# THE INFLUENCE OF PSYCHOSOCIAL FACTORS ON HIV ANTIRETROVIRAL DRUGS ADHERENCE AMONG YOUNG PEOPLE IN NAKURU CENTRAL DISTRICT, KENYA

By

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#### **DECLARATION**

This research project is my original work and has not been submitted to any university for any academic award.

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#### DEDICATION

I dedicate this research to Valyn Wanjiku Kamau, for the brave fight she put up against all odds and the lessons she taught us when we had her. To Jayden and Tyler, the boys with a fighting spirit. To Aby and Petra, with life full of excitement, fun and learning.

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#### ABBREVIATIONS AND ACRONYMS

APHIA II AIDS Population Health Integrated Assistance II

ARVs Anti-retroviral drugs

AIDS Acquired Immune Deficiency Syndrome

CCC Comprehensive Care Centre

DDP District Development Plan

FGD Focus Group Discussion

GDP Gross Domestic Product

HIV Human Immunodeficiency Virus

PLWHIV People Living With HIV

TB Tuberculosis

UNAIDS Joint United Nations program on HIV/AIDS

YPLWHIV Young People Living With HIV

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#### ABSTRACT

HIV and AIDS has had a devastating effect on humanity since its discovery in 1984. However gains made in research have seen improvements in managing the condition and transformed HIV from an acute condition to a chronic illness that is manageable and survivable. Since HIV has been present in the population for a while now, more and more young people are living with the virus as a result of being perinatally infected or behaviorally acquired. Such young people who are navigating through a critical part of their life undergo numerous challenges in maintaining adherence to medication. This study investigated the influence of psychosocial factors on adherence to treatment for HIV among young people. The study sought to investigate the extent ARV adherence among young people is influence by psychosocial factors; psychological factors, alcohol and drug abuse; patient's social environment; and the nature of health care provision. The study utilized descriptive survey design to collect primary and secondary data from representative sample. Structured questionnaires and oral interviews were used to collect primary data for the study from the respondents while secondary data was obtained from document reviews. Findings revealed a significant correlation between depression and adherence (-0.633) implying that that YPLWHIV who are experiencing depressive symptoms are less likely to adhere while those who are anxious are more likely to adhere. Alcohol abuse was a major contributing factor to depression and non-adherence with a significant correlation being established between alcohol and drug adherence (-0.664). The finding also revealed high disclosure rate as well as high drug self-efficacy and perception of social support which in turn positively influenced adherence. Provision of health care meets the youth expectations at the facility. The study proposes efforts to address depression, address alcohol and drug abuse and improve self-drug efficacy as a way of improving adherence.

#### **CHAPTER ONE: INTRODUCTION**

#### 1.1 Background to the Study

More than two decades since the first reported case, HIV/AIDs continue being the most serious health issue facing the world. The UNAIDS (UNAIDS, 2011) estimates that globally there are 34 million people living with HIV as at 2011. Although mortality related to HIV has declined in recent years, 1.8 million people lost their lives due to HIV related complication in 2010 alone and many more continue being infected annually with 2.7 million new cases of HIV being reported in 2010 (UNAIDS 2011: 6). It is estimated that more than half of these new infections occur among young people (Youthnet, 2005), a scenario which points to HIV being with us for a long time to come.

With such increasing numbers, monumental sums of money continue to be channeled towards fighting HIV with governments, development partners and multi-laterals committing lots of resources to addressing HIV. This has put pressure on the national resources and reduced investment towards other development and health programs. Moreover, countries with high HIV burden continue to experience reduced Gross Domestic Product (GDP) growth as a result of reduced productivity and increased commitment of meager national resources towards fighting the epidemic. It is estimated that where prevalence of HIV is higher than 20%, GDP will decreases by 20% annually (UNAIDS, 2002).

At household level, growth of number of people living with HIV has resulted in reduced productivity with a lot of people spending time to attend to HIV related ailments. The quality of life too has reduced as more families spend meager resources on managing the condition. The number of children orphaned as a result of AIDS related deaths has been on the increase posing problems to communities who have to shoulder the responsibility of raising such children and creating child headed households.

In Sub-saharan Africa where about 68% of those living with the virus reside, HIV prevalence has witnessed marginal changes from a prevalence of 5.9% in 2001 to 5% in 2011. The region also accounts for 70% of all new infections globally and has resulted to loss of 1.2 million lives as at the end of 2010 (UNAIDS 2011). Countries in the south

continue to shoulder a huge HIV burden with high prevalence rates as high as 23.9% in Botswana, 26.1% in Swaziland and 23.2% in Lesotho (UNAIDS, 2011)

It is however important to note that concerted global attention to HIV has forced the epidemic to decline. Since the 2001 Declarations on Commitment to HIV, governments have increased funding and attention to HIV programs with the objective of reducing new infections. In 2006 governments committed themselves to achieving universal access to prevention, treatment, care and support for people living with HIV. Since then, there has been renewed vigor with many governments declaring HIV/AIDs national disaster and increasing the resource allocation to campaigns to fight the epidemic. As a result of committed leadership, social change and innovation, there have been gains made in fighting HIV.

Research in HIV has led to the increased knowledge on HIV and developed the life prolonging Anti-retrovirals (ARVs) used in the management of HIV. Use of ARVs has improved the quality of life for those infected by HIV and reduced mortality. The UNAIDS estimates that due to use of ARVS close to 2.5 million deaths have been averted since 1995 (UNAIDS, 2011). Other research initiatives have led to discovery of new ways to reduce risk of infection such as voluntary medical male circumcision which has been shown to reduce risk by 60% (UNAIDS, 2011). Trials on an AIDS vaccine are ongoing with promising results.

Despite the gains made in the fight against HIV, the dynamic nature of the epidemic continues to pose challenges to the medical field. Notable among this is the movement of the epidemic from populations at risk to general populations, a fact which places everyone at risk and compounds prevention programs. Another critical challenge in the fight has been the low rate of enrolment into treatment programs, a situation driven by low access to ARVs. In Sub-saharan Africa for instance, only about 20% of those eligible for ARVs are currently enrolled in the program (UNAIDS 2011). Other factors leading to low enrollment to treatment include other socio-cultural barriers such as stigma.

Of equal concern is the huge number of patients who enroll into care but end up defaulting on their medication. It is estimated that 25% of ART (Anti-retroviral Therapy) users do not achieve optimal adherence in Africa (Hardon et al, 2007) due to multiple

reasons. Other studies have shown that ART programs in Africa experience discontinuation of treatment among 40% of patients on ARVs (Rosen et al, 2007). In Kenya, of the 1.4 million people estimated to be living with HIV 432,621 are on ARVs. HIV prevalence among young people is estimated at 3.8%, and young people who are on treatment and care are estimated at58% of the people living with HIV Kenya (National AIDS and STI Control Programme, Ministry of Health, Kenya). This huge cohort who are navigating a critical stage of life yet dealing with the challenge of being HIV positive are in unique setting that calls for investigation.

#### 1.2 Statement of the problem

The long term effect of ARVs is dependent on strict adherence to the prescribed regimen since resistance can develop with inconsistent usage of medication. Ability to adhere to treatment regimen is a crucial determinant of whether ARVs will work to prevent either transmission or acquisition of HIV (UNAIDS, 2011). Consequences of poor adherence include not only deteriorating health for patient but also poses public health concern with heightened possibilities for development of multi-drug resistant HIV similar to that observed among Tuberculosis (TB) patients (Mehta S, Moore R.D, Graham N.M.H, 1997).

Studies have however shown that youth are more prone to poor adherence increasing their risk and heightening risk for early mortality. Globally, young people constitute more than half of those infected by HIV with reports estimating that over 6000 youth get infected with HIV every day (UNAIDS 2011). This increasing number of young people getting infected means there are more young people being initiated into treatment programs. Moreover, many children born with the virus in the 90s are arguably now in their youthful ages and living with HIV (APHIA II operations research project in Kenya, 2010).

Behaviors associated with adherence such as taking doses at the same time every day, following food restrictions and skipping doses as a result of irregularity in routines remain a challenge to youth living with HIV (Reisner, Mimiaga, Skeer, Perkovich, Johnson & Safren, 2009: 14). Studies have shown that young people rarely achieve optimal adherence with rates ranging from 28.9% to 69.8% (Reisner et al, 2009:15).Other

studies have shown near similar rates (Naar-King, Templin, Wright, Frey Parsons and Lam, 2006; Murphy, Belzer, Durako, Sarr, Wilson & Muenz, 2005; Chandwani, Koenig, Sill, Abramowitz, Conner &D'Angelo, 2012). It is against this background that this study sought to investigate the factors influencing adherence to ARVs among youth.

In Kenya, years of progressive exposure to HIV since the first case reported in 1984 have resulted in growing population of youth living with HIV some of whom were infected with the virus at birth (APHIA II operations research project in Kenya, 2010). Nakuru Central district being one of the populous districts in Kenya has arguably a large proportion of these youth whose adherence behavior is yet to be investigated.

This study therefore sought to establish "The influence of psychosocial factors on ARV adherence among young people living with HIV in Nakuru Central District"

#### 1.3 Purpose of the study

The purpose of this study was to investigate the influence of psychosocial factors on ARV adherence among young people living with HIV in Nakuru Central District. The study focused on psychological factors; alcohol and drug abuse; social environment; health care provision and food availability and how these influence adherence patterns among this population.

#### 1.4 Objectives of the study

This research was guided by the following specific objectives

- 1. To establish the extent to which psychological factors influence HIV drug adherence among young people living with HIV in Nakuru Central district
  - 2. To establish the extent to which alcohol and drug abuse influence HIV drug adherence among young people living with HIV in Nakuru Central district
  - 3. To establish the extent to which patient social environment affects HIV drug adherence among young people living with HIV in Nakuru Central district
  - 4. To establish the extent to which health care provision influences HIV drug adherence among young people living with HIV in Nakuru Central district

#### 1.5 Research questions

- 1. Do psychological factors influence HIV drug adherence among young people living with HIV in Nakuru Central district
- 2. Does alcohol and drug abuse influence HIV drug adherence among young people living with HIV in Nakuru Central district
- 3. Does the patient's social environment influence HIV drug adherence among young people living with HIV in Nakuru Central district
  - 4. Does the nature of health care provision influence HIV drug adherence among young people living with HIV in Nakuru Central district

#### 1.6 Study hypothesis

This study sought to test the following hypothesis

1. There is a significant relationship between psychological factors and HIV drug adherence among youth living with HIV

#### 1.7 Significance of the study

While adherence has been studied extensively with adult patients, issues in youth adherence and possible reasons for their poor adherence have received little attention in the literature (Rao, Kekwaletswe, Hosek, Martinez & Rodriguez, 2007). This is despite the realization that both male and female youth have specific needs during treatment that are yet to be addressed (Zuurmond, 2008). Very little is known about adherence and the factors associated with it among young people. In Kenya where efforts to study the growing population of young people living with HIV have been minimal, there is very limited information as regards treatment behavior of this group. This study attempted to fill in this gap.

Drug resistance brought about by poor adherence necessitates second line drug treatment which can be more difficult to administer and the cost implications much higher (Zuurmond, 2008; Hardon et al, 2007: 658) strains of HIV is arguably much higher and consumes the limited resources available for HIV programs. Identifying the factors that cause non-adherence will enable the development of adherence enhancing strategies and put in place adherence supportive mechanisms.

#### 1.8 Scope of the study

The study limited itself to studying young people living with HIV in Nakuru Central district. The district is home to 309,424 people living in its urban and rural settlements (Nakuru DDP, 2009-2012), a fact that ensured that there was a good representation of respondents from the two divides. Moreover, the youth respondents selected were in proximity to the researcher and representative of young people living with HIV.

# 1.9 Limitations of the Study

This study limited itself to a representative sample of young people living with HIV in Nakuru. While this may raise questions of generalizability of the findings, the researcher made efforts to ensure the sampling was as representative as possible. To this end, the sample included young people of all ages within the study age bracket and drawn from diverse settings. The selected sample was chosen from those young people enrolled into care at the main treatment site in the district thus ensuring that those selected were already on ARVs. Selecting respondents who are attached to treatment sites ensured that any fears that may limit participation were addressed by a trusted health care provider who also addressed issues of ethics within the research.

This study involved administration of a self-report questionnaire. This by itself posed the risk of response bias as some respondents may have wished to give responses that they deem put them in good light. This may particularly have affected the measurement of adherence whose measurement through self-reports poses challenges to researchers (Reisner et al, 2009: 15) and is prone to self enhancement bias. To address this, the researcher triangulated information provided by respondents with health facility records and also conducted a key informant interview with the health service providers. The researcher assured respondents of anonymity as a way of increasing their confidence to give truthful responses.

#### 1.10 Delimitations of the study

This study delimited itself to studying the psychosocial factors that affect adherence and did not delve into biomedical factors (such as treatment regimen, disease factors and viral load) that have been shown to influence adherence. This was a deliberate effort to address the gap in addressing adherence from a social perspective as argued by Castro (2005) who decries an overemphasis on biomedical factors affecting adherence with limited regard to social dimensions. The researcher believes the study area allowed for an in-depth focus psychosocial factors previously unexplored.

#### 1.11 Assumptions of the Study

It is appreciable that issues of HIV are confidential by nature and the researcher anticipated reservations by respondents to participate in the study. The researcher made the assumptions that the health facilities approached would be willing to share information on their clients and play a big role in ensuring issues of ethics in the study are addressed with the participants in a comfortable environment. The researcher also made the assumption that the respondents to be recruited from Comprehensive Care Centers (CCCs) would be willing to participate in the study.

# 1.12 Definition of significant terms

Adherence - Patients ability to follow a treatment plan, take medications at the prescribed time and frequencies and follow restrictions regarding food and other medications.

ARVs - Drugs administered as part of HIV clinical care

Level 5 health facilities - The government of Kenya categorization for a provincial hospital

Young people

- Although the World Health Organization (WHO) considers young people as those aged 10-24 years this study has looked as young people as those aged 15-24

Antiretroviral adherence - Compliance in taking prescribed medication

#### 1.13 Organization of the study

This study is organized in five main chapters with the first chapter presenting an introduction of to the problem. The second chapter reviews related studies and presents empirical data that relates the variables under study. The third chapter presents the methodology to be employed in the study. The fourth chapter presents the research findings while the last chapter discussed the findings and makes recommendations and concludes the research. Each of the chapters has an introduction and a summary of the chapter to aid the reader while important tables and figures are listed in the list of tables and figures for ease of reference.

## 1.14 Chapter Summary

This chapter has presented a background to the problem and stated the problem, the study objectives in addition to looking at the significance of the study. The chapter has in addition stated the scope, assumptions, limitations and the delimitations that guided the study and defined significant terms used in the study.

# **CHAPTER TWO: LITERATURE REVIEW**

#### 2.1 Introduction

This chapter begins by reviewing the different health theories advanced to explain adherence behavior among PLWHIV and presents a theoretical review that formed the basis of this research. The chapter also reviews related studies and explores gaps in the available literature that the research sought to address. The chapter ends with a presentation of the conceptual framework that guided the research.

#### 2.2 Theoretical Review

With the emergence of HIV antiretroviral adherence as an area of research, several theoretical models have been advanced to explain the findings from research that can be used to consistently predict adherence behavior and inform the development of interventions. The models seek to identify the constructs that influence adherence and how the constructs co-exist and influence each other in a predictive manner (Simoni, Amico, Pearson and Malow, 2012).

Adherence theories are based on the commonly applied models of behavior such as health belief models, social cognitive theories, theories of reasoned actions, theories of planned behavior, and protective motivation theory (Simoni *et al*, 2012). These theories explain behavior in the context of an individual's attitude driven by their perception of outcomes and expectancies of the behavior occurrence. The health belief model for instance explains the occurrence of health behavior as a function of knowledge on perceived susceptibility, severity, benefits of undertaking the behavior vis a vis the barriers to the performance of the behavior (Schneiderman and Speers, 2001). The adhering person therefore is the one who comprehends the severity of the consequences of not adhering, sees the benefits of adhering and is able to overcome the personal/attitudinal barriers to adherence.

Social Cognitive theory, advanced by Albert Bandura in 1986 assumes that behavior occurrence is attributable to interactions among behavioral, physiological and cognitive factors and the environment. At the heart of carrying out the behavior is self-efficacy; the perception that one is able to carry out the behavior to achieve the desired outcomes (Schneiderman and Speers, 2001). Increasing self-efficacy in carrying out

behavior such as adherence thus serves as the motivation to change. The theory of reasoned action developed by Ajzen and Fishbein in 1980 and it later day modification, theory of planned behavior explain behavior in terms of anticipated material and social consequences in people's decisions and intentions to engage in health related behavior (Schneiderman and Speers, 2001). Intentions are influenced by attitudes and subjective norms thus adherence is a function of one's attitudes and norms.

Critics of the above theories however argue that the role of the external environment in influencing behavior such as adherence has not been well articulated by the theories and the theories do not adequately address the structural issues that influence adherence behavior (Simoniet al, 2012). They have thus proposed other models such as the Information-Motivation-Behavioral-Skills (IMBS) model to address this gap. The model proposed by Fischer, Amico and Harnam, in 2006 posits that adherence is a function of the information on the regimen being used and the treatment process, social and personal motivation and adherence related behavioral skills (Simoni et al, 2012).

This model has been modified to explain adherence in resource limited settings where adherence is in addition to information, motivation driven by self-efficacy, beliefs and behavioral strategies as influenced by structural determinants. The adhering person must thus have access to medication and treatment monitoring support, knowledge (on dosing schedule, resistance and possible side effects), motivation to take medications and the behavioral skills such as reminders to take medication (Starks et al in Simoni *et al* 2012).

The interaction between individual and social factors in explaining adherence is further captured in Social Action Theory (SAT) advanced by Ewart C. K in 1991. The SAT model is a public health framework that integrates social-cognitive models and recognizes that public health issues may be addressed at personal, interpersonal, organizational and societal level (Schneiderman and Speers, 2001). The SAT model advances that adherence is a function of the patients social environment, emotional state and self-regulatory mechanisms which include adherence self-efficacy, beliefs, and attitudes towards treatment adherence (Simoni *et al*, 2012). Because of its inclusivity, the model lends itself to use in explaining complex adherence issues and therefore formed the theoretical base of this study.

#### 2.2 HIV and drug adherence as a concern in health programs

Since the discovery of ARVs in the early 2000, the fight against HIV has taken new shape with growing success in managing HIV through use of combination therapies. HIV is now no longer an acute condition but a chronic illness that is manageable and survivable (Simoni, et al, 2012). Efforts by governments, development partners and civil society groups have seen many more people who have been diagnosed with HIV being put on care and accessing the life prolonging drugs. The UNAIDS (2010) reports that there are 5 million people on ART, 30% of whom were newly initiated into ART in 2009 alone.

There is widespread acceptance that optimal adherence requires an adherence rate of >95% (Catro, 2005; Zuurmond, 2008) since such high levels of adherence are associated with more viral suppression (Friedland, 2006). Poor drug adherence results in incomplete viral suppression and leading to development of drugs resistance. Optimal adherence relates not only to the ability to take the prescribed medication, but also the ability to comply with the timing schedules of taking drugs (Mehta, Moore & Graham, 1997). Other studies have even included taking the required food prescriptions as part of the measure of adherence (Amberbir, Woldemichael, Getachew, Girma & Deribe, 2008).

Arguments have however been put forth that due to the combination of different agents in a regimen and their varying drug to drug interaction, some treatment regimens require different levels of adherence (Friedland,2006; Castro 2005). Ritonovir boosted protease inhibitors for instance have more limited resistance regardless of the level of adherence while resistance is highest among those taking regimens containing non-boosted protease inhibitors, those with single dose regimens and non-nucleoside reverse transcriptase inhibitor regimens (Friedland, 2006; Castro 2005).

Despite the drugs regimens being simplified and tolerable, strict adherence to medication has continued being a challenge with studies showing varying levels of adherence. In a review of studies conducted in North America, Reisner et al(2009) found adherence levels varied from as low as 28.3% to 69.8%. Similar results are reported by Hardon et al (2006) who found an average adherence rate of 55% among the same populations. The varying nature of adherence levels is further demonstrated by findings

of higher adherence in African settings. In an evaluation of ART programs in Uganda, Zambia and Nigeria, Zuurmond (2008) found adherence rates of 94%, 88%, 90% respectively, almost similar to findings by Hardon et al (2006) of adherence rates of 77% in Sub Saharan Africa.

Similar dynamics are witnessed with studies conducted in Kenya with some studies reporting on lower adherence rates (56.8% of respondents failing to take their drugs on time as reported by Talam. Gatongi, Rotich and Kimaiyo, 2008) while other studies have reported on higher rates (74% reported by Wanjohi, 2009). Zuurmond (2008) reports on varying adherence levels in rural and urban areas with ART programs running in urban areas achieving adherence levels as high as 96% as compared to 76% in rural areas. Such could be attributable to issues of access to health care.

Young people have registered varying adherence with rates as low as 63.3% being reported in a study by Naar-King *et al*(2006). Near similar adherence rates were reported by Murphy et al (2005). However other studies reported rates as high as 94% (Filho*et al*, 2008). Among the reasons advanced for missing doses include forgetting, which was a commonly cited reason, being away from home, being busy or even falling asleep (Chandwani *et al*, in press), all reasons that are barely convincing.

Reduced adherence is not only an individual but a public concern. Small difference in adherence can result in major difference in virological control (Bangsberg et al in Murphy et al, 2005) and can precipitate resistance to medication. A patient who develops resistance is likely to transmit drug resistant strains (Naar-King et al, 2006) and is switched to second line drugs which cost around 10 times more than first line which will slow down efforts to provide universal access to ARVs.

# 2.3 Influence of psychological factors on adherence

Studies have shown that the mental health of the patient has an influence on their adherence behavior (Zuurmond, 2008; Reisneret al, 2009; Murphy et al, 2005). Aggravated levels of depression, anxiety, distress, despair have been associated with decreased adherence (Reisner et al, 2009) a fact demonstrated by youth in a focused group who admitted to stopping medication when experiencing depressive symptoms (Rao et al, 2007). In their studies among young people, Naar-King et al (2006) and

Murphy et al (2005) found a significant correlation (CI-95%) between adherence and psychological distress further strengthening this preposition. Similarly, Chandwani *et al*, (in press) found non-adherent participants in their study showed a tendency for higher depression scores (p=.08) than their adherent counterparts.

A patient's accepting attitude towards medication and belief that medication will improve health status is associated with increased adherence (Reisner *et al*, 2009; Castro, 2005, Simoni *et al*, 2012). Castro (2005) reports on clients in Senegal who increased adherence as a result of positive attitude to ARVs which they associated with weight gain which is highly valued in that society. Belzer, Fuchs, Luftman & Tucker (1999) found that youth who believed that HIV medication would improve the quality of their life were more likely to have >90% adherence rate (p=.01).

However perceived lack of need for ARVs due to improvement in health after taking the medication has resulted in defaulting. Mehta, Moore & Graham, 1997) report on study where 50% of the non-adherent group reported skipping the prescribed drugs because they did not believe they needed it. The reverse of this is true since negative attitudes towards medication may interfere with patient adherence. In one focused group discussion (Rao, et al 2007) some youth reported throwing away their medication because of the feeling the medication will change their lifestyle.

Self-efficacy, defined as an individual's confidence in their ability to engage in a behavior regardless of temptation not to engage in the behavior has been shown to positively influence adherence (Reisner et al, 2009). Garvie et al, (2011) found self-efficacy to be associated with adherence to Directly Observed Treatment (DOT), findings which are similar to those of Naar-King et al(2006:46) who found a significant correlation between self-efficacy and adherence.

Depressive symptoms and other psychological issues could be attributed to previous abuse and this could affect adherence. Young people living with HIV who experienced sexual abuse under age 12 and have a prior suicide attempt have poor adherence levels (Reisner et al, 2009). This could be attributed to the fact that young people living with HIV who have a history of abuse have a higher likelihood of attempted suicide (probably due to depression) engaging in drug abuse (Anaya, Swendeman &

Rotheram-Borus, 2005). Familiarity with the patient history could thus prove useful in predicting adherence behavior

While psychological factors have proved to be more stable predictors of adherence behavior, the varying rates of tests significance call for more studies to establish how well the factors relate to adherence.

#### 2.4 Use of alcohol and drugs and its effect on adherence

Studies have shown that young people who are living with HIV are not averse to alcohol and substance abuse with increased abuse being observed among youth who are depressive (Garvie et al, 2011). Indeed in their study with non-adhering youth, Garvie et al (2011) found up to 10% of the respondents reported frequent use of alcohol while a further 40% were using marijuana. Alcohol and substance abuse results in impaired decision making and is a critical predictor of adherence among young people (Reisner et al, 2009; Braithewaite, Conigliaro, McGinnis, Maisto, Bryant & Justice, 2008; Murphy et al, 2005). Non adhering patients have put alcohol as one of the reasons why they missed taking their doses (Wanjohi, 2009).

Significant association between alcohol use and adherence were reported in studies among adult HIV patients by Rintamaki, Davis, Skripkauskas, Bennet& Wolf, 2006 who found that patients who were treated for alcohol/drug abuse had lower adherence rates (63%) as compared to those who were not treated from any alcohol/drug related issue (70.3%). Similar result have been found among the youth with alcohol abuse being significantly correlated with adherence of the preceding Saturday and adherence during previous month (Murphy et al, 2005).

Increases in alcohol consumption which go beyond usual drinking levels are more likely to cause non-adherence than non-hazardous drinking which is not associated with brain functioning impairment (Braithewaite *et al*, 2008). This was demonstrated by Braithewaite *et al* (2008) who found that patient days on which greater quantities of alcohol were consumed showed more non-adherence than patient days on which no alcohol was consumed. At higher levels of alcohol consumption, the non-adherence levels were clinically significant.

Some youth living with HIV have however reported on taking medication even when drinking (Rao et al, 2007). Indeed 72% of the respondents in the focused group discussion reported on taking medication even when they drank alcohol. This seems to be supported by Braithewaite et al, (2008) who found no significant levels of non-adherence for non-hazardous drinking despite there being changes in adherence induced by alcohol. This conflicting results call for more studies in the area to establish the connection between alcohol and drug abuse and adherence.

#### 2.5 Social environment and adherence

The social context is a crucial element that plays a big role in ensuring adherence (Zuurmond, 2008). As the patient's social circumstances and their interpretations of them changes adherence levels are likely to change too with poor social relationships and activities leading to reduced levels of adherence (Castro, 2005). On the other hand, social isolation increases the risk of decreased compliance with medication among PLWHIV (Mehta et al, 1997). Social support towards such things as reminder to take medication, encouragement to visit the clinic and being accompanied to visit the clinic are dependent on the patient's social environment.

Cardinal to receiving social support is disclosure to the members within social cycle since support cannot be achieved unless one discloses. Zuurmond(2008; 8) found that patients who disclose their status to family members seem to do much better on adherence, a fact that is supported by Hardon *et al* (2007) who found most ARV users interviewed in Tanzania as a result of disclosure had received various forms of help such as food, reminder to take medicine and transport from family members and friends. Youth who disclosed their status to at least one person were more likely to begin taking medication and remain on treatment longer (Belzer *et al*, 1999). This did not however lead to observed relationship between disclosure and adherence (Belzer *et al*, 1999)

Despite the documented benefits of disclosure, it still remains a challenge among the PLWHIV. Non-disclosure may lead to patients taking medication secretly (Hardon et al, 2007, Reisner et al, 2009) to avoid family members and friends learning of status or altogether miss doses (Zuurmond, 2008). This preposition is supported by Rao et al(2007: 31) who found more than 50% of their respondents acknowledged skipping doses when

they feared that friends or family might discover their status. In the same study, some of the respondents admitted to not taking their medication when going out to-party.

Many studies attribute low disclosure to fear of stigma (Zuurmond, 2008; Hardon et al 2007; Rao et al, 2007; Rintamaki et al, 2006)which can in turn lead to exclusion by loved ones (Wanjohi, 2009; Dodds et al, 2003:). Stigma concerns are informed by a person's attitude towards HIV and PLWHIV, perceptions of other people's attitude towards HIV and experiences with expressions of discrimination directed towards self or other PLWHIV (Rintamaki et al, 2006). Studies such as that done by Talam et al (2008) have found that lack of adherence is attributable to stigma. Patients who are subjected to stigma reported being tired of taking medication in a study by Wanjohi (2009). The study found a significant relationship between stigma and adherence (p=.001<0.05).Rintamaki et al (2006:364) found that high concern for stigma was significantly associated with likelihood to be adherent and this variable was the only statistically significant predictor of missed medications (95% CI)

Other social support structures such as peer support groups have been associated with improved adherence levels. Such groups provide psychosocial support to PLWHIV which impacts on their self-esteem and builds their self-efficacy in medication (Zuurmond, 2008). The use of community based health workers and volunteers who provide personalized counseling support to PLWHIV not only improves adherence but also the quality of care (Zuurmond, 2008: Castro, 2005).

Among adolescents, adherence has been found to be higher when their peers are also positive (Zuurmond, 2008). Having peers who are positive allows for the young person not to be different and there are no challenges of trying to fit in. Reisner *et al* (2009) report on ART interventions where HIV positive youth in a support group go through discussions on difficult issues and as a result of which 91% of them were able to achieve high adherence levels.

Other studies have however contradicted the role of social support in adherence. In a review of studies, Reisner et al (2005) found no significant relationship between social support and adherence. Similar results are registered by Naar-king et al, 2006and this necessitated further studies in the area.

#### 2.6 Health care provision and adherence

Since HIV patients on treatment and care must regularly make visits to health facilities, studies on the interaction between health care provision and adherence have been conducted. Among the factors commonly studied are factors around access to health care, the quality of care services and the relationship between clients and the health care provider. Access to health care can be said to be a function of service availability, affordability and acceptability of the services (Moshabela, Schneider, Cleary, Pronyk & Eyles, 2011)

The cost of ARVs and the user fees charged in health facilities have been identified as physical barriers to patient adherence (Mehta et al, 1997). Efforts to provide ARVs at subsidized or no costs particularly in Sub-Sahara Africa have greatly contributed towards addressing this barrier. However, user fees charged at health facilities have led to reduced utilization of services. It is no wonder then that patients who are employed have been shown to have higher adherence rates than those unemployed (Wanjohi, 2009). Similar results were posted by Talam et al (2008) who found lower adherence rates (58.8%) among unemployed PLWHIV.

Other costs such as the costs of transportation to health facilities continue to adversely affect adherence. This is demonstrated by participants in a focused group discussions conducted by Hardon et al (2007) who said that lack of transport resulted in them failing to visit the health facility for refill. The further the distance the higher the transport cost and greater the risk of missing visits to collect drugs. Reducing the distance to health facility has been shown to improve adherence. A study by Moshabela et al, (2011) found improved adherence rates for patients on ARVs who were down referred as opposed to their hospital users compatriots. The down referred clients have less median transport costs and did not miss any clinic appointments

Long waiting time at the health facility has been cited as a major challenge to adherence (Hardon et al 2007). Waiting times of up to 5 or 6 hours consume a lot of time for clients and could be frustrating for clients who have to report to work. Losing such long work hours can be a problem for ARV users whose employers do not know they are HIV positive and are on care (Hardon et al, 2007). Long waiting times are a direct consequence of huge workloads witnessed in especially public health facilities which

despite scale-up of ART have not increased the personnel to cater for the increased numbers (Hardon et al 2007)

Humanised care in health services is a critical element in adherence (Zuurmond, 2008:10). At the core of quality care is a trusting relationship between health care providers and the patient that is built on the understanding that each client is different and requires and individualized approach (Friedland, 2006). Trust is important in ensuring patients especially youth who may view providers as adults with power and may fear reporting adherence. Rao et al, (2007) report on youth who could not admit to providers they missed doses since they feared being yelled at. Developing a collaborative patient doctor relationship that provides youth with feeling of mutual understanding might encourage youth to discuss adherence with service providers (Rao et al, 2007). Patients report improved adherence as a result of having a cordial relationship with health care providers (Wanjohi, 2009).

Communication is critical in not only nurturing this trust but also providing adequate information on the medication and the importance of adherence. Patients who received health education on how to take drugs register better adherence (Filho *et al*, 2008). Communicating to patients on the medication increases their ability to follow ARV treatment and increases their adherence (Wanjohi, 2009).

#### 2.7 The influence of food availability on adherence

There is a paucity of studies on the link between food security and adherence. The few studies that have investigated this relationship focus on studies conducted in Sub-Saharan Africa, perhaps an indication that this is the area where this relationship is mostly observed. Food is particularly important in the early stages of ART when the body needs extra nutrition as it regains weight (Hardon *et al.*, 2007).

Without food, some patients may not even start on ARVs (Zuurmond, 2008). Other patients report on resorting to taking medication especially those drugs that need to be taken with food only when it is available (Hardon et al 2007). Wanjohi, (2009) found that respondents who could afford three meals in a day adhered to ARV while of those who could only afford one meal a day 71% did not adhere. The patients reported that taking treatment without having eaten resulted in a feeling of dizziness and this

discouraged taking medication (Wanjohi, 2009). More studies are needed in this area to shed more light on the link between adherence and food availability.

#### 2.8 Demographic factors and adherence

Several studies have sought to investigate the relationship between adherence and demographic factors (Murphy et al, 2005; Reisner et al, 2005, Talam et al, 2008). The demographic factors commonly studied include age, sex, socio-economic factors and education levels. Among the youth, researchers have explored the relationship between adherence and factors such as age, sex, education and retention to school (Murphy et al, 2005) and reported mixed results.

Among the more stable predictor of adherence is level of education which has been shown to positively influence adherence. Wanjohi, (2009) found a significant correlation between the level of education and adherence to ARV treatment ( $x^2=8.38$ , df=3, p<0.039) with high levels of education increasing patient's adherence to treatment. Murphy *et al*, (2005) found a significant association between being adherent and not dropping out of school with remaining in school contributing to better adherence. However Talam *et al* (2008) in stark contrast found that 61.5% of respondents with secondary and post-secondary education failed to take drugs on time.

Other studies have shown that females have better adherence rates. Belzer et al (1999) found more females 73% reported adherence as opposed to males 53%. Similar results are posted by Wanjohi, (2009) who found that 75.57% of female respondents adhered to ART as opposed to 68.35% of males. This difference was however not statistically significant, a finding that is consistent with Murphy *et al*, (2005) who also found no relationship between failure to adhere and sex. Zuurmond (2008) argues that while women are more likely to adhere due the importance they place on remaining healthy, men on the other hand are less likely to disclose and will hide medication from their spouses, a fact that can reduce adherence.

Among the youth, younger ages are associated with failure to maintain adherence (Murphy et al, 2005). Adults aged between the ages of 30 and 39 showed more adherence (Wanjohi, 2009). More studies in the area are needed to establish if demographic factors can be considered predictors of adherence behaviors.

#### 2.9 Conceptual Framework

This conceptual framework is a graphic representation of the variables under study and their relationship. In this study psychosocial factors were identified as the independent variables while HIV drug adherence was the dependent variable. Psychosocial factors were conceptualized as a construct with four interrelated factors; Psychological factors, alcohol and drug abuse, social environment factors and health care provision. This is consistent with the classification done by Reisner *et al* (2009) who arrived at the categories after conducting a content analysis on all factors studied by several studies with a notable inclusion of health care provision in the categorization developed by Reisner *et al* (2009). This classification is similar to that arrived at by Naar-King et al (2006) and Mehta et al (1997).

The theories previously reviewed predict a relationship between the independent and the dependent variable, HIV drug adherence. The study identified food availability as a possible intervening variable and therefore sought to control for its effect.

# Independent Variable Dependent variable Psychological factors · Patient depression and anxiety state Patient attitude to drugs Self efficacy HIV Alcohol and drug abuse Antiretroviral Use of alcohol adherence Use of drugs · Taking all the prescribed drugs Social environment · Strictly following drug schedules Non-disclosure Perceived stigma Involvement in psychosocial support groups Perceived social support Intervening variable Food availability Health care provision · Meals taken in a day · Relationship with service provider

Fig 2.1: The conceptual framework showing relationship between variables

Source: Author

• Transport costs to

Time spent on serviceTime spent with client

facility

#### CHAPTER THREE: RESEARCH METHODOLOGY

#### 3.0 Introduction

This chapter details the methodology used in this study. The chapter presents the research design and describes the target group and how a representative sample was drawn from this group. The data collection procedures, instruments and data analysis procedures used are also discussed in this chapter

#### 3.1 Research design

The research design refers to the structure of an enquiry whose role is to minimize the chance of drawing incorrect causal inferences from the data. As such, it plays the same role an architectural design of a building plays. This study used a descriptive survey design ideal for studies that seek to determine the frequency with which variables occur (Kothari, 2004: 37). The design also allows for description of phenomenon in a systematic and accurate way that enable making of inferences while also establishing relationships among variables.

Qualitative and quantitative approaches were used in the study. Although the two paradigms have appeared to be on opposing sides, Cameron, (2009: 140) argues against the false dichotomy between them and advocates for the efficient use of both in research. This mixed methodologies approach that is advanced by pragmatists recognizes the strengths and weaknesses of each of the approach and seeks to compensate for such by their use in gathering and analyzing data (Cameron, 2009). This study thus employed both quantitative and qualitative approaches as a way of maximizing benefits in using both approaches to collect and analyze data.

#### 3.2 Target Population

The study population consisted of the estimated 300,000 young people living with HIV in Kenya ((National AIDS and STI control program, Ministry of Health Kenya, 2008). In their transition to adulthood, young people undergo a developmental period of experimentation, risk taking and confronting a host of choices with regard to identity formation, relationships, sexual behavior and drugs and substance abuse (Arnett in

Reisner et al (2009). A HIV diagnosis for youth further complicates the challenges they face and put young people on HIV in a unique situation.

The accessible population covered in this study is the young people living with HIV and receiving their medication from the Provincial General Hospital, the only level 5 health facilities in Nakuru Central district. These facility was selected since it has a Comprehensive Care Center (CCC) where ARVs and HIV management is provided. The facility is also within proximal distance to the researcher and serves the vast majority of youth living with HIV in the district. According to ART register at the facility there are approximately 568 youth receiving HIV care in the facility who reside in the study area.

# 3.3 Sample size and sample selection

The study observation unit was drawn from the accessible target population. The study sample comprised of 85 respondents, a number that has been derived by using the formula developed by Yamane (in Determining sample size) shown below

$$n = \frac{N}{1 + N(e)^2}$$

Where

n = desired sample size

N = accessible population size

e = desired level of precision (0.1)

Multi-stage sampling procedure was used in selecting the sample for the study. The researcher used purposive sampling to select the district of focus and the facility from which the sample was drawn. To get proportional representation of males and females, stratified random sampling was used with two strata of males and females. The table of random numbers was used to select study participants who were recruited from the CCC during days set aside for providing services to youth in the facility and from support group meetings.

#### 3.4 Data collection procedures

The study collected both primary and secondary data. Primary data was collected from respondents using an anonymously filled questionnaire distributed to respondents during the clinic days and collected after filling by the researcher and research assistants. To complement this, the researcher interviewed health care providers in the facility to get additional information on adherence. Finally, the researcher conducted a focused group discussions with groups of young people living with HIV to gain additional insights on the matter.

#### 3.5 Research instruments

To collect primary data from the respondents, the study utilized a structured self-administered questionnaire with a rating scale developed by researcher. Structured questionnaires are easier to administer score and analyze and allow for unambiguous responses (Mugenda & Mugenda, 2003:72). The questionnaire items were informed by different tools used by other studies to collect data on the different variables under study. Items to measure depression and anxiety were adapted from the Brief Symptom Inventory used by Naar-King et al (2006) which showed high reliability ( $\alpha$  0.95). Additional items to measure self-efficacy were adapted from self-efficacy measurement tool used by Naar-King et al (2006).

Items to measure alcohol and drug abuse were adapted from the Alcohol Timeline Follow Back (TFLB) assessment method used by Braithewaite et al, (2008) and the 4 question CAGE instruments used by Murphy et al, (2005). Social environment factors were measured through questionnaire items drawn from Social Provision Scale used by Naar-King et al (2006) and the PLWHIV Stigma Index tool (International Planned Parenthood Federation IPPF, 2008). Items to measure health care provision were developed during pilot work and tested for their validity.

Accurate measurement of adherence is a challenge to researchers and researchers have opted to use more than one measure to allow for triangulation of information and compensation of the tools (Wanjohi, 2009: 39: 20). Three methods have been used to measure adherence; subjective measures of adherence based on self-reports; pharmacologic measures of adherence eg pill count, pharmacy refill records;

physiological measures of adherence e.g. plasma HIV RNA levels, CD4+ counts and laboratory reports (Reisner et al, 2009: 15). This study utilized the first two methods largely owing to their ease of application. Items to measure adherence were sourced from the Patient Medication Adherence Questionnaire (PMAQ) that has been widely used to measure adherence (Murphy et al, 2005; Rintamaki et al, 2006) while interviews with health care providers were used to measure adherence through pharmacologic measures.

An open ended interview schedule was used to collect data from key informants who were drawn from CCC personnel who provide services to the youth. The open ended interview schedule is useful to allow for the researcher to probe for additional information. A similar tool was developed to guide the focused group discussions with 12 YPLWHIV. Question items in the two tools mirrored those in the questionnaire to the primary respondents to enable triangulation of information.

### 3.6 Validity of the research instrument

Validity is extent to which a given tool measures what it intended to measure. It is the degree to which results obtained from analysis of the data accurately represent the phenomenon under study (Mugenda & Mugenda, 2003:99). Data that is a true reflection of the variable under study will be useful in making accurate and meaningful inferences on the variables under study (Mugenda & Mugenda, 2003:99). In this study, validity of the data collection tool was achieved by; identifying and controlling for extraneous variables; using experts to assess the content validity of the tool; conducting a pre-test of the tool and using data collection tools that have been developed and tested by other researchers to measure the variables under study.

The study identified food availability as the extraneous variable and collected data which was used to compare the variable with the dependent variable. No relationship was established between the variable and any of the variables. The data collection tools were shared with clinical staff at the health facility who reviewed each item to establish whether it was measuring the intended variable. From the pre-test conducted, the researcher was able to identify the question items that needed review and subsequently reviewed item 12 whose language was deemed not easy to understand. Calculation of

Cronbach's alpha as will be discussed below also contributed to the validity of the research tool

## 3.7 Reliability of the research tool

A research instrument that yields consistent results after repeat trails can be said to be reliable. To achieve reliability, researcher must control for random errors due to inaccuracy in scoring, inaccuracy of the instrument or unexplained error (Mugenda & Mugenda, 2003:96). To strengthen the reliability of the tool, the study made use Cronbach's Coefficient Alpha (K-R 20) a measure of internal consistency which involves correlating a score in one item with scores obtained from other items in the instrument (split half technique). The Cronbach's Coefficient Alpha (K-R 20) was computed on the items to establish their correlation using the formula below.

$$KR_{20} = (K) (S^2 - \sum_{s}^{2}) (K-1)$$

Where:

 $KR_{20}$  = reliability of coefficient of internal consistency

K = Number of items used to measure the concept

 $S^2$  = Variance of the scores

 $s^2$  = Variance of individual items

$$KR_{20} = \frac{27 (13.942-39.177)^2}{(13.94)^2 (27-1)}$$

$$KR_{20} = 0.803$$

Application of the formula yielded a coefficient of 0.803 which implied high correlation among the items and thus internal consistency of the tool.

# 3.8 Data Analysis Techniques

Data collected from the respondents was systematically organized, coded and data entry done. Since the study yield both quantitative and qualitative data, both techniques of data analysis were utilized. Qualitative data from focused group discussions was be categorized by theme for analysis and categorization verified by two independent expert raters. Quantitative data was analyzed using statistical packages and descriptive statistics

generated to describe the data. To establish relationships between variables, the study calculated coefficient of correlation using the Pearson Product Moment correlation

#### 3.9 Ethical Considerations

Approvals to undertake this study were obtained from National Council of Research and Technology and UON Ethics Review Committee as required. The researcher also sought consent to conduct the study from the Senior Health Administrator, PGH, Nakuru and the in-charge at Comprehensive Care center from whence the sample was drawn. Respondents in the survey were assured of the confidentiality of the research and their consent to participate in the research willingly sought. Only those who accepted to participate in the study willingly were provided with questionnaires.

# 3.10 Chapter summary

This chapter has detailed the methodology that was used in the study. The chapter has explored the research design used, described the target population, sampling and how data was collected and analyzed.

Table 3.1: Operational definition of variables

Research questions	Variables	Indicators	Measurements	Measurement scale	Data collection	Tools analysis	of
Do psychological factors have an influence on HIV drug adherence among young people living with HIV in Nakuru Central district	Independent Variable • Psychological factors	Patient self-efficacy score     Patients depression score     Patients anxiety score     Patients drugs attitude score     Previous abuse	<ul> <li>Self-report rating on self- efficacy, depression, anxiety, attitude scales</li> </ul>	Ordinal scale	Self-     administered     questionnaire     Interviews     with Health     care workers	Descriptive statistics inferential statistics	and
Does alcohol and drug abuse have an influence of on HIV drug adherence among young people living with HIV in Nakuru Central district	Independent variable • Alcohol and drug abuse	Frequency of use of alcohol     Frequency of use of drugs	Self-reports on alcohol and drugs use	Ordinal	Self- administered questionnaire     Interviews with Health care workers	Descriptive statistics inferential statistics	and
Does the patient's social environment influence HIV drug adherence among young people living with HIV in Nakuru Central district	Independent variable • Social environment	Non-disclosure leading to stigma     Involvement in psychosocial support groups     Family and friends support     Counseling support	Self-reports on having disclosed     Self-reports on participation in support groups     Self-report rating of perceived social support and counselling	Ordinal	Self- administered questionnaire     Interviews with Health care workers	Descriptive statistics inferential statistics	and
Does the nature of health care provision influence HIV drug adherence among young people living with HIV in Nakuru Central district	Health care provision	Relationship with service provider     Transport costs to facility     Time spent on service     Time spent with client	Self-reported score on perceived relationship with health care provider, transport costs, time spent with provider	Ordinal	Self- administered questionnaire     Interviews with Health care workers	Descriptive statistics inferential statistics	and

# CHAPTER FOUR: DATA ANALYSIS, PRESENTATION AND INTERPRETATION

#### 4.0 Introduction

This chapter presents the findings of the study as presented using descriptive statistics. The chapter begins with a review of the response rate and then reviews the frequencies of observations of the variables under study and explores the observed relationships between the variables.

#### 4.1 Response rate

The researcher distributed a total of 100 questionnaires despite the desired sample size of 85. The extra questionnaires were to cater for non-response. Of the questionnaires distributed, 69 questionnaires were returned representing a response rate of 81%. This response rate is attributable to the difficulty of getting the respondents within the stipulated research time frame.

## 4.2 Respondents gender, age and level of education

The research was able to achieve a balanced representation of male and female with 52 % of the respondents interviewed being female while males constituted 48%. This suggests that most of the respondents were literate enough to be able to adequately respond to the questionnaire items.

Table 4.1: Table showing gender of the respondents

Variable	%
Gender of respondents	
Male	48
Female	52
Total	100

Majority of the respondents were aged 20-24 (73%) which is within the age bracket of the study.

Table 4.2: Table 4.3: Table showing age of respondents

Variable	%		
15 - 19	27		
20 - 24	73		
Total	100		

57% of the respondents were educated up to secondary school level. A further 20% of the respondents had college education while 20% of the respondents were educated up to primary school level.

Table 2.3: Table showing respondent's level of education

Variable	2/0
No education	3
Primary school level	20
Secondary school level	57
College/University level	20
Total	100
Iotai	

# 4.3 Occupation and living situation of the respondents

From the table below it will be noticed that a sizeable proportion of respondents are unemployed (35%) compared to only 14% who are employed. 26% of respondents are self-employed bringing the total number of respondents who are engaged in some form of work which earns them some income to 40%.

Table 4.4: Table showing occupation and living status of respondents

Variable	%
Work/occupation status	
Unemployed	35
In school/college	26
Self employed	26
Employed	14
Total	100

37% or respondents live with their biological parents while 26% of the respondents live alone. A further 20% of the respondents live with relatives. This would suggest despite being employed there are respondents who still live with parents and relatives.

Table 4.5: Table showing respondents living arrangements

Variable	0/0
Living alone	26
Living with biological parents	37
Living with foster parents	7
Living with other relatives	20
Living in a student hostel	10
Total	100

# 4.4 Membership to support groups

It is important to note that the vast majority of respondents are not members of any support group (53%) as compared to 47% who are in such groups that provide psychosocial support.

#### 4.5 Level of adherence

Only 56% of respondents were able to take their drugs all of the time while 24% of respondents took all their drugs most of the time. Interestingly 7% never took all the prescribed drugs while 6% rarely took their prescribed drugs. This suggests a significant level of non-adherence. Moreover only 61% of the respondents took all drugs at the right time thus achieving optimal adherence. Clinic attendance which is related to getting refills was ignored by 8% of the respondents while 3% rarely made it for their appointments. Only 68% of youth living with HIV attended all their clinic appointments as expected

Table 4.6: Table showing levels of adherence

	Never	Rarely	Sometimes	Most of the	All the time
Took all the prescribed drugs in the	7	2	10	24	56
ast 1 month  Fook all prescribed drugs at the right	7	5	10	34	44
ime last 1 month	8	3	8	15	68
Attended all clinic appointments in last months	8	3	8	15	

# 4.6 Respondents experience with depression and anxiety

A number of respondents exhibited symptoms of being anxious with 41% of the respondents admitting to feeling nervous a little bit while 12% had the same feeling a little bit more. Averagely 57% of the respondents did not experience any anxiety. On the other hand 21% of respondents felt lonely and 15% felt moody all indicators suggesting they experienced depressive symptoms. A further 35% and 39% experience some degree of loneliness and moodiness suggesting that youth living with HIV exhibit depressive symptoms

Table 4.7: Table showing frequence	of respondents experiencing	anxiety and depression
------------------------------------	-----------------------------	------------------------

Variable indictor	Not at all	A little bit %	Moderately %	Quite a bit	Extremely %
Indicators of anxiety					
Nervousness or shakiness inside	47	41		12	
Suddenly scared for no reason	59	26		9	6
Feeling fearful	49	30		16	5
Feeling tensed	63	27		10	
Spells of terror or panic	63	9		22	6
Feeling so restless you couldn't sit still	61	18		18	3
Indicators of depression					
Thoughts of ending your life	85	6			9
Feeling lonely	24	35		21	21
Feeling moody	33	39		12	15
Feeling no interest in things	39	36		15	9
Feeling hopeless about the future	51	29		9	11
Feeling worthlessness	64	17		8	11

Among the indicators of anxiety that showed a relationship with adherence was feeling fearful which was positively correlated with taking HIV drugs at the right time (0.404 signi. 0.05) and attending all clinic appointments (0.688). Feeling restlessness was also positively correlated with taking drugs at the right time (0.510) and attending all clinic appointments (0.549). Among indicators of distress, having thoughts of ending one's life was significantly and negatively correlated with taking all prescribed drugs (-0.633), taking drugs at the right time (-0.514) and attending all clinic appointments (-0.587) all significant at 0.01 level

Table 4.8: Table showing correlation between anxiety and distress with ART adherence

	Taking all the prescribed drugs	Taking prescribed drugs at right time	Attending all clinic appointments
Feeling fearful		0.404	0.688
Feeling restlessness		0.510	0.549
Having thoughts of ending one's life	-0.633	-0.514	-0.587

#### 4.7 Respondents drugs self-efficacy to HIV drugs

Nearly half of the respondents exhibited high levels of drug efficacy with 46% saying they were very sure they would take their medication while 38% said they were sure of doing the same. The same frequencies were observed in as far as taking

medication at the right time. This relatively high level of drug efficacy would suggest high accepting behavior.

# 4.8 Frequency of alcohol and drug use

27% of the respondents admitted to taking alcohol with 7% saying they take alcohol frequently while 10% said they took alcohol some of the time. 5% of the respondents took over 8 bottles of alcohol while 3% took between 5and 8 bottles. 18% of the respondents were light drinkers taking less than 2 bottles in a week as will be seen from the table below. Majority of the respondents do not take other drugs with 90% saying they never take any other drugs. That YPLWHIV take alcohol is a fact that was reinforced by findings from an FGD with YPLWHIV who also gave reasons why this happens.

"Most youth who are positive are in denial immediately they learn they are positive and they have not accepted that is the time they most use alcohol. Peer pressure from other colleagues also contributes to alcohol taking saying "maboyz wangu wanagauge kwa nini mimi nisigauge, watajua mimi ni mgonjwa" (my friends are taking alcohol. If I don't take with them they may suspect I am positive), participant in an FGD

Table 4.9: Table showing frequency of use of alcohol

Variable indicator		%
Take alcohol	Never	73
	Rarely	10
	Sometimes	10
	Often	7
Amount of alcohol consumed in a week	None	10
	Less than 2 bottles/glasses	18
	More than 2 less than 5 bottles/glasses	5
	Between 5 and 8 bottles/glasses	3
	Above 8 bottles/glasses	5
Use of other Non-Medical drugs in	Never	90
last 1 month	Rarely	2
	Sometimes	6
	Often	2

A comparison between the alcohol consumption and drug adherence revealed that 100% of the respondents who said they drank sometimes also reported never taking their

drugs in the last month. Of those who never drank, 75% reported taking their drugs most of the time in the past month. 33% of those who said they often take other non-medical drugs never took all the prescribed HIV drugs while 96% of those who said they never took any other non-medical drugs adhered. Only 6% and 11% of those who said they took their drugs all the time said they drunk often and sometimes respectively.

#### 4.9 Disclosure of HIV status

Majority of the respondents (79%) admitted to having disclosed their status to anyone. Of those who had disclosed their status, 55% had disclosed to an immediate family member, 36% to a friend and 9% to a relative. No significant correlation was observed between disclosure and adherence.

## 4.10 Perception and experiences of stigma

A third of the respondents had experienced stigma in form of gossip (29%) while 18% had been verbally confronted and insulted. The frequency of acts of stigma directed towards YPLWHIV was only high for 5-7% of the respondents who were called names and talked about. Other confrontational acts of stigma such as forceful eviction and being sacked from a job appeared less frequently. However it is significant to note that between 2-12% of respondents have been subjected to some form of confrontational stigma. This was confirmed by participants in the FGD who all said they had experienced stigma

"Actually the stigma that is there today is from the people living with us in the community. It is these who stigmatize us because we have accepted ourselves but the other community does not accept us. Like say I am positive, my mum my sisters do not accept me," participant in an FGD.

Table 4.10: Table showing frequencies of experiencing acts of stigma

Variable indicator	Never	Rarely %	Sometimes %	Often %	Always
Talked or gossiped about	39	20	29	7	5
Confronted and verbally insulted	59	18	18	3	3
Called names	64	14	12	2	7
Evicted from the house	85	2	12		
People refused to associate with you	62	19	17		2
Lost job	87	3	8	3	

Despite experiencing acts of stigma, there was no significant correlation established between stigma and any of the adherence measures suggesting stigma did not serve to encourage or discourage adherence.

# 4.12 Perceived social support

From the table below, a good proportion of youth living with HIV feel there are people who can help in case of need (53%). It is perhaps for this reason 54% feel they have people in their life who they can count on in case of an emergency and have an emotional bond with someone else (50%). This suggests strong feelings of social support. However a fifth of the respondents are cautious about talking to someone for guidance and admit there is no-one they feel comfortable sharing problems with.

Table 34.11: Table showing frequencies of perceived support

Variable indicator	Strongly disagree (%)	Disagree (%)	Don't know (%)	Agree (%)	Strongly agree (%)
There are people I can depend on to help me if I really need it.	9	9	19	53	9
There is no one I can turn to for guidance in times of stress.	28	42	7	21	2
There are people who enjoy the same social activities I do.	7		19	52	21
I feel part of a group of people who share my attitudes and beliefs	3	8	16	63	11
If something went wrong, no one would come to my assistance	24	38	21	10	7
There are people I can count on in an emergency.	10	10	15	54	12
I lack a feeling of intimacy with another person.	15	36	15	21	13
There is no one I feel comfortable talking about problems with.	20	56	2	17	5
I feel a strong emotional bond with at least one other person	16	13	8	50	13
There is someone I could talk to about important decisions in my life	5	20	7	46	22

A number of indicators of social support were significantly correlated with adherence measures. Perception that there are people to help one if they needed help correlated significantly with taking all the prescribed drugs (0.534) while perception that there a people to assist one in the event of an emergency registered a correlation of 0.605 with taking all prescribed drugs and 0.570 with keeping all clinic appointments. All correlations were significant at 0.01.

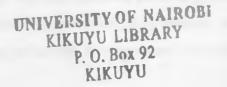


Table 4.12: Table showing correlation between social support indicators and ARV adherence

	Taking all the prescribed drugs	Taking all prescribed drugs at the right time	Attended all appointments	clinic
There are people to help if one needed help	0.534			
There are people to assist in case of	0.605		0.507	
emergency				

## 4.13 Perceptions of Health services

Nearly all of the respondents (90%) agree that taking drugs at the right time will improve their health. They further see the need to take drugs even when one is feeling well. The respondents appeared happy with the manner in which services are provided with 68% agreeing and strongly agreeing they are well served at the CCC. This perhaps stems from the fact that 76% of respondents feel they trust the health care providers as shown in the table below. However it is only 58% of respondents who believe the health care providers spent adequate time with the clients. The expenses incurred while coming to the CCC are viewed as high by 38% of respondents while a fifth of the respondents feel that the fees charged are high.

Table 4.13: Table showing the frequencies of perceptions on health care services

Variable indicator	Strongly disagree (%)	Disagree (%)	Don't know (%)	Agree (%)	Strongly agree (%)
Taking all my drugs at the right time will improve my health	5		5	49	41
I do not need to take all my drugs if I am feeling okay	59	28	5	8	
The service providers attend to the CCC clients in a friendly manner	12	15	5	56	12
The service providers spend adequate time with CCC clients	15	20	8	45	13
I trust the service providers	10	7	7	56	20
The health service providers give adequate information on the drugs	7	12		54	27
I incur a lot of expense when coming to the health facility	23	35	5	30	8
The fee I pay at the health facility when I go for HIV treatment is high	34	44	2	15	5

Belief that taking all the drugs will improve health was significantly correlated with taking all the prescribed drugs (0.560). The time spent with clients was significantly correlated to attending all clinic appointments (0.636) as was trusting health care providers (0.593). A significant correlation was also observed between providing information to clients with taking all prescribed drugs (.0489) and keeping clinic appointments (0.502). Expenses incurred in going to hospital also registered a significant

correlation with keeping appointments (0.534) suggesting that transport is a hindrance to keeping appointments, argument that was confirmed by the health care provider at the CCC who advanced similar sentiments in an oral interview.

"Sometimes they will come in a week or two after their appointment date and when you ask they say they did not have transport and you have no choice but to attend to them." CCC Nurse, PGH

Table 4.14: Table showing correlation between health care provision and adherence

	Taking all the prescribed drugs	Taking all prescribed drugs at the right time	Attended all appointments	clinic
Taking medication will improve my health Health providers spend	0.560		0.636	
adequate time with CCC clients I trust the health care providers			0.593	
Health providers give adequate information on the drugs		0.489		
I incur a lot of expenses when coming to the hospital			0.534	

# 4.14 Food availability and its influence

A third of the respondents disagreed and strongly disagreed with the statement that getting food is not a problem. This suggests that the group has challenges in getting food. No correlation was however observed between lack of food and any of the adherence measures.

#### 4.15 Testing the hypothesis

The study sought to test the hypothesis that 'there is a significant relationship between psychological factors and HIV drug adherence among youth living with HIV.' In testing the hypothesis, the researcher cross tabulated the indicators of psychological factors with item 9 which measured adherence rate and obtained p values of less than 0.05. P values of 0.05 or less rejects the null hypothesis. This led to the rejection of the null hypothesis and the accepting of the alternative hypothesis.

# 4.16 Chapter Summary

This chapter has presented the findings from the data analysis and interpreted the data collected. The chapter has explored the frequency of observations and the observed relationships from the analysis.

# CHAPTER FIVE: SUMMARY, DISCUSSIONS, CONLUSIONS AND RECCOMMENTIONS

#### 5.0 Introduction

This chapter summarizes the findings and discusses how the variables under study relate. The chapter also shows if the findings accept or reject the hypothesis, draws conclusions on the findings and makes recommendations.

# 5.1 Summary of findings

The study sought to explore how psychosocial factors; psychological factors, drug and substance abuse, social environment and health care provision influence drug adherence. A summary of the finding follows hereunder.

# 5.11 Influence of Psychological factors on ARV adherence

The study findings reveal evidence of anxiety symptoms among YPLWHIV with a sizeable proportion admitting that they do experience various forms of anxiety mildly (25%) and quite often (14%). Fear driven anxiety seems to be the main form of anxiety that they experience with 46% experiencing this form of anxiety. However, no strong negative correlation was found between anxiety and adherence meaning anxiety did not necessarily result to non-adherence. On the contrary a positive correlation was observed between feeling fearful and keeping clinic appointments (0.561). In particular feeling fearful was correlated to attending all clinic visit at 0.774 (significance at 0.01) implying that YPLWHIV respondent feelings of anxiety by being more strict on medication and clinic attendance. Similar observations were observed with feeling restlessness, another indicator of anxiety.

The study finding show that 76% of YPLWHIV experience feelings of loneliness while 67% experience moodiness. Thoughts of ending one's life were negatively correlated with all the measures of adherence; taking all the prescribed drugs (-0.633), taking the drugs at the right time (-0.514) and keeping clinic appointments (-0.587) all significant at 0.01. This suggests that despair with life discourages drug adherence. Of significant notice is the positive attitude YPLWHIV have towards medication with a majority believing medication will improve their lives (90%). The significant positive correlation observed (0.560) suggests positive attitude towards medication improves adherence. The negative correlation between the perception that one does not need to take

drugs when feeling okay with taking all the prescribed drugs (-0.445) further reinforces the observation that attitude towards drug taking influences adherence.

This in turn has affected their self-efficacy in drug taking and it is no wonder that 85% believe they have the ability to take their drugs at the right time even when influenced not to do so. No significant correlation was however observed between self-efficacy and adherence.

# 5.12 Influence of Alcohol on ARV adherence

That up to 27% of YPLWHIV take alcohol is a fact that was reinforced by their own admission in a focused group discussion conducted. The level of alcohol consumption varied with up to 8% of the respondents being heavy drinkers while a further 5% were moderate drinkers. 18% of the respondents admitted to being light drinkers.

Alcohol consumption was significantly correlated with adherence (-0.664) as was amount of alcohol taken (-0.611 signi. 0.01) suggesting those who took alcohol, were more likely to fail to take all the prescribed medications. Use of other drugs despite registering a low frequency (10%) was significantly correlated to the drugs at the right time (-0.446) suggesting that influence of the drugs may have contributed to failing to take medication on time.

Alcohol abuse was also strongly correlated with other variables. Significant correlation was observed between alcohol abuse and thoughts of ending one's life (0.643), feeling lonely (0.536), feeling moody (0.429) all significant at .01, lack of interest in things (0.310), feeling hopeless (0.373) and feeling worthless (0.396) all significant at 0.05. Alcohol abuse was also negatively correlated with the two measures of self-drug efficacy (-0.431 and -0.380) suggesting alcohol reduced an individual's self-efficacy.

#### 5.13 The social environment and ARV adherence

A high rate of disclosure of HIV status was observed among YPLWHIV with 79% saying they had disclosed their status. Preference to disclose seemed to favor immediate family members and friends with relatives being the least favored people to disclose to. Although not significant, a negative correlation was observed between non-disclosure and taking all the prescribed drugs (0.314).

Non-disclosure could have been affected by the perceived stigma experienced by YPLWHIV in different proportions. Up to 61% of respondents admitted experiencing being gossiped about at least once while up to 41 % had experienced being insulted as a result of their status. Up to 36% and 38% of YPLWHIV had experienced being called names and being avoided for the same reason. However only being called names was significantly correlated to keeping clinic attendance suggesting that name calling could have discouraged YPLWHIV from going for medication.

Positive feelings of social support were observed among averagely 50% of the respondents with 63% of respondents agreeing to the statement there were people who could assist them. Similarly 64% agreed and strongly agreed there were people who could help them in an emergency. Close to 74% of YPLWHIV felt there were people with whom they could share similar activities with almost a similar percentage (63%) admitting they had people they felt a strong emotional bond to. Significant positive correlation was observed between adherence and having people who can help (.534), having people with whom they share similar activities (.420) and having people who one can count on in case of an emergency (.612). This suggests that perceptions of social support boosted adherence levels.

# 5.14 Health care provision and its influence on ARV adherence

Most respondents agreed that the quality of service that they receive is acceptable. 68% of respondents said they are attended to in a friendly manner, 58% said the health care providers spent adequate time with them while 76% said they trust the service providers. Service providers also received a positive vote on providing adequate information to clients with 80% saying they do so.

The adequacy of time spent with clients, the trust clients have in the health care provider and the provision of adequate information to clients all were significantly correlated with keeping appointments at 0.639, 0.593 and 0.502 respectively strongly suggesting good provider attitude will increase adherence. Trusting service providers and receiving adequate information from service providers were also significantly related to taking all the prescribed drugs at 0.516 and 0.489 respectively. This suggests that

YPLWHIV who trusted the service providers were more likely to adhere in much the same way those who received adequate information from them did.

38% of respondents felt they incurred a lot of expenses when coming to hospital while 20% felt the user fees charged are high. This could have contributed to failure to keep hospital appointments since a significant correlation was observed between high expenses incurred and attending all appointments.

# 5.15 Influence of demographic factors on ARV adherence

The level of education was significantly correlated to all the measures of adherence; taking all the prescribed drugs (0.573), taking the drugs at the right time (0.500) and keeping all appointments (0.750) all significant at 0.01. This suggest that the higher the level of education, the higher the adherence. Level of education was also observed to influence participation in support groups with a significant correlation observed between membership in support groups and level of education. A negative correlation was also observed between level of education and experiences of being talked about (-0.439) being verbally insulted (-0.406) and being called names (-0.330) significance at 0.05.

There was an observed relationship between participation in support groups and all measures of adherence; taking all the prescribed drugs (-0.646), taking drugs at the right time (-0.439) and keeping clinic appointments (-0.792) all significant at 0.01. Participating in support groups also improved on attitude towards medication with significant (at 0.05) correlation of 0.391 and improved attitude towards health care providers (r=0.405) significance at 0.01). Working long hours was observed to be correlated with measures of anxiety, feeling scared (0.580), feeling fearful (0.596) and feeling restless (0.889) suggesting that anxiety could have been heightened by work related factors.

#### 5.3 Discussion of findings

Consistent with other findings, this study found that youth do not achieve optimal adherence levels. The adherence levels of averagely 54% observed in the study are similar to those observed in other studies reviewed (Murphy et al, 2005; Naar-King et al,

2006; Reisner et al, 2009). These moderate adherence rates also mirror those of studies conducted in Kenya by Talam et al (2008) where adherence rates of 68% were observed

Among the reasons advanced by YPLWHIV include being in a situation where one could not take drugs such as in company of friends who did not know their status and being in social functions. This implies that social and psychological factors have a big role to play in adherence. Consistent with findings by Chandwani et al (in press), Murphy et al (2005) Naar-King et al (2006), Rao et al (2007) and Reisner et al (2009) the study found relationship between distress and adherence with YPLWHIV who are distressed having lower adherence levels. The study however found some forms of anxiety increased adherence especially clinic appointments quite in contradiction to studies reported by Reisner et al, (2009). This implies anxiety creates a desire to be strict on medication.

Unlike studies conducted by Garvie et al, (2011) and Naar-King et al (2006) no significant relationship was found between self efficacy and drug adherence despite YPLWHIV showing high drug efficacy. The high drug efficacy could be as a result of the positive attitude to medication observed among YPLWHIV which was significantly correlated to adherence. Compared with the finding that 80% of respondents agree that health care providers provide information to clients means YPLWHIV are informed and thus are aware of the effects of proper drug use and adherence. This finding is similar to findings by Belzer et al, (1999) who found higher adherence rates among youth with positive attitude to medication.

Consistent with the findings by Braithewaite et al (2008) Murphy et al (2005) Rintamaki et al, (2006) the study found that abuse of alcohol negatively affects adherence with those who never take alcohol showing higher adherence levels unlike those who reported drinking moderately and frequently. Alcohol abuse was also correlated strongly with all measures of depression and this is consistent with findings by Garvie et al, (2011).

Similar to findings by Belzer et al, (1999) there was no observed relationship between disclosure and adherence despite observed high levels of disclosure. It would appear disclosure served to increase opportunity for YPLWHIV to receive social support and this contributed to observe positive feelings of social support. Then fact that nearly

50% of the youth are in psychosocial support groups could have added to their feeling that they have people they can rely on for advice and guidance. Although Naar-King et al (2006) and Reisner et al (2009) did not find any relationship between social support and adherence, this study found a significant relationship between the two variables supporting the assertion that social support positively influences adherence.

Negative perceptions of social support were found to negatively influence adherence. YPLWHIV who found themselves in a hostile social environment choose not to take their medication on time suggesting that social environment is a stable predictor of adherence levels. This is similar to arguments proffered by Rao et al, (2007). Unlike studies by Rao et al (2007), Rintamaki et al (2006) Talam et al (2008) and Wanjohi (2009) this study did not however establish a relationship between stigma and adherence.

The observed relationship between adherence and trusting relationship with health care providers is consistent with findings by Wanjohi (2009) and implies health care providers can play a big role in improving adherence levels. Similarly, providing information to clients will positively influence adherence as was shown in this study as well as studies by Filho *et al* (2008) and Wanjohi (2009). Consistent with findings by Hardon *et al* (2007), the study found a relationship between transport costs and keeping all appointments implying reduced costs would improve adherence levels. Of the demographic factors studied, it is only the level of education that was correlated with adherence consistent with findings by Murphy *et al* (2005) and Wanjohi (2009). No relationship was observed between age and gender and the dependent variable.

#### 5.4 Conclusions

It is of concern that nearly half of youth living with HIV do not achieve optimal adherence to HIV medication. This presents a public health concern since such youth are at the risk of developing drug resistance due to incomplete viral suppression. Viewed against the growing population of youth living with HIV, the fight against HIV would suffer major setbacks as more youth are put on 2<sup>nd</sup> line treatment as a result of developing resistance. A lot of effort should thus go towards establishing and addressing the factors that limit drug adherence.

Findings of this research suggest that YPLWHIV experience depression which negatively affects adherence. Minimizing depression by emphasizing positive feelings of

HIV drugs. Another key observation is the destructive role played by alcohol which not only hampers adherence but is the genesis of psychological problems such as depression. Interestingly, alcohol abuse was also related to feelings that there was no one to assist if anything went wrong and generally negatively affecting perception of social support, self-efficacy and attitude towards medication. Addressing alcohol and drug abuse needs to take center stage if optimal adherence is to be achieved.

To achieve optimal adherence rates, stigma needs to be exhaustively addressed. The fact that 38% YPLWHIV experienced social rejection as a result of their status means there are incidences of stigma that still need to be combated. Perceptions of stigma among YPLWHIV could be the cause of low disclosure and confirming those fears by subjecting YPLWHIV to gossip only strengthens the resolve not to disclose. Improving knowledge among YPLWHIV can also serve to minimize perceptions of stigma.

The observed positive perception towards health care provision could be attributable to the fact that the data for the study was collected on a day set aside for attending to youth at the CCC. This initiative by the hospital to set aside a day exclusive for young people seems to be working to improve client perception of health care. This also implies that providing services in a youth friendly environment can increase client satisfaction and trust and improve adherence rates. Adequate communication and time spent on client can ensure regularity of attendance boosting treatment.

There is need to enhance access to treatment by providing services closer to the community to avoid the expenses incurred by YPLWHIV while coming to hospital. This could be achieved through down referral to services points which are closer to clients and would eliminate the need for transport costs. This will reduce incidence of non-attendance to clinic appointments.

#### 5.5 Recommendations

It is important to understand the different challenges that youth go through and how these affect their levels of adherence. The interface between psychological and social factors need to be thoroughly investigated and understood by health care providers and a multi-faceted response that addresses the multiple behavioral factors that affect adherence adopted. Innovative ways of promoting adherence that are embedded within

facility structure such as providing services to YPLWHIV on select days as applied by PGH could be scaled up to improve adherence rates.

Further studies need to be conducted among the growing number of youth who were perinatally infected who probably have been on medication since birth. Such a group may have different adherence behavior. While this study did not delve into that, this would be an area of interest that could inform the behavior of the two categories of YPLWHIV. Another area of study that could be delved into that this research did not touch on is the interaction between these psychosocial and biomedical factors such viral load and type of treatment regime in determining adherence. Such as study could provide invaluable insights on the interaction between these factors and HIV drug adherence.

# 5.6 Chapter Summary

This chapter has presented a summary of the findings by variable and discussed those findings before drawing conclusions and making recommendations

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#### **APPENDICES**

# Appendix I: Questionnaire for survey participants

Thank you for agreeing to participate in this research by responding to the questions below. Kindly tick or circle the response that you best agree with

# **QUESTIONNAIRE IDENTIFICATION INFORMATION**

QUESTIONAIRRECode	[ _	
DATE OF INTERVIEW:	\	\ 2012

ART ONE	
Kindly indicate your gender	1. Male
	2. Female
2. Please indicate your age.	1. 15-19 2. 20-24
3. Please indicate your highest level of education?	1. No education
	2. Primary school level
	3. Secondary School level
	4. College/University level
	5. Post graduate
4. Please indicate your current living arrangement?	1. Living alone
	2. Living with biological parents
	3. Living with foster parents
	4. Living with other relatives
	5. Living with friend(s)
	6. Living in a student hostel
5. Please indicate your current occupation?	1. Unemployed
	2. In school/college

	3.	Self employ	/ed		
	4.	Employed			
6. If working, please indicate your working time?	1.	Daytime			
	2.	Night time			
7. If working, please indicate the number of you	1.	Less than 8	hours		
work in a day?	2.	8 hours			
	3.	More than 8	3 hours		
8. Please indicate if you are a member of any	1.	Yes			
support group?	2.	No			
PART TWO					
(Please indicate the most appropriate response)					
	I Never	2. Rarely	3 Someti mes	Most of the time	5 All the time
9. During the last 1 month you took all your					
prescribed drugs  10. During the last month you took all your					
prescribed drugs at the right time					
11. During the past three months you attended all					
your clinic appointments (Please tick how much the issues below have distres	sed vou i	n the past 1	month incl	uding toda	iy)
Te to a control of the control of th	1	2	3	4	5
	Not at all	A little bit	Moderat ely	Quite a bit	Extreme ly
12. During the past seven days, how much were you					
distressed by: a) Nervousness or shakiness inside					
b) Suddenly scared for no reason					
c) Feeling fearful					
d) Feeling tense					
e) Spells of terror or panic					
f) Feeling so restless you couldn't sit still					
g) Thoughts of ending your life					
h) Feeling lonely					
i) Feeling blue					

j) Feeling no interest in things					
k) Feeling hopeless about the future					
l) Feeling worthless					
(please pick the response that you most agree with	)	1	<u> </u>		
	Not very sure	2 Not sure	3 Somewh at sure	4 Sure	5 Very sure
<ul> <li>a) I am sure that I can take the right amounts of medicine at the right time</li> <li>b) I am sure I can take the right amounts of my medicine at the right time even if I was tempted not to</li> </ul>					
14. Please indicate if you drink alcohol?	l Never	2 Rarely	3 Someti mes	4 Often	5 Every time
15. Please indicate how much alcohol you take on average in a week	l None	Less than 2 bottles/ glasses	More than 2 less than 5 bottles/ glasses	Between 5 and 8 bottles/ glasses	5 Above 8 bottles/ glasses
<ol> <li>Please indicate if you have used any other non- medical drug/substance During the past one month</li> </ol>	l Never	2 Rarely	3 Someti mes	4 Often	5 Every time
17. Have you ever told anyone of your HIV status?	1. Y 2. N				
18. If so, who?	I Immediat e family member	2 Another relative	3 Friend	4 Church leader	5 Commu
Please indicate the frequency with which you have		ed any of t	he followin	ng during	the past
nonth	1 Never	2 Rarely	3 Someti mes	4 Often	5 Always
a. Have you been talked or gossiped about as a result of your status					
b. Have you been confronted and verbally insulted as a result of your status					
c. Have you been called names as a result of your status					

	ave you been evicted from your home as a sult of your status					
	as anyone refused to associate with you as sult of your status					
f. Ha	ave you lost your job as a result of your status					
family that ea	wering the next set of questions, please the members, co-workers, community members ach statement describes your current relation opinion.	, and so on	. Please te	ll me to v	vhat extent	you agree
give yo	и оринов.	Strongly	Disagree	Don't	Agree	Strongly
		disagree		know	"	agree
20.						
	ere are people I can depend on to help me if I ally need it.					
	ere is no one I can turn to for guidance in nes of stress.					
	ere are people who enjoy the same social ivities I do.					
	eel part of a group of people who share my itudes and beliefs.					
	something went wrong, no one would come to assistance					
	ere are people I can count on in an ergency.					
	ack a feeling of intimacy with another rson.					
,	ere is no one I feel comfortable talking out problems with.					
	eel a strong emotional bond with at least e other person					
3,	ere is someone I could talk to about portant decisions in my life					
The que	estions below relate to the health care service	s you recei	ve. Please	tick the e	xtent to wh	ich you
	ith the statement					
		Strongly disagree	Disagree	Don't know	Agree	Strongly
21 Tak	ing all my drugs at the right time will	usugree		AHOW		
	prove my health					

22. I do not need to take all my drugs if I am feeling okay	
23. The service providers attend to the CCC clients in a friendly manner	
24. The service providers spend adequate time with CCC clients	
25. I trust the service providers	
26. The health service providers give adequate information on the drugs	
27. I incur a lot of expense when coming to the health facility	
28. The fee I pay at the health facility when I go for HIV treatment is high	
29. Getting all my meals for the day is not a problem	

Thank you for your cooperation

# Appendix II: Key Informant Interview Schedule

#### Introduction:

Good morning/afternoon, my name is Rachael Manyeki, an MA student of the University of Nairobi (Nairobi campus). I am conducting a research on HIV drugs adherence among young people living with HIV as part of my studies.

Based on your knowledge, expertise and interaction with the subject of this research, I have selected you as an informant in this study and that is why I am sharing this questionnaire. Some of the questions may require you to divulge some information about your clients that may be confidential but I assure you that your answers will be used for the purposes of this research only and will not be shared with anyone else other than the researcher. Your honest response to these questions will help me better understand the behavior of young people towards medication and I would greatly appreciate your help. This interview will take about 25 minutes to complete this questionnaire. Would you be willing to participate?

#### 1. Yes 2. No

#### **OUESTIONNAIRE IDENTIFICATION INFORMATION**

QUESTIONAIRRE Code []
001 INTERVIEWER:
002 DATE OF INTERVIEW:\\\\_2012
003 INTERVIEWEE TITLE:
004 LENGTH OF TIME IN POSITION

(Kindly provide a response to the questions below)

- 1. Could you estimate the average HIV drugs adherence rate among young people enrolled for ARVs?
- 2. What unique aspects of medication adherence have you observed among young people?
- 3. What challenges would you say young people experience in achieving optimal adherence?

- 4. What are some of the reasons young people give for not adhering to medication?
- 5. Do you encounter young people who are exhibiting depressive symptoms?
- 6. Does this affect their adherence?
- 7. Do you encounter young people who are exhibiting anxiety symptoms?
- 8. Does this affect their adherence?
- 9. Do you know of young people living with HIV who take alcohol?
- 10. How would you say this affects their adherence levels?
- 11. Do you think young people living with HIV are subjected to stigma and discrimination acts?
- 12. How does this affect their adherence levels?
- 13. How do adherence rates compare among young people living with HIV who have a lot of social support and those who do not?
  - 14. Do you think that your workload allow you to spend adequate time with HIV patients?
  - 15. Do you ever encounter young people living with HIV who are unable to take medication due to lack of food?

Thank you for your cooperation.

# Appendix III: FGD Guide

#### Introduction:

Good morning/afternoon, my name is Rachael Manyeki, an MA student of the University of Nairobi (Nairobi campus). I am conducting a research on HIV drugs adherence among young people living with HIV as part of my studies.

I have selected you as participants in this study due to your knowledge and would like to have a discussion with you on the topic. Some of the questions may be require you to divulge some information touching on your relationship with others but I assure you that your answers will be used for the purposes of this research only and will not be shared with anyone else other than the researcher. Your honest response to these questions will help me better understand the behavior of young people towards medication and I would greatly appreciate your help. This discussion will take about 25 minutes. Would you be willing to participate?

#### 1. Yes 2. No

# DISCUSSION GUIDE IDENTIFICATION INFORMATION

QUESTIONAIRRE Code	
001 INTERVIEWER:	
002 DATE OF INTERVIEW	V:\\\\_2012

- 1. What do you understand optimal HIV drug adherence to be?
- 2. Are there young people living with HIV who fail to take their medication? Why?
- 3. What challenges do young people living with HIV have in achieving optimal adherence for HIV medication?
- 4. Are there any benefits in taking all the prescribed drugs at the right time?
- 5. Are there young people living with HIV who take alcohol and other drugs? How does this affect their drug adherence?
- 6. Do many youth living with HIV disclose their status?
- 7. What is your perception on stigma directed towards youth living with HIV?

- 8. How do you think stigma affects the attitudes of youth living with HIV towards HIV medication?
- 9. Do the health care providers at the health facilities serving youth living with HIV provide quality service? (probe for time spent on client, communication, information sharing)
- 10. Do young people living with HIV experience challenges in accessing food?

Thank you for your cooperation



#### UNIVERSITY OF NAIROBI

COLLEGE OF EDUCATION AND EXTERNAL STUDIES OF SCHOOL OF CONTINUING AND DISTANCE EDUCATION DEPARTMENT OF EXTRA-MURAL STUDIES NAIROBLEMC

Your Ref:

Our Ref:

Telephone: 318262 Ext. 120

Main Campus Gandhi Wing, Ground Floor P.O. Box 30197 NAIROBI

5th June, 2012

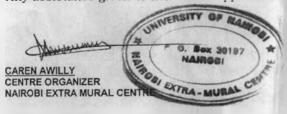
REF: UON/DEMS/NEMC/ 12/197

#### RE: RACHAEL W. MANYAKI - REG.NO. L50/72387/2008

The above named is a student at the University of Nairobi, College of Education and External Studies, School of Continuing and Distance Education, Department of Extra- Mural Studies pursuing Masters in project planning and Management.

She is proceeding for research entitled "influence of psychosocial factors on HTV ARV adherence among young people in Nakuru Central District, Kenya.

Any assistance given to her will be appreciated.



REPUBLIC OF KENYA



# NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

Telephone: 254-020-2213471, 2241349 254-020-310571, 2213123, 2219420 Fax: 254-020-318245, 318249 When replying please quote secretary@ncst.go.ke

NCST/RCD/12A/012/102

Our Ref

Rachael Wanjiru Manyeki University of Nairobi P.O. Box 30197 Nairobi P.O. Box 30623-00100 NAIROBI-KENYA Website: www.ncst.go.ke

6th July 2012

Date:

#### **RE: RESEARCH AUTHORIZATION**

Following your application for authority to carry out research on "The influence of psychological factors on HIV antiretroviral drugs adherence among young people living with HIV in Nakuru Central District, Kenya" I am pleased to inform you that you have been authorized to undertake research in Nakuru Central District for a period ending 31st August 2012.

You are advised to report to the District Commissioner and the District Education Officer, Nakuru Central District before embarking on the research project.

On completion of the research, you are expected to submit two hard copies and one soft copy in pdf of the research report/thesis to our office.

DR. M. K. RUGUTT, PhD, HSC. DEPUTY COUNCIL SECRETARY

Copy to:
District Commissioner
District Education Officer
Nakuru Central District

"The National Council for Science and Technology is Committed to the Promotion of Science and Technology for National Development."