NON-ADHERENCE TO ART MEDICATION REGIMENS AMONG PEOPLE LIVING WITH HIV, WHO ARE REGISTERED WITH LERATONG HOSPITAL IN GAUTENG PROVINCE, SOUTH AFRICA

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Assignment submitted in partial fulfillment of the requirement for the degree of Master of Philosophy (HIV/AIDS Management) at Stellenbosch University.

DECLARATION

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January 2012

ACRNONYMS AND ABBREVIAIONS

AIDS   - Acquired Immune Deficiency Syndrome

ART   – Antiretroviral Therapy/Treatment

AZT   - Azidothymidine

CASI   - Computer-Assisted Self-Interviewing

CD4   - Cluster of Differentiation 4

CDC   – Center for Disease Control and Prevention

DOT   - Directly Observed Treatment

HCT   – HIV Counseling and Testing

HIV   - Human Immunodeficiency Virus

MEMS   – Medication Events Monitoring System

MSM   – Men who have sex with men

NGOs   - Non-governmental organizations

NNRTI   - Nonnucleoside Reverse-Transcriptase Inhibitor

NRTIS   - Nucleaside Reverse Transcriptase Inhibitor

PI   - Protease Inhibitor

PIT   - Pill Identification Test

PLWHA   – People living with HIV/AIDS

PMTCT   - Prevention of Mother-To-Child Transmission

SANAC   - The South African National AIDS Council

STIs   - Sexually Transmitted Infections

TCA   - Thematic Content Analysis

TDM   - Therapeutic Drug Monitoring

UNAIDS   - Joint United Nations Programme on HIV/AIDS

UNGASS   - United Nations General Assembly Special Session (on HIV/AIDS)

UNICEF   - United Nations Children's Fund

WHO   - World Health Organization

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ACKNOWLEDGEMENTS

First I thank Jehovah God for giving me wisdom, strength and guidance during my study. I am indebted to my supervisor, Dr. Munro Greg for his professional guidance, tireless support and patience to assist me throughout the course of my study. My appreciation and thanks also go to Gauteng Department of Health and Social Development (GDHSD), and Mr. G.J. Dube, the CEO of Leratong hospital for granting me permission to carry out my research at the clinic.

I am grateful to Dr. E.T Mzobe of Leratong hospital and his health personnel for assistance and warmth they offered me while collecting data at the clinic, not forgetting the willful participants without whom the research could not be a success.

ABSTRACT

The study sought to establish the causes of non-adherence to ART medication regimens among people living with HIV. The research was conducted at Leratong Hospital in Johannesburg, Gauteng province, South Africa.

The researcher selected a qualitative design in which 24 patients on ART and six healthcare providers in the field of HIV/AIDS, who fulfilled inclusion criteria of 18 and above years, were interviewed. Tape-recorded interviews as an instrument of data collection was used and patient-participants were approached and requested to participate in one to one interview as they came to collect their medication. Health personnel were approached in their respective offices and asked to be interviewed. Thematic Content Analysis (TCA) was later used to generate themes.

The results indicated that adherence levels among the patients were sub optimal (less than 95%). Social economic related factors such as poverty, stigma and fear of disclosure; and medication side effects profoundly influenced adherence. Patient-related factors such as lack of social support, preference of traditional medicines, feeling better, substance abuse; and one health system-related factor being staff shortages, had a little contribution to poor medication adherence.

According to the study findings, the process of ART delivery at the clinic had no contribution to patients' non-compliance. In fact it was found to have been intended at providing extrinsic motivation to, and raising the levels of adherence among the patients. When the patients stated their views concerning the programme, the major problem lay with strict time rules and that gave birth to forgetfulness. Their suggestion directed not to the health centers, but sorely to the government and all stakeholders including the ARV drugs-manufacturers, was that ART be provided in the form of three to six months injection.

The findings revealed that stigma exacerbates non-adherence, so, there is a need to intensify health education campaigns against stigma in communities, workplaces and households.

The findings from this study showed a significant relationship between treatment adherence and gender, in which women are generally more compliant than men to ART, so it was recommended that men be given extra pre-ARV counseling and compliance checking.

OPSOMMING

Die primêre doel van hierdie studie was om die redes te bepaal waarom MIV-pasiënte nie hulle antiretrovirale medikasie volgens die voorgeskrewe protokol en voorskrif gebruik nie. Die studie is gedoen by die Leratong Hospitaal in Johannesburg, Gauteng, Suid-Afrika

Die navorser het 'n kwalitatiewe ontwerp gebruik en het onderhoude gevoer met 24 pasiënte (wat antiretroviale medikasie gebruik) en ses gesondheidsorgwerkers. Beide die pasiënte en die gesondheidsorgwerkers het aan die voorafbepaalde kriteria vir die studie voldoen.

Resultate toon dat pasiënte nie altyd by die voorskrifte vir die gebruik van hulle medikasie hou nie en dat dat daar 'n sub-optimale (minder as 95%) voldoening aan medisyne-voorskrifte was. Redes vir hierdie swak voldoening aan voorskrifte kan grootliks toegeskryf word aan armoede, stigma en newe-effekte van die medikasie. Pasiënt-verwante redes, soos die gebrek aan sosiale ondersteuning en voorkeur vir tradisionele medisyne, het 'n geringer bydrae gelewer tot hierdie swak voldoening aan medisyne-voorskrifte.

Volgens die studie het het die proses, waarvolgens antiretoviale medikasie deur die klinieke voorsien word, nie 'n beduidende rol gespeel in die geneigdheid van pasiënte om nie aan medisyne-voorskrifte te voldoen nie. Dit het egter geblyk dat die streng tydreëls wat deur die medisyne-protokolle voorgeskryf word, daartoe gelei het dat pasiënte dikwels vergeet het om hulle medikasie te neem. Pasiënte het sterk vertoë tot farmaseutiese ondernemings gerig om te probeer om medikasie te onwikkel wat op 'n drie- tot ses maandelikse basis per inspuiting toegedien kan word..

Die studie het ook aangetoon dat stigma die geneigdheid om nie te voldoen aan medisyne-vereistes nie vererger en dat opvoedkundige programme om stigma te verminder, versnel sal moet word binne ondernemings.

'n Laaste bevinding was dat daar 'n positiewe verwantskap is tussen geslag en die geneigdheid om by medisyne-voorskrifte te hou. Vroulike pasiënte is baie meer getrou in die neem van hulle antiretovirale medikasie.

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CHAPTER 1

1.1 INTRODUCTION

2011 marks the 30th year of HIV/AIDS as part of human experience. The first reported HIV cases were identified in the early 1980s and since then, HIV/AIDS has continued to be one of the most destructive epidemics in the history of mankind. Since the beginning of the epidemic, AIDS has claimed more than 25 million lives and more than 60 million people have become infected with HIV. Still, each day, more than 7000 people are newly infected with the virus including 1000 children (Report of the UN Secretary-General, 2011).

UNAIDS (2010) estimated a global population of people living with HIV/AIDS as 33.3 million at the end of 2009. Of these, 15.9 million were women and 2.5 million were children. UNAIDS Global Epidemic updates reveal that AIDS is responsible for a decrease in life expectancy and increase in orphaning. In 2009 alone, AIDS killed an estimated 1.8 million people worldwide. There were an estimated 2.2 million people newly infected with the virus, when 16.6 million children became orphans due to AIDS (UNAIDS, 2010).

Women are more vulnerable than men in some regions, and their deaths rob families of the primary caregivers (Ashford, 2006). Slightly more than half of all people living with HIV are women and girls. In Sub-Saharan Africa, more women than men are living with HIV, and younger women aged 15-24 years are as much as eight times more likely than men to be HIV positive (UNAIDS, 2010).

In severely affected countries, HIV/AIDS causes slow economic growth and development by destroying human capital, discouraging investment and eroding productivity (UNAIDS, 2005). It also threatens health and social progress. Health care systems experience enormous demands as expenses are rising for the treatment of AIDS and AIDS-related opportunistic infections (Ashford, 2006).

The business world has also been terribly affected by the HIV/AIDS epidemic. Employers are hard hit by the loss of workers, absenteeism, the rising costs of providing health-care benefits and the payment of death benefits. The pandemic has touched almost every facet of life and no

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country has escaped the devastation of this truly global epidemic (Ashford, 2006 and Report of the UN Secretary-General, 2011).

In the 2005 World Summit Outcome, the world leaders committed to measures to scale up a comprehensive response to achieve a multisectoral coverage of prevention, treatment, care and support with the intentions of getting close to the goal of universal access to treatment by 2015 (United Nations: General Assembly, 2005). The UN Secretary-General admitted that their efforts have started bearing fruit.

As at December 2010, more than six million people were estimated to be receiving antiretroviral therapy (ART) in low and middle-income countries (Report of the UN Secretary-General, 2011). In 2009 alone, 1.2 million people received ART for the first time, which was 30% increase of people receiving treatment in a single year. Expanding access to treatment has contributed to a 19% decline in deaths among PLWHA between 2004 and 2009 (UNAIDS, 2010).

New HIV infections are declining in many countries most affected by the pandemic. In 33 countries, of which 22 are in Sub-Saharan Africa, HIV incidence has fallen by more than 25% between 2001 and 2009. Among young people in 15 of the most severely affected countries, HIV prevalence has fallen by more than 25% (UNAIDS 2010).

Global coverage for antiretroviral prophylaxis to prevent the vertical transmission of HIV has exceeded 50%. As at December 2009, 15 countries had achieved the target set in the 2001 Declaration of at least 80% coverage of antiretroviral among pregnant women living with HIV, and an additional seven countries in Sub-Saharan Africa reported coverage between 50% and 80% (Report of the UN Secretary-General, 2011). As a result, 370 000 children were estimated to have contracted HIV during the perinatal and breastfeeding period in 2009, down from 500 000 in 2001 (UNAIDS, 2010).

However, with the year 2011 as a historic marker in the global response, the epidemic continues to outpace the response, underscoring the need to revolutionize efforts to prevent new infections (Report of the UN Secretary-General, 2011). The reports on HIV/AIDS indicate that HIV continues to weigh heavily on maternal and child mortality in some countries, and the world is still far from achieving the goal of protecting newborns from becoming infected (Report of the UN Secretary-General 2011, & UNAIDS 2010).

Having more than six million people receiving AIDS treatment marks the greatest public health achievement, but it represents only 35% of the population in need of HIV therapy (UNAIDS, 2011). The majority of people in need still lack access to the HIV treatment (Report of the UN Secretary-General, 2011). At the same time, non-adherence to HIV therapy (ART) still represents a significant challenge to the effective AIDS response in the world.

ART is not a cure for HIV infection and AIDS. It is a therapy that prolongs life by inhibiting viral replication. By reducing the viral load and easing the burden on the immune system, infected individuals are able to survive much longer than in the absence of the therapy (Andersen, 2011). Non-adherence, therefore, increases the risk of viral mutation which can result in cross-resistance to other medications or transmission of multiresistant virus strains, and thus the risk of initial therapy failure in subsequently infected individuals (Glass *et al.* 2006).

Non-adherence is perceived as the major problem and subsequently an obstacle to effective delivery of ART in Sub-Saharan Africa, especially in South Africa. This study was contacted with the intention of identifying reasons and causes of non-adherence in South Africa, particularly at Leratong Hospital in Johannesburg.

1.2 BACKGROUND AND RATIONALE

South Africa is experiencing a problem of high HIV prevalence which weighs heavily on the health care system. Estimates of prevalence come from surveys of specific groups (women attending antenatal clinics, STD clinic attendees, etc.) which are broadly representative of the general population (Whiteside *et al*. 2005). Determining the exact numbers of PLWHA in the country is barely possible, due to the fact that some people do not come forward for testing. For statistical adjustment that account for delays in reporting to the health department and missing risk factor information, estimated numbers are always used (CDC, 2009). This study, therefore, depends on the estimated HIV prevalence to reveal the current AIDS situation in South Africa.

1.2.1 The History of AIDS in South Africa

The first two cases of AIDS were identified in South Africa in 1982. For the first eight years, the epidemic was primarily located among white male homosexuals (Whiteside & Sunter, 2000). Quickly the disease spread outside of the gay population and by 1991, the heterosexual transmission rate equaled the rate of new infections among men who had sex with men. By mid-1990s, HIV rate had increased by 60% (Cichocki, 2011). At current, the country is characterized by high HIV prevalence rate, and low life expectancy.

1.2.2 The current status of HIV/AIDS in South Africa

South Africa is among the African countries which are most severely affected by the HIV/AIDS pandemic with the adult prevalence rate of 17.8% (UNICEF, 2010). It is 30 years since the first diagnoses of HIV, but the country's epidemiological situation is still marked by as large numbers as 5.6 million of PLWHA, (UNAIDS, 2010). Infection levels are highest among young females (Cichocki, 2011), and middle-aged men. Almost one in three women aged 20 to 29- and more than a quarter of men aged 30 to 34 are living with HIV in the country (White, 2010).

As indicated by The South African Department of Health Study (2009), the HIV antenatal prevalence by province ranged from a high of 39.5% (KwaZulu-Natal) to a low of 16.9% (Western Cape). Mpumalanga, which is the second worst affected, Free State, Gauteng and North West recorded prevalence higher than the national average of 29.4%. Eastern Cape, Limpopo, Northern Cape and Western Cape recorded prevalence below the national average of 29.4%.

An estimated 263 900 people died of AIDS in South Africa in 2009. There were a total of 1.91 million South African orphans due to the HIV/AIDS epidemic in the same year. The number of new HIV infections among adults aged 15 and more, was alarming estimated at 354 000, (Statistics South Africa, 2009).

Heterosexual sex is recognized as the predominant mode of HIV transmission in the country, followed by mother-to-child transmission (MTCT). The factors driving the epidemic include migration, low risk perceptions, multiple concurrent partnerships, intergenerational sex, low

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condom use, excessive use of alcohol, and low rates of male circumcision (USAID, 2011). Research on the burden of HIV among men who have sex with men (MSM) is currently being conducted in South Africa and is not a major source of HIV infection at present (Shisana *et al*. 2008).

The direct measurement of HIV incidence is extremely challenging, and there is presently no consensus in South Africa on the best method for measuring HIV incidence (Shisana *et al*. 2008 in UNGASS, 2011). However, efforts are made on a continuous basis within the research community to reach consensus on the best tool and methodologies for measuring HIV incidence. The epidemic trends in the country are measured through two methodologies namely: the annual antenatal HIV prevalence survey and various population or household-based surveys which suggest that the country's epidemic is stabilizing (USAID, 2011).

The economic impact of the AIDS epidemic is very severe, especially at household and community levels. Through deaths of young productive citizens, AIDS worsens dependency ratios and makes living standards deteriorate (Haacker, 2004:47). According to Ashford (2006), households experience the immediate impact of HIV/AIDS because families are the main caregivers for the sick and suffer AIDS-related financial hardships. During the long period of illness caused by AIDS, the loss of income and cost of caring for a dying family member can impoverish households (Ashford, 2006). The pandemic continues to be a serious threat to national economic security as it targets young, productive and innovative groups in South Africa.

1.2.3 The HIV/AIDS epidemic in Gauteng

Gauteng records one of the highest HIV prevalence rates of 29.8%, slightly above the national average of 29.4% (The South African Department of Health Study, 2009). Being the country's economic heartland, the province is characterized by the constant influx of migrants from other provinces; and neighbouring countries, who flock into Gauteng cities for employment opportunities, and this exacerbates the conditions of HIV/AIDS in the province.

In Gauteng, HIV prevalence rate among women (aged 15-49) attending antenatal clinics was 29.9% in 2008 alone. 46% of the population of children in need, under the age of 15 started ART

in the same year, while the estimated rate of HIV transmission from mother-to-child was 10.9% in 2009, (Yezingane Network: Provincial Profile, 2010).

According to MRCR (2001 in Denies, 2007), the population most vulnerable to HIV infection are people residing in informal urban settlements, who are between the ages of 25 to 34. Females living under these conditions are more at risk of infection than their male counterparts.

1.2.4 National Response to the AIDS epidemic

South Africa has shown a high level of commitment to providing care and treatment for PLWHA, and prevention interventions for the reminder of the population (USAID: HIV/AIDS Health Profile-South Africa, 2011). The country has implemented a range of measures both at national and provincial levels to fight the epidemic and mitigate its impact. A national AIDS plan was published in 1994 – 1995 and a Partnership against AIDS launched in 1998. SANAC was also established in 1999 (UNESCO, 2004). SANAC was formed to strengthen the political leadership as well as to ensure inclusion of civil society in the overall response to HIV/AIDS. The objective behind the establishment of the council was mainly to advise government on HIV/AIDS and STI policy and strategy (South African Government Information, 2009).

As indicated in HIV/AIDS Health Profile – South Africa (USAID, 2011), the government has since 2000 developed many policies and programmatic responses to ensure that there is a multisectoral response to HIV/AIDS. Campaigns came to exist in an effort to mitigate the HIV/AIDS epidemic in the country. These include education campaign aimed at imparting AIDS education to the nation, communication campaign, and HIV counseling and testing.

For dissemination of information and proper understanding of the nature of the epidemic HIV/AIDS is, many HIV/AIDS communication programmes came to exist. These include communication programmes conducted by NGOs; programmes within the workplaces and institutions of learning such as schools and universities; provincial government programmes and interactive communications that include community-level campaigns such as door-to-door activities, not to mention four national-level HIV/AIDS communication programmes utilizing the media, (Shisana *et al*. 2009).

On World AIDS day, under the theme 'I am responsible, we are responsible, South Africa is taking responsibility', new policies and measures to tackle HIV/AIDS, as well as a new HCT campaign to be taken in 2010, were announced. Included in the new policy on HIV/AIDS were:

- Treatment for all HIV-positive infants under the age of one, regardless of their CD4 count,
- AIDS treatment to be initiated at a CD4 count of 350 or below for pregnant women and TB-HIV co-infected patients,
- Mobilize testing for HIV through a mass national VCT campaign, and
- HIV positive pregnant women with a CD4 count above 350 to start ARVs at 14 weeks as part of the PMTCT of HIV programme (UNGASS Country Progress Report, 2010).

Antiretroviral therapy in South Africa

The first project to routinely offer ART in the public sector and on a district wide basis in South Africa was started in Khayelisha in May 2001, (Coetzee *et al*. 2004 in Andrew *et al*. 2008) followed by a project in Gugulethu in September 2002, (Andrew *et al*. 2088).In April 2004, the national antiretroviral treatment (ART) programme was launched in the country (WHO, 2011), and it became the largest antiretroviral treatment programme in the world. This has been provided in around 500 public sector health facilities, mainly hospitals, and also some community health centers and clinics, (UNGASS Country Progress Report, 2010).

By March 2006, there were 16 234 patients receiving ART (87% adults) across 43 sites, the majority being treated in primary-care settings; 67% in clinics and community health centres, and 13% in district hospitals (Andrew *et al*. 2008). Enrollment increased steadily, and by the end of 2009, around one million people were introduced and enrolled to ART (UNGASS Country Progress Report, 2010).

South Africa currently provides ART for free to HIV-positive patients whose CD4 count is 350 cells/mm3 (used to be 200), as per WHO recommendations. Pregnant women as well as TB-HIV co-infected patients were eligible to begin ART at the CD4 count of 350 cells/mm3 but now are

recommended to start HIV regardless of their CD4 count (Updated ART Treatment Guidelines: WHO and South Africa).

As it seems, the HIV/AIDS prevention interventions and treatment are bearing fruit in the country. UNAIDS (2010) mentioned South Africa among 22 of 33 Sub-Saharan African countries in which the biggest epidemics (including HIV/AIDS) have stabilized or are showing signs of decline. According to UNAIDS, the country has achieved almost 90% coverage of treatment to prevent mother-to-child transmission of HIV, and the result is that transmission to infants has been drastically reduced.

Researchers have discovered encouraging signs that change in prevalence and incidence are now occurring. HIV prevalence at national level has decreased among children aged 2-14, from 5.6% in 2002 to 2.5% in 2008, and HIV prevalence has decreased among youth aged 15-24 from 10.3% in 2005 to 8.6% in 2008. However, HIV prevalence remains disproportionately high for females overall in comparison to males, more than twice as high as that of males in the age groups 20-24, and 25-29, (Shisana *et al*. 2008).

1.3 RESEARCH PROBLEM

The current situation shows that efforts are made to mitigate the disease and help those living with HIV to live longer by way of providing free ART treatment. However, one can still observe that medication adherence is still a problem among PLWHA, even after being told several times about the importance of ART to their lives.

In some cases, the conditions of patients cannot be described in any form other than 'not extrinsically or intrinsically motivated to be adherent' if not 'fearing to take their ART medication '. But the bottom line is, some patients either take their medication irregularly, which is against their health providers' instructions, stop taking it at all or miss the dates scheduled for appointments. In any case, the reasons behind non-adherence may be complex. Circumstances beyond the patients control may be responsible for high levels of non-adherence in the country.

HIV/AIDS accounts for at least 43% of deaths in the country (Statistic South Africa, 2009), and this could obviously be one of the consequences of patients defaulting from ART treatment. The

causes differ from one area to another depending on the demographic characteristics of the patients, level of competence, dedication and commitment among the health personnel and economic situations in the community. But whatever the case may be, poor adherence and defaulting from treatment are the main challenges faced by ART programme in South Africa.

1.4 RESEARCH QUESTION

What are the reasons behind non-adherence to antiretroviral therapy (ART) among people who are living with HIV/AIDS?

1.5 SIGNIFICANCE OF THE STUDY

This study therefore, sought out to investigate and finally reveal the barriers, reasons and causes of non-adherence of PLWHA to antiretroviral therapy at Leratong Hospital. Key findings from this study will provide the Department of Health in Gauteng province, donors, policy makers and all other stakeholders with comprehensive information that will enable them to devise other strategies and appropriate mechanisms to raise the levels of ART adherence among those on ART treatment in the country.

Contributing to the evidence base for ART adherence should assist the Department to come up with the plan of improving uptake of drugs, ensure effectiveness of ART treatment and try to prevent the development of drug resistance. In the final analysis, the study will contribute to reduce early AIDS related deaths which bring about loss of skilled labour in the country, thus; threatening economic security.

1.6 AIM AND OBJECTIVES OF THE RESEARCH STUDY

1.6.1 Aim

To establish the main causes of non-adherence to ART medication at Leratong hospital in order to make recommendations to address ART non-adherence.

1.6.2 Objectives

(a) To establish factors contributing to non-adherence,

(b) To establish the process of ART delivery to the patients,

(c) To obtain health providers and patients view of the ART programme, and

(d) To make recommendations for effective delivery of the programme.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

The treatment of HIV/AIDS has evolved in the last 30 years since the beginning of the epidemic from no treatment to treatment with a single drug (AZT) to dual-drug therapy and, now to HAART, a treatment with at least three active antiretroviral medications (ARVs), either two NRTI's with PI or two NRTI's with a NNRTI (NYU Medical Center, 2009). Still, it is currently impossible to eliminate HIV/AIDS pandemic using available therapies. In the absence of cure, ART remains the only available option that offers the possibility of dramatically reducing HIV/AIDS-related morbidity and mortality, while improving the status of PLWHA (Wekesa, 2007).

As Andersen (2011) indicates, the purpose of ART is immune reconstitution, a process in which the therapy inhibits the viral load or suppresses the disease, thus, allowing the immune system to recover and regain its function. Immune reconstitution is associated with a replenishment of the destroyed CD4 or T cells and improvement in their function to fight the intruders and reduce the risk of HIV-associated diseases, thus, delaying progression to full blown AIDS (Andersen, 2011; NYU Medical Center, 2009).

Ever since the introduction of ART in the treatment and management of the HIV/AIDS epidemic, HIV infection has entered the stage of chronic disease management (Tracy *et al*. 2006). However, success of the therapy is dictated by proper clinical management and most importantly, effective involvement of patients as active agents in their own care and treatment (Webber, 2004). ART requires that patients maintain nearly perfect ($\geq 95\%$) adherence to the prescribed regimens (Mayer & Stone, 2001). However, non-adherence to ART medication regimens marks the major public health problem in the successful management of HIV/AIDS.

Medication non-adherence is most simply defined as the number of doses not taken or taken incorrectly that jeopardizes the patients' therapeutic income. Non-adherence can take a variety of forms, including not having a prescription filled, taking an incorrect dose, taking a medication at the wrong time, forgetting to take doses, or stopping therapy at all, (Bethesda, 1997).

At an individual level, failure to realize adequate levels of adherence is reflected in the effect of treatment on virologic, immunologic and clinical outcomes (Veenstra & Whiteside, 2010). Poor adherence to HAART leads to the exposure of the virus to inadequate concentrations of ARV medications. This in turn leads to ongoing viral replication, development of resistance to ARV medications and increased vertical transmission (Igwegbe *et al*. 2010), thereby quickening the virus progression to full blown AIDS stage. In harmony with the aim of the study, this part focuses its attention mainly on ART adherence and the reasons and barriers of adherence after initiation of ART.

2.2 ART ADHERENCE MEASUREMENT

The measurement of ART adherence of patients has been a major challenge because of the subjective and private nature of pill taking behaviour in ambulatory patients. This challenge is caused by the fact that adherence is not only affected by patients' behaviour alone, but also by health system, socioeconomic, disease-related and drug-related factors (Steel *et al*. 2007). Although no gold standard exists for the precise measurement of adherence to ART in clinical care, levels of adherence can be estimated by a number of approaches (AIDSTAR-One, 2010), which are direct and indirect.

Direct and objective measures include: DOT in which the health care workers directly administer medicines to patients and observe them taking the medicine (Steel *et al.*);TDM, which involves measuring drug levels in the blood; biological markers where monitoring viral load is used as an indicator of effectiveness of treatment and, thereby, of medication intake, (AIDSTAR-One, 2010) and MEMS. According to Poppa *et al*. 2004; Population Council *et al*. 2004 (in Wekesa, 2007) MEMS is a method that uses an electronic device that is fitted on the lid of the medication bottle. This device records the time and date of opening and closing the lid, which is assumed to coincide with intake of the medication. MEMS is considered to be the current state of the ART method of evaluating adherence, largely because adherence is most predictive of clinical outcome when measured with this methodology (Bangsberg *et al*. 2001; Arnsten *et al*. in 2001 in Steel et al, 2007).

As cited by Steel *et al.* (2007), indirect measures include: pharmacy refill records where patients collecting their medications regularly on due dates are assumed to be adherent; self-report (including CASI) – the most commonly used method, especially in resource-poor settings, in which the patients are asked to report on their own adherence through a series of questions (Wekesa, 2007); pill count, in which health care providers, pharmacists, and providers of DOT count the pills and the number of remaining pills is assessed to measure adherence to treatment over a specific period of time based on the refill date and daily dosage , (AIDSTAR-One, 2010); visual analogue scale, where the patient is asked to place a mark somewhere along the line from 0 to 10 that best describes their adherence to the prescribed ARVs. The last measure is PIT, which involves inviting patients to distinguish the pills in their regimen from a display of ARVs, including two 'twin pills' which are similar but not identical (Brown *et al*. 2004 in Steel *et al*. 2007). This is done to provide further evidence that the patient has a thorough understanding of how to take prescribed medicines (Steel *et al*).

2.3 THE MAGNITUDE OF NON-ADHERENCE

In all chronic diseases, non-adherence is a global problem. According to WHO (2003), adherence to long-term therapies in the general population is around 50% in developed countries, and is much lower in developing counties. In the treatment of HIV/AIDS, adherence to ARV agents varies between 37% to 83%, depending on the drug under study, (Stein *et al*. 2000; in WHO, 2003).

Different studies which were conducted in South Africa resulted in different levels of adherence. In the study that was conducted in Gauteng Pretoria, which evaluated 180 patients enrolled on ART between July 2004 and August 2005, only 52.2% of the participants reported taking at least or over 95% of their prescribed doses (Malangu, 2008). In another study that took place in Cape Town, in which 289 patients accessing treatment were evaluated, 63% of patients maintained adherence of 90% (Steel *et al*. 2007). It is estimated that 50% of prescriptions filled are not taken correctly .Generally, more that 10% of patients report missing one or more medication doses on any given day, and more than 33% reported missing doses in the space of two to four weeks (Chesney 2000; in Steel *et al*. 2007).

2.4 THE REASONS FOR NON-ADHERENCE

As revealed in studies conducted in both resource poor-settings and resource rich countries, it is quite clear that non-adherence to the strict ARV regimens is common for a variety of reasons which include:

2.4.1 Financial constraints.

Studies looking at adherence in resource limited-settings draw out a number of additional and generally more prevalent concerns highlighting economic burdens borne by patients and their families in accessing AIDS treatment (Veenstra *et al*. 2010). These burdens include the cost of medication, the cost of user fees, an inability to care for other members of the family during medical visits, and absenteeism from work (Castro, 2005 in Wanjohi, 2009; Veenstra *et al*. 2010). Even in the context of free drugs, the cost of transportation to obtain ARVs is one of the reasons given for non-adherence. Inability of patients to afford medication and the tendency to sell own drugs because the money is needed for something else also contribute to non-adherence, (Daniel, 2004; Yu in Uzochukwu *et al*. 2009).

2.4.2 Medication side effects

Investigators have reported finding an association between the occurrence of side effects during treatment with ART and decreased adherence to ART (Hechet 1998, & Stone *et al*. 1998 in Mayer & Stone 2001). Different drugs have different side effects some of which cause stomach irritation or nausea and others cause cramps and diarrhea. Some drugs are associated with sleeping disturbance, loss of concentration, nightmares and depression (Andersen, 2011).

Different drugs have different toxicity profiles (Andersen, 2011). As revealed by Fomundam, (2010), the use of PIs is likely to make the level of glucose rise, resulting in hyperglycemia. This subjects the victim to severe headache, fatigue and the patient might end up having vaginal and skin infections, nerve damage causing painful cold or insensitive feet, loss of hair on the lower extremities and many effects. PIs can also cause increases in the blood lipids (fats) and may

precipitate diabetes. Certain drugs such as AZT affect blood cells and may lead to a fall in the red-blood cells (anaemia) or white blood cells (leukopenia). Efavirenz causes depression, nightmares and psychosis (Andersen, 2011).

The researchers show that other anti-HIV medications have deadly side effects, (Andersen, 2011; Fomundam, 2010). Long term use of NRTI's can lead to fatty changes of the liver and the life-threatening disturbance in metabolism called lactic acidosis; and NRTI, NNRTI and TI proved to be the cause of hepatotoxicity, which is 'a general term for liver damage'. Fomundam goes further to indicate that, this toxicity can cause liver failure and death. Some non-preventable diseases such as lipodystrophy, (a condition characterized by changes in body-fat distribution), are a result of using anti-HIV medications such as (Zerit) NRTI and PIs. NRTIs, especially Zerit (stavudine), Videx (didanosine), and Retrovir (zidovudine), are associated with lactic acidosis and hepatic steatosis. NNRTIs, especially Viramune (nevirapine), are associated with hepatitis and hepatic necrosis, (AIDSinfo, 2005). Indinavir forms crystals in the kidney and urine and if the patient does not drink enough water, it is likely to lead to kidney damage or painful kidney stones (Andersen, 2011).

Researchers have discovered that deformation can be one of severe anti-HIV medication toxic effects (AIDSinfo, 2005; Fomundam, 2010). PIs increase a person's risk of developing osteopenia and osteoporosis (AIDSinfo, 2005). These are bone diseases characterized by the deterioration of bone tissue. People with these diseases are at a high risk of bone fractures, as the diseases cause the bones to become more fragile. The fracture may cause neck or back pain, bone pain or tenderness, loss of height and stooped posture, (Fomundam, 2010). If the bone becomes fragile, it is easy for the bones of a victim to be unable to carry him, resulting in deformation. The patients with side effects might logically be expected to reject medication (Blackwell, 1976) because some anti-HIV medications have excruciatingly painful side effects and can cause severe physical discomfort.

Even though ART improves survival of those infected with HIV, its use can be associated with adverse changes in body composition (Kim & Rutstein, 2010). Changes in the distribution of body fat that are associated with ART can be disturbing to patients. The loss of facial fat, especially around the cheek-bones make people look emaciated and feel that their HIV status is visible to everybody. Other changes are increased fat between the shoulder blades, on the

stomach, buttocks and breasts, (Andersen, 2011). In the study that was carried out to evaluate the metabolic and body composition changes among northern Indian patients receiving combination ART, in which 68 adult patients were studied in the period of six months after which the body mass index, waist circumference, total body fat and lean body mass had increased significantly, (Gupta *et al*. 2010). Changes in body compositions are the most disturbing consequences of taking ART on the part of some patients (Andersen, 2011).

The findings that experience of side effects is the commonest reason for non-adherence are plausible because, in the early period of treatment in particular, side effects occur relatively frequently and they have potential to substantially reduce the quality of life (Uzochukwu *et al.* 2009).

2.5 BARRIERS TO ADHERENCE TO ART

Despite the critical need for strict adherence to the medication regimens, barriers to ART adherence have increasingly become the major problems and center of attention in recent research studies conducted both in high-income and resource-limited countries. Factors affecting medication adherence are generally the same, but the difference is brought about by literacy levels, demographic characteristics of patients and economic situation from one place to another.

2.5.1 Patient related barriers

Barriers to treatment adherence include factors related to individuals such as forgetting, busy time schedules, excessive alcohol intake, poor disease and treatment literacy (Manda, 2011), low level of academic education which is associated with low levels of understanding of medical instructions (Kalichman *et al.* 2000 in Kagee, 2008). Other barriers to adherence are poor self-confidence, beliefs about the efficacy of the treatment and alternate therapies. There are eight other reported barriers falling under category of beliefs. These include side effects (real or anticipated), complicated regimens, taste, size, and frequency of dosing; having doubts about combination ART efficacy, feeling fine or healthy, decreased quality of life while taking

medications; feeling too sick and being uncertain about long term effects of HIV treatment (Mbori-Ngacha ,2004; Weller, 2004).

Depression and other psychiatric illnesses have been shown to be related to poor adherence to ART regimens as well as having a significant impact on the overall quality of life for PLWHA in both high-income and resource-limited countries (Amberbir *et al*. 2008; Byakika-Tusiime *et al*. 2009; Dalessandro *et al*. 2007; Starace *et al*. 2002 in AIDSTAR-One, 2010). Among general medical patients, researchers discovered that depressed patients are three times less likely than non-depressed patients to adhere to medical treatment (DiMatteo *et al*. 2000 in Kagee, 2008). Furthermore, depressed persons may be too unmotivated or fatigued to attend clinical appointments and may be overwhelmed by helplessness and hopelessness to the extent that they may question the purpose of optimal adherence. A diminished ability to think and concentrate, which is symptomatic of depressive episode, may negatively influence their memory to take their medication on time (Kagee, 2008).

Other factors associated with poor adherence include barriers such as wanting to be free of medication or preferring a natural approach due to treatment fatigue; feeling that treatment is a reminder of HIV positive status, wanting to be in control and lack of self-worth (Castro, 2005; Nikayemba *et al*. 2005; Mills *et al*. 2006 in Wanjohi, 2009). Unemployment, unstable living conditions, and lack of effective social support networks are factors reported to have a significant effect on adherence (AIDSTAR-One, 2010). Social support for adherence is obtained from different sources such as partners, children, friends and relatives (Wekesa, 2007). Scholars have identified that difficult family circumstances contributed by high migration rates, teenage pregnancy, overcrowded living conditions, family violence, substance abuse are conditions that may lead to poor social support in South Africa, resulting in compromised adherence rates (Kagee, 2008).

2.5.2 Health care team and system-related factors

Health system barriers such as inaccessibility of ART in health centers were reported to have had a significant effect on adherence to HIV treatment. In researches conducted in resource-poor settings, the frequent ARV drug stock-outs at several facilities, irregular and untimely supply of

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medication to patients, the inability to purchase more due to financial constraints were the major concerns compromising the rates of adherence to ART (AIDSTAR-One, 2010; Makhtar-Yola *et al.* 2006; Uzochukwu *et al.* 2009). Poor adherence to treatment was also the result of the lack of access to the health facility to pick up medications due to distance to the facility, constrained facility hours, and waiting times (Hardon *et al.* 2007; Kip, Ehlers, and van der Wal 2008; Weiser *et al.* 2003 in AIDSTAR-One, 2010).

Other barriers in this category are brought about by healthcare workers with a poor understanding of the dynamics of adherence, thus: achieving adherence is an interactive process, and that, achieving adherence is not a one-time-only event, resulting in failure to engage the patients as active agents in their therapy; overworked staff with insufficient time or energy to engage the patient effectively; poor linkages between the healthcare team and PLWHA community support groups; healthcare workers with a poor understanding of the client (Weller, 2004) and the therapy. When initiating new medications, physicians often fail to communicate critical elements of medication use, and this contributes to misunderstandings about medication directions or necessity and, in turn, leads to patient failure to take medication as required (Derjung, 2006).

Another barrier of paramount importance in the delivery of the therapy and its adherence is patient-healthcare provider relationship. A poor healthcare provider-patient relationship is highly associated with non-adherence as it blocks interaction between the two parties being the patient and health workers, and gives birth to negative attitudes on the part of the patient (Adherence to Medical Advice, 2011). Researchers found that patients are more compliant if their physician is warm, caring, friendly and interested, and, a successful healthcare provider-relationship requires a mutual respect, honesty and openness, which most healthcare practitioners lack. Such a relationship allows patients to benefit maximally from the healthcare knowledge and skill, and the health worker will be more likely to respond appropriately to the patient's needs and expectations. In the absence of this relationship, patients do not take medication as prescribed (Costello).

Research has demonstrated that adherence can be facilitated when a patient-provider relationship incorporates trust, good communication, adequate education about medication, and an overall

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perception of caring, including a culturally and linguistically appropriate approach to the relationship, (Peralta *et al*. 2007).

2.5.3 Fear of stigma and disclosure

High levels of stigma within the communities due to lack of education and awareness of HIV often leads to reduced levels of adherence to HIV treatment (AIDSTAR-One, 2010). Stigmatizing attitudes and actions include discrimination, avoidance, ridicule, harassment and even forceful removal of PLWHA from their homes (Rao *et al*. 2007; UNAIDS, 2005 in Wekesa, 2007). If PLWHA are seen by member of their social constellation such as neighbours, family members, or friends, to be taking ART, this is likely to convey a signal that they are HIV positive (Kagee, 2008). As a result, patients are likely to have frequent treatment interruptions since their tablets must be hidden and therefore not taken in the presence of others for fear of being stigmatized (Uzochukwu *et al*. 2009). This in the end gives birth to attempts to change dosing schedules or suppress observable side effects of treatment (kagee, 2008). According to Klitzman *et al*. (2004 in Kagee), even disclosure to others may result in negative attitudes that may inhibit adherence to medication regimens.

2.5.4 Daily life schedules

Studies show that adherence is affected by disruptions in daily life schedules which include travelling out of town for work or to visit family, long hours of absence from home, and not bringing medication (Watt et al. 2009 in Herstad, 2010), trouble incorporating work and family responsibilities with ART, and being too busy or distracted to comply properly (Manda, 2011). Other include difficulty of balancing the numerous dietary requirements associated with HAART; and having no time to refill prescriptions or other pharmacy related problems and difficulties with a particular dose, the middle-of-day or early-morning dose (Castro, 2005; Mills et al. 2006 in Wanjohi, 2009).

2.6 SUMMARY

The factors intruding upon the patients' decision to adhere to ART medication regimens were derived in many adherence quantitative studies and presented in the same sequence used by WHO. Researchers classified factors which influence adherence to treatment into four categories: therapy related factors which include side effects, complexity of regimen, food requirements, frequent changes in treatment and duration of treatment; healthcare team and system related factors being healthcare provider-patient relationship, clinical setting and service delivery factors such as counseling and appointment schedules; condition related factors which are illness related demands, and co-morbidities such as depression; and patient related factors which include psychological stress, anxiety about possible adverse effects, low motivation, lack of self-perceived need for treatment, poor literacy, beliefs about the efficacy of the treatment and alternate therapies, and medication fatigue, to mention but a few. The above mentioned non-adherence factors were further investigated in this study to examine the extent to which they were applicable to the study population (Weller, 2004; WHO, 2003).

CHAPTER 3: RESEARCH DESIGN AND METHODS

3.1 INTRODUCTION

This chapter sets out to explain methodology used in the entire study. It looks at the study setting; study design; research participants and sampling; data collection and data analysis technique; and ethical considerations. The above mentioned phases were considered in chronological order.

3.2 THE STUDY SETTING

Gauteng is situated in the northern-eastern part of the country, and it is landlocked by Limpopo in the north, Mpumalanga in the east, Free State in the south and North West in the west (Bradshaw *et al*. 2000). It comprises mainly of the three urban areas of Pretoria, Vereeniging and Johannesburg. Although the smallest province in surface area, it contributes 33% to the national economy and a phenomenal 10% to the GDP of the entire African continent (Bradshaw *et al*. 2000; South Africa.info, 2011). This contributes to influx of migrants who flock into the city of Johannesburg in search of job opportunities. Johannesburg is the capital, and the biggest city, not only in South Africa but in Africa as a whole. It is a single municipality that covers over 1645 square kilometers (Africa.info, 2011). Except for HIV/AIDS, homicide and road accidents feature highly for men and women as the leading causes of death in the province (Bradshaw *et al*. 2000).

The study was conducted at Leratong, a regional hospital based in the Western part of Gauteng Province in Johannesburg. The hospital has a bed capacity of 900, and it serves as a catchment area of 1.5 million people. The hospital key health problems are HIV/AIDS, Tuberculosis and Trauma (South Africa.info, 2011; Leratong hospital trauma unit gets major upgrade, 2011). It is a huge hospital with different sections. HIV/AIDS section named Kgothalang Clinic commenced its AIDS-related day-to-day operations in 2004. From 2004 to when the study was conducted in November 2011, the clinic ART initiations added up to 10347. Adult women constituted 55% of this number, men 36% and the remaining were children. (October Report, 2011).

3.3 RESEARCH DESIGN

The researcher selected qualitative design in which patients on ART and healthcare providers in the field of HIV/AIDS were interviewed. Thomson (2007) shows that qualitative research method is primarily concerned with 'why something happens'. This is an interpretive research approach, in which the researcher continually attempts to understand the data from the participants' subjective perspective hence it relies on multiple types of subjective data. Important task for the qualitative researcher is to understand the insiders' views, then take the role of objective outsider and relate the interpretive-subjective data to the research purpose and research question (Christensen, Johnson & Turner, 2011).

Since the purpose of the study was to research the reasons why some PLWHA adhere poorly to the treatment or stop taking their medication completely, qualitative approach was the best method of data collection to allow the researcher to explore a variety of issues behind ART non-adherence.

3.4 PARTICIPANTS AND SAMPLING

The sample size was 30 participants who were randomly selected to participate in the study. In this sample size of 30 participants, 24 were patients and six were healthcare providers. The patient-participants, both males and females were approached and requested to be interviewed when they already came to collect their medication at the hospital or had doctor's appointments. The timing of the interview was during the usual clinic visit process and the researcher adapted timing and participation to the convenience of the patient-participants to ensure that the process was not disrupted.

Only the participants who consented to take part in the study were immediately interviewed. The participants were only included if they fulfilled the inclusion criteria, that is, the patients who had been on the treatment for at least six months, 18 and more years old and patients whose physical and psychological conditions had not deteriorated. The six months and above stipulation was necessitated by both the physical and psychological conditions of the patients who have just been initiated to the therapy. In most cases they are still experiencing physical discomfort as a

result of medication side effects; others are still in the process of immune reconstitution, as such physically weak; when other patients are still adjusting to the fact of lifelong treatment, as a result, having a very compromised immune system due to psychological stress they are subjected to by knowledge that their lives are dependent on HIV drugs. In the South African constitution, 18 years of age marks the beginning of adulthood and only adults can, on their own, consent to participate in the study, hence the patients below 18 years of age could not satisfy inclusion criteria.

Healthcare providers' inclusion criterion was that they had to have been in service for at least 12 months. The researcher found a minimum of one-year experience necessary, given the purpose and objectives of the study, which required in-depth interviewing. As a consequence, the respondents' answers had to be more from experience than opinion.

Gender balance of a 1:1 ratio was unattainable. The reason for this imbalance was the lower number of male patients and their reluctance to be interviewed. Most male patients who were approached and asked to participate did not consent. Some men who were willing to take part did not fulfill the inclusion criteria. In the end, 15 female and nine male patients participated in the study. Due to fear of participants experiencing trauma incited by the interview, an experienced counselor was readily available in the nearby room to help the interviewees.

Healthcare personnel comprised of counselors, social workers, doctors, pharmacists and nurses. The doctors and pharmacists had, for the duration of the interviews, tied schedules that they obviously could not squeeze an interview in between the pressures that they had. In the remaining categories the researcher was able to interview at least one health practitioner. With regard to healthcare providers, gender did not count as their interview focused more on the delivery of the ART programme. Experience was the most important in this study. The personnel's service time ranged from two to seven years.

3.5 DATA COLLECTION AND ANALYSIS TECHNIQUE

Tape recorded semi-structured interview was used as an instrument of data collection. Semi-structured interviews are conducted with a fairly open framework which allows for focused,

conversational, two-way communication (Case, 1990), resulting in greater exploration of the issue. Data collection was done through a face to face interview with one participant at the time. Interview schedule consisted mainly of open-ended and closed questions. Probes and rephrasing were used quite often during the interview sessions for patient-participants to understand the questions thoroughly and provide detailed information. The interviews lasted 12 to 30 minutes each, and interviews with the patients were conducted in the closed room at the clinic to make them feel secure and not exposed, while interviews with health practitioners took place in their respective offices.

Thematic Content Analysis (TCA) was later used to generate themes. TCA is analysis that is based on identifying themes in qualitative material, often by means of coding scheme. It is a descriptive presentation of qualitative data, and this qualitative data may take the form interview transcripts collected from research participants or other identified texts that reflect experientially on the topic of study (Anderson, 2007). Distinct thematic units emerging from the interviews were identified, similar and dissimilar units grouped (Anderson), and thematic concerns which emanated from the interview were translated and presented into English.

3.6 ETHICAL CONSIDERATIONS

Permission was sought from Gauteng Department of Health and Social Development (GDHSD). Informed consent was sought from all the study participants who were also guaranteed of confidentiality, anonymity and privacy. All interviews were conducted in a private setting where participants could not feel exposed, and only the researcher interviewed the respondents in one to one interview. The respondents were also assured that no information would be linked to any individual person who participated in the research study. Health workers participating in this research had to sign a confidentiality agreement to protect patient-participants from being exposed either directly or indirectly. All patient-participants were given monetary incentives.

CHAPTER 4: RESULTS AND DISCUSSION

4.1 INTRODUCTION

This chapter sets out to present the qualitative findings of the study, with the patient-participants results presented first and separately from health personnel's and then discussion of findings. Both patients' experiences with the therapy, which could be the causes or barrier to medication adherence for some patients; and the manner in which the patient responded to each challenge, which determined the magnitude of non-adherence; are presented in charts, graphs and tables. The presentation of the findings of this study is mainly descriptive.

4.2 PATIENT-PARTICIPANTS

A total of 24 adult participants consented to participate in the interviews. Of this, 62.5% were females, when males constituted only 37.5%. The number of men attending the clinic was smaller than that of women; and they were unwilling to take part as interviewees in the study, which revealed the fact that women are generally more open than men to talk about their HIV status. Patient-participants' age experience with the therapy ranged from six month to 11 years as demonstrated in figure 4.1 below.
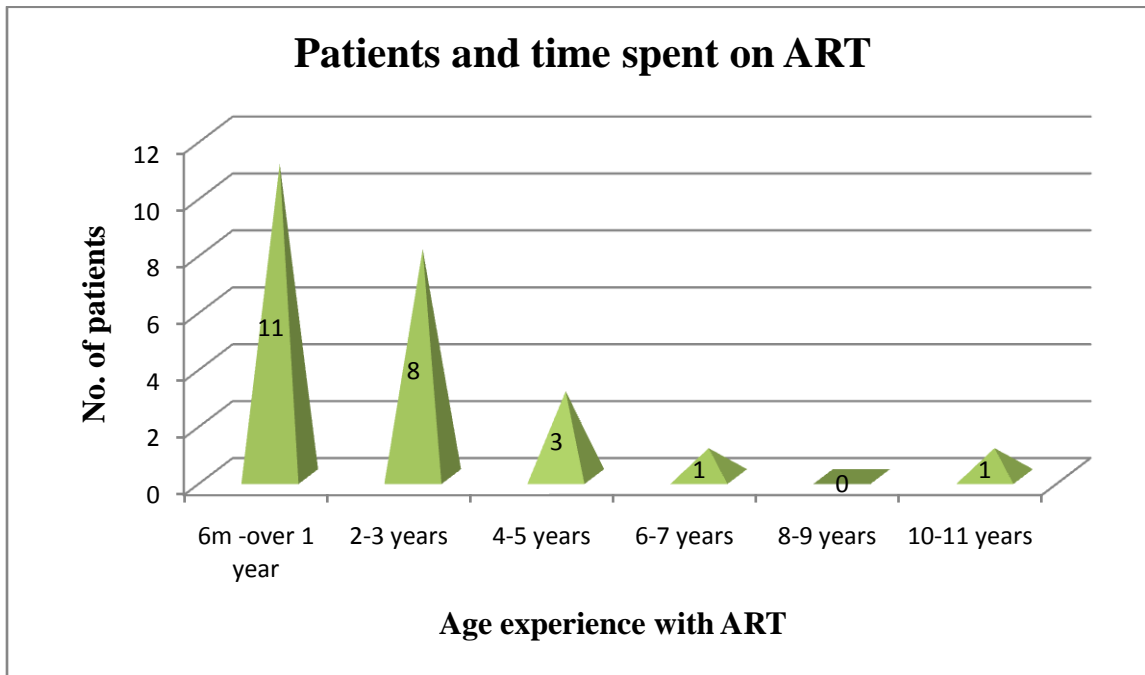
Figure 4.1

Figure 4.1 Distribution of respondents according to age experience with ART

Figure 1 illustrates that 11 participants' (45.8%) age experience, which was the lowest but constituting the majority, ranged from six to 23 months, and the highest age experience with ART was 11 years, but there was only one patient (4.2%) who had been on ART for that long.

4.2.1 Problems experienced with medications

a) **Medication side effects**

When the patients were asked to provide a detailed account on how their bodies responded to medication shortly after ART initiation, 83% reported experiencing side effects some of which were severe. The table below depicts both side effects and the numbers of patients to whom medication caused physical discomfort.

Table 1 Depicting side effects experienced by respondents

GENERAL PATIENTS EXPERICES WITH ART	GENDER DIFFERENCES	TOTAL # OF PATIENTS	PERCENTAGE
Minor side effects included: Nausea, sweating, dizziness, fatigue,	*Males:* 5 *Females:* 5	10	41.7%
Severe side effects included: Body sores, big stomach, big breasts, rush, red lips, diarrhea, painful leg bones, mental disturbance.	*Males:* 2 *Females*: 8	10	41.7%
No side effects	*Males*: 2 *Females*: 2	4	16.7%

Table 1

Table 1 depicts side effects experienced by the study participants. One out of 10 patients constituting 41.7% experienced one, two or three of severe side effects mentioned in the table above, and the same thing applied with minor side effects. Patients who experienced both minor and severe side effects were counted under severe side effects. Although 83% of the patient-respondents reported experiencing side effects, only five (21%) defaulted from ARV treatment. In these five default cases, only two came into being as a result of medication side effects. One default case was due to severe sickness, but this sickness was caused by medication. 8.3% of patients nearly stopped the treatment as a result of severe side effects but 58% did not get even close to defaulting from their ARVs.

The study population consisted of more women than men. Among the defaulters, four were men and one a female. No women reported getting tempted to stop their medication while two close-to-quitting medication cases emanated from male respondents.

b) Medication time-related requirements

When the patients were asked as to how much of a challenge was presented by keeping dates scheduled for appointment and sticking to specified times for taking pills, they provided many various responses demonstrated in the bar chart below.

Figure 4.2
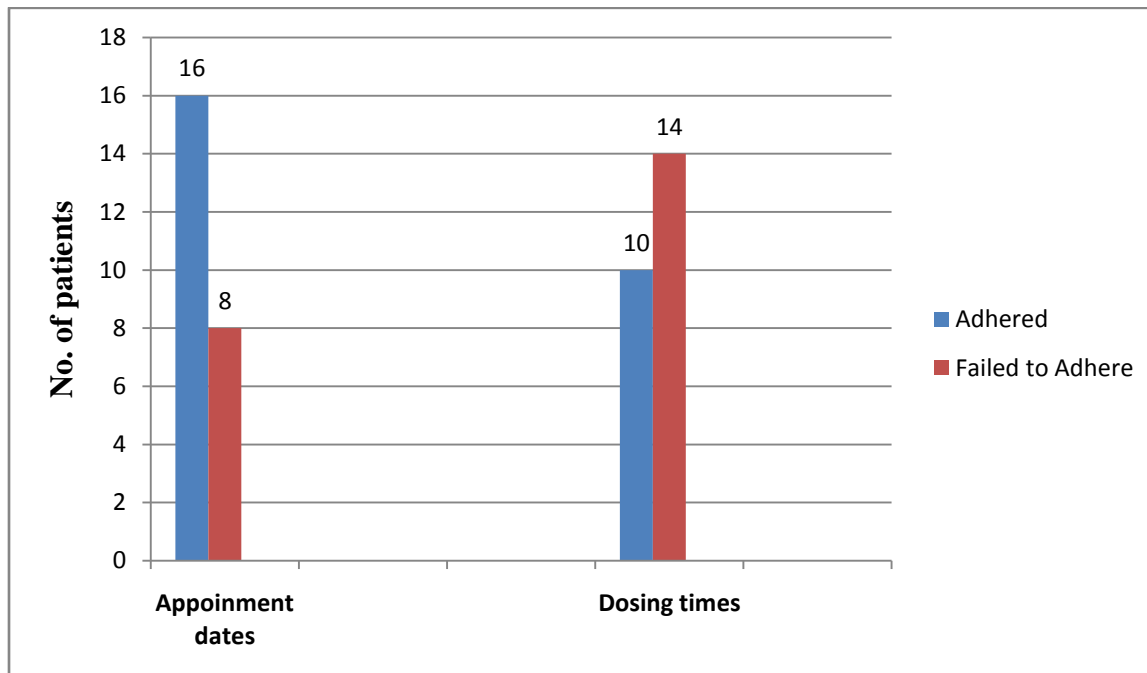
Figure 4.2 Patients' adherence to time

Only 67% never missed a date scheduled for appointments, 33% missed a date once, twice or thrice. The reasons mentioned by the participants were different. Three patients reported appointment time coming when they had defaulted from the treatment, one had fallen sick, two mentioned work commitments denying them time to report at the clinic, and two said they experienced transport problems.

As for dosing times, only 42% of the respondents indicated to have maintained the required adherence levels in that they had never skipped a dose. 58% reported to have skipped several doses since their initiation to the therapy; one time, two or three times in a space of a month, but

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most said they did not allow the whole day to go without them taking their pills; and at times they went through a month-period without a dose being missed.

4.2.2 Reason(s) for missing dose(s) of ARV treatment

The bar chart below shows the reasons for skipping doses and the number of times each was mentioned in the qualitative research interviews.

Figure 4.3
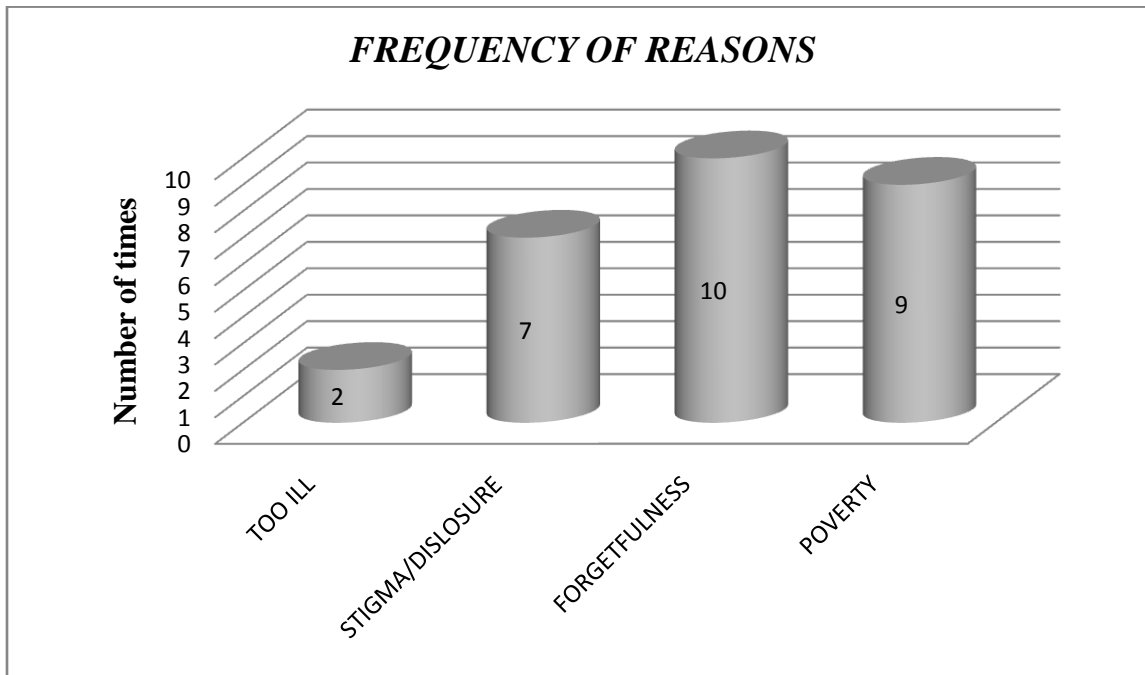
Figure 4.3 Frequency of reasons for missing doses of ART

In some cases, one patient mentioned more than one reason. The most frequently mentioned reasons were forgetfulness and poverty. Forgetfulness was mentioned by 71% of patients who failed to adhere to specified times, as one of the reasons and poverty by 64%. In 64%, two respondents reported failing to keep appointment dates due to lack of transport money. Seven patients reported that they frequently experienced food shortages and could not take medication on empty stomach. With regard to stigma/disclosure, two respondents mentioned staying with a

lover for whom the HIV status was concealed, and that affecting adherence as the patients had to take the tablets only in the absence of the partner. Five patients reported having fear of taking medication in public view, that is, in taxis, at work or at any place where the patients felt exposed to the sight of people.

Two of the five patients reported that they could not take medication at all should the time for medication come when they were in public view, and three said that they found ways to take the pills. They might take them a few minutes late but they made sure that the pills were taken within the timeframe.

4.2.3 Adherence tools used as reminders by patients

The patients who reported having not skipped a dose disclosed different ways in which they were reminded to take their medication. Figure 4.4 below presents adherence reminders mentioned by the respondents.
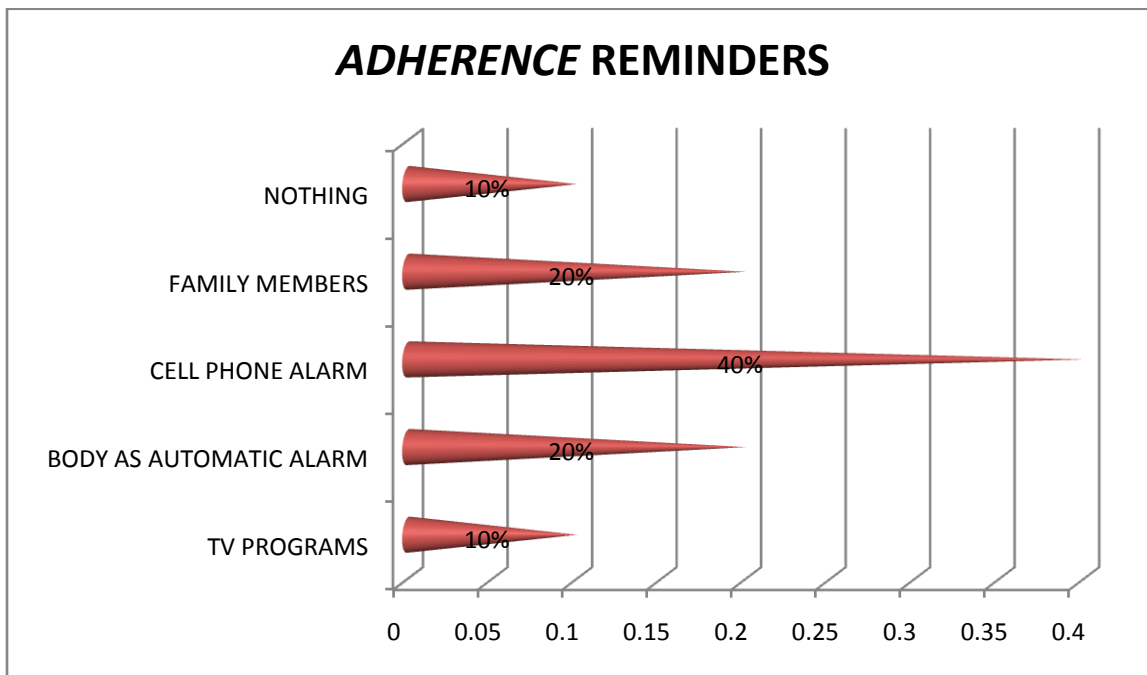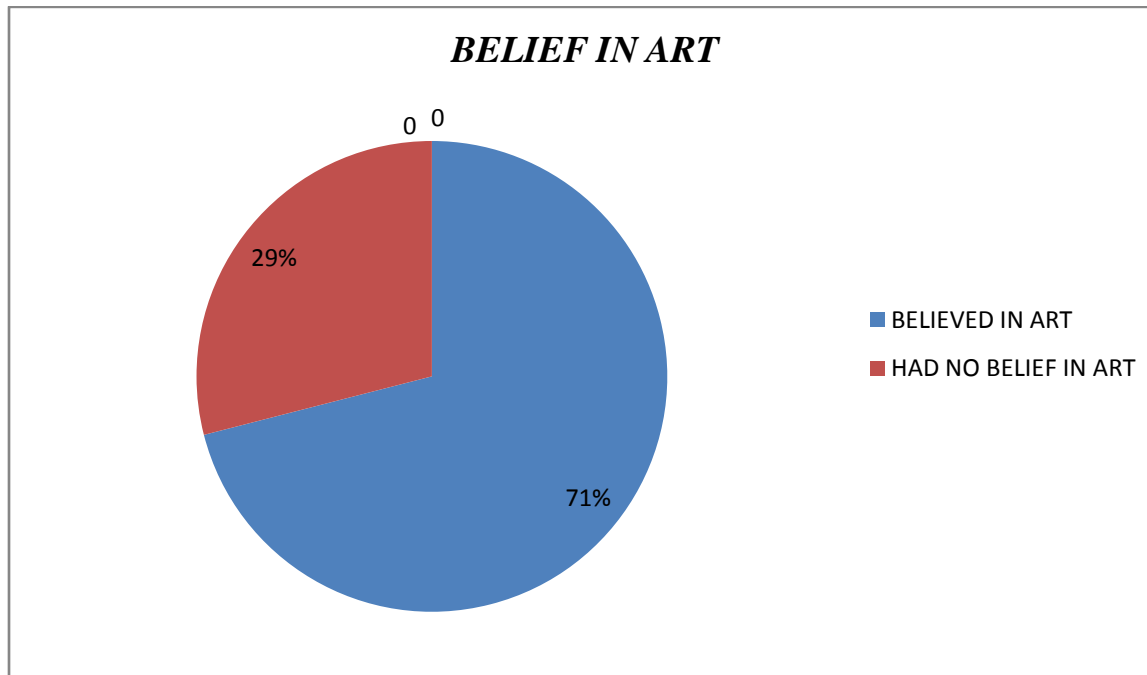
Figure 4.4

Figure 4.4 Presenting adherence tools used by the patients

Four respondents said that they set phone alarm to remind them when the time for medication had come. Two of them mentioned family members, especially their children; two indicated their bodies as automatic alarms for them to take their pills. They stated that they felt when they should take medication; one mentioned TV programs as the reminder and one patient did not use anything as a reminder, the patient just remembered when that time for HIV drugs had come.

When the patients were asked as to how often they came across situations whereby times for medication came when they were far from home; and if that did prevent them from taking their drugs, 71% indicated that they carried their pills with them every time. 17% reported taking their medication only at night, as such, not seeing the need to carry their ARV drugs when they left their respective homes; and the rest indicated that they made sure to take their pills before they left their residential places in the morning, and other doses would be taken in the evening when they were back home. In this 71% of patients who reported taking their pills with them, four were men and 13 were women, and two patients disclosed having problems at work in that, their workplaces were non-eating zones and that preventing them to take the pills when they were at work.

4.2.4 Respondents attitude/perceptions towards ARV treatment

All the patients (100%) had a positive attitude towards ARV drugs although some disclosed that at the initiation stage, they had absolutely no belief in ART. The pie chart below demonstrates distribution of the participants according to their belief in ART at the initiation stage.

Figure 4.5

BELIEF IN ART

- 71% BELIEVED IN ART
- 29% HAD NO BELIEF IN ART

Figure 4.5 Distribution of the respondents according to their belief in ART

Although seven respondents had no belief in ART at the beginning of the treatment, no patient reported stopping medication. Disbelief in the therapy came into being as a result of severely compromised immune system.

One patient believed:

"My health conditions at the initiation stage of the therapy had deteriorated so much that I doubted the potential for ARVs to reform my health and physical conditions, and sustain my life."

When the patients were confronted with the question of how ARVs as a life-long treatment affected their attitude towards the therapy, 88% reported having no problem with ART as a life-long treatment. The remaining 12% found having to take tablets daily irritating.

A respondent admitted:

"*Sometimes it feels unbelievable that my life hinges on these tablets, and their smell, especially in the morning, is disgusting.*"

The common opinion among the respondents was that ARVs should be in the form of three to six months injection. None of these patients reported having stopped medication as a result.

4.2.5 The influence of religion and other social aspects of life

Almost all the patients (96%) did not find their religion as encumbering their medication intake. 4% reported having trouble with the church at the beginning.

The respondent disclosed:

"I encountered a big problem with the church leaders all because they recommended black tea given at the church as a substitute for ARVs."

But for 100%, religion was not a factor. 12% found having to drop some of their social habits such as excessive drinking and smoking a huge challenge at the beginning, or during merry-making times. But all the patients (100%) could not let their social life affect adherence to ART.

4.2.6 Factors emanating from provision of services at the hospital

a) Provision of excellent service

The majority of respondents reported receiving excellent services at the clinic. These included the manner in which the healthcare providers communicated with them while in the queues awaiting medication, the way they were given instructions on how to take medication and how motivating were the counseling processes. The bar chart below provides the statistics of patients who were satisfied and those who were not, concerning the services at the hospital.
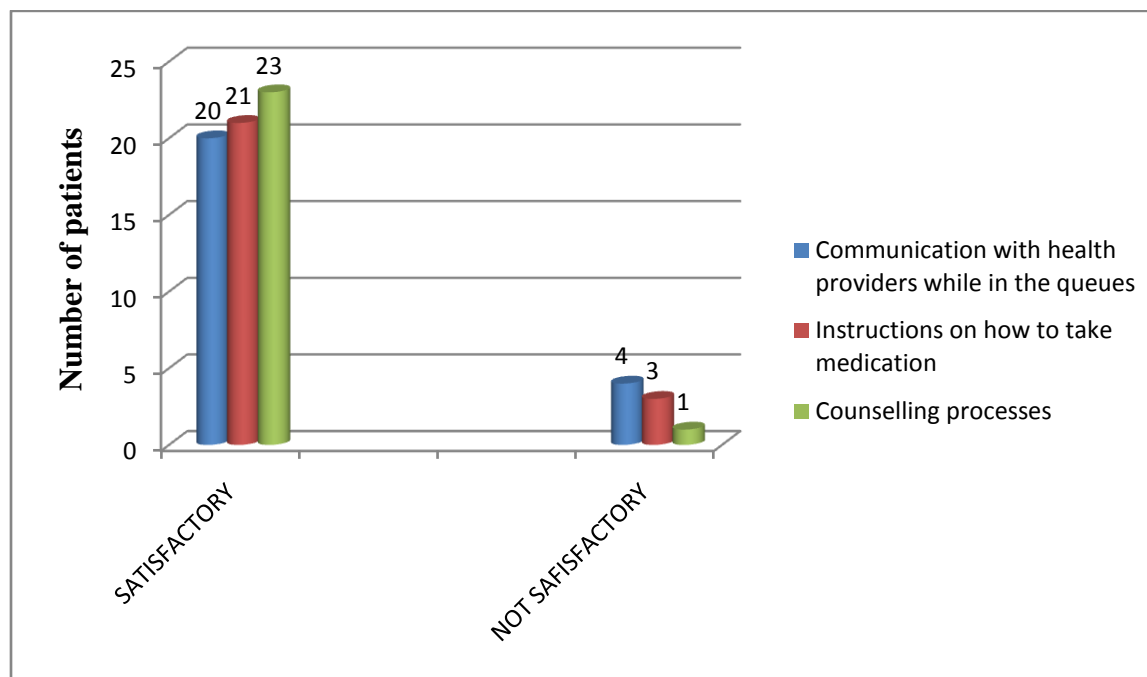
Figure 4.6

Figure 4.6 Distribution of participants according to their feelings concerning the services at the hospital.

On average, 89% of the respondents were satisfied with the manner in which the health personnel treated them when they came to collect their medication, while 11% reported not receiving satisfying services from the healthcare practitioners. The four unhappy patients mentioned one or two incidences in which they did not receive fair treatment at the clinic. One patient even held the personnel responsible for his default.

The patient stated:

"*A rude provider made me feel disrespected and compelled never to set my foot at this clinic. While at home I sought remedy from traditional healers. My health conditions became worse and forced me to return. Since my return I never had any conflict with any physician, and I realize it was just a bad day for the poor provider.*"

The majority of respondents (92%) on average were ecstatic about the way instruction were given and counseling processes which were some kind of extrinsic motivation for adherence. 8% were not happy with the length of time counseling processes took at the initial stage of ART.

The patient indicated:

"*When I started ART, I was physically weak; my health conditions had deteriorated so badly. The counseling processes took me full two weeks. Sometimes I would come here and leave late in the afternoon, hungry and exhausted. Given my health conditions at that time, the processes were time-consuming and not fair to me at all.*"

b) Number of times to report and time spent at the clinic

On being asked how many times they had to report at the hospital to collect their medications, the respondents provided different answers shown below.

Figure 4.7

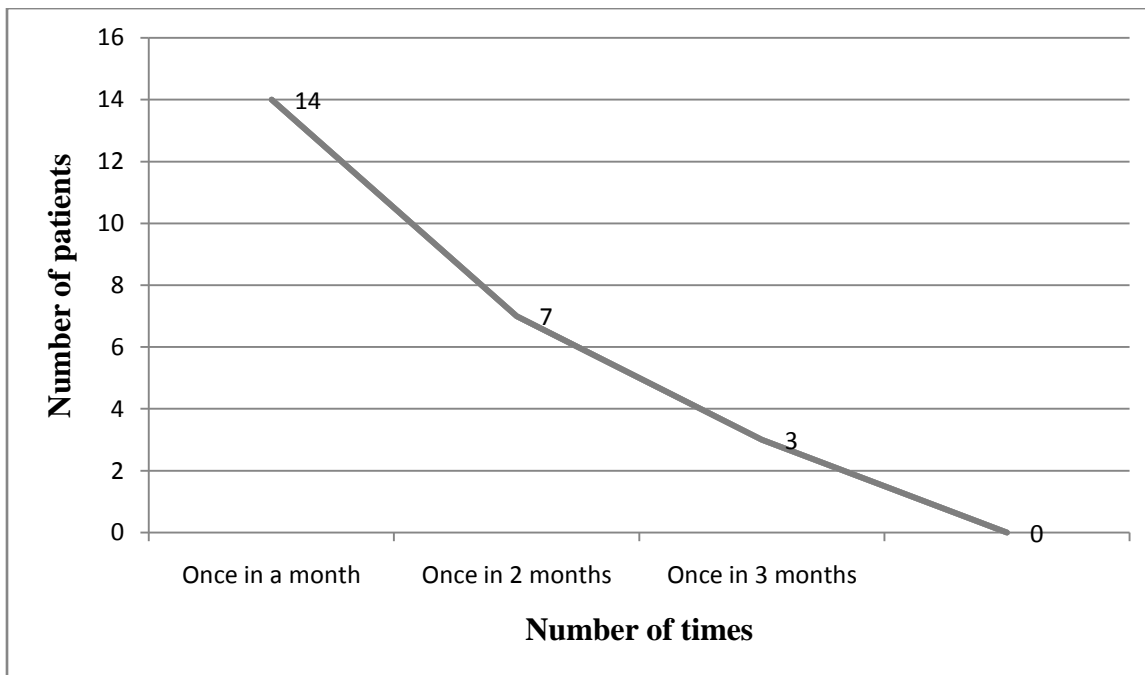**Figure 4.7 Distribution of respondents according to number of times they had to report at the clinic.**

No patient reported having to report at the hospital a number of times in a month, and patients were happy with that. On being asked how much time they normally spent at the clinic when they had come for their treatment, the respondents mentioned times ranging from two –three hours, and they were satisfied with that.

4.2.7 Barriers, causes and reasons behind non-adherence found from qualitative research interviews with patient-participants

Factors affecting adherence to ART found from the interview with the patients are summarized in the table below.

Table 2 Summary of all the factors prevalent in the study population

FACTORS	FREQUENCY	PERCENT
Medication side effects	3	9.0
Illness	2	6.0
Forgetfulness	10	30.3
Poverty	9	27.2
Fear of stigma/disclosure	7	21.2
Relocation	1	3.0
Provider – patient relationships	1	3.0

Table 2

4.3 HEALTHCARE PROVIDER-PARTICIPANTS

In total, six health personnel who fulfilled inclusion criteria of 12 months of experience in HIV/AIDS field consented to participant in the study. The participants' number of years in the field ranged from two to six. The line of questions in this category was more inclined to establish the process of ART delivery to the patients.

4.3.1 Patient loss to follow-up (LTFU)/Default cases

In October 2011, 11 patients were deregistered from the hospital patients' registry, following their death as a result of defaulting from the treatment (October Report 2011-Leratong Hospital). On being asked about default cases in the clinic, all the provider-participants (100%) defined ART default rate as alarming and believed that it posed a serious threat in the management of

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HIV/AIDS. The table below depicts the reasons behind the growing number of default cases provided by the respondents.

Table 3 Depicting the reasons behind the escalating ART default rate

REASONS BEHIND ART NON-ADHERENCE/DEFAULT CASES	FREQUENCY OR NUMBER OF PARTICIPANTS WHO MENTIONED IT	PERCENT OF PARTICIPANTS MENTIONING THE CAUSE
1. Medication specific reasons		
• Side effects	6	100%
• Taste of treatment	1	17%
• Size of tablets	1	17%
• Strict medication rules, e.g. No smoking, drinking, etc.	2	33%
2. Social and economic reasons		
• Poverty (unemployment, lack of/low income, no food).	6	100%
• Non-disclosure/stigma	4	67%
• Dependency	2	33%
3. Patient related reasons		
• Relocation	1	17%
• Feeling/getting better	5	83%
• Lack of social support	3	50%
• Social aspects of life such as alcohol, smoking, etc.	3	50%
• Denial	2	33%
• Traditional medication	2	33%
4. Healthcare team & system reasons		
• No monitoring staff / staff shortages	2	33%

Table 3

All respondents (100%) found medication side effects and poverty as responsible for the growing number of defaulters at the clinic while relocation, taste of the treatment and size of the pills were mentioned by few participants. Four participants (67%) did not find any factors related to the healthcare team and system. In this 67%, one highlighted shortage of staff and that subjecting them to a lot of work, which compelled them to work over time. But in the final analysis, the respondent did not see that as contributing to patients defaulting from treatment as the respondent's closing statement was that they were managing. Two physicians (33%) reported

shortage of staff resulting in inefficiency, as such, failing the patients. One participant said that there was no adequate staff to do monitoring and that created gaps, which contributed to defaulting of the patients.

With regard to the question of assisting patients to cope with medication side effects, 100% of the respondents mentioned ongoing counseling in which patients were informed about side effects, monitoring and finally change of medication in case side effects persisted.

On being asked about the kind of mechanisms they employed to have their patients psychologically prepared for ART, all the participants (100%) mentioned that patients went through two counseling sessions prior to ART initiation. 67% saw these mechanisms working towards achieving the primary objective of raising the levels of adherence.

The participant believed:

"*Our mechanisms are working because some patients really maintain high level of adherence.*"

However, 33% of the participants did not see the mechanisms employed by the staff as working. One of the respondents had it that:

"*We cannot say they are working when there is this huge number of defaulters. These two counseling sessions before ART initiations are not enough. Four counseling sessions are necessary so that, when the patient starts the treatment, he/she has thorough knowledge and understanding of ARVs.*"

On being asked if their patients were honest about their reasons behind defaulting or non-adhering to the treatment, 100% said that their patients were not honest at all.

4.3.2 Availability/accessibility of ARV drugs at the clinic

One hundred percent of the respondents indicated that they never experienced any shortages of drugs in the clinic. ART was always available and accessible.

4.3.3 ART delivery to the patients

When the participants were asked to provide a detailed account on how the ART programme was delivered to the patients, similar points which were presented differently emerged from their responses. In a nutshell, the respondents reported that they received patients from local clinics with referral letters.

The participant explained:

"*A patient is initiated with CD4 count of 350 according to the new protocol. A file for the patient is opened and then we stabilize the patient for treatment initiation: two counseling sessions commence in which we prepare our patients for possible side effects and explain to them that the treatment is a life-long thing. The patient is then sent to a social worker, from there to a dietician, then to ex-tray and then to a doctor. All these happen prior to ART initiation. When the patient has gone through all these processes, we know he/she is ready for ART. All these processes will take him/her two weeks after which we initiate our patient to the therapy.*"

"For patients whose health and physical conditions have deteriorated, all these processes may take a lot of time at the expense of health of the patients. Do you ignore the urgency of a need to give the patient medical attention all in the name of the processes that have to come prior to initiation?"

"*Some patients come here in critical conditions, with CD4 count that has dropped significantly-far below 100. In that case initiation is done instantly.*"

On being asked if they saw the programme delivery contributing to medication non-adherence, the majority (67%) said that the manner in which the programme was delivered to the patients had no contribution whatsoever to non-adherence. 33% had their reasons for saying it had some contribution. One said that there was no monitoring staff, and that caused default cases. Another one mentioned that the patients were put to the treatment after a short time when they had not fully understood ARVs.

Concerning the question of how the defaulters were helped not to default for the second time, the respondents said that defaulters were called and initiated to six months adherence counseling sessions.

"The nature of the phenomenon of adherence tells that high levels of patience are necessary to deal with patients of this disease. How do you ensure that your staff has what it takes to deal with the patients in such a manner that they will be motivated to adhere?"

"*In-service training and refresher courses are done on regular basis to enable the staff to deal with patients with that required level of patience.*"

4.4 DISCUSSION OF FINDINGS

From qualitative findings, distinct similar and dissimilar thematic units were identified and aggregated into the following themes: the relationship between gender and treatment compliance; medication specific factors, socio economic factors, patient-related factors and patients' relationship with healthcare providers.

4.4.1 The relationship between gender and treatment compliance

There was a higher number of female (62.5%) than males (37.5%) in the study. The reasons for this imbalance were a lower proportion of men attending the clinic, compared to women, and men's reluctance to participate in the study. This revealed that women in general are more open to discuss their health-related matters than men. One of the key findings in this study was that, on average, 54% of the respondents were adherent to medication, but the required adherence level of ≥95% was achieved only by 41% of the participants. There were four default cases in this study, of which 80% were men and 20% women. From 20%, the reason behind defaulting was severe sickness while those from 80% included among others unfair treatment. This shows adherence counseling did not have any significant impact in this regard.

4.4.2 Medication specific factors

ART medication regimens have severe side (adverse) effects and strict time requirements that presented a real challenge to adherence. 83% of patient-participants experienced physical

discomfort soon after ART initiation, of which two even decided to stop medication because of intolerable adverse effects when one was left with no option but to quit medication due to illness. Medication side effects was one of the most frequently reported contextual factors by both provider-participants. 100% mentioned side effects as highly influencing adherence among PLWHA.

Strict time requirements subject the patients to a huge challenge. 71% of the respondents had a problem adhering to specified times for medication intake. The most frequently mentioned reason was forgetfulness. The findings in this study are similar to those in the study conducted by Mahlangu (2008) between July 2004 and August 2005 at the Dr George Mukhari Hospital in Pretoria, in which forgetting was the most common reason for missing doses, constituting 26.6% of all the reasons. These show the extent to which the above mentioned medication specific factors are a cause for concern in the management of HIV/AIDS.

4.4.3 Socio economic factors

Social and economic factors highly prevalent among the patients were poverty and stigma. From the majority of patient-participants, transportation costs and food shortages were the main factors hampering adherence to ART. Both provider and patient-participants reported poverty as rendering the patients failure to adhere to both dates scheduled for appointments and times specified for medication intake.

Fear of stigma was one of the chief determinants of non-adherence. Fears to take medication in the public view forced the patients to skip their doses. In this study, stigma was linked to non-disclosure in that patients concealed their status due to fear of being stigmatized. Fear of being divorced or abandoned by the partners compelled dependent women to remain silent about their HIV-status. Most people who reported having fears to disclose their HIV-status to their partners indicated that they were financially dependent on those partners and they could not risk it as disclosure might give birth to the end of marriage or cohabitation. Poverty was in a way exacerbating stigma. There is a growing recognition that social support is vital in fostering ART adherence. The findings revealed a significant relationship between non-adherence and poverty, stigma as well as non-disclosure, the latter denying the patients opportunity for social support.

4.4.4 Patient-related factors

In this category, factors which were found to be a challenge to adherence included belief about efficacy of ARVs, ART as a life-long treatment, religious beliefs and social practices, as well as relocation. With reference to the issue of efficacy of the therapy, all the patients (100%) were aware of the need to take their ARV drugs as prescribed by physicians and they even approved ART for effective management of AIDS. The majority of the patients had no problem with ART as a life-long treatment. A few who had negative attitude toward ART as a life-long treatment had been on the therapy for a long time, so the thought of the pills and how they tasted initiated for them a bad feeling about the drugs. Those were patients who even suggested that the government should provide ARVs in the form of three to six months injection.

All the patients did not see religious or traditional beliefs and social habits as factors that should hamper adherence. This revealed a thorough understanding the patients had of the importance of ART in the management of the disease, and the knowledge that traditional beliefs and medicines were more likely to waste their time and exacerbate their health conditions rather than helping them. But what the patients said was contrary to what their physicians divulged. Providers said that some patients had a tendency of substituting ARVs with traditional medicines, or denying being HIV positive on the grounds that they were being bewitched.

4.4.5 Patients' relationship with healthcare providers

Harmonious relationships cultivated for a growth of trust in patients for their physician knowledge and expertise, and that was a key factor in patients adherence to dates scheduled for appointments. The majority of patients believed that health personnel were competent advocates of ART medication, who prescribed it with all patience and adequacy. A few patients who reported having been treated unfairly by the physicians also quoted a few instances in which unfair treatment was administered upon them, by one or two personnel. They believed that the majority of the personnel treated them with all patience, respect and nonjudgmental attitude and they were happy. This confirms Marelich et al (in Wekesa, 2007) thus: a great deal of adherence hinges on the positive interaction between patients and their health care providers.

Dealing with PLWHA on ART is straining work as a result of explaining one thing or dealing with the same people several times. It requires a lot of patience as other patients default while others grow hostile. The complexities of ART treatment which require patients to be involved in their treatment decisions, and the fact that patients need to be adequately informed about their treatment schedules and the importance of adhering to treatment regimen (Wekesa, 2007), combined with all the reported processes followed before ART initiation, require a high level of patience from the side of the health personnel. The in-service training that the health practitioners reported to be regularly attending was working if in the end, 89% of the patient-participants were happy with service delivery at Kgothalang clinic.

CHAPTER 5: CONCLUSION AND RECOMMENDATIONS

5.1 CONCLUSION

The study set out to investigate the causes of non-adherence to ART medication regimens among PLWHA at Leratong hospital. The sampled population of patients (24) was very small to be representative of hundreds of people attending the clinic for ARVs, and to give a true reflection of adherence problems. So, the population was complemented with six healthcare providers whose knowledge of daily ART-related problems and experience of attending to hundreds of the clinic ART attendees gave the real picture concerning factors that affected adherence among the patients on HIV treatment.

The study findings demonstrated that the research question and objectives had been met. Concluding from the sample that was used in this study, adherence levels among patients was not satisfactory. The findings indicated that the majority of PLWHA did not meet the required adherence level of $\geq$ 95%. Generally, adherence level among the patients was sub optimal (less than 95%). Social economic related factors such as poverty (transportation costs and insufficient food), stigma and fear of disclosure; and medication side effects significantly contributed to non-adherence. Patient-related factors such as lack of social support, preference of traditional medicines, feeling better, substance abuse; and one health system-related factor being staff shortages, had a little contribution to poor medication adherence.

The process of ART delivery to the patients was intended to provide extrinsic motivation to the patients and raise adherence levels. The sequential steps followed in the process were stabilization of the patients, preparing the patients for ART and its possible concomitant side effects through counseling sessions in which the patients were adequately informed about ART as a life-long treatment and the importance of adhering to treatment, after which the patients would pass through a social worker, dietician and doctor. From there ART initiation followed. The process lasted two weeks. The newly initiated and non-compliant patients reported to the hospital every month, when the compliant patients with a relatively long time on ART reported once in two or three months. Defaulters were initiated to six month counseling sessions in order to minimize the chances of the same patients defaulting again.

The processes executed prior to ART initiation had potentially facilitated adherence, as they were meant to equip the patients with knowledge of ART. On the contrary, there was possibility of some patients finding them time-consuming and stopping the treatment even before it was commenced; the main determinants possibly being transportation costs, lack of food and feeling physically weak to come to the clinic when no medication was given. The minimum of a month for the patients to report at the hospital for their ARV drugs was enough for effective monitoring of the patients and treatment. It also saved the patients the trouble to incur more expenses through transport and food, and the patient-participants were very happy about it.

The patients' view of the programme was that, the programme itself was a challenge to the patients in terms of its dos and don'ts that patients usually fail to adhere to due to forgetfulness. Their suggestion directed not to the health centers, but to the government and all stakeholders including the ARV drugs-manufacturers, was that ART be provided in the form of three to six months injection, and that would give birth to relatively low levels of non-adherence if not zero.

From the view of the majority of the personnel, the programme was fine and not contributing in any significant manner to non-adherence. A few who had a problem with the programme indicated its contribution to non-adherence emanating from a small number of counseling sessions that the patients passed through before ART initiation, which failed to equip them with thorough knowledge of ART programme. Another concern was inadequate staff in health facilities that delivered the programme to the patients. The personnel indicated that it gave birth to inefficiency in the delivery of the programme, as such, failing the patients who in the end did not adhere to ARV drugs.

According to the health personnel, during immune reconstitution, the drugs picked out opportunistic infections which were still concealed, and the possibility was that the patient would feel seriously ill, and that was when the patient needed more attention, failing which non-adherence would follow. So, in the situation where there was no adequate staff, there would be no monitoring and in the absence of proper monitoring, patients would quit medication.

5.2 RECOMMENDATIONS

The participants stated a range of reasons behind non-adherence to ART medication regimens, of which poverty (insufficient food and transportation costs), stigma and fear of disclosure were a big threat to adherence. To enhance adherence to HIV treatment, the study recommends the Department of Health in Gauteng province and all other stakeholders to:

❖ Look at ways to improve adherence in the face of poverty, by way of ensuring a greater interaction between the social development and Health components of government in relation to HIV.

❖ Eradicate stigmatization of PLWHA by way of intensifying health education campaigns against stigma in communities, workplaces and households.

❖ Develop a binding policy for the managers and employers, which will allow our patients on ART to take their bottles of water into "Non-eating zone" workplaces in order to take their pills when time for medication intake has come**.**

❖ Evaluate and reinforce mechanisms for monitoring of patients on ART by way of ensuring the presence of adequate staff in health facilities.

The study revealed that forgetfulness is profoundly influencing adherence among the patients. So, it is recommended that patients:

❖ Be encouraged and supported to have an effective family and social support system that will assist in ensuring that they always carry their drugs with them, and take them when the time has come.

❖ Be encouraged to choose the time that is convenient for them and the adherence family support system should be knowledgeable of that time.

The findings from this study show that there is a significant relationship between treatment adherence and gender, in which women are generally more compliant than men to ART, so it is recommended that men be given extra pre-ARV counseling and compliance checking.

The findings further show that, the more time people have on ART, the less adherent they are likely to become. There is a need for more compliance checking as treatment goes on.

5.3 SUGGESTION FOR FURTHER RESEARCH

(a) There is a need for a similar study with similar objectives to be conducted in resource-poor settings/ rural areas whose sample population will be bigger than the one used in this study, to determine adherence situation in the province/country.

(b) This study did not examine if age has any relationship with adherence, so further research should also look into that.

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