PREVALENCE AND FACTORS ASSOCIATED WITH LATE ANTI–RETROVIRAL THERAPY AT EKURHULENI- NORTH CLINICS.

By

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Declaration

I, Tshifhiwa Ramavhulela declare that the mini-dissertation hereby submitted to School of Public Health at Sefako Makgatho Health Sciences University, for the degree of Master of Public Health, has not been previously submitted by me for a degree at this and any other university. This is my work in design and execution and every literature used as reference had been acknowledged.

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Acknowledgement

This journey was not easy; it can only be God the Almighty who saw me through. He gave me strength when I needed it. **To God be the Glory!**

To my spouse, Nathaniel, little Aluwani and my entire family, I thank you for your patience. This piece of work is evidence that my absence from family gatherings was not in vain.

To my children (Lutendo and Keletso) it is possible if only you persevere.

To the staff at Ekurhuleni- North clinics, you humbled me; your willingness to assist was out of this World.

My Supervisor, Dr. Van Der Heever, I thank you because you silently pushed me to do this. Thank you for all your support and guidance.
**Abstract**

**Background:** Literature indicate that in Sub-Saharan Africa, large number of people are living with HIV and majority of these people do not know their status. It is through HIV testing that a person gets to know his/her status. Antiretroviral Therapy (ART) was proved a successful treatment that suppresses the virus and reduces the chances of developing opportunistic infections and passing the virus to others. Most HIV positive patients in Sub – Saharan region were reported to initiate ART in the advanced stage of the disease. ART eligibility criteria was changed several times in the past few years. Currently South Africa had adopted the “Universal Test and Treat” programme, which allows everyone who is HIV positive, irrespective of their CD4 count to be on ART. Early diagnosis and linkage to care is key to timeously ART initiation, which could be achieved through service integration. Status disclosure and closing the gap of gender disparities could reduce this problem.

**Aim:** The aim of the study was to determine prevalence of late ART initiation in Ekurhuleni- North clinics and to determine factors associated with this problem.

**Method:** A cross-sectional, descriptive quantitative study was conducted. Structured questionnaires were administered to randomly selected respondents during their regular clinic visit. Data collected included demographic information, ART initiation, reasons for late ART initiation, etc. Data was captured into Excel, cleaned, coded and imported to small STATA version 13.0 (statistics software) for analysis. Statistical tests were conducted to determine association between late ART initiation and different variables.

**Results:** A sample (n=352) of study respondents was obtained through random selection. Majority of the respondents, n= 239 (68.9%) were females. Average age was 40 years. Almost half of the respondents, n= 178 (50.6%) were single at HIV first diagnosis and lived in townships. Sixty-seven percent (n= 236) had secondary education and n=143 (40.6%) had a full-time job. Prevalence of late ART initiation was 46.0%, (95% CI: 40.7% - 51.4%). Majority of respondents, n=140 (39.8%) took HIV test because they had HIV symptoms and n=58 (58%) initiated ART late because they were not ready to test for HIV. The univariate analysis showed some evidence of association between late ART initiation and age (p= 0.025) and employment status (p= 0.026). The logistic regression model used was adjusted to
age and gender, age ($p=0.04$) and level of education was found to be associated with late ART initiation. Other variables did not show any statistical significance.

**Conclusion:** The prevalence of late ART initiation of 46.0% is a matter of concern. This study also indicated that most people only test for HIV when they have symptoms. A reason for starting the treatment late is that they were not ready to be tested and therefore they did not know their status. Much effort is needed to get people to test regularly in order to reduce the rate of late ART initiation, especially men and elderly people in general.
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ABBREVIATION AND ACCRONYMS.

AIDS - Acquired Immune Deficiency Syndrome
ANC – Ante Natal Clinic
ART - Antiretroviral Therapy/Treatment
CD4 - Cluster of Differentiation 4
CDC - Centre for Disease Control
EMTCT – Elimination of mother to child transmission
HIV - Human Immunodeficiency Virus
HPCSA - Health Professions Council of South Africa
NDoH - National Department of Health
PEPFAR - President Emergency Plan for AIDS Relief
PHC – Primary Health Care
PLWHIV - People living with HIV
PMTCT - Prevention of mother to child transmission
STI – Sexually Transmitted Infections
TB - Tuberculosis
UNAIDS - Joint United Nations Programme on HIV/AIDS
UTT - Universal Test and Treat
VCT - Voluntary Counselling and Testing
WHO - World Health Organization.
Chapter 1. Introduction

1.1 Introduction

In this chapter, factors associated with late antiretroviral initiation are introduced with reference to the global and South African context. The problem statement, study aim, objectives and questions are stated and supported by justification of conducting the study.

1.2 Background

1.2.1 Global situation

UNAIDS (2014) reported that approximately 35 million people worldwide were living with HIV at the end of 2014, 24.7 million of these people are in Sub-Saharan Africa. Majority of these people (19 million) do not know they have the virus. These are people who need to be reached with HIV testing services (UNAIDS, 2014). Antiretroviral Therapy (ART) had been proven a successful treatment that suppresses the virus and reduces the chances of developing opportunistic infections.

It is more beneficial for People Living with HIV (PLWHIV) to start ART early in order to suppress the virus (Palmer et al, 2014). Palmer et al (2014) further explains that people who manage to suppress the viral load early are unlikely to pass the virus to their sexual partners, intravenous drug user partners and their unborn infants. Most HIV positive patients in Sub-Saharan region were reported to initiate ART in the advanced stage of the disease, which results in early mortality and more complicated and costly clinical management (Lahuerta et al, 2013). The criteria for patient’s eligibility to ART are based on the Cluster of Differentiation 4 (CD4 +) cell count and World Health Organization (WHO) clinical staging. (Lahuerta et al, 2013; Kiertiburanakul et al, 2014).

In April 2013 all TB/HIV co-infected people, all children and pregnant women were eligible for ART, irrespective of their CD4 cell count (Becker et al, 2014). Since the introduction of the ART program in the Sub-Saharan region, ART eligibility criteria changed several times. In 2010, WHO reviewed ART eligibility criteria and changed these from a CD4 count of <200 cells to <350 cells (Lahuerta et al, 2013). Most countries in the Sub-Saharan region adopted the new ART initiation criteria, which resulted in 56% of PLWHIV accessing ART by year 2010 (Lahuerta et al, 2012). The WHO ART eligibility criterion was again changed in 2015 to CD4 count < 500 cells.
Despite these changes, there are still patients who initiate ART with CD4 count < 200 cells. The studies done at four of the Sub-Saharan countries showed that from 2010 to 2013, the prevalence or proportion of late ART initiation was 30% on average, with a CD4 count of 185 cells. In 2011, another study done in India showed that 36.3% of people start ART with a CD4 count of 150 cells. Late ART initiation seems to be a global challenge that questions the success of this program.

1.2.2 South African context

The provision of comprehensive ART in South Africa was initiated in 2004 with only 48 000 people enrolled in the program (Simelela & Venter, 2014). By 2012, 1.79 Million people were on ART. South Africa has the largest number of people living with HIV, with a projection of 215 000 newly diagnosed adult aged between 15 – 49 years in 2016 (Simelela & Venter, 2014). South African government, with assistance from the US agencies such as the President Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund spend a huge amount of money on ART programmes to ensure that at least 80% of PLWHIV have access to treatment (SANAC, 2013). Despite this initiative, there are still people who present late for testing and treatment (Simelela & Venter, 2014) and sadly, some of these people never initiate treatment; they disappear after the diagnosis (Plazy et al, 2015). Scott et al (2011) conducted a meta-analysis review of health facilities in Cape Town, to assess the effectiveness of Pre-ART care. Their findings were that health facility managers usually neglects Pre-ART services. Their recommendations were that more support from facility managers was required as well as standard operation procedures to roll out the implementation of available HIV guidelines in facilities (Scott et al, 2011). In KwaZulu-Natal, South Africa, another study was done amongst adult patients who accessed ART clinics between 2007 and 2011. The study investigated factors associated with ART initiation within 3 months of becoming eligible for ART. Of the 797 men and 1598 women who were initially included in the study, 8% and 5.5% respectively died before ART initiation (Plazy et al, 2015).

1.2.3 The antiretroviral programme

The success of an ART program strongly depends on timeous initiation of treatment, which totally relies on early diagnosis. This means that there is a need to put more efforts into HIV testing and linkage to care (Lahuerta et al, 2013). Patients who test
HIV positive and are not yet eligible for ART should be enrolled into the program and treatment initiated once they are eligible. Barriers to health care access and social environment could be another reason for late initiation of ART (Ndawinz et al, 2013). The Prevention of Mother to Child Transmission (PMTCT), Voluntary Counselling and Testing (VCT) and Tuberculosis (TB) programs are good entry points for HIV care and early ART initiation (Ndawinz et al, 2013).

Pre and post counselling is one of the activities within the HIV care cascade. During post counselling patients should be encouraged to disclose their status to their sexual partners and their closest family members. Failure to disclose HIV status may be one of the individuals’ factors that are associated with late presentation for ART (Parrott et al, 2011). People who disclose their HIV status to their partners and closest family are able to get support and encouragement to initiate and adhere to treatment (Parrott et al, 2011). In addition, Parrott et al (2011) further explained that men found it difficult to disclose their HIV status, some of the reasons being fear of losing their independence and respect as well as their chances of remarriage (Parrott et al, 2011). Health services should offer sufficient privacy and encourage couple’s counselling.

1.3 Problem Statement

Late ART initiation is a challenge in the Sub- Saharan region and it usually results in early mortality and complications that are costly to manage (Lahuerta et al 2012, 2013; Plazy 2015). Early HIV diagnosis and linkage to health care after diagnosis could yield timeous ART initiation that reduces viral load and risks of disease transmission to others (Abaynew et al, 2011 & Palmer et al, 2014). Interventions to achieve this could be the use of point-of-care CD4 count testing and service integration where PMTCT and TB treatment programs are integrated with other services (Lahuerta et al, 2012; Nash et al, 2016). The implementation of the Universal Test and Treat (UTT) strategy in South African health facilities was launched in September 1, 2016. According to UTT strategy, every individual who tested HIV positive should be offered ART regardless of the CD4 count (NDoH, 2016). This expanded programme is expected to correct the current trend of people presenting to the health facilities during the advanced stage of the disease (Parrott et al, 2011). This study seeks to determine the prevalence and factors associated with
late antiretroviral therapy that affects the outcome among the community following the universal test and treat strategy.
1.4 OPERATIONAL DEFINITIONS

1.4.1 Antiretroviral therapy (ART)

The WHO defines ‘Antiretroviral Therapy’ as a combination of at least three antiretroviral (ARV) drugs that are taken as directed by a health care worker, that aim to suppress the virus and reduce the progressive development of HIV disease (WHO Guidelines 2013:14).

ART is a lifelong therapeutic intervention that requires eligible patients to adhere to complex treatment regimens. Adherence to ART encourages viral load suppression and improvements in CD4 cell counts, which optimize clinical outcomes (NDoH Consolidated Guideline, 2015). In this study, ‘ART’ will be referring to the non-nucleoside reverse transcriptase inhibitors, nucleotide reverse transcriptase inhibitors and protease inhibitors that are given to HIV-positive patients when their CD4 and WHO Clinical Staging levels reach the eligibility criteria (Previous guidelines), and every individuals who is ready and willing to take the lifelong therapy (UTT).

1.4.2 Late ART initiation

Lahuerta et al (2013) defined late ART initiation as starting to take ART when already in an advanced stage of AIDS, when CD4+ count < 200 cells/μL or WHO stage 4.

In this study, late ART initiation referred to any person who started ART with CD4 cell count < 200 cells or WHO clinical stage IV, including those who were diagnosed while in advanced stage of AIDS.

1.4.3 WHO Clinical Staging

This refers to the use of a clinical tool that determines a patient’s eligibility for ART. The WHO has classified ‘health status’ into four components (I, II, III, and IV), each of which gives an indication of the level of HIV disease progression and specify the need for ART. WHO Clinical Staging becomes the essential decision-making tool to decide whether to initiate a patient on ART. Patients who are defined to be on WHO Clinical Stage III or IV are initiated on ART regardless of their CD4 cell count. For this study, ART-eligible patients are those who have clinical stage III or IV. Pre-ART patients who are therefore determined as WHO Clinical Stage III or IV will be eligible for ART initiation.
1.4.4 Advanced stage
Lahuerta et al (2012) defined the advanced stage of the AIDS disease as having a CD4+ count < 200 cells/μL or WHO stage 4 or prior HIV/AIDS diagnosis.

1.4.5 Opportunistic infections
The Centre for Disease Control and Prevention (CDC 24/7, 2017) defines opportunistic infections as infections that occur more frequently and severely on individuals with weakened immune systems, including people living with HIV. Despite the presence of ARVs, either people still get opportunistic infections either because they do not know their HIV status and therefore are not on ARVs, or the ARVs are not suppressing the virus as expected (CDC 24/7, 2017). Examples of opportunistic infections are invasive cervical cancer, TB, recurrent Pneumonia, etc.

1.4.6 Viral Load
This is a measure of the number of viral particles present in an organism or environment, especially the number of HIV viruses in the bloodstream.

1.4.7 Linkage to care
This is when newly diagnosed HIV patients are introduced to the continuum of HIV care or a health facility, where complete physical examination and history taking will be conducted as well as assessment of baseline bloods to determine their eligibility to initiate ART. A patient who is not yet eligible to start ART will be enrolled at Pre-ART or wellness programmes where he/she would be seen in the clinic every 6 months. For this study, the linkage to care will be regarded as the second treatment cascade for patients who are eligible (NDoH, 2015).

1.4.8 Universal Test and Treat
This is a same day ART initiation strategy for every individual who test HIV positive and is clinically ready and willing to commit to a lifelong treatment (NDoH, 2016)
1.5 Study Aim
The aim of this study is to determine the prevalence of late ART initiation and investigate factors associated with late initiation among adult patients (18 years and older) at Ekurhuleni North - clinics.

1.6 Study Questions
The study question is:
What is the prevalence and factors associated with late ART initiation among adult patients in Ekurhuleni North clinics?

1.7 Study Objectives
The study objectives are to determine the prevalence of late ART initiation among adult patients at Ekurhuleni North Clinics and to establish factors associated with late ART initiation.

1.8 Study justification
The background discussed previously indicates that South Africa has a large number of people living with HIV, resulting in an extensive program for managing this endemic. South Africa has adopted the United Nations’ 90 -90 -90 programme on HIV/AIDS which was introduced in 2013, which consists of a set of goals. The first 90 implies that by 2020, 90% of people who are infected with HIV will be diagnosed and know their HIV status, the second 90 addresses that 90% of people who are diagnosed HIV positive would be initiated on ART, and the third 90 would be ensuring that 90% of people on ART are virally suppressed (UNAIDS, 2014). Late ART initiation could be a limitation for South Africa to achieve this goal. This context motivated the researcher to conduct a study to determine the prevalence of late ART initiation in Ekurhuleni North, East of Johannesburg (South Africa) and factors associated with this problem, to determine whether this problem also applies to this area. The findings of the study could assist the Ekurhuleni District in HIV services planning and implementation.

1.9 Inclusion and exclusion criteria
In South Africa, the UTT guideline was first implemented in 1 September 2016, which reduces the period between HIV diagnosis and ART initiation. This study will
include people who initiated ART from 2000 to date, including those who were initiated on ART after the introduction of UTT in 1st September 2016.
1.10. Summary

In this chapter, the global and South African context on ART initiation was discussed which outlined that late ART initiation had been a problem globally. The high costs of treating opportunistic infections as well as disease transmission and early mortality are some of the consequences of late ART initiation. Early diagnosis, linkage to care and services integration could lead to early ART initiation. In Chapter two, the researcher will show literature on similar studies done previously.
Chapter 2. Literature review

2.1 Introduction

Globally, several studies had been conducted to determine factors associated with late ART initiation. In this review, several factors were identified; i.e. late diagnosis and loss to follow-up, lack of services integration which results in discrimination, lack of HIV status disclosure leading to poor social support and gender disparities. Some of the initiatives that could minimize late ART initiation were also indicated in the literature; which are early diagnosis and linkage to care, services integration, encouraging status disclosure etc.

2.2 Prevalence of late ART initiation

Late ART initiation seems to be a global problem. In a study done in a rural district of India from 2007 to 2011, two - thirds of people on ART started treatment with CD4 counts below 350 cells/μL and 46% was below 200 cells/μL (Alvarez - Uria et al, 2012). A 60% rate of late ART initiation was also found in an Italian cohort of HIV infected individuals (Monforte et al, 2011). Similar to study findings in other countries, the Sub-Saharan countries are also experiencing late ART initiation. A study was conducted between 2006 and 2011 in four Sub-Saharan countries. The study aim was to examine trends in advanced HIV disease and determinants of advanced HIV disease at ART initiation (Lahuerta et al, 2013). This study finding were that median CD4 cell counts at ART initiation increased from 125 to 185 cells/μL and the proportion of late ART initiation decreased from 42% to 29% (Lahuerta et al, 2013). Even though there was a decrease in late ART initiation, people were still presenting late for ART, which was more common in men than women were.

In South Africa, researchers investigated the continuum in HIV care from entry to ART initiation, 37 749 adults were followed from 2007 to 2011 in order to quantify time from entry into HIV care until ART initiation. Among this people, 24 398 adults were eligible to initiate ART, but only 65.5% actually initiated, of which women were more than men (Plazy et al, 2015). In contrary to this study, Gesesew et al (2016) found that in Southwest Ethiopia, women who were HIV/TB co-infected accounted more for late presentation for ART (55.8%) as compared to men.
2.3. Demographic factors associated with late ART initiation

2.3.1 Age

Lahuerta et al (2013) found that late ART initiation in Sub-Saharan countries was associated with an older age group (46-55 years) and people older than 56 years, probably due to late diagnosis. These findings were also similar to the ones from other studies done in China, Canada, India and Italy (Sun et al, 2017; Palmer et al, 2014; Alvarez-Uria et al, 2012 and Monforte et al, 2011). Monforte et al (2011) later suggested that there is a need to increase HIV testing programs for elderly people.

2.3.2 Gender

Several studies revealed that male as compared to female were most likely to initiate ART at an advanced stage of HIV; probably due to their reluctance to access health care facilities until they have HIV defining conditions (Lahuerta et al, 2013; Nash et al, 2016; Sun et al, 2017 and Ndawinz et al, 2013). It was also assumed that women have more chances to engage themselves in health seeking behaviors that involves HIV testing such as PMTCT, family planning, gynecological screenings and follow-up (Lahuerta et al, 2013; Sun et al, 2017). Pregnant women were more likely to initiate ART than non-pregnant women, which supports the assumption than most women were entering into ART care through PMTCT (Abaynew et al, 2011; Nash et al, 2016). In Sub-Saharan countries, the proportion of women enrolling in ART treatment through PMTCT doubled from 7% in 2006 to 14% in 2011 (Lahuerta et al, 2013). However, in developed countries such as Canada, women were more likely to initiate ART at a later stage, possibly because they did not perceive themselves as being “at risk”. People who regularly test for HIV were gay men and intravenous drug users (Palmer et al, 2014). Sun et al (2017) recommended that older heterosexual man should be given more opportunity for frequent screening, earlier diagnoses and timeous treatment initiation.

2.3.3 Marital status

A study done in four Sub-Saharan African countries found that individuals who were single had more odds of initiating ART late as compared to those who were married or living with a partner (Lahuerta et al, 2013). This could be linked with the importance of status disclosure and social support which is more possible when one has a full time partner. Alvarez-Uria et al (2012) found that in India, women who were separated, divorced or widowed had higher inclination of initiating ART late,
which indicated that women in rural settings have difficulties in reaching health care facilities due to lack of finances. Their marital status together with lower educational level and ultimately lower income all contributed to late ART initiation (Alvarez - Uria et al, 2012).

### 2.3.4 Level of education

In Northern Ethiopia, Beyene and Beyene (2015) found that people who never had a formal education as compared to those whose educational status was at certificate level and above; were more likely to initiate ART in an advanced stage. This group of individuals were also found to have low level of knowledge about HIV/AIDS. The same authors recommended strengthening health promotion and health education among people without a formal education (Beyene and Beyene, 2015).

### 2.3.5 Residential type

People who live in non-permanent houses (rented houses) were likely to initiate ART late (Alvarez - Uria et al, 2012; Abaynew et al, 2011). This association also needs to be explored further since it was only found in a small number of literature.

### 2.3.6 Employment status

In developed countries like Canada, women with high income were reported to have higher odds of initiating ART late, reason being that they do not perceive themselves at risk and therefore are reluctant to test for HIV (Palmer et al, 2014). In the Italian cohort study, Monforte et al (2011) found that people who were retired were different from those who were unemployed; unemployment was associated with late ART initiation.

### 2.4 Patient’s practices and perception on HIV testing, ARVs and access to care

#### 2.4.1 HIV testing practices

In Ethiopia, Nash et al (2016) found that patients whose HIV testing was initiated by the health care service provider, including doctors, were more likely to initiate ART late, as compared to those who were tested through voluntary counselling and testing (VCT). These were similar findings by Moreira et al (2016) on their study conducted in Cape Verde, Portugal. People who were asymptomatic but requested HIV tests after a death of a partner or having a risk factor such as Sexually Transmitted Infection (STI) had lower odds of initiating ART late (Nash et al, 2013;
Alvarez - Uria et al, 2012). In agreement with Nash’s findings, Beyene and Beyene (2015) also found that patients who were advised to take HIV testing by friends and families were most likely to initiate ART early than those who took the HIV test initiated by service provider.

2.4.2 Patients’ perception of ART

ART side effects are common and therefore can be one factor that causes reluctance in ART initiation or loss to follow-up after diagnosis, which is the reason for a need for essential counselling on ART side effects and the long-term benefits of the drugs (Alvarez - Uria et al, 2012).

2.4.3 Perception on access to health facilities and care

Alvarez - Uria et al (2012) suggested that in developing countries like India, integrated counselling and testing centres were able to provide good pre and post-test counselling, however patients are reluctant to access those services due to HIV associated stigma. In a study conducted by Ndou et al (2016) at Vhembe district, South Africa, with the aim to explore perceptions of HIV positive patients on the care received in a particular health care facility. The study findings were that the environment and staff attitude were friendly, but there were negative practices by health care providers that discouraged patients to access treatment in those facilities. Isolation of HIV positive patient and using double gloves while single gloves are worn when treating other patients were some of concerns raised by patients receiving care at those facilities. Ndou et al (2016) recommended that health care workers should practice correct procedures in caring for all patients without discriminating against those who are HIV positive.

2.5 Measures that could eliminate late ART initiation

2.5.1 Early diagnosis and linkage to care

The success of the ART program strongly depends on timeous initiation of treatment, which totally relies on early diagnosis. This means that there is a need to put more efforts into HIV testing and linkage to care (Lahuerta et al, 2013). Patients who test HIV positive and not yet eligible for ART had to be enrolled into the program and treatment initiated once they are eligible.

Lahuerta et al (2013) and Nash et al (2016) observed that patients who had a gap of more than 12 months in pre-ART care had twice the odds of initiating ART with
advanced HIV disease; hence, these patients need regular monitoring. Research also proved that not all patients who tested HIV positive have CD4 count measured following the HIV diagnosis, which is another possible factor that leads to patients being lost between HIV testing and linkage to HIV care (Scott et al., 2011). The same authors recommended that for continuity of HIV care there should be collaboration between HIV counsellors and nurses/ doctors rendering the HIV care as well as collaboration between ART services, e.g. PMTCT and HIV care and treatment programmes, which might prevent loss to follow-up HIV positive mothers after delivery. Mothers who become loss to follow-up could have been linked into HIV care cascade if there was integration of services (Scott et al., 2011). In their study conducted in Cape Town (South Africa) Scott et al (2011) identified missed opportunities of linking newly diagnosed HIV patient to care due to failure to monitor patient for eligibility for ART, (only 45.7% of pre-ART patients were staged clinically, and 88.5% had their CD4 count measured according to the current protocol. Only 47.2% of patients who were monitored and found to be eligible for ART were referred appropriately to an ART service point. ART mostly functions as a separate referral service within the primary care setting.

Abaynew et al (2011) identified groups of individuals that need to be encouraged to take HIV test. The authors referred to people that are less likely to seek medical attention until they have symptoms. The groups to be targeted that are single non-pregnant women, people who live in rented houses, those who consume alcohol, who perceive HIV stigma, those who have symptoms at HIV diagnosis and those who believe ART have side effects (Abaynew et al, 2011). Young males are the other group that tends to delay seeking medical help. In a study done in Cameroon in 2012, it was observed and reported that late ART initiation among young males is due to late presentation to health care services due to several reasons. Some of the reasons were men’s fear of losing their position in the family, their responsibility within the family, high rate of alcohol use and high mobility occupations such as long distance truck drivers (Parrott et al., 2011). The same authors also identified men’s commitment to a wider social network, their masculine idea of strength and their success with sexual and marital partners as factors that lead them to refuse treatment until they are sick. On the other hand, women’s frequency of testing, their general health awareness and commitment to children’s health lead to early uptake
of ART treatment. Ndawinz et al (2012) concluded that interventions to reduce late initiation should include promotion of HIV testing among young males.

2.5.2 Service integration

ART initiation in Cameroon was associated with some individual characteristics, HIV testing behavior as well as health care access and social environment (Ndawinz et al, 2012). A survey was conducted between January and February 2011 in a nationally representative sample of 55 HIV treatment facilities out of the 145 functioning at the time of the study period (Ndawinz et al, 2012). The purpose of the study was to investigate the effect of individual, facility and regional factors associated with late ART initiation in Cameroon. The results indicated that facility level factors associated with late ART initiation were lack of a PMTCT program in the facilities, which suggested that a stronger linkage of the ART and PMTCT programs might enable early ART initiation. VCT and TB programs were also regarded as good entry points into HIV care and early ART initiation (Ndawinz et al, 2012).

Dovel et al (2016) studied trends of ART initiation among men and non-pregnant, non-breastfeeding women in Malawi, their findings were that since the implementation of option B+, there were an increased number (48%) of new female ART initiates through PMTCT than those initiated due to CD4 count and WHO staging. Option B+ is a policy that aimed at offering all pregnant and breast feeding women a lifelong ART, regardless of their CD4 count (Dovel et al, 2016).

2.5.3 HIV Status disclosure

Despite the high prevalence of HIV/AIDS and the global challenges it poses for all, a person’s HIV status remains a private affair, primarily due to the way in which it is generally transmitted and the lack of a cure (Le Roux- Kemp,2013). This brings ethical dilemma in the disclosure of HIV status (Le Roux- Kemp, 2013). The same author further explained that health practitioners often find themselves in a dilemma of whether or not to disclose a patient’s HIV status to his/her spouse? In South Africa, health professionals are currently using the Health Professions Council of South Africa (HPCSA) guidelines in dealing with status disclosure to patient’s spouses or partners, which states that the a patient had to be counselled and the importance of disclosure should be emphasized . It is only if the patient still refuses
to disclose his/her status to the partner where health care professionals are left with no choice than to inform the spouse, but also informs the patient about the decision (Le Roux-Kemp, 2013). The importance of status disclosure would be to protect the patient’s spouse from possible transmission and to enable the spouse to seek medical help.

In a study conducted in Malawi between 2008 and 2009, Parrott et al (2011) explained that disclosure of positive HIV status to closest relatives was very important because the patient’s relatives or spouses would have encouraged the patients to attend clinic visits and adhere to treatment. The study further alluded that women are able to get relatives’ support in terms of transport costs, food and housing. Parents who disclosed their diagnosis to their older children were able to get support and assistance (Parrott et al, 2011; Abaynew et al, 2011). Parrott et al (2011) indicated that men found it difficult to disclose their status due to fear of losing their independence and respect, as well as their chances of remarriage. The same authors concluded that there is a need to develop health services that guarantee privacy and reduces public disclosure. They also supported expansion of couples’ counselling practice with strong linkage between testing and screening (Parrott et al, 2011). Lastly, they suggested community interventions that will encourage older respectable men to seek medical help earlier. Psychological distress was identified by Nash et al (2016) as another factor associated with late ART initiation, therefore people experiencing psychological distress should be encouraged to disclose their status in order to get some targeted support prior to ART initiation (Nash et al, 2016). Perceived lack of family support was reported as one factor leading to late presentation for ART initiation (Monforte et al, 2011).

2.5.4 Closing the gap of gender disparities

Rwanda also had a challenge of late ART initiation, a study was done from 2007 to 2008 to better understand barriers and enablers to timely ART initiation (Mutimura et al, 2015). The study assessed trends and correlates of CD4+ cell count at ART initiation and the proportion of people initiating ART with advanced HIV disease (CD4+ <200 cells/μl or WHO stage 4). Results showed that men start ART at lower median CD4+ cell count, and the rate of change in CD4+ cell count over time was significantly lower in men than women. Gender difference was explained by men
being more likely to be ART eligible at enrollment than women, mostly because of later diagnosis and/or delayed linkage to HIV care. Mutimura et al (2015) concluded that guideline changes and a strong HIV care system alone would not eliminate gender disparities in late treatment initiation. The same authors recommended that more research is needed on how to address this important gender disparity in the timeliness of ART initiation, which appears to be worsening with time.

2.6 Summary

This literature review highlighted that indeed late ART initiation is a global problem. Demographic factors such as age, gender, marital status, residential type and employment type were some factors that lead to people initiating ART late, however residential and employment type still requires more investigation since a few literature supporting these variables was found. Most authors recommended strengthening HIV early diagnosis and linkage to care. Incorporation of HIV testing should be included in routine discussions with primary health care providers. The following chapter outlines the methodology of the study.
Chapter 3. Research Methodology

3.1 Introduction

This chapter presents the methodology of the study, which explains the study design used, where the study was done, how clinics and respondents were selected, ethical considerations observed, the method and procedure used to collect data as well as how data was analyzed.

3.2 Study design

This quantitative, descriptive cross-sectional survey involved collection of information using a standardized questionnaire to describe different variables and their relationship. Descriptive research can be qualitative or quantitative in nature, based on the aim of the study. In qualitative studies, researchers seek to intensively examine a phenomenon and its deeper meaning, while in quantitative studies, the researcher seek to describe characteristics of a population (De Vos et al, 2005). Van der Walt and Van Rensburg (2007) also stipulated that descriptive designs are concerned with gathering information from a representative sample of the population through structured observation, questionnaires or interviews. In this study, the researcher conducted a survey to describe characteristics of patients who initiated ART with a CD4 count less than 200, therefore it was descriptive design. Although patients were informed about the significance of conducting the study, the researcher avoided giving health education as that could have manipulated patient’s responses.

The study is cross-sectional because the researcher examined data at one point in time that is data was collected on one occasion from the different respondents (Van der Walt & Van Rensburg, 2007). The researcher mainly studied the relationships between late ART initiation and other variables such as individual’s demographic factors, social factors and ART services (Detels et al, 2015). The researcher gathered information on the factors associated with late ART initiation and its prevalence, which is the characteristic of a cross-sectional study. The respondents of the study will not be followed up; hence, cross-sectional studies are viewed as exploring a snapshot on a particular population (Detels et al, 2015).
The study is a survey since it involved collection of data through a standardized questionnaire. The researcher interviewed the study respondents asking same questions that are in the questionnaire.

3.3 Study setting
The study was conducted at Primary Health Care facilities that provides HIV and TB related treatment, care and support services. These clinics are situated at Ekurhuleni North, East of Johannesburg, South Africa. All these clinics are government facilities that were accredited as Antiretroviral (ARV) treatment initiation and on-going treatment sites. Other services rendered in these facilities are mother & childcare, non-communicable and communicable diseases, Nutrition supplement services for malnourished and underweight TB, HIV and AIDS patients as well as mental health assessment, referrals and rehabilitation (Info4Africa, 2017). Most clinics have since realized that the integrated approach in rendering primary health care services as it has been recognized as the most viable option to achieve effective and quality services (Ndhambi, 2012). In clinics that are implementing services integration, patients receiving ART are assisted together with all other patients who attend the clinic.

3.4 Study population
A study population refers to individuals who possess specific characteristics that are of interest to a researcher (De Vos et al, 2005). Since it is not possible for the researcher to access the entire population, the population that the researchers have access to is called study population provided a permission is given by the relevant authorities (Van der Walt and Van Rensburg, 2007). The study population is made more accessible if it is further reduced to a smaller number. In this study, the researcher’s focus was on HIV/AIDS adult patients (male and female), 18 years and older, who were receiving anti-retroviral treatment (ART), which was then reduced to respondents with the same characteristics but only in Ekurhuleni-North clinics.

3.5 Sampling technique and sample size
In cross – sectional studies, representativeness of a study is a prerequisite, which requires proper sampling and sample size (Detels et al, 2015). Representativeness means that the sample should have the same characteristics as the population.
Random sampling was done to ensure representativeness of the sample (De Vos et al, 2005). The actual population size was unknown to the researcher; therefore, the study population was an estimation of 20 000 patients. The sample size was calculated to 377, with a 5% margin of error, 95% level of confidence and 50% response distribution.

Multi stage sampling method was used, which requires two or more stages of sampling.

First level (selecting clinics to be included in the study) – The initial step was to group clinics at Ekurhuleni- North into clusters, according to areas where they are situated, separating clinics in urban area (suburbs and towns) vs peri-urban area (townships and farms). In order to randomly select two clinics from each cluster, a list of four clinic clusters was drawn. Each clinic was allocated a number which was written in a piece of paper. The papers were placed in four different containers; the researcher blindly picked two papers from each container, which were then included in the study.

Second level (The secondary sample unit) – At the selected clinics, individual respondents were selected through systematic random sampling. The researcher visited each of the four selected clinics during ART follow-ups days. The study was introduced to patients while they were sitting at the waiting area before consultations. Patients were given tags that were labelled 1 to 30; the numbering of tags was for the researcher to see the number of respondents as compared to number of those patients who were selected. The tags were given to every second patient. Every patient with a tag was asked to see the researcher only if they are willing to participate in the study, those who were not willing to participate were advised to drop the tag in a box supplied. In clinics where services were integrated, there was no specific waiting area for ART patients; all patients who came to the clinic for different reasons were sitting in one queue. The researcher would just address everyone and only mentioned that she is conducting a study, patients were selected in similar manner to the other clinics, but the study details were only given when the respondent come in to see the researcher. The process took longer in these clinics because of explaining the study details to every respondent and some of them would be irrelevant for the study since they were not in clinic for ART.
The researcher administered the questionnaire as each patient volunteered to participate, after obtaining a signed consent form. Some of patients who were selected but were unable to see the researcher on that particular day were willing to give the researcher their mobile numbers to send them SMS to inform them when she visited the clinic again. Some kept their promises and came back to the clinic on the specific day. The researcher had a list of these patients who were only identified by their cell phone numbers.

3.6 Inclusion and exclusion criteria

Respondents were adult patients, male and female (18 years and older) who were HIV positive. The patients were diagnosed since 2000 to date, when ART initiation criteria was CD4 less than ≤ 200 cells/μL and WHO clinical stage III and IV (NDoH, 2010). Patients who were diagnosed from 1 September 2016 during the implementation of UTT were also included in the study. Patients who failed to sign the consent form were not included in the study.

3.7 Data collection tool

A researcher administered questionnaire was used for data collection. A questionnaire is a set of questions on a form which is completed by respondents in respect of a research project (De Vos et al, 2005). The objective of a questionnaire is to obtain facts and opinions about a particular matter from relevant people (De Vos et al, 2005). The questionnaires could either be administered by the researcher or completed by respondents. In this study, the questionnaires were administered by the researcher after being translated in Sepedi and IsiZulu, which are the common languages spoken around Ekurhuleni. Data collection was done in a private room at each clinic when patients come for the collection of their treatment.

As suggested by De Vos et al (2005), the questionnaire was divided into three sections for the sake of easy processing of data; (i) demographic parameters section; (ii) HIV diagnosis; and (iii) ART initiation. The following demographic information were collected: age, gender, marital status, level of education, employment status, housing or residential type and distance travelled to ART clinic. The second group of questions covered individual and programmatic factors that are associated with late ART initiation. Most of questions were multiple choice questions, where three or more choices were offered (De Vos et al, 2005); however, when the
respondent’s answer was not included in the list, respondent were allowed to give a different answer, that was then written as “other”

3.8 Questionnaire testing

De Vos et al (2005) recommended the testing of the measuring instrument as an activity to be conducted before the actual data collection. He further explained that it implies that the researcher should administer the data collection tool to few people who have similar characteristics to those in the actual research site. The aim of this activity would be to identify those questions that seems to cause confusion, annoyance, boredom, etc. Once that is done, De Vos et al (2005) further explained that the data collection tool (the questionnaire) should then be modified to develop a final version. In this study, the questionnaire was tested at a clinic that was included in the study. The questionnaire was administered to 15 people who did meet the inclusion criteria but whose results were excluded from analysis. The questionnaire was tested to check if respondents understood the questions and whether the questions were addressing the objectives of the study. The questionnaire was slightly amended based on questionnaire testing results.

3.9 Data entry and data analysis

Van der Walt and Van Rensburg (2007) explained that statistics is the most powerful tool available for researchers to analyze quantitative data, with exception of nominal data. They further explained that statistical methods enable researchers to reduce, summarize, organize, manipulate, evaluate, interpret and communicate quantitative data. A descriptive approach uses measures such as frequency distributions and measures of central tendency (Van der Walt and Van Rensburg, 2007). In this study, the numerical data collected through structured questionnaires were captured into a Microsoft Excel spreadsheet and imported into STATA (statistics software) for analysis. Analysis refers to categorizing, coding and summarizing of data in order to get answers for the study in hand (De Vos et al, 2005). A code sheet was used to understand the meaning of values; most were dichotomized, meaning that three to four responses were minimized to two (De Vos et al, 2005). Data was then analyzed in a form of univariate, bivariate and multivariate analysis. In univariate analysis, only one variable is analyzed, while in bivariate analysis is amongst two variables, and multivariate analysis refers to analysis of multiple variables (De Vos et al, 2005).
A summary of the analysis was presented in form of tables and graphs. In this study the relationship between late ART initiation and patients’ age, gender, educational level, employment status etc. was analyzed. Chi- squared tests was used to assess statistical significance and odds ratio was used to test for associations between variables. Responses of open ended questions were allocated codes so that they could also be captured on the spreadsheet.

3.10 Reliability and validity

Reliability – De Vos et al (2005) explained that reliability of measurement refers to its consistency and stability; that is the measuring instruments should be able to yield similar results each time it is applied. Pre- testing of questionnaire was conducted to test its reliability. Respondents had similar characteristics with the study samples but they were informed that their responses will not be included in the study. Testing of the questionnaire was conducted to guard against ambiguity and misinterpretation of questions and also to establish the amount of time required to complete the questionnaire. The questionnaires were checked for completeness. Each study variable was assessed by at least two questions, to ensure objectivity of the responses (De Vos et al, 2005).

Validity – De Vos et al (2005) defined validity as the extent to which measuring instrument accurately reflects what it is intended to measure. This concept has two aspects; that is the instrument addresses the problem in question and that the question is addressed accurately (De Vos et al, 2005). In this study the researcher ensured validity by administering the questionnaire personally to ensure completion of the responses. Questionnaires were interpreted into two commonly used languages in the area (IsiZulu and Sepedi); to ensure that respondents are addressed in languages they understood most. Most questions were closed ended, simple and easy to understand. Double meaning questions were avoided so that each question addressed one issue.

Bias - To minimize bias, the researcher ensured that questions were clear and logical. Questionnaires were interpreted in local languages to minimize language bias. Vaguely phrased questions were avoided. Respondents were encouraged to give honest and true answers to the questions asked. Selection bias was avoided by applying simple random sampling.
3.11 Ethical consideration

Permission to conduct the research - The researcher obtained a clearance from Sefako Makgatho Health Sciences University Research Ethics Committee to conduct this study (see annexure 1), permission from Ekurhuleni district health ethics committee and permission from the managers of each clinic that were selected (see annexure 2).

Informed consent - Every respondent had to give a written consent before completing the questionnaire (see annexure 3). The researcher compiled a questionnaire cover letter which was given to every respondent. The cover letter consisted of the information about the objectives/goal of the study, procedure to be followed and the credentials of the researcher. The leaflet also stipulated that the respondents were not obliged to participate, and that they have the rights to quit participating anytime if they are no longer comfortable. The researcher ensured that respondents who gave their own consent were legally and psychologically competent to do so. Respondents were given chance to ask questions before the study commences as well as during the interview session.

Privacy and confidentiality – Respondents’ privacy was observed at all time. To ensure privacy, interviews were conducted in private rooms. Clinics that did not have a private room for the researcher to use would improvise and create a space for the interviews. Respondents were reassured (mentioned on the cover letter) that their information will be handled with confidentiality. Since this study contains sensitive matters, respondent’s identity remained anonymous.

3.12 Summary

This chapter presented the methodology of the study, which included the study design, the population and how the samples were drawn from the population, how data was collected and also the data collection tool used. The chapter also covered how collected data was captured and analyzed. The validity and reliability of the collected data was also discussed. Lastly, the observed ethical considerations were also discussed. The next chapter will present the results of the study.
Chapter 4. Results

4.1. Introduction

The previous chapter outlined the method used to conduct this study. Chapter 4 presents findings of the study. As the study followed a quantitative, descriptive design, its results will be presented in tables and graphs as stipulated by De Vos (2005) and already mentioned in the previous chapter. The researcher engaged a qualified statistician to assist with data analysis and verify the results as understood by the researcher.

4.2. Description of the collected data

The study respondents were sampled from four clinics in Ekurhuleni – North sub-district. A structured questionnaire, consisting of 28 questions was administered to randomly selected respondents, n=352. The demographic data collected through the questionnaires were the following; Age, gender, marital status, level of education, residential type, whether patient travelled to nearest clinic and employment status. Demographic data was followed by HIV first diagnosis information, ART initiation and experiences underwent before, during and after initiating treatment.

4.3. Demographic characteristics

Table 4.1 below outlined the demographic data of study respondents. Majority of the respondents were females (n= 239, 68.9%). Age range was from 18 to 67 years, with average of 40. Most of the respondents were single, n= 178 (50.6%). Most of the respondent’s highest level of education was secondary school (n=236, 67%), while those without any formal education were only n=8, (2.3%). Almost half of respondents (n= 183, 52.0%) were first diagnosed HIV positive while living in townships and the rest lived in urban n= 117, (33.2%) and rural areas n=52 (14.8%). Fifty-one comma seven percent (n=182) of respondents travelled to clinic while 48.3%, n=170 could walk to their clinics. The respondents who were full time employed were n=143, (40.6%) while the number of unemployed were 128 (36.4%).
Table 4.1 Demographic characteristics of study respondents (N=352)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Total (N)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>352</td>
<td>93.3%</td>
</tr>
<tr>
<td>Age, Mean (SD) = 40 (±9.3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18 - 25</td>
<td>16</td>
<td>4.6%</td>
</tr>
<tr>
<td>26 - 35</td>
<td>99</td>
<td>28%</td>
</tr>
<tr>
<td>36 - 45</td>
<td>152</td>
<td>43.3%</td>
</tr>
<tr>
<td>46 - 55</td>
<td>62</td>
<td>18%</td>
</tr>
<tr>
<td>≥ 56</td>
<td>22</td>
<td>6.2%</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>113</td>
<td>32.1%</td>
</tr>
<tr>
<td>Female</td>
<td>239</td>
<td>68.9%</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>178</td>
<td>50.6%</td>
</tr>
<tr>
<td>Married</td>
<td>103</td>
<td>29.3%</td>
</tr>
<tr>
<td>Co-habiting</td>
<td>35</td>
<td>9.9%</td>
</tr>
<tr>
<td>Divorced</td>
<td>17</td>
<td>4.8%</td>
</tr>
<tr>
<td>Widow</td>
<td>19</td>
<td>5.4%</td>
</tr>
<tr>
<td>Level of education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Formal education</td>
<td>08</td>
<td>2.3%</td>
</tr>
<tr>
<td>Primary school</td>
<td>48</td>
<td>13.6%</td>
</tr>
<tr>
<td>Secondary school</td>
<td>236</td>
<td>67.0%</td>
</tr>
<tr>
<td>College/University</td>
<td>60</td>
<td>17.0%</td>
</tr>
<tr>
<td>Residential type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban (suburbs)</td>
<td>117</td>
<td>33.2%</td>
</tr>
<tr>
<td>Sub - urban (Township)</td>
<td>183</td>
<td>52.0%</td>
</tr>
<tr>
<td>Rural (Villages)</td>
<td>52</td>
<td>14.8%</td>
</tr>
<tr>
<td>Travelled to clinic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>182</td>
<td>51.7%</td>
</tr>
<tr>
<td>No</td>
<td>170</td>
<td>48.3%</td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>128</td>
<td>36.4%</td>
</tr>
<tr>
<td>Self - employed</td>
<td>20</td>
<td>42%</td>
</tr>
<tr>
<td>Part - time employed</td>
<td>54</td>
<td>15.3%</td>
</tr>
<tr>
<td>Full - time employed</td>
<td>143</td>
<td>40.6%</td>
</tr>
<tr>
<td>Student</td>
<td>07</td>
<td>2.0%</td>
</tr>
</tbody>
</table>
4.4. HIV testing and diagnosis

4.4.1 Reason for HIV testing

In table 4.2 below, respondent’s main reasons for taking HIV test are listed, with option “other” for those who mentioned a reason that was not in the list. The “other” options were not captured on data spreadsheet.

Table 4.2 Main reasons for HIV testing, (N=352)

<table>
<thead>
<tr>
<th>Main reason for HIV testing</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Requested by nurse while I was pregnant</td>
<td>53</td>
<td>15.0%</td>
</tr>
<tr>
<td>I had HIV symptoms</td>
<td>140</td>
<td>39.8%</td>
</tr>
<tr>
<td>I was diagnosed with TB</td>
<td>37</td>
<td>10.5%</td>
</tr>
<tr>
<td>Sexual partner HIV positive</td>
<td>25</td>
<td>7.1%</td>
</tr>
<tr>
<td>Regular HIV testing</td>
<td>90</td>
<td>25.6%</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>2.0%</td>
</tr>
<tr>
<td>Total</td>
<td>352</td>
<td>100%</td>
</tr>
</tbody>
</table>

Majority of the female respondents (n=140, 39.8%) were tested because they had HIV symptoms. That was followed by those who were randomly testing or who regularly tested (n=90, 25.6%). Fifty-three respondents (15.1%) tested for HIV while attending the ante - natal clinic (ANC) while pregnant. Others took the test after being diagnosed with TB (n= 37, 10.5%), while others (n=25, 7.1%) tested after finding out that their sexual partner was HIV positive. Only seven (2.0%) respondents mentioned other reasons for testing. Those who were diagnosed HIV positive while attending ANC were further asked if they were initiated on ART during pregnancy and if they continued or discontinued the treatment after delivery. Table 4.3 below indicate their responses:
Table 4.3 ART initiation for female respondents diagnosed HIV positive while pregnant, (n=53)

<table>
<thead>
<tr>
<th>Responses</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>ART initiated during pregnancy</td>
<td>41</td>
<td>77.4%</td>
</tr>
<tr>
<td>ART not initiated during pregnancy</td>
<td>11</td>
<td>20.7%</td>
</tr>
<tr>
<td>ART initiated during pregnancy but stopped after delivery</td>
<td>1</td>
<td>1.9%</td>
</tr>
<tr>
<td>Total</td>
<td>53</td>
<td>100%</td>
</tr>
</tbody>
</table>

From the 239 female respondents, n= 53 (15.0%) were diagnosed HIV positive when attending ANC. Forty one (77.4%) of the 53 respondents initiated ART while pregnant, probably through the “Prevention of mother to child transmission” programme (PMTCT). Eleven (20.7%) of the respondents were not part of the PMTCT programme and therefore did not initiate ART during pregnancy. Only one woman started ART during pregnancy and discontinued after delivery.

4.5. Respondent's experiences about HIV diagnosis

4.5.1 Perception of HIV Pre and Post counselling

Respondents were asked if HIV pre and post counselling assisted them to accept their status. Four (4) options of responses were given, which were; counselling assisted them, counselling did not assist them, they were not given any counselling and lastly they do not remember what the counsellor told them. The responses are listed on table 4.4 below:

Table 4.4 Respondent's perception of HIV Pre and Post Counselling, (N=352)

<table>
<thead>
<tr>
<th>Responses</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counselling assisted me to accept my status</td>
<td>303</td>
<td>86.1%</td>
</tr>
<tr>
<td>Counselling did not assist me to accept my status</td>
<td>24</td>
<td>6.8%</td>
</tr>
<tr>
<td>I did not receive any counselling</td>
<td>15</td>
<td>4.3%</td>
</tr>
<tr>
<td>I do not remember what the counsellor told me.</td>
<td>10</td>
<td>2.8%</td>
</tr>
<tr>
<td>Total</td>
<td>352</td>
<td>100%</td>
</tr>
</tbody>
</table>
Pre and post HIV counselling assisted most of the respondents, \( n=303 \) (86.0\%) to accept their status. Twenty-four respondents (6.8\%) reported that they found it difficult to accept their status despite being counselled pre and post HIV testing. There were 15 respondents (4.2\%) who claimed that they were never offered HIV pre and post counselling, or only counselled after the test and 10 respondents (2.8\%) could not remember what the counsellors told them, therefore could not tell if counselling did assist them or not.

4.5.2. Respondent's emotional experiences after HIV diagnosis

Amongst the \( n=352 \) respondents, \( n=217 \) (62.0\%) indicated that they experienced some emotional stress after learning that they are HIV positive, while \( n=135 \) (38.0\%) did not experience any emotional stress. Thirty-two comma two percent, \( n=70 \) of those who experienced emotional stress had someone to talk to and received some emotional support, while \( n=174 \) (67.7 \%) did not share their experiences with anyone or did not have anyone to talk to. The type of emotional stress the respondents went through is summarized in figure 4.1 below:

![Figure 4.1 Type of emotional stress experienced by respondents after HIV diagnosis, (N=352)](image-url)
Thirty-five point two percent (n= 124) of the respondents who experienced emotional stress after knowing their HIV status had stress and tension, n= 39 (11%) experienced anxiety, n= 31 (8.8 %) experienced depression, n= 21 (5.9 %) were angry with either themselves or their sexual partners and the remaining 1%, n=4 experienced other kind of emotional stress.

4.5.3. HIV status disclosure

Most of the respondents (n=315, 89.4%) disclosed their HIV status either to spouse, a family member, a friend and other people such as employers. Only 38 respondents (10.7%) did not disclose their status to anyone. As illustrated on figure 4.2, half a number of respondents (n=179) disclosed their HIV status to a family member (mother, sibling, etcetera), while n= 111 respondents (31.5%) disclosed to their spouses and n= 24 (6.8%) disclosed to a friend. Only one person disclosed to other person not on the list.

![Pie chart showing HIV status disclosure pattern](image)

Figure 4.2 HIV status disclosure pattern, (N=352)

From the n=352 respondents, n= 37 (10.5%) did not disclose their status, while n= 315 (89.4%) disclosed their HIV status. From those who disclosed, n=219 (69.5 %) were females and n=96 (30.4%) were males. Most males n=53 (55.7 %) were more comfortable disclosing to their spouses than family, n= 39 (41%); whereas females were comfortable disclosing to a family member n= 140 (63.6%) than to their spouses, n=58 (26.3%). This is illustrated in figure 4.3 below:
### 4.6. ART initiation

#### 4.6.1 Feelings and knowledge about Antiretroviral therapy (ART)

Respondents were asked how they felt when they were first informed about ART, which is a lifelong treatment that need to be taken daily at the same time. They were also asked if they were given information about ART and its side effects before they were initiated, and whether the information was easy or difficult to understand. If they knew about side effects, they were asked whether they were concerned or worried about the side-effects and if fear of side effects lead to delaying or stopping taking the treatment. Table 4.5 illustrates how participants reacted when advised to initiate ART.

Table 4.5 Respondent’s reaction towards the idea of ART initiation, (N=352)

<table>
<thead>
<tr>
<th>Respondent’s reaction</th>
<th>Males (n=113)</th>
<th>Females (n=239)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relieved and hopeful</td>
<td>54 (47.8%)</td>
<td>106 (44.3%)</td>
</tr>
<tr>
<td>Happy</td>
<td>22 (19.5%)</td>
<td>47 (19.7%)</td>
</tr>
<tr>
<td>Worried</td>
<td>20 (17.7%)</td>
<td>48 (20.1%)</td>
</tr>
<tr>
<td>Worthless and unhappy</td>
<td>10 (8.8%)</td>
<td>30 (12.6%)</td>
</tr>
<tr>
<td>Other</td>
<td>7 (6.2%)</td>
<td>8 (3.3%)</td>
</tr>
<tr>
<td>Total</td>
<td>113 (100 %)</td>
<td>239 (100%)</td>
</tr>
</tbody>
</table>
Majority of both males and females, n=54 (47.8%) and n=106 (44.3%) respectively, were relieved and hopeful when they were told they need to start ART. Some felt happy, males n=22(19.5%) and females, n=47 (19.7%). More females, n=48 (20.1%) were worried, while only n=20 males (17.7%) were worried. More females, n=30 (12.6%) felt completely worthless and unhappy than males, n= 10 (8.8%). Some respondents; seven males (6.2%) and eight females (3.3%) respectively, expressed “other” feelings about ART.

4.6.2 Knowledge about ART and side effects

Most of respondents, n=299 (84.9%) understood the information about ART, only 11.9% (n=42) found the information difficult to understand, while 2.5%, (n=9) indicated that they were not given information about ART, a very small number of respondents (0.5%) gave a different response that was not listed. Majority of the respondents n=329 (93.5%) knew about side effects prior to ART initiation, while only n=23 (6.5%) did not know about the side effects before they initiated ART. Amongst those who had knowledge about side effects, n= 160 (45.5 %) were worried about them while n= 183 (51.9%) did not worry about them. Only n= 24 (6.8 %) of those who were worried did stop or delay ART because of side effects, while the larger number, n=142 (52.8%) did not stop or delay ART. Table 4.6 show summary of knowledge and information about ART:

Table 4.6 Information about ART, (N=352)

<table>
<thead>
<tr>
<th>Responses</th>
<th>Total</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information easy to understand</td>
<td>299</td>
<td>84.9%</td>
</tr>
<tr>
<td>Information was difficult to understand</td>
<td>42</td>
<td>11.9%</td>
</tr>
<tr>
<td>I wasn’t given any information</td>
<td>9</td>
<td>2.6%</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>0.6%</td>
</tr>
<tr>
<td>Total</td>
<td>352</td>
<td>100%</td>
</tr>
</tbody>
</table>

4.7 Late ART initiation

In this study, late ART initiation referred to any person who started ART with CD4 cell count < 200 cells/μL or WHO clinical stage IV, including those who were diagnosed while in advanced stage of AIDS.
4.7.1 Extent of late ART initiation

Hundred and sixty-two respondents initiated ART late, giving a prevalence of 46.0% (CI 40.7% - 51.4%). Most respondents, n= 107 (66.0%) initiated ART late because they did not know they were HIV positive, because they were not ready to test. Late ART initiation was more prevalent in males, n= 113 (51.3%) than in females, n= 239 (43.5%). The minimum CD4 count was 1 cells/µL and maximum 1525 cells/µL, mean of 256 cells/µL. Respondent’s CD4 counts prior to ART initiation is summarized in table 4.7 below:

Table 4.7 Summary of participant’s CD4 count prior to ART initiation, (N=352)

<table>
<thead>
<tr>
<th>CD4 count, Mean (256)</th>
<th>Frequency (n)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 200</td>
<td>162</td>
<td>46.0%</td>
</tr>
<tr>
<td>≥ 200</td>
<td>190</td>
<td>54.0%</td>
</tr>
</tbody>
</table>

4.7.2 Characteristics of late ART initiators

In the group with CD4 count of less than 200, majority were females n= 104 (64.2%). Most of these people, n= 85 (52.2%) were single. Most of them, n= 109 (67.3%) had secondary education as their highest level of education and most were unemployed, n= 69 (42.3%). Many of them, n= 95 (58.6%) stayed in townships and they had to travel to clinics to collect their treatment. Table 4.8 below illustrate a summary of these characteristics:
Table 4.8 Summary of characteristics of late ART initiators, (n=162)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total (n= 162)</th>
<th>Percentage (46.0%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age; Mean (SD)= 41.4( 8.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>58</td>
<td>35.8%</td>
</tr>
<tr>
<td>Females</td>
<td>104</td>
<td>64.2%</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>85</td>
<td>52.5%</td>
</tr>
<tr>
<td>Married</td>
<td>47</td>
<td>29.0%</td>
</tr>
<tr>
<td>Co-habiting</td>
<td>16</td>
<td>9.9%</td>
</tr>
<tr>
<td>Divorced</td>
<td>5</td>
<td>3.1%</td>
</tr>
<tr>
<td>Widow</td>
<td>9</td>
<td>5.6%</td>
</tr>
<tr>
<td>Educational status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No formal education</td>
<td>4</td>
<td>2.5%</td>
</tr>
<tr>
<td>Primary School</td>
<td>27</td>
<td>16.7%</td>
</tr>
<tr>
<td>Secondary School</td>
<td>109</td>
<td>67.3%</td>
</tr>
<tr>
<td>Tertiary Education</td>
<td>13.6</td>
<td>13.6%</td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployment</td>
<td>69</td>
<td>42.6%</td>
</tr>
<tr>
<td>Self-Employed</td>
<td>9</td>
<td>5.6%</td>
</tr>
<tr>
<td>Part-time employed</td>
<td>25</td>
<td>15.4%</td>
</tr>
<tr>
<td>Full-time employed</td>
<td>58</td>
<td>35.8%</td>
</tr>
<tr>
<td>Full-time student</td>
<td>1</td>
<td>0.6%</td>
</tr>
<tr>
<td>Residential type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban (Town &amp; Suburbs)</td>
<td>43</td>
<td>26.5%</td>
</tr>
<tr>
<td>Sub-urban (Township)</td>
<td>95</td>
<td>58.6%</td>
</tr>
<tr>
<td>Rural</td>
<td>24</td>
<td>14.6%</td>
</tr>
<tr>
<td>Travelled to clinic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>85</td>
<td>52.5%</td>
</tr>
<tr>
<td>No</td>
<td>77</td>
<td>47.5%</td>
</tr>
</tbody>
</table>

4.7.3 Reasons for late ART initiation

Respondents who initiated ART late (n=162; 46.0%) were asked what was the reasons for initiating ART when their CD4 count was already low. Most respondents (n=59; 36.4%) responded that they were not ready, and were referring to either not ready to take HIV test or not ready to initiate ART, whilst n= 55 respondents (34.1%) responded that they did not know their status (HIV Positive). Other reasons given were that respondents were afraid of treatment side effects (n=19; 11.7%), they were still on TB treatment (n=12; 7.4%) and that they did not have money to go to clinic (n=9; 5.6%). Others (n=6) gave reasons such as reluctance due to pill burden, pastors’ influences, doubtful of the status and CD4 count that was still high. Their responses are displayed in table 4.9 below:
Table 4.9 Late ART initiator’s reasons for delaying ART, (n= 162)

<table>
<thead>
<tr>
<th>Reason for late ART initiation</th>
<th>Total (n= 162)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was on TB treatment</td>
<td>12</td>
<td>7.4 %</td>
</tr>
<tr>
<td>I was not ready</td>
<td>59</td>
<td>36.4 %</td>
</tr>
<tr>
<td>I did not know my status</td>
<td>55</td>
<td>34.1 %</td>
</tr>
<tr>
<td>I was afraid of side effects</td>
<td>19</td>
<td>11.7 %</td>
</tr>
<tr>
<td>I did not have enough money</td>
<td>9</td>
<td>5.6 %</td>
</tr>
<tr>
<td>My CD4 count was still high</td>
<td>2</td>
<td>1.2 %</td>
</tr>
<tr>
<td>I was doubting the status/denial</td>
<td>2</td>
<td>1.2 %</td>
</tr>
<tr>
<td>Pastor said I was healed</td>
<td>2</td>
<td>1.2 %</td>
</tr>
<tr>
<td>Pill burden</td>
<td>2</td>
<td>1.2 %</td>
</tr>
<tr>
<td>Total</td>
<td>162</td>
<td>100%</td>
</tr>
</tbody>
</table>

4.7.4 Factors associated with late ART initiation

To determine factors associated with late ART initiation, a risk factor analysis was conducted using a multivariate logistic regression. Prior to conducting the multivariate logistic regression, a univariable analysis was done for a selected set of variables from literature to identify variables that could be included in the multivariable analysis. Age was the only variable that was associated with late ART initiation, which was statistically significant, \( p \)-value = 0.05. The researcher then continued with univariable logistic regression, but variables with a \( p \)-value \( \leq 0.25 \) were identified to be included in the multivariate logistic regression. This test was done based on the work done by Hosmer et al (2013), who indicated that the use of the traditional level of the \( (p\)-value \( =0.05 \)) as a screening criteria often fails to identify variables that are known to be important for a specific phenomenon, therefore they recommended that a lower \( p \)-value (0.20 or 0.25) could also be used. Table 4.10 illustrate results of logistic regression model conducted to test association between late ART initiation and the variables identified from the univariable (those with \( p \)-value \( \leq 0.25 \)) regression:
Table 4.10 Test conducted to test association between late ART initiation and independent variables, (N=352)

<table>
<thead>
<tr>
<th>Factors</th>
<th>Unadjusted univariate model</th>
<th></th>
<th>Adjusted model</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>OR</td>
<td>95% CI</td>
<td>p-value</td>
<td>OR</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>1</td>
<td></td>
<td>0.17</td>
<td>1</td>
</tr>
<tr>
<td>Male</td>
<td>1.37</td>
<td>0.87-2.14</td>
<td>0.17</td>
<td>1.26</td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-29 years</td>
<td>1</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>30-39 years</td>
<td>1.83</td>
<td>0.84-3.98</td>
<td>0.13</td>
<td>1.34</td>
</tr>
<tr>
<td>40-49 years</td>
<td>2.82</td>
<td>1.28-6.20</td>
<td>0.01</td>
<td>2.51</td>
</tr>
<tr>
<td>50+ years</td>
<td>1.86</td>
<td>0.76-4.56</td>
<td>0.18</td>
<td>1.39</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None/primary</td>
<td>1</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Secondary</td>
<td>0.69</td>
<td>0.39-1.24</td>
<td>0.22</td>
<td>0.67</td>
</tr>
<tr>
<td>College/University</td>
<td>0.47</td>
<td>0.22-0.98</td>
<td>0.05</td>
<td>0.47</td>
</tr>
<tr>
<td>Counselling effect</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helped to accept</td>
<td>1</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Did not help to accept</td>
<td>0.63</td>
<td>0.34-1.20</td>
<td>0.63</td>
<td>0.33</td>
</tr>
</tbody>
</table>

4.7.5 Other alternative remedies used
In general, majority of respondents (n=293) did not use any remedies to supplement ART, however from the n=162 respondents who delayed ART initiation, 3.6% (n=13) used traditional herbs, 5.1% (n= 18) used Immune boosters, while 6.5 % (n=23) used religious remedies (holy water, salts, oil etc.).
4.8. Fear of discrimination

4.8.1. Discrimination by clinic staff

Fear of discrimination, by either clinic staff or community, was likely to be one of reasons for late ART initiation, as indicated by Ndou et al (2016). Respondents were asked about their perception of clinic staff and community’s reaction towards an HIV positive person, the idea was to find out if they did feel discriminated against or not. Most respondents, n=316 (89.7%) were happy with clinic staff and felt that they were treated like any other patient. Only n=25 respondents (7.1%) stated that they felt discriminated against by clinic staff. There were eleven respondents (3.1%) who were happy with most clinic staff, but they acknowledged that people differ; meaning some clinic staff treated them with respect while others discriminated against them. Amongst those with CD4 count of less than 200, majority of them, n= 144 (88.9%) did not feel discriminated against by clinic staff.

4.8.2. Discrimination by Community

Majority of respondents, 72.4% (n=255) did not feel discriminated against by the community, only 20.7% (n=73) felt discriminated against. The remaining 6.8% respondents (n=24) had a different view about the treatment they received from the community. Majority of respondents (n=119, 73.5%) who initiated ART late also did not feel discriminated against by the community.

4.9. Respondents’ believes in ART

As a closing statement, respondents were asked if they view HIV as a death sentence or not, this statements’ aim was to determine if respondents believe that ART is effective and that they could live longer if they remain on ART. Majority of respondents, n= 343 (97.4%) agreed that HIV is no longer a death sentence because of access to ART, and n= 9 (2.5 %) still feels that HIV is like a death sentence.

4.10. Summary

In this chapter, the characteristics of respondents were summarized. Results were described in the form of tables, graphs and short discussions. A sample (n=352) of study respondents was obtained through random selection. Majority of the respondents (68.9%) were females. Average age was 40 years. Almost half of the
respondents (50.6%) were single at HIV first diagnosis and lived in townships. Sixty-seven percent had secondary education and 40.6% had a full-time job.

Prevalence of late ART initiation was determined (objective 1) and reasons for late ART initiations were outlined. Prevalence of late ART initiation was 46.0%, more males (51%) initiated ART late than females. Majority (35.8%) of the respondents indicated that their reason for late ART initiation was that they did not know their status, mainly because they were not ready to test for HIV. Statistical tests were conducted to establish factors associated with late ART initiation (objective 2) using univariable logistic regression. From a univariate analysis done, four variables (gender, age, level of education and effect of HIV counselling) were identified for inclusion in the multivariable model. The results from the multivariable regression indicated that older respondents had more odds of late ART initiation as compared to younger respondents (AOR = 2.51, \( p \)-value = 0.024; 95% CI 1.13-5.58).

The odds of initiating ART late decreased as respondent’s level of education increased. However, this was not statistically significant.

Respondents who felt that counselling was not effective were less likely to initiate ART late (OR=0.63, CI: 0.33-1.20) compared to those who felt counselling was effective. This is not statistically significant though, \( (p=0.44) \). This finding support information from literature that suggested that people still find it difficult to access HIV treatment facilities despite receiving HIV counselling, reasons being staff attitude, fear of discrimination and unfriendliness of health care facilities which contributed to the late initiation on ART. Chapter 5 will present a summary of interpretation of results, conclusion and recommendations.
Chapter 5. Discussions, Conclusion and Recommendations

5.1 Introduction

This chapter presents an interpretation of results discussed in chapter 4. Conclusions will be reached based on the results and recommendations will be given accordingly. Limitations of the study will be outlined and suggestions be made for further studies as well as suggesting interventions to resolve the matter in hand.

5.2. Prevalence of late ART initiation in Ekurhuleni-North clinics (OBJECTIVE 1)

Hundred and sixty-two participants initiated ART late, giving a prevalence of 46.0% (CI: 40.7% - 51.4%), with median CD4 count of 113 cells/μL, and interquartile range (IQR=104). The extent of late ART initiation in this study has increased when compared to the results found by Lahuerta et al (2013) from the study conducted in four Sub-Saharan countries between 2006 and 2011, prevalence was 29% with median CD4 count of 185 cells/μL. The prevalence of late ART initiation was similar (46.0%) to that in India in 2011, although the median CD4 count was higher, 218 cells/μL (Alvarez - Uria et al, 2012). In most of the respondents (79.0 %), the reason for initiating ART at an advanced stage was that they were not ready to test for HIV and therefore only tested when having HIV symptoms. There seem to be no similar study done in South Africa to determine the prevalence of late ART initiation before, the only study done by Johnson (2012) presented 380 000 ART naïve patients entering the services in 2004 and 2011, but the prevalence rate was not given.

5.3. Factors associated with late ART initiation (OBJECTIVE 2)

5.3.1. Gender

The prevalence of late ART initiation were higher in men as compared to women (OR=1.37; p-value = 0.17; 95% CI: 0.79 to 2.0). Similar results were found in a study conducted in four Sub-Saharan countries (Lahuerta et al, 2012) and one done in Ethiopia (Nash et al, 2016). Contrary to these findings, Palmer et al (2013) found that in developed countries such as Canada, women were more likely to initiate ART at a later stage, possibly because they did not perceive themselves as being “at risk” and therefore would not do regular HIV testing. This is however different in low-income countries such as India; women with lower education, widowed or separated were more likely to initiate ART late than men (Alvarez - Uria et al, 2012).
In general women have more chances to engage themselves in health seeking behaviors that involves HIV testing such as PMTCT, family planning and gynecological screenings and follow-up (Lahuerta et al, 2013; Sun et al, 2017). In this study 10.5% of women were diagnosed HIV positive during their Antenatal clinic and other women could be part of those (24.1%) who took the test during regular clinic visit, including Family planning visits. These disparities indicate that more effort is needed to get men and women with lower level of education to do regular HIV test.

5.3.2. Age

The results suggest that the older people become, the higher the prevalence of initiating ART late. Late ART initiation in the age group (30 to 39 years old), were higher than that of age group (18 to 29 years old). The trend was also observed within the age group (40 to 49 years old); with significant association of late ART initiation and age, p-value 0.01. The adjusted odds ratio (AOR) was 2.51, 95% CI: 1.13 -5.58. Lahuerta et al (2013) reported similar results, amongst men (46-55 years) and those older than 56 years, late ART initiation was probably due to late diagnosis. These findings were similar in studies done in China, Canada, India and Italy (Sun et al, 2017; Palmer et al, 2014; Alvarez - Uria et al, 2012 and Monforte et al, 2011), which brought the conclusion that HIV testing should be strengthened for elderly people, especially men (Monforte et al, 2011).

5.3.3. Level of Education

As level of education increases, the odds of late ART initiation decreases, with (AOR 0.67, 95% CI: 0.36 – 1.27). This could be the indication that these people’s level of understanding ART was higher than for those with lower level of education. Contrary to these findings, majority of people (88.3%) who initiated ART late stated that prior to initiating ART, information about ART was easy to understand. In India, Alvarez-Uria et al (2012) found that the odds of late ART initiation in women was higher in those with lower level of education as well as being widow or separated. The same authors concluded that the cause of late ART initiation could be due to difficulties to reach health care facilities because of lack of income, having income is usually associated with the level of education. However, in Cape Vrede, the results were different as reported by Moreira et al (2011), the odds of initiating ART late was higher in people with higher level of education, (UOR 1.75, CI: 0.18- 3.13) p-value 0.04. The inconsistency of this variable might be suggesting vast reasons behind it, it
might indicate that people with high level of education have trouble to access health care services due to their work and social commitments.

5.3.4. Effectiveness of Pre and Post HIV test counselling

Prevalence of late ART initiation was higher in respondents who felt that Pre and Post HIV counselling helped them to accept their status, with (AOR 0.63, CI: 0.33-1.20). Respondents were asked whether they experienced any emotional stress upon learning about their HIV status, which was a question to test if Pre and Post counselling was effective in helping them accept their status or not. The results above were in contrary with the number of respondents who experienced emotional stress on diagnosis of HIV and ultimately delayed initiation of treatment (59.3%) as compared to 3.7% who did not experience any emotional stress, as emotional stress could be associated with ineffectiveness of counselling. Nash et al (2016) found that in Ethiopia, people who experienced emotional distress upon hearing their HIV status had higher odds to initiate ART late than those who did not have any emotional or psychological distress, (AOR 1.96, 95% CI: 1.34 to 2.87).

5.4. Discussion

The prevalence of late ART initiation in Ekurhuleni- North Clinics (46.0%) is a matter of concern, especially because it is higher than prevalence rate found in lower income countries (Kenya, Mozambique, Rwanda, and Tanzania) on studies that were done more than five years ago. South Africa has a very huge HIV management programme (National Strategic Plan 2012 – 2016) and the ART eligibility had been constantly aligned with the WHO guidelines. Since 2004, ART had been made accessible to patients receiving care in public health facilities (Aids Info), therefore the prevalence of late ART initiation should at least be decreasing. There are limited studies done in South Africa that measured prevalence of late ART initiation, which is a limitation for this study since there is no point of reference.

Most patients initiated ART in less than two months of ART eligibility, this trend was also observed on patients who initiated ART prior to implementation of UTT, which supports the fact that most of these patients only knew about the eligibility status when CD4 count is already low. Majority of respondents who initiated ART late (54.7%) tested for HIV while they already have HIV symptoms, while only 24.1% of respondents were diagnosed through regular HIV testing. Most respondents (66%)
indicated that the reasons for initiating ART late was that they did not know their status because they were not ready either to test for HIV or to be on a lifelong treatment. For the respondents who tested after having HIV symptoms, it could be that some were already at the advance stage of the disease (Stage IV), which might be an explanation for the short duration between eligibility date and ART initiation date. This study included people who initiated ART from 2000 to date, recall bias is very likely since some respondents couldn't remember their exact state of health upon diagnosis, therefore clinical staging was not considered to determine whether a respondent was late starter or not, only CD4 count was considered.

The rate of late ART initiation (46.0%) also raises concern about the quality of counselling done prior to ART initiation. Although most patients (88.9%) indicated that the Pre and Post counselling they received was effective and actually assisted them to accept their HIV status, the legibility of this information is questionable because it is in contrary with the rate of late ART initiation amongst these respondents who mentioned that counselling was effective. The study design (quantitative) limited the researcher to probe respondents to talk more about their emotional stresses they went through.

Late ART initiation was higher in men than in women, and was most prominent and statistical significant (p-value 0.04) amongst people at the age group 40 – 45 years old. Other studies stated that some of the reason men initiate ART late is their poor health seeking behavior in general, while women have more contact with health care professionals during family planning and ante natal care visits (Nash et al, 2015). This could also be the reason why late ART initiation is high in people of age group 40-45 years, who are no longer at child bearing age and possibly not attending family planning clinics. Interventions are required to improve men's access to health care facilities and to advocate for HIV testing whenever health care professionals are in contact with men.

ART is a life-time treatment and therefore needs to be accepted by the patients, which also depend on the level of understanding the treatment plan. The level of understanding also depend on the level of education and the literacy of the patient. The respondents with higher level of education (post-secondary level) had lower odds to initiate ART late. These findings are similar with those of Alvarez-Uria et al.
(2012) that women with lower level of education had higher odds of initiating ART late. This suggest that more efforts are required to ensure that health information reaches both the literate and illiterate population group.

5.5. Limitation of the study

Due to the requirements of the programme the researcher was registered for, the study design could either be qualitative or quantitative, mixed method was not advised for this level. The quantitative nature of the study limited the researcher to obtain in-depth information about the matter in question. According to De Vos (2005), data collection tools (questionnaire) used in quantitative study designs should have more of closed ended questions which limited the researcher to obtain more information. The small sample size was determined by calculations based on estimated population size. A bigger sample size could require a bigger geographical coverage and therefore yield generalizable results. Other limitations were the following:

- The researcher could not find adequate literature with South African data on prevalence of late ART initiation, which made it difficult to determine whether the rate is increasing or decreasing. Johnson (2012) reported South African data of 380 000 ART naïve patients entering the ART services between 2004 and 2011, but prevalence of late initiators was not given.
- The researcher did not request to review respondent’s clinic documents, which was a limitation to get some information that respondents had forgotten. Although some respondents had their files and would allow the researcher to review their records, some respondents did not have and therefore the researcher could not verify information given by the respondents.

5.6. Recommendations for further research

5.6.1. More studies are required in South Africa to determine the prevalence of late ART initiation, which could be used as a monitoring and evaluation process for the success of South Africa’s HIV programme.

5.6.2. A qualitative study or a mixed method study, including records review might meet some of this study’s limitations, since most of the information was not fully obtained due to the nature of the study. For example, qualitative study will probe
further to determine people’s own perspective of reasons for reluctance in testing for HIV as well as reasons for late ART initiation. Records review will also close the possible recall bias that is very likely in this study.

5.6.3. More efforts or interventions are required to encourage people to do regular HIV testing. The older age group should not be excluded when suggesting an HIV test. Health care professionals should encourage people to test each time they are in contact with a patient, especially men.

5.7. Conclusion
Prevalence of late ART initiation in Ekurhuleni- North clinics is 46.0% (CI: 40.7% - 51.4%). Age and level of education were factors found to be associated with late ART initiation. People at the age group 40-49 years old had higher odds of initiating ART late (p-value 0.04), and most of those with lower level of education were ART late starters than those with lower level of education. Gender and effectiveness of Pre and Post HIV counselling were also considered to be associated with late ART initiation, although with no statistical significance. What emerged most was that most people are diagnosed HIV positive while already in an advanced stage (having HIV symptoms) and reasons given was that they were not ready to take the test. It is recommended that more studies done to determine prevalence of late ART initiation in South Africa, as this study cannot be generalized due to low sample size. A mixed method (qualitative and quantitative) might yield more insight into this matter. A strategy is required to encourage people to test for HIV in order to know their status. This should focus more on men and elderly people in general.
References


Accessed by 10 April 2018.


APPENDIX 1. Approval Notice: Sefako Makgatho University Research Committee.

Sefako Makgatho Health Sciences University
Research & Postgraduate Studies Directorate
Sefako Makgatho University Research Ethics Committee
(SMUREC)

Molollegi Street, Ga-Rankuwa 0208
tel: (012) 521 5617/3698 | fax: (012) 521 3749
Email: lorato.phiri@amu.ac.za
P.O. Box 163 Medunsas 0204

02 February 2017

Miss TF Ramavhulela
Department of Public Health
P.O. Box 215
Medunsas, 0204

MEETING: 02/2017

SMUREC Ethics Reference Number: SMUREC/H/12/2017: PG

The New Application received on 18 January 2017 was reviewed by members of Sefako Makgatho University Research Ethics Committee on 02 February 2017 and was approved on 02 February 2017.

Title: Prevalence and factors associated with late ART initiation in Ekurhuleni North Clinics

Researcher: Miss TF Ramavhulela
Supervisor: Dr H Van der Heever
Department: Public Health
School: Health Care Sciences
Degree: MPH

Please note the following information about your approved research protocol:

Protocol Approval Period: 02 February 2017 – 02 February 2018

Please remember to use your protocol number (SMUREC/H/12/2017: PG) on any documents or correspondence with the REC concerning your research protocol.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modification, or monitor the conduct of your research and the consent process.

After Ethical Review: Please note a template of the progress report is obtainable in the Research Office and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit. Translation of the consent document in the language applicable to the study participants should be submitted.

International Organisation (IORG0008651), Institutional Review Board (IRB000010386) Expiry date: 09 December 2018, Federal Wide Assurance (FWA000023843) Expiry date: 31 August 2017 and NHREC No: REC 21M08-003

Sincerely

[Signature]
APPENDIX 2. Ekurhuleni Research Clearance Committee.

EKURHULENI RESEARCH CLEARANCE CERTIFICATE

Research Project Title: A survey of Prevalence and factors associated with late Antiretroviral Therapy initiation at Ekurhuleni north clinics.

NHRD No: GP_2017RP18_596

Research Project Number: 09/06/2017-5

Name of Researcher(s): Ms TF Ramahulela

Division/Institution/Company: Sefako Makgatho Health Science University

DECISION TAKEN BY THE EKURHULENI HEALTH DISTRICT RESEARCH COMMITTEE (EHDRP)

- THIS DOCUMENT CERTIFIES THAT THE ABOVE RESEARCH PROJECT HAS BEEN FULLY APPROVED BY THE EHDP. THE RESEARCHER(S) MAY THEREFORE COMMENCE WITH THE INTENDED RESEARCH PROJECT.

- NOTE THAT THE RESEARCHER WILL BE EXPECTED TO PRESENT THE RESEARCH FINDINGS OF THE PROPOSED RESEARCH PROJECT AT THE ANNUAL EKURHULENI RESEARCH CONFERENCE.

- THE RESEARCH COMMITTEE WISHES THE RESEARCHER(S) THE BEST OF SUCCESS.

DEPUTY CHAIRPERSON: EKURHULENI METROPOLITAN MUNICIPALITY
Dated: 20/6/2017

CHAIRPERSON: GAUTENG DEPARTMENT OF HEALTH (EKURHULENI REGION)
Dated: 20/6/13
Statement concerning participation in a Research Project.

Name of study:

Prevalence and factors associated with late ART initiation in Ekurhuleni North clinics.

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

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

I know that this Study has been approved by the Sefako Makgatho Health Sciences University and Ekurhuleni Health Research Committee. I am fully aware that the results of this results of this Study will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

I hereby give consent to participate in this study.

..................................................................................................................................................................................................................................................................................................................
Name of patient/volunteer Signature of patient or guardian.
..................................................................................................................................................................................................................................................................................................................
Place. Date. Witness

Statement by the Researcher

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

..................................................................................................................................................................................................................................................................................................................
Name of Researcher Signature Date Place
Notice to participants

Dear Participant

My name is Tshifhiwa Ramavhulela. I am studying Masters of Public Health at Sefako Makgatho Health Sciences University. I am conducting this survey as part of my school practical work (academic exercise). The purpose of the survey is to determine the reasons why people who are HIV positive sometimes delay starting ARV drugs when they are supposed to, and also to find out the experiences they go through before they finally start ARVs. Every information gathered through this questionnaire will be handled with confidentiality. Please try to answer questions with honesty. It might take 30 – 40 minutes to go through the questionnaire.

Thanking you in advance on taking your time to participate.

Yours truly

Tshifhiwa Ramavhulela

Cell: 079 163 1870

Email: Tshifhiwa@hotmail.com
APPENDIX 4-B. English Questionnaire

<table>
<thead>
<tr>
<th>No</th>
<th>Question</th>
<th>Response</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>How old are you?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>What is your gender?</td>
<td>1. Male</td>
<td>1,2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Female</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The following questions relate to the time you were diagnosed HIV positive.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>What was your marital status?</td>
<td>1. Single</td>
<td>1,2,3,4,5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Married</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Co-habiting/living with partner</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Divorced</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Widow</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Level of Education</td>
<td>1. No formal education</td>
<td>1,2,3,4,5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Primary school</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Secondary school</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. College/University</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Education</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>What was your residential type?</td>
<td>1. Urban (Town &amp; Suburbs)</td>
<td>1,2,3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Sub-urban (Township)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Rural (Farms &amp; Informal settlement)</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Did you travel to clinic by transport</td>
<td>1. Yes</td>
<td>1,2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. No</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>What was your employment status?</td>
<td>1. Unemployed</td>
<td>1,2,3,4,5,6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Self-employed</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Part-time employed</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Full-time employed</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Full time student</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>6. Other</td>
<td></td>
</tr>
</tbody>
</table>

SECTION 1 - SOCIAL DEMOGRAPHICS
### SECTION 2  HIV TESTING, DIAGNOSIS & TREATMENT INITIATION.

**Participant No:**

**Clinic Name:**

<table>
<thead>
<tr>
<th>No</th>
<th>Question</th>
<th>Response</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>Indicate your HIV diagnosis date</td>
<td>1. Requested by nurses during clinic for pregnant women</td>
<td>1,2,3,4,5,6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. I had HIV symptoms</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. I was diagnosed with TB</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. My sexual partner was diagnosed HIV positive</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Regular HIV test/Medical check-up</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>6. Other, Explain….</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>What was the <strong>Main</strong> reason for HIV testing?</td>
<td>1. Requested by nurses during clinic for pregnant women</td>
<td>1,2,3,4,5,6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. I had HIV symptoms</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. I was diagnosed with TB</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. My sexual partner was diagnosed HIV positive</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Regular HIV test/Medical check-up</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>6. Other, Explain….</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>If you started ARV when pregnant, did you continue after you delivered?</td>
<td>1. Yes</td>
<td>1,2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. No</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Started and stopped after delivery</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>How do you feel about Pre and Post HIV counselling that you were given?</td>
<td>1. Counselling helped me to accept my condition</td>
<td>1,2,3,4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Counselling did not help me to accept my condition</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. I did not receive any counselling</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. I do not remember what counsellor told me</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Did you experience any emotional stress after hearing you are HIV positive?</td>
<td>1. Yes</td>
<td>1,2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. No</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>What kind of emotional stress did you experience? Please choose</td>
<td>1. Depression</td>
<td>1,2,3,4,5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Anxiety</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Stress and tension</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Question</td>
<td>Options</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>--------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
<td>---</td>
</tr>
</tbody>
</table>
| 14| If you experienced any of above, was there anyone available to talk to you when you felt like that? | 1. Yes  
2. No  
3. N/A                                                                 | 1,2,3 |
| 15| Did you disclose your HIV status to anyone?                              | 1. Yes  
2. No                                                                                  | 1,2 |
| 16| If yes, who did you disclose to (relationship)                          | 1. Spouse  
2. Family  
3. Friend  
4. Other  
5. N/A                                                                 | 1,2,3,4,5 |
| 17| When were you first told you need to start taking ARVs? (Yyy, mm)       |                                                                                       |   |
| 18| When did you start taking ARVs? (Yyy, mm)                                |                                                                                       |   |
| 19| What was the CD4 count?                                                 |                                                                                       |   |
| 20| How did you feel about the idea of taking ARVs? Please choose the most appropriate | 1. Relieved & hopeful  
2. Happy  
3. Worried  
4. Completely worthless & Unhappy  
5. Other | 1,2,3,4,5 |
| 21| How did you find the information about ARVs?                            | 1. Easy to understand  
2. Difficult to understand  
3. I wasn’t given any information on ARVs | 1,2,3 |
| 22| Were you informed about ARVs side effects?                              | 1. Yes  
2. No                                                                                  | 1,2 |
| 23| Were you concerned/ worried about the ARVs side effects before starting ARVs? | 1. Yes  
2. No                                                                                  | 1,2 |
| 24| If Yes to Qs 22, did you stop ARVs due to side effect                    | 1. Yes  
2. No                                                                                  | 1,2 |
| 25| How are people taking ARVs treated by clinic staff?                     | 1. They are discriminated  
2. They are treated as any other person  
3. Other, explain...... | 1,2,3 |
| 26| How are people taking ARVs treated by community?                        | 1. They are discriminated  
2. They are treated as any other person  
3. Other, explain...... | 1,2,3 |
<p>| 27| If you started ARVs more than a                                         | 1. Traditional medicines/ | 1,2,3,4,5 |</p>
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
<th>Codes</th>
</tr>
</thead>
</table>
| How long after you were advised to start, please select other methods you used to treat HIV. | herbs  
2. Over the counter immune boosters  
3. Religious remedies e.g. Holy water, oil, salts etc.  
4. None  
5. N/A | ------- |
| What is the reason(s) you delayed starting ARVs?                        | 1. I was on TB treatment  
2. I was not ready  
3. I was unable to go to clinic due to money  
4. I was afraid of side-effects  
5. N/A | 1,2,3,4,5 |
| 24. HIV/AIDS is no-longer a death sentence because of ARVs.             | 1. Agree  
2. Disagree | 1,2 |
APPENDIX 5

Request to conduct research at the health facility.

Attention: The Health facility manager
Birchleigh- North clinic

Dear Sir/ Madam

Re: Request for permission to conduct research

I hereby request your permission to conduct a research at your facility. I am an enrolled student at Sefako Makgatho Health Sciences University pursuing a degree of Masters in Public Health and conducting a research is a requirement for completion of the degree. I will be administering a 29 questions questionnaire to adult patients who are receiving Anti retro viral treatment at the facility during their regular clinic visits. I will try my best not to distract the normal flow of clinic daily activities. Data collection might take 4-6 months as I am employed as well. If it is possible, I would appreciate any available room or area that will be conducive for patient’s privacy.

Attached is a clearance letter from Ekurhuleni Research Committee. Should you require more information or any clarity please don't hesitate to contact me at 079 163 1870/ email: tshifhiwa@hotmail.com

Sincerely yours

Tshifhiwa Ramavhulela
Student Number: 201609201.