

**An Evaluation of the “Antiretroviral Programme” in two informal townships in the Western Cape, South Africa: Exploring AIDS Patients’ access to and experiences of the Programme**

by

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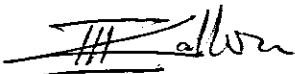
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## Declaration

I, Idriss Ibrahim Kallon, declare that the contents of this thesis represent my own work, and that the thesis has not previously been submitted for academic examination towards any qualification. Furthermore, it represents my own opinions and not necessarily those of the Cape Peninsula University of Technology.



Signed

12<sup>th</sup> August 2010

Date

## **Abstract**

*This study aimed to evaluate the “Antiretroviral Programme” in two informal townships, Du Noon and Doombacht, in the Western Cape, South Africa. It evaluated how AIDS patients access Antiretroviral Therapy (ART<sup>1</sup>), their knowledge of ART’s efficacy, their adherence to ART as well as their experiences of the quality of service at the Du Noon Clinic. Employing a questionnaire survey among 124 (12%) respondents on ART of the registered 1, 050 clients at the Du Noon Clinic, a systematic sampling of every 9<sup>th</sup> client (of the 1,050) was done. To generate findings of a qualitative nature, the study also used focus group discussions with a total of 36 AIDS patients on ART (18 of this number were also part of the survey), 11 community health/home-based workers and in-depth interviews with 2 nurses in charge of the rollout programme at the Clinic.*

*Based on the survey results, the study determined that 93% (n=115) of AIDS patients access ART at the Du Noon Clinic, 75% (n=93) of respondents reported to ART adherence and 75% (n=93) displayed an understanding of ART’s efficacy. It also revealed that 77% (n=95) of AIDS patients made good comments regarding the quality of service at the Du Noon Clinic. However, 25% (n=31) of AIDS patients were not adhering to ART. A Mann Whitney U test confirmed a significant relationship between the respondents’ length of time on ART and the increase in CD4 count ( $p=0.01$ ). However, AIDS patients who adhered to ART with the same length of time on ART have a higher CD4 count difference ( $p=0.04$ ). The focus group discussions revealed AIDS patients’ experiences of lack of confidentiality at the Du Noon Clinic. In addition, in five of the six focus group discussions, respondents expressed concern over disability grants not being awarded to patients with CD4 counts 200 cells/ML and below<sup>2</sup>. Notably, more than half of the respondents have been on treatment for more than one year.*

*The study concluded that ART access is humanizing in the Western Cape and controversial AIDS treatment discourse has not significantly influenced the perceptions of AIDS patients regarding ART’s efficacy. A high percentage (75%) of AIDS patients were adhering to ART in Du Noon and Doombacht. Addressing concerns over lack of confidentiality when accessing ART at the Du Noon Clinic, as well as the quest for disability grants within the context of AIDS treatment, could have further improved ART adherence in these communities.*

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<sup>1</sup> ART refers to the treatment with a combination of Antiretrovirals. A combination of two or more ARVs is regarded as Highly Active Antiretroviral Therapy (HAART). ARVs are the specific drugs used. Both terms will be used in those contexts.

<sup>2</sup> AIDS patients can now start treatment with a CD4 count of 350 cells/ML. At the time of the interview, it was 200 cells/ML and below.

*The study recommends that monitoring and evaluation (M&E) should involve measuring factors that influence adherence alongside accessibility to ART. Secondly, there should be mechanisms in place to maintain confidentiality in accessing ART as it is with Voluntary Counselling and Testing (VCT) services to facilitate appropriate adherence to ART. Thirdly, future research needs to determine factors that have contributed to the success of the Antiretroviral rollout at the Du Noon Clinic as well as to confirm a relationship between access to disability grant and the level of adherence in resource-poor communities.*

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## List of Figures and Tables

### Figures

Figure 1	Prevalence of HIV in South African Population, 2008 .....	10
Figure 2	Impact of interventions on the number of people infected with HIV in the Western Cape .....	13
Figure 3	Impact of interventions on the number of new infections per annum .....	14
Figure 4	Impact of interventions on the number of deaths in the Western Cape .....	14
Figure 5	Age-sex distribution of respondents in the survey .....	31
Figure 6	Current marital status of respondents in the survey.....	32
Figure 7	Population group of respondents in the survey.....	33
Figure 8	Township residence of respondents in the survey.....	34
Figure 9	Employment status of respondents in the survey .....	35
Figure 10	Completed educational level of respondents in the survey .....	36
Figure 11	Availability of ARVs at the Du Noon Clinic.....	37
Figure 12	Respondents' knowledge of ART's efficacy.....	38
Figure 13	Respondents' recommendation of the best form of treatment for AIDS patients .....	39
Figure 14	Respondents associate ARVs with Government hospitals and clinics .....	40
Figure 15	Respondents' CD4 count before starting ART .....	41
Figure 16	Respondent's length of time on ART.....	42
Figure 17	Respondent's present CD4 count.....	43
Figure 18	Respondents' level of adherence to ART .....	44
Figure 19	Comparison of CD4 count between adherent and non-adherent groups ...	45
Figure 20	Length of time on ART and CD4 count difference .....	46
Figure 21	Comparison of CD4 count between adherent and non-adherent groups Who have been on ART for more than a year .....	47
Figure 22	Respondents' rating of the quality of service regarding ART at the Du Noon Clinic.....	48
Figure 23	Respondents currently on ART and are sexually active.....	49
Figure 24	Respondents on ART and condom use.....	50
Figure 25	Respondents on ART whose partners are aware of their status.....	51
Table 1	Conceptualisation of poverty and unemployment over the past four decades .....	18

## **Dedication**

I dedicate this work to my late aunt, Finda Squire, who succumbed to AIDS-related disease in Sierra Leone, never having had the opportunity nor the privilege of receiving ART.

## **Acronyms**

<b>AIDS</b>	<i>Acquired Immune Deficiency Syndrome</i>
<b>ART</b>	<i>Antiretroviral Therapy</i>
<b>ARVs</b>	<i>Antiretrovirals</i>
<b>BCC</b>	<i>Behaviour Change Communication</i>
<b>DLG</b>	<i>Developmental Local Government</i>
<b>EU</b>	<i>European Union</i>
<b>HAART</b>	<i>Highly Active Antiretroviral Therapy</i>
<b>HIV</b>	<i>Human Immunodeficiency Virus</i>
<b>IEC</b>	<i>Information Education and Communication</i>
<b>NGO</b>	<i>Non-Governmental Organisation</i>
<b>MTCT</b>	<i>Mother-to-Child Transmission</i>
<b>NPO</b>	<i>Non-Profit Organisation</i>
<b>NSP</b>	<i>National Strategic Plan</i>
<b>OI</b>	<i>Opportunistic Infection</i>
<b>PLWHAs</b>	<i>People Living with HIV/AIDS</i>
<b>PMTCT</b>	<i>Prevention of Mother-to-Child Transmission</i>
<b>SANAC</b>	<i>South African National AIDS Council</i>
<b>SHD</b>	<i>Sustainable Human Development</i>
<b>SLSD</b>	<i>Statistics on Living Standards and Development</i>
<b>SALDRU</b>	<i>South African Labour and Development Research Unit</i>
<b>STI</b>	<i>Sexually Transmitted Infection</i>
<b>TAC</b>	<i>Treatment Action Campaign</i>
<b>UNAIDS</b>	<i>United Nations Programme on HIV/AIDS</i>
<b>UN</b>	<i>United Nations</i>
<b>VCT</b>	<i>Voluntary Counselling and Testing</i>
<b>WHO</b>	<i>World Health Organisation</i>



<b>Abstract</b> .....	i
<b>Acknowledgements</b> .....	iii
<b>List of figures and tables</b> .....	iv
<b>Dedication</b> .....	v
<b>Acronyms</b> .....	vi
<b>CHAPTER ONE</b> .....	1
<b>Introduction</b> .....	1
1.1 Background.....	1
1.2 Research problem.....	2
1.3 Aim and objectives.....	2
1.4 Significance of the study.....	3
1.5 Thesis layout.....	3
<b>CHAPTER TWO</b> .....	4
<b>Literature Review</b> .....	4
2.1 Introduction.....	4
2.2 The Global and Sub-Saharan trend of HIV/AIDS.....	4
2.2.1 ART scale-up.....	5
2.2.2 The essence of ART.....	6
2.2.3 Measuring the immune state.....	6
2.2.4 Adverse effects of ARVs.....	7
2.2.5 Starting ART and quality of service in resource-poor communities.....	7
2.3 HIV Prevalence in South Africa.....	9
2.4 An overview of the treatment strategy in the "HIV/AIDS and STI Strategic Plan for South Africa (2007-2011)".....	10
2.5 The HIV/AIDS population projections for the Western Cape.....	12
2.6 Cost and theories of safe use of ART in South Africa.....	15
2.7 Themes of poverty and unemployment in AIDS treatment discourse.....	17

2.8	Scientific and non-scientific controversy of AIDS causation and therapy in South Africa .....	19
2.9	Political denialism and the discourse of AIDS treatment .....	20
2.10	Conclusion .....	21
<b>CHAPTER THREE .....</b>		<b>23</b>
<b>Methodology .....</b>		<b>23</b>
3.1	Introduction .....	23
3.2	Pilot study .....	23
3.3.1	Demographics of Du Noon .....	25
3.3.2	Demographics of Doombacht .....	25
3.4	Overview of health situation in target population .....	25
3.5	Sampling and selection strategy for the survey .....	26
3.6	Sampling and selection strategy for focus group discussions and in-depth interviews .....	26
3.7	Methods of data collection .....	27
3.8	Inclusion criteria .....	28
3.9	Exclusion criteria .....	28
3.10	Data analysis .....	27
3.11	Limitations of the study .....	29
3.12	Maximising validity and reliability of the study .....	30
3.13	Conclusion .....	30
<b>CHAPTER FOUR .....</b>		<b>31</b>
<b>Results .....</b>		<b>31</b>
4.1	Quantitative results .....	31
4.1.1	Demographics of respondents in the survey .....	31
4.1.2	Availability of ARVs at the Du Noon Clinic .....	37
4.1.3	AIDS patients' knowledge of ART's efficacy and alternative AIDS treatment strategies .....	38
4.1.4	The best form of treatment for AIDS patients .....	39
4.1.5	Areas of accessing ARVs .....	40

4.1.6	Before and after ART and increase in CD4 Count.....	41
4.1.7	AIDS patients' level of adherence to ART .....	44
4.1.8	A comparison of respondents who adhered to ART and those who did not adhere to ART and the difference in CD4 count .....	45
4.1.9	A comparison of the length of time of respondents on ART and the difference in CD4 count .....	46
4.1.10	The adherence level of those who have been on ART for more than a year and increase in CD4 count .....	47
4.1.11	Quality of service regarding ART at the Du Noon Clinic .....	48
4.1.12	ART and sexual behaviour.....	49
4.2	Qualitative results .....	51
4.2.1	Access to ART .....	51
4.2.2	The best form of treatment for AIDS patients .....	52
4.2.3	Adherence to ART and increase in CD4 count.....	53
4.2.4	Disability grant request.....	54
4.2.5	Good adherence and the changing structure of disability grant at the Du Noon Clinic.....	55
4.2.6	Lack of confidentiality at the Du Noon Clinic.....	57
4.2.7	Untimely doctor's consultation.....	58
4.2.8	Long hours of waiting for treatment.....	58
4.2.9	ART and condom use .....	59
4.2.10	Unsuitable working environment .....	60
4.2.11	Summary .....	61
<b>CHAPTER FIVE .....</b>		<b>62</b>
<b>Discussion.....</b>		<b>62</b>
5.1	Introduction .....	62
5.2	Moving towards national access to ART.....	62
5.3	AIDS patients' knowledge of ART's efficacy and AIDS patients' thoughts on the best form of treatment .....	63
5.4	Adherence to ART, increase in CD4 count and disability grant.....	66
5.5	The quality of service regarding ART at the Du Noon Clinic.....	67
5.6	Summary of discussion.....	69

**CHAPTER SIX**..... 70

**Conclusion and Recommendations** ..... 70

6.1 Conclusion..... 70

6.2 Recommendations ..... 71

**References**

**Appendices**

- Appendix 1 Faculty ethics approval letter
- Appendix 2 Approval letter from community leader
- Appendix 3 Cover letter for respondents/participants
- Appendix 4 Participants' consent form
- Appendix 5 Structured questionnaire
- Appendix 6 Semi-structured focus group questions for AIDS patients
- Appendix 7 Semi-structured focus group questions for community health workers
- Appendix 8 Semi-structured in-depth interview questions

## CHAPTER ONE

### Introduction

#### 1.1 Background

ART is the scientifically tested combination of drugs used to treat AIDS patients (Tayler, 2004). These drugs boost the immune system, minimize the impact of opportunistic infections (OIs) and prolong the life of AIDS patients. Between 2000 and 2004, South Africa went through a phase of poor and inadequate ART rollout plan (Heywood, 2004; Nattrass, 2006, 2007; Robins, 2004). This phase saw series of conflicts between the Treatment Action Campaign (TAC) and the South African Government. TAC claimed that the South African Government under Thabo Mbeki was reluctant to rollout ART effectively (Robins, 2004). Furthermore, there were controversial debates about ART's efficacy to improve the health of AIDS patients in South Africa since 2000 (Mbeki, 2000; Rath, 2004). These controversial debates were projected through various means. These include media's representation of the toxicity of ART (Kallon, 2008) as well as political denialism, especially when Mbeki questioned the causal link between HIV and AIDS and the former health Minister encouraged AIDS patients to take lemon, garlic, olive oil and African potatoes as AIDS treatment (Nattrass, 2006, 2007).

Following these controversies regarding ART, many studies have surmised that the failure to adequately rollout ART in South Africa as a result of AIDS denialism may have exacerbated the increase of early deaths from AIDS related diseases (Heywood, 2004; Robins, 2004; Nattrass, 2007). Research studies have also maintained that collaborative traditional and biomedical healing strategies are imbedded in South African communities, which in some cases, affect appropriate adherence to ART (Mills, 2006). Indigenous knowledge in the context of AIDS treatment, such as suggested remedies by the former health minister, posed an affront to biomedical treatment of AIDS patients.

Africa is still home to more than 20 million people living with HIV/AIDS (PLWHAs). HIV/AIDS-related diseases remain one of the leading causes of deaths on the continent (UNAIDS, 2009). In 2006, close to 4 million people have died from AIDS-related diseases in the world and

Southern Africa is the hardest-hit region. In the same year (2006), in South Africa, it is recorded that 370, 000 people died of AIDS-related diseases (UNAIDS, 2006).

## **1. 2 Research problem**

Drawing on the background of controversial AIDS discourse, political denialism and traditional healing strategies, there have not been sufficient research papers on how AIDS patients' perceptions of ART's efficacy and the quality of service at primary health care (PHC) units influence their adherence to ART. Few studies have analysed the media's role in propagating a controversial AIDS discourse that may have negatively influenced the choices people make regarding what causes AIDS and ART's efficacy (Geffen, 2006; Kallon, 2008). Furthermore, there are studies about the experiences of AIDS patients being exposed to collaborative treatment strategies (Mills, 2006). However, an understanding of the relationships between AIDS patients' knowledge of ART's efficacy, the quality of service regarding ART and the level of adherence to ART in resource-poor communities is largely unknown.

## **1.3 Aim and objectives**

This study aimed to evaluate the "Antiretroviral Rollout Programme" in two informal townships, Du Noon and Doornbacht, Cape Town, in the context of AIDS patients' access to ART, their understanding of ART's efficacy, experiences of the quality of service at the Du Noon Clinic and level of adherence to ART. The objectives of the study were:

- To measure AIDS patients' access to ART at the Du Noon Clinic that serves the Du Noon and Doornbacht townships
- To determine AIDS patients' knowledge of ART's efficacy in the context of controversial AIDS discourse in South Africa
- To assess AIDS patients' experiences of the quality of service regarding ART at the Du Noon Clinic and their level of adherence to ART

#### **1. 4 Significance of the study**

A research study on how AIDS patients access ART as well as their knowledge of ART's efficacy and experiences of the quality of service regarding ART may provide some understanding of how these factors influence AIDS patients' level of adherence to ART; especially in communities, such as Du Noon and Doombacht that may struggle to provide the human and material resources to maintain effective ART rollout. Consequently, this study may provide some of the reasons AIDS patients do not adhere to ART in resource-poor communities in South Africa.

#### **1. 5 Thesis layout**

The first chapter gives the background to the research problem, the research problem statement, the significance and objectives of the study. It also explains the layout of the thesis. The second chapter reviews literature on the global and Sub-Saharan HIV/AIDS landscape and ART scale-up. This includes an apt linkage between the increase in HIV infection and the corresponding demand for universal access to ART, the measuring of the CD4 cells, benefits and adverse effects of ART. This chapter also reviews literature on the nature and response to the South African burden of disease, the HIV/AIDS & STI National Strategic Plan (NSP), which stipulates 80% target of national access to ART by 2011 and the HIV/AIDS population projection for the Western Cape. It also incorporates discourses on the cost and safe use of ART as well as scientific and non-scientific controversy on AIDS causation and treatment. Theories of healing strategies that maintain the co-existence of Western/biomedical treatment and traditional medicine supposedly substantiated by political denialism since early 2000 to the mid 2000, are also reviewed in this chapter. The third chapter gives a detailed methodology of the study and the demographics of the target population. Chapter Four presents both quantitative and qualitative findings, including the Mann-Whitney U test on adherent and non-adherent groups and difference in CD4 counts. Chapter Five discusses the main findings followed by a conclusion and recommendations in Chapter Six.

## **CHAPTER TWO**

### **Literature review**

#### **2.1 Introduction**

This chapter reviews literature on the global and Sub-Saharan trend of HIV/AIDS and the demand for ART scale-up. Universal access to ART has been one of the key aspects to mitigate the HIV/AIDS pandemic. The global impact of AIDS shows a rationale for governments' commitments to ART rollout. Sub-Saharan Africa, which is the most affected region regarding HIV prevalence, clearly features in this response to revitalise HIV/AIDS prevention and treatment programmes. The review of literature on what makes up the immune system and how it is measured including the benefits and adverse effects of ART is relevant, as the study maintained that among the signs of good adherence to ART is the increase in the CD4 cells. This section also reviews what informs the start of ART in resource-poor communities compared to highly industrialised countries with better resources. These aspects are significant as the study seeks to assess the adherence level of AIDS patients in resource-poor communities in particular. This chapter also reviews literature on the impact of HIV/AIDS in South Africa in the second half of 2000 and the NSP, which seems to pave the way for a better ART rollout plan up to 2011. However, the 80% national target does not correlate with the 100% universal access. There is also no clear monitoring plan for adherence in the NSP. Finally, a review of controversial scientific and non-scientific discourses regarding AIDS causation and treatment is presented, which suggests in theory, that the perceptions AIDS patients have about ART's efficacy and quality of service may have an influence on their level of adherence to ART.

#### **2.2 The Global and Sub Saharan trend of HIV/AIDS**

The global HIV/AIDS statistics have not shown a downward trend since the discovery of the AIDS virus in 1981 (AIDS Images of the Epidemic, 1994, UNAIDS, 2000, 2006, 2009). By the end of 2009, the global HIV infection rate had reached 34 million with an increase of virtually a million new HIV infections that subsequently increases the number of PLWHAs (UNAIDS, 2009). In East and Central Africa alone, between 3.1 and 5.5 million children lost their mothers to AIDS during the 1990s (AIDS Images of the Epidemic, 1994). The annual deaths of people of all ages



increased from 1.7 million in 2001 to 2.1 million in 2007 (UNAIDS, 2007, Kaiser Family Foundation/UNAID/SCSIS, 2007).

Sub-Saharan Africa, being the hardest-hit region of the world, carries over 67% of the world's HIV infection rates and almost 72% of the global AIDS-related deaths (UNAIDS, 2009). Towards the mid 1990s, one of the notable impacts of AIDS in Sub-Saharan Africa was the alarming loss of life since the late 80s. It was envisaged that life expectancy would have grown since 1985 without AIDS (AIDS Images of the Epidemic, 1994). However, between 1985 and 1990, AIDS added an average of 10% to the annual death rates of people 15–49 years (AIDS Images of the Epidemic, 1994). World Health Organization (WHO) predicts that by the close of the 21<sup>st</sup> Century, mothers of 5-10 million children under 10 years would have succumbed to the pandemic (UNAIDS, 2007). Since the 1990s and in the first half of the 21<sup>st</sup> century, there has been a steady increase in adult death rates by more than 40% (AIDS Images of the Epidemic, 1994, AIDS Epidemic Update, 2006). Research has predicted that by the beginning of the next decade South Africa, which represents about 40% of Sub-Saharan Africa's economic output, faces a real Gross Domestic Product (GDP), which would be 17% lower than it would have been without AIDS (Report on Global AIDS Epidemic, 2002).

Research has also shown that youth and young adults in the Sub-Saharan region (as well as globally) are at higher risk of HIV infection (Clark, 2003). At least 10% of those aged between 15 and 49 are infected in 16 African countries (UNAIDS, 2000, 2006). In recent times, demographic studies show that HIV/AIDS has become the leading cause of deaths in Sub-Saharan Africa. It is predicted that between 2000 and 2020, 68 million people would succumb to the AIDS virus (Report on Global AIDS Epidemic, 2006, 2008). These proposed statistics threaten the future of productive life in Sub-Saharan Africa.

### **2.2.1 ART scale-up**

The magnitude of this impact and future projections, among other socio-economic factors, since the early 2000, led to ART scale-up being highly considered, both globally and in the African region in particular, to minimise the growing predicament caused by the AIDS pandemic. According to UNAIDS (2006), Sub-Saharan Africa scaled-up ART tremendously through implementing the 3 x 5 treatment strategy plan. In just two years, (2003-2005) AIDS patients

needing ART increased by 700,000 (UNAIDS, 2006). Each of these countries, Kenya, Zambia, South Africa and India has over 100,000 people receiving ART. However, it must be noted though that the number of those needing ART is much higher than those who have access to them. In South Africa, about 116, 000 people receive ART but over 300, 000 need them (Global Fund to Fight AIDS, Tuberculosis and Malaria, 2007).

### **2.2.2 The essence of ART**

The human body has certain protective cells such as the CD4+ T-cells. These cells fall in the category of "lymphocyte", which help to fight against common viruses or bacteria that affect the body. HIV falls in the category of retroviruses and this virus has the propensity to replicate whilst it is inside the cells of the human body using "two viral envelop glycoproteins, gp120 and gp41 (Nattrass, 2007) (cited in Greene and Peterlin, 2005:30). "This glycoprotein springs open and 'harpoons' the target cell, leading to the release of the viral core into the interior" (Nattrass, 2007:41). This process means that the virus is being aided by these glycoproteins to gradually destroy the CD4+ T-cells, leaving the immune system of the body unprotected to the attack of other viruses or bacteria.

ART reduces damage to the immune system (CD4+ T-cells) and minimises the risk of HIV transmission (Tayler, 2004). In other words, it suppresses what is referred to as the viral load (HIV content in the blood) and gradually improves the immune state of the patient. The impact of OIs such as diarrhoea and tuberculosis are also curtailed. The first set of ARV drugs known as Azidothymidine (or AZT) emerged as very successful (Nattrass, 2007:42). However, the changing nature of the virus rendered AZT as a monotherapy ineffective to deal with the mutating nature of HIV. Therefore, the standard to treat AIDS patients evolved into two or more combination of drugs, hence the term Highly Active Antiretroviral Therapy (HAART) (Nattrass, 2007: 42-43).

### **2.2.3 Measuring the immune state**

Clinical research has established that one of the major aspects in measuring the effectiveness of ART is the progress of the CD4 count (Ananworanich, *et al*, 2005; Calmy, 2004). Ananworanich *et al* (2005) discussed clinical trails where HAART was terminated at some point (studying particular patients' information) and kept track of the progression of the CD4 count, which forms a vital component of how the immune state of AIDS patients progresses. This does not overlook other significant factors, such as the viral load and the uniqueness of individual patients' medical

situations. In addition, the study concludes that a CD4 guided HAART can be a viable option as well as a cost-saving strategy to treat AIDS patients and recommends that it should be considered for clinical practice based on the confirmation of larger trials. This refers to the process of employing similar strategies with larger sample sizes and with longer follow-up systems (Ananworanich *et al*, 2005: 528).

#### **2.2.4 Adverse effects of ARVs**

As much as ARVs have been successful in minimising the replication of HIV in the body and improving the health of patients, there are known adverse effects as is the case with many other strong drugs. These adverse effects include "Nucleoside Reverse Transcriptase Inhibitors (NTRIs). These are linked with "body fat redistribution, hypetensitivity syndrome (fever, nausea, vomiting, symptoms suggestive of upper respiratory tract infection, rash, headache and diarrhoea)" (Natrass, 2007: 42-43).

#### **2.2.5 Starting ART and quality of service in resource-poor communities**

ART rollout in resource-poor communities, especially in Africa, has been a serious concern because most Sub-Saharan African communities struggle to provide the adequate resources and accurate testing instruments for CD4 cells and viral load (Wilson & Blower, 2005: 133; Calmy, *et al*, 2004: 2353; Singler & Farmer, 2002: 1650). This problem sometimes causes prioritisation of ART, i.e., treating those who are in greater need of treatment than those whose health may not be too severe. (Calmy, *et al*, 2004: 2354). In the context of the inadequacy of measuring the CD4 cells and viral load, this phenomenon has attracted researchers to understand the best ART systems to employ in low and medium countries. In relation to this inadequacy of measuring the CD4 cells, some authors have argued that introducing HAART may not be a priority in low-income countries where there are no adequate resources to manage it therefore, rendering it counterproductive (Baggaley, 1998). In highly industrialised countries, such as the United States of America, the introduction of HAART has reduced AIDS related morbidity and mortality by 90% (Singler & Farmer, 2002: 1651) because in these countries, the discourse of ART treatment has become both a health and human rights issue. However, it is noted that these countries have the resources to manage effective ART rollout.

Conversely, research in Haiti, which is one of the poorest countries in the Western hemisphere, with an HIV prevalence rate of more than 6% of the adult population, revealed that in 1998 ART rollout saved many lives that would have been lost had it not been for timely introduction of ART

(Singler & Farmer, 2002: 1652). Interestingly, ART was introduced in spite of the ill-equipped medical system to conduct tests for CD4 cells and viral load. The measuring levels used to determine the commencement of ART "were based on the criteria that include nature and frequency of opportunistic infections, weight, neurologic status and severe hematologic abnormalities to identify those patients in greatest need" (Singler & Farmer, 2002: 1652). In this resource-poor community, it is reported that about 200 of the more than 2100 HIV-positive patients received HAART based on the criteria stated above. Furthermore, to maintain adherence, there are community-based workers referred to as "accompagnateurs" who follow up patients on a daily basis - a system called "directly observed therapy [DOT]-HAART" (Singler & Farmer, 2002: 1652).

Lessons can be learnt from the Haitian ART rollout plan, which displayed a unique form of ART rollout service based not only on the monitoring plan of those who access treatment at the PHC units, but starting ART in spite of limited resources; particularly in the context of inadequacy to measure CD4 cells and viral loads. In addition, the daily monitoring by community health workers ensured consistent treatment, which subsequently led to a reduction on mortality rates (Singler & Farmer, 2002: 1653). This was not seen among patients who were not on treatment, as most patients who were hospitalised, were those who were not on ART.

In Brazil as well, quality of service regarding ART started with a feasible rollout plan. It is observed that no regimen was prescribed that did not comply with a particular standard that has been set. Furthermore, the ART rollout plan was followed by a very good tracking system of adherence (Carmody, et al, 2003: 381). This notion of tracking adherence to ART is simultaneously carried out as AIDS patients access ART.

Comparatively in South Africa, with more PLWHAs and even with applied technology in measuring CD4 cells and viral loads, it was a contentious process before 2010 whether to start ART at 200 cells/ML and below or at 350 cells/ML and below. This issue was extensively discussed in one of the recent AIDS conferences held in Durban, South Africa in March and April 2009. The outcomes of research presentations at this conference may have contributed to the commencement of ART at the threshold of 350 cells/ML. Had this been done much earlier, it would have prevented severe impacts of AIDS in the country.

From the experiences in the above countries, such as Haiti and Brazil that share many socio-economic factors with South Africa, it is important that some resource-poor communities explore similar measuring guidelines to start ART in spite of inadequate facilities to adequately measure

the immune system, as people in need of ART may be showing visible signs and symptoms of full blown AIDS. These may include frequency of opportunistic infections; weight, neurologic status and severe hematologic abnormalities as in the case of Haiti. ART rollout alongside a proper monitoring plan that includes community health workers, has proven to be a vital component to consider in both access and adherence to ART. These lessons may inform good practices in the South African situation of ART response in resource-poor communities.

However, it must be noted that one of the good practices already shown at the Du Noon Clinic is the use of community health workers offering counselling services to AIDS patients who may be facing diverse socio-economic problems that may affect their adherence to ART. This practice is similar to the Haitian and Brazilian situations of monitoring good adherence to ART.

Finally, to ensure improvement and sustainability regarding ART rollout in resource-poor communities such as Du Noon and Doombacht, one of other explored areas is to improve on the capacity of medical personnel trained in global health. It has been observed that very few medical schools globally offer relevant and sufficient training to respond to these health challenges in Africa, since most of these trainings require internal institutional support, which is limited (Singler & Farmer, 2002: 1651).

### **2.3 HIV prevalence in South Africa**

More than five million people are living with HIV in South Africa (Department of Health, 2005). By early 2000, AIDS has become one of the leading causes of deaths in the country (Department of Health, 2004). In 2006, it was reported that South Africa, as well as some of her immediate neighbours, Botswana, Lesotho and Swaziland, have the highest antenatal HIV prevalence in the world (South African AIDS Council, 2007).

The figure below shows an estimated HIV prevalence among the whole population, antenatal Clinic attendees and adults (aged 20-64) (Department of Health, 2008).

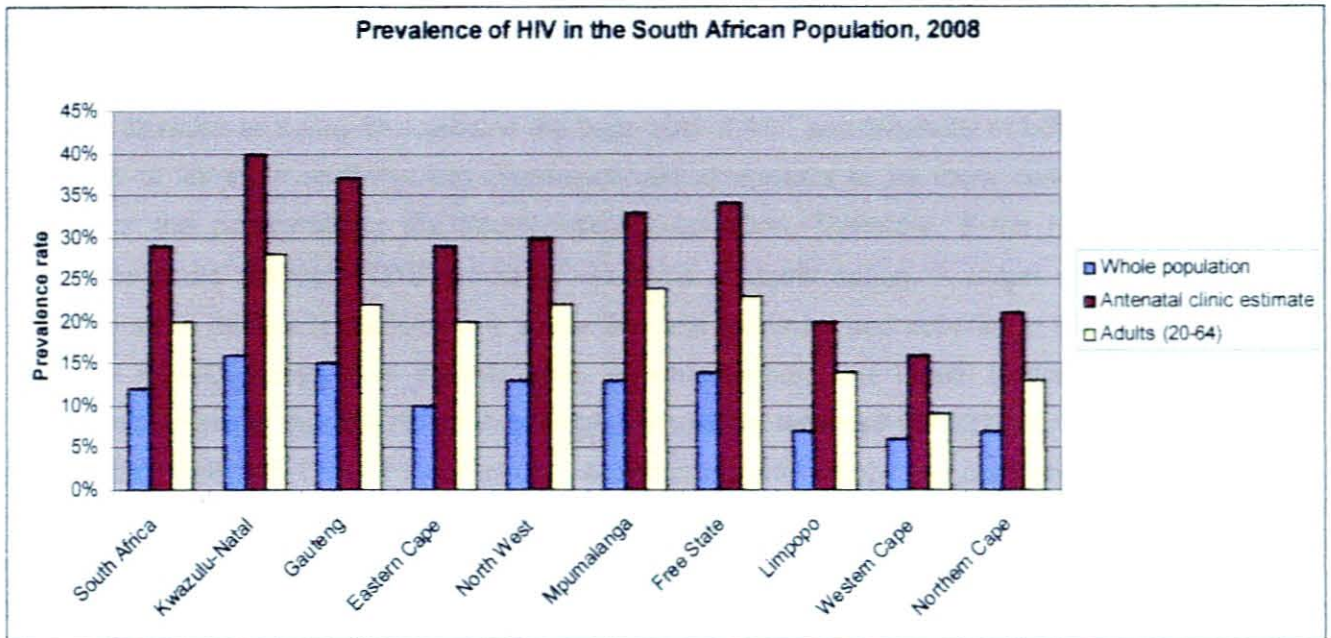


Figure 1 Prevalence of HIV in the South African population, 2008

Taylor (2004:1) records that “treatment to Prevent Mother to Child Transmission (PMTCT) during birth or through breastfeeding can reduce pediatric infection rates by as much as 70% percent when combined with care for the mother and changes in feeding practices”. In this regard, treatment circumstantially is clearly a form of prevention (Taylor, 2004). With almost 30% of South African women in 2006 being infected with HIV, it could result in alarming number of HIV positive babies and a subsequent high death toll without adequate treatment (Department of Health, 2006). The above figure (Figure1) also shows a high HIV prevalence among adults in South Africa with the lowest being 9% in the Western Cape Province and the highest, 28% in Kwazulu Natal Province.

#### 2.4 An overview of the treatment strategy in the “HIV/AIDS & STI National Strategic Plan for South Africa (2007-2011)”

The NSP (2007- 2011) draws significantly from the National Strategic Plan (2000-2005) as a main guiding document for the past five years prior to the revised document (South African AIDS Council (SANAC, 2007). The primary aims of the NSP (2007-2011) plan are “ (1) to reduce the rate of new HIV infections by 50% by 2011, and (2) to reduce the impact of HIV/AIDS on individuals, families, communities and societies by expanding access to treatment, care and support to 80% of all HIV positive people and their families by 2011. There are certain key issues that are worth noting about the NSP. Firstly, the national target of 80% national access

does not correspond with the 100% universal access to treatment put forward for governments to embark on. The rationale for 80% national access to ART is also not clearly stated in the NSP. In as much as it may be related to the huge cost of ART and feasibility of achieving 100%, a review of literature confirms that inadequate rollout appears to be more costly noting the impact of the pandemic on the South African population. Therefore, if the health budget resources could manage 100% rollout, it would be a viable option. A target of 100% can motivate stake holders to scale-up HIV prevention and treatment and activities in this regard. In a recent HEAIDS conference (March 2010) in Johannesburg, the health minister Dr. Aaron Motsoaledi stressed that PMTCT, for example, should be renamed EMTCT, which stands for Eradicating Mother-to-Child Transmission. According to this stance, no child should be born with HIV in subsequent years as there is the availability of ART to completely eradicate it. This can only be done when every mother is tested before child birth. The two proactive strategies, which are HIV testing and adequate access (100%) to ART, among other factors, may signal hope to deal with the impact of the pandemic in South Africa.

The NSP highlighted some of the causes and determinants of the epidemic in South Africa. These include contextual factors such as cultural attitude and practices, as well as the disadvantages of residing in informal settlements in the context of the impact of AIDS (SANAC, 2007: 30-32). These interconnected issues include unemployment, and inadequate and poor public health education. Furthermore, the NSP highlights that cultural attitudes and practices, which may compound HIV infection, is an under-researched area (SANAC, 2007: 31). Some cultural and traditional practices that include piercing with unsterilised instruments, male dominance and women subservience have been identified as determinants of the epidemic in South Africa. Research has shown that HIV prevalence in informal settlements is almost twice as that in urban formal areas (13.9% higher) (SANAC, 2007: 32). It is argued that the factors envisaged stemmed from "social fragmentation" that may increase the unsafe sex practices including inadequate housing, and aforementioned poor health facilities (SANAC, 2007: 32). The Du Noon and Doornbacht communities show evidence of some of the issues highlighted by the NSP. These will be discussed further in the next chapter.

The treatment, care and support plan within the NSP aims to provide national and equitable treatment and strengthening of health systems (SANAC, 2007: 45). A key aspect in this plan is the provision of antiretrovirals and nutritional supplements as well as the training of health personnel and community workers, including refurbishment of health institutions. Community home-based care and organisations have positively responded to the pandemic, which signalled a revitalised approach to the pandemic (SANAC, 2007: 45). However, in the Du Noon and



Doombacht communities there is evidence of insufficient personnel to respond to the growing number of AIDS patients as well as poor working conditions and health facilities. This will be discussed further in the next chapter. The document further mentions that South Africa has the largest number of people enrolled on antiretroviral therapy in the world even though there are still more people in need of this and related interventions to reduce morbidity and mortality from HIV and AIDS (SANAC, 2007: 45) This number should have increased had it not been for a delay in ART rollout in the country.

The second aspect of the NSP that is worthy of note is the priority areas that the SANAC has identified following a monitoring and evaluation system. There is not a clearly defined monitoring system for measuring levels of ART adherence alongside access to ART in this document. In reviewing outcomes of the NSP, certain areas form the basis of monitoring and evaluation. These include:

- The level of coverage of services for prevention, treatment, care, support and legal and human rights that has been reached
- The affected populations that are not being adequately reached
- The major obstacles in reaching these populations and the strategies that can be devised to overcome these challenges
- The resources that are needed to move significantly to achieve the goals of the NSP (SANAC: 105-109).

The aforementioned primary aims of the NSP and the areas of monitoring further show that there is not a clear plan to monitor AIDS patients' adherence among the aforementioned services provided. The NSP focuses more on access, even though not 100% as expected by the universal access plan that governments are encouraged to adopt.

## **2.5 The HIV/AIDS population projections for the Western Cape**

The Western Cape commenced ART rollout as early as May 2001 in spite of the government's procrastination (Nattrass, 2007: 165). In this regard, there have been success stories about the cooperation of the Western Cape government as opposed to the national commitment to ART rollout. Goemare, who was head of Medicines Sans Frontieres in South Africa stated that his working relationship with the Western Cape Government was the best he has ever had; whereas his relationship with the South African National Government was the worst (Nattrass (2007:



165). According to the *Projection Population for the Western Cape 2001 to 2025* (Dorrington, 2005), following the impact of HIV/AIDS, the Actuarial Society of South Africa (ASSA) 2003 model was adapted to correspond to the situation in the Western Cape.

Excerpts from one of the summary results show that ART is expected to have an immediate impact on the mortality of adults but the extent of this impact diminishes over time since ART is only expected to increase life expectancy by some five years on average (Dorrington, 2005: i). The graph (Figure 2) shows the projected impact of interventions on the number of people infected with HIV/AIDS. There will be an increase of close to 50,000 of those on ART between 2008 and 2014.

Number of patients on ART in thousands

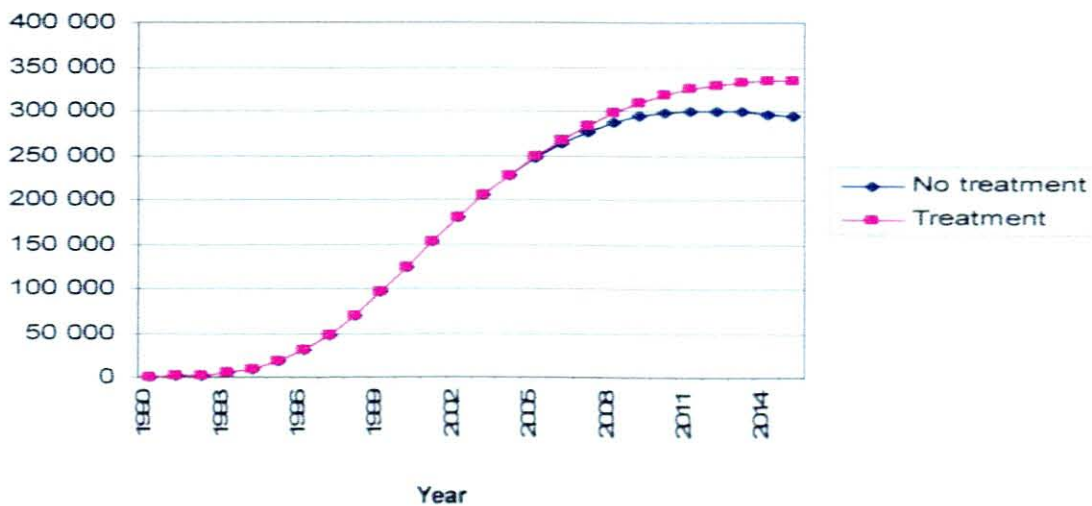
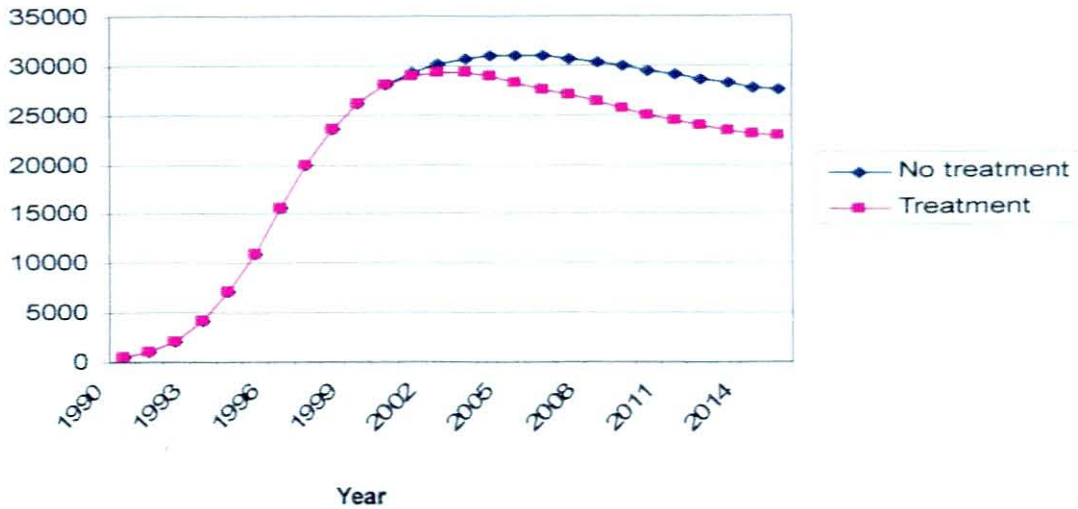


Figure 2 Impact of interventions on the number of people infected with HIV in the Western Cape (Dorrington, 2005: 17).

The next graph (Figure 3) shows the number of new infections per annum and project that with the increase of treatment, there will more decline of new infections since 2010 which will continue until 2014 if treatment continues.

**Number of new infections in thousands**

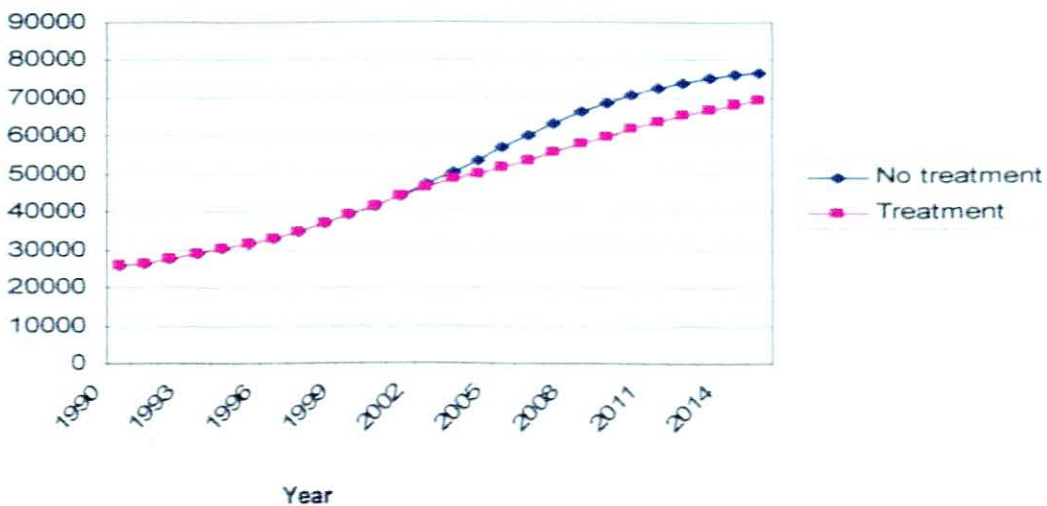


**Figure 3 Impact of interventions on the number of new infections per annum**  
(Dorrington, 2005: 15).

Conversely, there is a projection that there would be an increase in the number of deaths with those who are not on treatment (Figure 4).

These projections intimate that there would be a further decline in the infection rate (in thousands against the years 1990-2014) following continuing ART and there would conversely be an increase in the deaths if these treatments are curtailed. This resonates with scientific findings regarding the efficacy of ART (Tayler, 2004; Schneider, *et al*, 2007).

**Number of AIDS patients in thousands**



**Figure 4 Impact of interventions on the number of deaths**  
(Dorrington, 2005: 14).

However, these projections are based on expectations of a continuing availability to ART, including PMTCT. They do not include the projections of the adherence level of AIDS patients as well as the quality of service in resource-poor communities.

## **2.6 Cost and theories of safe use of ART in South Africa**

The cost of AIDS treatment remains one of the challenges to the effective fight of the pandemic in South Africa. The highest numbers of people needing ART are normally found in resource-poor communities (South African Health Department, 2006). Treatment of all those infected in South Africa may have cost the South African government over \$1 billion dollars according to the plan for treatment that was adopted in 2004 (However, this cost of treatment could save the lives of about 1.7 million people by 2010 if all those who need ART have access to it). Without adequate treatment of AIDS, this can cause the rise of 1.8 million orphans by 2010 (Schneider, *et al*, 2007) which may militate against the productivity of the future generation.

In response to the universal access to the ART Programme, the health budget of South Africa comes under scrutiny. Firstly, universal access to ART was clearly defined to understand the scope and its impact on the government's budget, which means that the government must be able to meet "100% ART coverage" (Schneider, *et al*, 2007) from the moment it was introduced in 2004 - not the levels achieved. It is stated that if this hypothetical stance of universal access were met, a cumulative 3.3 million people would remain in care by 2014 at an accumulative cost of \$12.5 billion. In addition, it is estimated that if the health budget was constant (in real terms) over the period, 16% and 47% of the budget would need to be allocated to the ART programme in 2006 and 2014 respectively (Schneider, *et al*, 2007: 9). With all indications, effective ART rollout may require 20% of the health budget by 2014 (Health systems and antiretroviral access, 2007).

However, it has been noted that the NSP stated 80% ART coverage by 2011. This may be as a result of the high cost of ART. In addition, because of inadequate facilities in PHC units, achieving 80% national access may be feasible. Nevertheless, weighing the cost of those who will not have access (theoretically, 20%) may not augur well for PLWHAs in the South African population.

On the other hand, the misuse of drugs is a common problem worldwide, not only in South Africa. Educationally disadvantaged communities as well as those with comparatively better

educational outputs have evidence of the misuse of drugs (Department of Health, 2002). Thus, even though ART is available, it can still be misused. With possible inadequate health facilities and the misuse of drugs coupled with limited trained medical doctors, insufficient care, and support mechanisms to monitor ART usage (Baggaley, 1998; Wilson & Blower, 2005: 133; Calmy, et al, 2004: 2353) the tendency for people needing ART but have it in short supply, may be encouraged to seek other means of treatment.

Qualitative studies in South Africa have shown shifts in the experiences of some people as they search for the cause of their disease and methods of treatment (Mills, 2006). People referred to as pseudo-scientists and/or African herbalists, now put forward new forms of treatments, which may be counter-productive to AIDS patients (Geffen, 2006, 2007; Kahn, 2005; Farber, 2006; Rath, 2004). In relation to the essence and starting of ART, the question pertaining to actual places of accessing ART is significant. There have been series of controversial healing strategies by "quack" doctors and healers who claim to possess medicines that cure AIDS patients (Nattrass, 2006, 2007; Geffen, 2006; Rath, 2004). Most recently, on the popular ETV show, "3<sup>rd</sup> Degree", presented by Deborah Patta, on 17<sup>th</sup> November 2009, discussions pointed to AIDS patients believing that they had access to a variety of areas and sources to cure AIDS what they believed cured AIDS from a variety of areas and sources. These include traditional healers/sangomas. Traditional and alternative medicines threaten the successful biomedical approach to AIDS treatment, "one which has seen an unholy alliance between the Rath Health Foundation and some traditional healers" (Nattrass, 2007: 233). Traditional healing has been part of the life of most African communities and post-modern theories have ushered in a rethink of development strategies in Africa, which reveals the significance of indigenous knowledge and have become a serious affront to Western forms of treatment in South Africa and Africa as a whole.

Drawing from this theoretical framework, as well as the misuse of drugs, the appropriate use of ARVs may come as a challenge to communities embedded in traditional healing forms (Kallon, 2008: 12). Previously, indigenous knowledge was seen as "obstacles to development" but now it is claimed by some that these are pivotal to discussions on sustainable resource use and balanced development (Briggs and Sharp's, 2004: 671).

## **2.7 Themes of poverty and unemployment in AIDS treatment discourse**

Alternative treatment and unsafe uses of ART are not the only challenges that face South Africa. Poverty and unemployment are two themes that run through the literature of AIDS treatment in South Africa. A look at a poverty and unemployment model, Scott (2003) sheds some light on possible interventions to help disadvantage communities, (such as Du Noon and Doombacht) to maintain good adherence. This model shows that an engagement with communities about their needs can be useful to facilitate better outcomes regarding service delivery in the context of ART rollout. Even though the clients did not mention that they kept their CD4 count low to access continuing disability grants, further discussions with community health workers revealed that some clients deliberately refused to take their ARVs accordingly because they wanted to be eligible to apply for disability grant.

The South African government acknowledged how inadequate the local government policy was in terms of addressing “anticipated levels of development” (Nel & Binns, 2001: 355). Two of the key issues that precipitated this policy and legal processes were to salvage the high employment rate within local communities and to promote social and economic development. Scott’s (2003) model firstly outlines a school of thought on measuring unemployment and poverty. Poverty has been poorly measured over the years (Table 1). This may have hindered a clear approach to design strategies to address continuing problems in disadvantaged communities. He summarised a metamorphose nature of poverty and how it can be measured at the turn of the new millennium. The fourth measurement of poverty looks at sustainable livelihoods and the conceptual model is the emphasis on multi-dimensional aspect of poverty which is to develop human capacity and service delivery. In the framework of adherence to ART, the improvement in the service delivery and development of human economic capacity to provide for themselves, may alleviate the desperate economic situation of AIDS patients who hinge on grants from government that may not even offset the expenses of their basic needs.

1. Income-based kind (widely used)	2. Basic needs (1970s)	3. Social Exclusion (1980s)	4. Sustainable Livelihoods (1990s)
<ul style="list-style-type: none"> <li>• Unemployment rates</li> <li>• Income levels</li> <li>• Expenditure levels</li> <li>• Proportions of population below defined poverty lines</li> </ul>	<ul style="list-style-type: none"> <li>• Availability of social and physical infrastructure → hospital services, pipe borne water supply, proportion of formal housing</li> </ul>	<ul style="list-style-type: none"> <li>• Maintain Political and cultural norms → spatial arrangement, immigrant employment, access to water and fuel, gender parity</li> </ul>	<ul style="list-style-type: none"> <li>• Economic and environmental sustainability → enhance the asset bases of the poor, prioritize needs, monitor levels of alcoholism, rape statistics, housing delivery, quality of housing, etc.</li> </ul>
↓ Conceptual model	↓ Conceptual model	↓ Conceptual model	↓ Conceptual model
Emphasis on money → wages, grants, subsidies, etc	Emphasis on meeting specific needs such as housing, services, basic health facility, educational and transport facilities	Emphasis on things not satisfied by money → institutionalized racism, sexism, marginalization, etc. Policy focus must address such issues.	Emphasis on multi-dimensional aspect of poverty → develop human capacity and service delivery

Table 1 Conceptualisation of poverty and unemployment over the past four decades

Scott (2003) explains that, 'percentage population in housing' against 'average household income' as against 'rate of tuberculosis infection' against 'annual incidence of rape', could quite well lead to very different proposed strategies of intervention" (Scott, 2003: 490). This aspect leads us to Scott's (2003) concluding analyses, which presents a hybrid or nuanced poverty indicator system. This hybrid approach issued to lead to what is termed "a composite index of indicators that is a collection of measures representing each approach" (Scott, 2003 491). Even though there would be different interventions as well as possible contradictions, it would be helpful if it "implies a significant commitment with respect to poverty relief at the local administrative level... [and use] a paradigm that is both participatory and transparent" (Scott, 2003: 492).

These issues lead to developing a framework of indicators, which would incorporate:

- process of poverty and outcome oriented
- viewing poverty from the perspective of the poor
- inputs that are data specific and sensitive to imbalances in power
- encourage integrated management with emphasis on communication between tiers of government and comparisons between localities

This participatory approach to development, some studies have outlined, is the essence of community-based and participatory approaches to HIV prevention and treatment. Wyk, et al, (2006:11), examine the crucial role communities play in addressing social and health problems. It emphasises a bottom-up approach and understanding of a particular commodity's behaviour on certain phenomena. Drawing from several other sources, the author indicates "participatory programmes draw on the active participation of members of the community in the implementation of the intervention (e.g. [AIDS] peer educators) or some or all the stages of development and implementation..." (Wyk, et al, 2006:11).

Scotts' (2003) model portrays a sound reference for addressing high employment and poverty, where community stake holders actively participate in solving problems, including the impact of AIDS in their respective communities.

## **2.8 Scientific and non-scientific controversy of AIDS causation and therapy in South Africa**

Peter Duesberg and David Rasnick were part of the Presidential AIDS Advisory panel that met on two occasions (Presidential AIDS Advisory Panel, 2001). This group of AIDS denialists substantiates their presentations from scientific research. Rasnick claimed that the use of ART can be toxic and can have adverse effects on the natural immune response to HIV (Presidential AIDS Advisory Panel, 2000). Baker (2000), a specialist registrar in infectious diseases and HIV, maintains that providing ARVs to PLWHAs in Africa may not reduce the spread of AIDS; it is likely that these drugs can even compound the ailment. One of his reasons for such a declaration was that people who are infected with the virus would not be able to take the drugs appropriately. Therefore, it would be necessary to emphasise prevention rather than treatment. However, in 2006, 82 HIV activists, medical doctors and scientists appended their signatures in a letter addressed to President Mbeki stating that "ARTs are the only medications currently available that alleviate the consequences of HIV infection" (Letter to South Africa's President Thabo Mbeki, 2006).

On the other hand, public/popular controversial debates on AIDS treatment are worth noting. Geffen (2007) expounded on the wide media coverage the views of denialists have enjoyed, which may have had a far-reaching effect on the choices people would have to make about what causes AIDS and the best forms of treatment for AIDS. Instances of denial cases and

proponents of the new treatment that received media attention and coverage include that of the Van der Maas' Africa concoction for the treatment of AIDS patient, Chrisella Kamanda on Kaya FM as well as David Rasnick and Sam Mlilongo's views widely published in the Citizen. It was purported that these media organisations have many subscribers to their programmes and publications and thus can affect the views and perceptions of people regarding the cause of AIDS and treatment.

## 2.9 Political denialism and the discourse of AIDS Treatment

Gevisser refers to Mbeki's use of "unsolicited dossiers from two determined South Africans urging him to rethink the paradigm driving his government's fight against AIDS" (2007: 727). He also expresses the view that Mbeki was influenced by the "paradigm" shift where Africans have to do things differently (Gevisser, 2007: 727). Some contents of Mbeki's letter to world leaders tend to comply with this analysis which states that: "*Accordingly, as Africans, we have to deal with this uniquely African catastrophe ... We will not ourselves, condemn our own people to death by giving up the search for specific and targeted responses to the specifically African incidence of HIV/Aids*" (Mbeki, 2000).

Mbeki's statement about "*...not giving up the search for specific targeted responses to the specifically African incidence of HIV/Aids*" highlights the aspect of traditional medicine that was propagated by his Health Minister, Manto-Tshabalala Msimang (Nattrass, 2007, Kallon, 2008). Even before these assertions, traditional healing methods have been part of the social and cultural life of many South Africans. The Health Minister, Manto Tshabalala-Msimang on the other hand urged AIDS patients to "take lemon, garlic, olive oil and African potatoes to boost their immune systems..." (Nattrass, 2007: 133) and maintained that the Health Minister was reluctant to allow the expected HAART rollout in spite of its economic advantage on government revenue. It was only after "bruising TAC [Treatment Action Campaign] civil disobedience and a cabinet revolt in 2003 that the government committed to a HAART rollout" (Nattrass, 2007: 5). The Health Minister also "failed to spend the resources allocated to her by the Finance Minister for this purpose" (Nattrass, 2007: 6).

Following the attitude of the former Health Minister (now deceased), there appeared two theoretical strands. Firstly, influencing AIDS patients to take other forms of treatment poses a health hazard in the context of the impact of the AIDS in South Africa. Secondly, the unspent resources allocated for ART rollout also exacerbates the problem of AIDS patients not only taking wrong treatment but not having access to adequate ART rollout.



Trying to unravel some of the possible reasons for Mbeki's questioning of AIDS science, Natrass (2003) initially thought that it was because of the high cost of ARVs. As highlighted, the cost of ARV rollout appeared to have severe economic implications for government revenue and "Mbeki's critique of AIDS science [was perhaps] a political smoke-screen to disguise a hidden economic calculus" (Natrass, 2007: 4). However, research revealed that the government could "save" more if there was the expected rollout of ART modified because there would be a higher cost to treat AIDS patients (Natrass, 2003: 5). This argument was supported (Robins, 2004) as a result of the reduction of drug prices, which showed that HAART rollout was economically feasible (Natrass 2003: 5).

Conversely, other analysts claim that during Mbeki's reign the media and some AIDS activists have handled some of the issues regarding AIDS badly. Roberts (2007: 180-181) claims that Mbeki has never been an AIDS dissident and has maintained that the Finance Minister under Mbeki's reign allocated R1.7 billion to fight HIV/AIDS in 2007 and an anticipated budget of R5 billion in 2009/10. (Roberts, 2007: 186).

These controversial discourses of AIDS treatment both scientific and non-scientific may have confused and influenced a significant number of people regarding the best option for AIDS treatment in South Africa (Kallon, 2008).

## **2.10 Conclusion**

As a result of these controversial HIV/AIDS discourses in different forms, it is theorised that firstly, many people may have doubted the effectiveness of the ART rollout plan and HIV/AIDS policy throughout the first half and the beginning of the second half of the year 2000. Secondly, the perceptions of many, including AIDS patients may have been negatively influenced regarding ART's efficacy and ineffective ART rollout services. The extent to which this discourse has affected AIDS patients' knowledge of ART's efficacy and their level of adherence in the target population will be investigated. It is worth considering how this confusion surrounding the virus that causes AIDS and the kinds of treatment has filtered down to AIDS patients in South Africa. How have these controversies influenced their perception or their attitude to ART? Do AIDS patients refer to some statements of denialists as true? Do they think indiscriminate sexual intercourse without condoms is risky? According to what they have heard from dissidents, are there other ways to treat AIDS patients apart from ART? These thoughts inform the broader research questions for the first part of the survey to understand AIDS patients' accessibility to

ART as well their understanding of ART's efficacy. As stated in the objectives, an understanding of AIDS patients' access to ART will be measured alongside determining their knowledge of ART's efficacy, and assessing the quality of service at the Du Noon Clinic and level of adherence to ART.

## **CHAPTER THREE**

### **Methodology of the study**

#### **3.1 Introduction**

The study involved a combination of quantitative and qualitative research methods. The study design was descriptive. Qualitative research complements quantitative surveys to understand complex social phenomena, such as HIV/AIDS where HIV positive patients do not always feel comfortable to speak about their experiences. Quite often qualitative studies precede quantitative surveys to inform the proper designing of questions (Bauman & Adair, 1992). However, in this study, apart from a pilot study that included a brief qualitative interview, the qualitative method followed the quantitative one because the research team needed to gain further understanding of certain phenomena rather than informing the designing of a structured questionnaire. This chapter explains a detailed process of both the quantitative and qualitative methods undertaken in this study. It also gives demographics of the target population and health situation of the target population.

#### **3.2 Pilot study**

Several visits were made to the study areas, Du Noon and Doombacht, to understand certain socio-economic and behavioural patterns of potential respondents. A brief interview was conducted with one of the nurses in charge of the ART rollout programme at the Du Noon Clinic that serves both Du Noon and Doombacht. A pre-testing of survey questions with a small sample of AIDS patients at the Du Noon Clinic was also conducted. These visits were also geared towards establishing a good relationship with community health leaders in the area, as they work directly with AIDS patients, in order to gain smooth access to the information needed for the study. Respondents' understanding of questions and honesty in reporting their experiences help researchers collect reliable sources (Meriwether, 2001).

The first step in the pilot study was to make contact with the nurses in charge of the rollout programme at the Du Noon Clinic and have a brief discussion regarding the structure of the ART rollout programme. Responding to some questions drafted about the access and adherence to ART, the nurses explained about the start of the ART rollout programme in Du Noon, the number of clients that come for treatment on a daily and weekly basis, and their attitude towards

treatment. In this interview, it was initially revealed that the health of most patients improved since the start of the programme. This brief interview informed the designing of in-depth interview questions (Bauman & Adair, 1992). Some of the issues expressed by the nurses, such as the community health ART monitoring plan available at the Du Noon Clinic, informed the design of survey questions for AIDS patients. These included having the understanding of the length of time AIDS patients have been on ART and their present CD4 count, which to a large extent tells us about the improvement of the immune state of the clients. An agreed date and venue was reached for the in-depth interview.

The second step in the pilot study was to make contact with three community health workers and four AIDS patients to pretest focus group questions. These community health workers in the pilot study helped to locate potential respondents after the computer systematic sampling process of respondents for the study was done.

Two group discussions were held. The first discussion was to generate responses to the focus group questions and to identify any problems in the area of clarity and better wording (Bauman & Adair, 1992) with the community health workers. The second group discussion was done with four AIDS patients, who were clients of three community health workers. These discussions were also geared towards having an understanding about the educational standard of the potential AIDS respondents. This process helped the researcher to simplify some of the questions. In addition, suitable dates and times were agreed upon for those potential AIDS patients who were expected to fill in the questionnaires and hand them in. This was to ensure participation of the expected number of AIDS patients required for the study as well as adequate response to the questions (Meriwether, 2001).

Finally, each of these community health workers had two volunteers among their clients to fill in the structured questionnaire for the survey part of the study. Each of the questionnaires was filled in and was collected at an agreed date. The responses to these questions helped the researcher understand that a self-administered questionnaire to respondents in Du Noon and Doombacht, who have not gone as far as tertiary education, can still answer the questions. However, some questions were not answered. When asked if they failed to answer a question because they did not understand it, they said no. It was mostly a case of not being sure of the answer, rather than not understanding the question.

It must be noted that the community health workers and one of the nurses in charge of the ART rollout programme at the Du Noon Clinic also formed part of the participants for the actual focus groups and in-depth interviews respectively.

The pilot studies were done in December 2009 and the actual interviews were done on selected dates in January and February 2010 for the survey, focus group and in-depth interviews. Before explaining the sampling procedure and strategy it is important to have an understanding of the demographics and health situation of the target population.

### **3.3.1 Demographics of Du Noon**

Du Noon has a population of 9,036 people. The African population is the largest, which is 90% of the total population. The other groupings, namely Coloured, 9%, Indian/Asian and White, make up only one percent. Most (46%) of the population is between the ages 18-34. The educational level of most (73%) residents, who are above 20 years, falls between grades 1-12. More than half (53%) of the population is unemployed. Ninety percent of those employed earn less than R1, 700 per month (Statistics South Africa, 2001).

### **3.3.2 Demographics of Doornbacht**

Doornbacht has a population of 4,082, and 99% of this population is African. Sixty percent of this number is between the ages of 18-34. As it is with Du Noon, 73% of the population attained grades 1-11; 57 % are unemployed; and 84 % earn below R1,700 (Statistics South Africa, 2001).

## **3.4 Overview of health situation in target population**

Du Noon and Doornbacht are within the Blauwberg sub-district of the Western Cape and with an HIV/AIDS prevalence rate of 9% from antenatal attendees (Western Cape Department of Health, 2007). From the pilot studies it was discovered that there is a lack of adequate housing infrastructure in these populations, especially Doornbacht, which is usually referred to as a squatter camp. There are problems of overcrowding and alcohol abuse. Following from the problems identified in the NSP, these communities are struggling in the area of proper health facilities. There are limited or no skills training centres in Du Noon and Doornbacht to equip residents with required skills and knowledge to maintain healthier lifestyle. Furthermore, there is only one clinic in Du Noon that serves both the populations of Du Noon and Doornbacht. The

researcher has worked in these communities in the area of AIDS prevention and distribution of food and non-food items. He has seen evidence of families suffering from financial instability and poor nutrition among the aforementioned social problems.

Regarding ART, it has been established from the pilot studies that the rollout programme started at the Du Noon Clinic in August 2004 with only 15 patients (3 males and 12 females). By November 2009, the Clinic had about 1, 050 registered clients on ART.

### **3.5 Sampling and selection strategy for the survey**

A systematic sampling of 124 clients on ART from a computer-generated list of 1,050 AIDS patients on ART in the Du Noon Clinic that serves AIDS patients in Du Noon and Doornbacht was done. The sampling procedure was two-fold.

The first procedure was purposive as each of the participants must had to be HIV positive, had to have developed AIDS and be on ART. Purposive sampling is done when potential participants of a study have unique characteristics that may not be shared by everyone in the community (de Vaus, 2002c).

Secondly, a systematic sampling procedure was conducted. From the clinic list, a number between 1 and 9 was randomly selected. Number 2 was selected and this represented that the 2<sup>nd</sup> patient on the list was selected and thereafter every ninth patient was selected in accordance with systematic sampling. This brought the number to 124 from a list of 1050 AIDS patients on ART. This sampling procedure was suitable for the study as there is evidence of homogeneity in that residents of the two communities share similar socio-economic and health factors.

Thirdly, with the help of the TB coordinator and community health workers, the 124 potential respondents were contacted by letter and consent forms, indicating the purpose for the study methods of the interviews and assurance of participants' anonymity and confidentiality (see appendices for details of the cover letter and consent forms).

### **3.6 Sampling and selection strategy for focus group discussions and in-depth interviews**

Firstly, the respondents who were contacted for the survey were already informed that they would be part of the focus group discussions, having received cover letters and consent forms. Eighteen of these respondents volunteered to be part of the focus group discussions. With the

help of the TB coordinator and community health workers, another eighteen AIDS patients (who were not part of the 124) volunteered to be part of the focus group discussions. These eighteen AIDS patients formed part of the clientele that are serviced by the community health workers.

The community health workers, who had helped in contacting patients from the computer-generated list, also volunteered to be part of separate focus groups, as their experiences with clients would also be needed. In total, 11 community health workers volunteered to be part of the study and completed consent forms which assured participants' anonymity and confidentiality (see also appendices for details of the cover letter and consent forms).

Finally, the only two nurses in charge of the ART rollout programme were included to be part of the in-depth interviews as they had already volunteered to be part of the interviews when the pilot study was conducted.

### **3.7 Methods of data collection**

Methods of data collection used were two-fold:

The first method used for data collection was self-administered structured questionnaire. However, trained community health workers helped to administer questionnaires. The questions designed avoided double-barrelled words, loaded language or phrases that may carry misleading implications (Research in the Social Sciences, 2000). The survey aimed to understand respondents' knowledge of ART and ART's efficacy, their access to and adherence to ART, the quality of service at the Du Noon Clinic, the relationship between ART and their sexual habits, and of demographics. Respondents completed and submitted the questionnaires at an agreed date.

The second method used was focus group discussions as well as the in-depth interview. These qualitative methods for data collection help to lead researchers to the perceptions and experiences of people of certain phenomena across several groups with similar backgrounds (Krueger & Casey, 2000).

Six focus group discussions were done with six groups of six participants each. Four groups were members from Du Noon and two groups were members resident in Doornbacht. Focus groups were also done with two groups of community health workers. One group was made up of six participants and another group was made up of five participants. It is important to keep the

participants within a focus group small to prevent group fragmentation (Krueger & Casey, 2000). This is where people withdraw from participating in the discussion because the facilitator finds it hard to manage a large group. In-depth interviews were done with the two nurses in charge of the ART rollout programme in Du Noon. Each focus group discussion and in-depth interview followed a guided moderation/facilitation (Morgan, 1997) and a semi-structured question route. Each discussion was audio taped.

### **3.8 Inclusion criteria**

Following the purposive sampling procedure, chosen participants of the study were based on certain criteria. Participants who were

- adults (18 and above) and who were be able to communicate their own personal experiences without the help from other people
- AIDS patients that have started any kind of treatment, irrespective of ARV regimen
- able to communicate in English and/or Xhosa as the research assistant/interpreter understands and speaks these languages fluently
- community health workers who have at least one patient that they were currently helping with ART
- nurses currently involved with the ART rollout programme at the Du Noon Clinic

### **3.9 Exclusion criteria**

Those excluded from the study were

- AIDS patients who have not yet started any form of ART
- AIDS patients 18 years and above who are on ART but are too sick and unable to speak about their experiences
- community health workers who have not been involved in the treatment of AIDS patients
- nurses at the Du Noon Clinic who attend to AIDS patients but are not currently involved in the ART rollout programme



### **3.10 Data analysis**

The Statistics SoftWare for the Social Sciences (SPSS) 17.0 and Statistica version 9 were used to analyse and run tests on certain variables. In this regard, univariate and bivariate analyses were done. The software packages offered tools that enabled the researcher to present findings graphically and to test variables thus showing the relationships between them.

For the qualitative data, after manual transcriptions, the focus group discussions and in-depth interviews were analysed through computer-aided coding with the Nvivo software package (a software package that is used for qualitative data analysis) following the steps of grounded theory (Fielding and Lee, 1998). This process includes the assigning of labels or codes of bits of the data to specific categories leading to data fragmentation (Dey, 1993). Finally, these labels informed the development of relevant themes.

### **3.11 Limitations of the study**

The following have been identified as limitations of this study:

The study largely relied on the perceptions and experiences of AIDS patients about the progress of their immune system. No data regarding each AIDS patient's CD4 counts, length of time on ART and present CD4 count was accessed. Furthermore, the study does not show the different regimens, which may influence the increase of CD4 cells and AIDS patients' experiences of improved health and/or adverse effects.

Finally, both males and females were interviewed in each focus group interview. This may limit the study in the area of inability to collect relevant information because of gender disparity. For example, the males in the group may not be able to share certain experiences in the presence of their female counterparts. However, discussion questions were not gender sensitive.

### **3.12 Maximising validity and reliability of the study**

The following steps were taken to maximise validity and reliability of the study.

Focus group discussions were employed with similar questions (though unstructured) mainly requiring further details on important issues that were measured in the survey. These

discussions complemented survey findings because the researchers could probe some of the questions during the discussions which required further understanding and clarity.

With permission granted by all participants, all focus group discussions were audio taped. Participants were assured that the tape recorder was only meant for the accuracy of recording information. Another researcher who was not part of the discussions, helped to interpret these audio tape discussions for further understanding of the responses.

Participants interviewed had never met the researchers before. This allowed them to speak freely because the atmosphere was less intimidating. In addition, each group comprised of a small number of participants to prevent group fragmentation and confusion (Krueger & Casey, 2000; Morgan, 1997). In larger focus group discussions, there is the possibility of losing the participation of some the members of the group.

### **3.13 Conclusion**

The chapter explained detailed methodology of the study, which was both quantitative and qualitative, and described the demographics of the target area and respondents in the study. The systematic sampling procedure provided a good representation of the two communities. HIV/AIDS and other socio-economic problems may pose a threat to the productive life of these communities. This provides further rationale for conducting a study to measure the accessibility and adherence to ART in Du Noon and Doombacht.

## CHAPTER FOUR

### Results

#### 4.1 Quantitative results

##### 4.1.1 Demographics of respondents in the survey

There were more female respondents than males, which could mean that there are more females on ART that are accessing the Du Noon Clinic. Research has revealed that women are mostly infected by HIV/AIDS (World Bank, 2003; Clark, 2003). Most (over 70%) of the respondents fell between the ages of 21-40 (Figure 5). This also supports research findings showing that young adults are mostly at risk of HIV infection (UNICEF, UNAIDS and WHO, 2000) and other sexually infectious diseases (Clark, 2003). As most of the respondents are single, multi-concurrent sexual partners can be a crucial factor in the community (Clark, 2003)

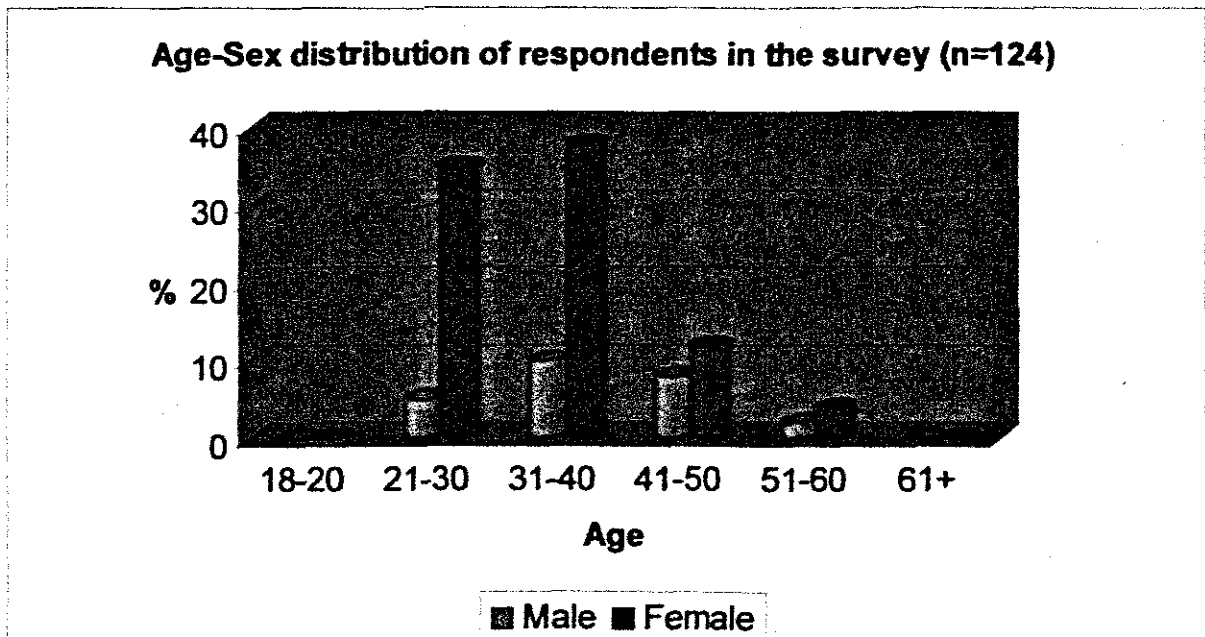


Figure 5 Age-Sex distribution of respondents in the survey

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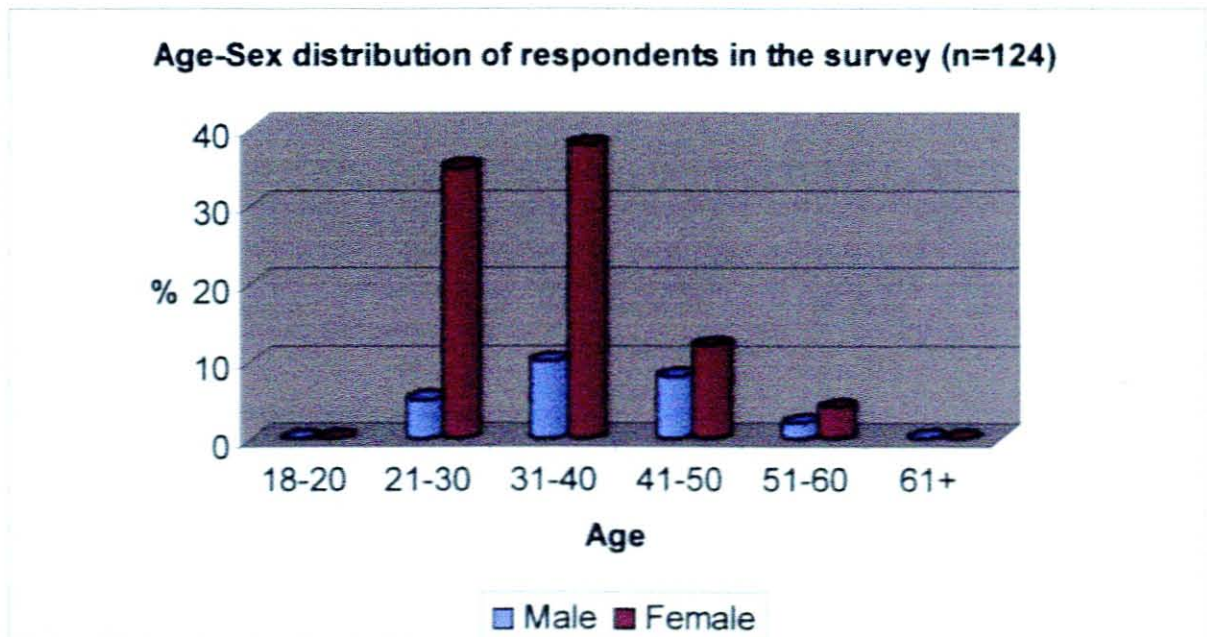


Figure 5 Age-Sex distribution of respondents in the survey

Seventy-three percent of respondents in the survey were single (Figure 6). Even though this does not mean that there may be indiscriminate sexual behaviour prevalent among this group of singles, research has revealed that unmarried youth/young adults are more prone to involvement in multi-concurrent sexual practices and sometimes lack the ability to have a safe sexual debut (Clark, 2003).

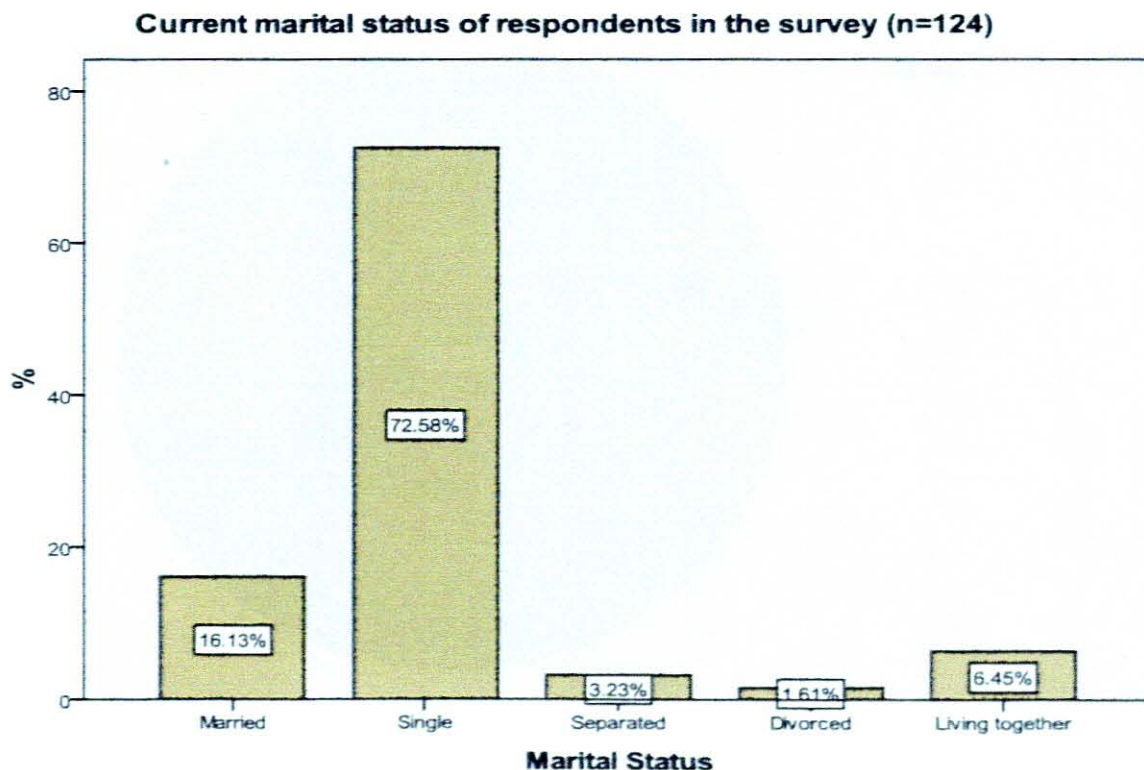


Figure 6 Current marital status of respondents in the survey

In the survey, over 90% of the respondents associated themselves with the black (African) population (Figure 7). This is not surprising as the demographics of the target population show that there are very small percentages of Coloureds, Indians and Whites in Du Noon and Doornbacht.

**Population group of respondents who participated in the survey (n=124)**

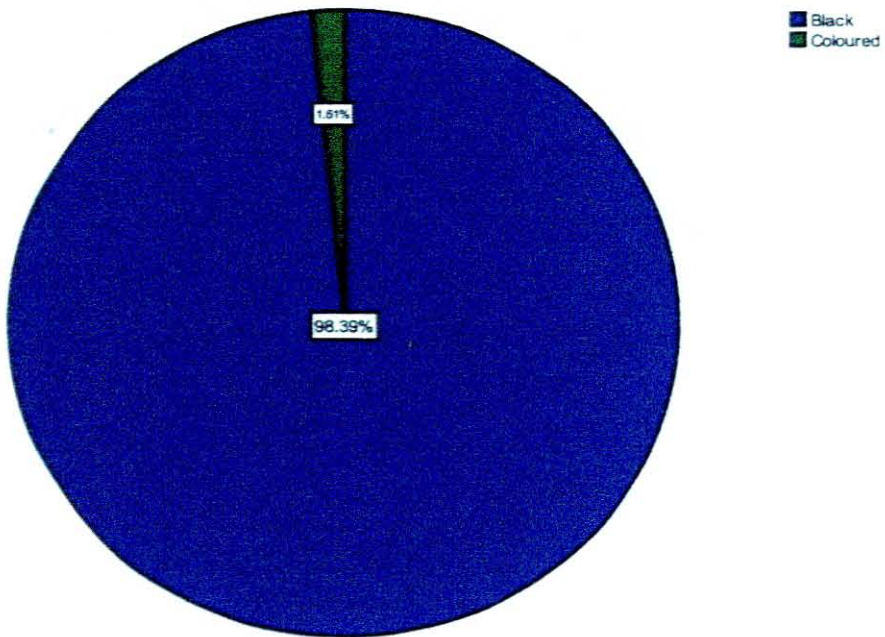


Figure 7 Population group of respondents in the survey



Seventy percent of the respondents in the survey were from the Du Noon community (Figure 8). Drawing from the demographics of the target population also, Du Noon has twice as many residents as Doornbacht.

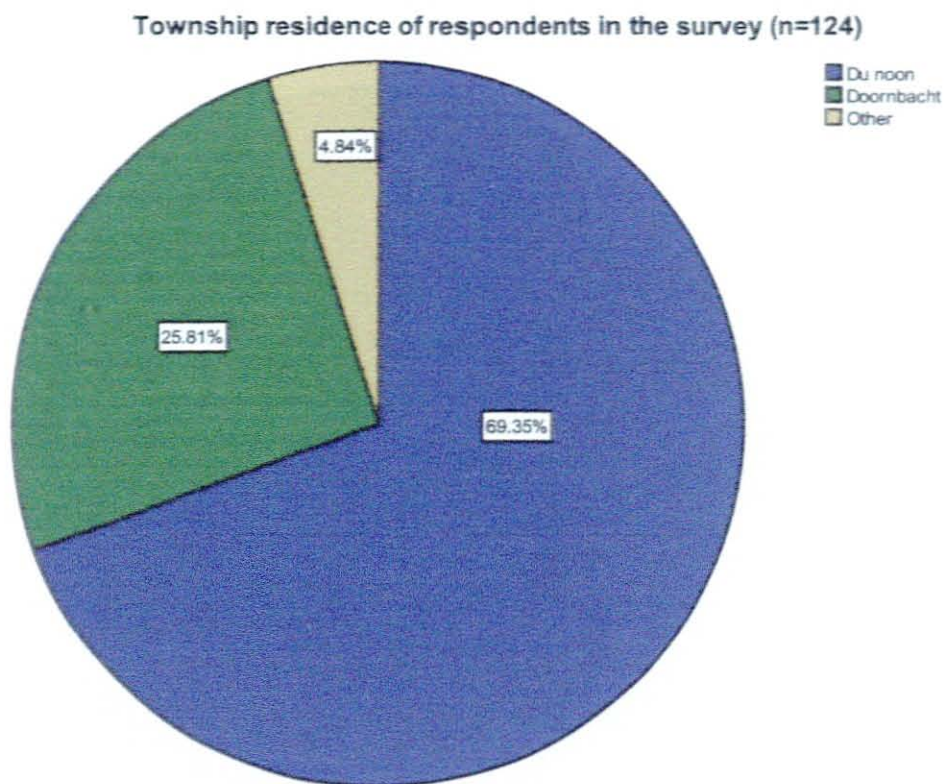


Figure 8 Township residence of respondents in the survey

Ninety-eight of the respondents were unemployed (Figure 9). These figures support the increasing unemployment rate in South Africa, which appears to be worst in resource-poor communities (Department of Social Development, 2004).

**Employment status of respondents in the survey (n=124)**

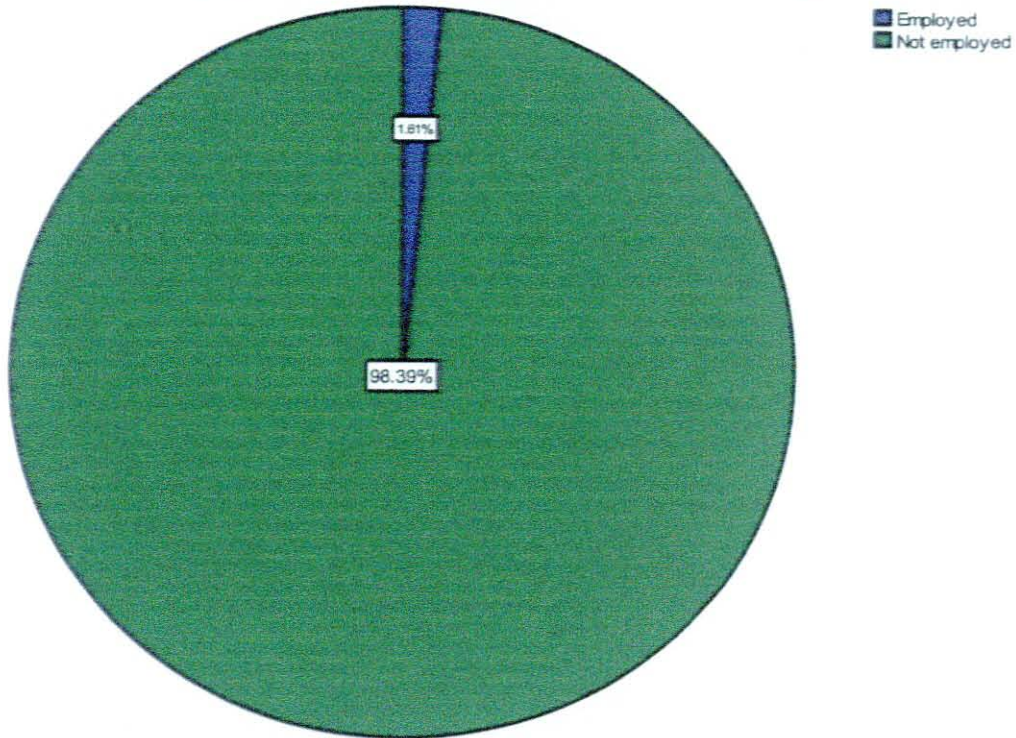


Figure 9 Employment status of respondents in the survey



The educational level shows that 53% of the respondents have completed secondary education (or Matric) (Figure 10). However, according to Statistics South Africa in 2001, most of the education population (over 70%) falls between grades 1-11.

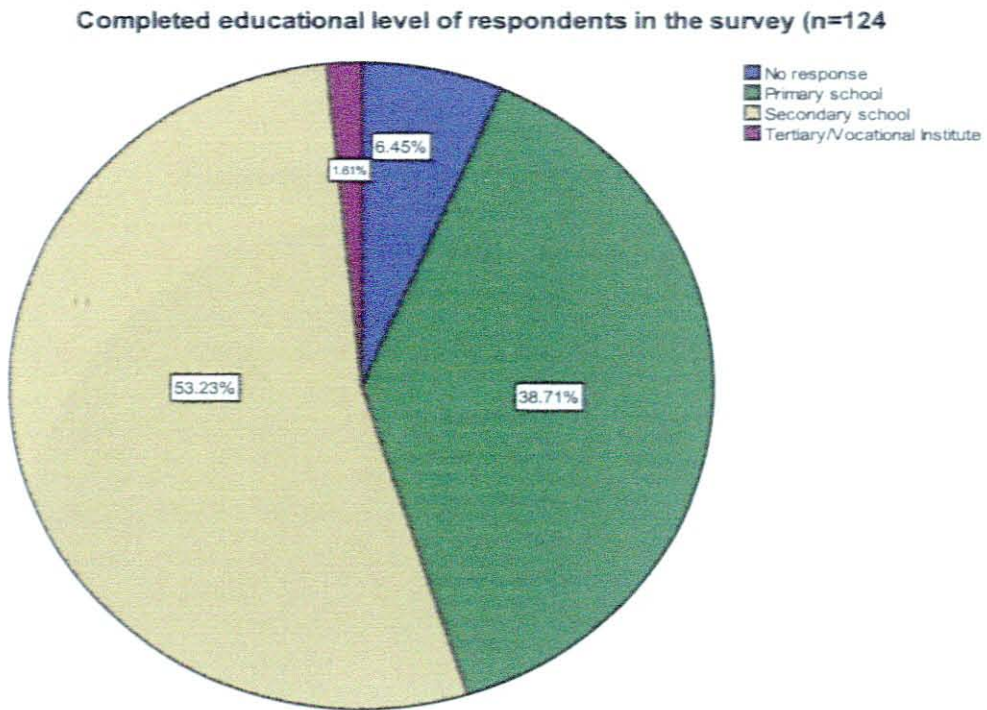


Figure 10 Completed educational level of respondents in the survey

#### 4.1.2 Availability of ARVs at the Du Noon Clinic

The pie chart below shows that 90% (n=117) of respondents reported that they access ART at the Du Noon Clinic all the time, although there were isolated cases reported by community health workers complained about not having received ART at a particular time when it was needed (more of this will be presented under qualitative results).

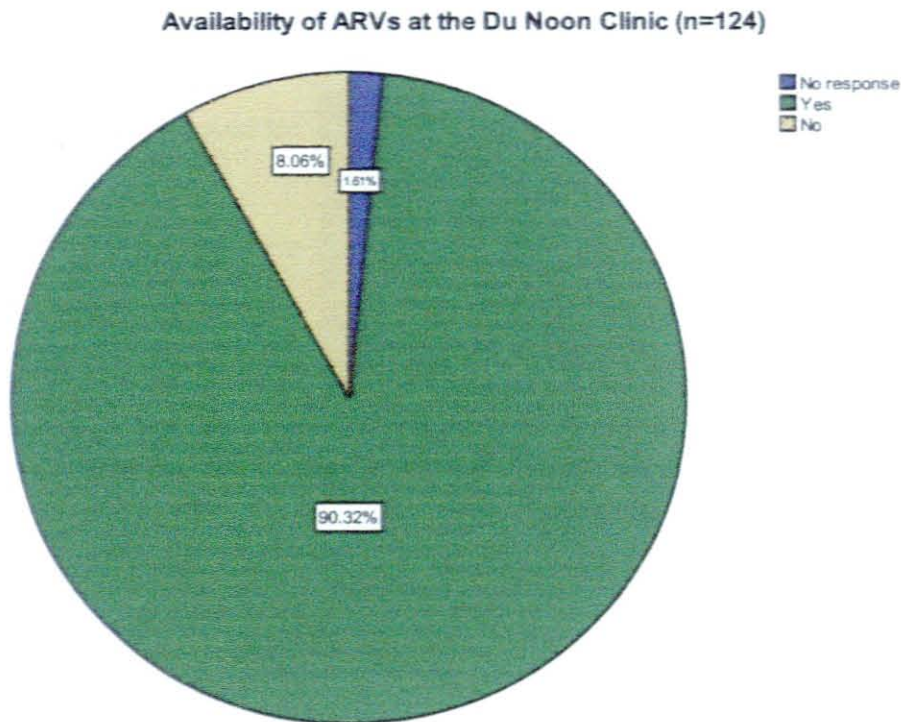


Figure 11 Availability of ARVs at the Du Noon Clinic

The total number of registered AIDS patients on ART at the Du Noon Clinic was 1050. The number of HIV prevalence of antenatal attendees in Blaauwberg (sub-district of Cape Town where Du Noon and Doornbacht communities are based) is 9% (Western Cape Department of Health, 2007). With an estimated number of 1181 HIV cases in 2009, of which 1050 AIDS patients are on ART, this figure projects an estimated 89% access to ART in Du Noon and Doornbacht. This percentage surpasses the established target of 80% of the NSP (2007-2011). However, it must be noted that Blaauwberg communities do not have high HIV prevalence among antenatal attendees compared to areas such as Khayelitsha with 37.2%, Nyanga with 28% and 18.2% in Central Cape Town, (Western Cape Department of Health, 2007).

#### 4.1.3 AIDS patients' knowledge of ART's efficacy and alternative AIDS treatment strategies

The graph (Figure 12) shows that 76% (n=94) of AIDS patients agreed that ARVs are the only scientifically tested drugs to treat AIDS patients and 81% (n=100) disagreed that ARVs can be used with other drugs that are not prescribed by the doctor.

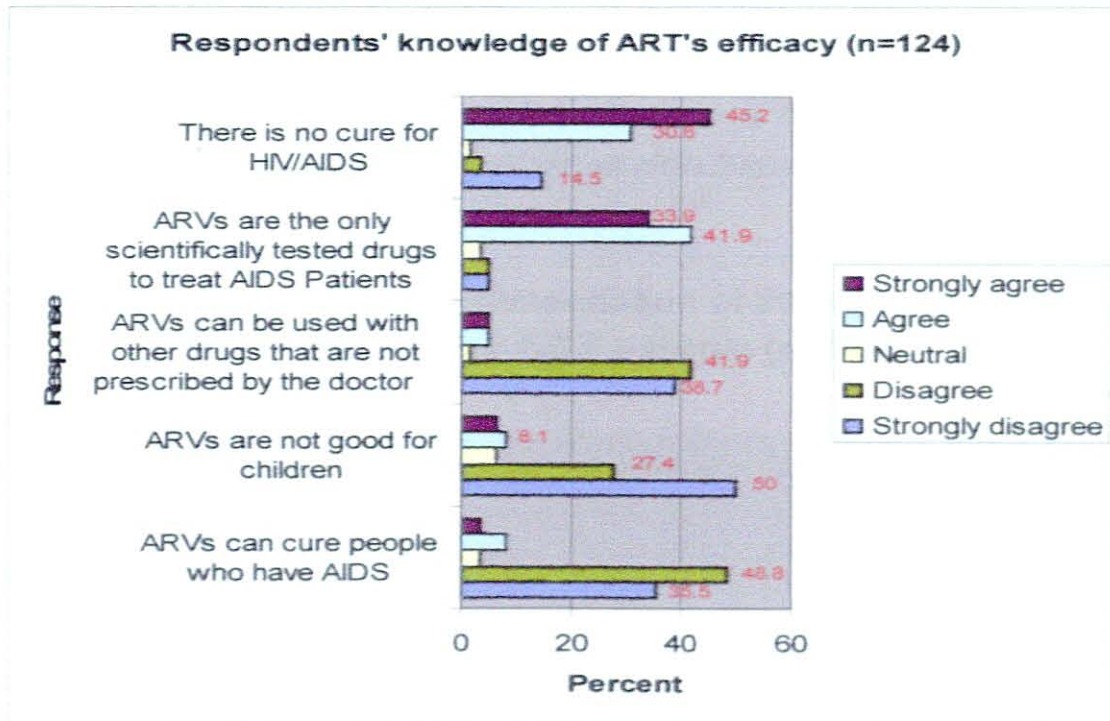


Figure 12 Respondents' knowledge of ART's efficacy



#### 4.1.4 The best form of treatment for AIDS patients

To gain further understanding on this phenomenon of the knowledge of ART's efficacy that forms a crucial aspect of the research, an open ended question about the best form of treatment for AIDS patients was asked in the survey. Sixty-five percent (n=80) of the respondents asserted that ARVs are the scientifically tested drugs to treat AIDS patients. However, 30% (n=37) of the respondents did not clearly state that ARVs are the best form of treatment. Nineteen percent (n=24) stated that the best form of treatment was daily treatment, probably assuming that the researcher understood that they were referring to ARVs. In addition, 11% (n=14) did not respond to the question and 12% (n=15) indicated different kinds of support mechanisms, such as traditional medicine and some biomedical, but not ARVs (Figure 13).

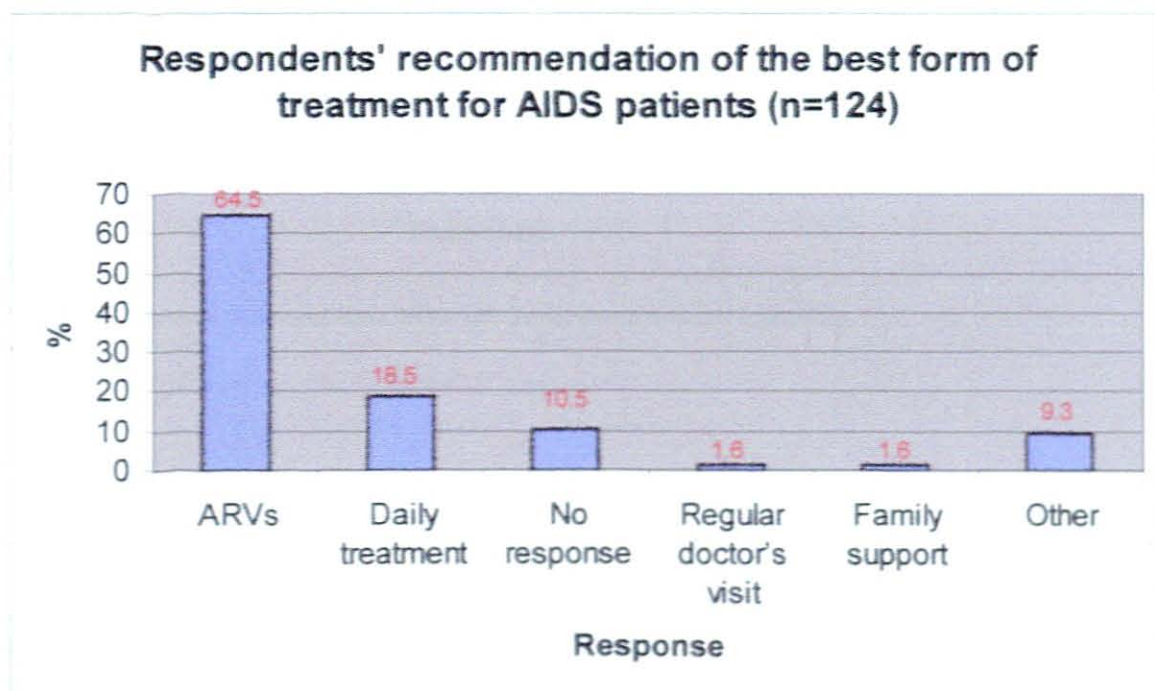


Figure 13 Respondents' recommendation of the best form of treatment for AIDS patients

#### 4.1.5 Areas of accessing ARVs

Respondents claimed that the suitable areas to access ARVs are at the clinic and Government hospitals. None of the respondents associated securing ARVs with any pharmacy in their areas, nor from traditional healers or sangomas (Figure 14).

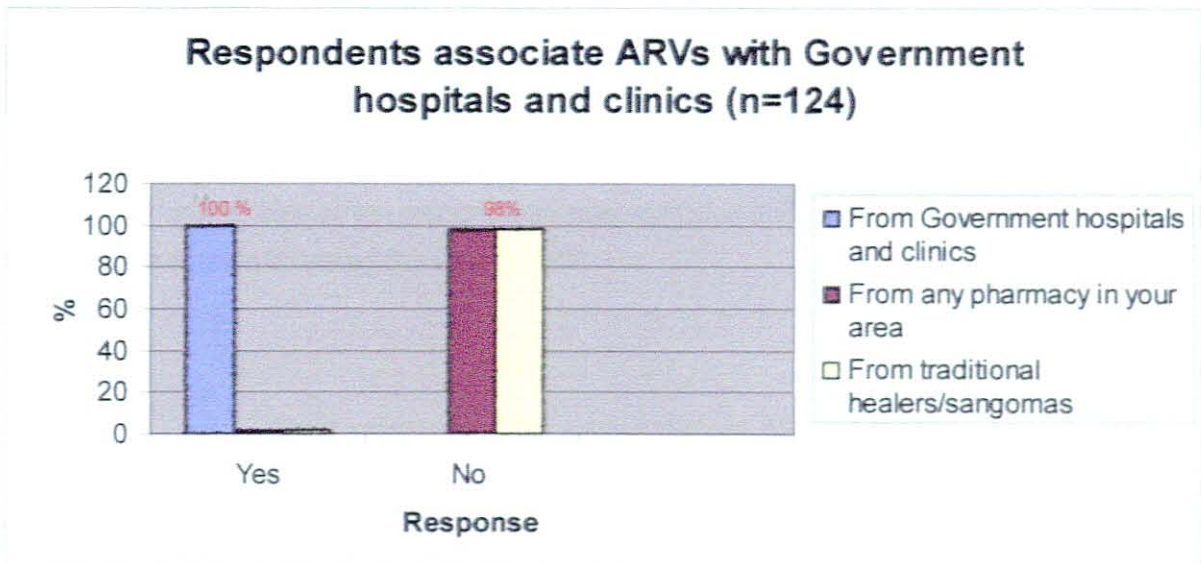


Figure 14 Respondents associate ARVs with Government hospitals and clinics

#### 4.1.6 Before and after ART and increase in CD4 count

Eighty-one percent (n=100) of the respondents reported that their CD4 count was low (200 *cells/ML* and below) before they started ART. The figures below (Figures 15, 16 & 17) show the level of CD4 count of respondents in the survey before starting ART, the length of time on ART and the present CD4 count.

Before starting ART, 70% of respondents (n=87) had a CD4 count of 200 *cell/ML* and below, 2% (n=3) had a CD4 count between 200 and 299 *cell/ML*, 10% (n=12) did not know the state of their immune system before the start of ART and 18% (n=22) did not respond to the question (Fig 15). In other words, 28% of the respondents may not have been able to monitor the progress of their immune system following the start of ART.

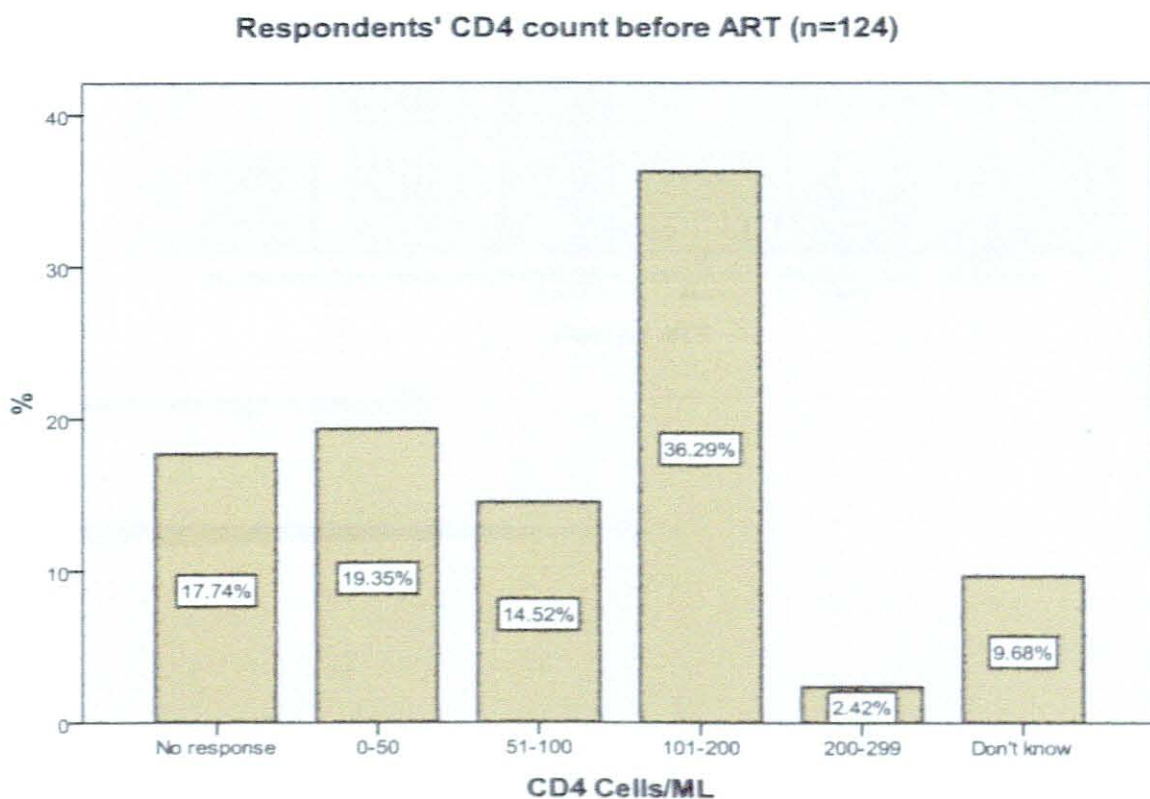


Figure 15 Respondents' CD4 count before starting ART

Fifty-five percent of the respondents (n=68) have been on ART for more than a year while 35% (n=43) have been on ART for less than a year. A total of 10% (n=13) either deliberately refused to answer the question or did not know the length of time they have been on ART (Figure 16).

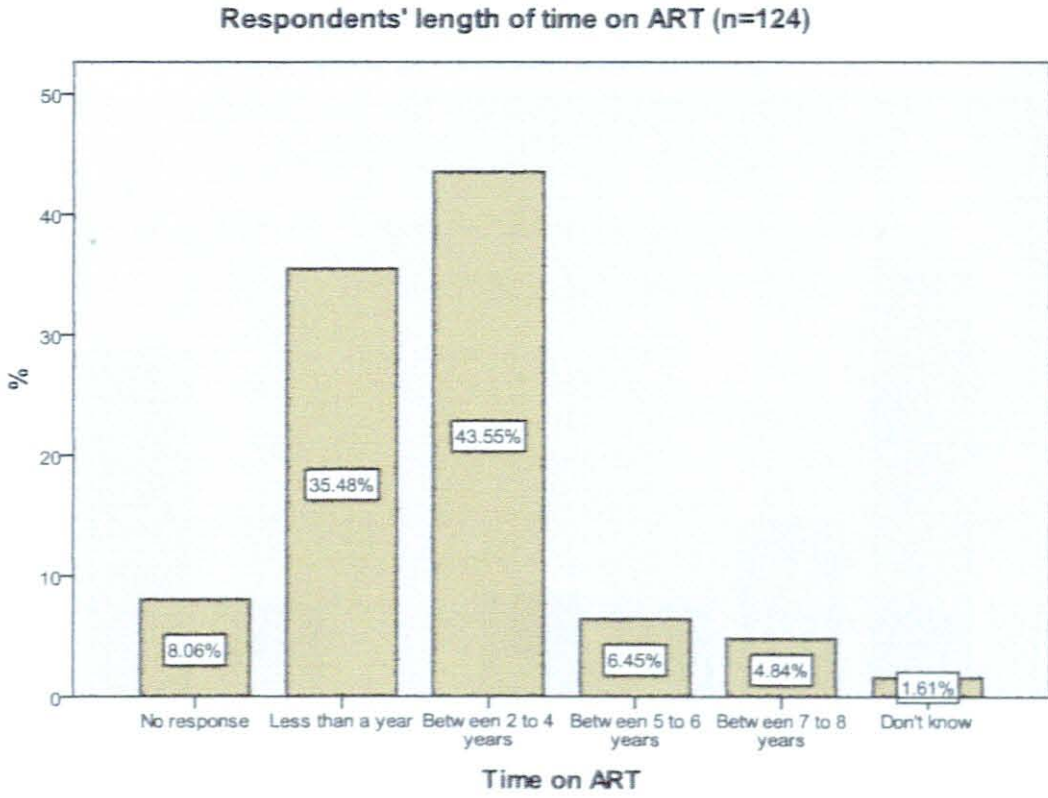


Figure 16 Respondents' length of time on ART



Fifty-four percent (n=67) have realised a CD4 cell increase of 300 above *cells/ML*, while 20% (n=25) at 200 CD4 *cells/ML* and below. Twenty-eight percent (n=32) did not respond to the question, which may confirm that a good number of respondents have not been able to keep track of the progress of their immune system during treatment.

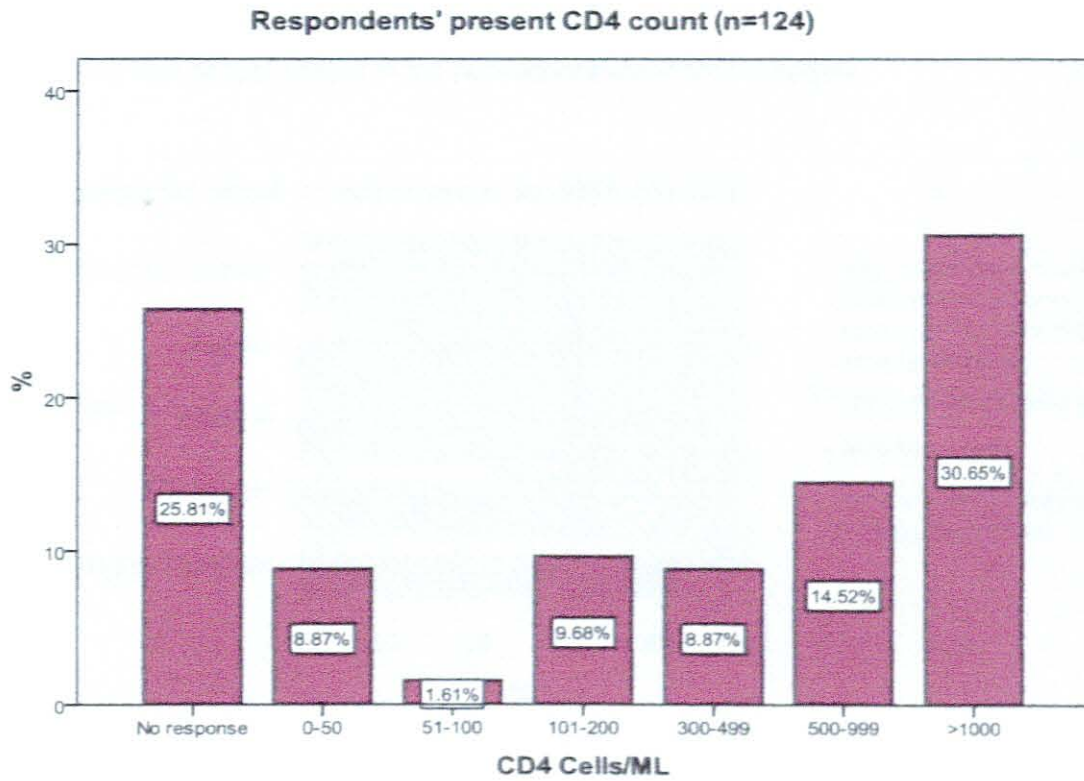


Figure 17 Respondents' present CD4 count



#### 4.1.7 AIDS patients' level of adherence to ART

Seventy-six percent (n=94) of the respondents reported that they took their ARVs daily and at designated times (Figure 18). Those who strongly agreed and agreed were categorised as the adherent group and those who were neutral and who strongly disagreed and disagreed were categorised as the non-adherent group. As has been established, ART is a daily form of treatment. Therefore, any patient that did not clearly affirm (in this case those who remained neutral) to adherence was placed in the non-adherence to ART category.

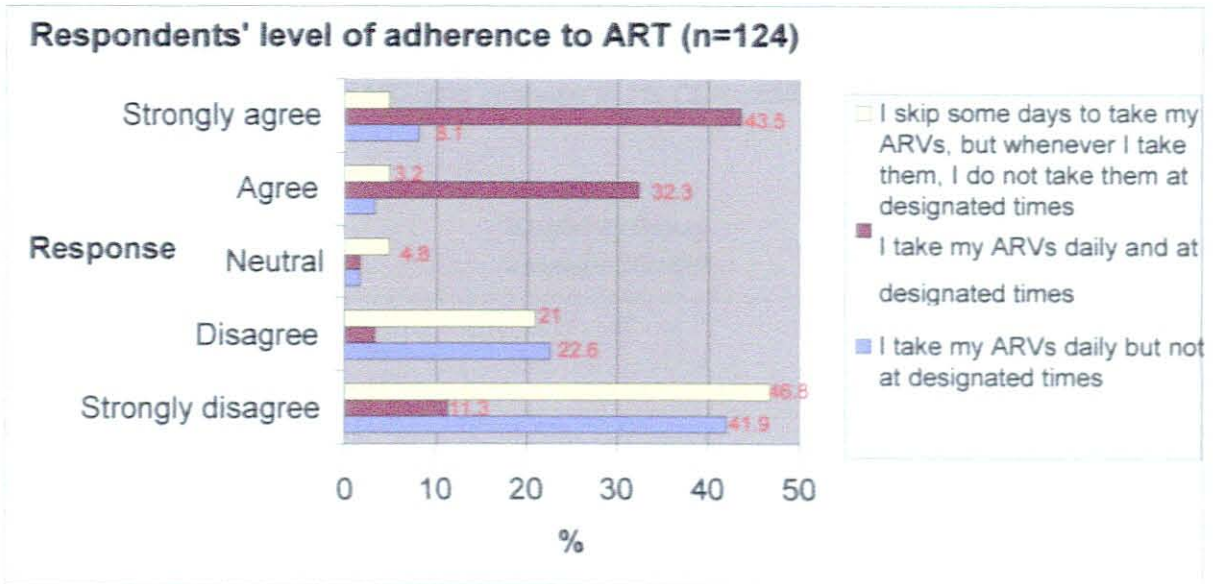


Figure 18 Respondents' level of adherence to ART

#### 4.1.8 A comparison of respondents who adhered to ART and those who did not adhere to ART and the difference in CD4 count (n=92)

AIDS patients that responded to all the questions formed 74% (n=92) of the total sample (124). The remaining did not respond to the three questions to measure the CD4 cells before ART, the length of time on ART and the present CD4 cells. Thus, they were not included in the Mann-Whitney U test that was done on the two groups, namely the adherent and non-adherent group to ART. Figure 19 shows that there is a higher percentage (75%) of those who adhere to ART than those who do not (25%). Consequently, there is a higher CD4 cell count with a maximum of slightly over 1000 cells/ML, by those who adhere to ART as compared to those who did not, and this falls below 800 ( $p= 0.01$ ). This result confirms that there is a strong relationship between good adherence to ART and increase in the CD4 cells.

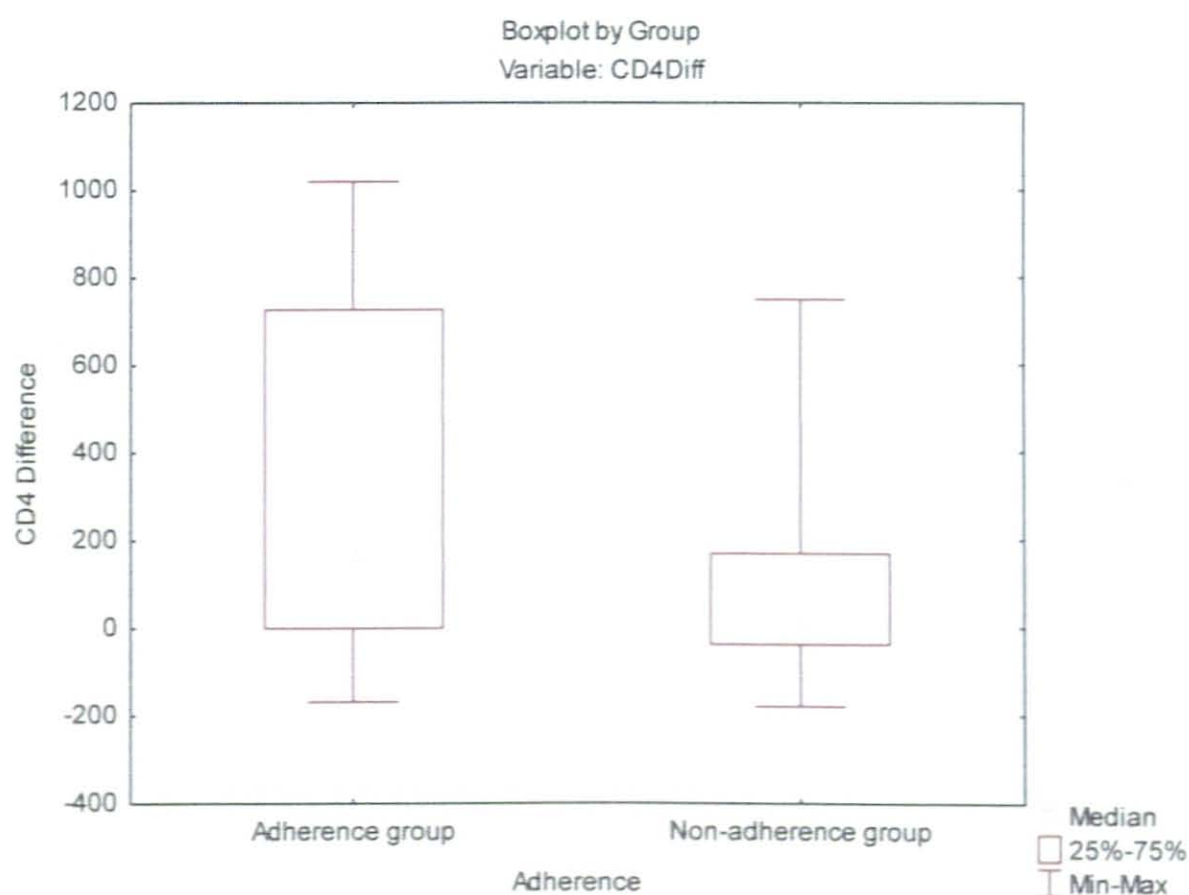


Figure 19 Comparison of CD4 count between adherent and non-adherent groups

#### 4.1.9 A comparison of the length of time on ART of respondents and the difference in CD4 count (n=90)

It has been noted that there are more respondents who have been on ART for over a year than those who have been on ART for less than a year (55% against 35% respectively) (n=112). Ninety patients (73% of total) responded to the three related questions about the start of ART, the length of time and the present CD4 count. Thus, they were the only groups involved in this the Mann Whitney test. The figure below (Fig 20) shows that those who have been on ART for more than one year have a higher CD4 count than those who have been on ART for less than a year (a maximum of 1000 CD4 cells against slightly less than 800) (p=0.00). However, it must be noted that those who have been on ART for over a year and have higher CD4 difference are those who adhered to ART (see Figure 21).

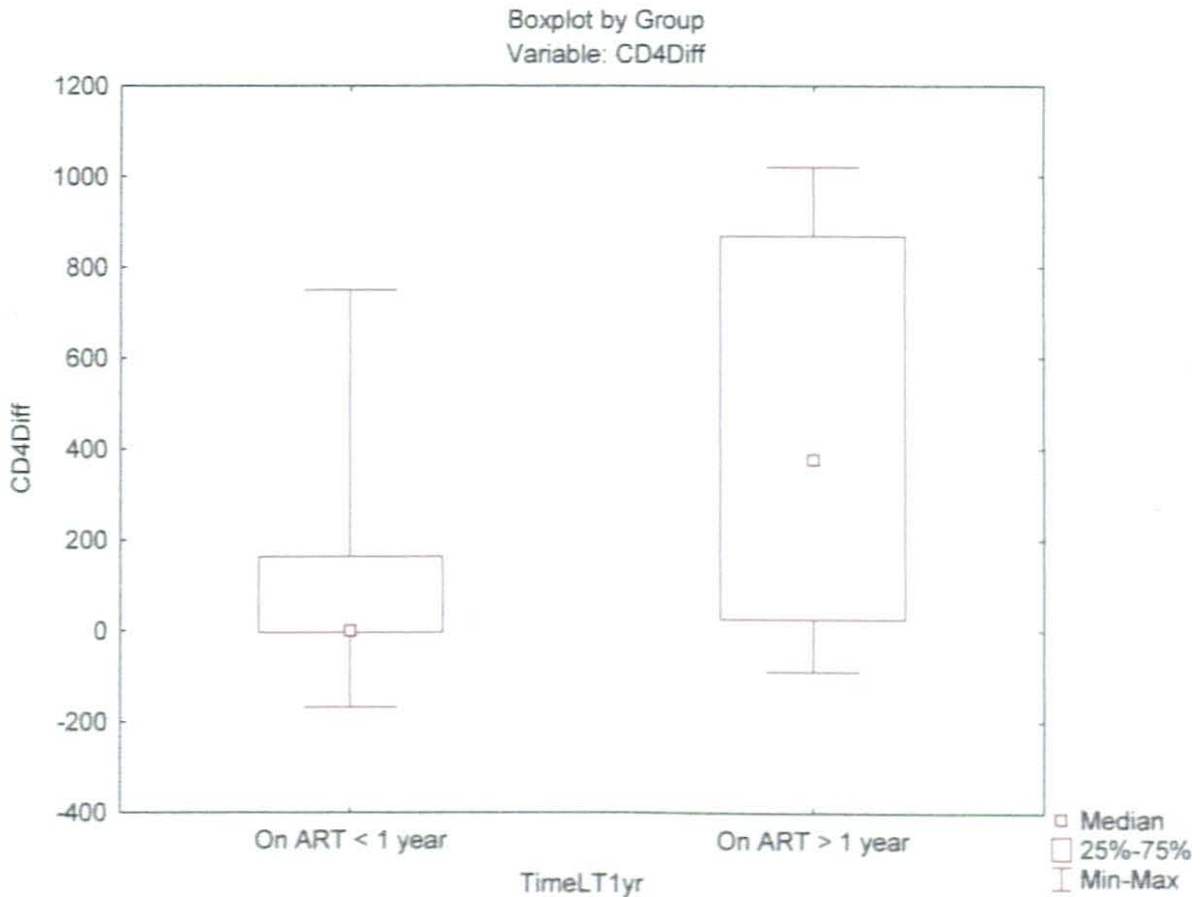


Figure 20 Length of time on ART and CD4 count difference

**4.1.10 The adherence level of those who have been on ART for more than a year and increase in CD4 count (n=52)**

There is a difference in the progression of CD4 counts of the two groups of AIDS patients who have been on ART for more than a year based on their level of adherence to ART ( $p=0.04$ ). The adherence group shows a maximum of 1000 CD4 cells as compared to those who also have been on ART for more than a year. This non-adherent group falls below 200 cells/ML, far below the present threshold of 350 cells/ML.

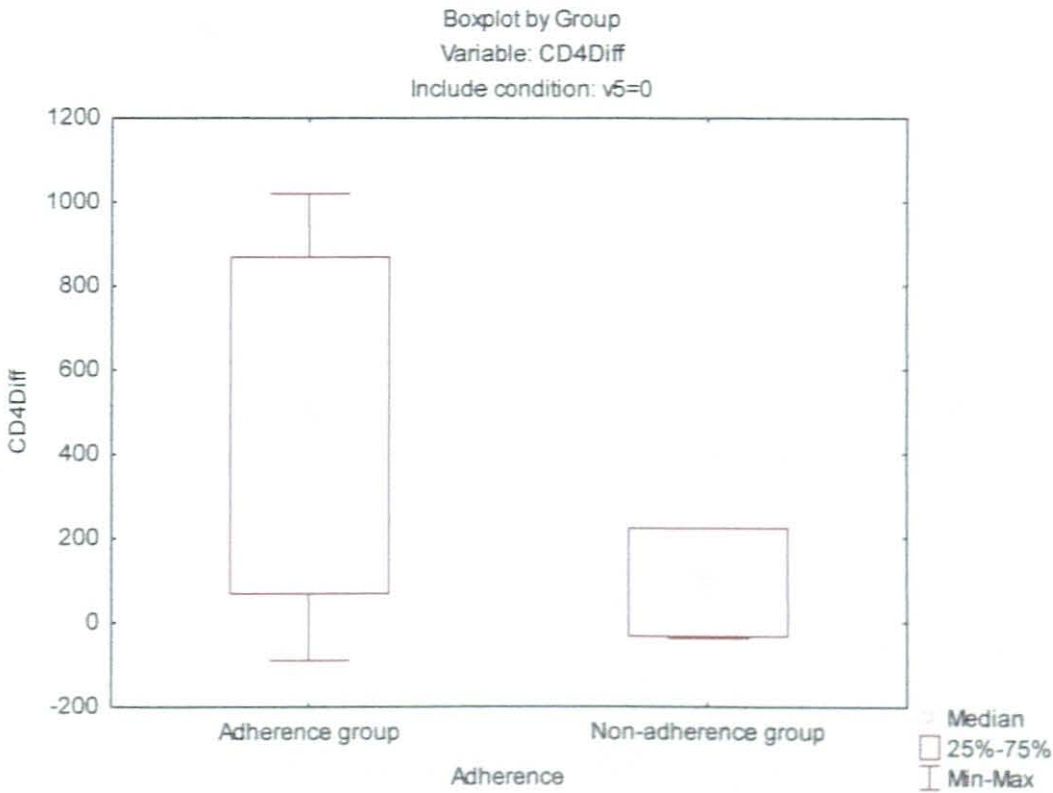


Figure 21 Comparison of CD4 count between adherent and non-adherent groups who have been on ART for more than 1 year



#### 4.1.11 Quality of service regarding ART at the Du Noon Clinic

The graph (Figure 22) shows the ratings of the quality of service regarding ART of patients at the Du Noon Clinic. In the survey, open-ended questions were used to understand the quality of service from the perspectives and experiences of AIDS patients. Sixty-five percent (n=81) of the respondents clearly stated that the service regarding their ART at the Du Noon Clinic was good. This response does not apparently inform us about the level of quality but it suggests that this percentage of respondents was satisfied with the ART programme including the behaviour of personnel in charge of the rollout programme. Eight percent (n=10) responded that the nurses were helpful and 3% (n=4) asserted that they get information and knowledge on ART. In other words, in total, 77% (n=94) of the respondents made favourable comments regarding the quality of service.

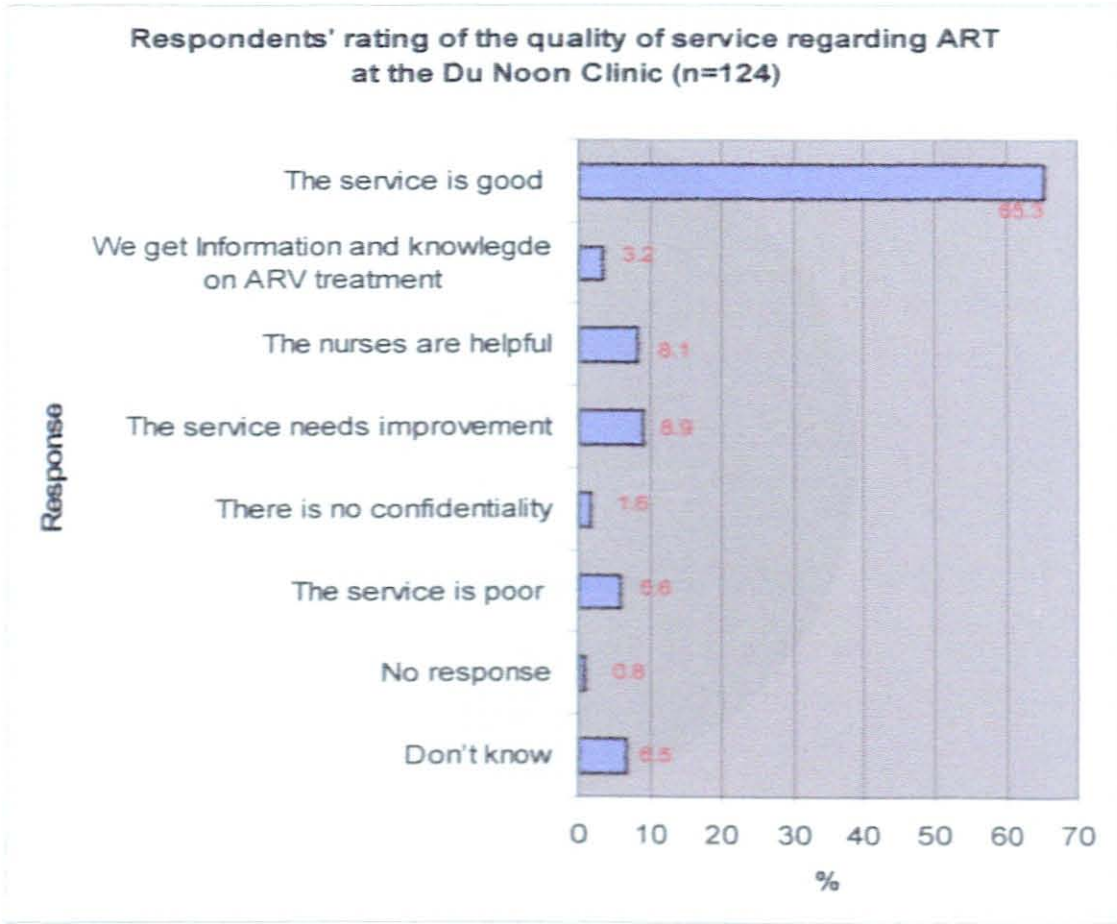


Figure 22 Respondents' rating of the quality of service regarding ART at the Du Noon Clinic

About 15% (n=18) of the respondents did not think that the service was good, hence responses such as “the service needs improvement”; “there is no confidentiality”; “the service is poor” and 7% (n=9) of “no responses”. It is difficult to gain a clear understanding of the actual meaning of these responses from the survey results. However, the focus group discussions provided further insight on the 15% respondents who were not sure that the quality of service was good. More of this will be presented in the qualitative results section.

#### 4.1.12 ART and sexual behaviour

Those that were questioned if they were on ARVs and sexually active, 48% (n=61) of the respondents said yes and the remaining (48%) said no. Only about 3% (n=2) did not respond to the question (Figure 23).

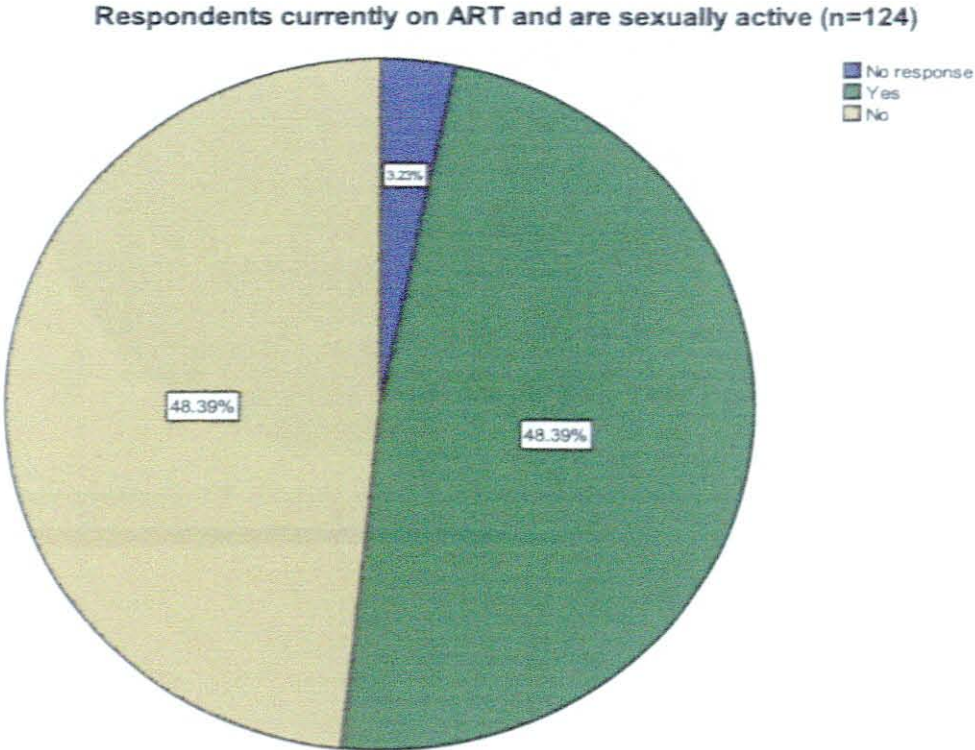


Figure 23 Respondents currently on ART and are sexually active

AIDS patients on ART are encouraged to use condoms every time they have sex. However, among those who responded to being on ART and sexually active (n=61), only 45% (n=27) clearly stated that they use condoms every time they have sex. Thirteen percent (n=8) said never and others claimed they used condoms sometimes. Almost the same percentage (40%) (n=24) did not respond to the question about condom use, even though they claimed in the previous question that they were sexually active.

**Respondents currently on ART and sexually active, but use condoms every time they have sex (n=61)**

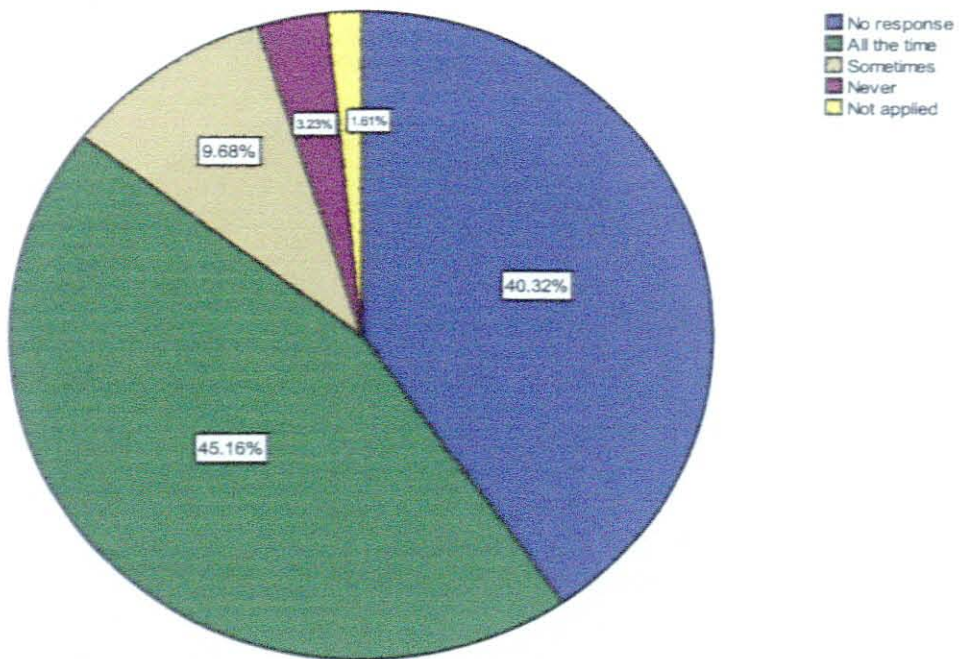


Figure 24 Respondents on ART and condom use

long queue to access ART at the Du Noon Clinic, but eventually most clients secure their ARVs. The nurses and clients both confirmed that AIDS patients receive their supply of ARVs every second month.

A participant said, *"We always get our ARVs at the Du Noon Clinic. In fact, we get it after every two months. ...We have never been to Du Noon and did not get ARVs"*

Few cases were exceptions where a community health worker said, - *"one day I went there [Du Noon Clinic] and could not get ARVs"*

From the pilot study and survey it has already been established that AIDS patients in Du Noon and Doombacht adequately access ART at the Du Noon Clinic. The overwhelming positive response confirmed this theme. According to the nurses as well, ART rollout at the DU Noon Clinic started in August 2004 with only 15 patients and as at November 2009, the clinic has about 1, 050 registered clients on ART, which establishes a steady increase of about 1035 clients on ART over a period of five years.

#### **4.2.2 The best form of treatment for AIDS Patients**

Five participants of each focus group of six participants believed that there are confusing AIDS treatment discourses but expounded on the efficacy of ART as the best form of treatment because they have been exposed to training, counselling and have had experiences of treatment.

A participant said, *"...There is nothing... There's nothing...There's nothing, except hearing rumours that are confusing people that there is something [that treat AIDS apart from ARVs], they are confusing people that there is something that can help treat HIV".*

Another participant said, *"I have heard of Makokota, Aluvera, and Forever, but I stick to ARVs. The nurses told us that we must not use any other medicines apart from ARVs".*

Another participant confirmed that there are many drugs she has heard about that can cure HIV, but she uses only ARVs. She said,

*"Other people said its Makokota, but I do not use any of that what theses people are talking about.... There are many medicines we have heard people think can help AIDS*



*patients. These include Makokota, African potatoes, Forever, Aloe and Herbalife. But none of these should be used to treat AIDS patients”.*

However, one participant of every three focus groups of six (which is 2 out of 36) maintained that they had once believed in other forms of healing process including traditional medicine and had administered some of these at the initial stage of discovering their HIV positive status. Three of the 11 community health workers also expressed similar ordeals with close family members who refused to start ART but continued with traditional healing until the realisation that their health was failing and then started on ART. By that time, it was too late for some of them, as they passed on, due to HIV/AIDS related diseases.

One of the participants explained that she used a medicine called “Aluvela gel” *“I have used Aluvela gel for one month before I started ARVs”.*

Another participant supported this by narrating a story of her brother who refused to take ARVs, but instead preferred traditional medicine. She said,

*“A family member of mine who was about 28 years old was using “Makokota” and “Forever” and later died as he refused to go for proper treatment. My brother also, after he tested positive with HIV, he was using a concoction of traditional medicine for a year and refused to take ARVs. I used to tell him everyday to go for treatment. He later decided to go for ARVs, but it was too late as he passed on as soon as he started treatment. I think men are stubborn when it comes to going to the hospital for the appropriate treatment for whatever sickness they have”.*

An observation of how some patients accessed ART at the Du Noon Clinic, including nurses' responses to some of their experiences with clients, unravel some problems in the area of adherence to ART. The nurses reported that increasing numbers of AIDS patients respond to treatment. This experience corresponds with survey data where 65% of the respondents clearly stated that ARVs are the best form of treatment, (see Fig 13).

#### **4.2.3 Adherence to ART and increase in CD4 count**

In an in-depth interview, the nurses in charge of the rollout programme mentioned that about 20% of the registered clients do not adhere to prescribed medication owing to a number of factors. These included frequent mobility of clients on treatment and those who claim to simply forget to take their medication. Furthermore, the focus group discussions with the community

health workers also revealed that some of their clients do not always adhere to their treatment. This confirms the survey result where 25% of the respondents fall under the non-adherent group (see Fig 19).

Following this non-adherence by some clients, the ARV rollout staff at the Du Noon Clinic devised a strategy to minimise this lapse by placing stickers with different colours on the stats sheet of each patient. A green sticker is a good sign, which shows that the client is adhering to her/his treatment; a yellow sticker is a sign for those who are not adhering entirely and may need some monitoring; and a red sign signifies that the client needs counselling because he/she is not adhering to the appropriate treatment. Members of the latter group are then often monitored by community health workers, who report to the nurses on their experience with some of their clients.

In addition, the researcher was encouraged to observe the process when AIDS patients access treatment. One patient presented her stats sheet, which is normally used to keep track of adherence. The sheet indicated that she went for about a week without using her prescribed ARVs as she had travelled to another city and forgot that she had run out of her medication. Evidence from the focus group discussions supports these discrepancies. Some clients also take their ARVs at different times of the day. A participant recounted that *"sometimes I forget to take my ARVs at 8, when I remember, I'll take it at 9 o' clock. Sometimes when I travel and there's no water and the time passes, I don't take them at all"*.

#### **4.2.4 Disability grant request**

Disability grant request was not one of the variables measured in this study. However, it was interesting to note that as no question in the focus group was designed to understand why some of the AIDS patients do not adhere to ART, but rather how they take their drugs. When asked if they would like to say anything regarding their ART at the Du Noon Clinic, the participants linked three variables together to express a concern. These were adherence to ART, CD4 count and disability grant.

A participant remarked, *"What I am saying now is that we want help. We are not getting any grant, we need help, and we are not working. We are only getting handouts from other people. What we need is disability grants. Because we want to buy healthy foods. When your CD 4 count is high, they confiscate the grant from you. You do not get disability grant. You are OK, but you are still on drugs..."*

Another participant said, *"I am satisfied about treatment and everything. I just need long time grant. Because the doctor gives us only six months grant I am married to somebody. Sometimes the husband does not give me enough money so I suffer sometimes...I want school uniforms for the children. The schools are going to be re-opened in a couple of months, again. I will love to be assisted"*.

Other participants said, *"I want government to give grant to everyone, everybody, no matter what your CD4 count, whether it is 2000 or 1000, but the government must give us the grant. We cannot eat tablet without eating food. Really, we cannot. If you eat tablet without food you will die"*.

*"I am suffering because I don't have a job. I am looking for a job but I cannot find a job. I have a child, and everything is on the child's grant. I am suffering for food... clothes"*

*"I have a very, very, very difficult life. The poverty is up to me just because I am not working, not married. Sometimes my boyfriend only gives me a sum of R100, not every time, so I don't know what to do. Government can give you grants for children and can give you a grant for ARVs but not for a long time, only six months sometimes"*

#### **4.2.5 Good adherence and the changing structure of disability grant at the Du Noon Clinic**

According to the interview with the nurses in charge of the rollout programme, measuring good adherence to ART is not only about the use of the drugs but also looks at refraining from behaviours that hinder the potency of the drugs. Thus the key standards set for measuring good adherence include:

1. Timely and daily use of prescribed ARVs
2. Securing prescribed ARVs at the clinic on the specific date given
3. Evidence of increased weight and appetite to eat well

In addition to the above, AIDS patients are advised to consult the appropriate nurses or doctors at the Du Noon Clinic upon discovery of any adverse effects that suggest a change in regimen; refrain from any form of substance abuse or smoking and are advised to use condoms every time they have sex.

Respondents mentioned the theme of a disability grant, which provides an understanding of what the structure of the disability grant has been at the Du Noon Clinic. According to one of the nurses in charge of the ARV programme at the clinic, the structure of disability grant at the Clinic has changed. Between September 2007 – November 2009, disability grants were given to AIDS patients with CD4 counts 200 *cells/ML* and below, showing signs of physical disability. These signs of physical disability are illnesses that cause an inability to work and support oneself. In other words, the grants were awarded to help patients get back on their feet as they respond to their medication. After showing signs of improvement (both in an increase of CD4 count and physical strength), preferably after six months, they stopped issuing disability grants to these patients.

However, the nurse noted that since December 2009, the strategy has changed. The doctors do not recommend grants based on one of the criteria stated above, which is CD4 count 200 *cells/ML* (now being 350 *cells/ML*) and below. The only criterion considered, and only in rare cases, is the apparent sign of acute illness that causes one not to function properly; no being able to support oneself. This comes with the realisation that some patients may not be adhering to their medication (ARVs) properly if their CD4 count is not increasing.

In addition, the nurse clarified that the CD4 count is not the only criterion to determine the health state of the patients; rather, it is a combination of many other factors. These include the viral load and the patients' unique medical condition. The latter explains the fact that some patients may have a low CD4 count and also a low viral load but according to the nurse, "The patient eats well, is not constantly sick and looks well", which includes no signs of OIs. Therefore, such patients are not entitled to disability grants.

The nurse also emphasised that those AIDS patients who are eager to receive disability grants are mostly from the Eastern Cape, where AIDS patients are awarded disability grants because they do not have access to ART, as contrary to those in the Western Cape. In the Western Cape, which has a better ART rollout plan and implementation, disability grants are not automatically awarded to all those AIDS patients with CD4 count, which is now 350 *cells/ML*. Furthermore, the nurse maintained that there are other support mechanisms put in place for AIDS patients to explore and be, largely, self-reliant and productive. There are activities such as, art works, bead making and gardening funded by the Department of Social Development for AIDS patients. Unfortunately, "some of them refrain from participating in these activities to help support themselves and their immediate families, but they depend on handouts".

#### 4.2.6 Lack of confidentiality at the Du Noon Clinic

One of the dominant themes that emerged from the focus group discussions was that of lack of confidentiality at the clinic when patients access treatment. This theme gives clarity to the response "lack of confidentiality" in the survey. When asked in the focus group discussions how they would rate the quality of service at the clinic, two of six participants in all the focus groups gave further insight as to what the possible meaning of "lack of confidentiality" was. Some of the excerpts are as follows:

*"The problem with the clinic is obvious. Those who are taking the drugs at the clinic are isolated. For instance, when it comes to the ARVs the queue is separate. When we are going for ARV treatment, we do not want the clinic to isolate us". "It is evident that if you go to room no 2 you are going for ARVs. If you go to room no 1 you are going to see a doctor, like everyone else, no 3 is for TB (coughing). We do not want that isolation. We are suggesting that it should not be separate, please. As a result, people are scared to go to the clinic. Before you came, we were talking about that. People stay in Du Noon they will go to Sommerset Hospital to get their treatment because they don't want to be stigmatized".*

*"They don't treat us confidentially. If you are in the reception, they will ask you, what do you want for today? Therefore, you must answer that question in front of everyone. Everyone will know that you are coming for ARVs. There is no confidentiality. We want our own place to take ARVs. We do not want to mix with children. We want a section for ARVs only. At Sommerset, they have their own place to get ARVs. They want a different place for TB clients, STIs etc".*

Some community workers supported the claims that confidentiality is at often overlooked at the clinic, as patients' affairs are not always handled in a confidential manner. At times, some nurses at the reception desk discuss patient issues openly within listening distance of a waiting crowd at the counter. These health workers suggest that those who feel stigmatised in the community may shy away from the Du Noon Clinic and go somewhere else for their ARV treatment.

#### 4.2.7 Untimely doctor's consultation

This theme is best represented with an excerpt of a client's experience of untimely doctor's visit. Other participants supported this client about instances of negligence. The participant thought that she was not properly attended to. She maintained:

*"Yes, the quality is right but there is something wrong at the Du Noon Clinic. Because we are eating ARVs, they are not, maybe some of them are but they did not take ARVs. Like you feel something, then you ask the nurses, I want to see the doctor. They will say you are looking good why do you want to see the doctor? They don't feel that pain, you see? By 2007, I was having a pain here in the stomach and then I wanted to report to the doctor, I reported to the nurses as they usually ask when they give you the treatment. How do you feel? It was June. I reported, and said I was feeling this pain and they gave me painkillers. They did not allow me to go to the doctor. I just left. It took a year. I still felt this pain. I decided now to spend my own money, went to the chemist, bought some medicine. Last year again I went back to the clinic. I usually go after two months for ARVs and then they weigh me and saw that my weight was coming down and then they ask me why is your weight coming down? You are not feeling right. I said you cannot tell me that my weight is coming down because I reported last year that I was feeling this pain and it is still persistent. They took me to the doctor, tested me and said I have high blood, my sugar was up and then he took me to the Sommerset Hospital. So I want to say. If you say to them you are sick now they want you to fall and be on a wheel chair and then they take the steps".*

#### 4.2.8 Long hours of waiting for treatment

Some participants expressed dissatisfaction over the long hours they had to wait to receive their ARVs. The few participants who have part-time jobs complained.

A participant said, *"I have a problem with it. Sometimes we wake up 5 o'clock, 6 o'clock until 7pm and I have to go to work. Anytime you have to go to the clinic, just forget about work for the day".*

Another participant claimed, *"We wait for too long to get our drugs. It is as if you have to sacrifice the whole day to receive them. However, it is not that bad because sometimes you wait for few hours and then you only come after every two months".*

As much as the long wait was a concern, most people seemed not to mind the time because they considered having their treatment more important than any job they had to do. In fact, most of them are unemployed. Community health workers also believed patients are prepared to wait the long hours because ARVs are worth waiting for. One of the community health workers maintained that it was better than just leaving and failing to get the drugs, as proper adherence is dependent on daily and timeous administration. However, as there are some people who still subscribe to traditional and other forms of healing apart from ARVs, the long queue for ARVs as well as lack of confidentiality may affect proper adherence.

#### 4.2.9 ART and condom use

Focus group discussions revealed some important projections about the use of a moisturiser or gel referred to as "cube" that some participants claim was as effective as condoms. Responding to the question if they have heard of any other medicine that can treat HIV/AIDS patients, participants engaged in a discussion about a unique substance that can prevent HIV. Even though participants claimed that they use condoms every time they have sex, a lengthy discussion about this unique method of HIV prevention seemed to be practised in the community. The short debate went as follows:

Participant 1: *"This cube is like a gel, you must use it anytime you have sex. It's some kind of a moisturizer"*

Interviewer: *"What does it do?"*

Participant: 1 *"It helps; I don't know...it's like a condom. If you do not use condom you can use the "cube" instead of condoms".*

Participant: 2 *"Ok, Ok, it's like a gel. This 'cube' works like condom so that you cannot get the virus because of the moisture. I do not understand. What about the sperms? Will that "cube" block the sperms? Because when you wear your condom all the sperms go into that condom"*

Participant 3: *"Does the sperm have the virus? The blood has the virus".*

Participant 1: *"The blood has the virus so, that means the "cube" will protect you not to get the cracks, because the sperms do not have the virus".*

Participant 2: *"What about STIs and STDs?"*

Participant 1: *"I am just explaining what I heard from some people".*

The debate posed unanswered questions. The participant who raised the use of this substance, claimed she had never used it before. However, she spoke passionately about its usefulness in preventing HIV infection and preventing re-infection.

#### **4.2.10 Unsuitable working environment**

Nurses, clients and community health workers expressed dissatisfaction about the little space to operate effectively at the Du Noon Clinic. The researcher observed the process of how patients consult nurses. The whole environment looked very overcrowded. The office where clients are called in for treatment has very little ventilation and is not spacious enough as both nurses and community workers use it. Clients receive counselling and treatment in this same office. From the researcher's observation, the sister normally calls clients in after their names are announced. She checks the stats sheet card of the client to examine the date the client last visited the hospital to establish if the client is complying with the ARV treatment. The sister then checks the weight and height of the patients, who then receive their supply for the next two months.

According to one of the nurses, there have been plans to construct a proper clinic where there would be enough room for proper services to clients. These plans are yet to be implemented. Initially there was land, but there was not enough money to start the construction. Ironically, now that there seems to be sufficient funds to start the process, there is no available land in the community.

One of the sisters described the working conditions as *"depressing"* and *"stressful"*. The salary received is far below other salaries. The community workers expressed similar concerns about having so much to do in the community, yet receiving meager stipends.



#### 4.2.11 Summary

This chapter presented detailed results of the survey, focus group discussions and in-depth interviews. The key findings are summarised below.

- Ninety percent (n=112) of AIDS patients claimed to access ART at the Du Noon Clinic all the time, which suggests a high level accessibility to the ARV programme at the clinic.
- Seventy-five percent (n=93) claimed to adhere to ART.
- Seventy-six percent (n=94) displayed a good understanding of ART's efficacy
- Seventy-seven percent (n=95) of AIDS patients commented favourably about the service received at the Du Noon Clinic.
- Sixty-eight percent of the respondents have been on ART for more than one year. There is a difference in the progression of CD4 count of the two groups of AIDS patients who have been on ART for more than a year based on their level of adherence to ART ( $p < 0.04$ ). Thus, this confirms a correlation between good adherence and increase in CD4 cells.
- The focus group discussions revealed that respondents showed great concern about the lack of confidentiality at the clinic every time they access ART. They felt their HIV status was being disclosed without consent.
- Finally, even though disability grants are not one of the variables the study aimed to evaluate, AIDS patients apparently expressed dissatisfaction about disability grants not being awarded to those who have higher CD4 count. This theme has a relationship with the quality of service as well as adherence to ART. The next chapter will discuss these findings.

## **CHAPTER FIVE**

### **Discussion**

#### **5.1 Introduction**

This chapter discusses the key findings from the survey, focus group and in-depth interviews. The discussion focuses on the outlined objectives of the study and analyses one additional variable, namely disability grants that can be discussed in the context of the experiences of the quality of service and adherence to ART by AIDS patients. Thus the key findings discussed are the state of ART's accessibility in Du Noon and Doombacht communities and in the Western Cape as a whole; the relationship between AIDS patients' knowledge of ART's efficacy; experiences of the quality of service at the Du Noon Clinic, and the level of adherence to ART.

#### **5.2 Moving towards national access to ART**

The results show that AIDS patients in the Du Noon and Doombacht communities access ART at the Du Noon Clinic. Over 55% of respondents has been on ART for over 2 years. Furthermore, according to the infection rate of Du Noon and Doombacht, over 85% of those needing ART are accessing treatment. By 2008, The Western Cape has achieved ART coverage up to 70% which is the highest in the country (Adam & Johnson, 2009). The NSP's proposed target of 80% national access seems to be a reality in these communities (Schneider, et al, 2007: 9). From the results of accessibility, ART access in these target communities supports findings showing that the Western Cape is making great strides in relation to the corresponding increase of AIDS patients with higher CD4 counts (Schneider, et al, 2007: 16, Adam & Johnson, 2009). Accessibility to ART at the Du Noon Clinic may be a good indicator to adherence. A relentless commitment and dedication on the part of the Western Cape district to rollout ART to those in need in spite of Government's lack of commitment may have led to achieving close to 90% ART access in Du Noon and Doombacht. Since almost 90% target of ART access was achieved in Du Noon and Doombacht, this may be possible for the Western Cape. Future ART rollout plan may be consider the proposition to meet the 90% universal ART access.

However, as noted in the presentation of the results, there are other areas in Cape Town as well as other parts of South Africa, with higher HIV infection rates. Following good accessibility, sustainability of ART is crucial. Even though the cost for ART is heavy on the Government

Health Budget, as projected by Susan Cleary, a member of the School of Public Health and Family Medicine, University of Cape Town (Schneider, et al, 2007: 9), it has been established that ART scale up is the better option. The cost of reducing treatment will still consume an estimated 20% of the health budget in 2014, but the corresponding impact without adequate ART rollout will not augur well for the South African population as the projection of the Western Cape estimates an increase in new infections and deaths without treatment. In a recent AIDS conference in Durban in 2009, former health Minister, Babara Hogan, emphasised that the health budget must not be curtailed, in spite of the growing global economic crisis in order to meet the demands of national access to ART in South Africa.

Economic implications of ART on African government's revenue may not be the only constraint. AIDS patients have challenges to access ART due to transportation costs. Research in Khayelitsha (Cleary, et al, 2006: 12) revealed that some AIDS patients struggle with transportation costs to gain access to ART. In the case of Du Noon and Doombacht, most of the AIDS patients reside a walking distance to the clinic. Those who expressed dissatisfaction over lack of confidentiality with the treatment at the clinic may be left with no choice but to go to other clinics and hospitals, such as Sommerset Hospital in Cape Town, creating transport costs and problems to smooth access to ART. It must be noted that nearly all of the respondents and participants in this study are unemployed.

### **5.3 AIDS patients' knowledge of ART's efficacy and AIDS patient's thoughts on the best form of treatment**

With five years (2000 – 2005) of political and scientific controversial debates regarding AIDS treatment in South Africa, it was theoretically projected that this may have negatively influenced the perceptions of people and therefore may have caused fear and subsequent recalcitrance on the part of some people to misunderstand or downplay the efficacy of ART. Foucault's work on the conceptions of power (cited in Hall, 2001: 77) explores the notion that knowledge does not always flow from top to bottom.

*"The efforts to control sexuality produce a veritable explosion of discourse - talk about sex, television and radio programmes... as well as new sexual practices ("safe sex")....Without denying that the state, the law, the dominant class may have positions of dominance, Foucault shifts out attention away from the grand, overall strategies towards the many localized circuits, tactics, mechanisms and effect through which power circulates..." (Cited in Hall, 2001: 77).*

Someone with specialised knowledge or political status does not necessarily influence decisions concerning one's health, (whether political or scientific). The study found that AIDS patients' knowledge and psychosocial experience of AIDS treatment phenomenon stand as a greater influence in itself. AIDS patients in Du Noon and Doornbacht confirmed the propagation of other forms of treatment but maintained the continuation of ART because of their personal experiences of ART's efficacy.

Regarding the best form of treatment, even though the results show that most patients have good knowledge of ART's efficacy and understand the different uses of ART, thirty percent (n=37) of respondents did not clearly state that ARVs are the best form of treatment, but rather stated that the best form of treatment is to take it daily. It is not clear whether AIDS patients meant ARVs or other forms of treatment or were insinuating that the researcher understood what they were referring to. In addition, 11% (n=14) did not respond to the question and 12% (n=15) indicated different kinds of support mechanisms, some traditional and some biomedical but not ARVs, even though they responded to accessing ART at the clinic.

This may suggest that the use of traditional herbalists and retailers of different health products may still have some influence in the communities thus competing with ART. Qualitative results show that alternative forms of treatment are prevalent in these localities. Could it be that the anticipated efficacies of alternative concoctions may have negatively circumvented appropriate behaviour change among some people in the community and not the controversial AIDS discourse? As highlighted in the presentation of findings from the focus groups, some participants only re-utilised ART after experiencing the failures of other forms of treatment strategies, not because of what they may have heard through political debates and AIDS denialists. Most of the respondents have been on ART between 2 to 8 years and have weighed the adverse effects against misrepresented toxicity that the drugs contain. It should not be difficult to clearly state its efficacy.

On the other hand, we may be perusing a reflection of the basic educational level in a community where more than half of respondents claimed to have completed primary school. Coupled with intermittent counselling sessions from community health workers, AIDS patients in these communities may have developed further understanding of the efficacy of ART through these discussions. The role of community health workers in this regard has a crucial role to play in educating their clients on health phenomena. It was noted in the study that in some cases, AIDS patients, confide in and reveal personal issues to these community health workers.

It must also be noted that some of the respondents may not have been adequately accessing media representation of AIDS treatment controversy, which should have impacted their knowledge of ART's efficacy negatively. As most of the respondents are unemployed, they may not be able to afford to buy newspapers nor have the luxury of a television set.

However, literacy alone may not be a strong determinant for adherence to ART after knowing the efficacy of ART. Managing the process of knowledge acquisition comes from other factors. In other words, it entails facilitating the ability to act upon what you know rather than what you have personally experienced to be effective. AIDS patients may not necessarily have to be literate or have started treatment to understand the efficacy of ART. Managing knowledge acquisition is not limited to academic institutions but any community with a lower level and/or non-formal learners, like Du Noon and Doornbacht stems from the fact that social actors at whatever levels, develop the desire to change their socio-economic and political circumstances irrespective of negative influence and low educational level.

Furthermore, the decision to understand the efficacy of ART comes not only through literacy but also the power of "choice". This is a concept explored in Nattrass' (2007: 186) work where "Mbeki's minister, Tshabalala Msimang consistently pointed to the benefits of nutritional interventions, and to the side effects of HAART, saying that patients must be given 'a choice' with regard to their treatment strategies. Msimang maintained that

*"People living with HIV had three choices; nutrition, micronutrients or ARVs; maybe someone can stand up and function if they have antiretrovirals. With nutrition they are functional and there is no information that it has side effects....". Similarly, she said "ARVs do not cure; they have side effects. I do not know of any side effects of eating proper food".* In this study, most of the AIDS patients used the option of ART and assert their choice in this regard.

Knowledge goes beyond personal experience of a phenomenon. Secondly, the educational level of respondents may be partly responsible for making a reasonable choice about the efficacy of ARVs in spite of expected negative influence. However, the power of choice (Geffen, 2006) demonstrated by the AIDS patients accessing treatment at the Du Noon Clinic affirms different conceptions of power. Power indeed circulates, and that knowledge does not necessarily flow from top to bottom.

#### 5.4 Adherence to ART, increase in CD4 Count and disability grants

According to the Mann Whitney U tests, good adherence to ART causes a rise in the CD4 Count ( $p=0.04$ ). The adherent group has a maximum of 1000 CD4 cells as compared to the non-adherent group that has a maximum of below 800 cells/ML and the minimum cells that fall below the threshold of 350 cells/ML.

It must be noted that there are other factors that may hinder the rise of the CD4 cells in spite of good adherence to ART. Research found that some AIDS patients on ART reach a level where the CD4 count stabilises (Ananworanich et al, 2005; Calmy, 2004). On the other hand, some patients may be involved in certain practices that hinder the progress of the immune system. Some of these factors include alcohol and other forms of substance abuse. Having sex without condoms can be another factor. Ten percent of AIDS patients are not using condoms but are sexually active. The use of condoms is necessary in AIDS management as well as prevention.

Furthermore, there is possible use of a substance referred to as "cube" which some AIDS patients may be using instead of condoms. The brief debate indicated in the focus groups may suggest that there may be some misunderstanding among some group of AIDS patients regarding the use of condoms in the community. This resonates with the survey results where only half the respondents expressed that they use condoms every time they have sex. However, a good number of them claimed that condoms are necessary even though both partners are HIV positive. This may inform further research to measure the use of other forms of preventive methods apart from condoms, which is one of the key responses in the internationally used model for HIV/AIDS prevention.

Conversely, even though this study does not conclude that AIDS patients' desire for disability grant have led them to not to adhere to ART to maintain a low CD4 count, a deliberate ploy to maintain a low CD4 count to secure a disability grant, which has been regarded as one major source of income for AIDS patients cannot be overlooked (Chloe & Richter, 2006; Department of Social Development, 2004). Having a CD4 count of 200 cells/ML and below, (the level of count at the time of the study), makes one eligible for re-application for disability grants. In this regard, unemployment and poverty may have some relationship to poor adherence. This may mean among other things, because members of these communities including AIDS patients are in desperate need of economic stability, some AIDS patients in Du Noon and Doornbacht may have the dilemma of adhering to treatment and having a high CD4 count and being classified as someone not eligible to get a disability grant or having a low CD4 count (350 cells/ML and

below) which means losing the eligibility to be awarded a disability grant (see Chloe & Richter, 2006). The Social Development offers grants to patients whose CD4 count are now 350 *cells/mL* and below. One AIDS patient expressed that:

*"I want government to give grant to everyone, everybody, no matter what your CD4 count, whether it is 2000 or 1000... the government must give us the grant. We cannot eat tablet [ARVs] without eating food. Really, we cannot. If you eat tablet without food you will die".*

Recent studies have found that a disability grant not offered to patients whose CD4 count has improved can be counterproductive (Chloe & Richter 2006:85) . Excerpts from this study reads:

*"Towards the end of 2004 the AIDS Law Project was approached by the staff of a state clinic in Johannesburg. They raised the concern that the loss of disability grants might discourage PWAs [also referred to as PLWHAs] from starting treatment, or might provide a disincentive to adhering to their treatment regime. Put differently, they were worried that patients would have to choose between life-saving treatment and maintaining their and their families' only means of support-indeed an alarming dilemma"*

It was an interesting theme as no direct question was asked in the present study about disability grants, but the theme emerged from five of the six focus group discussions. The important question worth asking is: How can AIDS patients continue to be on ART and maintain a high CD4 count but lose grant money when they are still unemployed? To what extent can an AIDS patient prefer to be ill if he/she is so desperate for economic stability and sustenance with an extended family to take care of? These research questions can drive another study on the relationship between disability grant and adherence to ART.

### **5.5 The quality of service regarding ART at the Du Noon Clinic**

A total of 77% of the respondents made good comments about the quality of service at the Du Noon Clinic. However, 15% respondents mentioned the following: "the service needs improvement", "there is no confidentiality at the Clinic" and "the service is poor" might have had the broad theme of "no confidentiality" in mind, considering further clarity on these responses in the focus group interviews. The suggestions to solve the problem appeared contrasting. Some preferred to have a separate section to receive ARVs, while others believed it would work best if there was no separate section to receive ARVs. Nevertheless, the theme "lack of confidentiality"

was the cause for concern. When Voluntary Counselling and Testing (VCT) are done, there is great emphasis on confidentiality. The fact remains that most of the areas where VCT is conducted, emphasis is placed on confidentiality because it will encourage more people to go for HIV test. Even though most people are yet to know their status, those who have voluntarily (or involuntarily) tested, have helped the South African Health Department to collate statistics of HIV infection in the country.

Based on the above evidence, the aspect of confidentiality has been neglected to some extent in the area of accessing ART at the Du Noon Clinic. Drawing from various published works about AIDS in Africa, an article in the New York Times by Kristof (2006) states,

*" you visit an AIDS Clinic there, and see the efforts to save babies by using cheap medicines like Nevirapine to block mother-child-transmission of HIV during pregnancy. Then the Clinic gives the infant formula to take home, so that they do not infect the babies with the HIV during breastfeeding. A hundred yards down the road, you see piles of abandoned formula, where the women have dumped it. Any woman feeding her baby formula, rather than nursing directly, is presumed to have tested positive for HIV, and no woman wants stigma".*

Stigma and discrimination to those infected with HIV are still prevalent in most societies in the world today. The results show that some AIDS patients as well as community health workers in Du Noon and Doombacht are concerned about the lack of confidentiality when clients access treatment. This may discourage some AIDS patients from continuing treatment at the Du Noon Clinic. With challenges of unemployment and poverty, incurring cost for transportation to access ART elsewhere, as mentioned, could also derail proper adherence.

There is a proximate relationship between health and social development and good service delivery in the context of AIDS treatment (Patel & Layte, 2004:23). One of the indicators to measure sustainable human development (SHD) is the access people have to necessities of life. These include ART, which has become a daily consumption of thousands of people in South Africa, spatial housing, better health infrastructure and educational facilities. However, it goes further than providing most needed services. The manner in which some services are provided can affect positive behavioural outcomes, especially in the context of health phenomena.

In spite of efforts from the three spheres of government, inappropriate service delivery has created wide discontent among the public. Atkinson (2007) explores recent mass protests in



South Africa. The main problem outlined in these protests was that municipalities or councillors were unable to deliver most needed services. He observes that municipalities may not be "solely" blamed for the failure to support local government adequately and maintains that municipalities are constrained in attempting to deal with rising poverty, unemployment, disadvantaged communities, urbanization and HIV/AIDS (Atkinson, 2007: 53). These problems also relate to ineffective policy, evidences of corruption, and unresponsiveness on the part of councillors to address problems of resource-poor communities (Atkinson: 2007: 53).

### **5.5 Summary of discussion**

The Western Cape has shown strides towards national access (Schneider, et al, 2007: 16, Adam & Johnson, 2009); however, follow-up mechanisms, which tie up with addressing high levels of unemployment may project a proper adherence to ART in the future. The widely disseminated negative influence of AIDS treatment discourse does not seem to be prevalent in these communities. Foucault's trajectory of the "power of choice" is explored where individual's knowledge of a phenomenon can be made manifest even in the midst of a form of discourse that flows from top to bottom. Not downplaying state power, with its accompanying influence on its subjects, social actors also coin and exert their own form of power. The study found that confidentiality is a crucial aspect of HIV/AIDS response, which must not be underestimated. A good number of AIDS patients expressed concern about revealing their status at the clinic, which could lead to them shying away from ART at the Clinic. Finally, disability grant emerged as one of the themes that was not part of the variables that this study aimed to evaluate. However, the same AIDS patients drew a link between service delivery, adherence and the increase in the CD4 cells. It may be helpful to undertake further research to measure the level in which disability grants influence adherence in resource-poor communities in South Africa.

## CHAPTER SIX

### Conclusion and recommendations

#### 6.1 Conclusion

This study aimed to answer the following broad research questions. (1) What is the level of ART's accessibility at the Du Noon Clinic? (2) What are AIDS patient's perceptions of ART's efficacy and experiences of the quality of service at the Du Noon Clinic? (3) What do the access, perceptions of ART's efficacy and experiences of the quality of service tell us about adherence to ART in resource-poor communities?

This study affirms that AIDS patients in Du Noon have very good access to ART. A year to the deadline of reaching the expected national progression of minimising the effect of HIV/AIDS by expanding access to treatment, care and support by 2011 may not be far fetched (SANAC, 2007; Schneider, et al, 2007: 9). Even though the cost for ART is heavy on the government health budget, ART scale-up is still imperative that a target of 100% be set, owing to the growing number of AIDS patients in South Africa.

More AIDS patients displayed a good capacity of understanding the efficacy of ART. Respondents in the survey and participants of the focus groups have not been negatively swayed by controversial AIDS treatment discourse in South Africa. Most of them experienced the need and essence of ART. This finding shows that there is some relationship between AIDS patients' knowledge of ART's efficacy and their level of adherence to ART.

However, about 20% of the respondents did not communicate an understanding of ART's efficacy. This does not necessarily mean the particular number of respondents did not know nor experience the effectiveness of ART, as an overwhelming percentage (80%) claimed that they have experienced improved health after starting ART. Therefore, the possibility of not experiencing high CD4 count within more than a year of treatment may not be as a result of the lack of knowledge of how one should adhere to ART.

Although the study noted that there could be other medical explanations for some AIDS patients whose immune system may not conform to a first or second line of treatment, and this being evident in an unimproved immune system, as well as some negative health behaviour, the Mann Whitney U tests show that AIDS patients who adhere to ART have a higher CD4 count as

compared to those with the same length of time but do not adhere to ART. Thus there could be other possible reasons for some AIDS patients not adhering to ART.

Following from the themes of knowledge and adherence, AIDS patients are not entirely satisfied with the quality of service regarding ART at the Du Noon Clinic. The aspect of lack of confidentiality when accessing treatment at the Du Noon Clinic is a crucial element to facilitate proper adherence. This theme runs through every discussion with AIDS patients and community workers.

Furthermore, community health workers asserted that some of their clients refused to adhere to ART because they wanted to maintain a low CD4 count and be eligible for re-application for a disability grant. The medical personnel at the Du Noon Clinic maintained that the changing structure at the Du Noon Clinic regarding disability grant focuses on evidence of disability rather than low CD4 count (*350 cells/ML*).

The demographics of the target population showed a high unemployment rate. There is qualitative evidence showing that AIDS patients were not only concerned about their health but also food, rentals and education of their children. Therefore, maintaining a high CD4 count and losing monthly grants may not be a reasonable option for them. It must be noted that a literature review on disability grants was not done prior to data collection. Furthermore, no question was designed to measure respondents' attitude or perception regarding disability grants. It is then evident that AIDS patients on treatment would prefer to get better but at the same time access disability grants (Chloe & Richter, 2006). Research has shown that unemployment and poverty affect many institutions in South Africa (Scott, 2003; Nel & Binns, 2001; Parnell & Pieterse, 1998; Department of Social Department, 2004). ART's adherence could not have possibly been spared. Some AIDS patients believed that they have been cheated from something they deserved to secure. Thus, they may consider this aspect as poor service delivery as they might not fully comprehend the changing structure of disability grant at the Du Noon Clinic.

## **6.2 Recommendations**

The study recommends the following:

Following evidence from nurses, the ART programme does not curtail the approximately 25% patients who are not adhering to treatment. M&E highlighted in the NSP should incorporate steps to monitor adherence as well as accessibility. ART rollout, which has been established as

a costly and continuing strain on government health budget, should be followed by an M&E programme that assures or measures good ART usage. This nuanced approach should include measuring the perceptions and attitude of AIDS patients regarding the treatment they receive alongside their sexual habits, which this study has explored as a possible risk factor for a slow progression of the immune state of AIDS patients. This process may complement the already established client's ART monitoring plan at PHC units. This process should also consider the state of the populations' socio-economic status and be able to predict behaviours that show the complex relationship between health phenomena and economic sustainability.

This nuanced M&E that could incorporate the aforementioned variables can complement the established monitoring system that is already in existence in Du Noon where AIDS patients are categorised by their level of adherence to ART. This will make it easier for further evaluation. This process can be strengthened through effective follow-up measures to track defaulters. Basically, this M&E can be a collaboration of Government and other stake holders, like NGOs that work in Du Noon as well as the PHC unit. Community health workers can be effectively used in this regard as in Brazil where community-based workers follow-up on AIDS patients on ART on a daily basis, a system referred to "directly observed therapy [DOT]-HAART" (Singler & Farmer, 2002: 1652).

Secondly, it is important that the same level of confidentiality that is maintained during VCT should also be a priority when accessing ART. In as much as many people access treatment and there appears a form of expected and accepted routine, a considerable number is still cautious in revealing their status. Therefore, accessing treatment does not necessarily mean AIDS patients readily want to disclose their HIV status. It may be useful that every area of ART access maintains confidentiality.

Finally, future research needs to determine the antiretroviral rollout in these communities and this should be replicated in other parts of the country. Furthermore, as the access to ART increases, awareness programmes through education to explain the link between disability grant and CD4 counts is essential. AIDS patients may need further education and/or a revisit of the grant system in relation to the progress of the immune system. What has come out of the discussions indicate that there is the expectation of having a permanent income, as it is with child support, and other forms of grants that the government offers. It is seen that AIDS patients have focused on economic stability as well as continuing with ART. However, further research is needed to clearly understand the link between these two important variables - disability grant

and adherence to ART. Community health workers can be mobilised to achieve this objective based on the premise that AIDS patients listen to and confide in them.

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Cape Peninsula  
University of Technology

**FACULTY OF APPLIED SCIENCES**

Dr Mohammed  
HIV Department  
CPUT

20 January 2010

Dear Dr Mohammed,

**An evaluation of the antiretroviral rollout programme in two informal townships in the Western Cape, South Africa: Exploring patients' access and experiences of the programme. Applicant – Il Kallon**

The Ethics committee of the Faculty of Applied Sciences has considered your application and wish to recommend that:

- an opt out option should be included in the proposal,
- the applicant should obtain a letter of approval from the local health authorities and or community leaders,
- Provisional approval of the study is hereby granted on condition that the above issues are addressed.
- 

Yours Sincerely

Prof. AJS Benade  
Chairperson  
Research Ethics Committee  
Faculty of Applied Sciences

## Appendix 2-Approval letter from community leader



# TB/HIV Care Association

ESTABLISHED 1929 • NPO 002845 • PBO 18/11/13/2233

WORKING TOWARDS A TB & HIV FREE COMMUNITY

To Whom It May Concern:  
Cape Peninsula University of Technology  
Cape Town

Dear Sir/Madam,

### Approval of research study

TB/HIV Care Association has been involved in providing support to TB and HIV patients in Du Noon and Doornbacht (Site 5) area for a number of years.

Mr. Idriss I Kallon approached us to undertake a study with our clients. The title of this proposed study is *"An Evaluation of the Antiretroviral Rollout Programme in two informal townships of the Western Cape: Exploring Patient's access to and experiences of the Programme"*.

Mr. Kallon submitted participants' consent forms with assurance of voluntary involvement, participants' confidentiality and anonymity. Both clients and community health workers voluntarily accepted to be part of this study and signed the participants consent forms.

Therefore, I approved of this research study proposal by Mr. Kallon to interview selected groups of our community health workers and clients at the Du Noon Clinic.

I would like to request a copy of the research findings to present to our Medical Director.

Yours Sincerely

DEBORAH ESAU  
DISTRICT CO-ORDINATOR

 29-01-2010

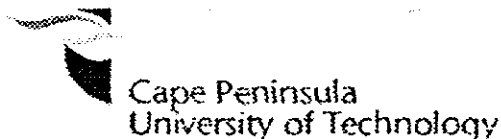
POSTAL ADDRESS: PO Box 2589, Cape Town 8000

WESTERN CAPE: 8th Floor ABSA House, 25 St Georges Mall, Cape Town 8001. Tel: +27 (0)21 425 0050. Fax: +27 (0)21 421 9439  
Cheshire Complex, C/O Turfloop & Bellmore Roads, Harwood Park 7764. Tel: +27 (0)21 692 3027. Fax: +27 (0)21 692 3078

KWAZULU-NATAL: 1st Floor ABSA Bank/Fairdeal Building, Margaret Street, Durban 3276. Tel: +27 (0)39 834 0087. Fax: +27 (0)39 834 0093

e-mail: info@tbhivcare.org | www.tbhivcare.org

## Appendix 3-Cover letter for respondents/participants



Cape Peninsula University of  
Technology  
Department of Environmental Health and Occupational Studies/HIV/AIDS Unit  
Tel. 0214603194/021 4604252/3  
Fax: 021 4604244  
Student email: iikallon@yahoo.com  
Student number: 208218750

### Letter for Consent

Dear Participant,

We are carrying out a research study, which forms part of my MTech course in the Department of Environmental Health and Occupational Studies/HIV/AIDS Unit at the Cape Peninsula University of Technology (CPUT) based in Cape Town.

This study aimed to evaluate the "Antiretroviral Rollout Programme" in two informal townships, Du Noon and Doombacht, Cape Town, in the context of AIDS patients' access to ART, their understanding of ART's efficacy, experiences of the quality of service at the Du Noon Clinic and level of adherence to ART

Kindly be assured that as a participant:

- Your participation is entirely voluntary and may not continue with the interview at any time if you so wish.
- No information, which relates to your response, will identify you or your household.
- Should you choose to take part in this study, you will be involved in one group discussion with a small group of your peers or with you, my research assistant and me.
- You have the right to ask questions before, during or after the interview.

I invite you to be part of this study, which will contribute to the enhancement of the quality of service for those that are receiving ARVs.

#### **Appendix 4-Participants' consent form**

I.....resident of Du Noon/Doornbacht give my informed consent to Mr. Idriss kallon, a post-graduate student at the Cape Peninsula University of Technology based in Cape Town.

I do so with the knowledge that this study aimed to evaluate the "Antiretroviral Rollout Programme" in two informal townships, Du Noon and Doornbacht, Cape Town, in the context of AIDS patients' access to ART, their understanding of ART's efficacy, experiences of the quality of service at the Du Noon Clinic and level of adherence to ART

I am assured of the following:

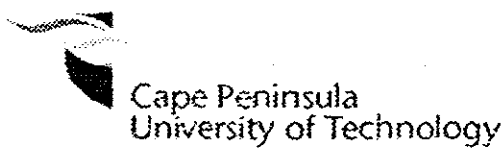
- My participation in the study is voluntary and that it involves participating in a focus group interview or/and one-on-one interview.
- I can refuse to participate in such interview or have the right to skip any particular question in the focus group or one-one-interview.
- Confidentiality will be maintained and none of the responses could be identified to my household or me.
- I have the right to ask any question before, during and after the interview.

I hereby give my consent to participate in this study on my own free will and be part of a focus group and/or one-on-one interview with the hope that this will contribute to the enhancement of the quality of service for those receiving ARVs.

Signature of Participant: .....



**Appendix 5-Structured questionnaire**



Cape Peninsula University of Technology  
 Department for Environmental Health and Occupational Studies/HIV/AIDS Unit  
 Tel. 0214603194/021 4604252/3  
 Fax: 021 4604244  
 Researcher's email: iikallon@yahoo.com  
 Researcher's contact no: 0794842269 (Cell)

Thank you for your willingness to participate in this research project.

This study aimed to evaluate the "Antiretroviral Rollout Programme" in two informal townships, Du Noon and Doornbacht, Cape Town, in the context of AIDS patients' access to ART, their understanding of ART's efficacy, experiences of the quality of service at the Du Noon Clinic and level of adherence to ART

Your information is of importance for the success of this study. There are no right or wrong answers and we are only interested in your honest opinion.

All information will be treated as confidential and the researcher undertakes not to reveal any individual information that appears in this questionnaire. Your name is not asked anywhere and we are only interested in your honest answers.

**How to complete the questionnaire:**

**Encircle** the number in the block next to the response category that corresponds best with your answer, or where there is a dotted line, please write your response, opinion or experience.

**Example:**

Your gender

Male	1	
Female	2	10

Office

Do you think ARVs have improved your health?

*Yes, it has improved my health/ No, it has not improved my health.*

11
----

Researcher: Mr. Idriss Kallon  
 Supervisors: Dr. Ashraf Mohammed  
 Prof. De Wet Schutte

## Knowledge of ART

1. What do you think ART stands for?

ART	Yes	No	
Active Response Treatment	1	2	1
Antiretroviral Therapy	1	2	2
Antiseptic Rigorous Viruses	1	2	3
AIDS Resistance Virus	1	2	4
None of the above	1	2	5

2. What does ARVs stand for?

ARVs	Yes	No	
Active Response Treatment	1	2	6
Antiretroviral Therapy	1	2	7
Antiretroviral drugs	1	2	8
AIDS Resistance Virus	1	2	9
None of the above	1	2	10

3. Indicate whether you agree or disagree with the following statements. If you can make a decision, indicate whether you **strongly agree** or just **agree**, or **strongly disagree** or just **disagree**. If you cannot make any decision, you may indicate that you are **neutral** to the statement.

Statement	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	
Antiretrovirals (ARVs) can cure people who have AIDS	1	2	3	4	5	11
Antiretrovirals are not good for children	1	2	3	4	5	12
Antiretrovirals can be used with other kinds of drugs that have not been prescribed by the doctor	1	2	3	4	5	13
ARVs are the only scientifically tested drugs to treat AIDS Patients	1	2	3	4	5	14
There is no cure for HIV/AIDS	1	2	3	4	5	15

4. When are patients expected to start treatment with ARVs?

Start treatment ...	Yes	No	Don't know	
When their CD4 count is 200 or below	1	2	3	16
When they are feeling sick	1	2	3	17
When symptoms of Diarrhoea is showing	1	2	3	18
When their CD4 count is 350 or below	1	2	3	19

5. Are there other kinds of medicines that you know apart from ARVs?

Yes	1
No	2
Not sure	3

20

6.1. If yes to question 5, name them:

.....

.....

.....

.....

.....

21

22

23

24

25

7. Which of the following kinds of medicines do you think treat people with AIDS?

Medicines	Yes	No
Vitamins	1	2
African Potatoes	1	2
Beetroot	1	2
Garlic	1	2
None of the above	1	2

26

27

28

29

30

8. Where is the most suitable place to get ARVs to treat AIDS patients?

Suitable place	Yes	No	Don't know
From Government Hospitals and Clinics	1	2	3
From any pharmacy in your area	1	2	3
From the traditional healers/sangomas	1	2	3
Other (Please specify)	1	2	3

31

32

33

34

9. State three advantages of the use of ARVs

1.....

2.....

3.....

35

36

37

10. State three disadvantages of the use of ARVs

1.....

2.....

3.....

38

39

40

11. Briefly explain in your own words the best form of treatment for HIV/AIDS patients

.....

.....

.....

41

42

43

Access and adherence to ART

12. Have you been visiting the Du Noon Clinic?

Yes	1
No	2
Not sure	3

44

13. Do you get your ARVs at the Du Noon Clinic?

Yes	1
No	2
Not sure	3

45

14. Do you always get the ARVs you need at the Clinic?

Yes	1
No	2
Not sure	3

46

15. How would you rate the quality of service regarding your ARV treatment at the Clinic?

47

16. Was your CD4 count low before you started taking ARVs?

Yes	1
No	2
Not sure	3

48

17. What was your CD4 count before you started taking ARVs?

49

18. How long have you been on ARVs?

Less than a year	1
Between 2 to 4 years	2
Between 5 to 6 years	3
Between 7 to 8 years	4
Between 9 to 10 years	5
Above 10 years	6

50

19. What is your CD4 count now?

51

20. Indicate whether you agree or disagree with the following statements. If you can make a decision, indicate whether you strongly agree or just agree, or strongly disagree, Or just disagree. If you cannot make any decision, you may indicate that you are neutral to the statement.

Statement	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	
I take my ARVs on a daily basis but not on the specific designated time	1	2	3	4	5	52
I take my ARVs daily and on designated times	1	2	3	4	5	53
I skip some days to take my ARVs, but whenever I take them, I do not take them on a designate time	1	2	3	4	5	54

21. Briefly describe your feelings after taking ARVs?

.....

.....

.....

.....

55

56

57

58

22. Are there other kinds of medicines that you use apart from ARVs?

Yes	1
No	2
Not sure	3

59

23. If your child is HIV positive, is he/she on ARVs?

No	1
Yes	2

60

**ARVs and Sexual Behaviour**

24. Are you currently on ARVs and sexually active?

No	1
Yes	2

61

24.1. If yes, do you use condoms anytime you have sex?

All the time	1
Sometimes	2
Never	3

62

25. Is your sexual partner aware of your HIV status?

Yes	1
No	2
Not sure	3

63

26. Do you think ARVs have improved your health?

Yes	1
No	2
Not sure	3

64

27. If yes, please state the ways ARVs have improved your health

.....

**Demographic Information**

28. Gender?

Male	1
Female	2

66

29. In which of the following age categories do you fall?

Age	
18-20	1
21-30	2
31-40	3
41-50	4
51-60	5
61+	6

67

30. Where do you presently reside?

Residence	
Du Noon	1
Doornbacht	2
Other: .....	3

68

31 With which population group do you associate yourself most?

Population group	
Black	1
Indian	2
Coloured	3
White	4
Other: .....	5

69

32. What is your current marital status?

Marital status	
Married	1
Single	2
Separated	3
Divorced	4
Living together	5
Other: .....	6

70

33. Are you presently full-time employed?

No	1
Yes	2

71

34.1 If yes, how much do you earn?

Weekly		Monthly		Yearly	
-115	=	- R500	=	- R6 000	1
116 - 232	=	R501-R1 000	=	R6 001 -R12 000	2
233 - 465	=	R1 001-R2 000	=	R12 001-R24 000	3
466 - 697	=	R2 001-R3 000	=	R24 001-R36 000	4
698 - 930	=	R3 001-R4 000	=	R36 001-R48 000	5
931 -1 162	=	R4 001-R5 000	=	R48 001-R60 000	6
R1 163+	=	R5 000+	=	R60 001 +	7

72

35. Are you currently on a permanent or temporary work contract?

Contract	
Permanent	1
Contract/temporary	2
Don't know	3

73

36. What is your highest educational level completed?

Qualification	
Primary school	1
High School	2
Tertiary/Vocational Institute	3
Graduate	4
Post-graduate	5
No formal education	6

74

## Appendix 6 Semi-structured focus group questions for AIDS Patients



Cape Peninsula  
University of Technology

Cape Peninsula University of  
Technology  
Department of Environmental Health and Occupational Studies/HIV/AIDS Unit  
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Researcher's email: iikallon@yahoo.com  
Researcher's contact no: 0794842269 (Cell)

Thank you for your willingness to participate in this research project.

The aim of this study is to evaluate the "Antiretroviral Rollout Programme" in Du Noon and Doornbacht, in the context of AIDS patients' access to ART, their understanding of ART's efficacy, experiences of the quality of service at the Du Noon Clinic and level of adherence to ART

Your information is of importance for the success of this study. There are no right or wrong answers and we are only interested in your honest opinion.

All information will be treated as confidential and the researcher undertakes not to reveal any individual information that appears in this questionnaire. Your name is not asked anywhere and we are only interested in your honest answers.

### Opening Questions

1. Demographic Information
  - a. Researcher indicates sex of participants
  - b. Marital Status
  - c. Education completed
  - d. Occupation
  
2. What are you expecting from this discussion?

### Introductory Questions

3. What is the first thing that comes to mind when you hear about HIV/AIDS?
4. What kinds of medicines have you heard about to treat people with HIV/AIDS?



### **Transition Questions**

5. Please think back to the first time you got the news of your HIV status, how you did react?
6. When were you informed of your HIV status?
7. Where did you get the result of your HIV status?

### **Key Questions**

8. Please tell us the kind of treatment you have been taking for your sickness
9. Where have you been getting your drugs?
10. Do you always get the drugs you need at the clinic?
11. Do you sometimes go somewhere else for ARVs apart from the clinic?
12. When and how do you normally take ARVs?
13. How do you feel after taking these drugs?
14. Do you think there are other drugs that are good to treat AIDS patients apart from ARVs?
15. Please explain how you would rate the quality of service regarding your ARV treatment at the clinic
16. If any, what suggestions or recommendations you may have to improve the service delivery regarding ART at the clinic?

### **Concluding Question**

17. Is there something of importance that we did not mention that you would want to speak about?

## **Appendix 7 Semi-structured focus group questions for community health workers**



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Researcher's contact no: 0794842269 (Cell)

Thank you for your willingness to participate in this research project.

The aim of this study is to evaluate the "Antiretroviral Rollout Programme" in Du Noon and Doombacht, in the context of AIDS patients' access to ART, their understanding of ART's efficacy, experiences of the quality of service at the Du Noon Clinic and level of adherence to ART

Your information is of importance for the success of this study. There are no right or wrong answers and we are only interested in your honest opinion.

All information will be treated as confidential and the researcher undertakes not to reveal any individual information that appears in this questionnaire. Your name is not asked anywhere and we are only interested in your honest answers.

### **Opening Questions**

#### **18. Demographic Information**

- a. Researcher indicates sex of participants
- b. Marital Status
- c. Education completed
- d. Occupation

#### **19. What are you expecting from this discussion?**

### **Introductory Questions**

**20. What is the first thing that comes to mind when you hear about HIV/AIDS?**

**21. What kinds of medicines have you heard about to treat people with HIV/AIDS?**

### **Transition Questions**

22. Please think back to the first time you got the news of your clients' HIV status, how you did they react?
23. Would you know where they were informed of their HIV status?
24. Would you know where they got the result of their HIV status?

### **Key Questions**

25. Please tell us the kind of treatment you have been helping your clients with
26. Where have you been getting your drugs?
27. Do you always get the drugs you need at the clinic?
28. Do you sometimes go somewhere else for ARVs apart from the clinic?
29. When do you advise your clients to take their ARVs?
30. Do they always adhere to treatment with ARVs?
31. What kinds of feedback do you get from your clients regarding how they feel after taking these drugs?
32. Do you think there are other drugs that are good to treat AIDS patients apart from ARVs?
33. Please explain how you would rate the quality of service regarding your ARV treatment at the clinic
34. If any, what suggestions or recommendations you may have to improve the service delivery regarding ART at the clinic?

### **Concluding Question**

35. Is there something of importance that we did not mention that you would want to speak about?

## Appendix 8 Semi-structured In-depth interview questions



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Thank you for your willingness to participate in this research project.

The aim of this study is to evaluate the "Antiretroviral Rollout Programme" in Du Noon and Doornbacht, in the context of AIDS patients' access to ART, their understanding of ART's efficacy, experiences of the quality of service at the Du Noon Clinic and level of adherence to ART

Your information is of importance for the success of this study. There are no right or wrong answers and we are only interested in your honest opinion.

All information will be treated as confidential and the researcher undertakes not to reveal any individual information that appears in this questionnaire. Your name is not asked anywhere and we are only interested in your honest answers.

### In-depth interview<sup>3</sup> with medical personnel to explore their experiences with clients on ART

#### Opening Questions

1. Demographic Information
  - a. Researcher indicates sex of participants
  - b. Marital Status
  - c. Education completed
  - d. Occupation
  
2. What are you expecting from this discussion?

---

<sup>3</sup> This does not include probing questions where further information was needed.

### **Introductory Questions**

3. How long have you been working at this hospital/clinic?
4. What kinds of drugs; prescribed or non-prescribed, that are used to treat people with HIV/AIDS?

### **Transition Questions**

5. Can you estimate the number of clients on ARVs on a daily basis?
6. Do you have any documentation to the effect?

### **Key Questions**

7. Where have you been getting ARVs?
8. Please explain if there have been any delays to receive ARVs for the clinic
9. Do you think there are other drugs that are necessary to use with ARVs?
10. Would you know how some of your clients normally take ARVs?
11. How well would you rate the level of adherence to ART of the clients at the Du Noon clinic?
12. What kinds of feedback do you normally get from your clients after taking ARVs?
13. Do you think these feedbacks are helpful in any way?
14. Have any of these feedbacks improved service delivery regarding ART at the clinic?

### **Concluding Question**

15. Is there something of importance that we did not mention that you would want to speak about?