# THE CHALLENGES EXPERIENCED BY NON GOVERNMENTAL ORGANISATIONS WITH REGARDS TO THE ROLL-OUT OF ANTIRETROVIRAL DRUGS IN KWAZULU-NATAL

by

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SUPERVISOR: MS MC MATLAKALA

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## DEDICATION

I dedicate this dissertation to my loving family especially to my husband Joerg for his unfailing optimism, encouragement and belief in me. Without your support and shoulder to lean on, I would not have made it. Heartfelt thanks to our two children Tafi and Nyasha, for their endurance, sacrifice, support and understanding. You are the joy of our lives. I must also thank my mother Irene Gundani, for her belief in me and my sister in law Elsa for her selflessness and wisdom. Finally I dedicate this work to my late father Tonderayi Buddy Gundani, who believed in diligence and perseverance**.**

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## DECLARATION

I declare that **THE CHALLENGES EXPERIENCED BY NON GOVERNMENTAL ORGANISATIONS WITH REGARDS TO THE ROLL-OUT OF ANTI RETROVIRAL DRUGS IN KWAZULU-NATAL** is my own work and that all sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

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| **Signature** | **Date** |
| **Janet Michel** | **January 2012** |

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## ABSTRACT


The purpose of this study is to explore and describe the challenges experienced by non-governmental organisations with regards to the roll-out of ART, with an aim to facilitate strategy development to overcome the challenges and enhance the success of ART rollout by the NGOs. A qualitative, exploratory and descriptive study was conducted. Data collection was done using in-depth semi-structured interviews. Three groups of respondents participated in the study; programme coordinators who directed and supervised ART programmes; doctors who were responsible for prescribing, monitoring and dealing with ART complications; and registered nurses who were responsible for monitoring, referring and providing nursing care to patients on ART. The findings revealed five broad areas of challenges namely; challenges related to sustainability, challenges related to adherence, challenges related to health systems, challenges related to stigma and challenges related to behavior. Of interest were the surge of whoonga and the infiltration of ART roll-out by crime and violence.



**KEY CONCEPTS**

Challenges; experience; Non governmental organisation; roll-out; anti retroviral therapy.

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## ABBREVIATIONS

Abbreviations are defined as words made shorter by leaving out letters or using only the first letter of each word (Oxford Advanced Learners Dictionary).

| | |
|---|---|
| ART | Antiretroviral Therapy |
| AIDS | Acquired Immune Deficiency Syndrome |
| DoH | Department of Health |
| IEC | Information, Education and Communication |
| KZN | KwaZulu-Natal |
| WHO | World Health Organization |
| US | United States |
| UNAIDS | Joint United Nations Programme on HIV and AIDS |
| PEPFAR | Presidents Emergency Plan for AIDS Relief |
| ASA | Advertising Standards Authority |
| NACA | National Aids Coordinating Agency |
| PLWHA | People living with HIV and AIDS |
| TCMA | Traditional Complementary and Alternative Medicine |
| SASSA | South African Social Security Agency |
| TAC | Treatment Action Campaign |
| PMTCT | Prevention of Mother to Child Transmission |
| AFB | Acid Fast Bacilli |
| NGO | Non governmental organisation |
| PHC | Primary Health Care |

| | |
|---|---|
| STI | Sexually Transmitted Infections |

# CHAPTER 1

# ORIENTATION TO THE STUDY

## 1.1 INTRODUCTION

KwaZulu-Natal (KZN) is the province with the highest Human Immunodeficiency Virus (HIV) prevalence in South Africa (National Antenatal Sentinel HIV and Syphilis Prevalence Survey 2008:v). Nationally, HIV prevalence amongst the women surveyed has remained stable over the past four years at 29.1% in 2006; 29.4% in 2007, 29.3% in 2008, 29.4% in 2009 and 30.2% in 2010. KwaZulu–Natal on the other hand has consistently had the highest provincial HIV prevalence amongst 15 to 49 year antenatal women. KwaZulu–Natal had an HIV prevalence of 38.7% in 2008, 39.5% in 2009, stabilising at 39,5% in 2010 (National Antenatal Sentinel HIV and Syphilis Prevalence Survey 2010: 41- 47). The Department of Health (DoH) has introduced a new policy for the roll-out of antiretroviral therapy (ART), shifting the eligibility criteria for ART with pregnant women and children benefitting the most. This is a step in the right direction but it also means more people will now be in need of ART.

In KwaZulu-Natal, Non-Governmental Organisations (NGO), namely, Catholic Bishops Conference, Africa Centre and Amangwe village have been spearheading the roll-out of ART in the region. The main funder is the Presidents Emergency Plan for AIDS Relief (PEPFAR). The United States (US) responded to the fact that countries hardest hit by HIV and AIDS are those countries with the least resources to combat the problem (Cichocki 2008:1).

As one of the developed countries in the world and one of the countries that had some success in managing the epidemic, the US saw the need to help those countries struggling with HIV by providing AIDS funding leading to the enactment of PEFAR in 2003. Fourteen countries were chosen as the focus and South Africa is amongst them along with Botswana. Fifty five percent of the funds was allocated for medications that treat HIV, 15% was to be used to improve the lives of those patients living with HIV, 20% was allocated for prevention programs (with 30% of those funds mandated to be used for abstinence only education) and the last 10% was allocated to assist children and orphans of HIV positive patients (Challenges faced by Botswana 2005).

## 1.2 BACKGROUND TO THE STUDY

1n 2003, World Health Organisation (WHO) called the treatment gap a global public health emergency on World Aids Day and launched the 3 by 5 initiative (UNAIDS Report on the Global aids 2006:150). The 3 by 5 initiative, launched by UNAIDS (United Nations and AIDS) and WHO in 2003 was a global target to provide 3 million people living with HIV and AIDS in low and middle income countries with life prolonging ART by the end of 2005 (www.who.int/3by 5.accessed 13 May 2011). The 3 by 5 target was missed, in that only 17% of those who needed ART had accessed treatment by end of 2005.

Lessons learned in 3 by 5 should guide efforts to move towards universal access to treatment by 2010 (WHO report 2010). In 2005 the Global Fund, PEPFAR and a group of eight leading industrialized countries called on the world to move as close as possible towards universal access to ART by 2010.

After years of denialism in South Africa, from mixed messages from the Mbeki Presidency and the Department of Health under Dr Manto Tshabalala Msimang, committed leadership and effective response to HIV was delayed (AIDS Foundation South Africa 1987-2010). In the absence of an effective government response in South Africa, many NGOs were established to purely address HIV and AIDS.

NGOs drove the campaign for access to treatment, lower drug prices, improved care and more effective policy on HIV and AIDS led by Treatment Action Campaign (TAC) and AIDS Law project (AIDS Foundation South Africa 1987-2010)). The South African government then responded to the call and adopted the new ART policy (The South African Anti Retroviral Treatment Guidelines 2010:1). The 2010 ART guidelines entail the following as objectives:

1. To prioritize ARVs for
   - Patients with CD4 count of less than 200 cell/$mm^3$ or with severe HIV disease irrespective of CD4 cell count.
   - Patients co-infected with TB/HIV with CD4 count less than 350 cells/$mm^3$
   - Pregnant women with CD4 count of less than 350 cell/$mm^3$ for lifelong ART and a CD4 count of more than 350 cell/$mm^3$ for prophylaxis.
2. To test all HIV exposed children below one year and treat all those found to be infected with HIV.

3. To standardize first and second line therapy for children, adolescents and adults in the public and private sector.
4. To reduce the use of stavudine.
5. To expand the use of fixed dose and co-packaged formulations.
6. To enable nurses to initiate ARVs for treatment and prevention.
7. To enable PHC facilities to initiate, manage, monitor and refer patients.

(The South African Anti Retroviral Treatment Guidelines 2010:1)

This was a giant step considering the ART guidelines of 2004 which were as follows;

Criteria for ART initiation in adults and adolescents including pregnant women;

1. CD4 of less than 200 cell/$mm^3$ irrespective of stage
   Or
2. WHO stage iv AIDS defining illness irrespective of CD4 count
   And

Patient expresses willingness and readiness to take ART adherently

(National Antiretroviral Treatment Guidelines 2004:3)

The policy was to be implemented with immediate effect raising the interest of challenges this could bring upon those involved in the roll-out of ART. Botswana was one of the first African countries to embark on a large scale roll-out of ART in 2002. National roll-out was completed by 2004 with patient follow ups at 90% and adherence levels of 86%. Botswana has showcased successful ART roll-out in the public sector (Medical news today 2010).

The eligibility criteria for South Africa is slightly different from the following Botswana criteria:

1. To prioritize ARVs for;

- Adolescents and adult patients with CD4 count of less than 250 cell/$mm^3$ or with severe HIV disease WHO stage 3 or 4.
- Pregnant women with CD4 count of less than 250 cell/$mm^3$ or WHO stage 3 or 4 for lifelong ART.

2. To test all HIV exposed children below one year and treat all those found to be infected with HIV (HIV Treatment guidelines Botswana 2008:35).

Southern African Catholic Bishops Conference Aids programme was created as a Catholic Church`s response to HIV and AIDS in the Kwazulu-Natal (KZN) province of South Africa. It was the first front runner in ensuring universal access to ART long before the South African Government had made a pledge to ensure universal access to ART (Munro 2002:1). Africa Centre was established in 1997 with the objectives of conducting population research in an ethical manner as well as to enhance the capacity of Sub-Saharan Africa to do research. The Centre responded to the high HIV prevalence by signing a memorandum with the South African Government aimed at delivering safe, effective, efficient, equitable and sustainable ART to all who need it in Hlabisa district, KZN. Staff from both the Department of Health and Africa centre is involved and provide ART services in one hospital and 17 clinics (www.africacentre.ac.za/aboutus/background.accessed 7 September 2010).

Amangwe village was born as a response of the industry and business community of Richards Bay to the HIV epidemic. Zululand Chamber of Business Foundation Health and Welfare portfolio recognized the devastating effects of HIV and, after research and consultation with stakeholders, established Amangwe village, an HIV and AIDS intervention that addresses a broad spectrum of HIV related problems namely;

- Ethembeni Care Centre for inpatient and outpatient care of HIV infected patients.
- Orphans and vulnerable children programme and an Outreach, Education and Training programme.

The centre works hand in hand with the Department of Health getting referrals that need HIV Care and Treatment as well as a subsidy(www.zcbf.org.za/projects_amangwe.htm). Even with the growing provision of drugs by the public health systems, treatment often involves considerable out of pocket costs including fees charged to patients for the use of public services as well as transport fees ( UNAIDS Report on the global Aids epidemic 2006: 155). Discontinuation or interruption of therapy is even more dangerous than periodic non adherence (Lucas 2005:35). ART roll-out is fraught with many challenges including stigma, human resources and reliable drug supply.

Although funding has increased rapidly, a variety of obstacles remain to scaling up treatment access at the same rate. Large numbers of HIV positive people live in rural areas, yet treatment is largely confined to urban areas requiring residents either to go without treatment or to travel long distances to obtain essential care (Global AIDS

epidemic 2006: 156). Between 2001 and 2005, the number of people in need of antiretroviral therapy in low- and middle-income countries increased more than five- fold (Global AIDS epidemic 2006:151). This raises the question of what challenges the NGOs are experiencing with regards to the roll-out of ART following the adoption of the new 2010 ART guidelines.

**1.3 RESEARCH PROBLEM**

South African eligibility criteria for ART look more inclusive with a lot of investment into pregnant women and children. Botswana however raised the CD4 cell count eligibility to 250 cell/$mm^3$ to reflect international consensus that ART should ideally be initiated before the CD4 cell count falls below 200 cell/$mm^3$ (HIV in Botswana 2008:35). To properly implement the new guidelines and ensure that HIV counseling and testing campaign is sustainable over time, government must address the shortage of health care workers, a concern raised by South African National Aids Council (www.tac.org.za/community).

In KZN the worst affected province, 35.6% of Health posts were vacant in 2007 and some hospitals did not have a pharmacist (George, Quinlan & Reardon 2009:17). Furthermore it has been recognized that poor budgeting and poor financial management has led to weak health systems and health care delivery. It was estimated that 30 people were dying daily in Free State, South Africa after ART ran out towards the end of 2009 financial year (Universal access to AIDS treatment 2010).

Scaling up the number of people on ARV treatment involves great challenges including the need for

- Lifelong commitment to ARVs including supporting patients to adhere to a daily regimen.
- Adequate health infrastructure including health staff.
- Supply chains of effective drugs.
- Widespread awareness of the value of testing and subsequent treatment.

All of these require immense financial resources and political will and it is unlikely that the current rate of investment will be sufficient to achieve the universal target of 2010 (Universal access to AIDS treatment 2010). On the other hand, the Medicines Control

Council (MCC) has been slow to register new drugs particularly fixed dose combinations (Venter 2009:3). Despite eight years of experience, Botswana a country that implemented a large scale ART programme is still experiencing human resource shortages, poor networking amongst NGOs and disharmony within the national Monitoring and Evaluation system among other challenges (HIV in Botswana 2008).

According to a report on AIDS in eight Sub Saharan countries, major donors have decided to cap, cut or halt spending on HIV treatment and AIDS drugs in the past one and half year (Kelland 2010:11). South African National AIDS Council (SANAC) is a national body established to oversee and advise the government on HIV and AIDS in South Africa. In 2007, the council adopted the National AIDS Strategy and recommended it to government. The government finally responded to the call by adopting the New ART Policy in April 2010.

Grubb, Perriens and Schwartlander (2003:3) maintain that the introduction of ART needs a well functioning health system with adequately trained health professionals, laboratory support, constant supplies of drugs and social systems to assist patients' adherence and prevent future treatment failures. The decrease in financial funding accompanied by an increase in demand for ART brings in additional challenges. In KZN, NGOs have been leading the roll-out of ART as a result of the slow response by Government hence the interest in the challenges experienced by Non-governmental organisations with regards to the roll-out of ART. New policy of large scale ART roll-out, global recession and a cut in HIV financial aid are some of the issues South Africans are facing. Of interest to the researcher are the challenges NGOs are experiencing in this context in order to describe the effect of the challenges on the roll-out of ART.

## 1.4 PURPOSE OF THE STUDY

The purpose of this study is to explore and describe the challenges experienced by non-governmental organisations with regards to the roll-out of ART, with an aim to facilitate strategy development to overcome the challenges and enhance the success of ART rollout by the NGOs.

### 1.4.1 Research objectives

The objectives of this study are to:

- Explore and describe the challenges experienced by NGOs with regards to the roll-out of ART.
- Develop recommendations to the DoH to facilitate strategy development to overcome the challenges and to enhance the success of ART rollout by the NGOs.

### 1.4.2 Assumptions underlying the study

Assumptions are basic principles that are accepted as true on the basis of logic or reasoning without proof or verification (Polit and Hungler, 2003:528). In research, the assumptions are embedded in the philosophical base of the framework or study. These assumptions influence the development and implementation of the research process. Their recognition leads to the development of a more rigorous study (Burns and Grove, 2001:146). Assumptions are not intended to be empirically tested, but are underlying propositions, which can be challenged meta-theoretically. With regard to paradigmatic assumptions, the process of research, principles and ideas which researchers base their procedures on is referred to as the methodological assumptions. De Vos (2000:243) and Creswell (2003:5) suggest some fundamental interrelated questions that the inquirer should ask in order to understand the assumptions of each paradigm. These questions are:

- **Ontological question**: What is the nature of reality?
- **Methodological question**: How can the researcher go about finding out whatever he/she believes can be known (process)?

Within the context of this study, the researcher selected certain assumptions from the perspective in response to her interaction with the phenomenon. These assumptions included the meta-theoretical, ontological and methodological assumptions.

*Meta-theoretical assumptions:* The term “meta-theory” refers to critical reflection on the nature of scientific inquiry. Meta-theoretical reflection typically addresses issues such as the nature and the structure of scientific theories, the nature of scientific growth, the meaning of truth, explanations and objectivity (Babbie and Mouton, 2002:20). Meta-theoretical assumptions are interrelated sets of concepts, beliefs, commitments and propositions that constitute the study. Their origin is philosophical in nature, and therefore not meant to be tested. Meta-theoretical assumptions denote commitment to the truth of the theories and laws of a particular paradigm. Creswell (2003:11) postulates that qualitative research focuses on the process occurring as well as the

product. The assumptions that were made about the rollout of ART, which intricately linked to nursing practice, were related to the person, environment and health. Florence Nightingale Environmental theory has been applied in this study. In this regard it is assumed that

- **Person:** The NGOs are self directed, in constant interaction and co-existence with their lived world in the clinical setting and the HIV and AIDS patient who is the main concern for ART rollout.
- **Environment:** The clinics are the clinical setting (lived world) where rollout is implemented to enable the patients to access their treatment and care.
- **Health:** The rollout of ART is experiential in nature.

*Ontological assumptions (the nature of reality):* Ontology is the study of the nature of existence and of coming to being. The ontological assumptions deal with the nature of reality as an object of inquiry. The reality in this study is the experiences of the NGOs in the rollout of ART. Ontological assumption was that individual realities are subjectively constructed and are self created. The realities are the experiences including challenges of the NGOs in the rollout of ART. In this regard it can be assumed that the reality of ART rollout can only be understood within the context of the experiences of each participant (Blaikie 1993:68).

*Methodological assumptions:* Qualitative research reports faithfully on these realities and on the voices and interpretations of participants (Creswell, 2003:6). In this study the assumptions are related to the rollout of ART. Qualitative data collection and analysis was meant to capture the challenges experienced by the NGOs with regard to the rollout of ART.

## 1.5 SIGNIFICANCE OF THE STUDY

Successful administration of ART requires the patient to adhere fully to the regimen for life (95%). Inadequate adherence could lead to treatment failure and ARV drug resistance. Large scale ART programs with inadequate attention and support for drug adherence could render the available ARV drugs unproductive and negate the advances made in creating effective ARV therapy (Tawfik, Kinoti & Blain 2002:3).

The findings of this study will be used to make recommendations to the Department of Health and other Non-governmental Organisations regarding the challenges to the successful roll-out of ART in KZN. To the Department of Health, the results of the study will provide reliable data for planning strategies for ART provision as the pool of recipients who need to take medication for life increases. To the patients receiving ART, the results will provide valuable information regarding expectations from their local service providers and if possible make contingency plans to achieve positive outcomes.

## 1.6 DEFINITIONS OF KEY CONCEPTS

Concepts are described as general ideas derived or inferred from specific instances or occurrences. Concepts can also be described as something conceived in the mind, abstract or generic ideas generalised from particular instances (Merria-Webster`s Medical Dictionary 2007:201)

According to Mouton (2008:175) concepts are described as cognitive units of meaning or abstract ideas, mental symbols defined as units of knowledge, word pictures, and mental ideas of a phenomenon or meaning of words. Conceptual definitions are described in books and dictionaries and an operational definition is the meaning given in the context of the study. The following concepts are defined in the context of this study:

**1.6.1 Challenge**: a demanding or stimulating situation (Collins English Dictionary 2009:267). In the context of this study, the challenges are the negative factors affecting the roll-out of ART.

**1.6.2 Experience**: a particular incident that a person has undergone. A particular instance of personally encountering or undergoing something (Random House Webster`s College Dictionary 2011:441). In this study it includes situations the NGOs involved in the roll-out of ART have been affected by, seen, gone through or dealt with during the execution of their duty.

**1.6.3 Non-governmental organisation**: an independent, not for profit voluntary group organised at local, national or international level (Random House Webster`s College Dictionary 2011:947. The NGOs in this study are the organisations that are spearheading the roll-out of ART in KZN, as identified in this study.

**1.6.4 Roll-out**: to launch. The introduction or inauguration of a new product or service (Random House Webster`s College Dictionary 2011:1334). Roll-out in this study refers to the process of assessment, diagnosis and initiation of treatment and ongoing monitoring of patients in need of ART.

**1.6.5 ART**: medication for the treatment of infection by retroviruses, primarily HIV. The treatment aims to suppress viral replication nearly totally (The Merck Manual 2006:1635)

## 1.7 RESEARCH DESIGN AND METHODS

A research design is a plan for collecting and utilising data so that desired information can be obtained with sufficient precision or so that a hypothesis can be tested properly. It is also described as a plan or blueprint of how you intend conducting the research (De Vos, Strydom, Fouche and Delport 2007:132). A qualitative approach, with exploratory and descriptive design was used. Qualitative research`s hallmark is the richness of information. The types of settings are modified to enrich understanding (Mouton 2008: 75).

In a qualitative study, the researcher attempts to understand people in terms of their own definition of the world. According to Baily (1997:18-22), the significance of qualitative research is in the emphasis on describing and understanding complex phenomenon. Qualitative research validates the information received. People are interviewed one after the other so that the obtained data can be taken as correct and believable reports of their opinions and experiences (Baily 1997:18-22).

By utilising a qualitative approach, an attempt was made to understand the challenges experienced by NGOs from the subjective perspective of the individuals involved namely project coordinators, doctors and nurses involved in the roll-out of ART. Complexities, richness and diversity of their work can only be captured by describing what really goes on in their day to day work, incorporating the context in which they operate as well as their frame of reference (Mouton 2008:195). The challenges experienced by the NGOs with regards to the roll-out of ART were explored and described.

### 1.7.1 Setting

Setting is defined as a quiet environment that provides privacy, is comfortable, non threatening and easily accessible to facilitate the interview process (De Vos et al 2007: 294-295). The setting was offices of the NGOs for the project coordinators and the hospital/clinic where the project took place (roll-out of ART) for doctors and nurses.

### 1.7.2 Population and sample

A population is defined as a group of target units in a specified area that clearly manifests the condition of concern to the programme (De Vos et al 2007:372). A sample is defined as a set of individuals selected from a population for analysis to yield estimates of the whole population or a subset of the population that is selected to represent the population (Brink 2011:214).

The universal population comprised all the individuals working in NGOs involved in ART roll-out in KZN. The target population was the programme leaders, doctors and nurses involved in ART roll-out in three NGOs from KZN. The sample was selected from the programme leaders, doctors and nurses working in the NGOs selected, who were at work at the time of the study.

### 1.7.3 Sampling method and sample size

Sampling method refers to the approach used to obtain a sample which can be probability or random sampling and non probability sampling (Brink 2011:134).

Sample size refers to the number of observations being used to make population estimates (Brink 2011:141). Purposive sampling was used to select the sample. The researcher chose purposive sampling because it allowed for selection of individuals that contained the most characteristic, representative or typical attributes of the population (De Vos et al 2007:202) from the spectrum of interest and in this case ART section in NGOs.

A purposive sample of nine people was included in the study in the form of three programme leaders, three doctors and three nurses from each of the three NGOs.

However, the sample size depended on the saturation of information during data collection.

## 1.8 DATA COLLECTION

Data may be gathered by a variety of data collection methods. These methods correspond with data sources (Mouton 2008:104). Interviewing is the predominant mode of data or information collection in qualitative research (De Vos 2007:287). In this study, semi-structured one to one interviews were used. The researcher used semi-structured interviews in order to gain a detailed picture of the participants' beliefs, perceptions or accounts of ART roll out. The method gave both researcher and participant more flexibility. It also enabled the researcher to follow up particular interesting avenues that emerged in the interview enabling the participant to give more information (De Vos 2007:296). The process of data collection is described in detail in chapter 3.

## 1.9 ETHICAL CONSIDERATIONS

**Permission to conduct the study:** Permission to conduct the study was sought from the Higher Degrees Committee of the Department of Health Studies, UNISA and the relevant NGO authorities responsible for the hospitals and clinics where the study was conducted (see annexure). Informed consent to participate in the study was obtained from the project coordinators, doctors and nurses.

**Maintaining confidentiality and privacy:** Confidentiality and privacy was ensured by using a password, restricted access computer; and anonymity was guaranteed by assigning interviewees codes instead of names. Beneficence will be ensured by making the research results known to the Department of Health and other NGOs thereby benefiting people in need of ART in the form of preparedness as a result of the guidelines and recommendations. Any false hopes or expectations that the interview might cause was respected and talked through to prevent emotional or any other risk.

**Autonomy and respect for persons:** participation in the study was voluntary and the participants were assured that they could withdraw from the study at any time if they so wished, without penalty.

**Act on findings and Publishing:** The work of others was acknowledged and negative and positive findings were reported. The findings of this study will be disseminated in the form of publications.

## 1.10 DATA ANALYSIS

Analysis involves breaking up the data into manageable themes, patterns, trends and relationships. The aim of analysis is to understand the various constitutive elements of one`s data through inspection of the relationships between concepts, constructs or variables and to see whether there are any patterns or trends that can be identified or isolated to establish themes in the data (Mouton 2008:108).

Content analysis was done to explore in detail for common themes and these were then established into units of meaning or codes (Mouton 2008:198). The advantages are that these were descriptions of real situations and the information gained was rich. The disadvantages are that transcribing and data analysis was time consuming and researcher subjectivity often brought problems of subjectivity.

The researcher used a computer analysis ATLAS/ti to aid in the management of textual data, for storage and retrieval of information more quickly and accurately. Data analysis will be described in detail in chapter three.

### 1.10.1 Measures to ensure trustworthiness

Trustworthiness refers to the confidence qualitative researchers have in their data. This is assessed using criteria of credibility, transferability, dependability and conformability (Polit & Beck 2006:511). In this study, member checking was done by having research participants review, validate and verify researcher`s interpretations and conclusion (Brink 2011:124). In addition, triangulation which denotes the use of more than one data source, that is programme coordinators, doctors and nurses was also utilised (De Vos et al 2007:362).

## 1.11 SCOPE OF THE STUDY

The scope of this study is limited to the roll-out of ART by three Non Governmental organisations only.

## 1.12 STRUCTURE OF THE DISSERTATION

Chapter 1: Introduction to the study

Chapter 2: Literature review

Chapter 3: Research methodology

Chapter 4: Data analysis and findings

Chapter 5: Conclusions and recommendations

## 1.13 CONCLUSION

In this chapter the introduction, purpose of the study, research problem, objectives and significance of research was outlined. Key concepts were defined and an overview of research methodology presented. In the next chapter a detailed review of relevant literature is presented.

# CHAPTER 2

# LITERATURE REVIEW

## 2.1 INTRODUCTION

The purpose of the literature review is orientation of the reader on the context of the setting (Speziale & Carpenter 2002: 21). The researcher acknowledges the critics about literature review in a qualitative study, which can lead to bracketing. However, the literature background may help focus the study (Speziale & Carpenter 2002: 21).

The literature background for this study will examine the African experience of HIV and AIDS, emerging issues regarding ART and the bio-social variables for understanding ART adherence. The review will include literature from sources available from books, journals and internet websites.

The World Health organisation (WHO) released new HIV guidelines in December 2009 calling for, amongst other criteria, the initiation of anti retroviral therapy (ART) at a CD4 count of 350cells/$mm^3$ or below. President Jacob Zuma, in his World Aids Day address in 2009, committed government to raising the threshold to 350 albeit only for pregnant women and those with tuberculosis. South Africa has by far the largest ART programme in the world by numbers, and alterations in treatment guidelines have far ranging consequences for the country`s health system (Francois 2009:3).

A person who is infected with HIV is likely to become sick with AIDS within 1-10 years, but if treated with ART, their life can be prolonged. However, every day nearly 6000 people globally are dying from a disease which can be treated, but which all too often is not. The goal of universal access to ART by the year 2010 meant putting many more people on treatment (UNAIDS/WHO REPORT 2006:20). Tawfik, Kinoti and Blain (2002:6) suggest guidelines that could be followed when planning a large scale ART program. The guidelines are follows:

- Develop eligibility criteria for receiving ART
- Decide on treatment protocol
- Decide on essential laboratory, clinical, counseling and pharmaceutical services and their levels.
- Develop national clinical guidelines

- Develop a plan for patient registration and follow up
- Identify human resources and training needs
- Develop an information, education and communication (IEC) strategy
- Estimate program cost
- Develop a financing strategy to help patients afford payments (Tawfik et al 2002:6).

The goal of ART is improvement of patients` quality of life consequent to the reduction in morbidity and mortality, restoration of immunologic function and maximal and durable suppression of viral replication (Nyambura 2009:13). Anything that hinders any of the above processes poses challenges to ART roll-out.

## 2.2 THE AFRICAN EXPERIENCE OF HIV AND AIDS

### 2.2.1 Botswana

Botswana has been hard hit by AIDS. In 2007, there was an estimated 300 000 people living with HIV, almost one in four adults. HIV and AIDS has had a devastating impact on Botswana. Life expectancy at birth fell from 65 years in 1990-1995 to less than 40 years in 2000-2005, a figure about 28 years lower than it would have been without AIDS. The loss of adults in their productive years has economic implications with families being pushed into poverty through the cost of HIV and AIDS medical care, loss of income and funerals. The Agriculture and Mining sector are the worst affected. In addressing the UN Assembly in June 2001, President Festus Mogae summed up the situation by indicating that the country is threatened by extinction with people dying in high numbers. Mogae further indicated that it is a crisis of the first magnitude (HIV in Botswana 2008).

Botswana became the first African Country to aim to provide ART to all its needy citizens and it had a fair of challenges as is the case with any new programme. Some of the challenges Botswana went through were described by Dr Khan, the then head of NACA. They included among others issues the brain drain which puts additional demands on the organisations (Khan 2005:3).

In a study titled nurses perceptions about Botswana patients` anti-retroviral therapy adherence, the findings indicated that patients` adherence to ART was influenced by service related and patient related factors (Kip, Ehlers & Van der Wal 2009:2). Service related factors included the inaccessibility of ART clinics, limited clinic hours, health workers inability to communicate in patients' local languages, long waiting times at clinics and delays in being informed about their CD4 and viral load results (Kip et al 2009:4). Nurses could not trace defaulters nor contact them by phone, and also had to work night shifts, disrupting nurse-patient relationships.

Patient related factors included patients` lack of education, inability to understand the significance of CD4 and viral load results, financial hardships, non-disclosure and non-acceptance of their positive HIV status, alcohol abuse, and the utilisation of traditional medicine and side effects of ART. The challenges of life-long ART adherence are multifaceted involving both patient and service related factors. Supplying free antiretrovirals does not ensure high levels of ART adherence (Kip et al 2009:8).

Another study in Botswana by Kgatlwane et al (2005 in Nyambura 2009:18) showed ART adherence rate of 77%, which is comparable to that of developed countries. According to Nyambura (2009:23), the effect that the clinic setting has on ART adherence should not be underestimated. Clinic characteristics that impact on adherence include: proximity to the patients home or place of work, expense of getting there, lengthy delays between appointments, clinic opening and closing times, lack of services such as child care and unsympathetic and inconsiderate staff (Nyambura 2009:23). Patient factors include fear of disclosure and of taking medication in public places, feeling depressed, hopeless or overwhelmed, having a concurrent addiction, suspicious of treatment, low level of education and a decreased quality of life (Mills, Nachenga, Bangsberg, Singh, Rachlis, Buchan, Gill & Cooper 2006).

These findings were supported by Dr Linda Distlerath, Mercks Vice President for Global Health Policy who revealed that people are still reluctant to come forward to be tested, because of the fear of discrimination and stigma associated with HIV. Distlerath further mentioned that unless people are tested, they will not know whether or not they are positive and therefore might not benefit from treatment (Challenges faced by Botswana 2010).

### 2.2.2 Cameroon

Muko, Ngwa, Chigang, Ngwa, Meiburg and Shu (2004:107-113) in their study revealed that more men were willing to pay for ART than women even though more women were affected than men. According to Muko et al (2004), the majority of the patients stopped taking ART due to financial constraints emphasizing accessibility to drugs as an overriding factor. In addition, stigma, disbelief and side effects were also pointed as stumbling blocks to willingness to pay for ART.

### 2.2.3 Uganda

Uganda ran the first pilot ARV programmes in Africa. It begun in 1998 and aimed to see how an ARV programme could be set up and run in a resource poor country. The 399 patients involved were responsible for paying for their treatment and bought their drugs at negotiated reduced prices. At the end of the two year pilot, patients reported good adherence to treatment and virologic and immunological response to ART similar to those found in western countries (Byakika, Oyugi, Tumwikiirize, Katabira, Mugyenyi & Bangsberg 2005:2).The country`s adult HIV prevalence fell from around 15% in the early 1990`s to 6.7% at the end of 2005 (UNAIDS/WHO REPORT UPDATE 2005).

Uganda has been highlighted as a success story in the fight against AIDS. The prevalence rates are slowly rising again due to structural constraints and drug resistance, causing many patients to eventually have virology failure in the long-term. Another challenge is the inability to adhere to ART due to endemic poverty; not to mention the deteriorating public services, poor employment prospects and ignorance (Barlette & Gallent 2005:16).

### 2.2.4 South Africa

In the South African context, common barriers to adherence identified include fear of disclosure, alcohol abuse, use of traditional medicine, stigma, transport costs, discrimination, depression and hopelessness, lack of food, service-related factors and patients beliefs and behaviors (Peltzer, du Preez, Ramlagan & Anderson 2010:1).

## 2.3 EMERGING ISSUES REGARDING ART

Several factors such as drug shortages, personnel and infrastructure, stigma, poverty factors, drug abuse and corruption and funding for NGOs will be described in the section that follows, in relation to emerging issues.

### 2.3.1 Drug shortages

According to Barlette and Gallent (2005:14), a report on drug shortages indicate that stock outs were common in China, India, Uganda, Russia and Zimbabwe. It was conservatively estimated that 30 people were dying daily in the Free state, South Africa after ART ran out towards the end of 2009 financial year (Thom 2009). Such events not only adversely affect those who desperately need to begin treatment but also patients on treatment who may develop resistance (Barlette & Gallent 2005:14).

According to Nyambura (2009:10) missing even only one tablet a week translates to only 92.8% adherence which is below the desired 95%. Anything less than the desired 95% can potentially lead to the development of viral resistance and adverse clinical and immunological outcomes.

### 2.3.2 Inadequate Personnel and Infrastructure

Shortage of staff in health facilities of both government and private not-for-profit sector is an issue well known to the public and the government. Alongside financial constraints, the distribution of ARVs in Malawi is hindered by a low number of health care workers available to administer drugs. Orach (2005:22) indicates that related to the strain on personnel and infrastructure is the increasing difficulty to cope with increasing demand or clients.

Laboratory equipment is also inadequate, such that CD4 count machines exist only in 12 regional centres. The rest depend on clinical judgment (Orach 2005:22). Storage of medication needs to be safe and secure, facilitating an efficient process of ordering and distributing ARVs to health facilities. Orach (2005) further indicates that local facilities should be able to safely and securely store medication at controlled temperatures. According to World Health Organisation Director of HIV/AIDS, Gottfried Hirnschall, all these requirements mean that the costs involved in distributing drugs are higher than the antiretroviral drugs themselves (Universal access to AIDS Treatment 2010).

There is increasing evidence that ART in resource limited settings can be very effective. Egger, Boulle, Schechter and Miotti (2005:509) indicate that the debate on the rollout of ART has moved from the question of whether the introduction of ART is feasible in the light of competing priorities and fragile health systems, to questions of how effective ART and care can best be delivered. In a specific township in KZN province, South Africa, a recent analysis of patients with advanced immunodeficiency disease showed excellent adherence to treatment and good clinical outcomes (Egger et al 2005:509).

### 2.3.3 Stigma against HIV and AIDS

The intimate nature in which HIV is transmitted has contributed to the extreme levels of stigma and discrimination surrounding those infected by the virus. In developing countries especially, the disease has had profound effects adding to already high levels of poverty, unemployment and mortality (Morrison 2005:6). HIV related stigma and discrimination remain a key concern in South Africa despite the multitude of HIV awareness campaigns that have been launched by government and civil society organisations (Palitza 2009:1).

A survey by Maughan-Brown (2006) from Centre of Social Sciences research at the University of Cape Town revealed that stigma has increased despite public sector campaigns and improved treatment and care services.

According to Kiapi (2009:1), in Uganda children are faced with stigma and discrimination and there are no laws or policies to protect them. The mentioned author further indicates that there are even reports of head teachers rejecting pupils who are HIV positive. Kyomukama in (Kiapi 2009:1) mentions that the issue of HIV positive children is a critical one that should be legislated.

### 2.3.4 Socio economic and cultural climate

The socio-economic status of women in South Africa places them at an increased risk of infection (Soul City & Khomanani 2004:15-16). The generally low status of women in South African Society and within relationships, economic dependency and threat of rejection or violence and abandonment may also mean that women are less likely to disclose their HIV status to their partners or seek help and treatment for HIV/AIDS (Soul City & Khomanani 2004:16).

For people taking ART, the challenges to living with HIV successfully include not only those related to ART pharmacology such as toxicity, side effects and treatment failure but also difficult economic and social circumstances. These economic and social factors heavily influence peoples' adjustments to living with and managing chronic illness. Strategies to rebuild a sustainable livelihood on ART are hindered by the harsh economic realities of asset and income poverty, food insecurity and vulnerability (Russel S, Seeley J, Ezati E, Wamai N, Were W, Bunnel R 2007:344-347)

Productive and financial assets from an earlier livelihood have often been depleted to cover the income losses and expenditures incurred due to long term illness. Rebuilding these asset portfolios and returning to feasible livelihood strategies may be a daunting task. People living with HIV and AIDS (PLWH) seeking to return to work may struggle to find a job in the context of high unemployment. This difficulty might be compounded by loss of physical strength or skill level due to long term illness and absence from work and employer prejudices (Russel & Seeley 2005:20). In a study by Palitza (2009:1), the findings indicated that the illness lead to loss of jobs due to lack of strength to work.

According to Love life (2000:6) cultural and social norms that accept and even encourage a high number of sexual partners especially amongst men and that resist the use of condoms impede safer sexual practices that could control the epidemic (Love life 2000:6). Complex bidirectional relationship between HIV/AIDS and poverty is an important determinant of the disease in South Africa (Morrison 2005:9) According to Parker *et al* (1998:2), the disease affects poorer communities sooner and more vigorously than other communities. A number of social factors synonymous with poverty may contribute to HIV infection including lack of access to health and social services, rapid urbanization, unemployment, poor education, illiteracy, gender inequalities, diversities in language and culture, crime, political instability and war (Morrison 2005:9-10)

The lessons learned from HIV Equity Initiative in Haiti showed that in the context of poverty, factors such as lack of access to transport, food security and user fees posed more significant barriers to adhering to long term therapy than a patient's individual behavior (Murkherjee et al 2006:1).

A study by Peltzer et al (2010:111) revealed that greater adherence was found amongst those with lower levels of education and among single, separated, divorced or widowed

groups compared to those married and cohabiting. This was also supported by a study by Mukherjee et al (2006:1) who stated that studies in developing countries have shown comparable or better levels of individual adherence than what is seen in North America and European populations disputing level of education as a barrier to ART adherence.

### 2.3.5 Prevalence of Mental Disorders amongst PLWHA South Africa

In another study titled towards the establishment of a pilot programme for detection and treatment of common mental disorders in people living with HIV/AIDS in Cape Town, the editorial argued that the role of mental health in ARV programmes is central. The prevalence of mental disorders in PLWHA is higher than in the general population and the impact of these conditions is substantial. Screening tools for mental disorders are both available and feasible. These should be incorporated into routine ARV care with support from dedicated HIV mental health services (Joska, Stein, Flisher 2008:122,124).

Patient characteristics and lifestyle, especially depression and poor mental health which is estimated to be between 20-50% in people living with HIV, are predictors of adherence (Morrison 2005:22). Most clinics in South Africa do not provide Mental Health Services, making it a real challenge to deal with.

### 2.3.6 Currently Available ART

In a study by Wood (2005:32) it was argued that despite the present number of antiretrovirals, there continues to be a need for new medications with improved tolerability and activity against resistant virus. The findings concur with research by Venter, Osih, Andrew and Conradie (2008:44, 46-49) which indicated that though the choice of antiretroviral drugs seems quite vast, the reality is that many of these drugs cannot be used simultaneously or in patients with extensive drug resistance. In addition, some drugs have unacceptable toxicities and are not favoured in current treatment regimens. Although currently available, ARV drugs are far from ideal, and ongoing pharmacological research may in future produce drugs that are less costly, easier to administer and with fewer adverse effects and or resistance, the likelihood of adherence to a given regimen declines with polypharmacy, frequency of dosing, the frequency and severity of side effects and the complexity of the regimen (Nyambura 2009:12-23).

According to the World Health Organisation, 80% of Africa`s population uses traditional medicine for primary health care. Ojikutu, Jack and Ramjee (2007:10-11) in their study

indicated that in South Africa, 75% of HIV infected people use remedies dispensed by traditional healers. Therefore, there is a concern that traditional medicine is a barrier to ART roll-out in South Africa. Several studies have demonstrated the toxicity of standard traditional therapies (Stewart, Steenkamp, Van Der Merwe, Zuckerman & Crowther 2002:1) . High rates of dehydration, vomiting, diarrhea, altered mental status and renal failure were found among patients at Chris Baragwanath Hospital in Gauteng who reported use of traditional remedies. When therapies that cause these adverse effects are used with ART, untoward toxicities may occur and the efficacy of the antiretroviral regimen may be compromised (Ojikutu et al 2007:10-11).

### 2.3.7 Poverty factors

Research is urgently needed to determine factors for ART adherence in developing world settings (Mills et al 2006: 438). A number of factors have been found to affect adherence. These include levels of knowledge and understanding (treatment literacy), health beliefs or belief that ART has significant benefits, drug regimen with as few drugs as possible and minimal side effects. In addition patient characteristics, life style especially depression, poor mental health, social support, health care providers who are able to nurture a good clinician patient relationship all play a pivotal role in adherence ( Martin L R, Williams S L, Haskard K B & DiMatteo MR 2005:189-199). In the South African context, however, hunger, poverty and violence have been identified as major obstacles to adherence (Morrison 2005:22). With millions of dollars being invested in the scale up of ART, a lack of food security in most heavily HIV burdened countries threaten HIV programs and the health and survival of the most vulnerable (Murkherjee, Ivers, Leandre, Farmer & Behforouz 2006:125).

Treatment adherence in HIV disease is a complex clinical, cultural and social problem. It has been estimated that an adherence rate of 95% is required to achieve adequate viral suppression. Demanding this near perfect rate is difficult and poses challenges (McIntyre, Gray, Struthers & Skhosana 2006:18). Why does it pose a challenge? A study by Zacharia, Harries, Manzi, Gomani, Teck, Phillips & Firmenich (2006:121) revealed that ART acceptance among TB patients in a rural district in Malawi was low and associated with cost of transport to the ART site. Decentralizing to centres closer to home communities would be an essential step towards reducing the overall cost and burden of travel, a barrier to adherence.

According to Nyambura (2009:26) ART has been delivered free in Kenya since 2005, but the users bear the cost of medical support service and transport. These additional costs are often an inseparable financial burden, which causes patients to default on their treatment. The report by WHO (2003) on adherence to long term therapies cautions that efforts to understand adherence related behaviors should go beyond a focus on patient related factors and also include provider and health system related determinants (McIntyre et al 2006:17).

A study by Castro (2005:4) conducted in poor settings overlook how direct and indirect economic burdens borne by patients affect their ability to access a steady supply of antiretrovirals and take them on time. Such burdens may include the cost of missing work, the cost of elder or child care during medical visits, the cost of transportation to a health centre, the cost of user fees, the cost of tests and supplies. Although these costs may seem minimal to health professionals and decision makers, bearing these costs often translates into difficult household decisions about who eats, who works and who goes to school. In addition this might include the challenging task of obtaining food and safe water or readjusting food intake to fit drug regimen. Despite all these difficulties, the inability of a person living in poverty to obtain and take medication after initiating therapy is often labeled non-adherence or non-compliance or patient related characteristics, ignoring social and economic causes or failure on the part of public health interventions to address those causes (Castro 2005:4).

### 2.3.8 Whoonga and ARV abuse

Whoonga is the most addictive drug made from antiretroviral drugs (E- news 2011. third degree---). According to Ramsay (2010:1) in an article titled Deadly gamble, the report made revelations that in a desperate attempt to cook up new, deadly and addictive dagga concoctions, Zululand drug dealers are now enticing AIDS patients into selling their life saving antiretrovirals. This comes as the latest wave of the drug whoonga has landed on Zululand shores, spreading rapidly in rural townships among users as young as 14 years of age.

While Police in Durban have reported an increase in the number of muggings of AIDS patients outside clinics, in Zululand patients are now selling their ARVs to the detriment

of their health. As the patients make deals for selling individual pills, they end up demanding more which lead to the clinics running short of supplies. Ramsay (2010:1) further indicated that the trend of selling patients pills is now spreading to families living with HIV/AIDS who effectively take turns each month to sell their ARVs and then share medication with family members. The concern is that the patients may be having such deals to sell the drugs because they are offered free of charge.

### 2.3.9 Corruption

According to an article titled “Fund loses millions to corruption” by Reporter unknown (2011:4), 21.7 Billion dollar development fund backed by celebrities and hailed as an alternative to the bureaucracy of the United Nations, sees as much as two thirds of some grants eaten by corruption. Much of the money is accounted for with forged documents or improper book keeping, indicating it was pocketed. In a related article posted on South African Government Information (2011) two men were arrested by police after they were found in possession of ARVs worth R 200 000. Police believe the suspects stole the drugs for use in manufacturing an illegal drug known as whoonga.

According to the director of the Global Fund to fight AIDS Tuberculosis and Malaria, Sir Richard Feachem, all organisations involved in development finance face the constant risk of possible misappropriation of funds and of corruption. The key is to minimize the risk and to have in place oversight systems and to identify problems before they occur (Eaton 2005:718).

### 2.3.10 Funding for Non Governmental Organisation

The 2008-2009 global economic crisis has been linked to decreased donor spending for the HIV/AIDS epidemic in low and middle income countries. In October 2009 UNAIDS released a series of country studies on the impact of economic crisis on HIV prevention and treatment programmes. The summary report states that the negative impact of the crisis on AIDS is real and getting worse. The percentage of countries where antiretroviral treatment programmes were adversely affected by reduced external funding rose from 11% to 21% from July 2008 to July 2009 (Funding for the HIV /AIDS epidemic 2011).

Donating more money is not enough. Many of the countries where the largest donations are being received are under-resourced and lack the infrastructure to absorb the funding. There is great emphasis among the international community on raising money for AIDS, but once that money has been allocated not enough attention seems to be paid to where it goes (Funding for the HIV/AIDS epidemic 2011).

Frank (2011) in an article published on the Sangonet (2011) indicated that non-profit agencies live and operate in extremely difficult times and generally the fundraising is not going to improve for non-profits in South Africa, but is actually going to get worse. United States and maybe Cordaid from Netherlands has already started stopping funding and this will be a major blow for many non-profits who receive their funding from these sources. PEPFAR funding for HIV /AIDS will be phased out in 2012 based on a decision by the Obama administration of 2010 (Frank 2011:1).

More than 500 000 needy South Africans, many of them women and children could be plunged into further desperation as many South African NGOs face a funding crisis. NGOs which represent 30% of Social Services in the country will have R 3 Billion less to spend on crucial development issues this year because of recession (Frank 2011).

According to Rapoo (2011:1), the pre-democratic era of funding plenty for many is well and truly over. The past two years have witnessed a dramatic decline sometimes between 40% and 50% in funding mainly from foreign donor agencies. This has rendered a large number of not-for-profit organisations extremely vulnerable to collapse with many not only losing their experienced staff and leadership to government and business where conditions of employment and remuneration are better, but many have been forced to introduce drastic cuts to their budget, operational activities as well as staff thereby destroying their capacity to render services or projects. A study by Agnarson, Masanja, Ekstrom, Eriksen, Tomson and Thorson (2010:1) revealed widespread lack of trust in ART programme sustainability.

## 2.4 THE BIO-SOCIAL VARIABLES FOR UNDERSTANDING ART ADHERENCE

The use of a biosocial approach to causes of non-adherence and challenges in ART roll-out sheds more light on the multifaceted nature of ART challenges (Castro 2005:5). The following are some of the factors mentioned in relation to adherence:

**Socio-economic factors**

- Poverty inequality
- Cost of medications
- Cost of CD4 counts and viral load
- Transportation costs
- Cost of missing days from work
- Costs of food and safe water
- Costs associated to changes in life style

**Health care system factors**

- Health care infrastructure
- Drug stock shortages
- Financing mechanism including user fees
- Quality of relationship with health care provider

**Psychological factors**

- Self esteem and motivation
- Mental health conditions

**Clinical factors**

- Immunological or clinical stage of HIV disease
- Occurrence and severity of opportunistic infections
- Side effects desirable and non desirable
- Symptomatology at onset of treatment
- Effect of pregnancy or lactation (Castro 2005:5).

The success of an ART programme is measured by its adherence rate. Castro (2005:5) indicates that only by understanding the complicated interplay of social and clinical factors can the challenges to ART adherence be overcome.

## 2.5 CONCLUSION

This chapter has explored the context of challenges around the roll-out of ART. Through a review of relevant literature, this chapter has demonstrated the need to appropriately gauge the challenges being experienced in the roll-out of ART in South Africa. In so doing it has provided a background to the study of Challenges experienced by Non-Governmental Organisations in the roll-out of ART in KwaZulu-Natal.

# CHAPTER 3

# RESEARCH DESIGN AND METHOD

## 3.1 INTRODUCTION

The purpose of this study is to explore and describe the challenges experienced by non-governmental organisations with regards to the roll-out of ART, with an aim to facilitate strategy development to overcome the challenges and enhance the success of ART rollout by the NGOs. In this chapter the research design, sample type and techniques for data collection and analysis will be described. The process of gaining permission to conduct the study will be outlined. Ethical consideration and issues pertaining to the rigor and trustworthiness of the study will also be discussed, as well as the strength and weaknesses inherent in the design.

## 3.2 RESEARCH DESIGN

A research design is a plan for collecting and utilizing data so that desired information can be obtained with sufficient precision or so that a hypothesis can be tested properly. In short it refers to the plan or blueprint of how the researcher intends conducting the research. It focuses on the logic of research such as, the kind of evidence required to address the research question adequately (Mouton 2008:55-56).

A qualitative, exploratory and descriptive design was used. Qualitative research is designed to allow researchers to get in-depth information on their subjects generally by talking to them or observing them. The central problems are to identify how people interact with their world and then determine how they experience and understand that world; how they feel, what they believe and how they explain structure and relationships within some segment of their existence (Locke, Spirduso & Silverman 2000:98).

In this qualitative study, the researcher attempted to understand people in terms of their own definition of the world. By utilizing a qualitative approach, an attempt was made to understand the challenges experienced by NGOs from the subjective perspective of the individuals involved namely, project coordinators, doctors and nurses involved in the roll-out of ART. Complexities, richness and diversity of their work could only be captured

by describing what really goes on in their day to day work, incorporating the context in which they operate as well as their frame of reference (Mouton 2008:195).

### 3.2.1 Exploratory research

Exploratory research is conducted to gain insight into a situation, phenomenon, community or individual. Generally exploratory research has a basic research goal and researchers frequently use qualitative data (De Vos, Strydom, Fouche & Delport 2007:106). In this study, the researcher attempted to gain insight into a phenomenon by asking the central question "What are the challenges you experience with regards to the roll-out of ART?"

### 3.2.2 Descriptive research

Descriptive research presents a picture of the specific details of a situation, social setting or relationships. A descriptive study is more likely to refer to a more intensive examination of phenomenon and their deeper meanings thus leading to a thicker description (De Vos et al 2007:106). In this study the researcher attempted to get a deeper meaning of the phenomenon by following up with probes depending on the answer given.

## 3.3 RESEARCH METHOD

A research design is a plan for collecting and utilizing data so that desired information can be obtained with sufficient precision or so that a hypothesis can be tested properly (De Vos et al 2007:132). De Vos et al (2007: 132) describe a research design as a plan or blueprint of how the researcher intended conducting the research. A qualitative approach, with exploratory and descriptive design was used. Qualitative research`s hallmark is the richness of information and the types of settings that are modified to enrich understanding (Mouton 2008: 75).

### 3.3.1 Population

A population is defined as a complete set of persons or objects that possess some common characteristic that is of interest to the researcher (Brink 2011:213). The universal population comprised all programme leaders, doctors and professional nurses working in NGOs involved in ART roll-out in northern KZN. The target population was programme leaders, doctors and professional nurses involved in ART roll-out in the three NGOs from Northern KZN at work at the time of the study.

### *3.3.1.1 Setting*

Setting is defined as a quiet environment that provides privacy, is comfortable, non-threatening and easily accessible to facilitate the interview process (De Vos et al 2007:294-295). The setting was clinics and offices in KZN, where NGOs were involved in the roll-out of ART. The map that follows depicts the health districts in KZN, adopted from clinical service map of HKZN division of Medicine (2009).

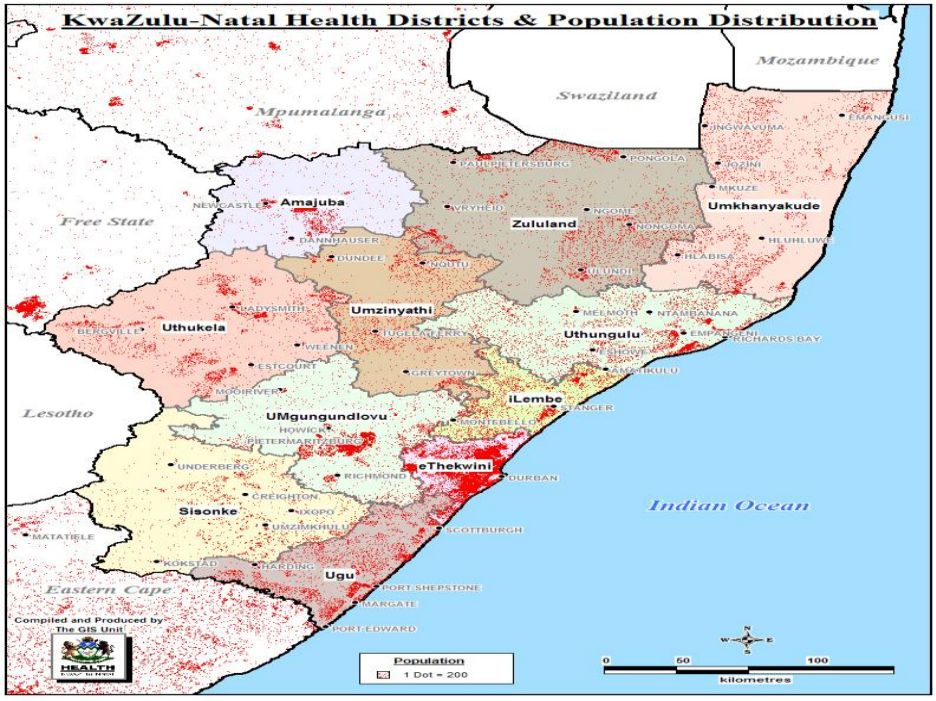


**Figure 3. 1 Health Districts KZN**

**Source: Clinical Service Map of UKZN Division of Medicine (2009)**

### *3.3.1.2 Sample and sampling method*

A sample is defined as a set of individuals selected from a population for analysis to yield estimates of the whole population or a subset of the population that is selected to represent the population (Brink 2011:214). The sample consisted of targeted programme leaders, doctors and nurses working for the NGOs selected.

Purposive sampling was used to select the participants. The researcher obtained a sample that was representative of important subgroups of the population by targeting specific sectors (Katzellenbogen 2007:179). The researcher chose purposive sampling because it allowed for selection of individuals from the spectrum the researcher was interested in and in this case ART section in NGOs focusing on the three main

categories of staff (Katzellenbogen 2007:179). A purposive sample of nine participants was included in the study in the form of three programme leaders, three doctors and three professional nurses from the three NGOs. The sample size depended on the saturation of data.

#### *3.3.1.3 Eligibility criteria*

Specific criteria were used to decide whether an individual would or would not be classified as a member of the population in question (Brink 2011:133). The eligibility criteria were as follows:

**Inclusion criteria:** ART programme coordinators, doctors and nurses from Africa Centre, Southern African Catholic Bishops Conference and Amangwe village who are involved in ART roll-out.

**Exclusion criteria:** ART programme coordinators, doctors and nurses not at work on the day of data collection and those not involved in the roll-out of ART.

### 3.3.2 Data collection

Data was collected by means of face-to-face interviews with participants. The interviews took place in eThekwini, uThungulu and uMkhanyakude districts in offices on the premises of the NGOs and at the clinics.

Individual interviews were held with programme coordinators, doctors and nurses from each NGO in the afternoon between 14.00 and 16.00 when the clinics were less busy. The structured format was followed and each interview lasted about 20 minutes. The in-depth interview was suitable for this study because structured interviews follow a well defined structure to prevent participants from placing their own interpretation on the question. The interview schedule offered more flexibility, which is a hallmark of qualitative research (Holloway 2003:48). The central question was the same, with the same probes and clarifications, while recording was uniform (Katzellenbogen 2007:83). The interviews were recorded on an audio recorder with the permission of the interviewees (Katzellenbogen 2007:177). The central question was ***"What are the challenges you experience with regards to the roll-out of ART?"*** This question was followed by probing questions based on the initial response from the participant.

Data was collected by audio-taped face-to-face interviews. The researcher used an interview schedule to guide the dialogue, and an audio recorder was placed with the participant's permission on a nearby surface such as a desk. Notes were written down on the interview schedule during the interview and written up during the transcription to capture the researcher's own observations. The observations made during data collection assisted the researcher during data analysis in providing additional insight into emergent themes and subthemes.

The interview schedule was based on one central question as stated, followed by prompts from the researcher. The interview schedule is included in annexure 5 of this dissertation.

#### *3.3.3.2 Advantages and disadvantages of interview*

- Advantages

The advantages of face-to-face interview were that:

- It offered flexibility which enabled the researcher to elicit more in-depth responses.
- In-depth interviews provided much more detailed information.
- The face-to-face element meant the researcher was certain of who would answer the questions (Hayden, Thompson & Levy 2007: 204).

- Disadvantages

- Interview responses were likely to be biased because of the influence exerted by the interviewer (Punch 2005:11)
- The busy schedules of the personnel involved might have been interrupted.
- On the researcher's part they proved costly in terms of time and transport costs.

#### *3.3.2.2 Data management*

The researcher`s observations were noted at the back of the interview schedule. Each taped interview was typed by the researcher in the form of a verbatim transcript. The researcher typed the transcripts within two days of the interview and completed the transcripts of one NGO before interviews with the next one.

### *3.3.2.3 Ethical Considerations*

**Permission to conduct the study:** Permission to conduct the study was sought from the Higher Degrees Committee of the Department of Health Studies at UNISA, Ethembeni Care Centre, Africa Centre and the SACBC where the study was conducted. Informed consent to participate in the study was also obtained verbally from the project coordinators, doctors and nurses.

**Maintaining confidentiality and privacy:** Confidentiality and privacy was ensured by using a password protected, restricted access computer to store information and anonymity was guaranteed by assigning interviewees pseudonyms and codes instead of names.

**Beneficence:** Beneficence will be ensured by making the research results known to the Department of Health and other NGOs thereby benefiting people in need of ART in the form of preparedness as a result of the recommendations.

**Autonomy and respect for persons:** Participation in the study was voluntary and the participants were assured that they could withdraw from the study at any time if they so wished, without penalty.

**Provision of debriefing, counseling and additional information:** Participants were provided with a brief background to the study prior to the commencement of interviews. They were asked if they wished to receive a summary of the interview transcript or the findings of the study. Any false hopes or expectations the interview could cause were respected and talked through to prevent emotional or any other risk. Participants were given the researcher's contact details in case they needed further information at a later date.

**Act on findings and Publishing:** The work of others was acknowledged and negative and positive findings were reported. The findings of this study will be disseminated in the form of publications in accredited journals and presentation at the relevant gatherings' such as conferences and workshops (Katzellenbogen 2011:27-34).

### 3.3.3 Data Analysis

Analysis involved breaking up the data into manageable themes, patterns, trends and relationships. The aim of analysis was to understand the various constitutive elements of the data through inspection of the relationships between variables and to see whether there were any patterns or trends that could be identified or isolated to establish themes in the data (Mouton 2008:108). Audio recorded data was transcribed verbatim and the resulting texts analyzed.

Creswell's (1998) analytic spiral as described by Marshall and Rossman (1999:150) was utilised to analyze data as follows;

1. Planning for recording of data.

2. Data collection and preliminary analysis.

3. Managing or organising data.

4. Reading and writing memos.

5. Generating categories, themes and patterns.

6. Coding the data.

7. Testing the emergent understandings.

8. Searching for alternative explanations.

9. Representing, visualising (i.e. writing report).

The disadvantages were that transcribing and data analysis was time consuming and researcher subjectivity often brought problems of subjectivity. The researcher made use of a computer to aid in the management of textual data, storage and retrieval of information quicker and more accurately.

## 3.4 MEASURES TO ENSURE TRUSTWORTHINESS

Trustworthiness refers to the confidence qualitative researchers have in their data. This was assessed using the criteria of credibility, transferability, dependability and conformability (Polit & Beck 2006:511).

Throughout the phase of data collection and data analysis, the researcher worked in close collaboration with the supervisor referring samples of interview transcripts and coded analysis for comments and guidance. In addition three strategies for ensuring rigor and trustworthiness in a qualitative study namely, reflexivity, audit trail and peer debriefing were applied to this research (Janesick 2006: 3387).

During the process of conducting interviews, the researcher was aware of the interaction between herself and the data. Acknowledgement and analysis of this process is termed reflexivity (Lietz, Langer & Furman 2006:1).

Lietz et al (2006:11) describe audit trail as keeping track of the decisions which led to the choice of particular steps in the research procedure. Reasons for the choice of research design, sampling type and sample size and methods of data collection and analysis were described in this chapter.

A senior doctor who is a District Consultant with a background of Public Health was requested to review and comment on the researchers understanding of the challenges experienced by NGOs in the roll-out of ART. In this study, member checking was also done by having research participants review, validate and verify the researcher`s interpretations and conclusion (Brink 2011:124).

### 3.4.1 Scope of study

The scope of this study is limited to the roll-out of ART only.

## 3.5 CONCLUSION

This chapter discussed the research design and methodology for the study. The data collection method and data analysis were explained. The next chapter will present the data analysis and findings of the study.

# CHAPTER 4

# DESCRIPTIVE DATA ANALYSIS

## 4.1 INTRODUCTION

In this chapter the research findings are discussed. This chapter begins with a description of how the interviews were arranged and conducted. The final section addresses the important themes and categories which emerged from analysis of the interview data. The findings are discussed with reference to the research objectives.

### 4.1.1 Purpose of the study

The purpose of this study was to explore and describe the challenges experienced by non-governmental organisations in KwaZulu-Natal with regards to the roll-out of ART. The aim was to develop recommendations to the DoH KZN to facilitate strategy development to overcome the challenges and to enhance the success of ART rollout by the NGOs.

### 4.1.2 Objectives

The objectives of the study were to

- Explore and describe the challenges experienced by NGOs with regards to the roll-out of ART.
- Develop recommendations to the DoH to facilitate strategy development to overcome the challenges.

## 4.2 DATA COLLECTION AND ANALYSIS

### 4.2.1 Data collection process

Data was collected from nine participants. Nine face-to-face interviews were held, all of which were held with participants who met the eligibility criteria as explained in chapter three of this study. The strata of the participants consisted of programme coordinators, doctors and professional nurses involved in ART roll-out.

The interviews took place at the offices of these NGOs and at the clinics involved in ART roll-out. The interview dates and times were arranged ahead of time by contacting programme coordinators who set up appointments. E-mail communication was used for confirmation of appointments. Upon arrival at an NGO the researcher was taken to the

office of the programme coordinator. Written consent earlier obtained from the institution was presented. The settings for the interviews were as follows:

- at Ethembeni, the interviews were held in the board room,
- at Mariannhill in the Matron's office and
- at Africa centre, the interviews were held at the clinic under a tree.

At one instance, the interview was held in the board room until halfway after which the interview was completed in the canteen on a secluded table. The interviews were held privately with doors closed in offices and with no-one else close by in outdoor settings under the tree and in the deserted canteen after lunch when all the employees had returned to their offices. The introductory statement was as follows:

*"I am the Master of Public Health Student that contacted you earlier to confirm the interview arrangements. I am conducting research on the challenges experienced by non-governmental organisations with regards to the roll-out of antiretroviral drugs in KwaZulu-Natal, as part of a requirement for the completion of a Masters degree. Are you still comfortable with going ahead with the interview?"*

The interview began with a brief introduction given by the researcher stating the purpose and objectives of the study. The participants were asked if an audio recorder could be used to record the interviews and all the participants agreed to be put on record. Consent was given verbally by the participants. At this stage participants were also informed that they were free to withdraw their participation at any time of the interview since participation was voluntary. In all cases, pseudonyms and interview codes were used and their places of work were not identified in order to promote confidentiality and anonymity. The central question was *"What are the challenges you experience with regards to the roll-out of ART?"*

### 4.2.2 Data Management

The interviews were audio recorded. Each audio recorded interview was listened to and written down by the researcher in the form of a verbatim transcript which was later analyzed. The researcher`s observations were noted at the back of the interview schedule and notes were also taken. The researcher transcribed the verbatim reports within a few days of the interview and completed the transcripts of one NGO before interviews with the next one began.

### 4.2.3 Topic guide

In response to the central question ”**What are the challenges you experience with regards to the roll out of ART”**, the following topic guide was used to probe the participants;

- The government introduced a new policy on ART shifting eligibility criteria: Was your organisation prepared for this? How has this policy affected you in rolling out ART?
- What challenges do you encounter?
- Adherence, follow up, transport, funding, pharmacists are some challenges found in literature. Do you share any of these challenges?
- Whoonga and drug abuse have been hitting the headlines. Is this a challenge for your organisation?
- HIV funding has been capped or drastically cut. Have you as an organisation been affected and if so in what way?
- What should NGOs do to overcome the challenges?

### 4.2.4 Typical challenges encountered during interviews

Most of the interviews went as planned. In two of the interviews, there were interruptions by telephone calls. In one instance the interviewee left the room for a short time to attend to something urgent. At one institution we had to move from the board room to a secluded table in the canteen because the interview coincided with an unscheduled meeting and the office would have been unsuitable because it was shared with another colleague.

### 4.2.5 Data analysis

Analysis involves breaking up the data into manageable themes, patterns, trends and relationships. Creswell (1998:144) states that classifying means taking the text or qualitative information apart and looking for categories, themes or dimensions of information. Data analysis was done according to Creswell’s analytic spiral. Five major themes emerged from the findings of this study (De Vos et al 2007:338).

## 4.3 DATA FINDINGS

### 4.3.1 Biographical information of the participants

Nine interviews were conducted. The participants comprised of six females and three males who met the eligibility criteria of the study. With regards to the level of expertise, they were three doctors, three programme coordinators and three professional nurses. Their ages ranged from 30 to 60 years.

### 4.3.2 Themes and categories

Five themes emerged from the findings as presented in table 4.1.

Table 4.1 Summary of findings using classification by theme and category

| **Theme** | **Category** | **Meaning unit** |
|---|---|---|
| 1. Challenges related to sustainability. | 1.1 Financial problems | • Funding and financial constraints due to budget cuts from main funder.<br>• Lack of capacity to manage grants effectively. |
| 2. Challenges related to adherence | 2.1 Socio-economic situation of patients or poverty factors.<br><br>2.2 Migration<br><br>2.3 Belief systems | • SASSA guidelines.<br>• Skipping of medication doses by patients when food is unavailable.<br>• Inability to collect medication due to lack of transport fees.<br>• Loss to follow up.<br>• Use of traditional medicine.<br>• Self ordained religious prophets. |

| | | |
|---|---|---|
| 3. Challenges related to the health system | 3.1 Health Infrastructure<br><br>3.2 Diagnostic apparatus.<br><br>3.3 Religion | • No laboratory services locally.<br>• Bad roads, shortage of water and poor communication networks.<br>• Human resource problems.<br>• Lack of a reliable tool to diagnose TB.<br>• Lack of family planning services in Catholic Health institutions. |
| 4. Challenges related to stigma | 4.1 Non-disclosure | • Non-disclosure of women<br>• Non-disclosure of parents to their teenage children who are HIV positive.<br>• Non-disclosure of teenage mothers when they leave the children in the care of grandmothers. |
| 5 Challenges related to behavior. | 5.1 Culture<br><br>5.2 Psychosocial factors and or Choice | • Unacceptability of condom use.<br>• 70-80% of pregnant women are teenagers<br>• Substance abuse, that is, alcohol and drug (whoonga) |

## 4.4 PRESENTATION OF DATA FINDINGS

### 4.4.1. Theme 1: Challenges related to sustainability

The challenges related to sustainability were highlighted by the participants in relation to financial problems. The category of financial problems is discussed as follows:

***Category 1.1: Financial problems***

From the findings of this study financial problems included factors related to funding and financial constraints, and lack of middle management to handle the funds.

- **Funding and Financial Constraints**

In a market driven economy, funding is a key determinant of any programme. Without funding, operations come to a grinding halt. It was indicated in the responses from participants that non-governmental organisations were experiencing financial constraints. This was in line with the speculation that the current global financial crisis might lead to an erosion of the gains that had been made in the fight against HIV/AIDS. The financial constraints were mentioned to be related to budget cuts from the main funders. A participant revealed the following:

*"PEFAR the main donor has cut funding on HIV/AIDS programmes in some cases by 25%."*

It was further revealed that due to financial problems, some of the employees had to be retrenched. On the other hand all the field visits had to be suspended and the workers were office based due to lack of funds to run the field works. It was also indicated that discussions with the Department of Health were underway to request the department to take over the salaries of some of the staff because of financial constraints. The participants mentioned that the inclusion of a project in Pinetown was because their sister project in uMkhanyakude had run out of ARVs and the establishment was forced to down size and refer patients to the government due to financial constraints.

The findings of this study concur with a report by the South African Catholic Bishops Conference (SACBC) which indicates that in the US, the American government reduced their support for AIDS relief in Africa. This has greatly impacted their AIDS-Treatment Programme. The AIDS treatment programme which was part of the SACBC programme, was no longer sponsored by the US government by the end of May 2011.

According to the SACBC official, this means that they have to bridge a financial gap of R3, 007,497.00 per annum (Southern African Catholic....2011).

In a report by Leonzon (2011:1), it was indicated that in Germany corruption has been blamed for the withdrawal of funding for HIV. The report revealed that following allegations of massive corruption involving grants from the Global Fund to Fight AIDS, Tuberculosis and Malaria, Germany has cancelled the payment of its contributions to the funding organisation. According to a report by The Associated Press ([S.a.]) as much as two-thirds of grants provided by the fund end up in corrupt activities. However, the Global Fund has refuted the report, saying misappropriated funding has amounted to only USD34 million out of a total disbursement of USD13 billion since 2002. (Leonzon 2011:1). Interestingly, in the findings of this study, corruption was not mentioned as a challenge by the participants.

- **Lack of capacity of middle management to handle the funds**

It was indicated that people in senior positions lacked the management and financial skills to deal with grants effectively. The findings further revealed that appointments of candidates for financial management were made on the grounds of affiliation rather than merit. It follows that grants were not used effectively. Some of the narratives from the participants were as follows:

*"Decentralisation is welcome but it has created other problems. Very few people have the management and financial skills to cope with such huge amounts of money. People did not know what to do once the budget got approved and the finance became available. The capacity of middle to senior managers is pathetic."*

"*Some managers lack the capacity to handle the grants effectively leading to under-spending while on the other hand service delivery is pathetic.*"

The findings concur with sentiments echoed by Dr Doyin Oluwole, the director of Africa's Health in 2010 who indicated that with a history of accidental managers, the health sector in Africa may not be able to achieve the health–related Millennium Development Goals (Kakaire & Kirunda 2007 in Oluwole 2010).

The lack of managerial capacity at all levels of the health system is increasingly cited as a binding constraint to scaling up services and achieving Millennium Development Goals (Kakaire & Kirunda 2007 in Oluwole 2010).

### 4.4.2 Theme 2. Challenges related to adherence

Adherence to ART means taking the ART drugs daily as per the prescribed regimen, like, once daily means precisely at the same time every day, twice daily means precisely every 12 hours (e.g. 6:00am and 6:00pm), three times daily means precisely every 8 hours (e.g. 6:00am, 2:00pm, 10:00pm). Once enrolled on ART, test results must be done to indicate that treatment is working. Failure to take appropriate action will result in a patient being designated non-adherent.

Successful administration requires the patient to adhere fully to the regimen for life (95%). Inadequate adherence could lead to treatment failure and ARV drug resistance. Large scale ART programs with inadequate attention and support for drug adherence could render the available ARV drugs useless and negate the advances made in creating effective ARV therapy (Hope & Caution 2002:3).

In this study the findings of the challenges related to adherence are discussed in relation to the category of the socio-economic situation of the patients.

#### *Category 2.1: Socio economic situation of patients*

Socio-economic problems of the patients were indicated to present a real challenge to the successful roll-out of ART. Considering the importance of adherence in ART, the socio-economic status and education level of the patients was a fundamental stumbling block. The following narratives were revealed by the participants:

*“Working mothers` children who are taken care of by child minders who change frequently thereby jeopardizing optimal therapy and adherence. In some cases baby minders change almost on a monthly basis and nurses have to begin with basic education each time they come for supplies.”*

*“Level of education is affecting adherence with more educated patients sticking better to treatment.”*

Several factors related to the socio economic situation of the patients were identified as aspects such as skipping of medication doses when food is unavailable, inability to collect medication due to lack of transport fees, use of traditional medicine, SASSA guidelines and loss to follow up which are discussed in the section that follows.

- **Skipping of medication doses when food is unavailable**.

Lack of food was indicated to contribute to patients not taking their treatment adherently. The following were some of the narratives from the participants in relation to skipping medication:

*“Socio-economic problems lead patients to skip doses of medication when food is unavailable.”*

*"Social problems lead to defaulting treatment. Many patients lack support at home. They miss review dates due to lack of transport fee and they do not take medicine when they do not have food. They say the tablets make one very sick when taken on an empty stomach."*

*"In this community we have an unemployment rate of 80%. Food becomes a problem and if they do not have food they also do not take the drugs. Economic and financial hardships make patients skip treatment."*

The importance of food security and nutrition is very crucial to adherence, and particularly in the early stages of ART. According to Zuurmond (2008:1) some people may not start treatment when they are not sure about the source of food. However, once they are on ARTs and begin to respond, their appetite is regained and the ARVs are perceived as medicines for hunger. On the other hand, if there is no food, the medication is not taken (Zuurmond 2008:11).

A study by Weiser, Tuller, Frongillo, Senkungu, Mukibi and Bangsberg (2010:1) reports that food insecurity is common and an important barrier to accessing medical care and ARV adherence. The following mechanisms emerged for how food insecurity can

contribute to ARV non-adherence and treatment interruptions or to postponing ARV initiation:

- ARVs increased appetite and lead to intolerable hunger in the absence of food
- Side effects of ARVs are exacerbated in the absence of food
- Doses are skipped or ARVs not started at all if there is added nutritional burden
- Competing demands between costs of food and medical expenses lead people either to default from treatment, or to give up food and wages to get medications

The other problem related to adherence was indicated to be related to being at work for long hours, where patients sometimes forgot to take medication. Non-adherence leads to incomplete viral suppression, continued destruction of the immune system, disease progression, emergence of resistant viral strains, and limited future treatment (Ethiopia 2011).

- **Inability to collect medication due to lack of transport fees**

Another socio-economic factor that was mentioned by participants was inability to collect medication due to lack of transport fees, which ultimately led to challenges related to adherence. The following narratives were mentioned by the participants in relation to transport:

*"Patients are usually weak and the centre is not located on the main road making transport to and fro difficult for patients".*

*"Patient transport to main hospital where investigations like X-rays are taken is provided once a week thereby delaying initiation of treatment."*

*"Patients discontinue treatment when there is lack of money for transport to collect medication supplies."*

Du Preez (2010:1) indicated that some of the problems hindering the fight against HIV/AIDS are unemployment and poverty; and that despite HIV treatment being free, transport costs are a major obstacle for people on ART.

- **SASSA guidelines**

SASSA guidelines stipulate the criteria to be used for an HIV positive patient to receive a grant. One of the criteria is a CD4 cell count of 200 and below. The participants indicated the SASSA guidelines as one of the factors leading to non- adherence. The participants mentioned that;

*"Patients skip their medication in order to keep the CD4 count low thereby making them eligible for a grant."*

*"Patients threaten us with unspecified consequences if we do not recommend them to receive a grant. Alternatively, they simply stop taking medication until the CD4 cell count has dropped below 200."*

*"SASSA guidelines are fuelling non adherence."*

According to literature (South African Social Security Agency 2011), SASSA likened HIV infection to chronic diseases such as diabetes mellitus or hypertension. However, in the case of HIV, a temporary grant is offered because the client can recover fully and perform all the activities of daily living should he or she comply with treatment. If after 12 months, a person`s condition is still moderate or severely impaired then they can reapply for the grant (South African Social Security Agency 2011).

A report by Craven ( 2010) concurs with the research findings in that SASSA are not doctors and cannot stop contracts for paying those affected once the doctor has proved that the patient is cured. According to Craven, SASSA is not concerned that proper quality food costs money and, how do people living with HIV/AIDS get food (Craven 2010).

***Category 2.2 Belief system***

A belief system can be religious, philosophical, ideological or a combination of these. It is a way of life, basis of culture, identity and moral values (Cohen & Kennedy 2000:347). The participants mentioned use of traditional medicine and religious prophets as systems people frequently fall back on to regain wellness and equilibrium.

- **Use of traditional medicine**

Use of traditional medicine is a wide spread practice affecting all the non-governmental organisations since it is routed in the culture. The participants mentioned use of traditional medicine as a challenge. Considering the proportion of the native population that seek help from traditional healers, this challenge is of utmost importance in ART roll-out. Van Dyk (2001: 110-130) mentions the need to take into consideration ancestors, witches, sorcerers, importance of having children, perception of condoms, the importance of community life and traditional healers when planning HIV and AIDS programmes. The participants verbalised the following:

*“60-70% of the patients mix traditional herbal medicine and ART.”*

*“Enemas given to children impair the absorption of ART.”*

*“ About 80% of our patients use enemas.”*

*"Traditional medicine is preferred by some to ART. The moment they start to feel a bit better, they ask for permission to go home. They say they want to help the doctors by consulting traditional healers in addition."*

*"We had cases of inpatients who died clearly from muti over dose. One had this blackish thing that got stuck in his throat and was pulled out during resuscitation."*

A study by Peltzer , Friend-du Preez , Ramlagan and Fomundam (2008:255) indicate that traditional herbal therapies and Traditional, Complementary and Alternative Medicine (TCAM) are commonly used by HIV treatment naive outpatients of public health facilities in South Africa. Health care providers should routinely screen patients on TCAM use when initiating ART and also during follow-up and monitoring keeping in mind that these patients may not fully disclose other therapies (Peltzer, Friend-du Preez , Ramlagan & Fomundam 2008:255)

- **Self ordained religious prophets.**

The findings indicated that some of the people hide behind religion and claimed to have healing powers for TB and HIV. The participants had this to say:

*“A patient disappeared to visit one of the prophets in Mpumalanga and later came back with a very low CD4 cell count and died a few days later.”*

*“Self ordained religious prophets tell patients that they have been prayed for and are now healed and need not take medication.”*

*"One patient was doing very well on treatment. She asked for leave to go home and was granted. Her CD4 cell count was 520 when she left. She returned some weeks later after having spent most of that time at a Prophets shrine in Johannesburg with a CD4 cell count of 28. We tried all we could but she died within a week."*

In an article by Vuvu (2011), Treatment Action Campaign (TAC), an HIV/AIDS rights organisation, took the church to the Advertising Standards Authority (ASA) over its claims that faith healing could cure tuberculosis (TB) and HIV/AIDS. It also revealed how some patients are misinformed by churches regarding their illness leading to the transmission of diseases such as XDR-TB to other family members.

***Category 2.3 Migration***

The movement of people especially pregnant women to cities where the health infrastructure is better, teenage mothers after birth and migrant workers when they return to their homes was indicated as a factor derailing adherence

- **Loss to follow up**

ART demands lifelong commitment. Difficulties arise when people that have been initiated on treatment do not show up on subsequent visits. Three main groups of loss to follow-up have been identified as challenges, which are namely, teenagers and their babies, migrant workers from Mozambique and PMTCT women post delivery since they came to urban centres seeking better antenatal care and returned to the rural areas post delivery. The narratives revealed the following:

*“Baby dumping at grandmothers who are oblivious to the baby`s HIV status especially in teenage pregnancies. We have cases of 7 grandmothers who sero-converted. All were looking after grandchildren that were HIV positive but nobody had informed them.*

*If they did not know the status of the baby, how on earth do you expect them to have understood the importance and adhered to the treatment as required?"*

*"Post delivery, girls go back to school. They seldom come back for review and follow up. "*

*"PMTCT women come to urban areas to access better health facilities. Post delivery, they return to the rural areas and so we lose touch to both mother and baby."*

*"A third of our patients are migrant workers from Mozambique. Once initiated on treatment, very few come back for review and follow up is impossible."*

Teenagers have a right to education despite pregnancy according to the Children's Rights Charter of South Africa. Post delivery, many teenagers opt to go back to school. This brings about the challenges of who will mind the baby. Many teenagers take the baby to their own mothers if the situation allows or to the mother or family member of the alleged boy friend.

### 4.4.3 Theme 3 Challenges related to the health system

According to the findings of this study, health system included infrastructure and processes to achieve outcomes in the delivery of good quality care and successful roll out of ART. Three categories that emerged from this theme included health infrastructure, diagnostic apparatus and religion.

#### *Category 3.1: Health Infrastructure*

Lack of laboratory services, bad roads, shortage of water and poor communication network were mentioned in relation to health infrastructure and are discussed in the section that follows.

- **No laboratory services locally**

CD4 cell count and viral load are two of the tests that are routinely done in ART roll-out. A functional laboratory with qualified personnel is necessary. The participants cited this factor as a challenge as they have to send specimens away thereby delaying interventions.

*“Results take up to 7 days to return. Specimens have to be sent away to the main hospital or Durban leading to a long turn-around time with many results getting lost during the manual transmission.”*

*"The amount of patients was overwhelming at the beginning of ART roll-out."*

*“Fast tracking still takes 2 weeks while you watch the patient die.”*

*“Viral load machine in Hlabisa Hospital the nearest laboratory is not working.”*

*“MDR diagnosis can take up to 6 weeks.”*

*“TB culture takes 2 months and results are often lost.”*

*“Specimens have to be sent away to the main hospital or Durban leading to a long turnaround time with many results getting lost during the manual transmission.”*

According to literature, the main barriers of access to treatment in South Africa include a lack of access to laboratory services for CD4 and viral load testing. These tests are a critical part of ART as patients need to be regularly monitored to see if the treatment is working properly (www.aidsbuzz.org.accessed 29 July 2011).

- **Bad roads, shortage of water and poor communication network**

In rural settings infrastructural problems such as bad roads, shortage of water and poor communication networks were indicated to be common. These challenges were serious as highlighted by the participants in the following narratives:

*“Patients are usually weak and the centre is not located on the main road making transport to and fro difficult for patients.”*

*“Some clinics have erratic water supply.”*

*“Some clinics have no telephone or reliable network reception. One has to stand at a special point to get signal.”*

*“Some roads are so bad especially after heavy rains.”*

*“Poor ambulance services leading sometimes to a waiting time of 8-10hrs.”*

*“Patient transport to main hospital for investigations like x-ray is only provided once a week thereby delaying initiation of treatment.”*

*“Even with cell phones one has to stand at a specific patch to get signal.”*

Since two of the three NGOS in this study were located in uMkhanyakude district, the research results concur with a survey that was done by The Health Systems Trust in 2005 which indicates that the three most deprived districts are OR Tambo (EC), Alfred Nzo (EC) and Umkhanyakude (KZN). It is of concern that all three of these districts also scored higher on the deprivation index in 2001 (Cosser 2005:1).

- **Human Resources problems**

Human resource shortages were found to be a problem in the health sector. The non-governmental organisations had not been spared either of the shortage of staff. Other aspects of human resources problems included salary disputes, recruitment and retention of staff and unprofessional behaviour of some of the staff when dealing with HIV affected patients. The participants explained as follows:

*“Recruitment and retention of staff is difficult due to rural setting. One has to rationalise the need for staff.”*

*“Staff is now unionised and are currently demanding salary increases despite a decline in funding”.*

*“Diminished orientation and retention capacity of very ill patients leads to repetition of work adding to the work load. Fast tracked patients need re-education since they become too sick to understand what is going on.”*

*"Staff motivation is a problem especially with young nurses. Health care workers are very problematic for their level of education and exposure is low. We had to fire one*

*after a patient complained of having been slapped during a bath. The patient reported even to have been called an Amoeba."*

It is mentioned that the main barriers to treatment access in South Africa include severe shortage of trained people, especially doctors, nurses, pharmacists and counsellors (ART roll-out 2011).

***Category 3.2 Diagnostic apparatus***

Diagnostic apparatus were needed for prompt diagnosis and initiation of treatment to patients. However, the apparatus were found to be unavailable or even unreliable.

- **Lack of a reliable tool to diagnose TB**

While the doctors who participated in this study cited this as a challenge, the government had already identified this challenge. It was indicated that the lack of reliable tools delayed diagnosis, initiation and continuation of treatment, or even led to misdiagnosis of patients. The narratives revealed the following:

*“MDR diagnosis can take up to 6 weeks.”*

*"Culture takes two months of waiting and the results often get lost."*

*"AFB microscopy takes two weeks and even then it is often negative and misleading."*

*"Some junior doctors miss to pick up the signs of TB on a chest X-ray early enough delaying treatment."*

Interestingly, according to Philp (2011:6) a solution has been found in the mean time, because the government received the world`s largest order of TB diagnostic machines. Thanks to GeneXpert machines, South African authorities can now diagnose patients in two hours instead of the minimum six weeks it usually takes (Philp 2011:6).

***Category 3.3 Religion***

Religion was indicated to interfere with treatment rollout, due to certain beliefs and restrictions. Family planning was indicated to be affected, especially in relation to the catholic religion.

- **Lack of family planning services on Catholic health institutions**

Religion was indicated to affect family planning services due to the site being catholic. The Catholic Church did not advise the use of modern day family planning methods as it was in contrast with the church doctrine. The narratives revealed the following:

*“Many females present with septic abortions and we unfortunately have little means to prevent this since we do not provide family planning services as a catholic institution.”*

*"No contraception is allowed at this site. It is against the Catholic doctrine."*

*"We cannot offer them the supermarket approach when it comes to family planning. We have to refer them to a governmental institution for family planning services."*

The research findings concur with literature related to the church doctrine, which indicate that Catholics do not have the right to help out in the administration of any birth control methods at all, such as Depo-Provera injections. Just as it is wrong for a physician to prescribe such treatments when used for birth control, so also is it wrong for a nurse to administer them to patients (Catholics Frequently Asked Questions 2011).

### 4.4.4. Theme 4 Challenges related to stigma

Non disclosure for fear of stigma was highlighted as a challenge. Some participants revealed the following about fear of stigma:

*“Patients refuse to be referred to local clinic”.*

*“We have staff members working here in an organisation that rolls out ART but people are unwilling to go present themselves at the clinic to get ART. Someone said I would rather die than to go to any of these clinics because the nurses know me”*

***Category 4.1 Non disclosure***

There was considerable evidence to suggest that ART is reducing 'self-stigma' and 'burden stigma', that is, people with HIV were feeling more able to integrate into their social networks because, on treatment, they perceived themselves as less of a social and financial burden. There was a sense that HIV was becoming more normalised as it was increasingly described as having become one of many difficult but manageable health problems faced by the population in that area (Roura , Urassa & Busza 2009:208)

*“Most patients do not want to be referred to local clinic, something that could help considering their financial problems.”*

*“Some women come back after two weeks to collect another drug supply. When asked what happened, they say they are sharing the tablets with the husband who himself is unwilling to come in person due to fear of his status being known”.*

*"They would rather travel 50km every month to take supplies than be seen at their local clinic".*

However the fact that most of the patients refused to be referred to a local clinic falls in line with research findings which state that while self stigma has dropped researchers found that a pervasive HIV-associated 'blame stigma' remained very prominent in the community. People with HIV were characterised as morally corrupt and irresponsible and were blamed for having caught the infection. In fact, some community leaders felt that ART was encouraging people to continue 'morally deviant' behaviours with no sanction. Some suggested that ART formulations should include drugs to induce impotence to ensure prevention of onward sexual transmission. ART was seen as making it more difficult to identify people living with HIV and was thus felt to encourage risky behaviours and increase the potential for HIV transmission (Roura et al 2009: 208).

The participants mentioned non disclosure as a challenge which manifested in different forms such as women to men and men to women, non-disclosure of parents to their (teenage) children who are HIV positive, non-disclosure by teenage mothers when they leave the children in the care of grandmothers. In some cases they stated that non

disclosure was frequent among men and in other cases they found the challenge in both sexes. Of concern was the non-disclosure of parents to their teenage children bringing up new challenges as this group is in the stage of exploring sexual relations.

*"Most women who are dependent on their boyfriends do not disclose for fear of loss of income."*

*"Parents do not disclose to their HIV positive teenagers making it difficult to explain to this group what medication they are taking."*

*"Teenage mothers do not disclose the status of the baby to the grandparents who are left to care for the child."*

*"Females do not like to disclose mostly due to fear of losing boyfriend who supports them financially."*

*"Both genders refrain from disclosing their statuses due to fear of desertion."*

The beliefs that disclosure may result in divorce or physical abuse identified in this study might form useful targets for interventions to improve disclosure of HIV status. Similar findings were obtained in Ethiopia and South Africa where women did not disclose because they were concerned about divorce/separation, physical attacks and acts of murder as a result of disclosure (Mucheto, Chadambuka, Shambara, Mufuta, Gombe & Nyamayaro 2009:9).

In another study, the research findings on teenage non disclosure were confirmed. In terms of working with adolescents, the main problem identified is the need to address the whole issue of 'positive prevention' (Zuurmond 2008:14).

### 4.4.5 Theme 5 Challenges related to behavior

The findings of this study indicated culture to be related to the behavior of the patients from which several meaning units emerged as discussed in the section that follows.

***Category .5.1 Behavior and Culture***

Unacceptability of condom use, teenage pregnancies and substance abuse were mentioned as the problems related to culture and behavior.

- **Unacceptability of condom use**

One of the ways of preventing HIV is through the use of the condom. The participants cited this as a challenge they were facing. Condom use seemed not to have been embraced in KwaZulu-Natal. The narratives revealed the following:

*“Many patients present with STIs despite education on the importance of condom use.”*

*“The patients have not embraced condoms and the prevalence of STIs speaks volumes.”*

*”Condom use has not been fully accepted in this community."*

*"Use of condoms is not widely accepted. They come back with STIs and yet claim to use condoms."*

A study conducted by the Africa Centre for Health and Population Studies (Chimbindi 2011:1) revealed that fewer females than males report use of condoms with their most recent partners. The study also found that despite millions of Rand having been poured into promoting the use of condoms to prevent the spread of HIV/AIDS, young people do not take the message seriously. Despite the high HIV prevalence rates, condom use is still relatively low. Fewer females than males reported using condoms with their most recent partner than a casual partner. Young people who had a partner older by at least a year had a low chance of using condoms (for both males and females) compared with those whose partner were the same age (Chimbindi 2011:1).

- **Teenage Pregnancies**

The participants mentioned teenage pregnancies as a real challenge. It was further speculated that the child grant could be peddling this trend. Some participants mentioned the following about teenage pregnancy:

*“70-80% of the pregnant women are teens. The children do not see the importance of education.”*

*“Desperation amongst teenage mothers is overwhelming. Crisis centre in Pinetown is full and cannot accommodate more desperate teenagers.”*

*“There are fifteen year old girls coming for the third pregnancy. They say with three kids you can get a decent amount of support grant to live on.”*

Makiwane and Udjo (2006) found no link between teenage fertility and child support grant. More research is called for into this area since little is known about what is enticing teenagers to fall pregnant despite knowledge and free availability of family planning methods.

- **Substance abuse**

Substance abuse manifested as a challenge in two forms namely, alcohol abuse and drug (whoonga abuse). Alcohol increases susceptibility to some infections that can occur as complications of AIDS. Infections associated with both alcohol and AIDS include tuberculosis, pneumonia, hepatitis C, which is a leading cause of death among people living with HIV. Alcohol may also increase the severity of AIDS -related brain damage which is characterised in its severest form by profound dementia and a high death rate (www.sciencedaily.com.accessed 1 August 2011). The narratives revealed that

*"A number of males patients often abuse alcohol. They say it helps them forget about their problems.”*

*"We have some patients who come to pick up their supplies totally drunk. One wonders how they can adhere to such a strict treatment."*

The problem of Drug abuse (whoonga) was cited by the participants as being rife in and around Pinetown. The problem seemed to be concentrated around Durban and the surroundings. This problem was also expressed in the media and a documentary film was recorded by E-news third degree (25 January 2011 at 21:30. South Africa). Some of the participants revealed the following;

*“Many patients come back to claim more drugs after allegedly been robbed. In some settings spouses share one monthly supply and sell the other supply to drug dealers. They then come back with an affidavit from the police and demand another drug supply.”*

*"Some patients have been mugged. They were followed from the hospital and when they alighted from the taxi, they were told to hand over their hand bags for something important was in there. All the muggers took out were ARVs."*

*"They stand at the gate and scout for candidates that are likely coming for ART supply. The thin and sickly are targeted and followed."*

East Coast Radio (22 June 2011) reported that more and more children are using whoonga. Children as young as 11 are smoking whoonga no longer to get high, but to avoid the pain experienced when the drug levels drop. According to the Choice theory, alcohol and drug abuse occur because of choices people make and not because of some type of disease (Glasser).Psychosocial factors like parenting, family environment and peers have been found to influence drug and alcohol dependence. Lack of parental support, monitoring and communication have been significantly related to drug and alcohol abuse among adolescents (Andrew, Hops & Ary 1993:285-310)

## 4.5 OVERVIEW OF DATA FINDINGS

During data analysis it emerged that that there were challenges that were common to all the participants, namely, nurses, doctors and programme coordinators. The challenges that were identified were related to sustainability, adherence, health system, stigma and behaviour. It also emerged that there were a several of factors that affected adherence.

The importance of adherence cannot be over emphasised. Poor adherence leads to a higher risk of drug resistance resulting in the need for a second-line drug treatment. This could be more difficult to administer, and the cost implications are considerable. If people living with HIV required second-line treatment, it could be more expensive than first line drugs (Zuurmond 2008:5).

## 4.6 CONCLUSION

In this chapter the major findings of the study have been presented according to the themes which emerged during data analysis. These have shown that according to the experiences of the participants, there are many challenges with regards to the roll-out of ART including challenges related to sustainability, challenges related to adherence, challenges related to the health system, challenges related to stigma and challenges related to behaviour.

In the next chapter, conclusions and recommendations to the study are discussed.

# CHAPTER 5

# CONCLUSIONS AND RECOMMENDATIONS

## 5.1 INTRODUCTION

In this last chapter, the findings are summarized in order to introduce major conclusions, recommendations and avenues for future research. It also mentions the limitations of this study so that they may be avoided in the future.

## 5.2 RESEARCH QUESTION

The study answered the following question: What are the challenges experienced by non-governmental organisations with regards to the roll-out of antiretroviral drugs in KwaZulu-Natal?

## 5.3 RESEARCH METHOD AND DESIGN

A qualitative approach, with exploratory and descriptive design was used. Data was collected by means of face-to-face interviews with participants. The structured interview format was followed and each interview lasted about 20 minutes. Permission to tape record was sought from participants and conversations were recorded. The in-depth interview was suitable for this study because structured interviews follow a well defined structure to prevent participants from placing their own interpretation on the question. The interview schedule was given preference because it offered more flexibility, which is a hallmark of qualitative research (Holloway 2003:48). The central question was the same, with the same probes and clarifications, while recording was uniform (Katzellenbogen 2007:83). The interviews were recorded on an audio recorder with the permission of the interviewees (Katzellenbogen 2007:177). These recordings were transcribed verbatim and the resulting texts analyzed.

## 5.4 INTERPRETATION OF THE RESEARCH FINDINGS

The study set out to establish the challenges experienced by non-governmental organisations with regards to the roll-out of antiretroviral drugs in KwaZulu-Natal. The study findings indicated a complex set of challenges, as follows:

### 5.4.1 Challenges related to sustainability

Funding and human resources' lack of capacity to manage grants posed profound challenges with all of the NGO's programme coordinators experiencing financial problems; as a real challenge that took them by surprise with the emergence of the global economic recession. The main funder for HIV and AIDS projects in Africa (PEPFAR) had cut spending and at the same time was in the process of winding down operations, posing real financial challenges for all these NGOs in the future.

### 5.4.2 Challenges related to adherence

The challenge of adherence emerged as multifaceted. The socio-economic situation of patients which manifested in different forms, namely, skipping of medication doses when food is unavailable and inability to collect medication due to lack of transport fees was reported by the participants. In this study, the participants reported use of traditional medicine and SASSA guidelines as major challenges contributing to non adherence to ART. Self ordained religious prophets and loss to follow up of migrants, pregnant women post delivery and teenage girls upon return to school were also cited as fuelling non adherence.

Food presented as a huge challenge. According to an article titled, "Desperate HIV positive people eat cow dung to sustain treatment", in Swaziland, rural residents are reported to have resorted to eating cow dung to give their stomachs something to digest before taking ART medication. Other research has shown that taking ART on an empty stomach can exacerbate the side effects of the drugs including headaches, dizziness and tremors (Swaziland….www.irinnews.org/report).

### 5.4.3 Challenges related to the Health system

Challenges related to the health system included bad roads, shortage of water and poor communication network in rural settings. In this study all the institutions experienced a lack of laboratory services and the participants cited a lack of a reliable tool to diagnose TB as a daily challenge. Lack of family planning services was experienced as a challenge only in Catholic health institutions. Shortage of skilled health personnel was a chronic problem in the health sector especially pharmacists and nurses who could initiate ART.

### 5.4.4 Challenges related to Stigma

In this study, challenges related to stigma were dominated by non disclosure issues. These ranged from non disclosure of women, of both sexes, of parents to their teenage children who are HIV positive and of teenage mothers when they leave the children in the care of grand-mothers.

### 5.5.5 Challenges related to behavior

Other challenges related to behavior in the society, namely, unacceptability of condom use cited by all nurses, high teenage pregnancies were cited; as well as substance abuse such as alcohol and drug abuse (whoonga). The participants mentioned the socio-economic problems of patients as having a very negative impact on ART roll-out especially as it affects adherence.

## 5.5 CONCLUSIONS

This study has used the experiences of nine participants to reach the conclusion that non-governmental organisations were faced with a complex set of challenges in the roll-out of antiretroviral drugs; ranging from challenges related to sustainability in the form of funding to challenges related to adherence, health system, stigma and behavior. The results indicated the need for a multi-sectoral collaboration in the roll-out of antiretroviral therapy. The Department of Health needs to work with other departments such as social welfare, agriculture, public works to ensure a concerted, comprehensive and sustainable roll-out of any programme.

## 5.6 RECOMMENDATIONS

Recommendations of this study have been categorized into sustainability, adherence, stigma, health system and behavior issues. To enhance the success of ART roll-out, the study recommends the DoH KZN and non-governmental organisations to consider the following when developing strategies:

### 5.6.1 Sustainability issues

Funding for HIV programmes is decreasing at a rapid rate after the withdrawal of PEPFAR. The sustainability of all ART programmes is hanging in balance. Government has to come up with contingency measures in case NGOs stop their programmes; and

the Public Health system should be prepared to absorb the influx of PLWHA who are currently being taken care of by NGOs.

The issue of human resources has been acknowledged by the DoH. Plans are underway to open nursing colleges across the country in an attempt to address the shortage of nurses. The DoH is advised to take into account the quality and quantity of the products these colleges produce. Many students pass through nursing colleges and come out ill equipped to deliver a high standard of nursing care due to a lack of quality assurance in training. The minimum entry requirement of achieving a minimum of 30% in the required subjects needs to be revised (Department of Education Higher Education Act 1997). In a profession where one's actions determine life or death, stringent entry requirements are needed to get staff of the highest caliber. A vigorous screening of interested candidates like the one used in the army could go a long way in addressing the lack of skill, compassion and commitment seen in the health sector today.

Governance and accountability are issues affecting many NGOs. The lack of capacity of middle management can be addressed by ensuring proper human resource practices where people are appointed on merit rather than political affiliation or nepotism.

### 5.6.2 Adherence Issues

Comprehensive needs assessment which spells out epidemiologic profile, assessment of service needs, resource inventory, profile of provider capacity and capability and unmet need and gap analysis should become the norm before any organisation or government rolls out a programme.

Taking the socio-economic aspects of the population or community into consideration before rolling out any programme is of utmost importance. Such measures ensure efficiency and effectiveness. The problem of skipping of doses when patients do not have food or inability to pick up monthly medicinal supplies due to lack of money for transport are aspects that should be taken into consideration before the actual roll-out of ART begins**.**

Poverty and unemployment are rife in KZN. If any programme is to be successful, these issues and how they can affect the programme have to be taken into account in the planning phase and contingency plans need to be put in place well ahead of time. For

example, comprehensively equipped mobile units could be used in such areas so that the service is taken to the people and hence eliminate the transport fee problems.

A sustainable approach is needed to deal with the challenge of food security that is hampering adherence. The NGOs and Department of Health must make nutrition an integral component of ART roll-out. Starting an ART programme in a resource poor area without provision of supplementary nutrition is detrimental. The threat is even compounded by skipping of medication doses when there is a lack of food affecting adherence, a hall mark of ART success. Sub-optimal adherence has implications for limiting the future impact of ART. Food hand-outs are not sustainable. A multi-sectoral approach which values sustainability is needed to deal with this urgent issue.

Review of SASSA guidelines in ART roll-out is recommended. A multi-sectoral approach to HIV/AIDS is not only a fashionable academic question but also determines what budgets are made available and which sectors and human resources get involved in the fight and allows addressing root causes of the epidemic as the most important factor of poverty. HIV and AIDS is inseparably linked with poverty.

SASSA guidelines need to be reviewed and adapted to promote compliance rather than the opposite. The Department of Health should design programmes jointly with other Departments also known as multi-sectoral Collaboration such as Social Welfare, Agriculture, Commerce, Education and Sports and Culture. Such joint programmes ensure synergy and help to minimize short comings and abuse such as it is with the SASSA guidelines. In addition it ensures a speedy and comprehensive response where such abuses emerge unlike the current silo system where the Department of Health experience the abuse but cannot do anything until the Department of Social Welfare has made its own studies to eventually identify and then deal with the issue. Multi-sectoral collaboration in the roll-out of ART is urgent. It generates demand for accountability and leads to coordinated political, economic and social efforts at different levels (Lele 2007:8).

The integration of traditional healers into the health system should be explored. If a large number of the population seeks care from traditional healers, the DoH should not ignore the role they play. Collaboration with traditional healers could win partners in

fostering adherence as well as lead to standardisation and testing of the herbs used eliminating overdose and toxicity problems encountered.

Health programmes should have a component which addresses poverty and the socio-economic circumstances of the patient if ART is to be successful. Socio- economic factors including poverty and unemployment emerged as one of the biggest challenge affecting ART roll-out. Synchronisation of all programmes could lead to efficiency and effectiveness in the public sector. HIV affects all departments and planning ART roll-out in an area with bad roads and telecommunication problems without the involvement of the relevant ministries dealing with road works and telecommunication, is a huge oversight. Multi-sectoral systematic planning would ensure that priority areas are set together before programme roll-out. Areas where such a programme could be started successfully are identified with all ministries ensuring smooth service delivery and concerted effort in that area before moving on. Synergy is needed in planning.

### 5.6.3 Health System issues

The Department of Health should step up provision of laboratory services on the premises that roll-out ART. This is a major challenge in ART roll-out and the government has to be persuaded to deal with this crucial aspect in ART roll-out. The seventh South African ART guideline is “to enable PHC facilities to initiate manage, monitor and refer patients” (The South African Anti Retroviral Treatment Guidelines 2010:1).

Many clinics and centres were still with no laboratory services making the monitoring of patients difficult. Results of CD4 cell count and viral loads took an average of 5 to 7 days; delaying necessary interventions.

Government should step up efforts to train nurses in PHC facilities to initiate ART, referring to the seventh ART guideline. The study revealed that the government had not yet started to train nurses in ART prescription as of February 2011 in KZN, leading to waiting times since patients could only be initiated by a doctor who sometimes visited the clinic only once a week. Literature suggests guidelines to be followed when starting a large scale ART one of which is to decide on essential laboratory, clinical, counseling and pharmaceutical services and their levels (Tawfik et al 2002:6).

The government is urged therefore to urgently address the issue of laboratory services on premises that roll-out ART, training of nurses in initiating treatment and provision of pharmaceutical services in institutions that roll-out ART.

### 5.6.4 Behavior related issues

Other preventive measures apart from condoms need to be investigated and promoted. Alternative prevention strategies need to be taught. The emergence of an epidemic in teenage pregnancies is evident to the fact that condoms are not being used. The high incidence of STDs amongst PLWHA also points to the unacceptability of condom use.

Positive reinforcements should be adopted when dealing with teenagers and sexual behaviors. Positive reinforcement refers to a reward that is given after a pleasing behavior to encourage its repetition (Mendoza 2010:1). Instead of awarding grants to teenagers that fall pregnant, these grants could be given to those that abstain from sex and successfully complete school in the form of bursaries to further their studies. A lot has been indicated about the abuse of the child grant by teenagers who fall pregnant for the sake of accessing funds. The government should take advantage of that by reversing the access to funds by granting it to those teenagers who exhibit good behavior. A different approach is needed and positive reinforcement is one alternative the government can adopt.

According to Rhone (2002) positive reinforcement and more engaged parenting results in children delaying or completely avoiding negative behaviors such as ill advised sexual activity and drug abuse. These sentiments were reiterated by Mendoza (2010) who states that positive reinforcement is a highly effective way you can encourage correct behavior and give your teenager the incentive to repeat the behavior. There are strategies for eliminating unwanted behaviors simply by using positive reinforcement rather than criticism or punishment. In the light of the above, the child grant could have been misconstrued by teenage girls as an incentive hence the adverse consequences of high teenage pregnancies.

Baby dumping and teenage pregnancies need to be prioritized and efforts need to be put in breaking the cycle. Deprived children are a breeding ground for all sorts of maladjustment behavior in the community. A high percentage of children in KwaZulu-Natal do not know their fathers let alone have experienced parental love. There are

children that come from a series of generations that have never experienced the love of an intact family life. The government, the community, the church and leaders from all walks of life need to come together and address the issue urgently. Every child has a right to be loved according to the South African Children Rights Charter (Children's Rights Charter of South Africa). These rights will quickly become legislation on a piece of paper without practical implications on the lives of those it is purports to protect.

Mental Health Services at primary health level could go a long way in assisting patients with depression and hopelessness. Many patients abusing drugs do so to escape their problems and psychologists at primary health care level could assist these patients to deal and cope with personal problems instead of succumbing to drugs.

### 5.6.5 Stigma issues

The respondents cited challenges related to stigma in the form of non-disclosure of HIV status. The fear of rejection especially of dependent women by boyfriend seemed to be the driving factor. The same fear of rejection seemed to be driving teenagers not to disclose HIV status of baby to carers; commonly grandmothers. In this study, discriminatory stigma after disclosure of status was not found to be a major challenge as has been reported in other studies. The church, community, political leaders and health care workers need to find ways of discussing the fear of rejection associated with HIV. Human beings are social beings and need to be loved despite their status. Eradication of fear of rejection campaigns could raise awareness and stimulate debate that could lead to solutions.

## 5.7 CONTRIBUTIONS OF THE STUDY

The findings of this study will be used to make recommendations to the Department of Health and other non-governmental organisations regarding the challenges to the successful roll-out of ART in KZN. To the Department of Health, the results of the study will provide reliable data for strategic plans for ART provision very importantly as the pool of recipients increases and the medication be taken for life. To the patients receiving ART, the results will provide valuable information as what to expect from their local service providers and if possible make contingency plans to achieve positive outcomes.

## 5.8 LIMITATIONS OF THE STUDY

The scope of this study is limited to the roll-out of ART in NGO's only. A study such as this is limited by virtue of a small sample. Data was collected from a few individuals from three organisations which mean that the findings of this study cannot be generalized to other NGOs. Thus an additional and important limitation is that the quality of the research is heavily dependent upon the prior knowledge and experience of the researcher (International Development Research Centre 2008:10)

### 5.8.1 Recommendations for further research

Further research is needed to explore why teenagers are falling pregnant despite free availability of knowledge and family planning methods in public institutions. Of interest to the researcher and worth researching is what contingency plans the Department of Health has to ensure a sustainable ART programme in KwaZulu-Natal in the face of a global crisis and withdrawal of PEPFAR.

## 5.9 CONCLUDING REMARKS

Data presented in this study provided sufficient information in relation to the research question and objectives. During the researcher's interactions with respondents, it became clear that ART roll-out by NGOs in KwaZulu-Natal is fraught with many challenges. The identification of the challenges would help in solving the problem. The researcher hopes that the Department of Health and NGOs in KZN will play their part in planning for a more concerted and sustainable ART roll-out for the benefit of the KZN communities.

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**Annexure 1. 1 Unisa Ethical Clearance**

UNISA university of south africa

**UNIVERSITY OF SOUTH AFRICA**
**Health Studies Research & Ethics Committee**
**(HSREC)**
**Faculty of Human Sciences**
**CLEARANCE CERTIFICATE**

Date of meeting: 9 November 2010 Project No: 3197-795-2

Project Title: The challenges experienced by the Non Governmental Organizations with regards to the roll-out of antiretroviral therapy in northern KwaZulu Natal

Researcher: Janet Michel

Supervisor/Promoter: Ms MC Matlakala

Joint Supervisor/Joint Promoter: N/A

Department: Health Studies

Degree: Masters in Public Health

**DECISION OF COMMITTEE**

**Approved** [√] **Conditionally Approved** [ ]

**Prof TR Mavundla**
**RESEARCH COORDINATOR**

**Prof MC Bezuidenhout**
**ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES**

**PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES**

## Annexure 1. 2 Letter of Permission from Africa Centre

AFRICA CENTRE FOR HEALTH AND POPULATION STUDIES

UNIVERSITY OF KWAZULU-NATAL

15 Febbruary 2011

Dear Mrs. Michel

**RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH**

Your letter dated 19 January 2011 has reference.

The Africa Centre through the ART Programme grants permission for you to conduct interviews regarding the programme as stated in yor letter of request.

Kindly inform us of the time you would like us to allocate for this exercise and we hope that we will be of great assistance towards your work.

Africa Centre would like to request that you also provide a copy of the full research report.

Kind Regards

HIV Care Programme Leader

Hilary Thulare

AN INITIATIVE OF THE UNIVERSITY OF KWAZULU-NATAL AND THE SOUTH AFRICAN MEDICAL RESEARCH COUNCIL

**Postal:** PO Box 198, Mtubatuba 3935, South Africa **Physical:** Africa Centre, R618 en route to Hlabisa, Somkhele
Tel: +27 (0)35 550 7500 Fax +27 (0)35 550 7565 E-mail: info@africacentre.ac.za
Website: www.africacentre.ac.za

**Annexure 1. 3 Letter of Permission from Mariannhill**

Private Bag X16
Ashwood
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KwaZulu-Natal
South Africa

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Email:
hospital@stmarys.co.za

Website:
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# ST. MARY'S HOSPITAL
## MARIANNHILL

11th February 2011

Ms Janet Michel
P O Box 188
Kwanbonambi
3915
South Africa

Dear Ms Michel

ETHICS APPROVAL FROM ETHICS COMMITTEE OF ST MARY'S HOSPITAL, MARIANNHILL, FOR MASTERS DISSERTATION PROJECT ENTITLED "THE CHALLENGES EXPERIENCED BY THE NON GOVERNMENTAL ORGANIZATIONS WITH REGARD TO THE ROLL-OUT OF ANTIRETROVIRAL THERAPY IN NORTHERN KWAZULU NATAL" (YOUR REFERENCE = PROJECT NO. 3197-795-2)

The Ethics Committee of St Mary's Hospital has reviewed the above mentioned Masters Dissertation Project, subject to clarification as to how St Mary's Hospital, Mariannhill, it can be considered to be in "Northern KwaZulu Natal". The Dissertation is given full ethics approval and may commence at the St Mary's Hospital site in February 2011.

This approval is valid for one year from the 11th February 2011.

Yours truly

Sister Regina Bachmann CPS
Member
Ethics Committee
St Mary's Hospital, Mariannhill

St Mary's Catholic
Mission Hospital Trust
(IT 2376/1995/N)
P.B.O No. 18/11/13/1877

**Annexure 1. 4 Letter of Permission from Ethembeni Care Centre**

| | | | |
|---|---|---|---|
| Von: | Tshabalala Sandile <Sandile.Tshabalala@kznhealth.gov.za> | Adresse speichern | Gesendet: 09.02.2011 11:25 |
| An: | janet.michel@bluewin.ch | | |
| Kopie/Cc: | Sithembile Pamela <sithembilepamela@yahoo.com> | | |
| Betreff: | RE: Permission for research | E-Mail lokal speichern | |
| Kopfzeilen: | Einblenden | | |

**Permission to do Research at Ethembeni Care Centre**

Dear Janet
Thank you for your interest in our institution. The permission to do the interviews is granted. Please liaise with the centre manager, Mrs. Tsipa.
As long as there is no disturbance of the patient care and other functions of the centre

Thank you
Dr. S .C .Tshabalala

-----OriginalMessage-----
From:janet.michel@bluewin.ch]
Sent:08February201108:55
To:TshabalalaSandile
Subject: Permission for research

**Annexure 1. 5 Interview Guide**

**Interview Guide**

The central question will be: **"What are the challenges you experience with regards to the roll-out of ART?"**

This question will be followed by probing questions based on the initial response from the participant.

- The government introduced a new Policy on ART shifting eligibility criteria: Was your organisation prepared for this? How has this policy affected you in rolling out ART?
- What challenges have you encountered?
- What solutions do you suggest to overcome the current challenges?
- The world is experiencing a financial crisis. HIV funding has been capped or drastically cut. Have you as an organisation been affected if so in what way?
- What should NGO do to overcome the challenges?

Thank you for your participation

**Annexure 1.6 Participant Responses --------Doctor 1**

**What are the challenges you experience with regards to the rollout of ART?**

| **Challenge** | **Suggested Solution** |
|---|---|
| 1. PEFAR the main donor has cut funding on HIV/AIDS programmes in some cases by 25%. | |
| 2. We have staff members working here in an organisation that rolls out ART but people are unwilling to go present themselves at the clinic to get ART. Someone said I would rather die than to go to any of these clinics because the nurses know me.<br><br>3. Use of condoms is not widely accepted. They come back with STIs and yet claim to use condoms.<br><br>4. Decentralisation is welcome but it has created other problems. Very few people have the management and financial skills to cope with such huge amounts of money. People did not know what to do once the budget got approved and the finance became available. The capacity of middle to senior managers is pathetic. | |
| 5. 60-70% of the patients mix traditional herbal medicine and ART | |
| 6. In this community we have an unemployment rate of 80%. Food becomes a problem and if they do not have food they also do not take the drugs. Economic and financial hardships make patients | |

| | |
|---|---|
| skip treatment. | |
| 7. Patients discontinue treatment when there is lack of money for transport to collect medication supplies.<br><br>8. SASSA guidelines are fuelling non adherence. | |
| 9. There are fifteen year old girls coming for the third pregnancy. They say with three kids you can get a decent amount of support grant to live on. | |
| 10. Baby dumping at grandmothers who are oblivious to the baby`s HIV status especially in teenage pregnancies. We have cases of 7 grandmothers who sero-converted. All were looking after grandchildren that were HIV positive but nobody had informed them. If they did not know the status of the baby, how on earth do you expect them to have understood the importance and adhered to the treatment as required | |
| 11. Some junior doctors miss to pick up the signs of TB on a chest X-ray early enough delaying treatment. | Curriculum for Doctors to be adjusted to equip the doctors better. |

| | |
|---|---|
| 12. Working mothers` children who are taken care of by child minders who change frequently thereby jeopardizing optimal therapy and adherence. In some cases baby minders change almost on a monthly basis and nurses have to begin with basic education each time they come for supplies. | |