD comprising of 10 participants from four civil society organisations. Participants were interviewed using an interview guide developed in English and translated into South Sotho. A brief questionnaire was used to collect demographic data. A voice recorder was utilised to record the responses during data collection.

Data analysis: Voice recordings from data collection were listened to repeatedly and verbatim transcripts done in South Sotho, the language used during data collection. The transcripts were translated into English and codes were identified. A code list was developed with themes and sub-themes, which were imported into NVivo10 software in order to present the codes thematically, with quotes from the participants’ experiences to support the themes.

Results: Ninety five percent of the total samples were females, age ranging from 18-55, with 45% having tertiary education. The data revealed that there were supplementary benefits to be derived from being a TB DOT supporter, such as learning new skills, increasing
one’s store of knowledge, and gaining confidence, through the continuous training received and career pathing. The data also revealed that TB DOT supporters received comfort and support from their patients, their families and their communities. They also gave other reasons that kept them working on a daily basis, such as a sense of altruism, and a sense that they were obliged to render such care due to their religious affiliation. However, they also reported that they routinely met challenges in their field of work, such as a lack of resources, poor financial support, and the long distances they had to travel.

**Conclusions:** The study showed that the success of the programme to control TB infection in the informal settlements is being challenged by several factors, which include the following: the delay in incentivising TB DOT supporters, the insecurity of TB DOT supporters while tracing TB patients, the lack of community support and management support, the high attrition rate, and the workload for TB DOT supporters who have to fill the gap caused by the resignation of others. High levels of stress were also mentioned in the study, as the TB DOT supporters faced many challenges while working and being exposed to TB due to lack of resources such as gloves and masks, and most of all by not being given a clear explanation about their salaries

**Recommendation:** There is a definite need for the improvement of working conditions for TB DOT supporters, and there should be a policy in place regarding their Basic Conditions of Employment and Remuneration. There is a need for the recruitment of more TB DOT supporters and to ensure the availability of transport. Therefore it is important to ensure the provision of resources for TB DOT supporters and that they obtain training from an accredited training institution.
# Table of Contents

DECLARATION AND COPYRIGHT ........................................................................................................... I
DEDICATION ......................................................................................................................................... II
ACKNOWLEDGEMENTS ...................................................................................................................... III
ABSTRACT ............................................................................................................................................. IV
ACRONYMS AND ABBREVIATIONS ................................................................................................... X

## CHAPTER 1 – INTRODUCTION ........................................................................................................ 1
1.1. BACKGROUND ................................................................................................................................. 1
1.1.1 The burden of TB in South Africa ................................................................................................. 1
1.1.2 Multi drug resistant (MDR) TB in South Africa ............................................................................ 2
1.1.3 TB mortalities .................................................................................................................................. 2
1.1.4 TB chemotherapy ......................................................................................................................... 3
1.1.5 The DOTS ..................................................................................................................................... 3
1.2. Problem statement ............................................................................................................................ 4
1.3. AIM OF THE STUDY ....................................................................................................................... 5
1.4. STUDY OBJECTIVES ..................................................................................................................... 5
1.5. RESEARCH QUESTIONS .................................................................................................................. 5
1.6. SIGNIFICANCE OF THIS STUDY ................................................................................................. 5
1.7. DEFINITION OF TERMS .................................................................................................................. 6
1.8. CONCLUSION ................................................................................................................................. 6

## CHAPTER 2 LITERATURE .................................................................................................................. 7
2.1. INTRODUCTION ............................................................................................................................... 7
2.1.1. The National tuberculosis Programme in South Africa ............................................................ 7
2.1.2. Arguments why the DOTS strategy is not effective ................................................................. 8
2.1.3. The state of health in rural and informal settlements .............................................................. 9
2.1.4. Community participation in TB health care ......................................................................... 10
2.1.5. The importance of Community Health Care Workers .......................................................... 10
2.1.6. Policy governing Community Health Care Workers ............................................................. 11
2.1.7. Community Health Care Workers’ involvement in TB management .................................. 11
2.2. THE ROLE OF DOT SUPPORTERS IN TB MANAGEMENT ........................................................ 12
2.3. HEALTH PROMOTION AND SOCIAL MOBILIZATION .............................................................. 13
2.4. REFERRAL OF TB PATIENTS ........................................................................................................ 13
2.5. OTHER DOT SUPPORTERS’ ACTIVITIES .................................................................................... 14
2.6. THE MOTIVATION OF TB DOT SUPPORTERS IN RENDERING TB SERVICES ..................... 15
2.6.1. Religious affiliation .................................................................................................................... 15
2.6.2. Sense of altruism ....................................................................................................................... 15
2.6.3. Unemployment and keeping busy ............................................................................................ 16
2.6.4. Giving back .............................................................................................................................. 17
2.6.5. Passion for work ....................................................................................................................... 17
2.7. REPORTED BENEFITS .................................................................................................................... 18
2.7.1. Intrinsic rewards ...................................................................................................................... 18

vi
2.7.2. Extrinsic rewards................................................................. 19

2.8. FAMILY SUPPORT............................................................................................... 19

2.9. CHALLENGES FACED BY TB DOT SUPPORTERS ........................................ 20
2.9.1. Delay in payment of TB supporters................................................................. 20
2.9.2. Impoverished TB client......................................................................................... 22
2.9.3. Walking long distances and long hours .............................................................. 23
2.9.4. Physical and emotional strain................................................................................ 24
2.9.5. Lack of supervision.............................................................................................. 24
2.9.6. Lack of medical supplies....................................................................................... 25

2.10. FEAR OF CONTRACTING TB INFECTION ................................................................ 26

CHAPTER 3 – METHODOLOGY................................................................................. 27
3.1. INTRODUCTION ......................................................................................................... 27
3.2. STUDY DESIGN ......................................................................................................... 27
3.3. STUDY SETTING ........................................................................................................ 27
3.4. STUDY POPULATION ............................................................................................... 28
3.5. SAMPLING TECHNIQUE AND SAMPLING SIZE .................................................. 28
3.6. INCLUSION AND EXCLUSION CRITERIA .............................................................. 29
3.8. DATA COLLECTION METHOD .............................................................................. 30
3.9. DATA MANAGEMENT ............................................................................................. 32
3.10 DATA ANALYSIS .................................................................................................. 33
3.11 TRUSTWORTHINESS .............................................................................................. 33
3.11.1 Credibility ........................................................................................................... 33
3.11.2 Transferability .................................................................................................... 34
3.11.3 Dependability .................................................................................................... 34
3.11.4 Conformability .................................................................................................. 35
3.12 ETHICAL CONSIDERATIONS .............................................................................. 35
3.12.1 INFORMED CONSENT .................................................................................... 36
3.12.2 ANONYMITY AND CONFIDENTIALITY ......................................................... 36
3.13 CONCLUSION ........................................................................................................ 36

CHAPTER 4 - DATA ANALYSIS............................................................................... 37
4.1. INTRODUCTION ....................................................................................................... 37
4.2. PARTICIPANTS’ SOCIO-DEMOGRAPHIC INFORMATION ................................... 37
4.3. QUALITATIVE FINDINGS AND THEMES IDENTIFIED ......................................... 41
4.3.1. Community participation in TB control.............................................................. 42
4.3.1.1. The roles of TB DOT supporters in TB control in Orange Farm .................. 43
4.3.1.2. Referral role .................................................................................................. 43
4.3.1.3. Other activities ............................................................................................. 44
4.3.1.4. Health promotion and social mobilization .................................................... 45
4.3.2. The motivation of TB DOT supporters in joining the TB programme .............. 46
4.3.3. Reported benefits of TB DOT supporters managing TB patients ..................... 50
4.3.3.1. Learning new skills ....................................................................................... 50
CHAPTER 5 – DISCUSSION

5.1. INTRODUCTION .................................................................................. 65
5.2. DESCRIPTION OF THE SAMPLE POPULATION ..................................... 65
  5.3.1. The Role of TB DOT supporters in TB management ......................... 66
  5.3.2. Referral role .................................................................................. 66
  5.3.3. Other activities ............................................................................ 67
  5.3.4. Health promotion and social mobilization ....................................... 67
5.4. THE MOTIVATION FOR DOT SUPPORTERS JOINING THE TB PROGRAMME .................................................................................. 68
  5.4.1. Sense of altruism ......................................................................... 68
  5.4.2. Religious obligation ...................................................................... 68
  5.4.3. Own illness .................................................................................. 69
  5.4.4. Keeping busy ............................................................................ 69
  5.4.5. Passion ....................................................................................... 70
  5.4.6. Positive experience .................................................................... 70
5.5. REPORTED BENEFITS ........................................................................ 71
  5.5.1. Learning new skills ..................................................................... 71
  5.5.2. Future employment ..................................................................... 72
5.6. SUPPORT RECEIVED BY TB DOT SUPPORTERS ................................ 73
  5.6.1. Support from management and clinic staff ..................................... 73
  5.6.2. Support from family members ..................................................... 73
5.7. CHALLENGES FACED BY DOT SUPPORTERS .................................... 74
  5.7.1. Monetary incentives .................................................................... 75
  5.7.2. Contact tracing .......................................................................... 75
  5.7.3. Safety of DOT supporters .......................................................... 76
  5.7.4. Lack of resources ....................................................................... 76
  5.7.5. Emotional and physical stress ..................................................... 77
5.8. CONCLUSION AND SUMMARY ................................................................. 78
5.9. STRENGTH OF THE STUDY ................................................................. 80
5.10. LIMITATIONS OF THE STUDY ............................................................ 80
5.11. RECOMMENDATIONS ........................................................................ 80

REFERENCE LIST .......................................................................................... 82

APPENDIX 1: RESEARCH ETHICS CLEARANCE CERTIFICATE ............................ 92
APPENDIX 2: APPROVAL TO CONDUCT RESEARCH WITHIN THE CITY OF JOHANNESBURG ......... 93
APPENDIX 3: RESEARCH PARTICIPANT CONSENT FORM ..................................... 94
APPENDIX 4: APPLICATION FOR APPROVAL TO CONDUCT RESEARCH ............................. 95
APPENDIX 5: FOCUS GROUP DISCUSSION CONSENT FORM ..................................... 97
APPENDIX 6: RESEARCH PARTICIPANT QUESTIONNAIRE .......................................... 99
# ACRONYMS AND ABBREVIATIONS

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immune-deficiency Syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Anti-retroviral Therapy</td>
</tr>
<tr>
<td>CBO</td>
<td>Community-based Organisation</td>
</tr>
<tr>
<td>CHW</td>
<td>Community Health Worker</td>
</tr>
<tr>
<td>DoH</td>
<td>Department of Health</td>
</tr>
<tr>
<td>DOTS</td>
<td>Directly Observed Treatment Strategy</td>
</tr>
<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
</tr>
<tr>
<td>HBC</td>
<td>Home-based Care</td>
</tr>
<tr>
<td>HCT</td>
<td>HIV Counselling and Testing</td>
</tr>
<tr>
<td>HCW</td>
<td>Healthcare Worker</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immune Deficiency Virus</td>
</tr>
<tr>
<td>IUAT</td>
<td>International Union against Tuberculosis</td>
</tr>
<tr>
<td>MDG</td>
<td>Millennium Development Goal</td>
</tr>
<tr>
<td>MDR-TB</td>
<td>Multidrug-resistant Tuberculosis</td>
</tr>
<tr>
<td>MTB</td>
<td><em>Mycobacterium</em> Tuberculosis</td>
</tr>
<tr>
<td>NDoH</td>
<td>National Department of Health</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-governmental Organisation</td>
</tr>
<tr>
<td>PCF</td>
<td>Passive Case Finding</td>
</tr>
<tr>
<td>PHC</td>
<td>Primary Health Care</td>
</tr>
<tr>
<td>SASSA</td>
<td>South African Social Security Agency</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>XDR-TB</td>
<td>Extreme Drug-resistant Tuberculosis</td>
</tr>
</tbody>
</table>
1.1. Background

The World Health Organisation 2004 (WHO) states that HIV drives the TB epidemic in populations where there is an overlap between those infected with HIV and those infected with TB. The intense transmission of mycobacterium TB increases the size of the group of HIV-infected people who are exposed to and subsequently infected with it. According to the World Health Organization (2013) the recorded incidence of TB globally was about 8.6 million in 2013, while the death rate was recorded to be 940 000 during the same period.

1.1.1 The burden of TB in South Africa

South Africa is facing a serious dual epidemic of HIV and TB. The country continues to be home to the world’s largest number of people living with HIV. It is estimated that 6.4 million South African were living with HIV in 2012. The country also ranks third amongst countries with the highest burden of TB in the world, after India and China (WHO, 2012). The levels of co-infection remain alarmingly high, with as many as 60% of patients having TB/HIV infection, and there is also an increasing incidence of MDR and XDR TB. (South African National Aids Council, 2014 and Statistics South Africa, 2013). One of the greatest challenges to South African health has been the burden of communicable diseases, particularly the concurrent HIV and TB epidemics (Abdool-Karim et al., 2009). While having only 0.7% of the world’s population, South Africa carries approximately 17% of the global burden of HIV/AIDS, and has “one of the world’s worst TB epidemics, compounded by rising drug resistance and TB/HIV co-infection” (Abdool-Karim et al., 2009).

It is estimated that in 2011 the prevalence of HIV/AIDS was 10.6%, representing just over 5.36 million people living with the disease, while the prevalence rate of TB stretched to 795 per 100 000 people, a rate that has increased over the past decade, according to Health Systems Trust, 2012). With the development of drug resistant strains of TB it has become increasingly evident that the South African health system cannot cope with high volumes of people who are infected (Abdool-Karim et al., 2009). Abdool-Karim et al. (2009) further argues that efforts to combat the HIV/AIDS and TB epidemics have been hampered by failures in the implementation of policies and an inability to successfully integrate HIV/AIDS
and TB services with each other and with the wider primary health care system, and furthermore, the progression of the disease has created a need for increasingly complex and more expensive interventions, which are persistently inaccessible to those who require them the most.

1.1.2. Multi drug resistant (MDR) TB in South Africa
MDR is the name given to TB when the bacteria that are causing it are resistant to at least isoniazid and rifampicin, the most effective TB drugs to cure TB disease. In 2010, WHO estimated that there were 290,000 cases of MDR-TB globally among those cases of pulmonary TB that were reported cases (WHO, 2013) Furthermore Fourie (2011) states that a serious contributor to the burden of TB in South Africa is the emergence of MDR strains of the mycobacterium tuberculosis bacilli, the organism which causes TB when resistance to TB drugs is present. Patients with MDR TB are highly infectious, and staff working in close proximity with them when providing nursing care are at risk of contracting this drug-resistant disease. Cases of MDR TB amongst nurses have been reported in KwaZulu-Natal (KZN) province. Fourier (2011) estimated the cost of MDR TB treatment was 100 times the cost of treating TB. It is therefore more expensive to treat MDRTB patients than ordinary pulmonary tuberculosis

1.1.3. TB mortalities
The mortality rate of TB remains alarmingly high, and it has been reported that TB accounts for most deaths from infectious disease worldwide, after HIV/AIDS, with estimates reaching 1.2-1.5 million deaths in 2010. Although incidence rates of TB have declined marginally at a rate of almost 1% per year since 2002, the total burden increased worldwide (Lawn and Zumla, 2011; WHO, 2011). There continues to be a cloud of vagueness surrounding estimates of TB prevalence and incidence due to poor investigation systems, which fail to capture all TB cases (WHO, 2011).

The majority of TB patients do not seek treatment early, some of these cases are not diagnosed, and in some instances their TB diagnosis goes unreported to the appropriate facilities, which is why such estimates may be even greater than reflected in most published reports (WHO, 2011). Nevertheless, the present estimates of TB incidence, and which
include that its prevalence is marginally declining by 1% per year, have suggested that the target of halving TB prevalence by 2015 and eliminating TB as a public health crisis by 2050 will not be met (Lawn and Zumla 2011; WHO 2011) In studies conducted in Johannesburg Academic Hospital by Wong et al., (2012), it was shown that the large majority of deaths (64%) amongst the 39 HIV-positive adult participants in her study were caused by TB. This finding was confirmed by post mortem investigation. According to Statistics South Africa, (2013) there were 62 827 deaths in 2010, with TB as the primary natural cause of death (11.6% of all deaths), growing to 69 791 (12.0%) in 2009 and 75 281 (12.6%) in 2008 (Statistics South Africa, 2013). Data from the National TB Programme reveals that 33 300 of all TB cases died in 2012 (including HIV-positive TB patients) (NDoH, 2013).

1.1.4 TB chemotherapy
The medication to treat and cure TB has existed for the last 50 years, but significant challenges remain for TB prevention and control. It is estimated that in every 15 seconds someone in the world dies from TB, and infections that remain untreated have the potential to induce 10 –15 other infections annually (Dye, 2004). To meet the challenges of TB, the WHO declared TB to be a public health crisis in 1993 (WHO, 2009). TB is the only disease to get that description since the WHO’s establishment in 1948. Furthermore, evidence has shown that timely chemotherapy has the capacity to produce economic benefits which can amount to ten times the investment (Lonnroth et al., 2010)

1.1.5. The DOTS
The DOTS strategy has been recommended as the key for TB control. Raider et al., (2009) explains that efforts to control TB have been continuing for centuries. However, realizing global TB control remains a difficult task. In 1993, WHO declared TB a global emergence and provided a five-point framework for the control of TB, which included (1) political commitment, (2) diagnosing TB using sputum smear microscopy, (3) the use of short-course chemotherapy under direct observation, (4) the regular supply of drugs and (5) a standardized recording and reporting system. By the mid 1990s most countries had adopted this approach (World Health Organisation and Stop TB Partnership, 2006).
The WHO (1991) stipulates that the DOTS targets, among other things, treatment compliance to TB medication, as this has been recognized as an effective means of controlling the global problem of TB. During the initial phase of DOTS therapy, patients take their medication daily under the direct observation of the healthcare worker or the nominated person. Completion of the TB medication is vital to curing TB. The DOTS can be used for the treatment of new TB cases, people who have relapsed, people who in the past have received treatment but failed to complete it, and those who need retreatment (Walley, 2001). Published reports show that HIV and Multiple Drug Resistant (MDR) TB or extensively drug-resistant (XDR) TB undermines the DOTS strategy, which in this situation is insufficient to control TB (De Cock and Chaisson, 1999; Harries et al., 2002). Currently, the recommended strategy for TB care is the Stop TB Strategy, which highlights the improvement of the quality of DOTS, addresses HIV and MDR-TB, strengthens health systems, engages all health care providers, empowers people with TB through engagement with communities, civil society organisations and care providers, and promotes research (WHO, 2010).

1.2. Problem statement
In South Africa, patients in informal settlements are often faced with poor and costly access to primary health services. Some studies (Pillay, 2009; Tlebere et al., 2007) conducted in South Africa concerning the accessibility and cost of health services point out that transport, the distance to services and the money needed for travel to services are the major problems. It is in this regard that DOT supporters have been incorporated into TB control programmes, to facilitate community involvement and participation in identifying health threats, vulnerable groups and individuals, and appropriate interventions for addressing these (Department of Health, 2010)

However, there are numerous challenges which TB DOT supporters are faced with in their daily activities as they manage TB patients in the informal settlements. Previous findings show limited information regarding experiences of DOT supporters in informal settlements and the challenges they face as they render their services. (Akintola, 2008 and Akintola 2010).
1.3. **Aim of the study**

To explore TB DOT supporters’ experiences in managing TB patients in the informal settlements of Orange farm

1.4. **Study objectives**

The objectives of this study are as follows:

- To explore DOT supporters’ experiences in managing TB patients in the informal settlements of Orange Farm
- To determine the challenges faced by DOT supporters in managing TB patients in the informal settlements of Orange Farm
- To investigate DOT supporters’ motivation for rendering TB services in the informal settlements of Orange Farm

1.5. **Research questions**

The following research questions were addressed in this report:

- What are the DOT supporter’s experiences in managing TB patients in the informal settlements of Orange Farm?
- What are the challenges faced by the TB DOT supporters in managing TB patients in the informal settlements of Orange Farm?
- What is the motivation of TB DOT supporters for rendering TB services in the informal settlements of Orange Farm?

1.6. **Significance of this Study**

In view of the important role DOTS play in efforts to control TB at community level, their poor working conditions, particularly in informal settlements, could impact negatively on TB DOTS supporters’ contribution towards TB control programmes. Not only will this study add to existing knowledge on TB DOT supporters work, but it could also potentially benefit both the Government and non-governmental sectors with policy-making and decision-making guidelines regarding the DOTS strategy.
1.7. Definition of terms

**Community Health Worker**: An adult person from the community who has been trained to function in the community as a health worker in close relation with the public.

**DOTS**: An acronym used for the WHO-initiated Directly Observed Treatment Short Course Strategy, which is a TB control strategy in which patients are physically observed by another person to ensure that the patients receive and ingest TB treatment drugs, and to ensure compliance with the treatment until the patient completes the six-month treatment programme.

**DOTS support**: Trained DOTS supporters conduct door-to-door visits to directly observe TB patients taking their medication against TB correctly and consistently. A DOTS supporter can be any responsible adult who is trained in the DOTS strategy. They can be recruited from the community, the family member of a TB patient, the workplace or a health facility. A trust relationship between the DOTS supporter and the TB patient improves compliance with treatment.

**Drug-resistance in TB**: Drug resistance is caused by a genetic mutation that makes a drug ineffective against the mutant *bacilli*. An inadequate or poorly administered treatment regimen allows a drug-resistant TB strain to become the dominant strain in a patient infected with TB (WHO, 2009).

**Observation**: Direct observation of a TB patient and/or research observations are made during fieldwork.

**Sputum smear microscopy**: Sputum smear microscopy is the main and often the only laboratory technique used for the diagnosis of tuberculosis. It is highly specific and capable of identifying the most infectious cases of TB (TB guideline, 2009).

**Sputum smear-positive patients**: Those patients who are the most potent sources of transmission of TB *bacilli* in the community due to the presence of the *Mycobacterium* TB in their sputum. This is detected by examining the patient’s sputum, having stained it in application of the Ziehl- Nielsen method (TB Guideline, 2009).

1.8. Conclusion

In this chapter the global burden of TB was elucidated, followed by an emphasis on the burden of TB in Sub-Saharan Africa and in South Africa. DOTS supporters, who are at the coalface of TB support services, can mobilize and raise awareness in the community and ensure that patients access health services and comply with TB treatment.
CHAPTER 2 LITERATURE

2.1. Introduction

This chapter reviews the literature on the experiences of TB DOT supporters managing TB patients, and it also explores the daily challenges faced by TB DOT supporters while managing TB patients in informal settlements. This will entail considering the following issues: the importance of community participation, the policy governing community health care workers, their positive experiences including their roles and motivation in TB control, and their challenges in informal settlements.

2.1.1. The National Tuberculosis Programme in South Africa

The National TB Control Programme (NTCP) is the South African plan for TB control, and was revised in 1995 based on the WHO's DOTS strategy. The DOTS strategy was first adopted in the 1960s in certain areas of India and in Hong Kong, and since then has been widely implemented in most countries with national tuberculosis treatment programmes (Volmink and Garner, 2007). According to the South African Department of Health (2004), the DOTS strategy necessitates:

- sustained government commitment to prioritizing TB control
- the diagnosis of TB through sputum microscopy
- standardized and supervised treatment in a supportive environment
- an uninterrupted drug supply, and
- regular monitoring

This programme replaced the non-standardized short-course chemotherapy, which had been available for several years. Since then, recommendations by the WHO's Stop TB Campaign and the Global Plan to Stop TB have modernized TB control within South Africa through introducing new and improved TB drugs (with shorter periods of treatment), using superior TB diagnostic tools and improved TB registration mechanisms, and setting clear performance targets.

The recommended treatment regimen for newly diagnosed, drug-susceptible TB consists of a 2-month intensive phase of isoniazid, rifampicin, and pyrazinamide and, optionally,
ethambutol, followed by a 4-month continuation phase of isoniazid and rifampicin. The goal of the National Strategic Plan (NSP) for 2012 - 2016 is reducing new HIV infections by at least 50% using combination prevention approaches. This involves the initiation of at least 80% of eligible patients on antiretroviral treatment (ART), which will prolong the lives of 70% of patients five years post-initiation. This will also reduce the number of new TB infections and deaths from TB by 50%. Thus, this strategy will ensure an enabling and accessible legal framework that protects and promotes human rights in order to support the implementation of the NSP and reduce self-reported stigma related to HIV and TB by at least 50% (Van den Boogaard et al., 2011).

2.1.2. Arguments why the DOTS strategy is not effective

According to WHO (2009 and 2011) the DOTS programme is intended to ensure both treatment completion and the cure of TB, and its effectiveness is recommended by the World Health Organization and the Stop TB Strategy. Despite the effort to improve DOTS coverage and improve treatment outcomes, the incidence of MDR-TB suggests issues of noncompliance as an ongoing concern regarding the implementation and practice of the DOTS programme in the community (Malmborg, et al., 2006; He, et al., 2011; Parsons, et al., 2011).

Factors contributing to the limitation of access to effective TB prevention and control services include the inadequate coverage of routine immunization with the BCG vaccine and isoniazid prophylaxis, and the limited numbers of available diagnostic and treatment centres (Atun et al., 2010). The lack of adherence or defaulting from treatment remains a challenge in some countries due to the cost of treatment, lack of access, lack of continuity of treatment after discharge from a health facility, and lack of information on the importance of adherence (WHO, 2012).

This problem is prevalent among vulnerable groups such as poor people, displaced populations, refugees, and people in areas of civil conflict. However, there are also a number of claims that the DOTS strategy is no more beneficial than self-supervised treatment. Critics who make this claim also assert that directly observing treatment can actually promote non-adherent behaviour by reverting to the former view of patients as passive recipients of treatment (Volmink and Garner, 2007).
These authors also note that the disadvantages associated with DOTS are that it moves away from adherence models of communication and cooperation between patient and provider and may make adherence worse if it is rigidly applied in an authoritarian setting, or where people are expected to travel considerable distances to have their treatment supervised. Furthermore, where caseloads are particularly high, the resources required to sustain the DOTS strategy as a national TB treatment programme are substantial (Volmink and Garner, 2007).

2.1.3. The state of health in rural and informal settlements

Studies conducted in high burden countries such as Thailand, Kenya and South Africa reveal that patients with the greatest health needs tend to live in remote rural areas (Blaauw et al., 2010). Health facilities in remote rural areas experience difficulties in attracting and retaining skilled health care workers and nurses. Therefore a lack of trained community health care workers leads to strain among nurses, and it is important that such personnel be available to strengthen the primary health care system (Blaauw et al., 2010).

In South African peri-urban informal settlements such as that of Orange Farm, a four to five digit property number, followed by the community name/identification number, marks dwellings used for accommodation. Thus, even an error such as a digit address error could have major implications for locating a household awaiting a TB follow-up visit. Not all informal settlements have been surveyed and many do not have allocated property numbers. In urban South African settings, on the other hand, three to six one-roomed backyard temporary shelters known as ‘shacks’ are constructed in close proximity to one another due to the shortage of expensive vacant land. Access is difficult in such congested environments.

An accurate address is required to trace TB patients who default treatment. Any intervention that could assist in locating patients and contacting persons in such settings is urgently needed. TB patients presenting late at the clinic, a high treatment default rate due to a lack of transport, and poor access to Primary Health Care (PHC) facilities are common in
Orange Farm. Patients in some communities in this informal settlement have to travel more than 80km to access TB service.

2.1.4. Community participation in TB health care

Several studies have addressed the aspect of community participation and explain that most countries in sub-Saharan Africa, including South Africa, are currently exploring ways to revitalize the Alma Ata PHC concept (WHO, 1978) with a focus on community participation and the integration of community care workers (CHWs) into health systems. Besides the potential benefits for increased access to care, there is growing evidence supporting the success of the involvement of CHWs as a strategy to address critical health workforce shortages. Zachariah et al. (2009) suggest that community health care workers are important as they have the potential to expand PHC beyond health facilities and address the crisis in the availability of human resources for health care (HRH) which exists in most settings where CHWs are under-utilized. Therefore, it is crucial to identify ways to maximize the involvement of CHWs in the implementation of collaborative TB/HIV/PMTCT services and the PHC system as whole.

2.1.5. The importance of Community Health Care Workers

In South Africa, community members such as CHWs, traditional healers and other groups have been involved in HIV prevention and care, advocacy, support and counselling in efforts to address high HIV-infection rates and to mitigate the impact of HIV (Friedman et al., 2007; Schneider et al., 2008). Community based organization (CBOs) introduce a particular advantage in the fight against TB, as they understand the local language as well as the culture of the communities.

Therefore, they serve as the link between non-governmental organisations (NGOs) and the recipients of the interventions in the communities. Members of the community trust community health care workers, as they have indigenous knowledge and are acquainted with the communities. This makes it easier for the NGOs to gain entry into the communities and to establish rapport with the community leaders. CHWs share the Afrocentric worldview with the members of the community, and this makes the implementation of
intervention easier. Most of this TB DOT Supporters are being recruited from local community based organization and affiliated home based care organization and sometimes this organizations not funded by government whereas others are being funded by the Department of Health. There are numerous challenges with the implementation of community based intervention. One of these is that there are many cadres of CHWs, home based carers (HBCs) and TB treatment supporters, and most of them have been trained in a single disease or a particular programme, and this has created conflicts among CHWs and discomfort to household members who are visited by more than one CHW (Clarke et al., 2008; Uwimana et al., 2010).

2.1.6. Policy governing Community Health Care Workers

Van Dyk (2007) finds that caregivers tend to feel unsupported by the government, and the health, social, and legal systems, which leads to a sense of frustration. The South African Government’s inability to provide adequate AIDS services creates a huge care gap in the pandemic (Akintola, 2010). According to Van Dyk (2007), many caregivers and health workers express frustration with government processes. Dageid et al. (2007) also indicate that CHWs have reported a lack of government support, and that they felt that they were not consulted when policies were planned and imposed on them by the DOH and Department of Education (DOE). In another study, the CHWs felt that neither their role nor their status is respected by the formal health services (Uys, 2002).

2.1.7. Community Health Care Workers’ involvement in TB management

In South Africa, community members such as CHWs, traditional healers and other groups have been involved in HIV prevention and care, advocacy, support and counselling in efforts to address the prevailing high HIV-infection rates and to mitigate the impact of HIV (Friedman et al., 2007; Schneider et al., 2008). Community based organization (CBOs) have a particular advantage in their fight against TB, as they understand the local language as well as the culture of the communities.
Therefore, they serve as the link between the non-governmental organisations (NGOs) and the recipients of the interventions in the communities. Members of the community trust Community health care workers, as they have indigenous knowledge and are acquainted with the communities. This makes it easier for the NGOs to gain entry into the communities and to establish rapport with the community leaders. CHWs share the Afrocentric worldview with the members of the community, and this makes the implementation of their intervention easier.

2.2. The role of DOT supporters in TB management

DOT supporters’ role and their responsibilities include the collection of tablets on a monthly or weekly basis, and their safe storage. They also directly observe the intake of the tablets and drugs (in the right number and dosage), record the daily intake of medication in the treatment supporter card, and encourage the patients to attend the health centre and hospital/clinic for follow up as required. They also identify possible side effects and refer patients to the health care facility if necessary. They help the patients to overcome treatment difficulties and continue the treatment, identify patients who do not arrive for support, and help to trace and retrieve them (Friedman et al., 2007; Schneider et al., 2008).

The National Tuberculosis Management Guidelines (2009) state that DOTS should follow up and take a record of defaulters, communicate and give feedback to the clinic, remind clients about the sputa that are due during the course of treatment, and keep records at the clinic indicating the location of treatment supporters and the clients allocated to them.

Their activities include taking care of patients’ personal hygiene like bathing them, feeding the patients and assisting them by taking helpless patients to toilet and making them comfortable; helping with the household chores like cleaning, washing, cooking and fetching firewood, and performing nursing care like dressing wounds, changing soiled linen, directly observing those patients that are on TB treatment, and counselling patients to enable them to cope better (Akintola, 2004; Pindani, 2008; McInerney and Brysiewicz, 2009; Mieh, 2010; Moetlo, Pengpid and Peltzer, 2011).
2.3. Health promotion and social mobilization

The most important delivery aspect of TB improvement is to strengthen community participation through TB DOT supporters, who play an important role in patient treatment, and adherence support. They play a significant role in case detection and treatment, as they are familiar with the layout of the community and have the trust of the members of the community. Moreover, a community-based approach helps empower each community to deal with its own problems and also provides patient with a greater degree of autonomy and satisfaction with the treatment regime (WHO, 2009). They stimulate people to talk to one another about TB issues. This happens through community-based dialogues, debates and support groups. They motivate one another during community dialogues, and this helps to strengthen behaviour-change strategies. They are able to answer patients during their conversations, unlike the social media system, where questions cannot be answered. In actual fact DOT supporters help bridge the gap between the health system and the community through support and coordination. They can mobilize the community at events that engage community leaders, which mobilisation is also one of the enabling tools for successful community-based programs in TB/HIV/PMTCT care (WHO, 2009).

2.4. Referral of TB patients

DOT supporters have been recognized as important pillars in healthcare, as they help to increase the accessibility and acceptability of health services (Munro et al., 2007). They coordinate up referrals and down referrals, making sure that the TB patients reach the correct destinations. They do give patients referral form. A study performed in Vhembe District, Limpopo Province, South Africa, found that the absence of a proper referral system is a wide problem in South Africa which should be urgently addressed in the effort to strengthen the health system (Moetlo et al., 2011).

They can only fulfil their role of linking clients with formal health care if they are well integrated into and accepted by a country’s health care system (Devi, 2008). For these linkages to be effective and successful, the relationship between CHWs and providers in the health system should be characterized by mutual respect and understanding (Celletti, 2010).
Several studies examined the effect that CHWs have on the uptake of HIV services, although this is often reported as “coverage” of services without objective measurements of coverage. CHWs in South Africa and Zambia actively mobilize and refer patients to HIV services including voluntary counselling and testing, ART initiation, the prevention of mother-to-child transmission (PMTCT) and the treatment of opportunistic and sexually transmitted infections (Uys, 2002), often leading to an increase in the uptake of these services (Zachariah, 2006).

2.5. Other DOT supporters’ activities

They provide TB services during the intensive and continuation phase of TB treatment and also provide care to terminally ill TB patients. Amongst other diverse duties, DOT supporters help to arrange TB patients’ funerals and coordinate support for the burial, especially for those who are staying alone without families; and they do these extra activities without even considering monetary incentives (Schwartz and Girdon, 2004). They play a central role when their patients die. As a result of the high costs of burials, volunteers try to ensure that their patients are admitted into the hospitals before they die so as to make certain that they will be given paupers’ burials. Quite a number of their patients live alone, without any family member.

They therefore try to locate family members before or after the death of the patients, and when they fail they assist in burying the patients (Schwartz and Girdon, 2004). DOT supporters also train family members to become primary caregivers, and they refer serious cases to a clinic or hospital. In a study by Root and Whiteside (2013) on the role of community care givers and antiretroviral compliance in Swaziland, 92 per cent of the participants indicated that since a TB DOT supporters started visiting them at home their health improved dramatically. Such improvements are attributable to the fact that TB DOT supporters stay close to their patients and are able to disseminate information easily.
2.6. The motivation of TB DOT supporters in rendering TB services

The following motivating factors for TB DOT supporters will be discussed: their religious affiliation, their altruism, their own illness, their history of family illness, keeping busy, improvements in their patients’ condition, and their positive experience with DOTS.

2.6.1. Religious affiliation

Faith based organizations (FBOs) often reach remote communities, as well as being prominent in large urban centres, and are uniquely placed to provide a range of quality HIV-related services (from the training of home-based caregivers to the provision of antiretroviral therapy) to those in need. The Catholic Church has been playing a coordination role in response to AIDS in South Africa through the Southern African Catholic Bishops Conference (SACBC) (Munro, 2005). The SACBC aims at complementing government programmes by providing antiretroviral therapy in areas where government-funded antiretroviral therapy is not available, notably in resource-poor communities (UNAIDS, 2006). As a result, the majority of faith-based initiatives have been on the front line of the war against the epidemic since the beginning. The literature suggests that the majority of carers are affiliated to church organization and caring for TB patients as a form of showing a humanitarian concern due to their feeling a religious obligation. Their affiliation to their church was helping DOT supporters to cope with workplace stressors (Russel and Schneider, 2000).

2.6.2. Sense of altruism

Living in communities means that members sometimes put the interests of others first. Acceptance within any group depends upon individuals acting according to their obligations towards the group. Such a duty to fulfil one’s obligations to the community as a whole may clash with an individual’s hopes, desires or even welfare. Yet this altruism has evolved within human societies throughout history into satisfying the need to protect the weak and to sacrifice oneself on their behalf (Mhkize, 2004). According to Akintola (2008) the common altruistic behaviour observed was based on the need that has arisen as a result of the impact of HIV/AIDS on families, households and communities, HIV/AIDS has infected
many people in the communities, and that those who fall sick sometimes do not have people to care for them and therefore need assistance, which need is difficult to ignore.

The Afrocentric worldview is categorized by a number of different philosophical assumptions and principles, which are reflected in the values, traditions, and customs of people of African origin. The Afrocentric worldview centres upon the belief that interdependence, cooperation, and collective responsibility are key values which people should strive to achieve (Mkhize 2004). The assumption is that everything in the universe is interdependent and inter-related, and that individuals cannot exist alone. Self-knowledge forms the basis of all knowledge in the Afrocentric paradigm, followed by external, segmented knowledge obtained from other disciplines (Mkhize, 2004). His Holiness the Dalai Lama (2014) has said that much illness can be cured by the one medicine of love and compassion. These qualities are the ultimate source of human happiness, and the need for them lies at the very core of our being. Unfortunately, love and compassion have been omitted from too many spheres of social interaction for too long. TB supporters are usually confined to their families and homes. Their practice in public life is considered impractical, even naïve, The Dalai Lama further explains that the practice of compassion is not just a symptom of unrealistic idealism but the most effective way to pursue the best interest of others as well as our own. The more the nation, groups or individuals depend upon others, the more it is in our own best interests to ensure their well-being.

2.6.3. Unemployment and keeping busy

Being a voluntary community health care worker offers a person a chance to try out a new career without making a long-term commitment. It is also a great way to gain experience in a new field. For example, the majority of DOT supporters give their services with the aim of climbing a ladder of new opportunities in health and social development. The literature documents that some DOT supporters join the programme because they are unemployed and want to keep busy.

Given the context of high unemployment occasioned primarily by a lack of skills (Statistics SA, 2009), it seems reasonable that unemployed individuals view volunteering as a way of fulfilling their dreams of getting skills training, thereby improving their opportunities in the
labour market. In Akintola’s (2008) qualitative focus group discussions with community health care workers in KwaZulu-Natal, participants in the study mentioned that they were volunteering to avoid idleness due to their being unemployed. Similarly Rödlach’s (2009) participants acknowledged the importance of having a wide social network, and said that they stayed committed to caregiving in anticipation of receiving benefits later. The small remuneration that these volunteer caregivers received for their services contributed to the well-being of their families, and they anticipated that their caregiving services would lead to full-time employment as a caregiver.

2.6.4. Giving back

Antikola (2004) explains that TB patients are sometimes abandoned by family members and government, and that there is a general sense that people who need care are not being given the care they require; hence the need for people who volunteer to care. A sense of community exists amongst those who volunteer. They see themselves as being their “brother’s keeper” (Antikola, 2004).

The literature shows that some DOT supporters and carers are motivated by the personal experience of being TB patients or by a history of family members dying from TB. Previous and current literature has documented that caregivers were HIV positive themselves, and were concerned about their future and what would happen to themselves and their children when they developed clinical AIDS. Volunteering provided them with access to information about care and support, and they were also able to access treatment for opportunistic infections (Schwartz 2004; Rödlach, 2009 and Antikola, 2010).

2.6.5. Passion for work

In his study Rodlach (2009) pointed out that DOT supporters have a sense of caring and concern for their patients and say that they care about the TB patients and are concerned about their condition. They want to ensure that their patients finish their treatment without interruption. They care for their patients in the hope that in future someone will show compassion to them when the need arises.
According to the Carers’ Manual (2014), DOT supporters should show compassion and have a passion for their work, as they are aware that their patients may be going through anger and an inability to accept their condition. They should have listening skills and should give family members privacy to be with their loved ones. The manual further explains that carers should be prepared to go the extra mile in ensuring that TB patients complete their medication, and states that it is this passion for their work which sustains them, as they are determined to see their patients returning to health.

2.7. Reported benefits

The following benefits will be discussed: intrinsic rewards, extrinsic rewards, on–the-job training, training and support.

2.7.1. Intrinsic rewards

Schwartz and Gidron (2002) note that caregiving can be a rewarding experience, giving meaning and heightening the caregiver’s sense of self-worth. Volunteer caregivers therefore play a major role in the provision of informal care and are the only source of support for many affected families, but many of them do not receive any pecuniary reward (Akintola, 2008). Although faith-based organizations constitute a large proportion of care organizations in South Africa, estimates of their proportion or the extent of their involvement in home-based care are unavailable. Volunteerism enables carers to achieve self-growth and personal emotional and psychological development as a result of direct engagement with terminally ill people with AIDS/TB, who have diverse care needs and are extremely demanding. These experiences lead to the discovery or development of “the self”, and as such DOT supporters view these internal rewards as virtues learnt while caring.

These beliefs were captured in statements made by Akintola’s participants such as: "volunteering has made me a better person"; and "my life is better now than before". Love and patience were the main virtues that these DOT supporters learnt during their interaction with terminally ill TB patients (Aitken and Akintola, 2008). Research among volunteers working in AIDS service organizations in Ontario, Canada, reveals that the
volunteers experience intrinsic rewards such as improved self-esteem and health, and self-actualization, as well as extrinsic rewards, such as recognition, constructive feedback and participation in decision making (Blinkhoff, 2006).

2.7.2. Extrinsic rewards

Akintola (2008) believes that one of the most significant rewards for volunteering is the gratitude shown by patients and their family members, as well as the recognition shown by community members and the care organization. Appreciation and recognition are very important for DOT supporters as they feel accepted and they view their role as being as important as that of nurses. They view being allowed access to patients as a form of reward, as this shows the trust and confidence that the health care system has about their performance of their duties. Another source of extrinsic reward is the pleasure that TB DOT supporters derive from making their patients and their family members happier. Their presence in the communities improves patients' access to care, thereby making their patients and family members happy. In this case, TB DOT supporter's satisfactions are inextricably linked to the happiness felt by the people that they serve (Akintola and Aiken, 2008).

2.8. Family support

HIV/AIDS and TB coincide, and caregiving therefore coincides with caring as a result the TB DOT supporters are poor and do not have the requisite skills, financial and material resources to provide home care and therefore find caring overwhelming. Home-based care programmes have therefore been set up across the country to assist families in caring for the ill. However, these care programmes receive very limited support from the government (Steinberg et al., 2002) and this, combined with the reluctance of donor agencies to fund caregiver salaries (Akintola 2004), leaves care organizations with little option but to rely mainly on volunteers to provide care (UNAIDS 2000; Akintola, 2004).

Volunteers constitute a substantial proportion of caregivers and people living with HIV. In a national study it was found that 50% of HIV/AIDS-affected households made use of
volunteers (Steinberg et al., 2002). Although a few studies in South Africa have documented the burden associated with volunteering (UNAIDS 2000; Marincowitz et al., 2004, Akintola 2006), little is known about the stress and coping process among volunteers. The support of family and community members is extremely important during the intensive phase of treatment because this to a large extent compensated for the inevitable loss of income arising from the patient’s illness. Even though TB causes fear and stigmatization, people are inclined to share resources in a time of crisis, and reciprocal arrangements have been found to provide most TB patients with some food. According to Streeter and Franklin, (1992) in Held and Brann (2007), “social support is considered to be anything from informal conversations to formal meetings”.

Studies suggest that social support helps people maintain their health (Hudson et al, 2001 in Held and Brann, 2007) and support is the strongest variable that influences the efficacy and performance of volunteers working with people affected by HIV/AIDS (Maslanka, 1996 in Held and Brann, 2007). In another study it was noted that social support from co-workers is as important as receiving support from supervisors (LaRocco et al., 1990, in Maslanka, 1996). In a study conducted in 1996 Maslanka found that staff support plays a more important role than the other variables in his study.

2.9. Challenges faced by TB DOT supporters

2.9.1. Delay in payment of TB supporters

Kangethe (2009) has detailed that the majority caregivers are poor and have no source of revenue, and attributed their poverty and the low quality of their care-giving to their lack of an income-generating activity or any other form of employment. Caregivers need monetary support. The income they obtain is low compared to their rising costs; thus they want to be provided with sound payment so that their financial problems can be lessened. This is also emphasized by Health and Development Networks (HDN) and Southern Africa HIV and AIDS Information and Dissemination Source (SAFAIDS), (2008), who point out that most of the caregivers are poor and that Government and the NGOs do not provide sufficient income, allowances or remuneration to compensate them adequately. Caregivers want their
employers to consider care-giving as an emotionally demanding activity that should attract some form of incentive.

According to the CCW Policy Framework, the remunerative structure for the national CHW programme entails the provision of financial support to qualifying NPOs to employ CHWs, who would receive stipends of R2260 per month for working for a minimum of 40 hours per week. The implementation of this policy has, however, been challenging, as studies have revealed that due to inadequate funds the health (and social development) sector still relies heavily on employing many unpaid CHWs (Lehmann and Matwa, 2008; HPCASA, 2009; Friedman et al., 2010). This has not only created tension between CHWs who are receiving stipends and those who are not, but has also resulted in some CHWs being less motivated about the work they do (Lehmann and Matwa, 2008). Some of the CHWs who are on stipends feel that the amount is inadequate, and the fact that the stipends are not paid regularly, due to late processing, have worsened the situation (Friedman et al., 2010).

In view of the deployment of CHWs for the PHC outreach initiative, it is imperative that the DOH (and DSD) put in place a proper remunerative system for the national CHW programme, as the current structure is not efficient. The majority of the volunteers are unemployed and not remunerated, yet they use their own meagre resources to help their patients (Blinkhoff et al., 2001; Akintola, 2008), as also presented in several studies conducted on home-based care (Sobuce 2007; Pindani 2008; Akintola, 2010; Mieh, 2010; Mabusela, 2011).

A possible solution to maintaining this support is to provide incentives. Maintaining the support is important, as it has been shown to improve compliance rates in numerous studies (Davidson et al., 2000; Volmink and Garner, 2004; Jakubowiak et al., 2007). Increasing the stipend is controversial, though, as the concept of volunteerism is associated with self-sacrifice. On the other hand, it is very doubtful whether one can expect people living in poverty to dedicate their energies towards assisting the health services to achieve its statutory objectives without any compensation (Dick et al., 2005). Further, studies in Southern Africa have shown that caregiving can create major time burdens for caregivers,
exacerbating poverty among previously poor caregivers (Lindsey et al., 2003, Akintola, 2004).

2.9.2. Impoverished TB client

TB has a significant economic impact on patients and their families through their spending on the diagnosis and treatment, transport to get to healthcare facilities, and the time lost from work (WHO 2006). Households incur much higher direct costs for TB (and HIV/AIDS) treatment than for any other disease (Russell 2004). The direct costs are (1) the household expenses related to seeking treatment, which include non-medical expenses such as transport or special foods, whilst (2) indirect costs are the loss of household productive labour time for patients and healthcare givers (Russell, 2004).

Moetlo et al. (2011) found that patients are not taking their medication as prescribed, probably because of their poverty and hunger. Sobuce (2007) agrees that poverty and hunger are major problems for chronically ill patients, and he reports that these patients do not have the money to pay the doctor for a consultation or for travel fare to the clinic and government offices. Some patients stay alone and there is no one to prepare food for them. They cannot do it themselves, as they are too weak.

Furthermore, the TB burden on households may impose cost burdens of 8 - 20 per cent of a family’s annual income in already impoverished settings. Again, if productive youths and adults contract TB, their productivity is lowered, which may lead to an increase in poverty in their families and their communities. This is because these individuals will be cared for by their families, and some will depend on the government for grants. When a large number of people are not employed and depend on the government for grants, it means less people are paying taxes. The financial burden is thus carried by only a few, which has a negative influence on the social and economic development of the country (Russell, 2004).

According to Singh et al. (2007), ten million South Africans, that is, one in four citizens are benefiting from government social welfare grants. Furthermore, approximately 27% of South Africans are unemployed, and consequently social grants often constitute the primary income of many households. It is been noted, though, that some patients do not have identification and birth certificates, and therefore are unable to access social grants. This is not a good picture as the burden of TB can be catastrophic on the economy of the country,
and this is worse in an informal settlement where the majority of population may be foreign nationals from Lesotho, Mozambique and Malawi, making it very difficult for them to access these services. Laxminarayan et al. (2007) state that lifting the TB disease burden is one of the UN’s Millennium Development Goals. The main aim is to reverse the incidence of TB by the year 2015. The STOP TB partnership goes further and aims to halve TB morbidity and mortality rates by 2015.

### 2.9.3. Walking long distances and long hours

The extreme number of days per week that unpaid workers or partially paid CHWs are often expected to work has blurred the boundaries of “voluntarism” and has sometimes over-extended the resources of very poor people. Sobuce (2007) and Moetlo et al. (2011) agree that there is a need that CHW supporter to be provided with transport to visit their distant patients and to go to government institutions on behalf of their patients. Conversely, a study conducted in Senegal found that DOTS delivered by a family member produced greater cure rates and lower defaulter rates than that implemented by nurses and CHWs (Frieden and Sbarbaro, 2007). DOT supporters are meant to observe their patients as they swallow their drugs daily. With these distances it becomes impossible to do that, because sometimes when they arrive at their clients’ homes the clients have not eaten yet, so they have to wait to observe the client swallowing the tablets.

CHWs work long hours and travel long distances in order to reach the homes of patients, which may be difficult to do when the weather is unfavourable, thereby negatively impacting on service delivery (Friedman, 2002). DOTS supporters work for five hours per day, according to their contract. The areas they are working in are so scattered from one another and they have to walk long distances as they don’t have transport. With up to eight clients per TB DOT supporter it becomes impossible for them to reach all the clients each day, or if they do reach all of their clients they do not deliver quality services. Transport constraints are a major obstacle in many programmes and for many CHWs. Locating patients due to wrong address has put a lot of physical strain on DOT, yet many remain committed and resolute to continue helping (Akintola, 2004).
2.9.4. Physical and emotional strain

The volunteers find it difficult to cope with the challenges of HIV and TB and the extent of the suffering within the households of their patients. Although some of them are able to overcome this state of shock after a few visits to the patients, others take a longer time to adjust to their situations, and yet others specifically ask to be excused from caring for patients with full-blown AIDS (Akintola, 2004). After reviewing the training content of the volunteer training manual Akintola (2008) suggested that the training curricula should be improved by including coping skills and other areas of psycho-social support. Mental healthcare nurses and psychosocial workers could also assist with giving the psychosocial support necessary for positive coping in the initial stages of volunteers’ work, and giving continuing support thereafter. In addition, people in the current support networks of volunteers such as the clergy, church members and other volunteers, need to be trained to offer emotional support to volunteers.

It is disturbing that some affected families treat the volunteers badly, thereby creating stress for them. The resilience of the volunteers can be explained as arising from a mix of several factors, in particular their strong altruistic and humanitarian motivation and the lack of other forms of employment in the local community. Nonetheless, this behaviour on the part of the affected families can cause psychological distress to the volunteers, is therefore a threat to the success of home-based care, and highlights the need for community education (Akintola, 2008).

2.9.5. Lack of supervision

In large-scale CHW programmes supervision is almost always inadequate, and those responsible for supervision frequently have other responsibilities, usually for patient care at a peripheral health facility. They generally have had neither formal training in nor a special inclination for supervising CHWs, and often have limited capacity to travel to the communities where CHWs work (Rahman et al., 2010).

Large-scale programmes are often chronically plagued by the insufficient involvement of communities and local health systems in programme planning and buy-in, inappropriate
CHW selection, inadequate CHW initial and on-going training, the overburdening of CHWs with too many tasks or too many clients, weak links to formal health systems and community resources, deficient supply chains and supervision, inappropriate and underutilized monitoring and evaluation systems, insufficient incentives and remuneration for CHWs (or delays in payment), and low CHW retention. (Rahman et al., 2010). According to the Community Care Worker Policy Framework (CCW), CHWs should always perform their work under the supervision of an appropriately qualified manager such as a CHW supervisor who is attached to a non-profit organisation (NPO), who in turn reports to a professional health worker or a social worker with experience in HCBC.

The professional health worker or social worker then reports to a programme CHW supervisor, who is employed by either the Department of Health or the Department of Social Development, which co-ordinates or manages the various programmes associated with the core service package. According to Friedman (2005), the CHWs are also accountable to the NPO manager, who is in turn accountable to the district health authority. In addition, they are accountable to the health facilities for the clinical component of their work; however, this is mostly for providing on-going training and technical support. CHWs are also supported by community-based facilitators (CHFs) who sometimes help to handle community conflict situations (Friedman, 2005). Thus; the CHW programme entails multiple levels of accountability (or reporting).

### 2.9.6. Lack of medical supplies

Both Akintola (2006) and Van Dyk (2007) observe that quality is compromised due to the insufficiency of the resources at the health care facility and also at patients’ homes, as caregivers are not provided with gloves, sanitation towels, bleach or incontinent sheets to handle patients adequately, and they are in frequent and close contact with mothers’ excreta such as vomitus, faeces and blood, and this exposes the caregivers to HIV and TB infections.

In addition, Rahman et al. (2010) argue that these factors, when combined with a weak management and organizational structure, can lead to a poor quality of work performed by CHWs, low morale, absenteeism and attrition. Sobuce (2007) and Wyngaard and Whiteside
(2013) document that resources like anti-retroviral therapy (ART) and other treatment, food parcels and home-based care kits as well as support from critical links with clinics, religious institutions and traditional/community leaders, act as imperative enablers in the home-based care programme. A literature study on caregivers (Orner, 2006) has identified a lack of transport is one of the gaps in the system. Volmink and Garner (2007) confirm that in South Africa the issue of a lack of access to transportation has been a factor affecting patients’ ability to seek health care in a timely and regular manner, and this affects the success of TB and PMTCT services, especially for patients in informal settlement.

2.10. Fear of contracting TB infection

Any delay in diagnosis leads to an increased period of infectiousness in the community and aggravates the disease in affected individuals. Non-compliance with the TB treatment regimen poses a serious risk for the individual, the community and the health workers (Volmink and Garner, 2007). As a result, the risk of the transmission of the disease is greater for close contacts that have prolonged exposure to the TB case over time. This includes household members, work or institutional colleagues, and close friends. People with compromised immune systems, when exposed to TB, have a greater chance of developing TB than healthy people. The incidence of TB in some populations is increasing, especially in communities with HIV or AIDS (Volmink and Garner, 2007).

Akintola (2004) states that there seems to be a lack of robust measures for infection control in the community, which poses a risk to care givers in the community. The same author further says that that carers ARE exposed to infection due to nature of their work, as they deal directly with patients excreta, and there is growing evidence of health care facility acquired transmission of tuberculosis (TB) to patients and health care workers (HCWs) by respiratory aerosols and through contaminated equipment. Pillay and Sturmhas (2010) state that there is an urgent need to put infection control practices in place. Global TB infection rates may be higher in HCWs than in the general population, with HCWs being diagnosed with both uncomplicated and complicated forms of TB.
CHAPTER 3 – METHODOLOGY

3.1. Introduction

According to Polit and Hungler (2004), the term “research methodology” refers to ways of obtaining, organising and analysing data. In this chapter the researcher describes the methodology used in conducting the study. The chapter outlines the study design, the setting and the population of the study, describes the sample and sampling techniques, the inclusion and exclusion criteria and how the participants were recruited, identifies the method of data collection and the tools used in data analysis, and describes how trustworthiness was ensured as well as the ethical considerations taken into account in this study.

3.2. Study design

The study used a qualitative exploratory design which led to the conducting of focus group discussions (FGDs) with TB DOT supporters working in Orange Farm. Focus group discussions were selected as the most appropriate method for data collection, because they can be used to discover what people think and why they think that way (Burns and Grove, 2007). Furthermore, the methodology helped the researcher to gain insight into and an understanding of the participant’s perspective (Babbie and Mouton, 2005), to explore the TB DOT supporters’ experiences and to identify the challenges they face in performing their duties.

3.3. Study setting

This study is based on the population of home based carers who are working as TB DOT supporters in Orange Farm, Johannesburg District, Gauteng Province. The FGD was conducted in four organizations namely: Vumani Project, Inkanyezi, HIV/AIDS Care, and Thalithakhumi PHC. These organizations are very active in the community with various responsibilities including OVC, Community Action Teams, Woman Abuse and Stop Crime,
and come from faith-based organizations in Orange Farm. They also mentor youth out of school with homework, and teach them about menstrual hygiene

3.4. Study population

The term “research population” refers to all the elements (individuals, events or circumstances) that meet the sample criteria for inclusion in a study. It is sometimes referred to as the target population (Burns and Grove, 2007). The accessible population is the portion of the target population to which the researcher has reasonable access (Burns and Grove 2005). The study population was composed of TB supporters working in Region G Sub-District (Orange Farm) as TB DOT supporters. TB supporters play an important role in the community, being responsible for the following activities:

- Case finding,
- Supervising patients’ medication,
- Social mobilization,
- Health education,
- Contact tracing,
- Referral to the clinics.

3.5. Sampling technique and sampling size

Brink et al., (2006) define a sample as a part or fraction of a whole, or a subset of a larger set selected by the researcher to participate in the study, while Burns and Grove (2005) explain that sampling is a process that involves selecting a group of people, events, behaviours, or other elements with which to conduct the study. According to Creswell (2007), in purposive sampling the researcher selects participants for the study because they can inform an understanding of the research problem. In this study, all TB supporters (60) working in the informal settlement of Orange Farm were selected, as they could meet the objectives of the study and answer the research questions.

According to Patton (2002) there are no rules for sample size in qualitative research, but data collection is guided by the need to reach the saturation point. A data base is regarded as having been saturated when no new ideas, concepts, categories or relevant themes
emerge (Krueger, 2000). A total of six FGDs were conducted, although the rule of thumb suggests that three to five focus groups are adequate to reach data saturation. The groups comprised of 10 participants each the initial intention was to have 6 to 8 participants per group, but the researcher was surprised by the large number of possible participants who volunteered to participate in the discussion.

Both males and females who work as TB supporters from four home-based care organizations were recruited for the focus group discussions. They were chosen on the grounds of their level of experience in the organization. There were fifty-seven females and three males across the groups. One group had one male in it, and another had two. The ages of the participants ranged from eighteen to fifty-five years. They had been involved in TB caring for between one and ten years. The researcher observed that no new responses were emerging from the participants during focus group number five, which indicated that the data had reached saturation point, but the researcher continued through focus group six to make sure that nothing had been left out.

3.6. Inclusion and exclusion criteria

Inclusion criteria

- DOTS Supporters working in Region G, informal settlement.
- Participants who had worked for at least one year within a TB programme.

Exclusion Criteria

- DOTS Supporters who had been working for less than one year

3.7. Recruitment of study participants

The researcher organized a meeting with two home based organization caring for TB in the community namely; Inkanyezi, and Thalithakhumi, for an appointment to present her proposal for the study. The two organizations were presented with copy of proposal and clearance letter from Sefako Makgato Research Ethics Committee (SMUREC) this two organization also informed the researcher about other homebased care organization.
The TB coordinator contacted the participants on behalf of the researcher requesting the participant’s availability to set the date and the venue on behalf of the researcher. TB DOT supporters from the two organizations were eager to participate and later the Coordinator contacted other two organizations. Participants then agreed to participate in the study then the management sent a written permission to the researcher. A date was set for the researcher to meet the TB DOT supporters where the aims and objectives of the study were presented and participants signed informed consent forms in agreement to participate. The research assistant and Researcher then called the management of Vumani Project and, HIV/AIDS Care. The proposal was presented to management telephonically and later sent the research assistant to present the proposal and meet with management on behalf of researcher. The meeting was successful as the research assistant was granted with a permission to conduct a research. On behalf of the researcher, the management contacted the carers and explained to them about the study requesting them to participate. The TB DOT supporters agreed to participate in the study then the management gave the research assistant the written permission letter on the day of data collection where the research assistant met the TB DOT and explained the aims and objectives of the study. TB DOT supporters signed informed consent forms to agree to participate in the study.

3.8. Data collection method

The aim of the researcher was to make sense of the relevant feelings, experiences, social situations, or phenomena as they occur in the real world. As the topic under study was practical; that is, TB DOT supporter’s daily activities and concerns. Focus group discussions would allow the TB DOT supporters to share their personal knowledge, thoughts and ideas with one another as well as with the researcher as they described their experiences (Brink, 2004).

Various strategies were used to develop trust and rapport across the members of each group of participants who, although they were doing similar work, did not know one another well. The focus group discussions were conducted on the premises of the organisations participating in the study. A focus group guide was used to assist the researcher in guiding the focus group discussion.
This guide was developed by the researcher in English, and then it was translated into South Sotho, which is a language common among the participants, to make sure that they understood the questions. The guide contained six semi-structured discussion questions. Preparation for data collection started with a half-day training session held between the researcher, the research Assistant and the TB Coordinator. The focus of the training was mainly on the focus group guide, the criteria for selection, preparation for and conducting the focus group discussions, administering the informed consent forms, and a brief overview of the objectives of the study. The interview guide was pretested with a small sample of respondents.

The aim of the pretesting was to check people’s understanding and ability to answer the questions, highlight areas of confusion, and look for any routing errors, as well as to provide an estimate of the average time that needed to be given to each question. Amendments to the interview guide were effected accordingly together with the Supervisor and the Research assistant. The amended collection tool includes question about the frequency with which they were paid their stipends, as some of the participants were saying that they did get the stipend but not on a regular basis.

Before the start of each discussion, the researcher and the assistant introduced themselves. The research assistant then explained the aims and objectives of the study and assured the participants of the confidentiality all that was to be discussed in the group. The assistant also administered individual informed consent forms to the participants in the language they preferred; either Sesotho or English. The participants were allowed to use pseudonyms during the discussion, but they kept on forgetting to use the names and the researcher had to keep on reminding them to do so.

The TB coordinator played the important role of making sure that the participants arrived on time and that the space was clean and free of any noise or disturbances of other kinds. A digital recorder, supplemented by note taking, was used to collect data. The researcher conducted all the FGDs and the research assistant acted as the note taker. The researcher tactfully moderated each session and probed those who were quiet, encouraging them to tell of their experiences too so that the expression of the participants’ views was balanced.
Each discussion was initiated with an ice-breaker as an opening question: “Please tell us how you started to work as a TB supporter”. Probing questions were asked in order to encourage participants to explore further issues. Participants were given some refreshments at the end of the discussion. Transport money was not provided as the meetings took place at their working environment during working hours. At the end of FGDs, participants were asked to complete a short demographic questionnaire which was distributed to them at the beginning of the session.

The questions, which were designed in order to obtain participants’ demographic data, had been developed in English and later translated into Sesotho. The supervisor of the research also played a major role in developing the demographic questionnaire. Variables in questionnaire included age, sex, marital status, level of education and duration in the TB programme, etc. Fortunately all participants were able to read and write, and the researcher and the research assistant supported those who were writing slowly, so all participants completed the questions as asked. The data collection process took too long, as the researcher encountered many challenges during the process, such as heavy rains, elections, a supporters’ strike, etc.

3.9. Data management

Voice recordings were taken during the discussions. After every focus group discussion the recording was checked for audibility and was downloaded into the researcher’s laptop with a security password to save the audio file. The researcher listened to the audio files and transcribed them verbatim, and thereafter translated the transcripts from the original mixture of isiZulu, South Sotho and English to English. Confidentiality was ensured at every stage by attaching pseudonyms to the quotes from the interviews, for a backup, the transcripts were saved in a memory stick and a CD, and the transcripts were also printed to hard copies, which were stored in a lockable cupboard in an office with limited access. After the themes had been identified, the transcripts were also imported into NVivo 10 to help with organizing the data for analysis.
3.10 Data analysis

Having translated and transcribed the data, the researcher spent hours reflecting on possible meanings and relationships, and systematically making sense of the data. Initial analysis of the interviews began during the fieldwork, when the researcher contacted the supervisor for clarification and debriefing. The researcher listened to voice recordings a number of times, transcribed verbatim in Sesotho and then translated the verbatim transcriptions into English. The researcher and the supervisor identified, defined and refined the emerging themes and sub-themes. On reaching an agreement the first version of the code list was identified and developed from the emerging themes.

The researcher had to re-do the code list, and there had to be mutual agreement with researcher and supervisor regarding the code list. Finally, this was achieved. Manual coding of transcript was the first step towards data reduction and identification of themes and sub-themes. Five themes were identified, with their related sub-themes. The researcher then imported the data into Nvivo 9 and started applying the codes. The demographic data was also captured using the Excel spreadsheet. The final data was presented in the form of quotations.

3.11 Trustworthiness

Trustworthiness has to do with validity and reliability in qualitative research, and the qualities one looks for include credibility, dependability, and transferability. Credibility refers to the ability of the researcher to accurately represent what the participants think, feel, and do. Patton (2002) states that dependability parallels the criterion of reliability in qualitative research and refers to the stability of the findings over time. This was ensured as follows.

3.11.1 Credibility

This requires that there is confidence that the study measures what it intends to test, and the findings relate closely to the testing (Shenton, 2004). Engaging the NGO and the TB DOT supporters was essential for building trust and a rapport with the participants, which in turn
made it more likely and accurate, rich information would be obtained. In this study the researcher used established methodology to ascertain in-depth information about the experiences of TB DOT supporters managing TB patients. The participants voluntarily participated without being forced to do so, which added to the confidence in the research findings. The participants were engaged in discussion until the data was saturated. A good digital recorder was used by the researcher. Nvivo also enabled the researcher in organising and analysing data. The researcher continuously verified with participants the themes and sub-themes that emerged from the data collected and analysed, to ensure that their views had been accurately captured.

3.11.2 Transferability

This refers to the probability that the findings of the study have meaning to others in similar situations (Streubert, Speziale and Carpenter, 2003). The researcher enhanced the transferability of this research by providing thick descriptions of the phenomenon under scrutiny. This was possible because information-rich participants were included in the sample. “Thick description” refers to a rich and thorough description of the research setting and of the observed transactions and processes (Polit and Beck, 2008).

Rich, detailed descriptions were used to capture the occurrences observed and the responses obtained, and to explain the context in which such occurrences and inputs unfolded. Similarly (Shenton, 2004) explains transferability as showing that the findings can be generalised and are applicable in other settings. A full description of the context and background information about the setting of the study and the population as well as details on the sampling and data collection were given with precision to enable other researchers to determine the extent of the transferability to their contexts.

3.11.3 Dependability

This generally requires the giving a full, detailed description of the processes followed in the study to allow future researchers to repeat the work. It amounts to showing that the findings are consistent and can be repeated in other settings (Shenton, 2004; Brink, 2004). A
full description of what was planned, what was done and how it was done was given in
detail in the methodology chapter, where it was explained how participants were recruited,
how data was collected and how it was analysed so that interested future researcher can
repeat the study in the hope of producing the same findings.

3.11.4 Conformability

This is the extent to which the findings of the study are objective and neutral and reflect the
experiences and ideas of the participants, without their being influenced by the preferences
and interests of the researcher (Shenton, 2004). Voice recordings of the group discussions
were listened to repeatedly, even after they had been transcribed verbatim and translated,
to ensure that the participants were not misinterpreted. NVivo10 was used to for the
organization and analysis of the data. Timely debriefing sessions online and face-to-face
were held with the research supervisor and served as the sounding board for the researcher
to guide the development of the themes as identified from the transcripts, in order to arrive
at an honest interpretation.

3.12 Ethical considerations

Brink et al. (2006) emphasize that conducting research in an ethical manner means that the
researcher must carry out the research competency and most importantly consider the
consequences of the research for society, especially the participants. Researchers have to be
aware of the rights of human subjects and other ethical issues when planning a research
project that deals with human subjects. The following are the relevant ethical principles and
procedures adhered to in this study:

- Permission to proceed with the study was sought from the management of the study
  organisations by writing request letters and presenting the study proposal to them
  after getting a clearance letter from the Sefako Makgatho Health Science University
  Research Ethics Committee. Permission was granted in the form of the letters of
  response attached as annexures
- Permission was also obtained from the Department of Health Johannesburg District
  and Vumani Project in Orange farm. (Annexure 2).
3.12.1 Informed consent

The researcher ensured that participant’s rights were observed. There was no any harm or embarrassment caused during the focus group discussion. The purpose of the research was explained to all the participants. A written informed consent was attained from the individual participant before starting with focus group discussion. Participants were informed that participation in the study was voluntary and that they are not forced and they can withdraw from the study without any fear of being intimidated by their organizations or fear of loosing their jobs.

3.12.2 Anonymity and confidentiality

Polit and Beck (2004) state that participants in research have the right to expect that any data they provide will be kept in the strictest assurance. Confidentiality is the protection of the participants in a study so that information provided is never divulged. Confidentiality is the researcher’s management of the private information shared by a participant that must not be shared with others without the permission of the participant (Burns and Grove, 2005). Confidentiality, anonymity and respect were maintained throughout the, participants were informed not to write their names or names of their institutions anywhere in the questionnaire.

3.13 Conclusion

This chapter has described the research design, the method of data collection and analysis, and the attempts to ensure trustworthiness and to honour the related ethical considerations
CHAPTER 4 - DATA ANALYSIS

4.1. Introduction
This chapter presents the findings from the analysis of the data collected from the six FGDs conducted in the Orange Farm informal settlement. Section One presents the demographic profile of the study participants, and Sections Two is an elucidation of themes identified from the qualitative data.

4.2. Participants’ socio-demographic information
A questionnaire asking for the personal particulars of the research participants was administered to the 60 participants. Data was collected on the following socio-demographic variables: age, educational level, marital status, distance travelled per day, frequency of remuneration, and the duration of the training receive.

![Figure 4.1: Distribution of research participants by gender](image.png)

Out of N=60 research participants, 95% (n=57) were females, and only 5.0% (n=3) were males. Gender distribution is summarized in Figure 4.1.
Figure 4.2: Distribution of research participants by age group
Out of N=60 research participants, 58.3% (n=35) were single, 23.3% (n=11) were divorced, and 18.3% (n=14) married (Figure 4.3)

Figure 4.3: Distribution of research participants by marital status
Out of N=60 research participants, 90.0% (n=54) received remuneration (stipends) irregularly, while 5.0% (n=3) always received theirs, and another 5.0% (n=3) were yet to receive a stipend at the time when the fieldwork was conducted for this research (Figure 4.4).
Out of N=60 research participants, 38.4% (n=23) had never received any TB-related training, 33.3% (n=20) had received the “69 days’ HBC” training, 15.0% (n=9) had received 3 days’ training, 8.3% (n=5) had received 10 days’ training, and 5.0% (3) had received 5 days’ training (Figure 4.5).

Out of N=60 research participants, 45.0% (n=27) had a tertiary-level qualification, 28.3% (n=17) had received secondary education, 23.3% (n=14) had only primary education, and 3.4% (n=2) had never received any schooling (Figure 4.6).
Figure 4.6: Distribution of research participants by level of education

Figure 4.7: Distribution of research participants by mode of daily transport

Out of N=60 research participants, 60.0% (n=36) walked to execute their work, 35.0% (n=21) used a 16-seater taxi when possible, while 5.0% (n=3) used other means of transport (Figure 4.7).
Figure 4.8: Distribution of research participants by average daily walking distance

Out of N=60 research participants, 70.0% (n=42) walked a daily total distance of 5km, 20.0% (n=12) walked 10km, and 10% (n=3) walked a distance exceeding 10km daily (Figure 4.8).

4.3. Qualitative findings and themes identified

Analysis of the qualitative data led to the identification of the following themes and their related sub-themes: Community participation of DOT TB supporters in TB control. Its sub-theme: the role of TB supporters in TB control, 1. referral role, other activities, health promotion. 2. Motivation of TB DOT supporters in joining the DOTS programme. Sub-themes: sense of altruism, religious obligation, own illness, passion, positive Experience, 3. Reported benefits of DOT supporters.

Sub-themes: learning new skills, future employment. 4. Support received by TB DOT supporters. Sub-themes: management support, family support, community support. 5. Challenges faced by TB DOT supporters. Sub-themes: monetary incentives, contact tracing, and safety of DOT supporters, lack of resources, emotional and physical strain
### Table 1. Themes and Sub-Themes

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Community Participation in TB Control</td>
<td>The Role of TB DOT supporters in Control of TB</td>
</tr>
<tr>
<td></td>
<td>The Referral Role</td>
</tr>
<tr>
<td></td>
<td>Other Activities</td>
</tr>
<tr>
<td></td>
<td>Health Promotion</td>
</tr>
<tr>
<td>2. Motivation of TB DOT supporters in joining the DOTS programme</td>
<td>Sense of Altruism</td>
</tr>
<tr>
<td></td>
<td>Religious Obligation</td>
</tr>
<tr>
<td></td>
<td>Own Illness</td>
</tr>
<tr>
<td></td>
<td>Passion,</td>
</tr>
<tr>
<td></td>
<td>Positive Experience</td>
</tr>
<tr>
<td>3. Reported benefits of TB DOT supporters managing TB patients</td>
<td>learning new skills,</td>
</tr>
<tr>
<td></td>
<td>future employment</td>
</tr>
<tr>
<td>4. Support received by TB DOT supporters</td>
<td>Management support</td>
</tr>
<tr>
<td></td>
<td>Family support</td>
</tr>
<tr>
<td></td>
<td>Community support.</td>
</tr>
<tr>
<td>5. Challenges faced by TB DOT supporters</td>
<td>Monetary incentives</td>
</tr>
<tr>
<td></td>
<td>contact tracing</td>
</tr>
<tr>
<td></td>
<td>safety of DOT supporters</td>
</tr>
<tr>
<td></td>
<td>lack of resources,</td>
</tr>
<tr>
<td></td>
<td>Emotional and physical strain.</td>
</tr>
</tbody>
</table>

#### 4.3.1. Community participation in TB control

The study found that communities were involved in various health care programmes which strengthen PHC re-engineering through the ward-based approach, and at the community level there are various cadres which aims at strengthening community health and working closely with primary health care services. This groups may be differentiated according to their deliverables e.g. Community care givers (CCG), Community Health Care
Workers(CHW), Carers, lay counsellors, treatment supporters, and adherence counsellors, among others. During implementation these cadres sometimes differ with one another due to a conflict of interest, but for the sake of this study the researcher will be focusing on TB DOT supporters. The data revealed that DOT supporters are involved in various activities to strengthen the TB programme, and the following sub-themes explain their involvement:

4.3.1.1. The roles of TB DOT supporters in TB control in Orange Farm

The data showed that most participants understood their role and duties regarding patient management and support during the treatment cycle of six months. The following statements were made:

“Sister... I know my job description and my role is as follows. Supervise medication and counselling TB PATIENTS. Education, talking to patients, counselling the TB patients about taking medicine, watch them take pills, encourage patients. Write, tick on patients green card when pills taken, assist in application for government social grants (36 year-old female DOT supporter)”.

“We visit TB patients on daily basis and on arrival we wash TB patients, we clean their houses, we bath them, we cook for them, we carry them to clinic when they are sick, we even work more than police. We take patient from their homes to the clinic”.

“You must be vigilant, some patients will tell you that they have taken their treatment but be just putting a pill under their tongue or under their beds, so you must observe them every day, and when there is improvement you will be sure that you are doing your work correctly. You have to make sure that he eats properly, that they don’t have skin/external opportunistic infections or if their feet don’t swell (25 year-old female TB supporter)”

4.3.1.2. Referral role

The DOT supporters serve as a link in the community. The participants perceived this link between themselves and the professional health care services as being important, as the majority of the TB patients receive medical attention, and the DOT supporters would have
to do a follow-up with the clinic and the clients to ensure that the patients had reached their destinations. The following sub-themes were mentioned by participants:

“We refer patients to the facility by using referral forms given to us. The facility also refers patients to the organisation for basic nursing care and Supervised TB care. The sister at the clinic will also do down referral to us so that we continue to assist the patient with treatment. (40 year-old female TB supporter)”.

“We refer for symptoms screening sometimes we receive clients complaining of so many symptoms during the home visit so that’s why we refer for further investigation and care and to add more we also refer children and all TB contacts for further management in the clinic. When we see patient improving it really makes us to be happier and more committed. (39 year-old female TB supporter)”.

4.3.1.3. Other activities
Although most participants were involved in TB care and support, the data revealed that the DOT supporters were also involved in other community activities such as the following:

“TB patients die in our hands; we are not receiving any counselling and you are on your own, you have to assist in arranging the last offices. (46 year-old female TB supporter)”.

“Some TB patients die alone without any relative next to them, I had an experience where I have to arrange the funeral, I contacted the mortuary owners to assist with a coffin and I also confronted the community leaders to assist with other logistic of funeral such as food and transport, this is more than a job, we go all out to assist in the community, we show love and support. (51 year’s Old female TB supporter)”

“We take care of people with different diseases like TB, epilepsy, mental health, HIV and other chronic diseases. We are the eyes and ears on the ground. (32 years old TB supporter)”
“We encourage community gardens, gardens at home and we give soup to communities especially those who are very poor.” (44 years old female TB supporter)

4.3.1.4. Health promotion and social mobilization

The DOT supporters in this study highlighted their role in health promotions, which they perform by promoting health advocacy, capacity building of communities through health education, and offering counselling to individuals. These activities are supported by the following statements from the participants:

“...We conduct TB campaign, last year when we were conducting door to door campaign I found an old woman who was bed ridden. She was close to death. We arranged an ambulance with the assistance of clinic supervisor. We are making a difference in the community. (32 year-old female TB supporter)’’.

“My interest in TB stems from the fact that in my 6 years as a community health care worker, I have seen TB sufferers and I have seen most critically ill patients at home despite the free treatment available, so something needed to be done so we are filling this gap to make sure that we mobilize the community at their doorstep to access TB care and support. And we don’t only mobilize but we make sure that patients access TB services. This gives me fulfilment. (48 year-old female TB supporter)’’.

“Teaching the community to know about TB symptoms and to seek health services early (22 years old female TB Supporter)”

“Our community needs information concerning HIV/AIDS, TB and healthy lifestyle. We give the community information on these topics. (28 year-old old TB supporter)’’.

“I would like to talk about patients “education”. This is what excites me, as I find our community without any knowledge or some have wrong information and I correct and impart new knowledge. This makes me feel good inside and outside. This is
amazing. The communities take ownership of their health status, when I educate them. Sometimes I scare them. I always teach them that “police are going to arrest them if they don’t complete their TB treatment” and this spread like “fire” that if you don’t complete TB treatment then jail is coming. Most patients are afraid to go to jail so they make sure that they adhere to their medication. (44 years old female TB supporter)

4.3.2. The motivation of TB DOT supporters in joining the TB programme

The DOT supporters often had intrinsic motives for joining the programme, quite independently of extrinsic motives such as money. The intrinsic motives were aligned with the DOT supporters’ personal values and personal attributes. The data shows that the participants were motivated by altruism, their sense of having a religious obligation, their own illness or their history of family illness, a desire to keep busy, and enjoying positive experiences as a result of offering DOTS support in the informal settlement. The following statements bear this out.

4.3.2.1. Sense of altruism

Participants in this study demonstrated their own altruism and their human concern by helping others who cannot cope with the challenges of the disease due their physical weakness:

“I have seen my community going through a lot and I have seen a need to help my community. (45 year-old female TB supporter)“.

“I meant to say that when I look at TB sufferers I just told myself that no one and then no one else is going to understand patients suffering better than I do, so maybe I need to understand it better than I and I have to do something( 29 years old female TB supporter ) “.

“I feel for the TB patients and when I get home at times I cannot sleep just thinking about the suffering of TB patients (35 years old female TB supporter)”
“I was worried about people who are sick particularly those who do not have someone caring for them. (44 years old female TB supporter) ”.

“I wanted to assist the community. (51 years old female TB supporter) ”.

“You see so many people are sick and they need some help and I can assist anytime when they need me. (46 years old female TB supporter)”.

4.3.2.2. Religious obligation
Some of the DOT supporters in this study described their work as a “calling” and expressed their love and dedication for the sick community. The following statements further clarify this sub-theme:

“I was influenced by my church background. I was always passionate about helping. I am learning more about the project help me realize how I can help my community but you have to be passionate otherwise you will not get far. (34 year-old female TB supporter)”.

“Mmm... For me working as a TB supporter is a calling from God. I work because I love my community and I don’t want them to suffer. Since I’ve worked as a TB supporter here I can witness that I am free and I’m able to have empathy even if a person is not my relative seeing him/her in the streets, I like the work and like helping the community. (49 years old Male TB supporter)”

4.3.2.3. History of own illness
The data in this study revealed that some DOT supporters joined the TB programme to gain more knowledge in order to save their families and community, this was related to their personal experience as TB sufferers, and their having to support family members affected by TB:

“I was motivated after my mother’s death. She was an HIV activist, and I was her DOT supporter when she was taking her treatment. After her death I saw the good work she was doing and now I’m following in her footsteps. My mother was a fighter,
she was delayed in the Hospital due to lack of x-ray. We have to be on a waiting list for x-ray in Bara, hence my mother was not started on correct medication and she passed on. We went to the Hospital for post-mortem. The result revealed that she died due to spine TB. (22 year-old female TB supporter)

“I am a TB survivor. I am currently having one lung and this was due to the fact that I defaulted TB treatment. Hence I am using my experience to teach and motivate the community about the importance of TB medication. (33 year-old male TB supporter)

“I was in jail and I got TB while I was in prison, so I am trying to work with prison to get the number of those that are in parole for discharge so that I can support them in the community, I have seen that the community is afraid of them. This is motivating for me as I am making a difference in the community. (29 year-old male TB supporter)

4.3.2.4. Keeping busy

The data shows that the participants were happy about having chosen to support TB patients. They cited several reasons, such as a need to help others, filling the health gap in the community, and keeping busy. The following statement supports this contention:

“I was at home unemployed, but something in me said I should help my community. I saw that a lot of people needed help. That’s what motivated me. (45 year-old female TB supporter)

“I was just an ordinary housewife and my husband wanted me not to do anything because he was looking after us, but one day I was watching TV and I saw a programme on HIV/AIDS and TB. Three weeks from there on our priest talked to us congregants about HIV/AIDS and TB. That’s when I started getting involved in helping my community and developing it. (47 years old female TB supporter) ”

48
4.3.2.5. Passion for TB support

The data shows that in general the TB DOT supporters were committed to rendering a service to humanity and that they were determined to continue to do this with a sense of pride and passion, as shown by the following statements:

“I have passion for my work. I share my skills with my community. I have identified that majority of TB patients are not educated about TB so I help to correct the misconception and I give them correct information and about the importance of medication. (36 year-old female TB supporter)”.

“Passion got me started, and even today I still love what I’m doing, I was involved in a car accident and I became a regular clinic attendee, so whilst we were waiting for the attention of the sisters we started talking, and I found out that there are people who are too sick to an extent that they can’t collect their own treatment. So I had a friend at the clinic and she and I started acting upon this. (47 year-old female TB supporter)”.

4.3.2.6. Positive experience of TB DOT supporters in managing TB patients

The data shows that the DOT supporters perceive receiving positive feedback from their patients and families as important, and they were also encouraged by the changes they saw in their communities as a result of their work:

“When TB patients recover and is converted from being infectious to being cured, TB supporters get motivated. They continue caring for the patients because they want to see them returning to their former life and going back to work. (44 year-old female TB supporter)”.

“We are excited by testimonies that TB patients have been cured and they are working. Patients give us feedback that we have worked hard and now the results are showing by means of weight gain and returning to work. (29 year-old female TB supporter)”.
“We are pleased that now our community are not dying at home. They call us at night and come to our homes for help and at times we are unable to assist but they are making an effort to come to us for help and that is why we are saying we are touching lives and we are change agents of doorstep TB prevention. (51 year-old female TB supporter”).

“Ah! I am so glad about my work. I know that there are people out there who trust and appreciate us, our patients really appreciate us, and they tell us anything about their health. We are happy about our job. (33 years female TB supporter)”

“When TB patients come back to thank us to say “You helped me, your presence here made a difference and I am happy”, this really excites us. (44 year-old female TB supporter)”.

4.3.3. Reported benefits of TB DOT supporters managing TB patients

The data shows that joining the TB programme was perceived by DOT supporters as a stepping stone to fulfilling their career aspirations and opportunities to learn new skills that can be utilized in future.

4.3.3.1. Learning new skills

The data show that most participants appreciated the knowledge and skills gained through working with TB patients and professional nurses. They had learnt how to talk to patients and members of the community and how to care for TB patients. This is supported by the following quotations:

“So as a TB supporter each and every day you’ve got a new day and a new challenge. You are always learning every day and you also learn how to cope and come up with solution that suit the TB patient. (32 year-old old TB supporter) ”.

“Sometimes patients don’t understand us. We have learnt to take time with TB patients. You need to sit down with the patient and explain your working conditions.
Patients have their own understanding about their condition; therefore we take a lot of time explaining. Sometimes patients ask us difficult questions just to test, but as indicated we apply our own listening skills. This has taught us that patience pays as they end up trusting us. (35 year-old female TB supporter).

“I have learnt other skills such as TB treatment side-effects, communication and listening skills. Without these skills you cannot win. In making sure that patients swallow medication, you need to be innovative and you need to have good understanding skills and you need to be extremely careful as other patients do not swallow their medication they hide them, so my observation skill is very important in winning patients to reality and completing TB treatment. (28 years old female TB supporter)”

“I was very quiet when I started as a TB supporter and patients used not to take me serious, but with time I have acquired assertive skills. I sometimes give instructions to patients with authority but in a very careful way, as they can be difficult during the time of smear conversion. They will say they don’t have sputum, so I tell them that two months is over we need to collect sputum and he must make sure that he does this in the early morning as I will not be around. I teach them that they must go outside so that they don’t infect others. (29 year-old female TB supporter)”

4.3.3.2. Future employment

Job creation in South Africa remains a huge challenge. Our data shows participants see supporting TB patients as a way towards a career and a stepping-stone to help them to join the health and social services. This view is supported by the following statements:

“I joined because I need job experience so that I can join the job market easy. I have completed B com degree in 2008. Since then I have been looking for a job. (28 year-old female TB supporter)”.

“Okay! I can say we are getting experience by working here and when you want to further yourself then you already have experience. I am 18 years and would like to
become a nurse. *This background is helpful for me.* (35 year-old female TB supporter)”.

“I believe that volunteering and on-the-job training will serve as channels for me to the right paying job and to career growth. I am having a degree and I have not worked for what I studied for. Now is an opportunity for to get employment. I know one colleague of mine who was volunteering now is an Assistant Director in one of the departments. (26 year-old female TB supporter)”.

“As for me I want to see myself out of here. I want to be a nurse, so that one day when I am in hospital I may know how to care for a sick person. At the NGO we are taught how to care for a person, so, I make it a stepping stone that it prepares me because I want to be a nurse. (30 year-old female TB supporter).”

**4.3.4. Support received by TB DOT supporters**

Support is one of the motivating factors for TB DOT supporters, as this encourages them to continue with their community work. The data shows that there are three sources of support: management support, family support, and community support. Below are the supporting quotations from the participants.

**4.3.4.1. Management support**

Our data shows that the majority of the participants were happy about the management support, and they mentioned that onsite visiting and mentoring was important, as this encouraged and motivated them to continue working:

“The TB co-ordinator offer onsite support visit and we are having scheduled days for her support visit. Her visit is not based on inspection but her visit is mainly for problem solving and on the spot teaching. At times she does accompany us for home visit and tracing of defaulters and assist in injecting MDR TB patients on injectable. (41 year-old female TB supporter)”. 

52
“Nurses from the clinic support us by offering us with training and meeting on quarterly basis. This meeting is a platform to discuss our challenges and this is also opportunity to discuss difficult TB patients and they offer in-service training. We are so grateful about the support from the clinic. (32 year-old male TB supporter)”. 

Some participants reported having opportunities to consult with their managers when having problems. They saw this as one form of support. One participant said that she has direct communication with the TB supervisor, who quickly answers her questions and solves her problems. Other participants reported being able to go to their facility managers with problems they encountered while performing their duties in the TB programme.

“If you have any problems we consult our TB coordinator and they help us in a way they can be able. We communicate by WhatsApp and sms and they respond immediately. They answer my questions and attend to the patient’s problem as well as the facility manager. (40 year-old female TB supporter)”.

Although the participants in this study perceived management support as very important, our data reveal that some participants viewed management as not being supportive when they came to the clinic:

“I am not feeling good at all about my job. Nurses are reprimanding us in the clinic. They always say, “Why do we arrive late in the clinic?” They don’t know our working conditions. (33 years male TB supporter)”

“I get frustrated when I am not supported. (26 years old female TB supporter)”

“It’s only the way management treat us. They undermine us and the work we are doing. (42 year-old female TB supporter)”.

“You become frustrated even yourself that you are not doing enough but trying hard to do things the right way. (44 yaers old TB supporter) ”
4.3.4.2. Family support

The patient’s family is the most important source of support for some of the DOT supporters. Our data reveal that the participants perceived that they had had both positive and negative experiences with the patients’ families. The data also shows that some participants had educated the family members about TB, and in return the family were show care and sympathy for the TB supporters:

“I educate the families about TB and the importance of TB medication and also the precautionary measures about TB infection. Families are supportive and they always make sure that they open windows and they make sure that the patient is outside and is kept clean and I really appreciate as they make my work as TB supporter very easy. (27 year-old female TB patient)”.

“TB patients also welcome us in their homes. They even introduce us to their children and other family members. We are bonding with TB patients and their families. We receive calls of appreciation from families and they also treat us as their own member. We are really making a difference as we know that families will also assist in transportation of patients to the clinic. (43 year-old female TB supporter)”.

“Most of the relatives show sympathy to me. Some also encourage and advises me to have a rest. They sometimes visit me at home and offer me time off to be with my family. I really appreciate families as they treat me as a human being. They can really cheer you up. (33 year-old female supporter)”.

“When families have opened their heart to you to treat their TB patients, then the issues of stigma and discrimination is not applicable at all. (26 year-old female TB supporter)”.

Some participant’s expressed negative feelings about families and TB patients:

“We don’t receive any family support. Families do not welcome us into their homes. They lock the gates. They are forever angry at us. If they can only know that we are
helping them and the TB patients, they should be welcoming us with cheerful smile. (49 year-old TB supporter)“.

“We see that family members are isolating TB patients as they fear TB infection, they put them in an outside room which is not good (32 years old TB supporter)”

“When we wanted to bath the sick TB patient they didn’t want, saying they will bath her. When we say may we cook soft porridge for her they say we will do it ourselves. When we want to call the ambulance they say they will call it. They say we must leave everything as they will do it, but when we come back we see that they haven’t done anything. We don’t give up as we see that they haven’t done it for her. (51 years old female TB supporter) “

“TB patients when they see us with uniform they hide themselves from us. They associate us with HIV and they feel that their condition is exposed. (28 years old female TB supporter) “

“Families have problems. They do not support TB patients. They only want their social grant and they are not even buying cosmetics for TB patients and food. All the care for TB patients is left with us TB supporters. We have to bring cosmetics such as bathing soap and others. We are concerned about families. I wish that we can have a family Imbizo where we can talk about importance of family support and how families should take care of TB patients and other chronic diseases. (39 yearsold TB supporter) “.

4.3.4.3. Support received by TB DOT supporters from Community

With regards to community support, the participants reported getting some support from the community members, and that this serves as source of motivation, as this is helping in facilitating their job in the community; whereas others mentioned that they were not getting enough support from the community.
“For me the Ward Counsellor and members of the clinic committees offer me their support and they recognise my effort they rely on me with TB in the community and all other health-related matters. (44 year-old female TB supporter) ”.

“Community show respect to me and depend on me. They come to my house at any time of the day. I distribute condoms and I demonstrate how to use a condom. They are so grateful that they call me “Our Sister” and some call me “Doctor”. My house is like a mini clinic. (38 year-old male TB supporter) ”.

“The community like me very much. They even fight for me. I am happy as they see me as important to them. They even consult me with non TB issues such as personal life and to also assist in caring for their children when they are on holiday. (24 years old female TB supporter) ”

“Communities are very helpful. They know that we are challenged by payment of stipend and lack of transport. When they see us wheel TB patient on a wheel chair they assist by arranging a taxi or a transport to the Hospital. Sometimes they accompany us to Hospital if it’s late. We are happy about the community support as it is really making our caring duties easy. (33 years old female TB supporter) ”

However, the study also finds that some community members have negative attitudes towards TB supporters, call them names as they associate them with TB and HIV infection, and are of the opinion that the TB supporters feel guilty about their condition and therefore volunteer to help:

“Communities are talking a lot when they see us wearing uniform. They say we are HIV-positive. I don’t care as HIV status is my own confidentiality and I don’t care. All I know is that I am serving patients who need me, and interestingly the same people who are laughing at us three months down the line they are the ones looking for us for help. Anyway we help. (23 year-old female TB supporter) ”.
“I know my status. Even if I am positive is not their problem. I am working because I serve my community. The community says that we are not to be married as we are sick with TB. They are saying that all DOT supporters are TB/HIV patients and they say that we are doing this to heal our soul. We feel very bad about these allegations. They speak badly about us, but when their family member is sick they come to us for help. But we continue to assist everyone irrespective of what they say, we love everybody. (24 years female TB supporter)”

“Communities perceive us as drug dealers as we collect patients’ medication. They say that we are also selling drugs and this affects us as sometimes we are being followed by police with the hope that they might find drugs only to find that it is TB medication. (33 year-old male TB supporter)”.

4.3.5. Challenges faced by TB DOT supporters

4.3.5.1. Monetary incentives

Despite the feeling of importance, the majority of TB DOT supporters were unhappy about the fact that they were not remunerated and provided with material incentives. The data shows that the participants were poor and did not have any other form of income, and not being remunerated affected them emotionally and even affected their love and care for the sick patients. Young TB supporters were exiting the TB programme for this reason:

“To be honest with you, Regina, the issue of non-payment of our stipend is interfering with support for TB patients. You know, we TB supporters, immediately the money is not there, we do not work fast. It affects our morale. We don’t want to work. Already it’s been six months since we were last paid. (41 year-old female TB supporter)”.

“Aaai..., I can’t take it. We end up not giving patients love as we are now pretending. We know that we are volunteers. Let them pay us. We are faced stress and burnout. I wish I can have money to further my studies. (45 years old TB supporter)”
“Very sad!! I can tell you in future we will not have volunteers. The young ones are starting to drop out as soon as they realise that they would not be paid for their work. I am not feeling good. I am angry inside but I have a commitment to help the community. Inside I am sick and depressed. (51 years female TB supporter)”

“I feel bad, we are poor and patients are poor. We are not allowed to take extra jobs. (48 year-old female TB supporter)”.

Furthermore, the participants feel that the government does not appreciate them despite the effort they put into the TB control programme. They complain about the “dry season” and say that sometimes they have to go for months without being compensated. This affects their personal lives as they have to pay for their transport and they bear the financial burden for their families:

“They say dry season is when the season is dry and we have to understand and we must come to work every day. We need transport money. Every time I have to borrow money for coming to work, it’s dry. Government does not have money but Nurse never have a dry season. (28 year-old female TB supporter)”.

“We work hard. At the end of the month you find that you are not going to get any money. We don’t know how we will pay school fees for our children because the Department of Health also say we must not mix this job with any other. What are we going to do everything is expensive? ... It is not good... de-motivating. (34 years old male TB supporter)”

“They are robbing us, they take their time to give us our money, they make promises they can't keep, and they hardly support us with our needs. We know we are regarded as volunteers but they promised to give us little something to motivate us but ... we are struggling. We always keep up with our work. (44 years old female TB supporter)”
“We are contributing a lot in the community. We work as if we are mini clinic. Our government does not pay us, we are struggling. We know that we are volunteers but at least they must just think of transport. Taxi is very expensive and we are raising children, unemployment is high, we need to be compensated to stay motivated. We are asking to be paid every month, please. (49 year-old female TB supporter)”

4.3.5.2. Difficulties in contact tracing

The tracing of defaulters was a major challenge, as most patients had not provided their correct addresses, and these results in TB supporters have to spend time tracing their TB patients. The data shows that DOT supporters have to walk long distances in search of the correct address, and work overtime. This is supported by the following statement:

“We walk long distance searching for addresses and when we find the patients we struggle for access into the house. After that we are not welcomed in many homes, as they think that we are disturbing them. If it’s windy and cold, families refuse us access into the house. They say we disturb their peace. (28 years old female TB supporters) ”

Furthermore, the data reveals that the majority of TB supporters were not happy about being called at night to assist TB patients, and having to walk long distances:

“We are working under difficult conditions. We are called to work at night and we have to walk a long distance to give treatment at night. Nobody cares for us, we are alone, and nobody is prepared to give us motivation. (25 years old female TB supporter)”

“We are starting at 8am-12pm each day, but we are unable to go home on time. We are walking long distances and we don’t have strong shoes. This is affecting my health and also affects our caring to TB patients. (39 year-old female TB supporter)”
“Considering the long distance we travel per week, we are unable to give total care to our patients, and if we don’t come at the scheduled time, patients report us to the clinic; they are also reporting us to the newspaper. (45 year-old TB supporter) ”

The data also reveals that some patients deliberately do not give the correct address due to poor services access in the nearby informal settlement and this affects the TB programme, especially contact tracing.

“Shacks are too close to each other, roads poorly constructed and no street names, patients sometimes stay in the backyard and are not easy to find them,. With MDR we are asking that they should be stabilized in the TB hospital as they spread TB. (29 year-old female TB supporter)”. 

“Okay! In my opinion contact tracing is a serious challenge. It is important that the discussion of contact tracing starts at the hospital before the patients is being discharged. It is essential that exposed contacts rights are respected as well and that they are given full information and offered screening and treatment as needed, especially MDR TB contacts. (42 year-old female TB supporter)”. 

“Contact tracing is more difficult if TB patients did not disclose to the family. Hence now the TB patients are fighting us that we are not respecting their rights to privacy and the rights to their conditions. For them when they see us with our uniform already they think that we are exposing them. (26 year-old female TB supporter)”. 

4.3.5.3. Safety of DOT supporters 

TB DOT supporters are faced with safety challenges in the community. Our data shows that the participants were worried about their welfare as they are often faced with the risk of being raped and robbed of their belongings, and they worry about the risk of contracting TB and/or HIV:
“Our greatest monster is fear of being sexually assaulted. Our situation is not good at all. The roads are poorly constructed, we are working in the squatter camps where there are many foreign nationals, and we have also seen some nyaope addicts trying to demand money from us. We are not safe. (27 year-old female TB supporter)”.

4.3.5.4. Lack of resources

TB DOT supporters contribute significantly to the TB control program in the community as they support TB patients, our data revealed that participants were faced with numerous challenges in carrying their day to day activities and some of this issues raised were the following: Lack of home–based kits, medical stock, uniforms, transport, reporting tools and training. The following quotation supports this statement:

“It is a real pain because with my experience, clinics in the district were running stock outs of TB medication, and patients sometimes are sent home without the right drugs because medicines aren’t received on time. Many patients don’t have the transport money to make an extra trip to clinics when they are told there aren’t medicines for them on their scheduled check-up days. (46 year-old female TB supporter)”.

The data furthermore shows that the main obstacle to access to TB services is transport, which then exposes the DOT supporters to the strain of caring for TB patients in extreme temperatures:

“I would like to speak about service delivery at our PHC. I have identified a challenge of lack of transport or ambulance services, for example. You are faced with someone who is dying, and you know that if he’s transported somewhere with better facilities, he’ll be saved. But the ambulance has to come all the way from Chris Hani Bara. If it’s still busy with another clinic then you have to wait … sometimes 12 hours. Sometimes it doesn’t even come. (49 year-old female TB supporter)”.

“What is making life difficult for me is the poor weather conditions. When it is raining and when it is windy, we are not welcome into people’s homes. We are not
provided with protective clothing for tracing. The weather can be so bad. When it is hot, it is also very difficult (33 year-old female TB supporter)“.

In addition the data reveals that the TB supporters are faced with many social ills which affect them. Difficulties with debriefing and training were mentioned as impediments that affect them in dealing with a diverse community:

“We are playing an import part in the community. We are not capacitated in most conditions. We are in the community. At times the community is suffering from all sorts of social ills, so we need to have information and be trained on holistic approach to care and service delivery. (23 year-old female TB supporter)”.

“We need to be trained on Infection Control TB and MDR, and we also need accredited training as we must be employed. (32 year-old female TB supporter)”.

Moreover, the TB DOT supporters complain about a lack of resources for managing community health. The majority of the participants complained about a lack of home-based kits such as aprons, masks and gloves, as a result of which they are exposed to the risk of TB infection:

“Lack of equipments to do our work (gloves and facial mask). We are only provided with one pair of gloves for the week. Infection control measures are poor. (37 years female TB supporter)”

“We also need gloves and protective clothing. Sometimes I understand about wearing of a mask, but we need to protect us against community TB. At times we are expected to do home testing but we are not offered with gloves to protect ourselves during testing. This is not fair. Nurses are more protected than us. (40 year-old TB supporter)”.

“We are also getting TB infection from TB patients and we are expected to work. We are not allowed to take a day off or sick leave, our manager is saying that our
patients need us daily, if we cannot work we can leave and they can find a replacement immediately. (37 year-old female TB supporter)”.

“The TB infectious patient coughs, sneezes, talks at us, and we are not allowed to wear facial mask, as we are told that this is humiliating for the TB patients. (27 years old male TB supporter)”

“If you get infected while caring for TB patients and nobody care about you, we don’t get a mask to protect ourselves. Nurses in the clinic they are protecting themselves, they even drink the medication to protect themselves. You can’t wear a mask while you are visiting clients at home. (25 year-old female TB supporter)”.  

4.3.5.5. Physical and emotional strain

Data analysis shows that TB supporters are often faced with backaches as they carry helpless and obese TB patients, and often they do this alone without any assistance:

“Patients are very overweight. We are unable to carry them to the clinic if they are too sick, so part of our duties now is to educate the community about good nutrition and exercise. Overweight is a problem. Especially when they are bed-ridden, we are unable to wheel them. We end up with back pain. (44 year-old female TB supporter)”.

The data reveal that due to long distances they have to walk the TB supporters sometimes develop blisters. They cannot walk properly due to their tight shoes, and they are faced with the situation of having to buy shoes almost every month:

“You’d go until you develop blisters on your feet only to find out that he the patient failed to give the correct directions when he gave the address…. (35 year-old female TB supporter)”.  

63
The data reveals that TB patients are often faced with weather challenges such as hot weather, cold and rain. Despite all the unfavourable weather conditions they are still expected to trace TB patients, and the families often do not welcome them in their houses:

“Generally, weather is affecting us, hot and cold weather is not good for us. We need support with transport. (25 years old female TB supporter)”

Furthermore, the data reveals that TB supporters are exposed to emotional pain and stress while caring for TB patients. They are forced to perform other activities that they don’t know much about. such as preparing a deceased patient for the mortuary:

“We face stress and burnout. I wish I had an alternative. (47 year-old female TB supporter)”

“If you are stressed, you are unable to show love to your patient and even your children. Our children expect something from us at the end of the month, but nothing is coming except to get infection from TB patients. (36 year-old female TB supporter)
CHAPTER 5 – DISCUSSION

5.1. Introduction

This chapter presents a discussion of the main findings of the study derived from the experiences of TB DOT supporters managing TB patients in Orange Farm. The discussion will be divided into two parts. First the researcher will discuss the demographic findings and the main themes, and then will follow a discussion of the limitations of the study, the conclusions drawn, the strengths of the study, and the recommendations arising from the findings.

5.2. Description of the sample population

The ages of the TB DOT supporters ranged between 18 and 55. The majority of TB DOT supporters were between the 46 and 55 years old. Collins and Swartz (2011) record that home-based carers have an average age of sixty-nine years and family caregivers an average of forty-nine years, whereas other studies reported similar findings about the ages of home based carers of 40 year and above. Moetlo, Pengpid and Peltzer (2011) also records that most home based carers are more than forty years.

This study also revealed that 58.3% of the participants were single, only 18.3% of the participants were married, and 23.3% were divorced. Similar results were observed by Lindsey et al (2003) in their study, that the majority of the community home-based workers were not married and were single.

About 45% of DOT TB supporters had tertiary qualification, 28.3% had received secondary education, 23.3% had received primary education, and only 3.3% had never received any schooling. This means that most of them are able to understand the concepts of TB, as all the training is in English, and that they are also able to understand the concepts used in the TB medication prevention and support programme.
5.3.1. The Role of TB DOT supporters in TB management

Our data shows that TB DOT supporters play an important role in delivering equitable health services to hard-to-reach communities in informal settlements and remote areas, and they help to fill the unmet demand for regular services. They offer services such as the supervision of medication, the counselling of TB patients, motivation and support, and before they leave the patient (ensuring that the patient is comfortable) they record all of their findings in the TB chart.

Previous and current studies conducted about TB DOT supporters provide more insight about the significant role of TB DOT supporters in treatment outcomes (Macq et al., 2009; World Health Organization, 2009; NTP, 2014). Other studies show that TB DOT supporters and CHW do not have the same abilities as trained doctors or nurses they are trained to recognize complicated cases and refer them to health facilities that TB DOT supporters provide basic health care and education in areas where there is often no access to formal health care. They are effective because they are members of the communities they serve, they and their clients have shared experiences, language, and understanding that allow for real trust to flourish (Sanders et al., 2007).

Some studies (Lehmann and Sanders 2007) also report that TB DOT supporters have an empowering role, serving as a link between patients/communities and the health system, creating a voice for people living with HIV and/or TB, fulfilling identity-related needs, institutionalizing notions of volunteering, and building lay knowledge and expertise on health issues.

5.3.2. Referral role

TB DOT supporters serve as change agents in their communities. The data reveals that they are the eyes and ears of the community. They are able to identify those social issues that the health care providers cannot observe, and furthermore the data show that they link the TB patients with the primary health care system for diagnosis and treatment. Similar findings were documented in previous studies, where researchers have agreed that
community-based health interventions increase case detection and improve treatment access. (Malmborg et al., 2006; Jaiswal et al., 2008; Kamat and Nyato, 2010).

5.3.3. Other activities

Furthermore the study found that TB DOT supporters were involved in different activities in the community such as dealing with bereavement arising from the death of TB patients, gardening projects, and taking care of other chronic conditions in the community. As shown by the data, the TB DOT supporters counsel family members after the death of a patient and help to arrange mortuary services, especially for those TB patients staying alone. Similar findings found in previous studies, where it was documented TB DOT supporters play a very important role in contacting the priest or minister, and arranging food and accommodation for those attending a funeral (Akintola 2004, and Daniels et al., 2012).

This study shows that in addition to the participants supporting patients with medical care but they are also involved in other activities such as doing household chores, personal hygiene, and feeding those who are chronically ill. Previous and current studies (Sobuce, 2007; Pindani, 2008 and Mieh 2010) have reported similar findings, noting that DOT supporters/CHWs were involved in the provision of basic physical care and were doing this with pride as they ensured the physical and emotional comfort of their patients.

5.3.4. Health promotion and social mobilization

WHO (2009) reports a lack of knowledge about TB in communities. The TB DOT supporters in this study also stated that they are responsible for creating a demand for TB services and for helping the community to avail itself of these services. Furthermore, they are responsible for educating and teaching TB patients about the symptoms and signs of TB. They expressed their excitement when TB patients thereafter took actions relating to their health. Some studies (Nemcecek and Sabattier, 2003 Van Zyle, 2003) also reported that TB supporters actvately educate and disseminate information, and play an important role in case finding through social mobilization.
5.4. The motivation for DOT supporters joining the TB programme

The study found that the participants experienced a high level of motivation, as they viewed themselves as change agents stimulating communities to participate in caring for their own health, and they thought they were successful in this because they understand the community dynamics, The following sub-themes emerged on this major topic: a sense of altruism, a sense of religious obligation, a previous history of own illness, being unemployed and wanting to keepi busy, a passion to help, feedback from positive and negative experiences, and giving back to the community.

5.4.1. Sense of altruism

The results showed that majority of TB DOT supporters expressed altruistic motives in caring for TB patients and the community. They do this job voluntarily due to their recognition of the devastating effects caused by HIV and TB. Furthermore the data revealed that there is a sense of commitment and willingness to help without expecting any reward. This is in line with several studies. Volunteers are people who provide care outside the formal health care system and are not employed or do not receive remuneration for their services.

They give their services without expecting any form of reward. (London et al., 2001; Akintola, 2006; Akintola, 2010).Furthermore, the data has shown that a sense of altruism has created a trust-based relationship with rural communities. This insight is supported by Javanparast et al., (2011), who state that voluntary carers with altruistic motivation serve rural people with sound health knowledge and skills, and are the most important factors facilitating the successful implementation of a CHW programme in Iran.

5.4.2. Religious obligation

The data in this study shows that the participant have a sense of sympathy and love for their patients, and these emotions are strongly influenced by the participants’ religious beliefs and affiliation to different church denominations. They view their job as fulfilling their spiritual obligations and as a call from God. They therefore perform the activities of caring for the sick, praying for them, visiting them and sharing the worg of God with them and
reading bible scriptures that are comforting. The literature further shows that the majority of the participants in the various studies volunteered for such service in the hope of receiving some sort of spiritual blessing from God. This benefit could be in the form of God’s “breaking through” into their lives, or their receiving mercy and grace from God. These findings are in line with other studies whereby participants also saw volunteering as a necessary response to their religious teachings and obligations. (Akintola, 2010; Akintola, 2011; Maes et al., 2012).

5.4.3. Own illness

The data reveals that some TB DOT supporters were motivated to do voluntary work due to their personal experience of specific health problem related to HIV and TB. The majority of the TB DOT supporters had had a direct experience of family members dying from TB. This is in accordance with the findings of Sobuce (2007), who demonstrated that TB DOT supporters saw assisting others as an exchange, meaning that in future somebody else would take care of them or their family if they were in the same condition.

5.4.4. Keeping busy

Furthermore, the data showed that the participants joined the TB programme as they wanted to keep themselves busy. They couldn’t simply do anything at home when the community needed help. The majority of the young women were not working, and they derived a sense of satisfaction from keeping themselves busy and assisting those in need of care, also, as they were assisting the TB patients they were also learning the art and skill of caring for others.

The data revealed that one of the participants has now opened her own NGO and is caring for orphans and vulnerable children. Literature documents that people were volunteering to become carers because of a lack of job or because they needed to do something. The findings of another study also reveal that volunteers want to keep themselves busy as there were no other jobs for them, so they will do this one until the find another. (Akintola, 2010).
5.4.5. Passion

The data in this study reveal that TB DOT supporters have a sense of caring and concern for their patients. They said that they care about their patients and are concerned about their condition and wellbeing. Given the fundamental support provided by TB DOT supporters, this finding is very important, as the TB DOT supporters passion and willingness to go the extra mile is an important intrinsic motivation that helps them to continue working even under difficult conditions. The literature shows that these personal qualities are important virtues and motivation for TB DOT supporters in caring for others who cannot help themselves, and furthermore the data shows us that some TB DOT supporters even work extra hours, over the weekends and after hours. One of the TB DOT supporters mentioned that families even call them at night to assist the TB patients, and as a result they have interrupted time with their families due to the demands of their work.

This confirms the findings by other researchers that caregivers have limited time for their families and friends because their attention is divided. They are unable to give their family members adequate attention and affection due to their dedication to and passion for their work. (Collins and Swartz, 2011).

5.4.6. Positive experience

The participants in this study stated that they had both positive and negative experiences while caring for their patients. There was a sense of satisfaction as they saw improvements in the condition of the TB patients under their care and supervision. In this study our data shows that the TB DOT supporters had a sense of joy and pride in their work, thought that their contribution had helped the TB patients in their care, who gave them positive feedback and thanked them for their continuous care. The literature shows that carers have a positive image and want to do more. When they receive positive feedback from colleagues, family members and patients and they feel that they have achieved something and reached their self-actualization (Akintola, 2008).
Although the data reveals that the TB DOT supporters experienced positive feelings about their day-to-day caring duties, the data also reveals that many of them sometimes experience negative feelings towards their caring duties. They feel that they are given more tasks than they could handle, and that this diverts them from their expected roles in the community. Several other studies have also found that the ever-increasing workload was a serious issue for community health care workers (Coovadia et al., 2009; Akintola, 2010).

The findings of this study pertaining to the positive experiences of TB DOT supporters are in accordance with those previously reported from Morogoro, where it was documented in several research projects that strong altruistic motivation was not incompatible with feeling the importance of financial compensation of some kind, particularly considering the vulnerability of livelihoods in such communities. This is so, despite the reasons why TB DOT supporters participate in community TB programmes, which include amongst others the wish to see their patients return to their normal lives and to improve community health rather than an aspiration for financial reward (Uys et al., 2002; Rahman et al., 2010; Javanparast et al., 2011).

5.5. Reported benefits

5.5.1. Learning new skills

Participants in this study states that they have learnt new skills such as assertiveness, how to conduct patient assessments, and counselling, and that this has made them better community health care workers, as they were now receiving a lot of recognition and support from the community. Furthermore, the data from the study revealed that learning new skills was not a challenge to the participants, as most of them had secondary schooling and were mature people. The findings in this regard are in line with those in other studies that education and learning skills in the management of TB are important for community health care workers, as these factors help to improve case detection by increasing the carer’s awareness of the signs and symptoms of diseases, improve the case holding by reducing stigma and promoting the community’s support of its members who are infected with TB.
Educated community health workers are also able to recognise the sign of side-effects and to refer appropriately (Wright et al., 2006).

Furthermore the data has revealed that there are other skills which can be learnt, such as communication skills, and the art of persuading TB patients to agree to disclose to fellow family members.

5.5.2. Future employment

The study found that the participants view voluntarism as a stepping stone towards greater heights and an entry into the nursing profession, as they thought they will be considered for training should an opportunity arise. The findings of this study are in line with those in other studies, where the authors state that the caregivers expressed interest in developing their skills and indicated that when opportunities arise they should be afforded the opportunity to attend workshops so that they can be kept updated and motivated (Dimmer, 2006; Van Dyk, 2007).

The participants in this study appreciated training as a form of reward for them, and they suggested that they should be given certificates after completion of the training, as these would serve as qualifications when they applied for jobs elsewhere. This finding is in line with the findings of Van Oyk (2007) and Kangethe (2009) that rewards in the form of certificates, bonuses, trophies and tokens should be provided to caregivers as a form of recognition.

In addition, the data has revealed that some participants felt that volunteering had helped them in placing them in a position to gain job experience. In accordance with this finding, the literature shows that volunteers join such programmes and see their action of volunteering as establishing a foothold in the system, making it possible for them to obtain first-hand information about vacancies for paid jobs in other organisations in the health field, and at the same time securing a recommendation from their managers for vacancies. One participant in Akintola’s study was captured as saying that “volunteerism was a channel for the right-paying job”. (Akintola, 2010)
5.6.  Support received by TB DOT supporters

In spite of the carers’ growing enthusiasm due to the opportunities for career growth and for employment, the data reveals that it was the support received from the families of their patients, the community and the management actually sustained them in their difficult situations.

5.6.1.  Support from management and clinic staff

Most participants reported that they do receive support visits from the TB co-ordinator, and that there is an open line of communication through the use of social media platforms including sms and email. Similar findings were reported in other studies, which showed that the role of the manager in supporting staff includes the ability to serve as a mentor to staff in order to enhance their job satisfaction and performance. Such managers are called participative managers, because they consult their employees and talk about their mutual problems. (Akintola, 2010).

On the other hand, if the TB DOT supporters perceive indifference on the part of their seniors or the seniors disagree with them, this can put a serious drain on their job satisfaction, and some participants felt that clinic staff and management are not supportive. The previous literature also find that managers often criticize their subordinates because they believe that criticism improves performance, forgetting that human performance is never completely consistent and that no one performs at their best or worst every day. (Akintola, 2010).

5.6.2.  Support from family members

The data from this study suggests that some TB DOT supporters in this intervention felt supported by the families of their patients, although other participants viewed family members as being unsupportive and demanding. Some participants reported that while working with patients and their families the families welcomed them in their home and showed love and sympathy towards the TB patients. The data further shows that TB DOT
supporters have to deal with the first-hand challenges faced by such families, such as poverty, stigmatisation and discrimination, and the demands of TB patients who expect a lot from them, such as food and toiletries. Similar finding were documented in previous findings, that volunteers were playing an important role in the delivery of informal care to the affected families and communities. They do so also by educating the families and supporting the TB patients. (Akintola, 2008).

The data reveal that some families show appreciation and offer support to the carers when they are being faced with a dry season challenge of not being remunerated with stipend on time, and are not receiving their stipends. They offer advice on how to cope with such challenges. They even communicate with the TB DOT supporters even when the TB patient is cured. They trust them with other health-related issues. (Akintola, 2008).

Contrary a notable number of participants reported high level of emotional stress due to family members who stigmatize patients due to their TB infection and amongst reasons cited by families was fear of contacting TB. Some participants also felt pain and hurt as they notice that family members only want TB patient’s social grants. TB infection has a negative and emotional impact amongst families and patient himself. Similarly Chanda and Gosnell (2006) indicated that family members sometimes lose interest in continued supervision and care for the patients and in developed countries the use of family members showed the worse adherence to TB (Chanda et al., 2008). This study adds to the findings of similar studies regarding lack of family support in care. Munthali’s findings (in Chanda and Gosnell 2006) correspond with those of Sagbakken et al., (2008), that the chronic nature of the disease and prolonged treatment protocol can affect compliance to treatment even with family support.

5.7. Challenges faced by DOT supporters

Several challenges were raised during the focus group discussions and the following were noted: the lack of monetary incentives, the difficulty of contact tracing, the insecurity of the DOT supporters, a lack of resources, and emotional strain.
5.7.1. Monetary incentives

All of the participants felt that the financial incentives linked with their jobs were insufficient, and the opportunity to gain income was agreed to be a motivator for the majority of the TB DOT supporters. The data in this study reveal that most of the participants were challenged by not receiving their stipends on time. They said that sometimes the department will go through a “dry season”, which will mean that they will have to work without any compensation or incentives for several months and at the same time be expected to work as normal. Some of the younger TB DOT supporters said that they would quit if they didn’t receive any material rewards.

This finding is supported by those in several studies that volunteers may quit if they are not satisfied financially. This may partly explain the high attrition rates of volunteers which have been recorded in one of the participating NGOs, and in many home-based care programmes in South Africa (Russel and Schneider, 2000; Akintola, 2004; Kangethe, 2009).

The studies further shows that participant were in a dilemma especially at the end of the month, as they could not afford to meet their basic needs such as food and transport. In this study participants showed bitterness and anger towards the government for not supporting them and making sure that they were integrated into the primary health system. This finding is confirmed by Van Dyk (2007), who says that on a policy level carers tend to feel unsupported by the government and the health, social, and legal systems, which leads to a sense of frustration. Similar finding are reported by Akintola (2010), that the South African government’s inability to provide adequate AIDS services creates a huge care gap in the pandemic.

5.7.2. Contact tracing

Contact tracing is one of the roles of TB supporters. In the event of a patient not completing his/her treatment for tuberculosis, for instance, the TB supporter is asked by the clinic to search for this person in the community. According to Lehman (2009), the DOTS programme allows for the tracing of the defaulters and ensuring that they are returned to treatment as
soon as possible. The TB supporter must then refer that person to the clinic and do the follow-up work. The TB DOT supporters also follow-up on the contacts of Children under five years old in the informal settlement. The participants in this study reported that the tracing of defaulters is physically exhausting as they have to travel long distances, and this affects their health in that they develop blisters. They also said that tracing is also costly, as they have to have their shoes repaired time and again. Several studies concur with the findings of in this regard, that the TB DOT supporters report that patients provide incorrect addresses, especially those residing in the informal settlements, that are increasingly difficult to trace (Tshabalala, 2007; Lehman, 2009).

5.7.3. Safety of DOT supporters

The study extends knowledge about the safety of TB DOT supporter’s in the community. The study shows that some of the areas in which they conduct their visits were very far away and unsafe, as such areas are famous high-crime areas in the informal settlement. Community based care is an important part of delivering treatment and services to HIV-infected people; however, many organisations do not realise the uneasiness that is caused in their workers due to their fear for their safety (Fransman et al., 2009) The data shows that young female DOT supporters were concerned about their welfare and safety in the area. Furthermore, the data reveals that TB DOT supporters were bitter and angry as they felt that they are not supported with transport in high crime areas. They also complained that they have to walk long distances in search of TB patients who spend their time in shebeens, which is behaviour inconsistent with their treatment regimen. (Teela et al., 2009).

5.7.4. Lack of resources

The DOT supporters need working tools and resources to enable them to positively and confidently perform their work. They described a sense of helpless and frustration, as there are so many patients but few resources. The data reveal that the TB DOT supporters were not provided with enough working tools such as protective clothes and facial masks to
protect them against TB infection, and sometimes they had to improvise by reusing the gloves and masks. This is unacceptable in terms of infection control and prevention practices. Similar data were observed and documented by several researchers (McInerney and Brysiewicz, 2009; Mieh, 2010; Moetlo et al., 2011).

The majority of the TB DOT supporters felt that they are at risk of contracting tuberculosis (TB) and other HIV-related infections from their patients. Many felt fearful of working with people with TB, as the risk of being infected with TB in such a situation made them feel uncomfortable and fearful, especially when their patients came back with MDRTB. In this study the fear of contracting TB was raised as an issue by the DOT supporters. Furthermore, they complained that they were ill-equipped and occasionally not provided with protective clothes, and as a result they ended up by reusing and washing gloves. This has a negative impact on the quality of care rendered to patients, as it undermines sound infection control practices, and is particularly dangerous as TB is highly contagious. Similar findings were also highlighted by Beylis (cited in HIV and AIDS treatment in practice, 2009), who described the risk of infection as being much higher due to the caregivers working so closely with infectious TB patients, especially if safety measures are not in place.

However, the uncertainties of the TB DOT supporters in the current study were alleviated to a certain extent when they were given training on infection control practices and how to protect themselves from acquiring TB. (Akintola (2006) and Van Dyk (2007) reinforced the issue that quality is compromised due to inadequate resources in clinics and also at homes if CHWs are not provided with gloves, sanitation towels, bleach or incontinent sheets to handle patients adequately.

5.7.5. Emotional and physical stress

The TB DOT supporters in the study were very vocal about the emotional and physical effects that caring for TB patients had on them. The study found the following as affecting TB supporters: the bad living conditions of impoverished TB patients, having to deal with the personal effects of dead TB patients, an increasing workload as they are expected to do everything in the community, the lack of training, and the high attrition rate amongst the TB
DOT supporters. The data also revealed that the TB DOT supporters were often faced with stubborn and uncooperative patients. Some studies (Miller et al., 2007; Mullins, 2009; Van Dyk, 2007) also reported that carers experienced feelings of distress, felt overworked, demoralised and emotionally distressed due to seeing patients with an incurable disease deteriorate over a long period. The data revealed that caring for TB patients has a negative impact on TB DOT supporter’s physical well-being, as they reported developing blisters and developing flu-like symptoms due to their exposure to unfavourable weather conditions. Similar results were found by Van Dyk (2012) in her research on the well-being of caregivers. This supports the finding that caring for people living with TB infection often has a negative impact on caregivers’ physical well-being.

5.8. Conclusion and summary

According to the results of this study, the success of TB control and treatment in the informal settlement of Orange Farm is being challenged by several factors, which include but are not limited to the following:

1. The delay in incentivising TB supporters,
2. Compromising the safety of DOT supporters while they trace TB patients in the informal settlement,
3. The lack of community support and management support,
4. The high attrition rate and being overworked, as they have to fill the gap caused by those who resigned.
5. High levels of stress as a result of the many challenges they face while working, being exposed to TB due to the lack of an adequate supply of resources such as gloves and masks, and most of all not being given a clear explanation about their salaries.

Furthermore, this study has shown that the TB supporters were involved not only in providing TB services but were also developing the community by promoting gardening for food and supporting TB patients by doing household chores such as cleaning, and taking care of the personal hygiene of chronically ill patient.
This study found that the participants had positive experience which gave them a sense of pride and prestige, as they had affected treatment outcomes, and their patients and the patients’ families showed their appreciation for what they had done. The study revealed that the TB supporters had a sense of joy and sense of job satisfaction as they engaged TB patients’ families and the community by educating families and conducting support groups with families. Sometimes participants met patients that are non-South African or South Africans that did not have important documents like birth certificates and identity cards. The participants would take it upon themselves to facilitate that these patients acquired such documents so that the patients may have access to services like the social grant and food parcels.

The TB DOT supporters in this study were motivated by their own illness and that of family members, and they had volunteered in order to give a helping hand to others, as they had learned a lot from experiencing the disease first hand, and they felt that their knowledge derived from their own experiences could assist the community. They felt happy when they gained new knowledge and experience, when communities referred clients to them, and when they were called nurses and doctors. They found volunteerism to be a stepping stone to a new life, as they believed that through their volunteering they would gain entry into the nursing profession and other professions in the fields of health and social development.

The carers expressed emotions of hurt, despair, exhaustion and stress owing to what they are confronted with on a daily basis as they care for dying TB patients. They are physically tired as they have to carry overweight TB patients alone, and they have to support many patients with limited resources. They complain of not being given resources such as facial masks and gloves, they are forever exposed to patient excreta, and they have to deal with the contact tracing of defaulters alone in very dangerous places without being provided with transport.

The TB programme faces many challenges that need the intervention of government. The participants were also not happy about the delay in the payment of their stipends. They are expected to work even during the “dry season” and no one explains anything to them.
Sometimes they are expected to work over the weekend and travel long distances with no compensation, and this affects their attitudes as carers.

Caring for TB patients is not easy. The DOT supporters are trying their best and they need to be supported by PHC and the community to continue to find more TB cases and to ensure that all patients are being retained in treatment. However, despite all the challenges they face, they always find a way out, and always have new ways of assisting TB patients

5.9. **Strength of the study**

This study adds to the body of knowledge on TB supporters. This information will assist in the planning, monitoring and implementation of TB supporters’ programmes. This will improve the TB outcomes and will benefit the TB supporters.

5.10. **Limitations of the Study**

In considering the findings in this study, it is important to bear in mind that the results from this study cannot be generalised to all NGOs in Orange Farm, since only a convenient sample was used. It would have been of benefit to conduct focus group discussions with TB patients and TB nurses as well, to find out their thoughts about the role of DOT supporters in TB treatment.

5.11. **Recommendations**

In line with the findings of this study, the following is recommended:

- **Political Commitment**: it is important that the government should show its leadership in the TB programme by providing the necessary resources such as face masks and other forms of protective clothing.

- **Policy**: although the South African government has a policy regarding the payment of DOT supporters, the data reveals that community health care workers are not compensated on time. It is important to make sure that funding is available and people are paid on time so that they can manage their own personal lives.
- **Training in all aspects of community service**: basic counselling skills, HIV/TB/STI/PMTCT, and such training should be certificated by an accredited trainer.

- **Basic Condition of employment** issues around sick leave, family responsibilities, the safety of TB supporters, study leave and overtime should be discussed with the TB supporters, and they should be allowed to do extra duties to make more money.

- **Transport and the ambulance** service should prioritize MDRTB patients, as such patients should not be travelling in public transport.

- The TB supporters should be provided with uniform including shoes, raincoats, umbrellas and other protective clothing necessary to their work in the community.

- Food parcels should be made available to impoverished TB patients.
REFERENCE LIST


Region G (Orange Farm) Metropolitan Municipality. (2010), Health and Social Development Annual Report J. Region G. Gauteng, South Africa


Patton, M.Q. (2002). Enhancing the quality and credibility of qualitative analysis: qualitative research and evaluation methods, Sage, California


APPENDIX 1: RESEARCH ETHICS CLEARANCE CERTIFICATE

UNIVERSITY OF LIMPOPO
Medunsa Campus

MEDUNSA RESEARCH & ETHICS COMMITTEE

CLEARANCE CERTIFICATE

MEETING: 06/2013
PROJECT NUMBER: MRECH/H/172/2013: PG
PROJECT:
Title: Experiences of Direct Observation treatment supporters in managing TB patients in the informal settlement of Orange farm
Researcher: Ms FM Mathuli
Supervisor: Ms Busi Ntsh-Ngcobo
Department: Public Health
School: Health Care Sciences
Degree: MPH

DECISION OF THE COMMITTEE:
MREC approved the project.

DATE: 01 August 2013

PROF GA OGBUNABUIJO
CHAIRPERSON MREC

The Medunsa Research Ethics Committee (MREC) for Health Research is registered with the US Department of Health and Human Services as an Institutional Organization (IRG0004319), as an Institutional Review Board (NDB0000512), and
is functions under a Federal Wide Assurance (FWA00009419)

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.

Finding Solutions for Africa

92
17 March 2014

Dear Ms Malthu

APPROVAL TO CONDUCT RESEARCH WITHIN THE JOHANNESBURG HEALTH DISTRICT

Permission has been granted to you to conduct research within the Johannesburg Health District.

Title: Experiences of Direct Observation Treatment supporters in Managing TB patients in the informal settlements of Orange Farm

Please contact the following person(s) before you commence with your project and to gain access to the Local Government clinics:

<table>
<thead>
<tr>
<th>Region</th>
<th>Regional Health Manager</th>
<th>Contact No.</th>
<th>Cell phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>G</td>
<td>Hlubi Nkanehi</td>
<td>011 211 8936</td>
<td>083 286 0388</td>
</tr>
</tbody>
</table>

Should you have any queries please do not hesitate to contact our department.

We look forward to your Final Research Report.

Thank you

DR. R. BISIMILLA
Executive Director
City of Johannesburg
Health Department
Statement concerning participation in a Research Project

Name of Study: EXPERIENCES OF DIRECT OBSERVATION TREATMENT STRATEGY SUPPORTERS IN MANAGING TUBERCULOSIS PATIENTS IN THE ORANGE FARM INFORMAL SETTLEMENT – SOUTH AFRICA

I have read the information/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 aim and objectives of the study are sufficiently clear to me. I have not been pressurized to participate in any way.

I know that sound recordings will be taken of me. I am aware that this material may be used in scientific publications which will be electronically available throughout the world. I consent to this provided that my name / and hospital number is / are not revealed.

I understand that participation in this study is completely voluntary 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 study has been approved by the Medunsa Research Ethics Committee of the University of Limpopo, Medunsa Campus. I am fully aware that the results of this study will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

I hereby give consent to participate in this study.

___________________  ________________
Name of the Volunteer    Date       Place

Statement by the Researcher

I provided verbal and/or written* information regarding this study

I agree to answer any future questions concerning the study as best as I am able.

I will adhere to the approved protocol.

___________________
Name of Researcher

___________________
Signature

Date
## APPLICATION FOR APPROVAL TO CONDUCT RESEARCH

<table>
<thead>
<tr>
<th>ENQ: Ms N. R.M.Maithufi</th>
<th>P O BOX 93270, Boordfontein.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cell: 079 741 9087</td>
<td>0201</td>
</tr>
<tr>
<td></td>
<td>4 April 2013</td>
</tr>
</tbody>
</table>

The Secretariat  
The Department of Health and Social Development  
Provincial Research Committee  
37 Sauer Street, Bank of Lisbon,  
Johannesburg

Dear Sir/ Madam

**Re: APPLICATION FOR APPROVAL TO CONDUCT RESEARCH**

I am a student for Master Degree in Public Management at the University of Limpopo (Medunsa Campus). As part of my degree requirement I would be conducting a study on “*Experiences of Direct Observation Tuberculosis Supporters managing Tuberculosis patients in the informal settlement of Orange farm Region G (Gauteng Province)*” and my subjects will be Direct Observation Tuberculosis supporters who are rendering Tuberculosis care and services in the informal settlement of Orange farm.

The duration of the interview will be 45 minutes to an hour. The date and time of the interview will be negotiated with you in order to avoid any interruption to the running the services. I would like to assure you that all information gathered will be utilized for the purposes of this study only.
I hope my letter will meet your approval.

Yours sincerely

Regina Moitsheki Maithufi (Ms)

Master’s in Public Management Student

Signature ........................................ Date........................................
APPENDIX 5: FOCUS GROUP DISCUSSION CONSENT FORM

FOCUS GROUP DISCUSSION CONSENT FORM

Thank you for agreeing to participate in this focus group interview, my name is Regina Maithufi; I am a Masters student at the school of public health in Medunsa. I understand that you are volunteers working in Orange farm; I would like to talk to you about your experiences managing TB patients in the informal settlement. I would like to reassure you that everything is confidential and please feel free to tell me everything about TB in the informal settlement, please let me know if you are not comfortable about any question asked.

The discussion we are going to have is called a focus group. For those of you who have never participated in one of these sessions I would like to explain a little bit about this type of research. Focus groups are used to gather information informally from a small group of individuals who have common interest in a particular subject—in this instance, your experiences in Managing TB patients in the Informal settlement of Orange farm. This discussion will provide invaluable information to the TB control programme in the Region. In focus groups, there are no right or wrong answers. We want to hear from everyone in the room. We are pleased you can be part of this group because we think you have important ideas regarding the TB programme. Don’t hesitate to speak up when you have a point you would like to raise during the discussion, my colleague will be taking notes and tape recording the discussion so that I do not miss anything you have to say during the discussion.

Participation in this study is voluntary and you are free to refuse to participate or to withdraw your consent and to discontinue participation at any time, such refusal or discontinuance will not affect your work as volunteer. Also, you do not have to answer all questions; you may answer some questions but not all. If you refuse to answer questions, it will not affect your performance at work. If you agree to participate in this study, would you please sign the consent form? We will not disclose your name or connect your name with anything you say. In conclusion you are allowed to ask any question in relation to the topic.
QUESTIONS

1. Please tell us how you started to work as TB supporter?

2. What are your experiences in doing your work as TB DOT supporter?
   
   *Probe from discussion*

3. What affects you most as TB DOT supporter?
   
   *Probe*
   - What do you find good in doing your work as DOTS Supporter?
   - What do you find not so good in doing your work as a DOTS Supporter?

4. What would you say helps you continue to do your work as a TB DOTS Supporter?
   
   *Probes from discussion*

5. What makes it difficult for you to do your work as DOTS Supporter?
   
   *Probes from discussion*

6. What are challenges that you experience in doing your work as DOTS supporter?
   
   *Probe From discussions*

*THANK YOU FOR YOUR TIME*
Appendix 6: Research Participant Questionnaire

QUESTIONNAIRE: DOTS SUPPORTERS

INSTRUCTIONS:

- Please read the questions carefully. Tick the appropriate answer with an X in the space provided. Provide information/ explanation where needed.
- Please answer the questions as honestly as possible.
- The information obtained will be used for research purposes only, not for personal gains.

Date:

QUESTIONS

1. What is your Age?

2. How long have you been working as TB DOT supporter? Please explain

3. Gender:

   Male  Female

4. Highest Educational Level

   Primary School  Primary Level  Tertiary Level  No Formal Education

5. Marital Status:

   Married  Single  Widow  Living with  Divorced
6. What distance do you travel for the home visit to DOT TB patients?

| Less than 5 km | 5 – 10 km | More than 10 km |

7. Means of transport:

| Walk | Bicycle | Taxi | Bus | Government vehicle |

8. Did you receive any training?

Yes | No

If yes, in what .................................................................
And for how many days............................................................
If, No, what kind of training would you want to enhance your work ..........................................................

9. How many clients do you support per day?

| 2 patients | 5 patients | 10 patients |

10. Do you receive monthly stipend?

Yes | No

If yes, how much do you receive per month? ..........................................................
..........................................................................................................................
If No, how does this affect your daily work as TB DOT supporter? ..........................
..........................................................................................................................

Thank you!!!