

**The University of the Western Cape**



**School of Government  
Institute for Social Development**

**Challenges Faced By Healthcare Workers in Conducting Clinical  
Research in Selected Western Cape Sites**

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A Mini-Thesis Submitted to the Institute for Social Development, Faculty of Arts, University of the Western Cape, in partial Fulfilment of the Requirement for the Master of Arts (MA) Degree in Development Studies

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## **KEY WORDS:**

1. Desmond Tutu TB Centre (DTTC)
2. Healthcare workers (HWCs)
3. Tuberculosis
4. HIV
6. AIDS
7. Risks of exposure
8. Stigma
9. Poverty
10. Clinical research



## DECLARATION

I, **Grace Colleen Bruintjies**, hereby declare that this mini-thesis entitled “*An exploration of the challenges healthcare workers face in conducting clinical research*” is my own work, that it has not been submitted before for any degree, or examination in any other university or college, and that all the sources I have used or quoted have been indicated and acknowledged as complete references.

**Grace Colleen Bruintjies**

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*Signature of candidate*



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*Date*

The work presented in this Mini-dissertation was undertaken in the Institute for Social Development, Faculty of Arts, University of the Western Cape, in partial Fulfilment of the Requirement for the Master of Arts (MA) Degree in Development Studies.

## DEDICATION

*To my husband, Mervin Jeffrey Bruintjies who has done the shopping, provided meals and looked after the household and children while I toiled at my computer – and supplied endless cups of coffee! Thank you. Your love and support has meant so much to me. To my two teenage children, Colleen Merle Bruintjies and Enrico Reagan Bruintjies for the inspiration, encouragement and for your understanding of me “for not having time for them” and providing me space to finish this thesis.*

*“The purpose of learning is growth, and our minds unlike our bodies, can continue growing as long as we live”.*

Mortimer Adler



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## TABLE OF CONTENTS

|   |          |
|---|----------|
| KEYWORDS.....   | ii       |
| DECLARATION.....  | iii      |
| DEDICATION.....   | iv       |
| ACKNOWLEDGEMENTS.....   | v        |
| TABLE OF CONTENTS.....  | vi       |
| LIST OF TABLES.....   | ix       |
| LIST OF FIGURES.....  | x        |
| ANNEXURES.....  | xi       |
| ABBREVIATIONS AND ACRONYMS.....   | xii      |
| ABSTRACT.....   | xiii     |
| <br>  |          |
| <b>CHAPTER ONE: INTRODUCTION AND BACKGROUND.....</b>                        | <b>1</b> |
| 1.1 Introduction.....   | 1        |
| 1.2 International perspective of healthcare worker.....                     | 1        |
| 1.3 The role of the healthcare worker in the clinical research process..... | 1        |
| 1.4 Brief overview of clinical research in South Africa.....                | 3        |
| 1.5 Brief overview of the Desmond Tutu TB Centre.....                       | 4        |
| 1.6 Statement of the research problem.....                                  | 6        |
| 1.7 Research question.....  | 6        |
| 1.8 Aims and Objectives.....  | 7        |
| 1.9 Motivation for the study.....   | 7        |
| 1.10 Significance of the study.....   | 8        |
| 1.11 Definitions of key concepts.....                                       | 8        |
| 1.11.1 Healthcare workers.....  | 8        |
| 1.11.2 Tuberculosis.....  | 9        |
| 1.11.3 HIV and AIDS.....  | 10       |
| 1.11.4 Risk of Exposure.....  | 10       |
| 1.11.5 Stigma.....  | 10       |
| 1.11.6 Clinical Research.....   | 12       |
| 1.11.7 Poverty.....   | 12       |
| 1.12 Research Agenda.....   | 13       |

|  |           |
|--|-----------|
| <b>CHAPTER TWO: LITERATURE REVIEW.....</b>                     | <b>14</b> |
| 2. Introduction.....   | 14        |
| 2.1 A Healthcare worker.....                                   | 15        |
| 2.2 Challenges confronting healthcare workers.....             | 15        |
| 2.2.1 Recruitment and Retention.....                           | 15        |
| 2.2.2 Psychological Impact.....                                | 16        |
| 2.2.3 Risk of exposure to TB and HIV: Health care workers..... | 17        |
| 2.2.4 Stigma and discrimination.....                           | 18        |
| 2.2.5 Safety.....  | 19        |
| 2.3 TB and HIV in South Africa.....                            | 20        |
| 2.4 The prevalence of TB in the Western Cape.....              | 23        |
| 2.5 Brief overview of the impact of TB and HIV/AIDS.....       | 25        |
| 2.6 TB: A disease of poverty.....                              | 26        |
| 2.6.1 Manifestation of poverty.....                            | 27        |
| 2.6.2 Poverty and TB, HIV/AIDS: Exploring a Link.....          | 29        |
| 2.7 Summary.....   | 30        |
| <br>   |           |
| <b>CHAPTER THREE: THEORETICAL FRAMEWORK.....</b>               | <b>31</b> |
| 3. Introduction.....   | 31        |
| 3.1 Phenomenology approach.....                                | 31        |
| 3.2 Summary.....   | 34        |
| <br>   |           |
| <b>CHAPTER FOUR: RESEARCH DESIGN AND METHODOLOGY.....</b>      | <b>35</b> |
| 4. Introduction.....   | 35        |
| 4.1 Research framework.....                                    | 35        |
| 4.2 Research design.....                                       | 36        |

|       |   |    |
|-------|---|----|
| 4.3   | Research Methodology.....                 | 37 |
| 4.3.1 | Data Collection Techniques.....           | 38 |
| 4.3.2 | Informal Discussions and Observation..... | 38 |
| 4.3.3 | In-depth Interviews.....                  | 38 |
| 4.3.4 | Data Collection instruments.....          | 39 |
| 4.3.5 | Reliability and Validity.....             | 40 |
| 4.4   | Sampling Method.....                      | 41 |
| 4.4.1 | Non-probability sampling.....             | 41 |
| 4.4.2 | Purposive Sampling.....                   | 41 |
| 4.5   | Data processing and analysis.....         | 42 |
| 4.6   | Ethical Statements.....                   | 43 |
| 4.6.1 | Authorisation to conduct research.....    | 43 |
| 4.7   | Time Frame.....                           | 44 |
| 4.8   | Limitations of the study.....             | 44 |
| 4.9   | Summary.....                              | 44 |



**CHAPTER FIVE: DISCUSSION AND PRESENTATION OF DATA ANALYSIS  
AND RESEARCH FINDINGS.....45**

|       |   |    |
|-------|---|----|
| 5.1   | Introduction.....   | 46 |
| 5.2   | Demographic profile of participants.....  | 46 |
| 5.2.1 | Gender and age distribution of participants (DTTC-healthcare workers).....            | 49 |
| 5.3   | Different challenges faced by healthcare workers.....                                 | 49 |
| 5.3.1 | Recruitment and Retention of participants in clinical research/health interventions.. | 49 |
| 5.3.2 | Migration of participants.....  | 50 |
| 5.4   | Psychological impact.....   | 51 |
| 5.4.1 | Emotional Trauma.....   | 51 |
| 5.5   | Risk of exposure to TB and HIV.....   | 53 |
| 5.5.1 | Safety.....   | 54 |
| 5.5.2 | Unsafe conditions that healthcare workers face.....                                   | 54 |
| 5.6   | Stigma.....   | 55 |



|   |   |           |
|---|---|-----------|
| 5.6.1   | The effect of stigma attached to/associated with TB an HIV/AIDS on<br>healthcare workers.....             | 56        |
| 5.7   | Mentoring and Debriefing.....   | 58        |
| 5.8   | Strategies/interventions to assist healthcare workers with emotional and<br>psychological challenges..... | 59        |
| 5.9   | Summary.....  | 60        |
| <b>SUMMARY, RECOMMENDATION AND CONCLUSIONS.....</b> |   | <b>61</b> |
| 6.1   | Introduction.....   | 61        |
| 6.2   | Recommendations.....  | 62        |
| 6.2.1   | Recommendations for psychological impact.....   | 62        |
| 6.2.2   | Improvement of Infection control, protection and Medical Insurance.....                                   | 63        |
| 6.2.3   | Development of Policies relating to Safety Related Issues.....  | 64        |
| 6.2.4   | Allocate renewed resources in countering impact of stigma attached to TB.....                             | 64        |
| 6.3   | Conclusion.....   | 65        |
| <b>REFERENCES.....</b>                              |   | <b>66</b> |
| <b>ANNEXURES.....</b>                               |   | <b>79</b> |



## LIST OF TABLES

|                 |  |    |
|-----------------|--|----|
| <b>Table 1</b>  | TB infection versus TB Disease.....                              | 9  |
| <b>Table 2</b>  | Definitions of Poverty.....                                      | 12 |
| <b>Table 3</b>  | Global burden of TB in 2010.....                                 | 20 |
| <b>Table 4</b>  | HIV prevalence estimates and the number of PLWHA, 2001-2010..... | 22 |
| <b>Table 5</b>  | Active Case Finding per Province.....                            | 23 |
| <b>Table 6</b>  | Registered Cases: Susceptible TB per province.....               | 24 |
| <b>Table 7</b>  | Registered Cases: MDR TB per province.....                       | 24 |
| <b>Table 8</b>  | What Phenomenology is and is not.....                            | 32 |
| <b>Table 9</b>  | Summary of Research Framework.....                               | 35 |
| <b>Table 10</b> | Four steps in pursuing phenomenological research.....            | 37 |



## LIST OF FIGURES

|                 |   |    |
|-----------------|---|----|
| <b>Figure 1</b> | Map of Epidemiology field site Ravensmead and Uitsig..... | 5  |
| <b>Figure 2</b> | Picture of Khayelitsha.....                               | 27 |
| <b>Figure 3</b> | Major Themes and Sub Themes.....                          | 45 |
| <b>Figure 4</b> | Thematic Codes.....                                       | 46 |
| <b>Figure 5</b> | Gender distribution of participants.....                  | 47 |
| <b>Figure 6</b> | Age distribution of participants.....                     | 47 |
| <b>Figure 7</b> | Highest Educational distribution of participants.....     | 48 |
| <b>Figure 8</b> | Interviewee's professional orientation.....               | 48 |



## ANNEXURES

|   |    |
|---|----|
| Annexure 1: Request for access to conduct the study.....      | 80 |
| Annexure 2 Permission Letter: Desmond Tutu TB Centre.....     | 81 |
| Annexure 3: Information Sheet.....                            | 83 |
| Annexure4: Consent to Participate.....                        | 84 |
| Annexure5: Informed Consent: Tape Recording of Interview..... | 86 |
| Annexure 6: Interview Schedule.....                           | 87 |
| Annexure 7: Example of a transcription of an interview.....   | 89 |



## **ABBREVIATIONS AND ACRONYMS**

|       |   |                                    |
|-------|---|------------------------------------|
| DTTC  | – | Desmond Tutu TB Centre             |
| WHO   | – | World health Organization          |
| MDG   | – | Millennium Development Goals       |
| TB    | – | Tuberculosis                       |
| SU    | – | Stellenbosch University            |
| HIV   | – | Human Immunodeficiency Virus       |
| AIDS  | – | Acquired Immunodeficiency syndrome |
| DOH   | – | Department of Health               |
| ASSAF | – | Academy of Science of South Africa |
| NIH   | – | National Institute of Health       |
| GCP   | – | Good Clinical Practice             |
| MDR   | – | Multi-drug resistance              |
| XDR   | – | Extensively-drug resistance        |
| NGO   | – | Non-governmental organisation      |
| ART   | – | Anti-retroviral Therapy            |
| PLWHA | – | People living with HIV/AIDS        |
| EAP   | – | Employee assistance programme      |

## **Abstract**

According to Lang (2011), the improvement in the health status of a country lies in the application of the results of continuous research studies that are inclusive of the poorest regions of the world. Casey (2004) though, holds the view that carrying out this critically important research i.e. the research process, is very different from what is portrayed in literature, since the challenges that face one in the field are often formidably more difficult to resolve than is typically suggested in literature.

This study is interested in understanding and describing the everyday reality of clinical researchers from the perspective of those who operate on the grassroots level –in this case, the field staff working under the guidance of the study coordinator and principal investigators. Since it is often healthcare workers who interact most with research participants, they are confronted with many of the inherent challenges of conducting research. However, their views and perspectives on these challenges generally go undocumented (Kingori, 2007).

This research comprises an exploratory study of the challenges that community-based healthcare workers face in the execution of their professional duties in impoverished and vulnerable communities of the Cape Metropolitan area. The Desmond Tutu TB Centre (DTTC) and three community-based recruitment sites have been selected as the study area. This research endeavoured to shed light on (some of) the numerous challenges facing community-based healthcare workers active in the said communities. This will assist the DTTC to ameliorate the problems related to such challenges, and to develop better strategies for dealing with them.

A qualitative research design was employed within the phenomenological paradigm. A phenomenological paradigm encouraged participants, through semi-structured interviews, to provide information based on how they experience the phenomenon. Healthcare workers – nurses, doctors, counsellors, drivers, and study co-ordinators of research projects –were interviewed to gather the relevant information. The findings of the study clearly substantiate the need for a programme to support healthcare workers in clinical research, to voice and highlight the challenges they experience in the field and that such initiatives are effective and accessible.

# CHAPTER ONE

## INTRODUCTION AND BACKGROUND

### 1.1 Introduction

Conducting programme intervention and research in impoverished urban areas is burdened with challenges and difficulties that are often not anticipated by the institutions or researchers involved in the research protocol. According to Mathee & Harpham (2010), researchers – who do the planning –are often unaware of the challenges that field staff (or workers) may encounter working in socio-economically marginalized urban communities. This exploratory study will essentially deal with this issue; in other words, investigate and explore the challenges that community-based healthcare workers face in executing their duties in vulnerable communities.

### 1.2 International perspective of the healthcare worker

Globally there are an estimated 59.8 million healthcare workers. About two-thirds i.e. 39.5 million provide health services while the other 19.8 million provide management and support services. These healthcare workers have a very important role that they play in terms of prevention and treatment of diseases and improvement in healthcare, as well as trying to reach those who need it the most. The sub-categories of healthcare workers do not only include those working in institutional hospitals, but also lay healthcare workers and community healthcare workers conducting clinical research (WHO: 2010).

### 1.3 The role of the healthcare worker in the clinical research process

According to Hill & MacArthur (2006), the healthcare worker in clinical research is often devalued and somewhat ridiculed as mere data collectors; the reality is however, that they are crucial members of the clinical research team, often delivering specialised care to patients. Healthcare workers regularly receive specialised training in protocol and research ethics by the principal investigators and institutions conducting the clinical research. Their roles demand that they not only adhere to the Nursing Act No. 33 of 2005 and codes of practice,

but also to national and international legislation and guidelines for Good Clinical Practice (GCP).

According to Niu (2010), healthcare workers are individuals whose distinct roles are to care for and enhance the health of the community at large. They are employees of governments and non-governmental bodies or institutions whose primary goals are to improve the health of a nation as well as to strengthen health systems and enforce related policy. Healthcare workers function differently depending on where they work. Healthcare workers in hospitals and primary healthcare facilities have clearly stated protocols and procedures, chain of commands, and shared institutional goals, whilst healthcare workers conducting community-based research face challenges related to the role in community settings. This wide variety of settings and tasks means that transferability of processes is not always straightforward (Oandasan et al., 2006).

McKinney & Vermeulen (2000), quoted in Hill & MacArthur (2006), describe the research healthcare worker as “a vital link between patient, principal investigator, study sponsor and administrative staff”. The healthcare worker conducting clinical research has a unique view and understanding of patients in their environment and is an important resource when engaged in the research process. The role of clinical research healthcare workers has been identified as a model to bridge the research gap between academia and clinical practice. Healthcare workers form an integral part at every level of the clinical research process, including providing care to participants and coordinating and implementing studies on ground level.

It has become important to describe and document the roles and contributions of healthcare workers in clinical settings. Contrary to the traditional role of the healthcare worker, the specialised activities and educational requirements for healthcare workers conducting clinical research are not well documented (Bevans et al., 2011). Although the principal investigator is primarily responsible for the study, it is often the research healthcare worker (i.e. the nurse) who co-ordinates the daily activities.

Healthcare workers also need to be knowledgeable of the research process, relevant legislation as well as the field of practice they work in. Protection of patients’ rights is also



an important responsibility of the clinical research healthcare worker. *The Good Clinical Practice guide* (GCP) and *The Declaration of Helsinki's Ethical Principles for Medical Research involving Human Subjects* highlight the protection, safety and wellbeing of participants of clinical research. Healthcare workers conducting clinical research should therefore undergo up-to-date training in GCP on a two-yearly basis (Pick et al., 2010).

#### **1.4 Brief overview of clinical research in South Africa**

Nuffield council on Bioethics (1999) is of the opinion that it is the duty of the scientific community to conduct sound research that protects the right of the patients. This is a critical requisite of all clinical research. However, this may be more difficult to achieve in under-developed countries where basic healthcare is not widely available. The authors hold the view that clinical research is based on two vital and moral commitments namely: the improvement of human wellbeing by advancement of scientific knowledge and understanding the disease, and to preserve the rights and health of the research participant.

The Academy of Science of South Africa (ASSAF), in its 2009 report on the revitalisation of clinical research in South Africa, notes that clinical research in a developing nation like South Africa influences healthcare at every level; i.e. identifying the causes of problems; enabling diagnosis and improving the effectiveness of care and propagation of good policy making. The Academy also supports the training of healthcare workers of all levels. This will contribute to an increase of knowledge locally with regards to prevalence of diseases and their prevention and treatment. The ASSAF report (2009) acknowledges that good clinical research is vital for the development of our country. ASSAF recommends that clinical research should be promoted and that the South African government should invest more in clinical research.

## **1.5 Brief overview of the Desmond Tutu TB Centre**

The Desmond Tutu TB Centre (DTTC) at the Department of Paediatrics and Child Health, Stellenbosch University (SU), is an academic research centre actively engaged in large-scale community-based research projects and clinical research with a view to reduce the burden of HIV and TB in severely affected communities in the Cape Town Metropole. Uitsig, Ravensmead and Khayelitsha Site C are three of more than twenty communities where the DTTC is working in close collaboration with the national and provincial Departments of Health, as well as other research partners to improve the well-being of the people in the community. These settlements are typical examples of high-density impoverished urban communities located on the Cape Flats (Beyers, 2009).

The results of research executed by the DTTC are, amongst others, used to influence health policy in general and more specifically, to assist in the formulation and delivery modalities of clinical interventions at primary healthcare facilities in the communities. Findings from these studies have impacted on the formulation of several South African and World Health Organization (WHO) policies, especially relating to paediatric TB. For example, the WHO has changed its guidelines on first-line drug dosages for children after several studies conducted by researchers at DTTC found that higher doses for children are needed for treatment of multidrug resistance (MDR) and extensively drug-resistant (XDR) TB in children (SAfAIDS, 2012). The DTTC has received the Stop TB Partnership and Kochon-foundation award in Kuala Lumpur, Malaysia, for pioneering community based approaches to TB and HIV care at the 43<sup>rd</sup> Union World Conference on Lung Health Union (Brits, 2012).



**Figure 1** - Source Adopted: Ravensmead and Uitsig. Epidemiology field site.

[sun025.sun.ac.za/portal/.../5051FCF5E2AC35A8E04400144F47F00...](http://sun025.sun.ac.za/portal/.../5051FCF5E2AC35A8E04400144F47F00...)

The Uitsig and Ravensmead epidemiology field sites were established nearly two decades ago in 1993 and since then continuous surveillance of routine TB services and data has been undertaken. Recent studies conducted by Statistics South Africa and Beko & Hughes (2012), who conducted research in Khayelitsha, have shown that there is a constant increase in the Human Immunodeficiency Virus (HIV)/Acquired Immunodeficiency syndrome (AIDS) burden in the epidemiology field sites, which offers an excellent opportunity to study the effect of HIV on the TB epidemic, a challenge that the DTTC has firmly embraced.

The healthcare workers interviewed in this study are all affiliated to the DTTC. They play a critically important role in that they operate at the coalface of the empirical research process. During the implementation of a community-based household TB contact study, for example, these fieldworkers interface directly with TB patients as well as their families within either a household or institutional context, or both. The research activities of healthcare workers involve interviewing TB patients and obtaining their informed consent to participate in the epidemiological study as well as doing regular home visits within these poor urban communities situated in the Cape Town Metropole.

The Desmond Tutu TB Centre and the three affiliated community-based recruitment sites are situated in the three impoverished urban settlements mentioned above. All three study communities are faced with an exceptionally high TB burden. They are in close proximity of each other and thus easily accessible from the DTTC.

## **1.6 Statement of the research problem**

According to Phiri & Simwaka (2006:59), healthcare workers and research assistants act as “cultural brokers” in research. They act as mediators between the principal investigator’s goals, the research institution and the community at large.

The researcher in this study (who was a staff member of the DTTC) has noted that negotiations between healthcare workers and their target communities are often tricky, sensitive and challenging, and that healthcare workers are often faced with ethical dilemmas and other problems in executing their tasks effectively and professionally.

A review of contemporary South African literature suggests that a gap exists in the knowledge and understanding around the challenges experienced by healthcare workers when they conduct clinical research in impoverished and challenging communities. Their voices have not been adequately and consistently heard in the quest to establish effective health delivery systems and models, which has exacerbated their difficulties and challenges as “cultural brokers” in the research process. There is thus a definite need to identify and better comprehend the challenges that they face. This will only be possible by systematically documenting first-hand accounts of their experiences and perspectives as well as the raft of challenges healthcare workers face in executing their duties, and to ascertain to what extent they feel they are capacitated to deal with these challenges and demands efficiently and professionally.

## **1.7 Research question**

The research question can be summarised as follows:

- What are the challenges faced by healthcare workers when conducting clinical research in densely populated low income human settlements in the Cape Metropole?

## **1.8 Aim**

The overarching aim of this study is to investigate the work-related challenges faced by healthcare workers employed at the DTTC who work on community-based research projects within the Cape Town Metropole. The purpose of this research is to explore the perception and experiences of challenges faced by healthcare workers in a clinical research setting in socially vulnerable communities in the Western Cape.

## **Objectives**

The specific objectives of this research are to:

- identify and describe the challenges that healthcare workers face in executing their duties in socially vulnerable and impoverished communities;
- explore suggestions from healthcare workers on how to overcome the challenges they face;
- inform the current training protocol of healthcare workers in order to enable healthcare workers to meet these challenges better; and
- provide feedback to stakeholders with recommendations based on the findings.

## **1.9 Motivation for the study**

According to Molyneux & Geissler (2008:5), fieldworkers who are responsible for implementing research in diverse communities are seldom heard. Fieldworkers who are engaged in vulnerable communities face significant challenges, acting as go-betweens for the various priorities of the research institutions. In the case of the DTTC, they not only face the risk of exposure to Tuberculosis (TB), but they also have to deal with the impact of high prevalence's of TB, Human Immunodeficiency Virus(HIV) or Acquired Immunodeficiency syndrome (AIDS), and incidences of crime in the respective communities and its concomitant trauma. In addition, fieldworkers are often called upon to listen to and manage the domestic conflicts and personal crises of participants. However, these and a raft of other challenges that community-based healthcare workers face are not generally known to project leaders and other strategic stakeholders and therefore not well documented.

The systematic observation, recording and analysis of these challenges could be valuable in offering new insight into the working environments of healthcare workers and in giving them

a human face. It is envisaged that the results from this study could generate fresh thinking and ideas regarding the context of their work as well as the range of challenges healthcare workers face within local projects and within the broader Desmond Tutu TB Centre (DTTC). This could lead to the amelioration of problems experienced by healthcare workers and to the development of better strategies to deal with such challenges. This will ultimately translate in more efficient, productive and contented health professional workers.

In view of the above, this study would like to explore the perceptions and experiences of healthcare workers in relation to the challenges and stresses that they encounter in their daily work situation. It is hoped that this would ultimately assist in refocusing (if necessary) the curriculum and training protocol of such workers in order to prepare them better for their often arduous tasks.

### **1.10 Significance of the study**

This study contributes to an understanding of the life-world of healthcare workers who not only regularly face the risk of exposure to Tuberculosis (TB) and Human Immunodeficiency Virus (HIV) /Acquired Immunodeficiency syndrome (AIDS), but also facing a high crime and unstable socio-economic environment. A better comprehension of the conditions healthcare workers are working under will assist the principal investigators and research institution when planning the research. The research findings could be used to develop a support base for healthcare workers conducting clinical research in poorer communities. The institution as an employer could pro-actively introduce strategies to mitigate the challenges their field staff face and incorporate this in their training protocols.

### **1.11 Definition of key terms**

For the sake of conceptual precision and for the reader to understand the content of the study, the following section provides the definitions of key terms used in this research.

### 1.11.1 Healthcare workers

Dal Poz, Kinfu, Dräger & Kunjumen (2007:1) define healthcare workers as “all people engaged in the promotion, protection or improvement of the health of the population”. According to the WHO, *Human Resources for Health* (HRH) comprise men and women who make healthcare happen. They include doctors, nurses, midwives, pharmacists, physicians, dentists and other health professionals. Healthcare workers also include auxiliary healthcare workers, community health workers, practitioners of traditional medicine, technicians and other para-professional personnel (Tawfik& Kinoti, 2006). Hassim, Heywood & Berger (2007) define healthcare workers as all individuals who are involved in the provision of health services to a user. Healthcare workers play a vital role in policy implementation and in the provision of healthcare services.

### 1.11.2 Tuberculosis

Tuberculosis is a highly contagious disease and bacterial infection that is passed from individual to individual through droplets in the air. It is spread by coming in contact with someone who is infected, who is actively coughing or talking. The bacteria multiply in the body, causing tissue and organ damage. Half of those with active TB infection will die if they do not get treatment (Oxfordimmunotec.com, 2012). Table 1 below shows the difference between TB infection and TB Disease.

**Table 1: TB Infection versus TB Disease**

| TB Infection                                   | TB Disease (in the lungs)                           |
|--|---|
| M. Tuberculosis in the body                    |   |
| Tuberculin skin test reaction usually positive |   |
| <b>No symptoms</b>                             | <b>Symptoms</b> such as cough, fever, weight loss   |
| Chest x-ray usually <b>normal</b>              | Chest x-ray usually <b>abnormal</b>                 |
| Sputum smears and cultures <b>negative</b>     | Sputum smears and cultures usually <b>positive*</b> |
| <b>Not infectious</b>                          | <b>Often infectious</b> before treatment            |
| <b>Not a case</b> of TB                        | <b>A case</b> of TB                                 |

Source Adopted: WHO Guidelines from Tuberculosis in Healthcare Facilities in Resource Limited Settings, 1999.

\*Sputum smears more often negative in HIV-infected TB cases

Tuberculosis (TB), an airborne infectious disease, is a preventable and curable illness, when detected early and treated. TB is a bacterial infection that normally attacks the lungs, although it can also cause disease in other parts of the body. *Mycobacterium Tuberculosis* (TB) is an airborne germ that can infect anyone (Altman et al., 1997). The population is at risk of being infected when TB patients talk, cough or sneeze; people can thus be infected by breathing in air infected by a TB patient. TB, along with malaria and HIV/AIDS, is regarded as one of the key preventable poverty related diseases that further marginalise the impoverished classes of society.

### **1.11.3 HIV and AIDS**

According Magezi (2007:13) HIV is an acronym for “Human immunodeficiency virus”, whilst AIDS is an acronym for “Acquired Immunodeficiency Syndrome”. Granich & Mermin (2001:5) state that HIV is referred to as “human” because it causes disease only in humans and attacks the immune system. HIV causes AIDS, which is the disease that develops once the virus has destroyed the immune system.

### **1.11.4 Risk(s) of exposure**

The Canadian Centre for Occupational Health and Safety (2009) defines “risk” in the context of TB as the likelihood of individuals coming into contact with a person infected with TB and experiencing an adverse health effect as a result. The degree of risk depends on the degree to which individuals are exposed to TB. The Association of National Health Occupational Physicians (2001) notes that risk varies according to the nature of the work those healthcare workers are involved in.

### **1.11.5 Stigma**

Moller (2008:39) notes that Goffman (1963) referred to stigmatisation as a trait assigned to people of a particular category or group. Moller (2008) again describes the term “stigma” as a



deeply discrediting attribute and emphasises that stigma should be viewed in terms of relationships rather than personal discrediting traits. Weiss & Ramakrishna (2006:536) define stigma related to health as “a social process or related personal experience characterized by exclusion, rejection, blame or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem.”

#### **1.11.6 Clinical research**

The National Institute of Health (NIH) (2012) defines clinical research as research that directly involves human subjects or uses material of human origin, e.g. observed behaviour or answers to questions or tissue samples obtained through direct contact with an individual that voluntarily agrees to participate in a research study.

The report of the Academy of Science of South Africa (ASSAF) of 2009 contained the following working definition of clinical research: “*research that are primarily conducted with human participants (and or material derived from them such as tissues specimens and cognitive phenomena) during which investigators examine the material, causes, detection, the progress and or reversal of human disease*”. Campbell, Weissman, Moy & Blumenthal (2001) concur with the above authors that clinical research involves humans as subjects and consists of a wide range of research types, such as “*clinical trials, translation research, epidemiological research, health services research and outcomes research*”.

### 1.11.7 Poverty

Poverty can be defined in many different ways. Poverty means a lack of money and (access to) basic items, such as food, clothing, water and shelter, as well as basic necessities to make a living. The table below depicts some of the different categorizations and definitions used to describe and contextualize poverty.

**Table 2: Definitions of Poverty**

| Agency                           | Extreme Poverty   | Moderate Poverty           | Relative Poverty   |
|----------------------------------|---|----------------------------|--|
| <b>World Health Organization</b> | Not meeting basic needs<br>Chronic hunger<br>Unable to access healthcare<br>No safe drinking water<br>Unsafe sanitation<br>Unable to afford education | Barely meeting basic needs | Household income level below a given proportion of average national income |
| <b>World Bank</b>                | ≤\$1 per day per person   | \$1-\$2 per day per person |  |

Source Adopted: Marais et al., (2008) Poverty and Human Immunodeficiency Virus in Children: A view from the Western Cape.

## 1.12 Research Agenda

This mini-thesis is divided into six chapters, which are structured as follows:

**Chapter 1:** (entitled **Introduction**) introduces the research problems, questions and aims, significance of the study, and procedures to be used. The chapter further outlines the background of the study and the contextualisation of the study.

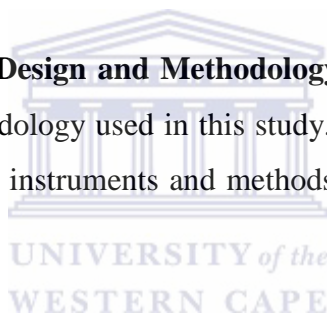
**Chapter 2:** (entitled **Literature review**) offers a review of the relevant literature, which lays a solid conceptual foundation for the research.

**Chapter 3:** (entitled **Theoretical Framework**) this chapter delineates the basic theoretical approach for this study.

**Chapter 4:** (entitled **Research Design and Methodology**) sketches a systematic approach of the research design and methodology used in this study. This chapter further outlines the sampling method, data collection instruments and methods, as well as the technique of data analysis.

**Chapter 5:** (entitled **Discussion and presentation of Data analysis and Findings**) provides a logical narrative of the analysis of the data and findings of the research. This chapter outlines the challenges of healthcare workers and reflects the results of the semi-structured interviews with interviewees conducted in community-based clinical research.

**Chapter 6:** (entitled **Summary, Recommendations and Conclusions**) presents the general conclusions and recommendations to ameliorate the challenges of healthcare workers.



# CHAPTER TWO

## LITERATURE REVIEW

### 2. Introduction

A thorough literature review is critical and indispensable to the success of an empirical study. DeVos, Strydom, Fouché & Delpont (2005) describe a literature review as a thoughtful and informed discussion of relevant literature that builds a logical framework for the research that sets it within the context of relevant studies. The literature review process involves finding, reading, understanding and forming conclusions about published research and presenting it in an organized manner (Brink, 2006). Relevant journal and research articles were also accessed through electronic journals, nursing times, PubMed and various other sources. For this research, the internet was used to access journal articles and conference publications.

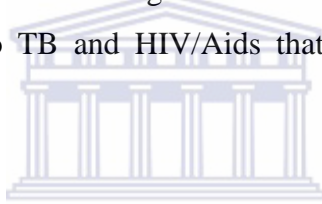
A review of the relevant literature was done to form a basis for the study, of which the main focus is on the perceptions and experiences of challenges of healthcare workers in clinical research settings in impoverished and vulnerable communities in the Western Cape Metropole. The purpose of the literature review to highlight some of the more significant challenges facing health care workers conducting community-based research. It is by no means a comprehensive review of all the challenges encountered by healthcare workers employed in research environments, but an exploration of what they have to deal with on a day to day basis. The researcher explores the following critical issues:

- Recruitment and retention
  - Psychological impact of their work on healthcare workers and the support programmes available to them
  - The risk of infection/exposure of health care workers to TB & HIV/Aids
  - Stigma and discrimination
- Environmental challenges, for example safety of health care workers

## **2.1 A Health care worker**

The widespread TB and HIV/Aids epidemic epitomizes a major public health crisis in South Africa, so much so that various policies and programmes have been roll-out in response to these non-communicable diseases, however the responsibility for successful implementation and outcome of these policies and programmes rest with the health care workers. Often these health care workers are ridiculed by the public, but they are tasked with the enormous responsibility of serving our communities and assisting our governments to reduce the burden of disease (Vawda & Variawa, 2012).

According to Akinboro et al, (2012:2) in a workforce of 35 million health care workers globally, about 3 million experience percutaneous exposure to blood-borne viruses. The ultimate objective of all health care workers globally is to maintain a healthy population and environment at large. However, the challenge confronting these health care workers is the risk of occupational exposure to TB and HIV/Aids that could de-motivate them to give quality care to patients.



The health care workers conducting community-based clinical research in the context of TB and HIV/Aids face many challenges in the course of their duties. As a result in them becoming consistently frustrated and de-motivated, which impacts negatively on service delivery and productivity. Some of these challenges, for example, risk of exposure to disease and stigma which have been thoroughly documented. However, many of the challenges faced by health care workers conducting community-based clinical research have not been adequately researched.

## **2.2 Challenges confronting health care workers**

### **2.2.1 Recruitment and Retention**

According to Dowling & Wiener (1997), cited in Patel, Doku & Tennekoon (2003), recruitment of participants is sometimes extremely challenging in clinical research studies and it is often left to junior and inexperienced field staff to do. Patel, Doku & Tennekoon (2003), writes that the retention of participants is an interrelated and essential aspect of the recruitment process. Poor retention rates could have serious scientific and financial

implications on the research process as well as undermine the adherence to timelines for completion of clinical research.

Leathem et al, (2009) concur with the abovementioned author that recruitment and retention of patients for clinical research is an important aspect of the research process as this would determine the effectiveness of the interventions. However, recruitment and retention are two of the most important challenges in clinical research. This could cause time delays to the research project as well as financial constraints, which could cause the study intervention duration to be shortened or making provision for alternatively funding.

### **2.2.2 Psychological Impact**

According to the literature, work-related stress and trauma can negatively impact on performance and well-being of the healthcare workers, which could lead to absenteeism, low levels of productivity, employee dissatisfaction and eventually a high staff turnover. Healthcare workers are particularly exposed to stress and trauma, and in conjunction with caring for and/or working with terminally ill MDR and XDR TB or HIV/AIDS patients (who are often impoverished), and especially young children, severely challenge the coping abilities of workers (Burr et al, 2006).

Kranzer et al, (2010) state that the high prevalence of Tuberculosis and HIV in vulnerable communities pose a serious threat to healthcare systems and healthcare workers. According to Zungu & Malotle (2011), healthcare workers in South Africa work under difficult circumstances, which include stress and burnout due to a shortage of healthcare workers, an increase in the population, the high burden of diseases, specifically HIV and TB, as well as a general deterioration of the healthcare infrastructure

### **2.2.3 Risks of exposure to TB and HIV: Community based healthcare workers**

In a study conducted by Claassens et al, (2010) on community-based healthcare researchers, she found that there is a distinct focus on occupational Tuberculosis<sup>1</sup>working in resource-poor settings with high prevalence of TB and HIV/AIDS. The study indicated that community health workers are at a higher risk of infection than the people living in the community they work in. According to Claassens et al,(2010) there is an urgent need to implement cost-effective and global infection control measures, specifically in middle and low-income countries.

According to Mulaudzi, Pengpid & Peltzer (2011) when people first became aware of the HIV/AIDS epidemic, healthcare workers reacted with fear and over-protectiveness and as a result, stringent infection control measures were implemented; however, with increasing knowledge of the disease and the mode of transmission and infection control measures, guidelines were established to ensure that healthcare workers and patients are adequately protected.

Transmission of Tuberculosis to both patient and healthcare workers has been reported globally (Baussano et al, 2011). The risk of exposure might differ in terms of occupational grouping, work setting, local prevalence rates of TB, patient population and the effective TB control measures in place. According to Baussano et al (2011), the risk of TB exposure among healthcare workers is higher than the risk among the general population globally, basically confirming what Claassens et al (2010) found.

Zungu & Malotle (2011) point out that the degree of risk varies by setting, occupational group and prevalence rate of Tuberculosis in the communities and patient population. The likelihood that healthcare workers who have been exposed to Tuberculosis will become infected depends predominantly on the concentration of droplets in the air and the duration of exposure to these droplets.

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<sup>1</sup>Occupational Tuberculosis refers to “the occupational exposure of an employee to anyone with a known case of active tuberculosis if the employee subsequently develops a tuberculosis infection. [Online] Available: <http://definitions.uselegal.com/o/occupational-tuberculosis> accessed 05/02/2013

According to Niu (2010), healthcare workers are in direct contact with patients, including those with infectious diseases (such as TB, hepatitis and HIV/AIDS), which are some of the potentially life threatening challenges that healthcare workers face routinely. Furthermore, the emergence of multidrug-resistant TB in many developing countries poses new challenges, not only to the healthcare system but also to healthcare workers. The WHO report of 2006 states that healthcare workers and other staff involved in caring and interacting with patients suffering from highly infectious diseases are at particularly high risk of infection because they are frequently exposed to patients with infectious TB disease (Tawfik & Kinoti, 2006).

However, according to Smart & Alcom (2009), healthcare workers are at risk merely because they are part of the population; therefore, if the incidence and prevalence of TB is high in the general population, we should anticipate a similar incidence in TB infection for healthcare workers regarding both TB and HIV.

#### **2.2.4 Stigma and discrimination**

According to Brown, Trujillo & Macintyre (2003), stigma is an everyday human reaction to disease. Several different diseases have, over time, carried substantial stigma (e.g. leprosy, alcoholism and mental illness); TB and particularly HIV/AIDS are merely the latest reported stigmatised diseases. The stigmatisation of TB and HIV/AIDS creates further challenges for the public healthcare system in combating these diseases, because a further increase in HIV/AIDS contributes to an increase in TB cases.

According to van Brakel (2005), various studies revealed that stigma attached to health related diseases such as HIV/AIDS and Tuberculosis is a global phenomenon. It affects diverse cultures across the world, in areas where the prevalence is high, as well as in areas of low prevalence. Stigma does not only impact on an individual level, but also the family, communities, public health programs, and research institutions. More importantly, it has a direct impact on the public health efforts to combat the disease.

Rahmati-Najarkolaei et al (2010) concur with the previous author that stigma affects individuals living with HIV/AIDS; disadvantaged people especially experience discrimination in their interactions with healthcare programs and systems. The authors note that stigma is regarded as a major barrier to efforts to combat the disease. Various studies done in India, Senegal and other countries identified three major causes of HIV-related



stigma namely: lack of awareness among health workers of what stigma *looks like* and why it is damaging; fear of casual contact stemming from incomplete knowledge about HIV transmission; and the association of HIV with improper or immoral sexual behaviour (Rahmati-Najarkolaeiet al., 2010).

The origin and impact of stigma surrounding TB and HIV are related. Both TB and HIV diseases are linked to poverty and lack of access to (quality) medical care. Factors that influence stigma for both TB and HIV diseases are that they yield several other illnesses, and that both are transmittable diseases and occur more often in populations perceived to be poor. The impact and consequences of stigma for the infected or sick person can be overwhelming. In 2010, 47% (6.6million) of the estimated 14.2 million people were accessing treatment for TB and HIV/AIDS. However, HIV and TB related stigma is a major barrier to accessing HIV testing as well as TB care and treatment services. (Nachega et al., 2012). The negative outcomes of stigma for people living with TB and HIV/AIDS (PLWHA) are many and diverse: feelings of shame or guilt, reluctance to disclose TB and HIV status, resulting in isolation from family and the broader community, as well as possible loss of employment. A study conducted in 2010 investigating the perceptions of HIV-related stigma among people infected with HIV globally, found that one quarter to one third of PLWHA live with a sense of isolation, depression associated with self-stigma and/or fear of discrimination due to their HIV status (Nachega et al., 2012). Stigma can also lead to stigmatized patients not seeking medical treatment (Jittimaneet al., 2009).

### **2.2.5 Safety**

The literature suggests that violence aimed at public field-workers is a regular occupational hazard (Schulte et al., 1998). Fazzone et al, (2000) concur with this and note that unsafe conditions are situations that threaten the personal safety of healthcare workers doing home visits in suburban and informal settlements.

Healthcare workers functioning in social and economically marginalised communities are exposed to many risks, which will vary depending on the demographical and socio-economic status of the particular area they are active in. Mpuang (2001) cited in Samuels (2010), posits that the individuals perpetrating crime are usually unemployed, impoverished, uneducated and because of the abovementioned socio-economic circumstances, often find themselves compelled to live a life of crime.

### 2.3 TB and HIV in South Africa

South Africa is one of 22 high-burden countries contributing approximately 80% of the total global burden of all TB cases, and TB continues to be one of the leading causes of death in South Africa, especially among people infected with HIV (DOH, 2007). According to the WHO report on global TB control (2008), South Africa has the fourth-highest annual TB incidence in the world.

The Strategic Plan for the period 2007 to 2011 of the Department of Health, reports that the control and management of TB is a priority for the government, who wants to realise its vision of “[a] South Africa that is free of Tuberculosis” as well as free from the stigma surrounding the disease (DOH 2007:5). Raising awareness of and improving knowledge about TB among South Africans is a core strategy of the Government in its fight against TB. At the 3<sup>rd</sup> SA TB Conference, held in Durban in 2012, the Treatment Action Campaign stated that TB is still the number one cause of mortality in South Africa (TAC, 2012). The WHO estimates that 1% of the South African population contract TB annually; this represents slightly more than half a million people.

**Table 3: The Global Burden of TB in 2010**

|  | <b>Estimated Number of Cases</b>              | <b>Estimated Number of Deaths</b>          |
|--|---|--|
| <b>All forms of TB (men and women)</b> | 8.8 million<br>(range, 8.5 – 9.2million)      | 1.1million*<br>(range, 0.9-1.2million)     |
| <b>All forms of TB (in women)</b>      | 3.2 million (38%)<br>(range, 3.0- 3.5million) | 0.3million<br>(range, 0.2 -0.4 million)    |
| <b>HIV-associated TB</b>               | 1.1million (13%)<br>(range, 1.0-1.2 million)  | 0.4 million<br>(range, 0.32 – 0.39million) |
| <b>Multidrug-resistant TB(MDR- TB)</b> | 0.65 million**                                | 0.15million                                |

Source Adopted: Presentation by David Mametja -3<sup>rd</sup> TB Conference 2012

\*excluding deaths among HIV+ people

\*\*prevalent cases

Table 3 offers an overview of the global burden of TB in 2010, where an estimated 1.1 million deaths were due to all forms of TB and 0.4 million was related to HIV-associated TB. Research results confirm that TB continues to be one of the leading causes of death among people living with HIV. Approximately one in four deaths among people living with HIV is related to TB, and several of these deaths occur in resource-limited settings (Sculier, 2010).

The WHO report (2005) reflects a global decrease in the number of TB cases reported; in Africa, however, the disease has spread and the number of TB cases and deaths linked to HIV has actually risen in recent years. The global TB prevalence has declined by 20% since 1990; in African countries with a high HIV prevalence, however, the TB incidence has tripled since 1990 and continues to increase at an annual rate of 3% to 4% (WHO, 2005b). This trend must be of serious concern to all involved and working in the health sector of African countries as well as the political elites of these states.

Notwithstanding effective treatment and TB control strategies, TB remains the leading cause of death globally among the youth and adults living with AIDS, with the interaction between TB and HIV being most fatal (Ngamvithayopong, Winkvist & Diwan, 2000). According to Van Rie et al, (2008), the HIV/AIDS global epidemic has hampered worldwide efforts to control TB. The WHO report of 2006 stated that one-third of the 42 million people living with HIV/AIDS globally are co-infected with TB and an anticipated 741 000 of the 8,9 million new reported cases of TB in 2004 were also infected with HIV (WHO, 2006).

According to Statistics South Africa (2010) the total number of people living with HIV in South Africa has increased from an estimated 4, 1 million in 2001 to 5, 24 million by 2010, as reflected in table 4. These statistics reflect that an estimated 10, 5% of the total South African population is HIV positive.

Table 4 below shows the prevalence estimates and the total number of people living with HIV from 2001 to 2010. In 2001 this number was 4.1 million. However, over a period of nine years it has increased to 5, 24 million people living with HIV in 2010, which reflects a significant increase.

**Table 4: HIV prevalence estimates and the number of people living with HIV, 2001-2010**

| Year | Population 15 -49   |                              | Percentage of the total population | Total Number of people living with HIV (in millions) |
|------|---------------------|------------------------------|------------------------------------|--|
|      | Percentage of women | Percentage of the population |                                    |  |
| 2001 | 18,7                | 15,4                         | 9,4                                | 4,10   |
| 2002 | 19,2                | 15,8                         | 9,6                                | 4,38   |
| 2003 | 19,4                | 16,1                         | 9,8                                | 4,53   |
| 2004 | 19,6                | 16,3                         | 9,9                                | 4,64   |
| 2005 | 19,7                | 16,5                         | 10,0                               | 4,74   |
| 2006 | 19,7                | 16,6                         | 10,1                               | 4,85   |
| 2007 | 19,7                | 16,7                         | 10,2                               | 4,93   |
| 2008 | 19,7                | 16,9                         | 10,3                               | 5,02   |
| 2009 | 19,6                | 17,0                         | 10,3                               | 5,11   |
| 2010 | 19,7                | 17,3                         | 10,5                               | 5,24   |

Source Adopted: Statistics South Africa Report: Mid-year population estimates 2010

Beko & Hughes (2012), in a study conducted in Khayelitsha, found that with a total population of 2 million people, the antenatal HIV prevalence was 30% with 6,000 new registered TB cases each year. Of these 75% were HIV infected. According to Fair Share (2009) in the Cape Town Metropolitan area, the prevalence of both HIV and TB is the highest in Khayelitsha, with antenatal HIV prevalence of 30.2% and 31% of all adults on antiretroviral therapy (ART). An estimated 400 newly diagnosed drug resistant TB cases are registered per year with only 10 health facilities providing critically needed TB and HIV care in the Western Cape.

The South African National Strategic Plan for HIV, STIs and TB for the period 2012–2016 (DOH, 2012) confirms that in 2009 an estimated 17, 9% of the adult population was living with HIV. This amounts to 5, 63 million people, including 3, 3 million women and 334 000 children. The prevalence in pregnant women has stabilised around 30%, whilst 70% of patients are co-infected with both HIV and TB diseases. People aged between 30-39 have a

very high TB infection rate, especially those living in townships and informal settlements. This is confirmation that TB is a disease that has a serious effect in underprivileged communities.

#### 2.4 The prevalence of TB and HIV in the provinces of South Africa

The Western Cape Province of South Africa has the highest incidence of new TB cases reported in the country. The provincial-registered TB caseload has increased by 8% to 10% annually in the last decade; concurrently, HIV prevalence in this province has increased by 11% to 12 % (Draper et al., 2007).

**Table 5: Active Cases Finding per Province**

| Province             | Suspects         |                  | Suspects Tested  |                  | *New SS+ with TB |                |
|----------------------|------------------|------------------|------------------|------------------|------------------|----------------|
|                      | 2010             | 2011             | 2010             | 2011             | 2010             | 2011           |
| <b>Eastern Cape</b>  | 450,123          | 612,792          | 426,452          | 576,798          | 28,762           | 33,749         |
| <b>Free State</b>    | 142,163          | 165,351          | 122,862          | 132,715          | 12,141           | 11,207         |
| <b>Gauteng</b>       | 337,032          | 321,162          | 315,439          | 302,085          | 22,612           | 19,320         |
| <b>KwaZulu Natal</b> | 511,864          | 526,977          | 458,110          | 477,428          | 31,714           | 32,686         |
| <b>Limpopo</b>       | 143,440          | 343,812          | 137,442          | 339,323          | 9,071            | 11,737         |
| <b>Mpumalanga</b>    | 109,432          | 127,399          | 107,071          | 123,442          | 10,910           | 9,854          |
| <b>North West</b>    | 74,814           | 401,911          | 69,748           | 169,301          | 5,659            | 14,750         |
| <b>Northern Cape</b> | 71,951           | 53,749           | 50,468           | 34,988           | 4,554            | 3,775          |
| <b>Western Cape</b>  | 189,838          | 165,786          | 189,273          | 163,464          | 18,181           | 15,040         |
| <b>RSA</b>           | <b>2,030,657</b> | <b>2,718,939</b> | <b>1,876,865</b> | <b>2,319,544</b> | <b>143,604</b>   | <b>152,118</b> |

Source Adopted: Presentation by David Mametja -3<sup>rd</sup> TB Conference, Durban 2012

\*New Sputum Smear Positive

From Table 5 it is clear that there has been a decline in the new SS+ with TB in the Western Cape over the period 2010 - 2011. The Department of Health's chief director for TB control and management stated at a TB Conference held in June 2012, that South Africa may be turning the tide against Tuberculosis, but he warned that it was too early to rejoice about this. Although 2011 data reflects a decline in the number of new confirmed TB cases, the country is still faced by a formidable challenge, as 1% of the population is infected with TB every year.

**Table 6: Registered Cases: Susceptible TB per province**

| Province      | Registered Cases |                | Smear Conversions |              | Not evaluated |              |
|---------------|------------------|----------------|-------------------|--------------|---------------|--------------|
|               | 2010             | 2011           | 2010              | 2011         | 2010          | 2011         |
| Eastern Cape  | 62,192           | 60,046         | 65.9%             | 63.6%        | 19.0%         | 17.8%        |
| Free State    | 24,470           | 22,772         | 73.3%             | 73.9%        | 5.4%          | 5.0%         |
| Gauteng       | 56,950           | 55,460         | 81.9%             | 80.6%        | 4.2%          | 3.1%         |
| KwaZulu Natal | 122,960          | 118,911        | 72.1%             | 71.8%        | 15.2%         | 14.4%        |
| Limpopo       | 22,084           | 22,158         | 70.5%             | 65.9%        | 12.1%         | 8.1%         |
| Mpumalanga    | 25,992           | 24,451         | 67.9%             | 68.1%        | 15.4%         | 13.8%        |
| North West    | 30,275           | 28,113         | 59.6%             | 57.6%        | 22.9%         | 22.7%        |
| Northern Cape | 10,291           | 10,044         | 70.5%             | 71.9%        | 14.5%         | 16.9%        |
| Western Cape  | 49,715           | 48,019         | 74.5%             | 76.8%        | 10.7%         | 13.3%        |
| <b>RSA</b>    | <b>404,929</b>   | <b>389,974</b> | <b>71.7%</b>      | <b>70.9%</b> | <b>13.2%</b>  | <b>12.5%</b> |

Source Adopted: Presentation by David Mametja -3<sup>rd</sup> TB Conference Durban 2012

Statistics (see table 6) released at the above-mentioned TB conference indicate a decline in the total number of registered TB cases from 404 929 in 2010 to 389 974 in 2011. Despite intensified efforts by the Department of Health in terms of case detection and contact tracing, KwaZulu–Natal was hardest hit with 118 911 registered cases in 2011 (Mametja, 2012).

**Table 7: Registered Cases: MDR TB per province**

| PROVINCE             | 2004        | 2005        | 2006        | 2007        | 2008        | 2009        | 2010        | TOTAL        |
|----------------------|-------------|-------------|-------------|-------------|-------------|-------------|-------------|--------------|
| <b>Eastern Cape</b>  | 379         | 545         | 836         | 1092        | 1501        | 1858        | 1782        | 7993         |
| <b>Free State</b>    | 116         | 151         | 198         | 179         | 381         | 253         | 267         | 1545         |
| <b>Gauteng</b>       | 537         | 676         | 732         | 986         | 1028        | 1307        | 938         | 6200         |
| <b>KwaZulu Natal</b> | 583         | 1024        | 2200        | 2208        | 1573        | 1773        | 2032        | 11393        |
| <b>Limpopo</b>       | 59          | 40          | 77          | 91          | 185         | 204         | 126         | 782          |
| <b>Mpumalanga</b>    | 162         | 134         | 139         | 506         | 657         | 446         | 312         | 2356         |
| <b>Northern Cape</b> | 168         | 155         | 188         | 199         | 290         | 631         | 353         | 1984         |
| <b>North West</b>    | 130         | 203         | 225         | 397         | 363         | 520         | 158         | 1996         |
| <b>Western Cape</b>  | 1085        | 1192        | 1179        | 1771        | 2220        | 2078        | 1422        | 10947        |
| <b>South Africa</b>  | <b>3219</b> | <b>4120</b> | <b>5774</b> | <b>7429</b> | <b>8198</b> | <b>9070</b> | <b>7386</b> | <b>45196</b> |

Source Adopted: Presentation by David Mametja -3<sup>rd</sup> TB Conference, Durban 2012

The TB crisis in South Africa has been heightened by the emergence and spread of multi-drug resistant (MDR) TB and the extensively drug-resistant (XDR) strains of TB. Table 7

reflects the registered MDR TB cases per province in South Africa from 2004–2010 with 45 196 cases in total. According to an article in the *Mail and Guardian* (2011), a report released by *Médecins sans Frontières*, Partners in Health and the Treatment Action Group, over the past 10 years an estimated 5 million new cases of MDR TB was reported and 1.5 million TB patients died of the disease over this period.

## **2.5 Brief overview of the impact of TB and HIV/AIDS in South Africa**

This section provides a brief overview of Tuberculosis (TB) and the human immunodeficiency virus (HIV) pandemics in South Africa, as these diseases have a considerable impact on both the public health services and society at large. Mayers (2010), states that TB has been present for many decades; however, the management of the disease has been compromised by various factors such as socio-economic and socio-cultural settings, widespread poverty, overcrowded living conditions, as well as the arrival of HIV.

Lawn & Churchyard (2009) posits that from the onset of the HIV epidemic, it was apparent that there was a strong association with Tuberculosis (TB), and emerged as one of the major factors undermining global TB control. This situation has further exacerbated by the emergence of the global multidrug-resistant Tuberculosis (MDR-TB) and extensively drug-resistant TB (and XDR-TB), specifically in Eastern Europe and South Africa. South Africa is a critical partner in the global fight against TB and is playing a leading role in the development of new tools to fight the disease. One of the Millennium Development Goals (MDG) is to reduce the number of reported incidences of TB by 2015. Globally the rate of TB has been falling by 1.3% per year since 2002. In South Africa however, the number of cases detected for all forms of TB has increased dramatically from 148,164 cases in 2004 to 401,048 cases in 2010 (Diacon, 2012).

Both provincial and national health departments have implemented various initiatives to improve the overall health status of the South African population; examples of such interventions include immunization of children, Voluntary Counselling Treatment (VCT) for HIV/AIDS and various other interventions relating specifically to Tuberculosis at the various public health facilities. In addition, programmes to strengthen the health systems are rolled out. Whether these interventions reach the communities and households in most need of it,

i.e. situated in impoverished and remote rural areas and poor urban informal settlements, is not always clear.

## **2.6 TB: “A disease of poverty”**

Mclean (1995), cited in Van Helden (2003), had this to say about TB: *“Everything interacts with everything else: each single factor conspires with the others to crush a man, break him physically and mentally, and lay him wide open to disease. Pack men together like herring in a barrel, deprive them every last ounce of resistance, batten them below decks for days at a time, and what do you get? TB. It’s inevitable.”*

Stop TB (2010), a non-governmental organisation (NGO) wrote that poverty has been and will remain for the foreseeable future a major barrier to health development because most people globally—estimated at over three billion—live on less than \$2.50 per day in either chronic or episodic poverty. The WHO (2005a) too, holds the notion that TB is “a disease of poverty”. According to this organisation, poor and marginalised groups are at higher risk of contracting TB, due to socio-economic conditions related to poverty. Most people in poor communities live in seriously overcrowded and high-density clustered informal housing and small backyard dwellings without proper ventilation, insulation and isolation; therefore, the probability of members of such households contracting the disease within and across households is high.





**Figure 2:** Picture of Khayelitsha

Figure 2 illustrates small informal housing structures clustered together in Khayelitsha. This is typical of the housing and living conditions prevailing in these impoverished communities that are characterized by high prevalence of TB in the Cape Metropole. TB Alert (2005:7) confirms this relationship between poverty and subsequent inferior living conditions, “TB is much more common in poor communities because of the following factors; overcrowding is widespread, many families live in a household in backyard dwellings with no ventilation and are therefore most likely to contract the disease.”

Mishara & Pathak (2011) state that unless poverty, overcrowding and the stigma attached to TB are addressed, little significant progress will be made in reducing the incidence of individuals contracting the disease. The authors hold the view that TB will remain a symptom of poverty and a social disease until a permanent solution is found to South Africa’s serious housing shortage (that leads to overcrowding of the existing stock) and successfully address the high rate of poverty.

### **2.6.1 Manifestation of Poverty**

The most critical challenge facing South Africa since the first democratic election is the unremitting poverty in this country. Approximately 40% of South Africans were living in poverty in 2003, with the poorest 15% attempting to survive this poverty trap (Bhorat, van den Berg & van Aardt, 2003).

“Poverty has various manifestations, including lack of income and productive resources sufficient to ensure sustainable livelihoods; hunger and malnutrition; ill health; limited or lack of access to education and other basic services; increased morbidity and mortality from illness; homelessness and inadequate housing; unsafe environments; and social discrimination, marginalization and exclusion” (United Nations, 1995:41).

According to Freemantle (2006:40), at least 3 billion (46%) of an international population of 6.5 billion live in extreme poverty. He mentioned that this figure is predicted to increase between six and nine billion (66%) by 2050. According to Freemantle, although the international economy has grown, the divide between the rich and the poor has widened. Theron (2008:24) states that although global poverty is persisting, governments have acknowledged the importance of attending to the needs of millions of people who lack access to proper housing, sufficient nutrition and a quality health sector and educational opportunities.

One such an initiative that envisaged the eradication of extreme poverty was initiated in September 2000, when 189 United Nations member states, including South Africa, adopted the Millennium Declaration and committed to achieve eight developmental goals by 2015, known as the Millennium Development Goals. The Millennium Declaration was accepted at the General Assembly of the United Nations to reinforce peace, development and human rights of people. In September 2001, the Millennium Development Goals were accepted by country leaders who committed themselves to attaining these goals by 2015 (Adelzadeh, 2003:3)

Sachs (2005:1) notes that these Millennium Development Goals are time bound and has set targets to eradicate poverty in all its spheres. This includes income - poverty, hunger, *disease*, lack of adequate shelter and social and economic exclusion, whilst promoting gender equality, education and environmental sustainability. He further writes that all of the abovementioned aspects are basic human rights, rights of every individual on earth, the right to healthcare, education and safety and security as it is found in the Universal Declaration of Human Rights.

Boccia et al, (2011) state that negative socio-economic factors associated with poverty will remain a major contributing factor to TB in developing countries, although it is challenging to comprehend just how poor living conditions associated with poverty contribute to the risk of contracting TB. Other risk factors, such as HIV, further impact the spread of the disease. The authors conclude that we can no longer ask *whether* TB is linked to poverty but *why* it is so and whether the HIV epidemic has distorted our understanding of the TB disease.

### **2.6.2 Poverty and TB, HIV/AIDS: Exploring a Link**

The continuance of the emergence and high prevalence of TB among socially disadvantaged communities in developing countries force the scientific community to review the existing explanations and management of the disease. (Ho, 2004). According to Van Donk (2002:3) the link between poverty, TB and HIV/AIDS is not simplistic; the majority of those living with TB and HIV/AIDS are poor, international evidence suggests that there is a close correlation. Poverty is thus seen as a co-factor amongst other factors. Marais, Esser, Godwin, Rabie & Cotton (2008) concur with the above author that TB and HIV/AIDS were identified as key factors contributing towards keeping affected populations poor.

The continued increase of costs of basic food products in South Africa impacts severely on the ability of poor livelihoods to access (nutritional) food and maintain food security. Poorer families spend 50% or more of their monthly income on food (Reddy & Moletsane, 2009). Food security and nutrition are critical for individuals, households and communities affected by TB and HIV/AIDS. Lack of food security and poor nutritional standing increase the progression of TB and AIDS-related illnesses. It also undermines the response to treatment and aggravates the socioeconomic impact of the disease. Good nutrition is key factor to a long and healthy life for a TB and/or HIV infected person. A healthy body and strong immune system allows people to resist the infections that affect individuals living with HIV, especially those in resource-poor settings where access to healthcare is not often readily available (UNAIDS, 2008).

Van Helden (2003) is of the opinion that TB is not just a medical problem, but also a problem of social inequality and poverty. The poor will continue to be the breeding ground for the TB disease, until we acknowledge that it is not only *Mycobacterium Tuberculosis* that is causing

the disease, but also accept the role played by the abhorrent conditions under which millions of people are forced to live globally. Globally, the magnitude of the problem is related to human density, globalization and extensive migration of populations, coupled with the HIV endemic. He further holds the view that the answers to TB and HIV/AIDS mortality are the alleviation of poverty and improved nutrition.

## **2.7 Summary**

This chapter gave an overview of TB and HIV/AIDS locally and globally and the impact of both TB and HIV/AIDS, as well as the prevalence of TB and HIV/AIDS in the provinces of South Africa. TB and HIV/AIDS are global phenomena that impact health services delivery worldwide. Conducting clinical community-based research health workers experience their own set of challenges. Healthcare workers working in TB and HIV/AIDS environments are at risk of exposure to contracting the disease. Stigmatisation attached to the disease (as Brown, Trujillo and Macintyre 2003 posit) contributes further to the challenges of the public health systems in their effort to fight TB and HIV/AIDS. The conclusion derived from the literature reviewed is that there is a definite link between TB and HIV/AIDS and poverty. In the following chapter the theoretical framework chosen for the study is discussed, i.e. the interpretive approach, focusing on phenomenological philosophy applied.

# **CHAPTER THREE**

## **THEORETICAL FRAMEWORK**

### **3. Introduction**

The theoretical framework that was used for this study is the interpretive approach. The interpretive approach focuses on the experiences, perceptions and meanings that individual's voice. De Vos, Strydom, Fouché & Delpont (2002) define theory as an attempt to explain or predict a phenomena or behaviour, that can be tested and which can indicate whether there is a relationship between various propositions. In this study, the phenomenological approach will be utilized to investigate the experiences and perceptions of healthcare workers and the challenges they face in conducting clinical research.

#### **3.1 Phenomenology approach**

Phenomenology has been described as having a philosophy, a research method and a central viewpoint from which all qualitative research is sourced. The emergence of phenomenology was in reaction to the then dominant scientific (positivist) view of philosophy and psychology in the late 19<sup>th</sup> century (Ehrich, 2005). The term phenomenology is derived from “phainomenon” (‘an appearance’) and ‘logos’ (‘reason’). The central focus of phenomenology is portrayed as the study of experiences with the intention of bringing out the ‘essences’ and the fundamental ‘reasoning’ (Pivcevic, 1970). Phenomenology has a compelling philosophical element. It draws heavily on the works and writings of, amongst others, Edmund Husserl (1859 – 1938) who has helped expand the field, along with Heidegger, Satre and Merleau–Ponty (Cresswell et al., 2007). This approach has been used by various disciplines as an explanatory tool e.g. social sciences, nursing and health sciences, psychology and sociology. However, across all these disciplines the central focus is studying the lived experiences of people, and arriving at a description of the real meaning of these experiences to the actors involved (Creswell et al., 2007).

Phenomenology does not only arrive at the description of the experiences, but it is also an interpretive process, where the researcher endeavours to make an interpretation of the meaning of the lived experience of actors (Van Manen 1990, p.26 cited in Cresswell et al., 2007). Lester (1999) is of the opinion that the phenomenological research design overlaps with other qualitative approaches such as ethnography, hermeneutics and symbolic interactionism, whilst pure phenomenological research basically describes rather than explains (behaviour) and from a viewpoint free of any preconceptions. Phenomenological approaches can be used on single cases as well as purposively selected samples. Phenomenological researchers make detailed observations about the individual circumstances and do not lend themselves to generalisations, like when conducting survey research. Phenomenological research is effective in bringing out deeper concerns and making voices heard. Various methods can be used when applying phenomenological-based approaches, such as in-depth interviews, informal conversations, participant observations, action research, focus groups and the analysis of personal texts. The table below illuminates the main features and characteristics of phenomenology as well as some focus on what this approach does not claim to be or to achieve.

**Table 8: What Phenomenology is and What it is not**

| IS   | IS NOT  |
|--|---|
| <b>Study of lived experience</b><br>As we immediately experience it  | <b>An empirical science</b><br>Does not generalize or develop theory  |
| <b>Clarification of phenomena as they present themselves to consciousness</b><br>Consciousness is retrospective, we cannot understand an experience until it is reflected on | <b>Not mere speculative inquiry in the sense of unworldly reflection</b><br>Concrete experiences understood through language  |
| <b>The study of essences</b><br>That which makes the ‘phenomenon’ what it is   | <b>Neither mere particularity, nor sheer universality</b><br>Paradoxically explains what makes something unique and different |
| <b>Description of the experiential meanings we live as we live them</b>  | <b>Does not solve problems</b><br>Meaning questions that allow for thoughtful and tactful action                              |
| <b>Human scientific study of phenomena</b><br>The systematic, explicit, self-critical and intersubjective analysis of the lived world  |   |

Source Adapted: Van Manen (1990) cited in Schumacher (2010)

According to Patton (2002), the theoretical traditions of phenomenology stem from the work of scientists such as Husserl (1859–1938) and Schutz (1899–1959), who strongly influenced the establishment of the theory of phenomenology in the field of the social sciences. Husserl, in his 1913 publication, holds the view that phenomenology is about how individuals explain phenomena and how they experience them consciously. The notion of phenomenology is based on the premise that anything that is perceived could be of relevance to a phenomenon, whether make-believe or real, measurable or an individual experience. According to Patton (2002), the goal of phenomenology is to obtain a better sense of and better insight into people's everyday experiences.

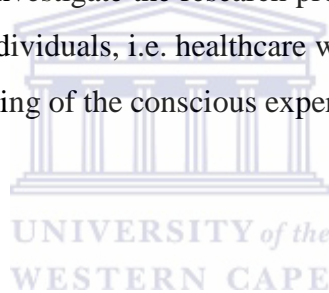
Wilson (2002) refers to phenomenology as the way in which individuals conceptualise meaning, the main factor being “intersubjectivity”. He further holds the view that our experiences of and thoughts about the world are “intersubjective” because we experience the world with and through others. According to Smith (2007), Schutz's view (cited in Wilson 2002) of the philosophy of phenomenology is that individuals are regularly involved in the process of making sense of the world and of their relations with others, and that researchers are regularly involved in the process of making sense of this sense-making. In using this phenomenological approach, we should certainly apply some process of interpretation as the regular individual in her or his environment. “The people in question tell their own story in their own terms.” So “fidelity to the phenomenon as it is lived” means apprehending and understanding it in the lived context of the person living through the situation (Wilson, 2002:194). Finlay (2009) agrees with Wilson that the phenomenological research process is introduced with narratives of lived experiences, frequently with real-life explanations interpreted in everyday language. According to Dalberg et al. (2008), as cited by Finlay (2008), the general aim of phenomenological research is to explain and interpret the lived realm in such a way that it increases our understanding of human beings and human experience.

Hayllar & Griffin (2005), and Merleau-Ponty et al. (1962: vii), are of the opinion that the philosophy of the phenomenological approach attempts to give a “direct description of the lived experience as it is” and does not take into account the psychological basis and elucidations that researchers and sociologists provide. The objective of the phenomenological approach is to clarify the specifics and to recognize the phenomena as they are perceived by the individuals in a situation; from a human perspective this can be explained as gathering of

“deep” information and perceptions through inductive, qualitative methods such as interviews, informal discussions and observations and presenting it from the perspective of the research participants (Lester, 1999).Lester (1999) writes that phenomenological methods are very effective in bringing the experiences and perceptions of individuals from the individual perspective to the fore, whilst adding the interpretive aspect to phenomenological approach, thus permitting it to be used as the core for a practical theory.

### **3.2 Summary**

Based on the discussion of the core characteristics and strengths of the phenomenological approach, the researcher has chosen this theoretical framework to describe and interpret the impact of work-related experiences of healthcare workers. To increase the general awareness of these experiences and challenges that they face, this study will use the phenomenological perspective as a theoretical orientation and research methodological design. It is argued that this theory can best explain and investigate the research problem, because it gives an account of the everyday experiences of individuals, i.e. healthcare workers. In this way, the researcher will be able to gain an understanding of the conscious experiences of healthcare workers.





# CHAPTER FOUR

## RESEARCH DESIGN AND METHODOLOGY

### 4. Introduction

This chapter offers a systematic description of the research design and methodology used in this study. This includes *inter alia* the sampling method, the data collection instruments and methods, as well as the technique of data analysis. The latter part of this chapter contains a discussion of the ethical considerations that applied to this research as well as the limitations of the study.

#### 4.1 Research framework

It is important that we are aware of the background knowledge, standpoint and the researcher's beliefs/attitudes, as these are all interrelated and rooted in our thinking. These factors can all influence how the researcher engages with the study, her or his understanding of the organization studied, the employees working for the organization and their external environment (Ross, 2009). The table below contains a summary of the research framework. It clearly shows the research process that would be used in the study.

**Table 9: Summary of Research Framework**

|                        |  |
|------------------------|--|
| <b>Philosophy</b>      | Phenomenological   |
| <b>Epistemology</b>    | Interpretive   |
| <b>Methodology</b>     | <b>Qualitative</b>   |
| <b>Approach</b>        | Inductive  |
| <b>Research design</b> | Exploratory  |
| <b>Methods</b>         | Primary: Semi-structured in-depth interviews<br>Secondary: informal observations and conversations with healthcare workers (attendance of meetings) do household visits with study teams |

## 4.2 Research Design

According to Babbie (2007) the research design acts as a blueprint for the research process. It necessitates making decisions regarding what your subject matter of investigation is going to be, who or what your target population is, what research methodology you are going to use and for what purpose. Terre Blanche, Kelly & Durham (2006) concur with the above-mentioned author and defines a research design as a plan of action and systematic observation that will guide the researcher when collecting and analysing data that is relevant to the research objectives. They describe the research design as a “bridge” between the research question and the implementation of the research. Mouton & Marais (1990), cited in Terre Blanche, Kelly & Durham (2006), note that the primary goal of a research design is to plan and give structure to a particular research project in a way that will validate the research findings.

This research can be described as an exploratory study. An exploratory design was selected as this study seeks to discover, explore and describe the challenges faced by healthcare workers implementing clinical research. The qualitative research design or approach was decided upon for this study as it concerned with describing and interpreting human phenomena from the perspective of those who experience it. Qualitative studies are often designed to be exploratory and are particularly relevant to the phenomenological approach as it “listens to participants and build an understanding based on their ideas without prejudice and preconceived ideas” of the researcher (Creswell, 2003).

Furthermore, the qualitative study design was deemed suitable because it allows the researcher direct interaction with the participants through in-depth semi-structured interviews and informal discussions. According to Babbie & Mouton (2001), the qualitative researcher focuses on studying individual action in its normal environment through the eyes of that individual. This method lends itself to an extensive methodological approach to the study of social action. The above-mentioned authors also note that the main objective of this approach is clearly defined as describing and understanding human behaviour rather than explaining it. They are of the opinion that qualitative studies aim at achieving new insights into, and comprehension of, a phenomenon.

De Vos et al. (2005) holds the view that the qualitative approach allows one to arrive at a deep and detailed comprehension of people’s feelings, experiences and/or perceptions. Babbie & Mouton (2001) refer to this as developing an “insider perspective”. They state that it also yields descriptive data in the individual’s own recorded written and verbal language. DE Vos et al. (2005:74), note that the qualitative approach falls in the domain of “interpretative, antipositivistic and idiographic” methods, of which the goals are primarily to identify with societal issues and the connotation that individuals attach to them on a daily basis.

According to Van Manen (1984), cited in Smyth (2004), there are four steps in executing or pursuing phenomenological research. The following table provides a summary of the process and the steps used to guide the process of phenomenological inquiry.

**Table 10: Four steps in pursuing phenomenological research**

| Step          | Aspect of the process of inquiry   | Area of research in which the step was applied   |
|---------------|--|--|
| <b>Step 1</b> | Firstly the researcher must turn to a phenomenon, in which she or he are genuinely interested, which “commits her or him them to the world.” | *Preparation of the researcher<br>*Sampling of participants<br>*Ethical Considerations |
| <b>Step 2</b> | Secondly, investigation of the experience must occur as the phenomenon is lived, rather than as it is conceptualised.                        | *Data Collection   |
| <b>Step 3</b> | Thirdly, a reflection on essential themes characterising the phenomenon must take place.   | *Data Analysis   |
| <b>Step 4</b> | Finally, phenomenon must be described through the art of writing.  | *Presentation of the data<br>*Results and Discussion                                   |

Adapted Source: Van Manen (1984) cited in Smyth (2004)

### 4.3 Research Methodology

According to Remenyi (1998), as cited by Ross (2009), the research methodology acts as a guide by which the reader can identify “the procedural framework within which the research is conducted”. A number of critical methodological issues will be discussed in this section. This includes the data collection methods, instruments and process (es); the sampling type and technique, as well as the data processing and analysis.

### **4.3.1 Data Collection Techniques**

According to Pilot & Beck (2010) the main data sources for phenomenological studies are in-depth conversations with researchers and participants. The primary data-gathering techniques employed in this study include informal discussions and in-depth semi-structured interviews. These techniques are suitable for the qualitative research process as it allows the researcher to gather nuanced, detailed and rich descriptions both in a systematic and structured way as well as in a more incidental and informal fashion. These techniques enable the researcher to develop a comprehensive and deeper understanding of the experiences and challenges that healthcare workers face in the execution of their tasks. Apart from the collection of data and information, relevant secondary sources are also used to add context and background and to establish more of a macro-context to the study.

### **4.3.2 Informal Discussions and Observation**

Informal discussions and observation happened within the immediate working environments of healthcare workers, and accurate notes were taken of all observations. The researcher visited the field offices and did household visits with the healthcare workers as they executed their professional duties in the communities. In addition, the researcher also attended the weekly clinical meetings of the research team to determine if some of the challenges were tabled and discussed at these meetings and what strategies were proposed to overcome these. Furthermore, the ability of healthcare workers to articulate and voice their concerns was monitored. The observation will be vital for the research question to be answered.

### **4.3.3 In-depth interviews**

Semi-structured interviews were conducted with the healthcare workers. A semi-structured interview is a conversation between interviewer and respondent (Babbie& Mouton, 2001). The interviewer determines the direction for the conversation by asking specific questions. Herbert (1995), cited in Babbie& Mouton (2001), is of the opinion that semi-structured interviewing is “flexible, iterative and continuous and not cast in stone”. The interviewer is aware of the areas that he/she would like to cover with the respondent, however allows the respondent to explore various thoughts and feelings.

Semi-structured interviewing is critical to the study in order to gather in-depth information relating to the research problem.

Kvale (1996) cited Babbie& Mouton (2001:490), states that there are seven steps in the interviewing process namely:

- i. “Thematizing: clarifying the purpose of the interviews and the concepts to be explored
- ii. Designing: Laying out the process through which you accomplish your purpose including consideration of the ethical dimension
- iii. Interviewing: doing the actual interviews
- iv. Transcribing: writing a text of the interviews
- v. Analysing: determining the meaning of gathered data in relation to the purpose of the study
- vi. Verifying: checking the reliability and validity of the materials
- vii. Reporting: telling others what you’ve learned”.

Semi-structured interviews were conducted with 23 healthcare workers in order to gather information relating to their perception and comprehension of the type and severity of challenges they experience daily in the course of executing their work in the field. These interviews will attempt to determine the challenges that healthcare workers experience in executing their duties in the communities and the shortcomings that they identify in their professional competencies due to shortcomings or weaknesses in their training programmes.

#### **4.3.4 Data Collection Instruments**

An interview schedule (Annexure 4) was used as the main data collection instrument. This self-compiled interview schedule was used to guide the interviews and to collect the data for the purpose of the research study. DE Vos et al. (2005) state that an interview schedule is a set of key thematic areas used to guide interviews. The interview schedule consisted of one open-ended question namely:

- i. What are the challenges faced by healthcare workers when conducting clinical research?

Probing questions were also asked during the interviews.

- Tell me about the recruitment and retention of participants on your studies.
- What is your experience of Stigma to TB and HIV in the community?

Refer to Annexure 6 discussion schedule and Annexure 7 transcript of interview for to review other questions.

The researcher conducted the semi-structured interviews until no new themes and data emerged. According to Streubert & Carpenter (1999), this is an acceptable technique and in accordance with methods applied for qualitative research involving a smaller sample size. It is referred to as the principle of data saturation.

#### **4.3.5 Reliability and Validity**

According to Selltiz, Wrightsman & Cook (1976), cited in Brink (2006), reliability is concerned with the consistency, stability and repeatability of the respondent's explanations, and the researcher's capability to collect and record the information accurately. Interview techniques, such as summarising, asking for clarification and avoiding asking leading questions were utilised. Interviews were audio-recorded to ensure that all data was correctly recorded. The researcher used a voice recorder to record the interview, and consent was obtained from the participant to do the recording.

Validity in qualitative research is concerned with whether the data collected for the study reflects what the respondents stated (Brink, 2006). According to Le Compte & Goetz (1982) cited in Brink (2006), validity relates to the accuracy and truthfulness of scientific conclusions. During the interview process, the researcher summarized the respondents' statements and asked questions to clarify certain aspects to ensure that the responses were fully understood and that the interviewer had an accurate understanding of what was said.

#### **4.4 Sampling Method**

Sampling as defined by De Vos, Strydom, Fouché & Delpont (2005:193) is an extraction of any percentage of a population or world as representative (although not necessarily statistically representative) of that particular population or world.

##### **4.4.1 Non-probability Sampling**

The sampling method that was used for the purposes of this study can be described as the non-probability type. Brink (2006) states that a non-probability sampling may or may not accurately embody a representative sample of the population. This type of sampling is however, not used when statistical representative samples of the research population is sought and is more convenient and economical than randomized probability sampling. It requires the researcher to select participants who are best informed about the phenomenon to be studied and thus would be able to solicit valid and reliable information. A number of different types of non-probability sampling types are available to the researcher employing the qualitative approach. This includes snowball sampling, purposive sampling and quota sampling.

##### **4.4.2 Purposive sampling**

Purposive sampling was used, since the study relied heavily on the availability of participants (Babbie & Mouton, 2001:166), in this instance, those who were employed by the DTTC. A purposive sample of 23 health care workers was selected from a research population of 150 male and female healthcare workers employed at DTTC. The following criteria were used to determine the selection of participants. They had to be:

- (i) Conducting community-based clinical research;
- (ii) Available and interested in the study, to be interviewed and have the interviewed being audio-taped; and
- (iii) Willing to share information concerning his/her experiences of conducting community-based clinical research.

In order to select the healthcare workers, a list with all the names of the 150 healthcare workers was requested from the HR Manager of DTTC. Of the 23 healthcare workers who participated, two of the participants were males and 21 were females. This is consistent with

the gender ratio of the healthcare workers employed by DTTC. The participants were also chosen because of their ability to provide the necessary information needed to address the objectives of the study (Strydom, 2005). The sampling was done in such a fashion to ensure maximum variability; the sample included the whole spectrum of health care workers employed at DTTC on various community-based research projects. Patton (2002:46) states that the reasoning and potential impact of purposive sampling stems from obtaining in-depth understanding.

#### **4.5 Data processing and analysis**

According to De Vos et al. (2005:333), data analysis brings order and shape, and gives meaning to the data collected. They further state that qualitative data analysis searches for common themes, statements and associations among categories of data. In the current study, the processing of information collected entailed the analysis and categorisation of the data collected through informal conversations, semi-structured interviews. Collected qualitative data are typically analysed thematically and presented according to emerging themes with narrative explanations. This approach was also followed in this study.

The recordings of the informal discussions held with the healthcare workers and semi-structured interviews with participants were transcribed and thematically analysed. The researcher familiarise herself with the data, by listening repeatedly to the audio tapes and then transcribing the interviews. All audio-taped interviews from participants were electronically transcribed into Microsoft Word. Participant interviews were numbered. Accuracy of transcription was verified by the researcher, any identifying information in the interviews was redacted to protect the confidentiality of participants. The transcribed interviews were imported into the qualitative software program, Atlas.ti, 5.25. The data analysis also partially involved the codification of responses and development of different thematic categories. This helped to give structure, systemization and order to the data and made the data analysis more manageable and effective.

The first phase of qualitative data analysis involved identifying themes from the questions asked, and developing a codebook reflecting a thematic coding structure underlying the conceptual domains. Codes for each theme were assigned to text using Atlas.ti by a pair of coders per transcript, and inter-coder reliability was assessed by having the coders resolve



any coding differences between them. The analytical process yielded discrete and systematically coded textual data. The coded data were processed and analysed and presented in the form of frequencies graphs and tables. The data are presented in the form of frequencies graphs and labelled categories and written textual quotes.

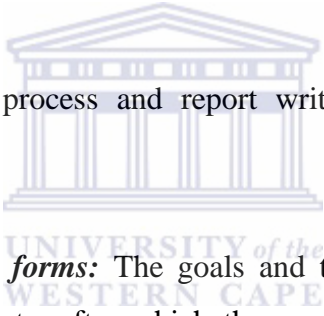
#### **4.6 Ethical Statement**

According to Burns & Grove (2003), researchers have an ethical responsibility to protect participants' human rights during research.

##### **4.6.1 Authorisation to conduct research**

This study was conducted after the research proposal had been approved by the University of the Western Cape Senate and the Institute for Social Development. Permission to conduct the research was granted by the Director of the Paediatrics' TB Research Programme at the DTTC.

Throughout the data collection process and report writing, the procedure included the following ethical considerations:

- 
- **Information and consent forms:** The goals and the purpose of the research were explained to the participants, after which they were asked to sign a consent form which stated what the objectives and nature of the study were, in addition to the voluntary and confidential nature of their participation. They were also informed that the interviews would be recorded and signed a consent form in this regard. The participants were also informed that participation is voluntary and they have the right to withdraw at any time during the study.
  - **Right to privacy** according to Burns & Grove (2003), an individual has the right to determine the time when and general conditions governing the information volunteered. The researcher communicated and agreed to the time and venue that was convenient for the participants and the interviews were conducted in privacy.
  - **Confidentiality:** The researcher explained to the participants that their identities will not be revealed and the data collected will be kept confidential.

- **Reporting:** The researcher also undertook to submit the research findings to the relevant role players.

#### **4.7 Time Frame**

The data was collected in the months May, June, and July 2012 at the Desmond Tutu TB Centre, University of Stellenbosch, and Tygerberg.

#### **4.8 Limitations of the Study**

This study was based on a sample of healthcare workers employed in a single research unit in Cape Town, i.e. the Desmond Tutu TB Centre, which obviously limits the generalization of its results. The results of the study, however, do offer the reader a good sense of the challenges healthcare workers experience in conducting clinical research.

The available time of both the healthcare workers and researcher for protracted discussions was also very limited as both parties had fulltime employment; this prevented many planned meetings from happening. Interviews are time consuming and expensive. Due to funding and time constraints, the study was limited to one setting and had a small sample size. Regardless of this, these findings raise important concerns about healthcare workers, specifically preventing them from functioning optimally in conducting clinical research.

#### **4.9 Summary**

In this chapter, the research design and methodology for this study was explored. An exploratory research design was used, with a qualitative approach, employing purposive sampling to collect samples for analysis. The participants were healthcare workers from the DTTC. They consented to being interviewed and audio-recorded, and these interviews were transcribed and verified by the researcher. An electronic software program, Atlas.ti was used to assist with the data analysis. The next chapter will focus on the analysis and discussion of the collected data.

## CHAPTER FIVE

### ANALYSIS AND DISCUSSION OF DATA AND FINDINGS

#### 5.1 Introduction

In this chapter the collected data is analysed and discussed. The analysis and interpretation of the data were carried out against the backdrop of the research objective of the study to answer the following research question:

- What are the challenges faced by healthcare workers when conducting clinical research in impoverished urban communities.<sup>2</sup>

This section explores the challenges experienced by healthcare workers conducting clinical research in a community-based study. Themes were identified before the research began and were used to guide the data collection and data analysis. . Figure 3 provides a summary of the themes with key words summarising the challenges experienced by the healthcare workers. These themes are linked and directly address the initial research objectives.

**Figure 3: Major Themes and Sub Themes**

|  |   |
|--|---|
| <b>Recruitment and Retention of participants</b>                             | <ul style="list-style-type: none"><li>• Migration of Participants</li></ul>   |
| <b>Psychological Impact</b>  | <ul style="list-style-type: none"><li>• Emotional trauma</li><li>• Safety</li></ul>   |
| <b>Risk of Exposure to TB and HIV</b>  | <ul style="list-style-type: none"><li>• Health</li><li>• Infection Control</li></ul>  |
| <b>Stigma</b>  | <ul style="list-style-type: none"><li>• Perceptions of community</li><li>• DTTC staff uniform and emblem on vehicle</li></ul> |
| <b>Interventions/Strategies to assist healthcare workers with challenges</b> | <ul style="list-style-type: none"><li>• Mentoring</li><li>• Debriefing</li></ul>  |

Participants in the research are referred to as ‘interviewees’ throughout the text (quotes are paraphrased in italics, accompanied by double quotation marks to indicate that these are not

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<sup>2</sup> The questions posed to the participants are included in Annexure 6

the words or opinions of the researcher, but those of the interviewees). Quotes from the interviewees will be used liberally to provide an insider perspective, i.e. insight into what emerged during the interviews relating to the important challenges for the healthcare worker. Every effort was made to present as many as possible of the participants' voices throughout the research findings.

Data were categorized into five themes. Themes that centred around the study aim and objectives were generated through data analysis. Upon analysis of the interviews five thematic codes were highlighted. These codes are explained in Figure 4.

**Figure 4: Thematic Codes**

| <b>CODES</b> | <b>DESCRIPTION</b>        |
|--------------|---------------------------|
| RE           | Recruitment and Retention |
| PS           | Psychological Impact      |
| RI           | Risk of Exposure          |
| STI          | Stigma                    |
| STR          | Strategies                |

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## **5.2 Demographic profile of participants**

Some of the salient demographic characteristics of the interviewees are discussed below.

### **5.2.1 Gender and age distribution of participants (DTTC –healthcare workers)**

The gender distribution of the research interviewees (DTTC–healthcare workers) who consented to participate, shows that 21 (91%) were females whilst 2 (9%) were males, as illustrated in figure 3 below. This is a typical trend within the nursing (healthcare) environment where more females opt for this career path than men tend to do (Wolfenden, 2011).

**Figure 5: Gender distribution of participants**

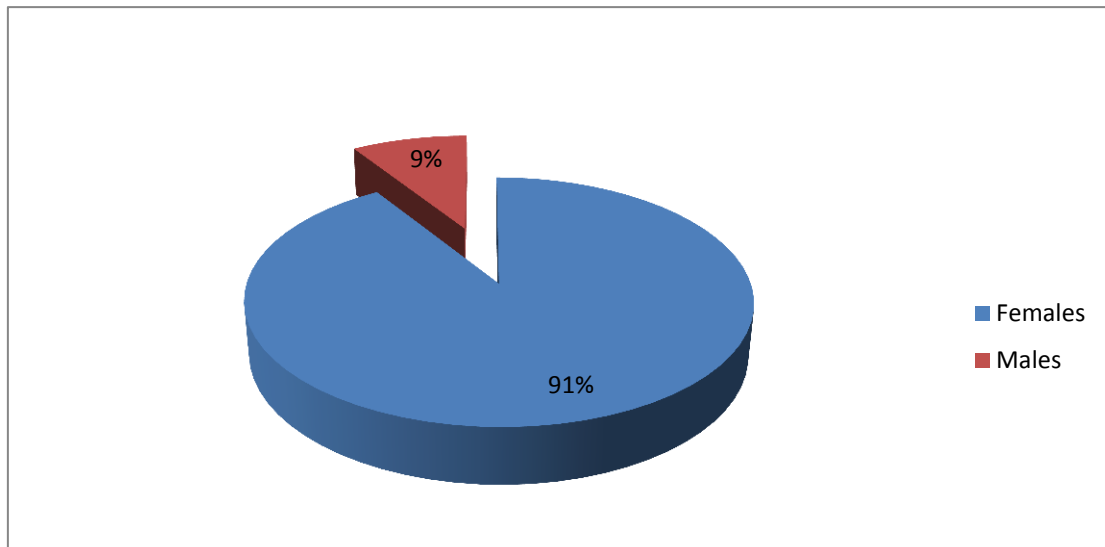
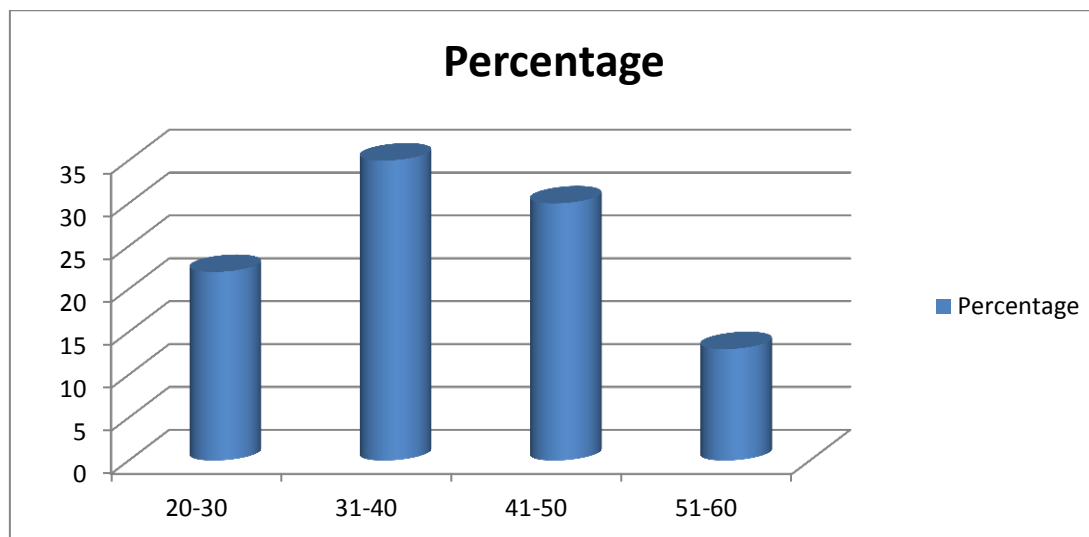


Figure 6 below shows that a substantial percentage of the interviewees i.e. 30%, fall within the 31–50 age category. It can be assumed, given the relative mature age of the majority of the workforce that they would be able to cope better with the often extreme psychological demands of working in TB and HIV/AIDS clinical research settings than younger workers. Only 13% fell within the 51–60 age cohort.

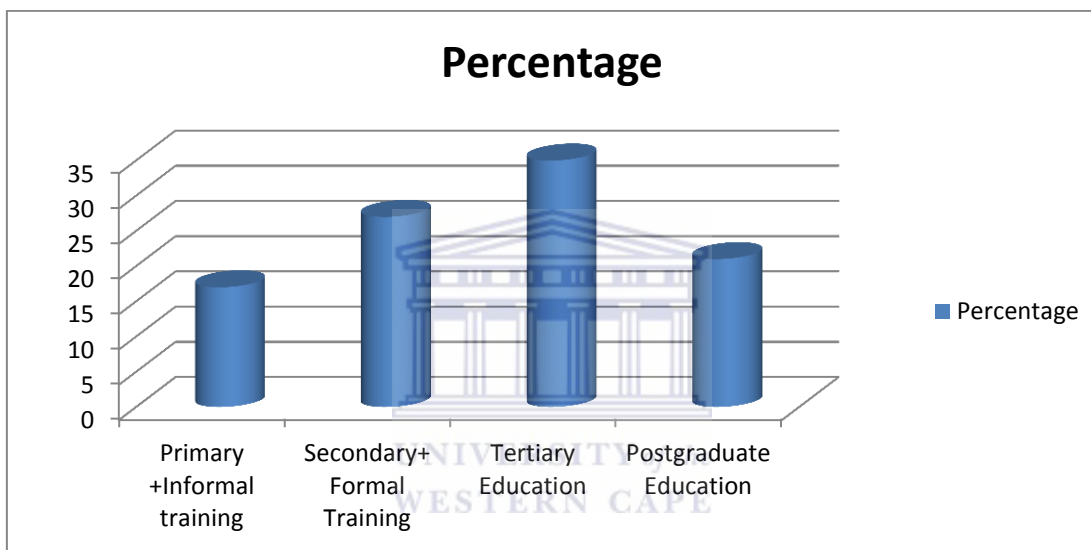
**Figure 6: Age distribution of Participants**



Results emanating from this study show that the highest educational qualification achieved by healthcare workers varies substantially. Figure 7 below shows that a relatively high

percentage, i.e. 35%, has obtained a tertiary education in nursing or related health and medical field, with another 20% obtaining a postgraduate qualification, whilst 21% only completed secondary education. Seventeen percent though had received only a very basic education. The fact that more than half of the participants held a tertiary education is encouraging. The wide range evident in the formal education qualification of the participants is an interesting finding in itself and suggests that this particular type of work is accessible as well as appealing to people from different academic achievements and competencies.

**Figure 7: Highest Educational distribution of Participants**



**Figure 8: Interviewee’s Professional orientation**

| Professional orientation | Number of participants |
|--------------------------|------------------------|
| Medical Doctor           | n=1                    |
| Study co-ordinators      | n=2                    |
| Professional Nurse       | n=5                    |
| Enrolled Nurse           | n=1                    |
| Field Managers           | n=3                    |
| Lay Counsellors          | n=4                    |
| Research Assistants      | n=2                    |
| Health advocates         | n=4                    |
| Drivers                  | n=1                    |

Figure 8 above gives an overview of the various professional orientations of the interviewees who consented to participate in the research study. A substantial number of the interviewees, 40%, are trained medical staff, which suggests that the number of healthcare workers who are employed to conduct clinical research need to have some form of clinical training.

### **5.3 Different Challenges faced by Health Workers**

#### **5.3.1 Recruitment and retention of participants in clinical research/health interventions**

When conducting the interviews with field healthcare workers, it became apparent that recruiting patients to participate in a longitudinal community based study and retaining them throughout the entire study was indeed problematic and presented a continuous challenge. Two of the interviewees stated that...

##### **Interviewee A**

*“The challenges that we face is that it is sometimes really difficult to retain the participant in the study. According to the informed consent they can withdraw from the study at any time during the study. So sometimes it’s really difficult to retain them. You have to explain to the parent (of the patient in the case of a minor) the benefits of the study. Some other challenges that we also face is participants not pitching for their study visits. Some other challenges that we face is that when we do recruitment we will find that the kids don’t live with the parents, they live with the grandparents and they do not have legal papers for them so that is some of the challenges we face out there.”*

##### **Interviewee B**

*“If I think just in participation of the participants one main challenge is just to – in order have those people stay throughout the study until completion of it. And then I think just the different strategies that one needs to have in mind in just retaining those patients or just recalling them back for their visits is not always easy because it’s multiple efforts in doing so and everything needs to be noted down.”*

Interviewees stated that the effort of retaining patients’ participations and commitment present the main challenges in conducting longitudinal community-based research and that

multiple efforts are needed to motivate them to stay in the research. This impacts on the cost of telephone calls and transport expenditure of doing multiple home visits, with participants sometimes ultimately withdrawing from the study. Participants provide various reasons for withdrawal from the study, for example job commitments, do not want family to know about their TB status and fear for the associated stigma. The withdrawal of participants has a definite impact on the morale of healthcare workers/ field staff and their productivity and motivation to perform and sustain their daily activities with enthusiasm. This challenge is also highlighted in literature which suggests that implementation strategies for recruitment and retention of participants are important aspects of the clinical research and should be deliberately and continuously applied and maintained throughout the entire research process.

Some of the sub-themes that emerged from this category were the logistics, timelines for follow-up visits, and particularly the migration of participants that impacted on the successful recruitment and retention of participants in their study.

### **5.3.2 Migration of participants**

According to Lassetter & Callister (2010) migration is a global phenomenon and more people are geographically mobile than in any other time in human history. Coetzee (2012) reported that foreigners are the second largest group of people who came to live in the Western Cape during the past decade. Altogether 26 percent, or 113 973, of nearly half a million people who moved to the province between 2001 and 2011 were from outside South Africa.

According to Coetzee (2012), the increase in population growth within the Western Cape is largely due to the influx of people from other provinces. The Western Cape recorded the second-biggest in-migration after Gauteng. Interviewees from the Khayelitsha, Site C field office reported that in this area, with its multi-cultural community, migration is very high, with the influx of foreigners from other countries as well as from other provinces. Migration in these communities directly impacts the recruitment and retention of participants on their studies. Whilst healthcare workers have to document every attempt they have made to trace the participant, including the date and time of the home visit, telephone calls made, and notifications left, if the participant does not come for the study visits after they have missed the timeline for their crucial three or six month follow-up visit, they have to register the

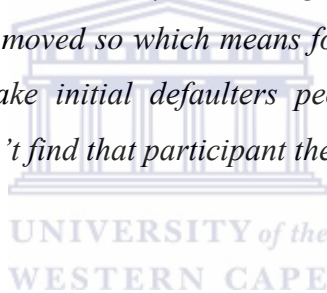


participant as lost to follow-up. The interviewees from Ravensmead and Uitsig reported some migration; however, the rate at which the community migrate was lower than in Khayelitsha. Migration (of participants) causes different problems and poses difficult challenges to healthcare workers to sustain contact with patients and successfully completed clinical trials.

One interviewee described the difficulty caused by migration as follows:

### **Interviewee C**

*“Migration - that was very difficult, firstly one of the communities that we worked in was an informal settlement, so went back to them in the following week, not even the following month when we went to our patients for the follow-ups, the community was moved, into another area, it was a lot of people, so it was difficult to find them, so in that communities we lost a lot of people. In other areas in the community when we going into participant houses, when you go there, the participant has moved so which means for instance with the study that I’m working on now working we take initial defaulters people that didn’t start with their treatments which means if we don’t find that participant then you don’t reach your target”.*



## **5.4 Psychological Impact**

Healthcare workers, who are exposed to the trauma experienced by others in their daily work, are often traumatised and overburdened by the narratives and experiences of their patients (Martin, 2006).

### **5.4.1 Emotional Trauma**

Healthcare workers are particularly affected emotionally and psychologically by the adverse social and economic position and lack of often very basic but critically important resources of the patient and the broader community they live in. According to Pearlman & Saakvitne (1995), cited in Martin (2006), the healthcare worker is emotionally vulnerable through the empathic engagement, as conveyor of negative or positive news to the patient, about their TB and or HIV/AIDS status. Being exposed to trauma over time affects a person’s professional and social identity (Dane & Chachkes, 2001 cited in Martin, 2006). According to Bell, Kulkarni & Dalton (2003) cited in Martin (2006), trauma may present with emotional exhaustion, depersonalisation and reduced personal accomplishment. The quote below clearly

illustrates the impact poverty and deprivation has on the emotional wellbeing of the healthcare worker working in impoverished communities of the Cape Flats:

#### **Interviewee D**

*“I think otherwise because of the community where the participants are coming from – it’s a poor community, the socio-economic situation is bad at some instances that play a major role on just how psychologically it affects you. So at times it’s hard because it’s not like you just can switch off and even if you go home even you think. You think even outside of your work spectrum. You wonder if it rains outside, are that person, are the house you visited ok, as you know that there are holes in the roof and you wonder what’s going on there. At times you kind of feel sorry for them. Just for the whole situation they are facing and they are in. So in that regard it’s a challenge but I think physically doing the work, taking the bloods and the gastric washings and all that – at first it was a bit I think even traumatizing for me because you have to do so many procedures on a child at the same time and if it’s a bigger child you can still reason with them, you can tell them why it needs to be done but with a small child you can’t.”*

From the above citation, it is patently clear that patients’ living conditions, socio-economic environment and lack of access to basic services, are contributing psychological stressors for the interviewees that they have little or no control over. It is clear that they experience feelings of helplessness, despair and are overwhelmed by circumstances beyond their control. They are powerless to intervene. It was mentioned, for example, that despite their best efforts to educate the patient about healthy eating and living habits, the majority of the patients are not able to afford the nutritional food required for this diet.

Emotional stress was also reported by interviewees regarding the type of work and duties that are expected of them to perform. For example, healthcare workers experienced having to convey the message to a patient that she or he is either HIV positive or have been diagnosed with MDR and XDR TB as hugely emotionally draining. This is typical of the kind of emotionally taxing and traumatic context healthcare workers are confronted with daily and that is reported to affect them psychologically.

## 5.5 Risk of exposure to TB and HIV and personal cover against infection

According to Brown, Trujillo & Macintyre (2003), fear of illness, and particularly of contracting TB and HIV/AIDS, is a normal response among healthcare workers, co-workers, and caregivers, as well as the general population. The risk of contracting TB or being infected by HIV is disturbingly high when working in an environment where TB or HIV/AIDS is prevalent. This is especially true in the case of health workers operating in the impoverished communities of the Western Cape.

During the interviews it became clear that most of the interviewees were aware that their employer had a health and safety policy and standard operating procedures in place for minimizing the risk of exposure to and contracting TB and HIV/AIDS. However, 60% of the healthcare workers participating in this study were still concerned about the possible risk of exposure to TB. This was mainly because some patients do not (initially) disclose their MDR- and XDR-TB status to healthcare workers. Another source of deep concern amongst the majority of these healthcare workers was the omnipresent threat and risk of needle stick injuries.

Another related issue raised by the workers concerned was that of being sufficiently covered (by medical and other insurances offered by their employer) against contracting and getting disabled or chronically ill due to TB or HIV/AIDS infection. The interviewees reported that only trained medical staff enjoys HIV/AIDS insurance, whilst non-medical/lay healthcare workers are not covered. The researcher, a former employee of the DTTC, was aware of healthcare workers who were exposed to TB and had needle stick injuries and how it affected them on a personal and professional level.

The quote below from one interviewee clearly illustrates a general concern amongst healthcare workers employed by the DTTC, in this regard:

### **Interviewee E**

*“Everyone must wear a mask, because it might have been that the household that we’re enrolling in that day they don’t have TB and the second one do have TB. So we don’t want to expose the one who doesn’t have TB. So all of them just put them to – we encourage them to wear a mask. And also for ourselves: we also protect ourselves and make it a point to wear*

*masks, we wear gloves every time when we're dealing with our patients. Whether they've got TB or not. When it comes to HIV it's not easy. Especially like in the position that we as counsellors are at. We are really at risk of getting like needle stick and other things but we're trying our best. And we try just because we are the people who are assisting the nurses with the phlebotomy and other things. So, yes we just try not to get those things. Because we know that – we don't have any policy that covers us”.*

### **5.5.1 Safety**

#### **5.5.1.1 Unsafe conditions that healthcare workers face**

The majority of interviewees reported that the communities they work in are unsafe. The researcher accompanied them for the purpose conducting informal observation when they undertook home visits in the various communities. It was clear that there are definitely potential dangers in their work environment and that they are indeed regularly exposed to crime and violence. A real concern is the strong presence and visibility of (young) unemployed men loitering in the streets of the different impoverished and marginalized communities that healthcare workers conduct their research in. These unemployed young men constitute a real danger to the health care workers; they could rob and attack health care workers from their cell phones and personal property. The female workers, who constitute the overwhelming majority of healthcare workers, reported a strong sense of vulnerability and lack of a sense of personal safety while moving from house to house. These workers sometimes need to enter exceedingly dangerous situations and locations in order to interact with their patients participating in clinical research. These include obscure backyard dwellings, shebeens and so called drug (lord) houses.

The following quotation from a young middle aged female healthcare worker dramatically illustrates the perilous and marginal situations the healthcare workers are sometimes caught in:

#### **Interviewee F**

*“I started working here- in those years there was a time whereby we didn't know the people that belonged to that house that we were interviewing that they were involved in crime but the police there were police vans and police people and we didn't even hear any noise we just*

*saw someone kicking the door and coming inside with guns and those participants also had guns and they also threw their guns and we are in the middle of them so it was too risky for us but we did manage to leave because the police officers told them they must let us go so they let us go they were not rude to us”.*

Some of the interviewees reported that they originate from the communities the studies are being carried out in and thus are well aware of local conditions. This intimate knowledge of the internal dynamics and functioning of these communities enables them to be pro-active in potentially threatening situations in marginal areas of the communities.

In order to aid healthcare workers and secure their protection, the employer provides a male driver to accompany female workers when doing household visits. Healthcare workers are also supplied with pepper spray in the event of being confronted by a threatening and / or violent situation in the community. However, they did concede that they constantly need to be aware of their immediate surroundings as the environments and situations that they are required to operate in when trying to locate patients are (potentially) very unsafe. Interviewees also suggested when doing work in a particular community, the police should be informed about their presence and that the police should increase their visibility whilst healthcare workers operate in that area to ensure their safety.

The high prevalence of substance abuse in the impoverished areas of the Western Cape, and especially the use of the drug “Tik”<sup>3</sup>, increases the possibility of gang, street and domestic violence, and therefore creates a particularly volatile and unpredictable environment for the healthcare worker to work in.

## **5.6 Stigma**

Stigmatization is a process that stem from the perception that a set of shared values and beliefs have been violated. This can lead to negative judgements and actions from governments, communities, healthcare workers, friends and families. Sources of stigma could include fear of contracting a disease or fear of death. According to Brown, Trujillo & Macintyre (2003) it is important to acknowledge that stigma affects health workers

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<sup>3</sup>The local name for crystal methamphetamine. [Online] Available: <http://www.allwords.com/word-tik.html> accessed 05/02/2013

themselves and is not limited to their patients(Cameron (1993); Jayaraman(1998); & Zieler et al.(2000) cited in Brown, Trujillo & Macintyre (2003).

However, it is important to try and understand why some illnesses are stigmatized by society. Why can a cancer sufferer be transparent about his/her illness, but not a person who has contracted TB (or HIV/AIDS)? It is argued that the stigma surrounding TB is partially rooted in the general and popular belief that this illness is strongly related to poverty; that means that if you are infected with TB you are by implication poor and thus tainted with all the stereotypes that are typically associated with being impoverished and poor. According to the Department of Health (DOH, 2003) report, stigma (associated with some illnesses) definitely has a physical and emotional impact on healthcare workers. Fear of isolation and rejection from family and communities, when diagnose or being exposed to the TB and HIV/AIDS contribute to stigma.

#### **5.6.1 The effect of stigma attached to/associated with TB and HIV/AIDS on healthcare workers**

Before the possible impact of the alleged stigma associated with TB or HIV/AIDS patients could be established (or on those associated or working with them), the researcher had first to determine whether the interviewees, based on their work related experiences, believed that stigma towards these illnesses existed within their work context. Thus, interviewees were firstly asked if there is a stigma attached to them by working within a TB and HIV/AIDS environment, and secondly, towards these illnesses in the communities they work in, as this would directly impact on the recruitment and retention of patients to participate in clinical research.

Stigma associated with TB amongst healthcare workers did exist, as interviewees expressed fear of contracting TB and possible risk of exposure to needle stick injuries, and getting HIV infected, with consequentially serious and often devastating personal ramifications in terms of fractured family relations and broken social and work-related networks.

Despite the successful awareness campaigns by the Department of Health and government partners in the media, this research confirmed that stigma associated with TB and HIV/AIDS

still exists and persists in communities on the Cape Flats. According to the interviewees, their patients are relatively well informed about TB and HIV/AIDS, although it depends largely on the educational level of the individual patient. However, patients remain fearful of neighbours and the community at large being aware of their positive TB or HIV status.

The majority (60%) of the interviewees included in this study pointed out that stigma associated with TB and HIV/AIDS pose a significant challenge with regards to the recruitment and retention of patients to participate in the studies. When doing follow-up visits of patients who had completed TB treatment, the healthcare workers were no longer welcome because the patient does not want to be associated with TB. Patients evade treatment and hide themselves from the communities due to fear of being ridiculed. The quotation below reflects that stigma associated with TB is still prevalent in these communities:

#### **Interviewee G**

*“On the study that I’m working on now I’ve done the interviews with the participants and I would I’ve asked them about the stigmas because in most of those communities I don’t stay in, so I don’t know what’s happening with stigma even with the clinic we not working a lot of time at the clinic we only work one day or two days at the clinic so when I asked them if there is still stigma, some of them they say no there’s no stigma ever since there were campaigns done about TB and HIV the stigma is not as it was before but when you interview patients and you carry on with them they are still hiding themselves they still don’t want people to know about their TB and HIV status and they will reflect when someone has TB or HIV they will refer to it as if is witchcraft”. “Or even when you go into the community wearing the DTTC jacket or T-shirt that is sometimes a bad label to the participants and to us, because they will say hey here that TB people, but some people they respected us and our work when we were wearing the uniform”.*

Interviewees also declared that TB is strongly linked to poverty in the communities where they are working. An overwhelming majority of interviewees also reported that wearing the DTTC maroon-uniform and the logo on their vehicles contributed to the stigma that the patients are subjected to.

## 5.7 Mentoring and debriefing

The sustained emotional and psychological stress and trauma that health workers internalize and process as part of their daily routine, will clearly cause deep emotional damage over time if not dealt with professionally. One such intervention is debriefing sessions for those exposed to this type of emotional pressure. Mitchell, Sakraida & Kameg (2003) define debriefing as a process where support is given to groups or individuals who are working in high risk occupations, including medical personnel. These authors are of the opinion that the main focus of debriefing is to relieve stress and emotional trauma that groups or individuals have been exposed to. Debriefing is frequently used in an attempt to ameliorate the impact of traumatic experiences on individuals or groups (Robinson, 1999).

An overwhelming majority of the interviewees (95%) reported that the employer had a formal mentoring and debriefing programme offered on a monthly basis by a trained psychologist for the research assistants/counsellors. There is, strangely, no mentoring and debriefing in place for clinical nursing staff who are exposed to the same types of challenges in the field. The quote from one of the interviewees below serves to illustrate the value and strategic importance of timely and regular debriefing sessions for healthcare workers repeatedly faced by emotional challenging situations and traumatic conditions:

### Interviewee H

*“In the beginning it was really hard because I couldn’t really handle it. I worked in a private hospital. So the setting was different than here, and it was the first time that I worked in the community and really sees what is happening out there. And it was very difficult for me – especially the children you can see the child is being physically abused, you can see the poverty, the hunger, and as I’ve mentioned before the drugs and the alcohol abuse. And it was very difficult but as I put it always, we debrief amongst each other, the study nurses, even the counsellor’s. We talk to each other about what we have seen and that is our, my way of handling this. For the counsellor’s there is a regular mentoring service, not for the nurses.”*

About 20% of the interviewees reported undergoing informal de-briefing as a positive intervention and strategy with co-workers or having informal discussions of certain (traumatic) events that they have experienced in the field. Informal debriefing in healthcare environments is often unplanned and unstructured and thus sometimes not viewed in very



positive terms and of real value as it may not meet the needs of the healthcare worker (Mitchell, Sakraida & Kameg, 2003). However, the interviewees felt that this type of intervention is indeed good; it offers a safe place, and a comfortable and confidential space where health workers could offload. However, the overwhelming majority of the clinically trained staff felt that all staff should have access to mentoring and debriefing on a more regular basis.

### **5.8 Strategies/interventions needed to assist healthcare workers with emotional and psychological challenges**

As mentioned earlier, counsellors and research assistants are debriefed and mentored on a regular basis, but this option is not available to the nursing staff and the minibus drivers. The interviewees feel strongly that this intervention be made available to all healthcare workers. The quotation below gives us a clear indication that there is a definite need for mentoring and debriefing:

#### **Interviewee I**

*“The study counsellor has got mentoring in process. But there’re also some issues that they don’t want to discuss in that meeting because there are colleagues with them and they also deal with personal issues. So for the study counsellors I think that the study nurse – who is the manager of the site – actually needs to set sessions where they can discuss and talk to each other to see where they are and what influence that can have on the daily work. For the study nurses I think a professional person especially – even though you can only have it for the first year of a study or the first few months of a new study – but to have a professional person for them to debrief. For the study coordinator needs to be open and listen to study nurses. Study drivers also don’t have counselling sessions. So they are also with the study counsellor and I think they should also have been included to the mentoring process because they go out with them to the houses. They get one-on-one with participants also.*

Sixty percent of the of healthcare workers interviewed expressed the need for intervention as discussed above to deal with work-related emotional challenges at an earlier stage and at more frequent intervals during the implementation of clinical trials. Healthcare workers also

felt that an employee assistant programme (EAP) <sup>4</sup>should be made available to all staff, as this is only available for those with permanent employment benefits.

## 5.9 Summary

This chapter presented the findings of the study. From the discussion it is clear that healthcare workers are subjected to a range of challenges while performing their duties. They reported their fears of being exposed to crime and violence, as well as to emotional trauma when working in situations of severe material and emotional hardships experienced by their patients. Healthcare workers reported that working in impoverished urban communities, and listening to and giving feedback to patients regarding their diagnosis, impacts on them emotionally. The healthcare workers gave feedback of stigma felt amongst healthcare workers and the communities they work in and how this impacted their recruitment and retention targets for the particular studies; the DTTC uniform and logo was also reported as a contributing factor to stigma when teams were doing home-visits.

By exploring and detailing the challenges faced by healthcare workers and identifying their main day-to-day issues and concerns while implementing community based clinical research, these findings provide insight into existing challenges facing these workers preventing them from executing their work effectively. These findings should create an awareness of the shortcomings in the support of healthcare workers in clinical settings. These findings also suggest possible solutions to address these constraints and challenges in order to facilitate better implementation of longitudinal community-based research in social and economic marginalised communities. This is dealt with in the following chapter.

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<sup>4</sup>An EAP entails assistance with regard to emotional trauma and psychological impact of working in socio-economic challenged communities and/or other challenges that may affect their job performance.

# CHAPTER SIX

## SUMMARY, RECOMMENDATIONS AND CONCLUSION

### 6.1 Introduction

A qualitative research design was chosen for this research because of the appropriateness of this approach to best answer the research question developed for this study. The researcher employed non-probability sampling and used the purposive technique to select the respondents. It was possible to interview 23 participants using semi-structured interviews. The interviews were audiotaped and transcribed for interpretative phenomenological analysis. The researcher focused on the distinctiveness of the experiences of the interviewees, how their experiences made meaning to them, and how these meanings manifested itself within the context of the person both as an individual and in the role of healthcare worker.

This qualitative study provided information about the experiences of healthcare workers conducting community-based clinical research. The nature of the study provided a deeper examination of their experiences in the community as fieldworkers. Although this study has attempted to contribute in making the voice heard of health workers operating at grassroots level (of conducting clinical research), care must be taken not to generalize its findings too ambitiously to other healthcare workers without further investigation, given the limitations of the study.

The research question posed in this study was: *What are the challenges faced by HCWs when conducting clinical research?* The intent of this research was to explore challenges, such as retention and recruitment of patients, the risk of exposure to TB and HIV/AIDS, stigma relating to these diseases and the psychological impact of this type of work given the specific work setting. Attention was also given to perceptions of personal safety of the selected group of health workers performing their duties, often under very risky and trying circumstances. This study was successful in addressing these issues as is evident from the previous chapter.

This chapter discusses some steps and strategies that could be considered to ameliorate (some of) the different problems and challenges faced and experienced by healthcare workers conducting clinical trials, as well as performing general medical and health related work in

socio-economically marginalised communities that are displaying *inter alia* deep levels of abject poverty and associated social pathologies, e.g. substance abuse, crime and violence as well as domestic problems.

## 6.2 Recommendations

This study makes the following recommendations based on the findings in order to enable healthcare workers to better perform their role in clinical research.

### 6.2.1 Recommendations for psychological impact

The study results reflect that the healthcare worker experienced various challenges, concerns and stressful situations in the course of the execution of their work. This takes on different forms and includes empathising with patients regarding their illness or supporting them emotionally with their difficult or often desperate socio-economic circumstances, as well as having to deal with their own concerns, like the fear of exposure to highly contagious diseases and concern about their physical wellbeing and safety.

Doing healthcare work is typically a stressful occupation; however, this stress is exacerbated within communities with a high prevalence of poverty, social problems, as well as TB and HIV/AIDS, resulting in high levels of exposure to personal injury and infection.

In order to address the possible negative impact on health workers due to sustained exposure to traumatic contexts and experiences and to minimize risks factors, the following recommendations could be considered for implementation by the DTTC, the employer of the healthcare workers:

- Continuous monitoring and evaluation of current policies, as well as standard operating procedures for healthcare workers to ensure that it is in line with the current environmental issues that the healthcare workers are confronted with. .
- Provide policy guidelines for the establishment of sustainable intervention programmes that will enable healthcare workers to discuss (mutual) concerns and impart strategies that could be helpful to ameliorate their **emotional trauma**.

The following interventions should be considered:

- Creating opportunities for feedback from healthcare workers with regard to factors that play a role in determining the level of psychological stress and identifying potential areas for future intervention.
- De-briefing should not be perceived as a stand-alone intervention; it must be part of a comprehensive method to prepare healthcare workers to cope effectively with the challenges of their working environment.
- Make professionally trained psychologists available to offer debriefing and mentoring sessions with all levels of healthcare workers to give them the opportunity to articulate their fears, frustrations and emotions associated with the work they do.

To affirm healthcare workers' contribution to community-based research and recognize the stressful nature of clinical research by management. Mentoring and debriefing by trained psychologists could assist all healthcare workers with personal growth and development, which could enhance their confidence and would assist them to better react to trauma and thus diminish their work-related stressors.

### **6.2.2 Improvement of Infection control, protection and Medical Insurance**

- Review and strengthen global infection control measures, to ensure that healthcare workers receive sustained high quality preventative care.
- Provide regular in-service training for healthcare workers relating to TB and HIV/AIDS infection control measures.
- On-going education and awareness should include safety strategies to minimize the risk of infection, and safety tips when doing home visits in the communities.
- Standard operating procedures as well as health and safety policy documents should be reviewed with staff input at regular intervals to ensure that it is relevant to the current working conditions.
- Provide medical insurance cover for all staff working with blood and sputum samples who are at risk of exposure to TB and HIV/AIDS.

### **6.2.3 Development of Policies relating to Safety Related Issues**

- Develop clear and precise policies and procedures relating to staff personal safety when working in the community health facilities.
- Employ strategies to increase safety of healthcare workers when visiting high risk areas.
- Provided emergency contact numbers, procedures and services to all staff.
- Develop clear guidelines for doing home visits – healthcare workers need to familiarize themselves with safety issues before visiting patients.
- Implementation of stringent safety measures to offer adequate protection for healthcare workers at all times that will enable them to conduct clinical research in the community effectively and professionally in a secure and sustainable fashion.

### **6.2.4 Allocate renewed resources in countering impact of stigma attached to TB**

In a study conducted by van Brakel (2005) on the effects of stigma, he concluded that stigma associated with specific illnesses profoundly influenced the quality of life of the affected individuals, as well as the effectiveness of associated public health programmes.

Specific policies and strategies should be developed to address the definite need to educate, create awareness and an environment of understanding of individuals living with the disease that will help to de-stigmatize TB. The findings of this study suggest that TB and HIV/AIDS-associated stigmas definitely exist in the communities where the interviewees conducted their clinical research. People's attitudes towards and their perceptions of people living with TB and HIV/AIDS remain a major challenge in communities where the prevalence of TB and HIV/AIDS is high. This stigma also impacted on patients consenting to participate in studies, which in turn influences the recruitment and retention of patients in research endeavours.

### 6.3 Conclusion

In conclusion, the purpose of the study was to explore the challenges healthcare workers face when conducting community-based clinical research. The findings of the study suggest that healthcare workers are definitely exposed to a variety of problems, challenges and psychologically stressful situations in conducting longitudinal community-based clinical research. Clinical research relies on the successful recruitment and retention of patients to participate in the research so as to produce the desired results for improved treatment programmes.

This study clearly showed that stigma associated with TB and HIV/AIDS presents a formidable challenge to the successful completion of clinical trials in socio economically marginalized communities of the Cape Metropole. It influences the public's acceptance of treatment programmes and participation in research projects. This attitude has off course serious health implications for both the general population of these communities in general and health care workers operating there in particular.

Migration of populations, including patients, is a reality in any developing country, also in South Africa. This is particularly the case in the Western Cape, a province that is a sought after destination for job seekers. This study established that this creates major challenges for healthcare workers to locate and retain their patients. Migration directly impacts on reaching the recruitment targets and timelines set for a particular study. It is of imperative that the relevant authorities take cognizance of this reality as well as the other issues and challenges illuminated in this limited study.

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## **Annexure 1**

### **Request letter for consent to conduct research**

**10 August 2011**

Professor and Director: Paediatric TB Research Program

Dear Prof. Anneke Hesseling

#### Request for access to conduct research

I, Grace Colleen Bruintjies, request approval to conduct a research project at your institution. I am currently registered with the University of Western Cape for a Master's Degree in Development studies. It is required that a study should be completed for the degree to be conferred.

The purpose of the study is to explore the challenges faced by healthcare workers in conducting clinical research at the Desmond Tutu TB Centre. Interviews will be conducted over a 2 month period.

Thank you in anticipation

Yours sincerely

Mrs GC Bruintjies

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*Every breath counts*

Date: 12 August 2011

To whom it may concern

Application to conduct study: Desmond Tutu TB Centre (DTTC): G.C. Bruintjies

I hereby give permission for Grace Bruintjies to implement her research project "An Exploration of Challenges Faced by Health Care Workers in Conducting Clinical Research" at the Desmond Tutu TB Centre.

This work will be towards a Masters Degree in Development Studies at the University of Western Cape in Bellville South.



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Field work for this project will be conducted at selected field offices affiliated with the DTTC including the communities of Ravensmead, Uitsig and Site C, Khayelitsha.

Please do not hesitate to contact me with any further queries.

Anneke C. Hesselning  
Professor and Director: Paediatric TB Research Program  
Desmond Tutu TB Centre  
Department of Paediatrics and Child Health  
Faculty of Health Sciences



UNIVERSITEIT-SYDNEY / UNIVERSITY OF SYDNEY  
UNIVERSITY OF THE WESTERN CAPE

Desmond Tutu TB Centre @ Centre @ UWC  
Faculty of Health Sciences @ Faculty of Health Sciences  
P.O. Box 19009, Tygerberg, 7530. Tel: (27) 21 959 2114, 1944. Fax: (27) 21 959 2119, 1944. Email: [tb@uwc.ac.za](mailto:tb@uwc.ac.za)  
Website: [www.tbcentre.org.za](http://www.tbcentre.org.za)

**ANNEXURE 3**  
**Information for Individual Interview**  
**The University of the Western Cape**



School of Government  
Institute for Social Development  
**INFORMATION SHEET**

***Challenges Faced by Healthcare Workers in Conducting Clinical  
Research in Selected Western Cape Sites***

**RESEARCHER: Grace Bruintjies**

**POSITION: Master's Student**

**INFORMATION FOR PARTICIPANT re: Ethics**

The project will ensure that the following will be adhered to:

1. Participation is voluntary and participants may withdraw at any time during prior to or during data collection
2. Participants' identity and information that will be obtained will be strictly confidential.
3. Participant will be fully informed about the nature of the research and provided with feedback.

**INFORMATION RE: RESEARCH PROJECT**

This study is concerned with gaining views on the everyday reality of clinical research from the perspective of those who conduct it. It will focus on the healthcare workers views of the challenges they face in conducting clinical research. The main aim of the study is to investigate the challenges faced by healthcare workers employed at Desmond Tutu TB Centre (DTTC) working on community based research projects within the Cape Town Metropole.

It is crucial to gather information from the fieldworker, because it is important to understand their views about the challenges in conducting clinical research. This study will attempt to shed light on the challenges of the community-based healthcare workers in order to assist

DTTC in the amelioration of problems related to and the development of better strategies to deal with such challenges.

## **RESEARCH OBJECTIVES**

The objectives of the study are to:

- Identify and describe the challenges healthcare workers face in executing their duties in vulnerable communities.
- Explore suggestions from healthcare workers to overcome the challenges they face;

## **PARTICIPANT INVOLVEMENT**

Participants who agree to participate in the research project will be interviewed on an individual basis. The individual interviews will take up to 30 to 45 minutes of the participant's time. The interviews will be audio-taped and transcribed by the researcher. Interviews will commence late September 2011. An outline of the interview questions is attached to this sheet.

## **FEEDBACK FINDINGS**

On completion of the data analysis, a summary of findings will be sent to each participant if requested and to all relevant stakeholders. It is also anticipated that the findings will be used for publication.

## **PROTECTION OF PRIVACY**

The researcher will ensure that confidentiality is adhered to regarding the identity of individual. It is the goal of the researcher to transcribe the data and all written material as well as tapes will be password protected in a folder on her computer. All written and audio recordings will be destroyed within 3 years after the research has been completed.



**ANNEXURE 4  
Consent Form  
The University of the Western Cape**



School of Government  
Institute for Social Development

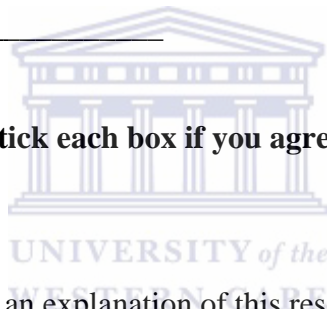
**CONSENT TO PARTICIPATE IN RESEARCH**

**Project Title:**

***Challenges Faced by Healthcare Workers in Conducting Clinical Research  
in Selected Western Cape Sites***

Reference Number: \_\_\_\_\_

**Please read information below, tick each box if you agree then sign if you wish to be part of this research**



I have been given and understood an explanation of this research project. I have had an opportunity to ask questions and have them answered to my satisfaction.

I understand that I may withdraw from this project prior to/or during data collection without having to give reasons or without penalty of any sort.

I understand that any information I provide will be kept confidential to the researcher and the supervisor.

I understand that the published results will not use my name, and no opinions will be attributed to me in any way that will identify me.

I understand that the audio recording of interviews will be electronically removed within 3 years after the research has been completed.

I understand that the data obtained may be used for conference papers and/or publications

I understand that I can receive a summary of the findings if I request it.

I agree to take part in this research.

**Name:** \_\_\_\_\_

**Institution:** \_\_\_\_\_

**Address for postal purposes:**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



**Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

**ANNEXURE 5**  
**Informed Consent Form**  
**The University of the Western Cape**



School of Government  
Institute for Social Development  
**INFORMED CONSENT FOR TAPE RECORDING OF THE INTERVIEW**

**Project Title:**

***Challenges Faced by Healthcare Workers in Conducting Clinical  
Research in Selected Western Cape Sites***

Reference Number: \_\_\_\_\_

The purpose of tape-recording this interview and the use, storage and final destruction of the tapes has been explained to me and I understand the explanation. I have been offered to answer any of my questions concerning the procedures involved in the recording of the interview and I have been given a copy of this form to keep.

**Participant Name:** \_\_\_\_\_

**Signature of Participant:** \_\_\_\_\_

**Date:** \_\_\_\_\_

**ANNEXURE 6**  
**The University of the Western Cape**



School of Government  
Institute for Social Development

**Project Title:**

***Challenges faced by Healthcare Workers in Conducting Clinical Research in Selected Western Cape Sites***

**DISCUSSION SCHEDULE FOR INTERVIEWER**

**Brief introductory question**

Now that you understand the purpose of the study I like to start by asking you to tell me about yourself.

Probes

Age

Work

Gender

Education level

Role as healthcare worker

How long have you been employed at DTTC



**Research question**

What are the challenges faced by HCWs when conducting clinical research?

**Recruitment of participants**

Retention of participants

Migration of participants

**Stigma attached to TB and HIV**

Stigma attached to TB

Link between TB and HIV

### **Risk of Exposure to TB and HIV**

Needle Stick injuries

Infection control strategies

### **Emotional Trauma**

Occupational burn-out

Impact of exposure to socio-economic environment

### **Crime and Violence**

Personal experiences of violence/crime

Types of violence

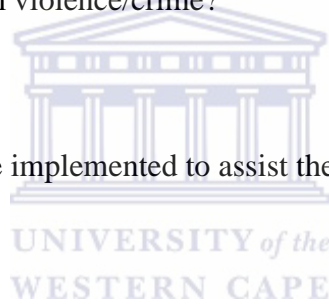
Who commits violence?

What are the main crimes that are a problem for healthcare workers in these communities?

How do you protect yourself from violence/crime?

### **Interventions/Strategies**

What would you suggest could be implemented to assist the healthcare worker to deal with these challenges?



## **Annexure 7 - Example of a transcription of an interview**

Interviewer: Welcome “X” thank you for availing yourself this morning for this interview as you have read in the information sheet, we are going to be discussing the challenges you have experienced since working in the communities of Uitsig and Ravensmead. Firstly I would like you to answer a few introductory questions about yourself namely, your age, your education level your years at employment at Desmond Tutu TB Centre as well as your role as a health worker.

Interviewer: So “X” you are welcome to just tell us about yourself

Interviewee: I’m “X” I’m 57 years old I am working at the Desmond Tutu Centre for the last 20 years since 1992 and I am a professional nurse and I studied nursing at this University of Stellenbosch I have a B-degree in nursing. I have worked at Ravensmead Clinic at first then we moved over to Uitsig and that is where I have been stationed for past 15 years and I am enjoying my work.

Interviewer: That is nice to hear, now “X”. I would like you to tell us about what are the challenges faced by you as a professional healthcare worker in the communities that you are doing research?

Interviewee: Of course Uitsig is a very economically challenged area. Unemployment is high and people are very poor and unfortunately they are also addicted to alcohol and drugs, which influences the patient’s attitude towards research studies because we do not compensate them to participate in the studies? Uhm they are sometimes difficult to keep in the studies, we give them incentive it is just a box of biscuit or rusks at about the price of R20 per visit just to give them something to eat because that’s not seen as money.

Interviewer: Monetary value yes

Interviewee: Monetary value and then people move around a lot because they do not have fixed

addresses they live in the backyard of someone else and then they have a fight with the people because they do not have rent money then they move to another yard so the people are constantly moving or they go to Delft they live with relatives. They come back because it's not working out uhm so we have to do home visits all the time and keep track of the people where they are it makes it difficult that's really a challenge.

Interviewer: So you telling me to retain the people on these studies to participate in research that is a major challenge also the fact that there's migration between moving from the one house other or other areas so that was some of the challenges that you are exposed to in your community where you working then "X" in terms of stigma in terms of the environment that you are working in the TB what is your perceptions or how do you see how's your patients perception on TB and what are your perceptions about stigma?

Interviewee: I think the stigma really isn't that much anymore because people are more educated they understand I always tell them if you don't want to get TB stop breathing so anyone that breathes can get TB so they understand that it is an air born disease. If people cough close to you can get the TB germs inhale it, but HIV is another matter they hide it and I can't understand it but we make appointments for the people who are HIV -positive at the--- Clinic at the Tygerberg Hospital and they just don't attend they don't keep their appointment some of the people the clinic sisters do that and they are a part of the study as well so I am involved I even offer them a lift to bring them to the hospital they always have an excuse I have to do this and that this morning I have to go there or something else they are afraid of ARV's they don't want to take ARV's so the consequence is that they die because ARV's prolong their lives although they have HIV they live with it for up to 20 years but they die they just give up and they tell you I don't want to live with this I don't want to take medicine for it I want to die and they die which is sad because they often have children they still have to raise and they are loved by their grand-children and families and then instead they die.

Interviewer Then from your perception do you think there's a link between TB and HIV?

Interviewee Definitely people who are HIV-positive are more prone to get TB their immune system Can't fight off the germs and we explain it to the people that they have the perception that T.B turns over into HIV and we don't know where they get it from but we are trying to kill that idea and we are explaining to them that it's the immune system that's not good when you are HIV positive and that's why you get TB and other infections, because they often have -----on their skin and the thrush in the mouth thrush and that if they see that they never had it before and now that they are HIV positive they realise that something's happening in my body so that's still we have do a lot of education to do

Interviewer Okay...so you telling me that there need to be more educational interventions in terms of the HIV for the community that you are based in

Interviewee Yes

Interviewer And then "X" as a professional nurse in terms of the risk of exposure in TB and HIV what infection control strategies do you implement in your site or in your community that you are working in?

Interviewee First of all I look after myself see that I have a healthy lifestyle I'm well-nourished I do have a fair amount of exercise and ventilation in the room and in the car to see that the doors and the windows are open of my field office so that there's a breeze through we don't have air conditioning but that's not the most important thing and be careful when you work with peoples blood prevents needles stick injuries be calm be organised have your---container ready always wear your gloves wear a masks.

I personally don't like wearing masks because if the people can't see your mouth they sometimes don't understand what you're saying. I depend on my good health and common sense not to get TB and if I should get TB I would take it in --- the tablets are free I will get cured I am sure but I am not afraid of



TB not at all and I am not afraid of HIV as well because I have a healthy lifestyle and it's also not a death sentence if you are HIV positive.

Interviewer Thank you for that input then "X" in terms of your work how do you cope emotionally with being exposed to the social economic environment that you work in and how does that impact you.

Interviewee I often cry with my patients you know if you know you when you have to tell someone that they are HIV positive it's not an easy thing to do sometimes it's their first boyfriend or their first girlfriend that they've ever had and person didn't disclose to them that they are HIV positive then they become HIV positive its emotional draining I feel that I leave my work at work and at home I'm in a happy environment and when I'm here I try and handle it best I could a year ago so we had a mentor with who we discussed things with that helped a lot I know that it's expensive that studies are almost done now so we not doing that anymore we don't have a mentor anymore but we as nursing personnel we support each other we talk to each other we listen to each other's problems and when you hear what the other nurses say you realise that it's exactly the same in all the sites you get close to people and when they die it's heart breaking and you feel sorry for them and you help where you can

Interviewer So what you telling me are that the mentoring was a good intervention from the DTTC side to help you cope with the situations and then "X" in terms of the area that you are working in terms of the crime and the violence what is your experience of the community that you are working in.