## BY

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## DECLARATION

I declare that this thesis is my original work and has not been submitted to any university or institution for any award.

Date--201812010

Milka Perez Nyariro

I certify that this thesis has been submitted by my approval as the University supervisor.


Dr. W. Onyango-Ouma

## DEDICATION

This study is dedicated to people living with HIV and AIDS in Kibera informal settlements that dedicated their time and accepted to give their views on the sensitive themes of HIV/AIDS and sexuality.

To my son Owen, I know it has been tough not to always have me around when you need me most. Thank you for understanding from such a tender age.

## TABLE OF CONTENTS

ACKNOWLEDGEMENT ..... vii
ABSTRACT ..... viii
LIST OF ABBREVIATIONS ..... ix
CHAPTER ONE
INTRODUCTION .....  1
1.1 Background to the Study ..... 1
1.2 Statement of the Problem ..... 3
1.3 Objectives ..... 5
1.3.1General Objective ..... 5
1.3.2 Specific Objectives ..... 5
1.4 Justification of the Study ..... 5
1.5 Limitation of the Study ..... 5
CHAPTER TWO
LITERATURE REVIEW ..... 7
2.1 Introduction ..... 7
2.2 Background to Sexuality Studies ..... 7
2.3 Sexuality Studies in Kenya ..... 9
2.4 HIV and AIDS Prevalence ..... 10
2.5 Effects of HIV Sexuality ..... 10
2.6 Influence of ART on Sexuality ..... 12
2.7 Theoretical Framework ..... 13
2.7.1 The Relevance of the Theory to the Study ..... 14
2.8 Assumption ..... 14
2.9 Definition of terms ..... 14
CHAPTER THREE
METHODOLOGY ..... 16
3.1 Introduction. ..... 16
3.2 Research Site ..... 16
3.3 Study Design ..... 18
3.4 Study Population ..... 18
3.5 Sample Population and Sampling Technique ..... 19
3.6 Methods of Data Collection. ..... 20
3.6.1 Survey Technique ..... 20
3.6.2 Narrative Method ..... 20
3.6.3 Focus Group Discussion. ..... 20
3.6.4 Key Informant Interviews ..... 21
3.6.5 Methods of Data Analysis ..... 21
3.7 Problems and their Solutions ..... 21
3.8 Ethical Considerations ..... 22
CHAPTER FOUR
DEMOGRAPHIC CHARACTERISTICS AND CHALLENGES FACING
PEOPLE LIVING WITH HIV/AIDS IN EXPRESSING THEIR SEXUALITY ..... 24
4.1 Introduction ..... 24
4.2 Getting a Long Term Partner ..... 26
4.3 Disclosure of HIV status among Sexual Partners ..... 27
4.4 Adhering to Protective Practices ..... 33
4.5 Avoidance of Risky Sexual Practices ..... 34
4.6 Protective Measures against Re-infection ..... 36
4.7 Living as a Discordant Couple ..... 40
CHAPTER FIVE
SEXUAL PLEASURES, DESIRES AND REPRODUCTIVE GOALS OF PEOPLE LIVING WITH HIV AND AIDS ..... 44
5.1 Introduction ..... 44
5.2 Influence of ART on Sexual Desire ..... 44
5.3 Sexual Desire and ways to Achieve Sexual Pleasures ..... 48
5.4 Bearing Children ..... 52
5.5 Marital Ambitions ..... 56
CHAPTER SIX
CONCLUSIONS AND RECOMMENDATIONS ..... 61
6.1 Introduction ..... 61
6.2 Conclusions ..... 61
6.3 Recommendations ..... 62
BIBLIOGRAPHY ..... 64
APPENDICES ..... 67
APPENDIX 1: QUESTIONNAIRE FOR PEOPLE ON ART ..... 67
APPENDIX II: NARRATIVE GUIDE FOR (PLWHA) AND ON ART ..... 77
APPENDIX III: INTERVIEW GUIDE FOR KEY INFORMANTS ..... 78
APPENDIX IV: FOCUS GROUP DISCUSSION GUIDE ..... 79

## LIST OF TABLES

Table 4.1 ..... 25
Table 4.2 ..... 34
Table 4.3 ..... 36
Table 5.1 ..... 47
Table 5.2 ..... 58
Figure 3.1 Map of Kibera Area ..... 17

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#### Abstract

This thesis focused on the sexuality of people living with HIV and AIDS and on Antiretroviral therapy. The study was conducted in Kibera informal settlements in Nairobi and the main objective was to investigate the sexual behaviour and practices of people living with HIV and AIDS and on ART. The study explored the challenges facing people living with HIV and AIDS in expressing their sexuality, practices that influence sexual pleasures and desires among people living with HIV and AIDS and the reproductive goals of people living with HIV and AIDS after regaining their health following the use of ART.

The study design was cross-sectional, combining both qualitative and quantitative methods of data collection. Survey questionnaires were administered to seventy three people living with HIV and AIDS and were on ART. Semi structured interviews, narratives, key informant interviews, and focus group discussions were also conducted based on purposive sampling technique. Quantitative data were analyzed using Statistical Package for the Social Sciences (SPSS) while qualitative data were analyzed using content analysis technique.

The study findings suggest that people living with HIV and AIDS face challenges such as difficulty in finding a long term partner, having to abstain from certain sexual practices perceived to give sexual pleasure, and obstacles in bearing children when desired. The study also showed that people living with HIV and AIDS engage in various sexual practices to achieve sexual pleasure and desire. The findings further suggested that the health benefits of ART did not create the desire to marry or re-marry or to have children by the people on ART.

It is concluded that as actors, people living with HIV and AIDS and are on ART have the ability to exercise their sexual and reproductive rights contrary to the common belief that HIV positive people do not have a sexual and reproductive life.


## LIST OF ABBREVIATIONS

| AIDS | Acquired Immunodeficiency Syndrome |
| :---: | :---: |
| APHRC | African Population and Health Research Center |
| ART | Anti-retroviral Therapy |
| ARV | Anti-retroviral |
| FGD | Focus Group Discussion |
| HIV | Human Immunodeficiency Virus |
| IAGAS | Institute of Anthropology, Gender and African Studies |
| KAIS | Kenya Aids Indicator Survey |
| KDHS | Kenya Demographic Health Survey |
| KIPOTEC | Kibera Post Test Clubs Network |
| KNH | Kenyatta National Hospital |
| NACC | National Aids Control Council |
| NASCOP | National AIDS and STDs Control Programmers |
| NCST | National Council of Science and Technology |
| PLWHA | People Living With HIV and AIDS |
| SPSS | Statistical Package for the Social Sciences |
| STD | Sexually Transmitted Disease |
| STI | Sexually Transmitted Infection |
| W H O | World Health Organization |

## CHAPTER ONE

## INTRODUCTION

### 1.1 Background to the Study

This chapter provides information on the background and development of sexuality studies. It highlights how the emergence of HIV and AIDS has shaped the society's perception of sexuality and hence most studies on sexuality being done in relation to HIV and AIDS. The chapter then gives an account of how studies on sexuality have recently taken a new dimension focusing on sexual pleasures and desires. The problem of study, study objectives, justification, scope and limitation of the study are also presented in this chapter.

Sexuality according to Undie and Benaya, is a very personal matter in the society yet in many ways it defines and dictates much of what goes on in society (Undie and Benaya 2006). The field of sexuality remains largely underdeveloped in Sub-Saharan Africa, Kenya included, and few scholars have demonstrated interest and focus in this area (Undie and Benaya 2006). However, sexuality is at the centre of our existence and is core to the socio-economic and development challenges confronting Sub-Saharan Africa.

We are all sexual beings whether we engage in sexual acts or behaviours or we stay celibate (Tarshi 2001). In many societies, sex remains a taboo subject and yet it permeates many aspects of our lives. As individuals, we have sexual desires and make conscious choice and effort in seeking meaningful sexual relationships as a way of contributing to our wellness. Sexuality is greatly influenced by ones gender. This is because in all societies gender roles define the ways in which the male and female members are expected to behave, thus exerting a powerful influence on their sexual behaviour. Sexual acts and behaviour are, however, just a partial component of sexuality.

Sexuality is a social, political and economic concern around which much of our traditional and modern societies are structured. In modern times, categories of sexuality have particularly determined how we think of ourselves (Arnold 2001). Arnold (2001) stresses that sexuality should not be confused with the genitals and the facts of sexuality encompass far much more than the facts of one's sex.

Sex can be defined as an act of erotic practices or can be used to categorize human beings as either male or female. Sexuality on the other hand, is an abstract noun referring to the quality of "being sexual" (Spronk 2006). Used as a concept, sexuality configures various aspects of social life including ideologies and practices of kinships, gender relations and reproduction. In as much as procreation is of importance in any culture, an exclusive focus on issues such as the risk of pregnancy and disease oversimplify the complex nature of sexuality (Undie and Benaya 2006).

Sexuality can refer to the social arena where power relations, symbolic meaning of moral discourses relating to sexual behaviour are played out. Sexuality on the other hand describes sexual desires, care for sexual pleasures, which relate to experience themselves and which are not directly related to sexual conduct (Spronk 2006).

World Health Organization (WHO) draft working definition (October 2002), cited in Undie and Benaya (2006) defines sexuality as a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviour, practices, roles and relationships. Overall, sexuality is complex and greatly influenced by how people think and feel, by their belief systems and by those around them (Tarshi 2001).

The emergence of HIV and AIDS has put sexuality at the centre of policy concerns in Africa as the need for low risk sexual behaviour is emphasized. The need to control the spread of HIV and AIDS has dominated the thinking in sexuality at the expense of other broader contexts or issues. In some cases, sexuality has been used as a tool for gender
oppression or has been seen as a vehicle for the spread of the killer disease -AIDS. Due to the devastating effects of the pandemic in Sub-Saharan Africa, the question of sexuality and sexual rights remains a contested field with many people living with HIV and AIDS wanting to exercise their rights to marriage and procreation but sometimes under sharp criticism.

In Africa discussions around sexuality and sexual rights has been generated through fear, disease and danger. Sexual pleasure as an expression of sexuality has received minimal attention and generally seen as the domain of the male. Currently, the study of sexuality has been further reinvented by HIV and AIDS where most sexuality studies are focused on determining the levels of HIV infection in a population. Sexual pleasure and desire have therefore been marginalized as discourse of fear and anxiety.

Research on the experience of sexuality (Spronk 2006) has provided the insight that there are different "sexualities", recognizing the diversity of sexual desires and behaviours. According to Spronk (2006), studies show that social identities do not necessarily coincide with sexual practices that are thought to be part and parcel of these identities. For example, societal identity of people living with HIV and AIDS is that they are either conservative in sexual behaviour or very promiscuous (Spronk 2006).

### 1.2 Statement of the Problem

In many African societies, sexuality is perceived as a tool for gender oppression and a vehicle for the spread of HIV/AIDS (Spronk 2006). In Kenya, like the rest of Africa, most communities think of sexuality as being affected by those around us and by our culture rather than being highly personalized and individualized decisions.

Currently, people living with HIV and AIDS have an increased worldwide access to antiretroviral therapy (ART) and this has begun to shift attention to the effects of treatment on prevention, and specifically the sexual behaviour of recipients. While
research in developing countries has addressed the possible connections between treatment and risky behaviour (Tiemoko 2006) this has not been done in Kenya.

The debilitating effects of HIV and AIDS on individuals are decreasing with increased access to affordable ART. The affected individuals are regaining health and strength and therefore beginning to lead normal sexual lives. Ordinarily, such individuals would want to have sexual partners, marry and even have children in very much the same way as individuals without HIV and AIDS. However, there are risks that come with the resurrection of reproductive life such as the danger of exposure to a different strain of the virus.

Despite the vast majority of people living with HIV and AIDS being mindful of the continued risks to themselves and others, among the valued parts of their lives is the chance to marry or remarry and have children (Horizon 2002). As a result, the dilemmas of how to marry and make families while living with HIV are at the centre of the sexuality of many people living with HIV and AIDS. It is therefore important to understand the sexuality of people living with HIV and AIDS in the context of their renewed expectations and aspirations in life. This is because the lives of people living with HIV remain naturally intertwined with the wider population of people who do not know their status. It is against this background that this study sought to investigate ways in which people living with HIV and AIDS express their sexuality by answering the following questions;-

1. What challenges do people living with HIV and AIDS and are on ART face in expressing their sexuality?
2. How do people living with HIV and AIDS experience sexual pleasures and desires?
3. What are the reproductive goals of people who have regained health as a result of ART?

### 1.3 Objectives

### 1.3.1 General Objective

The general objective of this study was to investigate the sexual behaviour and attitudes of people living with HIV and AIDS, especially after regaining health through ART.

### 1.3.2 Specific Objectives

The specific objectives of this study were:

1. To examine the challenges faced by people living with HIV and AIDS and on ART in expressing their sexuality
2. To explore sexual pleasures and desires among people living with HIV and AIDS.
3. To determine the reproductive goals of people living with HIV and AIDS after regaining health through the use of ART.

### 1.4 Justification of the Study

Few studies have been carried out on the sexuality of people living with HIV/AIDS especially on their marital and reproductive goals (Smith and Mbakwem 2006). There was therefore need to examine and establish how people living with HIV/AIDS express their sexuality and their attitudes towards sexual pleasures and desires as a way of promoting responsible sexuality. This will ensure that people living with HIV/AIDS and have regained health through ART will practice a responsible and yet pleasurable sexuality as a step and strategy in combating HIV/AIDS in the society.

### 1.5 Limitations of the Study

HIV/AIDS and sexuality are subjects that are often not discussed in the public sphere and people tend to individualize them. According to Spronk (2006), research on sexuality remains limited because sex is a sensitive subject in most societies and is therefore
difficult to study. Sexuality in most societies is never discussed openly while HIV and AIDS are still associated with stigma and discrimination in most societies. The sensitive nature of these issues may have lowered the response and reliability of the data.

This study was not designed to include observation on the daily lives of the participants as a method of data collection due to limited time and financial resources. Therefore, indepth information on sexuality of PLWHA was missed out. The use of a structured questionnaire did not generate adequate data on sexuality of PLWHA and were on ART due to the broad nature of the topic which could not be wholly handled in the questionnaire.

The narrative method of data collection may have failed to capture the most important parts of a person's experiences. This may not have been intentional, but may have occurred as a result of the participant not being able to recall the experiences or the participant may have deliberately omitted such experiences from the narration when he or she felt exposed. The focus group discussions may have not been able to gather honest responses because the participants were likely to give responses that conformed to the societal norms and values to avoid criticism.

Finally, the study was limited to the sexuality of people living with HIV and AIDS and was enrolled in a support group. The data therefore missed out the information from other people living with HIV and AIDS but were not members of a support group. This may have created some bias in the study findings.

## CHAPTER TWO

## LITERATURE REVIEW

### 2.1 Introduction

This chapter presents a review of the relevant literature on thematic areas of sexuality and HIV and AIDS, sexuality studies in Kenya, HIV and AIDS prevalence, effects of HIV and AIDS on sexuality and influence of ART on sexuality of people living with HIV and AIDS. The purpose of this chapter is to review and analyze the available knowledge in the subject matter of study and to identify the gaps that require further investigation. The chapter also outlines the theoretical framework used and its relevance to the study. Finally, the study assumptions, definition of key terms and concepts are presented.

### 2.2 Background to Sexuality Studies

According to Herdt (1997), sexuality has played a special part in the historical challenge posed by HIV and AIDS to science and it is now widely agreed that sexuality was ignored for the most part of twentieth century. The AIDS pandemic has now stimulated the greatest amount of sexuality researches in history.

Much of the research bordering on sexuality in Sub-Saharan Africa has been mostly on short-term urgent responses to HIV/AIDS and other reproductive health problems (Undie and Benaya 2006). Formerly, sexuality was treated in both biological and social sciences as a "natural" function whose ultimate purpose was restricted to procreation.

The new approach on sexuality displays a shift from a perspective in which sexual desire was understood as biologically determined, to one that emphasizes on how social context also structures sexual desires (Spronk 2006; Davidson 2001). Sexuality consists of a set of ideas and behaviour (Caplan 1987; Tarshi 2001) and knowledge about sexuality in a given society is often influenced by social norms and values of that particular society.

Since sexuality is part of human life (Tarshi 2001), all human beings have developed their sexuality from a variety of influences such as social, cultural, biological, economic and educational factors. According to Tarshi, sexuality shapes people's identity and relationships and is linked with gender power relations, health, economics, livelihoods and social development (Tarshi 2001). Sexuality has different meanings in different contexts and is understood differently by different people.

HIV/AIDS pandemic has continued to be a major health and development problem the world over and particularly in Sub-Saharan Africa, where its effects has been mostly felt (NACC 2005). 37.8 Million people were estimated to be infected worldwide. 17 million being women, 2.1 Million children and of these, $70 \%$ live in Sub-Saharan Africa. Twenty million lives have been claimed by HIV/AIDS since the first cases of AIDS were detected more than 20 years ago. The epidemic has also left 12 million orphans in SubSaharan Africa.

In Kenya the virus has infected and affected many, resulting in ill health and poverty among many households. According to the Kenya Demographic and Health Survey (2003), $67 \%$ of Kenyan adults are infected with HIV. Women are particularly vulnerable to infection. Almost $9 \%$ of women are infected with the virus compared to $4.6 \%$ of their male counterparts. Women between 20-30 years of age are especially more vulnerable.

NASCOP (2005) gives an estimated number of 150,000 deaths that are caused by AIDS every year, double the rate in 1998. Life expectancy in Kenya has also dropped from 60 years in 1993 to about 47 years currently because of HIV and AIDS.

Ministry of Health (2004) estimated 1.5 million people to be infected with HIV in Kenya, 200,000 of these being in urgent need for Anti-retroviral therapy. At the time, only 12,000 people were on ART in Kenya. Majority of these were managed within the private sector, Non-governmental Organizations (NGOs) and Faith Based Health facilities. This was to change as the Government of Kenya was committed to increasing access to Antiretroviral therapy as part of its wider declaration of 'Total War' on HIV/AIDS. The

Government developed a plan for the rapid up-scaling of Anti-retroviral therapy to Government Hospitals in every province in Kenya.

However, ART is only a component of the fight against the epidemic and it is important that efforts at preventing transmission are not diminished by providing them. For people who are dying of HIV related diseases, they offer the best hope for long term survival that is currently available in the absence of cure.

### 2.3 Sexuality Studies in Kenya

The first sexuality studies in Kenya focused on cultural and social aspects of institutions of sexuality by giving descriptions of initiations, marriages, birth and rites of passages. The main focus here was to explain how these cultural institutions are connected to the existence of the community. Among the Agikuyu of Central Kenya, there were ways in which boys and girls were allowed to enjoy their sexuality without engaging in the actual sexual intercourse (Kenyatta 1969).

Around 1960, the studies on sexuality shifted to an examination of how the above institutions were being transformed and describing cultural phenomena such as status, roles and powers vested in men by patriarchy, division of labour according to gender and reproduction. Sexuality here is taken as an indispensable aspect of a people's culture (Spronk 2006).

From the 1990 s, research on sexuality was conducted primarily from a medical or health perspective. For example, family planning, adolescent pregnancies, reproductive and sexual health and lately, the AIDS pandemic has changed the direction of sexuality research. This has further barred the expression of African sexuality by medicalizing sexuality mainly due to the need to determine the levels of Aids awareness (Spronk 2006).

In all the above studies, sexuality is studied only as a societal public health problem and lately in a context where AIDS underpins most researches. Looking at sexuality only as a
societal issue gives one aspect of sexuality, thereby ignoring the others such as the differences between sexual behaviour, sexual identity, desires for affection or the notion of pleasure (Spronk 2006).

### 2.4 HIV and AIDS Prevalence

Poor nutrition and lack of proper sanitation are among the major causes of many illnesses and disease in many parts of Kenya including Kibera. Deaths by disease and conflict are common inside this slum. HIV and AIDS account for the highest number of deaths in Kibera and it is estimated that one third of people living with HIV and AIDS live in these slums. Life expectancy is forty six years old and there are an estimated one hundred thousand orphaned children.

According to the Kenya Aids Indicator Survey (2007), more than 1.4 million Kenyans are living with HIV/AIDS. Seven percent of adult Kenyans between the ages of 15-64 years are infected with HIV, the virus that causes AIDS. The HIV prevalence rate has gone up to $7.4 \%$ from $6.7 \%$ in 2003 in the Kenya Demographic Health Survey (2003).

Nairobi province has a prevalence rate of $9.0 \%$, second to Nyanza province (15.4\%) in the distribution of HIV infections in Kenya (KDHS 2003). This is higher than the national prevalence rate. The number of infected adults in Nairobi is estimated to be 176,000 (KAIS 2007).

### 2.5 Effects of HIV on Sexuality

It is widely accepted that the emergence of HIV and AIDS has provided opportunities for open discussions on sexuality issues. The disease has somewhat reinforced the over moralization of sexuality and stigmatization of the sexual being; having various debilitating effects on an individual, and most of these being physical wasting and vulnerability to opportunistic infections.

In addition, there is the social stigma whereby an individual faces discrimination either in employment or insurance, and denial to access certain areas and facilities due to his/her HIV status. For the unmarried adults in Africa who learn that they are HIV positive, the devastation of the diagnosis comes not only from the fact that they will die young but also from the realization that they will die without marrying and having children.

Sexual rights are part of human rights which affirm the dignity, worth, respect, equality, and autonomy of all people in all aspects of their life (Tarshi 2001). It includes the rights of a person to have control over and decide freely and responsibly on matters related to sexuality, including sexual and reproductive health, free of coercion, discrimination and violence (Sheill 2006). Sexual rights are therefore necessary in order for women and men to express and enjoy their sexuality.

Despite the fact that everybody has sexual rights, individual aspiration of people living with HIV and AIDS, especially of reproduction continue to pose ethical predicaments, public health risks and existential dilemmas (Tiemoko 2006). Whether or not, when, and how to achieve personal ambitions, and simultaneously how to stay healthy are priority issues for people living with HIV and AIDS who have been provided another chance at life by the availability of ARV drugs.

HIV related stigma and discrimination are most closely related to sexual stigma because HIV is mainly sexually transmitted. In most areas of the world, the epidemic initially affected populations whose sexual practices or identities are different from the "norm". HIV related stigma and discrimination has therefore reinforced pre-existing sexual stigma associated with sexually transmitted diseases, homosexuality, promiscuity, prostitution and sexual "deviance".

Until the advent of ART, there was a perceived idea that HIV/AIDS was not only a physical but also a social death sentence in most parts of Africa. Stigmatization was produced both by the disease itself and the fact that a life cut short by AIDS was often a life without reproduction.

Currently, with the possibility of treatment and prolonged life, among the most important goals that people receiving ART pursue are marriage and childbearing. In most African countries, marriage and parenthood are the principal tasks of biological and social reproduction leading in the hierarchy of social expectations and individual aspirations.

### 2.6 Influence of ART on Sexuality

For most people living with HIV/AIDS, the HIV diagnosis generates a transitory loss or disappearance of sexual feelings, a degradation of the body images, self esteem and difficulties in maintaining a satisfying, long term relationships (Djemna et al. 2006). Despite all these emotions and problems it is obvious that people living with HIV/AIDS (PLWHA) are sexual beings and therefore engage in sexual acts.

ART is so far the most effective intervention for prolonging survival in people with HIV. When taken regularly, it is associated with a $90 \%$ reduction in mortality (KAIS 2007). According to the KAIS (2007), 390,000 infected Kenyans (35\%) are eligible for ART. Out of this, approximately 140,000 persons only were taking ART. The end of June 2008, preliminary service statistics reports indicated that approximately 190,000 HIVinfected Kenyan adults were receiving ART, an indication that ART is increasingly available in Kenya.

The invention of ART has made it possible for people living with HIV to lead normal lives, almost as that of people without HIV/AIDS. They now have aspirations such as marrying, having children and starting up families (Djemna et al. 2006). ART has resurrected the lives of its recipients and many people living with HIV/AIDS are now engaged in various economic and social activities such as businesses and employment. There are various support groups for people living with HIV/AIDS that involve its members in economic activities to support their livelihood. They are now able to work due to the regained physical strength given by the ART.

### 2.7 Theoretical Framework

This study applied Anthony Giddens' theory of structuration. According to Giddens (1979), structure refers to rules, values, customs and resources available in a society that determine human behaviour thereby enabling them to operate in certain ways. The theory holds that all human action is performed within the context of a pre-existing social structure which is governed by a set of norms or laws which are distinct from those of other social structures.

According to this theory, all human action is at least partly predetermined based on the varying contextual rules under which it occurs. Within the structure are agents/actors who are human beings with the ability to perform an act or behaviour. Giddens suggest that the human agency and the social structure are in a relationship with each other, and it is the repetition of the acts of individual agent which reproduces the structure.

This means that there is a social structure of traditions, institutions, moral codes, and established ways of doing things; but it also means that these can be changed when people start to ignore them, replace them, or reproduce them differently. The people, 'actors' in the structuration theory are knowledgeable 'agents' who use their interpretive schemes to constitute and communicate meaning and then take actions with intentional and unintentional consequences.

Giddens' theory examines how the structure and the agent are not independent of each other. Giddens explains that social structures make social action possible, and at the same time the social action creates those very structures. The two are involved in a dialectical relationship in which the structure, through its rules like laws, values, customs and resources produces the actor or agent through hi/her actions. Giddens argues that there is therefore no philosophical dualism between the structure and the agent, but there is what he refers to as the duality of structure.

### 2.7.1 The Relevance of the Theory to the Study

Structuration theory was relevant to this study in analyzing how the social structure shaped and influenced the expression of sexuality of people living with HIV and AIDS and were on ART. The theory is relevant in assessing how the society through its norms, values, beliefs and practices affects the reproductive goals and expression of sexual pleasure and desires among HIV infected people who had recovered their health by use of ART. The structure is the society which defines and institutionalizes sexuality, giving the rules, beliefs, norms and values, which regulate sexuality. Actors were the people living with HIV and AIDS and on ART.

### 2.8 Assumptions

Drawing from the theoretical framework, this study made the following assumptions:

1. People living with HIV/AIDS and on ART face challenges in expressing their sexuality.
2. People living with HIV/AIDS do experience sexual pleasures and desire.
3. The health benefits of ART creates desire to marry, re-marry and to have children among people living with HIV/AIDS.

### 2.9 Definition of Terms

Sexuality- sexual desires, pleasures, feelings and acts related to sexual conduct.

Attitude - An individual's degree of like or dislike of an act or behaviour.

Antiretroviral therapy - Therapeutic drugs, care education and counselling that a person living with HIV and AIDS is introduced to after testing HIV positive

Sexual health - The state of having an informed, enjoyable and safe sex life, based on self-esteem, positive approach to human sexuality, and mutual respect in sexual relations.

Sexual rights- The right to experience a responsible and pleasurable sexuality free from coercion or any restriction.

Sexual pleasures- Fundamental feelings and experiences that are positive, pleasant and joyful which are induced by sexual stimuli.

Sexual desire- This is a state where a person wants, longs or yearns for sex or related activities.

Social structure- This is the society with its rules, norms, values, customs and resources available to the actors.

Agent- A person living with HIV and AIDS and on ART, and has the capacity to act by making choices.

People living with HIV/AIDS - These are individuals who are infected with HI virus that later causes AIDS.

## CHAPTER THREE

## METHODOLOGY

### 3.1 Introduction

This chapter gives a description of the study site, the study design, the study population, the sample population and the sampling technique. The chapter also gives in detail the methods of data collection and methods of data analysis. A combination of different methods of data collection in this chapter enabled the generation of data that were amenable to comparison. It was apparent during data collection that one method of data collection was not superior to others, but they complimented one another for validity of the data to be realized. The problems encountered during data collection and their resolutions are also given. Finally, the chapter concludes by giving the ethical considerations.

### 3.2 Research Site

The study was conducted in Kibera informal settlements in Nairobi. Nairobi is the capital and the largest city of Kenya. The city and its environs also form the Nairobi province and district. Nairobi lies on the Nairobi River in the south of Kenya, and has an elevation of 1661 M above the sea level.

Kibera is an informal settlement in Nairobi. It originated in 1918 and is the second largest slum in Africa, the largest being Soweto in South Africa. The name Kibera was derived from a Nubian word 'Kibra', meaning "forest" or "jungle".

It is located southwest of Nairobi city centre, approximately five kilometres to the Southeast. It is subdivided into a number of villages namely; Kianda, Soweto, Gatwekera, Kisumu ndogo, Lindi, Laini Sabaa, Siranga,/Undugu, Makina, and Mashimoni. The
railway line to Kisumu and Uganda passes through Kibera. Each village has a village elder.

Figure 3.1: Map of Nairobi showing Kibera and its surroundings.


Kibera is roughly 2 Kilometres squared with an estimated population of 1 million people. The average house size here is 3 meters by 3 meters per dwelling. Houses are made of
corrugated tin, mud and cardboard and consist of one room that serves as living room, bedroom and kitchen. Urban services such as access to clean piped water and proper sanitation are minimal in this slum.

### 3.3 Study Design

This was a cross-sectional study that combined both quantitative and qualitative methods of data collection. Field work was conducted for two months and in two phases. The first phase involved survey research for the quantitative data and aimed at obtaining baseline information on sexuality of people on ART. The second phase involved collection of qualitative data using ethnographic methods of data collection to gather in-depth information. All the study instruments were piloted and pre-tested outside the study area before embarking on the actual data collection.

### 3.4 Study Population

Nairobi is the most populous city in East Africa, with an estimated urban population of between 3 and 4 million people. It is currently the fourth largest city in Africa. It is approximated that one third of Nairobi's population live in Kibera whose population is estimated to be one million or slightly above one million, and the population is estimated to grow by one percent every year.

Nairobi is a cosmopolitan and multicultural city. By mid twentieth century, many foreigners who had come during the construction of the Kampala-Mombasa railway had settled in Nairobi. They were mainly from other British colonies primarily India and Pakistan. Refugees from the Somali and Sudan communities are also settled in Nairobi.

Kibera informal settlement was formally occupied by the Nubian community. Currently, Kibera has residents coming from all the major ethnic groups in Kenya with some areas being specifically dominated by one ethnic group. The multiethnic nature of this informal settlement has been a foster for tribalism which has caused a lot of violence and deaths over the years.

Kibera is a home to many of the world's most issues of concern such as poverty, poor healthcare, lack of clean water, poor sanitation, violation of women rights and the spread of HIV infections. Despite all the challenging living conditions, Kibera is a self sustaining community. People in Kibera engage in different kind of economic activities. They sell vegetables and clothes, work as blacksmiths and carpenter, domestic and industrial workers among many others.

### 3.5 Sample Population and Sampling Procedures

The sample population consisted of men and women living with HIV and AIDS and residents in Kibera slums. The unit of analysis was the person living with HIV/AIDS and enrolled in a support group within the Kibera informal settlements. The minimum age of participating in the study was 18 years.

Simple random sampling technique was used to select 73 elements from the population. The ART support group register constituted a sampling frame from which the samples were drawn. Each person on the register was assigned a unique number. Elements were then selected, one at a time, until the desired sample size was reached. The questionnaire was administered to the 73 persons selected on a basis of simple random technique.

Focus group participants, Key informants, narrative and interview participants were selected on the basis of purposive sampling. These informants were a sub-set of the survey respondents and were selected on the basis of availability, ability to speak openly, and duration of being on ART. Health providers working with ART clients were also purposively selected due to their experience with ART clients. Purposive sampling allowed units to be deliberately selected to provide specific information about the population. The elements consisted of both male and female persons living with HIV/AIDS and on ART.

### 3.6 Methods of Data collection

### 3.6.1 Survey Technique

This technique was instrumental in yielding quantitative data. A standard questionnaire was administered by the researcher to 73 respondents. Through questionnaire, data on variables that lend themselves to quantitative methods of data analysis was collected. These were mainly the demographic characteristics of the respondents, occupation, education and income levels, marital status and the number of children. The questionnaire comprised both closed and open ended questions which allowed for probing.

### 3.6.2 Narrative Method

The narrative method was used to collect life stories of PLWHA and on ART. It allowed the respondents to give their experience on their lives before and after the therapy. The narratives were given in Kiswahili, translated into English and transcribed verbatim. The advantage of narrative method was that it allowed for probing to gather more information and the respondent was given the freedom to express himself or herself since the study topic was an emotive one.

### 3.6.3 Focus Group Discussions

This method was used to provide qualitative data on major themes such as practice of protective sex, ways of giving and getting sexual pleasures, and productive and reproductive goals. Four focus group discussions (FGDs), each with 10 participants were conducted. Two focus group discussions consisted of female only participants and the other two FGDs consisted of both female and male participants. There were no male only support group. Purposive sampling procedure was applied in the selection of participants.

Data from FGDs was useful for comparison with those obtained from the other methods. This method was economical both in time and other resources yet it still yielded detailed qualitative information from a relatively large number of respondents.

### 3.6.4 Key Informant Interviews

This method of data collection was used to get information from people who had special knowledge on the subject of study. They included health providers and support group trainers. A total of 6 key informants were selected outside the sample.

### 3.6.5 Methods of Data Analysis

The data collected was both quantitative and qualitative. To ensure quality control, data was checked to detect any error made during data recording. Coding of data helped in organizing responses into a limited number of categories.

Qualitative data was analyzed using qualitative techniques, mainly content analysis. Content analysis was done on emerging themes in the data, which were then related to the study objectives to find out how they contributed to answering the research questions. Direct quotes and selected comments from key informants in the field helped in understanding the attitudes of study participants.

Statistical package for social sciences (SPSS) version was used to analyze quantitative data. Descriptive statistics mainly frequencies and percentages of the measured variables were generated.

### 3.7 Problems and their Solutions

There emerged various challenges that the researcher encountered during field work. It was extremely difficult to access the study population owing to its closed nature. The researcher had to explain to the Executive committee, Kibera Post Test Clubs Network (KIPOTECT) that the research was not going to infringe on the rights of the participants and was going to be of benefit to them instead.

During focus group discussions, some of the support groups demanded direct monetary benefits which they claimed was a compensation for their time and would also carter towards
payment of the rent for their meeting venue. The support groups had schedules for various activities such as door to door campaigns on how to handle rape which the researcher could not interfere with. In order to be considered as an insider, the researcher had to participate in such activities and instead re-schedule the interviews or the focus group discussions to a convenient date and time.

### 3.8 Ethical Considerations

The sample population was handled with a lot of care and ethics. The study participants were informed of the objectives of the study and gave an informed consent before proceeding with the interviews and the group discussions. From the beginning of the study, the participants who accepted to participate in the study were treated as subjects and not as objects. They were given due respect and it was ensured that the researcher did not over use or abuse the power inequity that could have emerged as a result of the research encounters.

The researcher did not also override the social and cultural values of the participants and was on guard against undue intrusion. This was observed by reviewing of the semi structured questions for the study with the help of two of the committee members from the network and making the necessary changes to the research tools. The study subjects were informed of their right to choose whether or not to participate in the study and of their freedom to discontinue with the interviews or withdraw from the study whenever they wanted. They were also informed of their right not to respond to the questions which they did not feel comfortable with or those which they felt were intrusive without any penalties.

The participants were informed and reminded about their freedom to ask anything they found of their interest. The researcher also let them know that the study was being conducted exclusively for academic purposes at the University of Nairobi, Institute of Anthropology, Gender and African Studies (IAGAS) and the results would be made available to the participants through their network body (KIPOTEC). In the presentation of data, pseudo names were used instead of the respondents' real names.

The ethical principal of people's privacy was upheld during the entire period of the study. Information given by the participants was not shared with any other person, participants or organization and was solely used for the intended research purposes. Participants' names were not indicated in the interview forms and pseudo-names were used during recording of the narratives. The study was conducted in full knowledge and consent from the National Council of Science and Technology (NCST) and the Kibera Post Test Clubs Network (KIPOTEC). Finally, the researcher was aware of her responsibility to the discipline, the study population, the sponsors and the government hence cases of adulterating data were avoided at all costs.

## CHAPTER FOUR

## SOCIO-DEMOGRAPHIC CHARACTERISTICS AND CHALLENGES FACING PEOPLE LIVING WITH HIV AND AIDS IN EXPRESSING THEIR SEXUALITY

### 4.1 Introduction

This chapter presents on the challenges facing people living with HIV and AIDS in expressing their sexuality. People living with HIV and AIDS are confronted with various challenges including but not limited to getting a life partner, how to protect themselves against risky sexual practices, disclosing their HIV status to partners, knowing their partner's HIV status, dealing with discrimination from the society and living with a HIV negative partner. The findings of the study are then discussed and related to other studies that have been done in related fields of HIV and AIDS and sexuality. Table 4.1 shows the demographic characteristics of the study respondents.

From the data presented in table 4.1 , majority of the study participants were female. Out of the seventy three respondents enrolled in support groups, only ten were male. This is an indication that women are more likely to seek social support once they have known and accepted their HIV positive status. The data also shows that most of the participants were currently married or had been in a marital relationship before. Thirty four of the seventy three respondents were married at the time of the study. Twenty respondents were widowed while twelve were separated or divorced. Only seven respondents were single at the time of the study.

Majority ( 51 out of 73 ) of the study participants had attained a minimum level of primary education. Sixteen respondents had attained a minimum of secondary education. Only six respondents had no education at all. However, it was worth noting that none of the respondents had attained a college or university education. According to the data in table 4.1, majority of the respondents $(51 \%)$ had a monthly income of between Ksh1000 to Ksh5000. Thirty seven percent of the respondents had a monthly income of Ksh1000 and below. Eight percent (8\%) of
respondents earned between Ksh5001 to Ksh10000. A mere one percent ( $1 \%$ ) of the respondents had an income above Ksh10000 per month. However, three percent of the respondents had no source of a monthly income and depended on support from the well wishers and food distribution from the support group network.

Table 4.1: Socio-Demographic Characteristics of Respondents

| Characteristic of Respondents | Frequency | Percent (\%) |
| :--- | :---: | :---: |
| Age |  |  |
| $18-22$ years | 3 | 4.0 |
| $23-27$ years | 12 | 16.0 |
| $28-32$ years | 14 | 19.0 |
| $33-37$ years | 15 | 21.0 |
| $38-42$ year | 29 | 40.0 |
| Total | $\mathbf{7 3}$ | $\mathbf{1 0 0 . 0}$ |
| Average age $=$ | 34 |  |


| Gender |  |  |
| :--- | :---: | :---: |
| Male | 10 | 14.0 |
| Female | 63 | 86.0 |
|  |  |  |
| Total | $\mathbf{7 3}$ | $\mathbf{1 0 0 . 0}$ |


| Marital status |  |  |
| :--- | :---: | :---: |
| Single | 7 | 10.0 |
| Married | 34 | 47.0 |
| Separated/divorced | 12 | 16.0 |
| Widowed | 20 | 27.0 |
| Tint | $\mathbf{7 3}$ | $\mathbf{1 0 0 . 0}$ |

Total $73 \quad 100.0$

Level of education

| None | 6 | 8.0 |
| :--- | :---: | :---: |
| Primary | 51 | 70.0 |
| Secondary | 16 | 22.0 |
| College /University | 0 | 0.0 |
| Total | $\mathbf{7 3}$ | $\mathbf{1 0 0 . 0}$ |
| Income per month |  |  |
| 1000 and below | 27 | 37.0 |
| 1001 -5000 | 37 | 51.0 |
| $5001-1000$ | 6 | 8.0 |
| 10001 and above | 1 | 1.0 |
| None | 2 | 3.0 |
| Total | $\mathbf{7 3}$ | $\mathbf{1 0 0 . 0}$ |

### 4.2 Getting a Long term Partner

People living with HIV and AIDS are faced with a lot of challenges when they are seeking sexual partners for long term relationship. The findings of this study showed that $74 \%$ of respondents reported that they were faced with challenges when seeking a long term sexual partner. The stigma associated with HIV and AIDS played a major role making it difficult for a person living with HIV and AIDS to get into a known sexual relationship. A male participant asserted:
"Once people get to know that you are living with HIV, they intrude so much into your personal life. Any time they see you with a woman, they will go behind your back and tell her that you are HIV positive. They make you look like you are just out to spread the disease to other people intentionally, they don't want to understand that a person living with HIV is just like any other and is in need of love and companionship. It has happened to me twice and it is very frustrating. It makes me feel like I am not human." (Source: male participant, 38 years, focus group discussion)

Another informant reported:
"I really want to get married but the problem I have experienced is that I got a lady I liked very much but she was HIV negative. Once I disclosed to her that I am living with HIV, she just took off. I felt rejected by the incident and I now want to get into a relationship with a lady who is also HIV positive because we can understand each other better." (Source: male participant, 28 years, interview).

On another hand, only $26 \%$ of the survey respondents indicated that they did not face any challenges when seeking long term sexual partners. These were mainly the respondents who were divorced, separated or widowed and had children. These categories of people living with HIV did not experience any disruption in their social and sexual lives as compared to those who had neither married nor had children. In their view, they had achieved some of the most important aspirations of life. Consequently, some were not in need of an intimate relationship
that would lead to another marriage or required them to bear more children. For them, having a partner was only focused on companionship, sexual fulfilment and financial support as illustrated by the following informant.
"I have a partner who is HIV positive too. I met her during one of the network meetings. We give each other good company. We both have children and we don't plan to have any other." (Source: male respondent 40 years, interview).

Younger respondents between 18-22 years reported to have experienced challenges in seeking long term partners. This is the age bracket within which most individuals settle down to marriage life and these are also the most reproductive ages of an individual. It is therefore challenging to live with HIV at this age when a person expects to fulfil his or her marital and reproductive goals. However, respondents who were 33 years and above reported having faced lesser challenges in seeking long term partners. Majority of respondents within this age group had been married but some were widowed, separated or divorced. Those who faced challenges in seeking long term partners wished to re-marry or wanted partners for companionship. Individuals between the ages of 23 and 32 years least faced challenges in seeking partners because most of them were already in marital unions at the time of knowing their HIV status.

From this study, it was found that there were gender differentials in the experience of challenges in getting a long term partner. Male respondents reported to experience less challenges in comparison to their female counterparts. This is attributed to the patriarchal nature of this society. More men than women are employed and therefore more economically stable than women. A woman who is not financially stable would therefore overlook the HIV status of such a man in order to get financial support.

### 4.3 Disclosure of HIV Status among Sexual Partners

Disclosing HIV status between partners has been noted to be low among people living with HIV and AIDS. The study examined whether the disclosure of HIV status of respondents to their partners was challenging. Twenty six percent (26\%) of respondents admitted not to have
disclosed their HIV status to partners. These respondents feared that once their HIV status became public, it could lock them out of the sexual arena involving marriage or having sexual partners. This group of respondents wanted to continue participating in normal societal life, a position that could have been easily jeopardized once their HIV status was known.

Women were more likely not to disclose their HIV status to their partners compared to men. The study established that sixty percent $(60 \%)$ of the female respondents had not disclosed to their partners that they were HIV-positive. This was in fear of physical abuse, accusation of unfaithfulness or promiscuity that sometimes resulted in rejection or being abandoned by their partners who in most circumstances are the bread winners. On the contrary, only twenty percent ( $20 \%$ ) of the male respondents had not disclosed their HIV status to their partners. Majority of men disclosed their HIV status to their partners because they do not have high risk of physical abuse or being abandoned. Most men are also more economically stable and the women depend on them hence cannot abandon them despite being HIV positive.

Forty seven percent $(47 \%)$ of respondents between $18-27$ years also reported not to have disclosed to their partners that they were HIV positive. They feared rejection and being subjected to social death and yet they still aspired to fulfil their marital and reproductive ambitions. Respondents who were 28 years and above were more likely to disclose their HIV status to their partners since most of them were already in marital relationships.

Disclosure of HIV status was also reported to be low among single, widowed, separated and divorced respondents compared to the married respondents. Only eighteen percent ( $18 \%$ ) of the single respondents had disclosed to their partners that they were HIV positive. Thirty six percent $(36 \%)$ of the separated and divorced respondents had disclosed their HIV status to their current partners. Married individuals living with HIV had the highest level of HIV status disclosure compared to the unmarried as also found by Undie et al. (2009). Eighty four percent $(84 \%)$ of the married respondents had disclosed their HIV status to partners. According to these respondents, they had already participated in the social arena by getting married and
having children and were not at risk of being subjected to social and sexual death as those who had not been married and had no children.

Marriage as an institution was found to cushion individuals from stigmatization and discrimination. While disclosure of HIV sero-positivity in marriage was not a challenge as such, disclosing to relatives and extended family members seemed to be the real challenge (Undie et al. 2009). Community and family members were mentioned by most respondents as the major source of stigma and discrimination.

Naomi 30 years and unmarried when asked whether she had disclosed to her male partner of three years that she was infected with the HIV virus stated:
"I have not informed him of my status. I am quite afraid of how he will react to it. You know most men will always blame the women for promiscuity if they go for an HIV test. They [men] say that for you [woman] to want to know your status, you must have been unfaithful. I would have wanted him to get tested too but I don't know how to let him know that I had previously gone for the test and the result was positive."

Naomi was further probed on how she had planned to continue having a relationship with a sexual partner who is not aware of her HIV status, given that the condition requires certain behavioural changes such as consistent use of condoms, adherence to ART and a well balanced diet in order to maintain the regained heath status. She indicated that she would prefer that her partner knows about her HIV status but how to go about it was the dilemma. In this regard, Naomi suggested that she would have to act as if she had never gone for the test and convince her partner that they undertake the HIV test jointly. This was in the hope that her partner's status would turn out to be positive otherwise the rejection and blame would be the same as she stated:
"The only way to make my husband to know my status without being blamed is to try and convince him to go for the test together. I will have to act as if I have never been tested before. At least he will be there to see the result for himself without me telling him and I will also get
the chance to know whether he is positive or not. You know, the fact that I am positive does not make him positive too; we may be discordant couple which is very common within this network but I wish he also tests HIV positive." (Source: female informant, 30 years, single)

Naomi indicated that she would prefer a positive HIV status outcome for her partner. When Naomi was asked why she would wish her partner to also test HIV positive, her response was as follows:
"It is much better when both of you [couple] are positive than when one is negative and the other positive. The negative partner is more likely to abandon the infected partner. In case they stay together, the relationship is always reduced to being housemates, intimacy is lost and the unity and love that was there before is lost. If we are both living with the virus it would be easy to remind each other to adhere to the prescribed medication and there will not be as much tension in the relationship as there would be if my partner is HIV negative. The worst that I know can happen to me is that he might accuse me of infecting him or think that I had been unfaithful." (Source: female respondent, 30 years, single, interview)

In most traditional African cultures men were allowed to be polygynous or condoned to have multiple sexual partners. However, this was in contrast to the societal expectations of women. Women were expected to be submissive, docile, get married, be faithful and above all be the society's moral keepers. Among people living with HIV and AIDS, women who were married were therefore not blamed for contracting the virus as much as the unmarried ones. They were considered to be victims of the male dominance. Single women who were living with HIV on the other hand were perceived to be immoral, promiscuous, or prostitutes who deserved to be infected. This may have been the reason behind the low rate of HIV status disclosure to partners among the single, divorced and separated women.

Suzann 23 years and single had a boyfriend she had been dating for one year. She was asked whether her boyfriend was aware that she was living with HIV and she responded as follows:
"I cannot tell him that I am living with HIV. It can result into a big problem. I cannot tell how he will react the moment I disclose my status to him. He may decide to abandon me. I don't want to lose him now because he provides well for my needs. If he leaves right now, life can be unbearable for me and I have a child who has to be taken care of. We don't have a problem so far because we have never discussed about our HIV status. I also don't know if he is positive or negative but I cannot request him to be tested. He will be suspicious and may ask me to take the test too. " (Source: female respondent, 23 years, single)

When asked how she manages to attend the support group meetings which were held twice in a week without her partner demanding to know her where about. Her response was captured as follows:
"I don't have to tell him where I am going all the time. I live in my own house and I can go anywhere I want without reporting to him. I had told him that I attend chamaa (women group meeting) which he knows are always organized to meet on specific days of the week. He cannot bother so much with women issues, after all we do not live under the same roof and he has to call or send a sms (short message service) to find out if I am in the house before he comes over." (Source: female respondent, 23 years, single, interview)

Grace, another female respondent, 24 years and divorced was quoted to say that:
"We separated with my husband after we were tested HIV positive. I have dated two men since then. We parted ways with the first man because I was still suffering bitterness for contracting the disease from the previous relationship. I told him [boyfriend] about my HIV status and that marked the end of me and him. After the break up, I took a break for sometime before I got into another relationship. Currently, I am dating someone who is a widower and he wants us to settle on marriage. We have both not disclosed our HIV status to one another." (Source: female respondent, 24 years, interview)

An informant by the name Pamela had lived with the virus for close to ten years. She had become a peer group trainer and counsellor and was a reference to many female respondents
who had known how her husband abandoned her after she disclosed to him that she had tested HIV positive. In an interview with Pamela, the following excerpt was extracted on the effect of disclosing a person's HIV status to a partner. She narrated:
"I am a living example that being a woman is difficult and much difficult for those who are living with HIV. Everybody in this neighbourhood knows my story. I tested HIV positive ten years ago and life became a night mare when I disclosed to my husband that my HIV test results were positive. The next thing that he did was to pack everything that we had and he moved out of the house, living me in an empty single room with the children. What shocked me is that he did not bother to know whether he was infected or not because we had lived as husband and wife and I had tested positive. He married another woman immediately. My children had to drop out of school and we lived in the streets for a long time until a community based organization helping people living with HIV came to our rescue. Many women in these slums have been in the same situation as mine and some are still suffering in silence. Because of this, women here [Kibera slums] are quite afraid of knowing their status let alone disclosing it to their partners. "(Source: female participant, 39 years, key informant)

The fear of rejection and being abandoned was notably common among women, particularly the unmarried, as compared to men. However, testimonies exhibiting non disclosure of HIV status to partners were common among women who were not in marital relationships than those who were in marriages. In most cases, women who were in marriages either reported the support they received from their partners upon disclosure of their HIV-positive diagnosis or their partners' inability to believe their HIV positive status. In a few circumstances, those who disclosed their HIV status were abandoned by their partners as illustrated by the above narratives.

The process of disclosure of HIV status between partners varied accordingly. In cases where an individual felt that he/she was a victim of circumstances, the disclosure became confrontational. Contrary, in the unclear circumstances of who could have been the source of infection, the disclosure took am more passive nature. In some cases, the individuals lured their
partners into taking the test together so that the health provider can offer pre- test and post- test counselling. This was believed to reduce the intensity of negative reaction between partners.

### 4.4 Adhering to Protective Practices

The study endeavoured to establish how often the respondents engaged in protective sex and the challenges they faced in adhering to these protective sexual practices. The findings (table 4.2) show that sixty percent ( $60 \%$ ) of respondents reported to always engage in protective sex. Thirty four percent ( $34 \%$ ) reported that they sometimes engaged in protective sexual practices. Only six percent ( $6 \%$ ) of respondents reported to never engage in protected sexual practices. The study further revealed that respondents were aware of the importance of engaging in protective sex. As was corroborated by findings of Undie et al. (2009) in a similar study, a large number of respondents cited the major reason for engaging in safer sex as the prevention of contracting other strains of the HI virus. According to the findings of this study, a few respondents mentioned abstinence and being faithful to one partner as protective measures against re-infection with new strains of HIV and other STIs.

Six out of the ten male respondents reported to always engage in protective sex while $59 \%$ of the female respondents reported to engage in protective sex all the time. Women were found to have lesser power to negotiate condom use. This is as a result of the gender inequity which leads to power differences between men and women. It is more difficult for women to negotiate for safer sex than men since they are expected to be submissive on issues of sexuality.

Socio-cultural barriers to condom use in the African context also affect those living with HIV in much the same way as those who are not infected. As corroborated by findings of Undie et al. (2009), use of condoms is always seen as a sign of unfaithfulness and non commitment, therefore making condom use incompatible with committed relationships. Married couples were therefore less likely to negotiate for safer sex compared to the widowed and separated. The separated and the widowed respondents were more likely to use condom because they tended not to be committed in their sexual relationships. On the contrary, single respondents
did not often engage in protective sex for fear of being seen as unfaithful by their partners who could in turn perceive them as prostitutes.

The study findings also noted that adhering to protected sex was challenging because the respondents were not used to practicing such measures. Most of the protective practices that were recommended to people living with HIV and AIDS were also associated with reduced feeling of sexual pleasure or a complete lack of it. As a result, the adherence to protective sex was not consistent in the initial phases of life as a person living with HIV and AIDS.

Table 4.2: Adherence to Use of Condom

Adherence to use of condom

Never

Sometimes

Always
44
24
34.0
60.0
Total
73
100.0

## 4.5: Avoidance of Risky Sexual Practices

With continued efforts to reduce the prevalence rate of HIV and AIDS, one of the targeted areas is the behavioural change among people who have not contracted the virus. Research has disclosed the existence of different strains of the virus. The present availability of ARV drugs has also started to shift attention toward preventive behaviour change (Undie et al. 2009) for those who are infected with the virus. This is in effort to avoid re-infecting themselves with new strains of the virus which could lead to HIV drug resistance.

Behaviour changes call for disengaging in risky sexual practices such as having unprotected sex, particularly with multiple sexual partners. Statistics show that in Kenya, informal
settlements such as Kibera are a home to $71 \%$ of the urban population (UNHABITAT 2003). These informal settlements are characterized by extreme poverty, unhygienic living conditions and high level risk-related sexual behaviours. Slums such as Kibera therefore, have the highest HIV and AIDS prevalence in Kenya. The study therefore sought to assess the sexual practices that people living with HIV and AIDS in Kibera informal settlements abstained from as a measure of protecting themselves against re-infection.

The findings from this study were similar to a related one by Undie et al. (2009) and revealed that people living with HIV and AIDS were discouraged from engaging in certain sexual behaviour by health care providers and support group facilitators. Findings further showed that majority of respondents $(73 \%)$, reported to have been advised to abstain from certain sexual practices such as un-protected penetrative anal and genital sex, and frequent sexual activities.

Avoiding frequent sexual activities and having a regulated and moderated sexual life was mentioned regularly during in-depth interviews as one of the ways towards a positive living. According to the study respondents, sexual activities led to burning of a lot of calories in the body, which if not regulated could weaken the body leading to deterioration in the health status of the person living with HIV. However, there were other respondents ( $27 \%$ ), who reported not to practice any form of safer sexual practices. This category of respondents engaged in all convenient sexual practices such as; un-protected oral, genital, and anal sex. They reported to practice other measures of safer sex such as being faithful to one partner and having a HIV positive partner.

Married respondents were more likely to abstain from the sexual practices they had been advised to avoid by healthcare providers. Seventy eight percent (78\%) of the married individuals confirmed that there were certain risky sexual practices such as anal unprotected sex that they could not engage in with their partners. This explained the belief in most traditional African communities that sex is primarily reserved for procreation especially in marital unions. Sexual exploration in marital unions was therefore limited to genital penetrative sex. The widowed, single, separated and divorced respondents were likely to engage in risky
sexual practices. For this category of individuals, sex was more of a pleasure and not for reproduction, hence the exploration of practices that could put them at more risk.

According to findings of the study, more men than women had the option of not engaging in risky sexual practices. Ninety percent $(90 \%)$ of the male respondents confirmed that there were certain sexual practices they could not engage in. On the other hand, only seventy one percent $(71 \%)$ of the female respondents had the capability of avoiding risky sexual practices with their partners. This is because the female sexuality is suppressed and in some circumstances controlled by men and not the women themselves. In many cases, the practice of safe sex is always determined by the willingness of the man to use a protective measure.

### 4.6 Protective Measures against Re-infection

The study explored measures that the participants practiced to protect themselves from contracting sexually transmitted infection (STIs) and re-infection with other strains of HIV. Majority of respondents who participated in the study indicated to practice protective sexual practices. Table 4.3 gives a summary of the protective measures practiced by people living with HIV and AIDS in Kibera informal settlements.

Table 4.3: Protective Practices (Multiple Responses)

| Protective practices | Frequency | Percent |
| :--- | :---: | :---: |
| Use of condom | 64 | 84.0 |
| Being faithful | 1 | 1.0 |
| Abstinence | 10 | 14.0 |
| Pleasure driven sexual | 1 | 1.0 |
| practices (fondling, | $\mathbf{1 6}$ | $\mathbf{1 0 0 . 0}$ |
| Caressing) |  |  |
| Total |  |  |

From the study findings presented in table 4.3, condom use was reported to be the most commonly practiced measure. Eighty four percent ( $84 \%$ ) of respondents mentioned the use of condom as the most preferred measure to protect themselves from re-infection with different strains of HIV and other STIs. Fourteen percent (14\%) of the respondents however reported to practice abstinence as a measure of positive living. It was equated with other standardized forms of positive living such as maintaining a balanced diet and tacking the necessary medications at prescribed times. Respondents who mentioned abstinence as a protective measure against re-infection and a way of positive living were mainly women. Study results revealed that men opted to remain sexually active but practiced safer sex such as use of condom.

Findings from the study also found out that being faithful to one partner was glaringly absent from the narratives by the informants. Only $1 \%$ of the study respondents reported to practice faithfulness to one partner as a protective practice against sexually transmitted infections. Practicing non-penetrative forms of sexual pleasures such as; caressing, deep fondling and masturbation were also cited by a mere one percent $(1 \%)$ of respondents. Eight percent $(8 \%)$ of respondents within the age group of 22 to 32 years however reported the use of such alternative forms of sexual pleasure other than penetrative sex. This shows that in as much as the younger individuals are more explorative in their sexual experiences, the cultural norm of penetrative genital sex was still commonly held within the general population regardless of age and gender as the sole source of sexual pleasure.

Respondents who mentioned use of condom as a protective measure reported various challenges that came with it. Difficulty in adhering to the use of condom in the initial phases was cited as a big challenge. Another challenge mentioned by female respondents was that female condoms were not readily available yet their male partners were not willing to use the male condoms. It was evident that the study respondents adopted condom use not out of personal choice but as a result of persuasion by health care providers. The motivation of condom use by a good number of respondents was to avoid re-infection by a different strain of HIV.

From the study results, use of condoms was rarely mentioned by respondents as a method of family planning. Respondents noted that female condoms were expensive and a packet cost between Ksh120 and Ksh150. This was evidently beyond the purchasing power of majority of people living in the informal settlements such as the Kibera slums who had an average monthly income of Ksh 5000. According to some respondents, female condoms were not easy to use and when not properly inserted, made sound during coitus. This was embarrassing for the couple who lived with their children and relatives in single rooms typical of slum areas. The following excerpts sample some of the challenges associated with the protective practices.

Martin, 39 years and married stated:
"The use of condom is highly recommended in the campaign for a positive living by the counsellors and health care providers. It is however very difficult to use condom consistently. I mean, it is not as easy as $A B C$ as it is said. It requires understanding between the sexual partners, consistency in its use, acceptance of one's situation and having a goal to work towards in life. Generally, from my experience as a person who has been living with HIV for nine years and is currently a campaigner of positive living, I can admit that condoms reduce the sexual pleasure and because of this, the intimacy that the couple previously enjoyed is lost. " (Source: male informant, 39 years, Interview)

A female participant stated:
"I have been advised on the consistent and correct use of condoms as a way of protecting myself from contracting different strains of HIV, STDs and to prevent pregnancy. I did not like it [use of condom] at first because it reduced the natural sexual feeling and could not enjoy sex before I got used to it. My husband and I now use condoms all the time we are having sex. It has become our way of life since we want to live longer to take care of our children and there is no option out, we cannot abstain because we are married." (Source: female respondent, 32 years, interview)

A male participant, Jacob, during a focus group discussion was captured to have said that; "Condoms are very important in the control of the spread of HIV but people still fear to purchase or pick them from the public condom dispensers. When one is seen purchasing or picking condoms from the dispensers, people look at them as a person who is unfaithful and cannot keep to one partner. "(Source: male respondent, 33 years, focus group discussion)

The extract from Jacob shows that people associate the use of condom with partners who are not intimate and none committed to one partner. Therefore, using condoms among married couples or those in stable relationships could be hindered by the stigma that the society has attached to use of condom. The society therefore contradicts itself by demanding for behavioural change among its members as a way or combating the spread of HIV, but the same society stigmatizes the behavioural changes towards the same goal.

Study respondents also reported that some religious doctrines such as the Catholic Church and the Islamic faith disapprove condom use. This becomes a dilemma for persons living with HIV and AIDS and is a follower of such religious doctrines. Religion is one of the cultural aspects that define a persons' sexuality and its influence on the sexual behaviour therefore cannot be overemphasized. Islamic faith for example allows a man to be polygamous and condemns the use of condoms as promoting immorality and promiscuity. Hassan who was a study participant from the Islamic faith said the following on religion and the use of condoms.
"As a Muslim, I get in the dilemma on whether to follow my religious doctrine or the advice from health care providers. The health care providers advice that as a person living with HIV, I have to use a condom to sustain my health after recovering through the intervention of ART. On another hand, my faith condemns the use of condom. I get torn between my faith and health which are both of importance to me." (Source: male participant 37 years, focus group discussion)

Being one of the important aspects of culture, religion has a great influence on how a persons' world view is formed. From the above excerpt, it is evident that there is a conflict between religion and healthcare within the Muslim and Catholic religious belief systems on the use of
condom. This is likely to jeopardize the use of condom among members of such religious groups that do not condone it. This is because within a culture, many people tend to follow what their religious doctrines uphold.

### 4.7 Living as a Discordant Couple

Through in-depth interviews, it was established that a number of participants (10 out of 73 ) lived in discordant relationships. Study Participants who reported discordances were probed to further explore the challenges that they experienced as discordant couples. From the study findings, it was more challenging to live as a discordant couple than when the two partners were HIV positive.

Some respondents who had discordant partners reported to be isolated by their mates and in as much as they used condoms during sexual intercourse, their HIV negative partners were overly cautious. This did not make sex to be spontaneous thereby not being enjoyable. The study findings noted that women were more accommodative in cases where their partners were HIV positive than vice versa.

It was found from this study that women who were discordant did not abandon their relationships. The women opted to live with and give support to their HIV positive partners. They took over the responsibility of the households and became the bread winners of their families. This was however not the same case with men who were discordant. Most men on the other hand abandoned their partners who tested HIV positive for new partners. This was based on a mythical belief held by many people that the person who tests HIV positive first must also be the one who contracted it first. In this regard then, men whose partners tested HIV positive while they were discordant could not put up with such partners in the belief that they had been unfaithful.

Couple discordances were even more challenging in cases where the two were not in a more stable union like marriage. Marriage in the traditional African societies was intended to be permanent and therefore divorce was non-existent. It brought a sense of commitment between
the partners. Lack of marriage therefore, symbolized absence of commitment between the partners. One partner could not therefore hold another responsible where there was no form of a recognized marriage. It was for this reason that most unmarried individuals did not risk to disclose their HIV status to their partners. In cases where an individual disclosed his or her HIV status to such a casual partner, chances of the relationship breaking up were very high.

Violet a female respondent, 26 years and single narrated how she was abandoned by her boyfriend after they went for an HIV test prior to their marriage. She stated:
"My boyfriend and I had dated for one year. We decided to take a HIV test since we wanted to get more serious with our relationship. My HIV result was positive while his was negative. We were both counselled and he pretended to be caring and committed even after we turned out to be of different HIV status. After a short while, he started avoiding me and stopped fulfilling the responsibilities he did for me. It was difficult for me to cope after the break up because my job is not well paying and he used to carter for a lot of my needs. As a result, I am now scared of revealing my status to my current partner. I fear going through the same rejection. " (Source: female respondent, interview)

Anne was 35 years and married. She talked about her experience and challenges of living with HIV negative husband. She gave the following narration:
"I am HIV positive but my husband is not. I knew about my HIV status when I attended an ante-natal health care. I had to undergo the HIV test as part of the routine check-up which is a requirement for all the expectant women. I was counselled after my test results turned out to be positive. I was told to request my husband to accompany me to the health centre for him to be tested too. My husband accepted to go for the test but his HIV test result was negative. We were both counselled on how to live positively as a discordant couple. We had to start using condoms immediately after the test to avoid infecting the unborn baby. Although my husband has been supportive, it has not been easy. Sometimes he uses harsh words on me; he can at times tell me not to drink from his cup to avoid passing the virus to him. I can remember sometime back the condom broke as we were making love and he started crying that I have
infected him with HIV. It was just an accident but he blamed it all on me. Our sexual life is not active any more. He is no longer interested in making love to me as before and I suspect that he is having another woman on the side." (Source: female respondent, 35 years interview)

The narrative given by Anne shows that the fact that one partner is living with the HIV and the other one is not brings constraint in the relationship. The couples' sexual life is interfered with and this could bring a rift that sometimes is extended to social and financial separations. The partner who is not infected is always more likely to abandon the relationship for another, sometime not physically but emotionally and psychologically. Anne's husband felt obligated to stay in their relationship despite having another woman because of the sense of commitment that is brought by marriage. On the other hand, Violet's boyfriend abandoned their relationship because they were not committed to each other through marriage.

It was clear from the study findings that getting a partner for a long term relationship was challenging for everyone who was living with HIV and AIDS. However, this was different across gender and age. Men faced lesser challenges than women because more men are economically stable than women. Men are therefore more likely than women to get a partner due to their relatively higher economic status despite being HIV positive. A woman who is single and is living with HIV has a lot of difficulty getting a long term partner. She will be perceived as being of loose moral and a liability by the man especially if she is not economically independent, which majority of women are not.

Findings from this study also revealed that young adults living with HIV and had never been married faced a lot more challenges in seeking a lifetime partner as compared to those who had once been married. This is because of the social, sexual and physical death that is associated with HIV. A young adult living with HIV and is not yet married with no child is more often than not caught up between how to live a positive life and how to fulfil marital and reproductive ambitions. They are therefore perceived as social misfits by the society once their HIV status becomes public.

The study also revealed that respondents who were married disclosed their HIV status to their partners more than the unmarried ones. Married couples were committed and it was much difficult to abandon such a relationship than a casual one. It was also revealed from the findings that women were less likely to disclose their HIV status to their partners in casual relationships. In most circumstances, men are economically stable and women depend on them for upkeep and financial support. This is the reason despite being HIV positive, men tend to face lesser challenges in getting long term partners compared to women. The study also found that young adults are also less likely to disclose their HIV status to partners compared to the older individuals. The younger people participate actively in the social and sexual life and disclosing their HIV status would lock them out of this social arena.

From the findings, engaging in protective sex was found to be low in marital unions among people living with HIV than in casual relationships. This is because protection is associated with mistrust and non commitment between partners. The study also revealed that living in a discordant relationship was more challenging than when the two partners were all living with the virus. Further, relationships in which women are discordant are more likely to remain in tacked than those in which the man is the discordant partner.

## CHAPTER FIVE

## SEXUAL PLEASURES, DESIRES AND REPRODUCTIVE GOALS OF PEOPLE LIVING WITH HIV AND AIDS

### 5.1 Introduction

This chapter presents the finding of the study on the sexual pleasures, desire and reproductive goals of people living with HIV and AIDS as revealed both by qualitative and quantitative data. Ways in which people living with HIV and AIDS express their sexual desire and experience sexual pleasure are discussed. The influence of ART on the sexual desire and activity and the reproductive goals of people living with HIV and AIDS after regaining their health following the use of ART are explored and discussed. The findings are then discussed in relation to other studies that have been conducted in the related fields.

### 5.2 Influence of ART on Sexual Desires

Since the introduction of ARVs, many people who are infected with HIV and AIDS have been relieved of the devastating effects of the disease. ARVs have been credited with rejuvenating the lost or depreciated physical health of people living with HIV and AIDS. Through their continuous and consistence use, a number of people living with HIV and AIDS have regained back their physical and sexual lives. The study assessed the influence of the ARVs on the sexual lives of people living with HIV and AIDS.

Findings showed that $75 \%$ out of the 73 respondents reported that ART improved their sexual desire. The respondents indicated that the period immediately after a person tested HIV positive is always characterized with bitterness and self blame for contracting the virus. In most cases, this leads to criminalization of sex or related sexual activities and hence the disappearance of the desire for sex. The respondents in this study however stated that this condition was not experienced for long, especially when an individual joined a support group. The support groups enabled people living with HIV and AIDS to share experiences and challenges and therefore gave them emotional comfort and social support. ART has various
components such as counselling, nutrition, medication, support group therapy which all work together to improve the general physical health of the person living with HIV and AIDS.

Qualitative data further confirmed that abstaining from sex did not last long. An informant explained:
"The day I knew I was HIV positive, the world changed for me. I was worried of how life was going to be for my children after I had died. I thought I was going to die immediately. I became very sick because I had not accepted that it [contracting HIV] could happen to me. I can't remember thinking about sex during that time. I was convinced by my friend to join this support group and this is where I have learned many things that have helped me to live positively. I now have sex like any other person but I have to protect myself always so that I do not get re-infected. "(Source: female informant, 33 years, interview.)

Another informant stated:
"The moment I went to the VCT and was tested positive, I thought that my life had come to an end. I did not see the meaning of anything I had been doing before; after all I was going to die sooner than I had thought. I stopped everything I used to do like selling fruits and vegetables. I even stopped having sex with my husband because he had messed up my life. When I joined this support group, I gave my testimony and vowed never to have sex again. It did not take long before I accepted to be intimate with my husband again. "(Source: female participant, married, 36 years, focus group discussion.)

The two extracts above show that the informants regained back their sexual life not through the use of ARVs, but from the help of support group activities such as motivational talks and exchange of ideas. Various activities took place in the support groups. They included: economic activities such as weaving, beading, collecting money and lending to group members who were in need, distribution of food stuff to people who were entirely needy among others.

A peer group educator who had lived with HIV for nine years after knowing his status explained his experience with people who formed the support group. He explained:
"The period immediately after a person tests positive is always marked with a lot of confusion, bitterness, self quarantine and all a person thinks of is death. This situation in most cases when not attended with adequate social support and counselling can lead to degeneration of mental health, physical and sexual health. When the body degenerates physically, it affects the stability of the mind, I mean; you cannot be sick and be peaceful in your mind. The physical deterioration also makes it difficult to perform sexually because the body will be weak and therefore lack the energy required in love making. Usually, after counselling and being put on the necessary drugs, the person living with HIV whose health had gone down will be revived. It is not the ARVs that bring the person back to health, but usually it is a combination of the social support given to the person which include counselling, group interactions, and nutrition and in some cases, the medicines. I can tell you that in this group, there are many people who join swearing that they will never have anything to do with sex. After a few sessions, they always start opening up and before long, they actively participate in discussion on how to handle certain situations in the relationships that are as a result of HIV. They become sexually active once again and most of them have not even been put on any kind of medications. '(Source: male 37 years, key informant)

On the contrary, only $25 \%$ of the respondents in this study were of the opinion that the ART did not improve their desire to engage in sex. They reported having experienced no changes in their sexual lives even after being introduced to the ART. One informant narrates:
"I have not observed any changes in my sexual life. I hated anything to do with sex after testing HIV positive but then this changed after sometime. I am taking the ARVs but I don't think it has increased my desire to have sex. I am just the same as I was before being tested." (Source: Female informant, 34 years)

The above extract shows that the participant was referring to the Anti-retroviral drugs which she did not believe increased her sexual activity. She however admits that her sexual activity levels went down the period immediately after she tested HIV positive, but this improved with time. Considering that this informant was a member of a support group, she could have been
helped to cope with her condition during group therapies which helped in restoring her sexuality. During in-depth interviews, other participants also pointed out that ARVs alone could not revive a persons' sexual life but a comprehensive therapy which involved counselling, nutrition and group support helped an individual towards positive living. Table 5.1 shows the influence of ART on sexual desire.

Table 5.1: Influence of ART on Sexual Desires

| Sexual desire after ART | Frequency | Percent (\%) |
| :--- | :---: | :---: |
| No change | 18 | 25.0 |
| Change | 55 | 75.0 |
| Total | $\mathbf{7 3}$ | $\mathbf{1 0 0 . 0}$ |

More men than women admitted that ART increased their sexual desires. Out of the 10 male respondents, $50 \%$ reported that their sexual desire was increased after starting the use of ART compared to $46 \%$ of the 63 female respondents. This was possibly due to the fact that expression of the male sexuality was more liberated than that of women in the African settings. In as much as there was lose of the sexual urge in most respondents after an HIV positive diagnosis, men took a relatively shorter time to get their sex life back as compared to women.

According to the findings, younger respondents reported more improvement in their sexual activity as a result of ART compared to the older ones. Fifty three percent (53\%) of respondents below the age of 33 years mentioned that their sexual desire increased after starting the use of ART. Only $46 \%$ of respondents who were 33 years and above reported an increase in their sexual activity the period after commencing ART. This confirms that all human beings are sexual despite their HIV status. After an individual accepts his or her HIV status and adopts coping mechanisms, they regain their sexual activity much faster. However,
it was observed that the level of sexual activity of an individual diminished as they advanced in age. This could probably been the reason for the slow recovery of the sexual activity of respondents who were above 33 years.

### 5.3 Sexual Desires and Ways to Achieve Sexual Pleasures

Contrary to the assumptions that people living with HIV and AIDS do not experience sexual pleasure after being diagnosed with HIV, the study findings revealed that $78 \%$ of respondents reported to experience sexual desire and pleasure. However, this was not experienced immediately the period after a HIV positive diagnosis, but after a person living with HIV had been introduced to ART. Eighteen percent (18\%) of respondents however stated that they rarely experienced pleasure in their sexual lives after they were diagnosed to be HIV positive. The remaining four percent ( $4 \%$ ) of respondents indicated a complete lack of sexual pleasure after the HIV diagnosis.

Study respondents mentioned various ways in which they derived sexual pleasure. Genital penetrative sex was the most mentioned way of deriving sexual gratification by respondents. Other forms of sexual pleasure were non-penetrative ways of deriving sexual pleasure such as; touching, caressing, fondling, sweet and romantic talk, oral non penetrative sex and watching romantic movies. These alternative forms of deriving sexual pleasure were only mentioned by respondents who were between the ages of 23 to 28 years. This could have been due to change in the youth culture that has been introduced through various forms such as the media. The findings showed that study participants of age thirty three years and above were reserved in exploring sexual pleasures. They only reported the genital penetrative sex to be the source of their sexual pleasure.

In most traditional African societies, expression of the desire for sex and sexual pleasure was perceived to be a domain preserved for men. Sexuality in this context is used as a tool toward gender inequality between men and women and a way through which men dominate the women. Women in traditional African societies were not allowed to openly display and express their sexuality. A woman was in that case not expected to openly express her desire for sex or
sexual pleasure. Sexuality for women rotated around reproductive roles which the society expected them to fulfil for its continuity.

Sexuality of women living with HIV and AIDS in the African setting is even more muted than for those without the virus. Little is known about the sexuality of women who are living with HIV and AIDS outside the risk prevention and education. From the study finding, it was established that although women continued to be functional and sexually active following a positive diagnosis, decreased sexual functioning was very common and prevalent among them than among HIV-positive men. Ways in which women's sexuality was transformed by the experience of living with HIV and AIDS include, muting from sexual and reproductive lives such as total avoidance of sex or diminished intimacy with partner and lose of aspiration for childbearing.

During an in-depth interview on ways of experiencing sexual pleasure among people living with HIV and AIDS, a male informant explained that the way in which sexuality is constructed was responsible for the non participation of women in the sexual activities and strict adherence to certain sexual acts. He mentioned that there were less risky ways of deriving sexual pleasure without contracting new strains of HIV and other sexually transmitted infections. He further noted in his narrative that these alternative forms of sexual pleasures were not recognized in the traditional African definition of sexuality. He stated:
"Africans believe that the ultimate sexual pleasure is arrived when there is penetrative sex. I know there are other ways in which pleasure can be achieved such as caressing and kissing but those are not seen by Africans to be giving sexual pleasure. As an African man, I cannot just kiss and fondle a woman and leave it at that. It is impossible to resist the temptation for penetration because it will also be in the woman's expectation. That is how we African men prove that we are real men, therefore if one does not, the woman will doubt if you are a real man. Our women also believe that penetrative sex is the ultimate point of sexual pleasure. This is one of the negatives beliefs that we should discard, I believe if people start to think in that
direction, the spread of HIV and AIDS can be controlled. "(Source: male respondent 43 years, focus group discussion)

Findings further showed that female participants were more reserved in discussions on sexual desire and pleasure. Narratives from the female participants rarely mentioned sexual desire and pleasure compared to narratives from the male participants. The female respondents avoided any discussion around themes on sexual desire and pleasure. They treated these concepts to be of little importance to them thereby confirming that women's sexuality is suppressed by culture. The female respondents talked more openly about abstinence, being faithful to one partner and use of condoms. During interview, a female informant explained:
"I try not to involve myself in sex all the time. It is my husband who persists on us having[sex] it most of the time. When I refuse, he accuses me of being unfaithful and that I must be getting my sexual satisfaction from another man. Considering our status, it is not recommended that we have sex all the time otherwise our health is likely to get weak very fast. We therefore use condoms all the time when we are having sex." (Source: female informant, 33 years, married, interview)

Another female informant confirmed the above when she said:
"My husband demands that we have sex all the time even when I am not interested. I always have no otherwise but to accept. Sometime I am tired, having been moving up and down the whole day with the children and my business. It is not also a good thing to engage in too much sex because our CD4 counts will drastically go down which will not be good for us. "(Source: female respondent, 29 years, interview)

The above extracts confirm that women are silent on their desire for sex and on their experience of sexual pleasure. They remain silent and submissive in matters of sexuality because that is what it means to be a 'decent woman' in traditional African cultures. Living with HIV and AIDS has made decisions regarding sex to be characterized with difficulty which may have had the effect of a previously enjoyable activity turning into a source of anxiety,
conflict and confusion. Regulated sexual life was also mentioned by female respondents as a way of maintaining the body defence thereby enhancing a positive living. This was in contrast to the male participants who talked more liberally on sexual pleasure. The male respondents emphasized on the importance of sexual pleasure and the use of protective sex. They rarely mentioned abstinence and regulated sexual life.

From the findings it appears that sex became an activity of great potential danger and anxiety and created feelings of discredit and self doubt among people living with HIV and AIDS. In some cases, the notion of a failed body due to the lack or inability to perform sexually occurred. The results were that an individual went through self isolation and the decision to be asexual or sexually inactive was made.

The unmarried women are a sub-set within the female gender that further suffer stigma due to the central role played by sexual behaviour in the transmission of HIV. The popular discourse on HIV and AIDS attributes blame and induces guilt to sexual behaviour outside of a set of certain strict boundaries such as a committed relationship or a marital union. This has negative implications for those who are not married and have contracted HIV. These individuals are viewed by others as not morally upright and unable to settle with one partner, thereby spreading the virus to several people. This is predominantly for women whose sexuality is treated as sinful and dangerous outside a marital union as the society views them as the agents for the spread of HIV.

Anne, a female informant during an in-depth interview was quoted to have said the following when she was asked to mention ways through which she derived sexual pleasure as a person living with HIV.
"I try as much as possible to avoid thinking about sex. Whenever I find myself thinking towards that direction, I get myself busy with something that will divert my attention. If the feeling gets too much, I would rather use hot water and salt to cool myself down. "(Source: single informant, 34 years)

The statement captured from Anne confirms that women's perception of their sexuality has been constructed by culture. This has resulted in women being agents in silencing and suppressing their own sexuality. Safe sex for these respondents involved a radical change from their usual sexual repertoire to complete avoidance of sex or to forms which are regarded as less alteration to their sexual practices such as having sex with one regular partner.

Due to its wider components, ART reinstates the sexual lives of people living with HIV and AIDS which more often had degenerated after a positive diagnosis. In as much as ARVs are known for their rejuvenating effect on the physical bodies of those who have been wasted by HIV, their use alone without social support such as nutrition, counselling and group support is not enough to revive the sexual health of the person.

Sex involves both the physical body and the mind and the well being of both is therefore important for sexual activity of a person. Counselling by healthcare providers and group support where people living with HIV and AIDS shared about their sexual challenges, and exchanged ideas freely was important for both the psychological and mental health, which was then coordinated with the physical health regained through the use of ARVs to restore an individuals' sexual life.

Ways to derive sexual pleasure for most people was through penetrative genital sex. Nonpenetrative ways of getting sexual gratification were not culturally acceptable within the African context. However, it was found that there was an emerging youth culture that was beginning to embrace new cultural constructs of sexual pleasures such as fondling, touching, sweet talk among others, as ways of getting sexual gratification.

### 5.4 Bearing Children

People living with HIV and AIDS especially women are stigmatized by the society when they make a choice to bear children. Sixty three out of the73 study participants were women. The study revealed that women in the society were more likely to seek support and services such as medication, nutritional support and support group membership for people living with HIV and

AIDS. This was possibly tied to the perception of gender roles that meal preparation and healtheare was a domain for the women (Undie et al. 2009). As a result only 10 out of 73 respondents were men.

Sixty two percent ( $62 \%$ ) of the female respondents reported that they desired to have children. However, these ambitions were received negatively by criticism from family members and friends who were aware of their HIV status. Their main concern was that the child would get infected with the HI virus. The other $38 \%$ of female respondents did not want to have children even after being on ART. Reasons for not desiring children included: having had enough children, being of an advanced age (old) and being HIV positive was mentioned as the greatest impediment to achieving this reproductive goal.

Findings from the study indicated that even after regaining sound health through consistent use of ART, a number of people living with HIV and AIDS still suffered internal stigma. The choice to bear children was a combination of the desire to fulfil their earlier life aspirations before they were infected with the virus. It was also a way of leaving a legacy behind when they would finally succumb to AIDS.

Out of the 73 respondents, $85 \%$ reported to have between one to five children. Only three percent ( $3 \%$ ) of the respondents had no children. This was probably the reason why despite regaining health as a result of ART, some respondents did not aspire to have children. However, more male than female respondents who had children still had reproductive ambitions after regaining their health. This was because they were likely to re-marry and would therefore want to have other children with their new partners. This is because children are considered to create a strong bond between partners resulting into commitment and hence expected permanence of the union.

From the findings, respondents in the younger age bracket (between 23 to 27 years) had ambitions of getting children in the future. Those who did not want to have children in future were mainly female respondents who were 28 years and above. Most of them already had children and probably had diminished reproductive goals due to advanced age.

Maryanne, 31 years, when asked about the reproductive ambitions that she would want to accomplish after her health was restored as a result of ART asserted:
"When I knew of my [HIV] status, I was heartbroken because I knew that I would never be able to give birth to the number of children I had planned for. When we got married. my husband and I had planned to give birth to four children. I knew about my HIV status after we had gotten only two children and it was very devastating for us. We both had fears that we would get an infected child if I got pregnant. The burden of taking care of a HIV positive child is enormous and quite devastating to the child. We therefore settled on remaining with the two children that we had. It was during one of the seminars organized by KIPOTEC that we found out that we could have a child despite being HIV positive. It is not as easy however as it would have been if we were not infected... we now have to be under strict medical supervision before I am fit for conception. The CD4 counts of my husband and I have to be above 500 in order to conceive a healthy baby and to avoid re-infecting ourselves and the unborn child. We now have plans to fulfil our previous ambitions of having four children in the next few years. Children are a blessing because they remain as a legacy when a person passes on." (Source: female informant, 31 years, married)

Another informant, Beatrice, 24 years old and single had never had a child. When she was asked whether or not she had ambitions of having children given that she was living with HIV, she asserted:
"I wish to have children, at least one child in my life. It is my right to have a child like any other person. HIV is just a disease like any other and should not deter me from fulfilling my dream of making a family. Furthermore, medications are now available to prevent the mother from passing the virus to the baby. With the available medical care and following the instructions I am given by the doctors, I will be able to give birth to healthy babies if I wish. Having a child for me is important because that is the only way to leave behind a legacy, otherwise I will be forgotten immediately when I die." (Source: informant, single, 24 years, interview)

From the above excerpts, the biggest reason for having children for people living with HIV and AIDS is for the purpose of perpetuating their legacies. They consider HIV as a cause of physical and social death and therefore try to continue living through their children. According to them, people would continue seeing and remembering them long after they have died through their offspring.

Among informants who did not want to have more children was Gladys (38 years and married) who had two children. She reiterated her wish not to have children again as follows:
"I do not wish to have children even though I know my HIV status is not a hindrance. I had five children with my late husband and I think they are enough for me. I re-married my brother inlaw whom I live with after my husband's death. He has been demanding for children but I am not ready to give birth to another child. My age has advanced and I have now left that task to my daughters. It is not right that I continue giving birth and my children are also doing the same. " (Source: female informant, 38 years, interview.)

Some female respondents however cited their HIV status as a deterrent to having children. These were mainly the new members of the support groups who had not undergone the various thematic trainings that were organized by the network. An informant argued:
"I had planned to have three children before I discovered that I was infected. Being HIV positive changed so many things in my life. I knew that my life had changed and therefore I had to re-organize my plans. I discovered that I had HIV when my second child was very sick and the doctors at Kenyatta National Hospital (KNH) decided to test him for HIV. I was informed that the baby had tested HIV positive and I had to be tested too. I was found to be HIV positive as well. The doctors then asked me to bring my husband so that he could also be tested. When I told him, he refused to take the test. We don't know his HIV status up to this moment. It has been very painful to see the child suffer continuously from every kind of ailment. He cannot lead a normal life like the other children who have been told by their parents not to get into contact with him because he will infect them. I don't want to have another experience like this;

I would never want to give birth to another child." (Source: female participant, 28 years, focus group discussion)

It was found that informants who did not want to have other children already had the desired number and were mostly women. Some of these women also mentioned that they were past the age of having children. This was socially constructed than biologically determined since in this society (the slum); girls were involved in child bearing from a very tender age. However, very few female informants cited their HIV status to be the reason they did not want to have other children. Even in this respect, these informants were well aware that it was possible for them to have children who were HIV negative. Their main concern was the economic struggle involved in bringing up such a child.

In addition, the study revealed that bringing up a child for a person living with HIV and AIDS had its shortcomings. The mother had to breastfeed the child exclusively for six months or the child had to be introduced on formula milk immediately after birth. Both of these had adverse economic implications on the parents, especially on the woman. The decision to breastfeed exclusively for a period of six months meant that the mother always had to stay around the home to keep on breastfeeding the child. On another hand, the decision to have the child introduced on formula milk immediately after birth was very costly for the parents considering the harsh economic situations that faced most of the respondents.

### 5.5 Marital Ambitions

The study found that majority of respondents on ART who had been married did not desire to re-marry after the death of their partners. Seventy five percent ( $75 \%$ ) of the respondents who had been divorced, separated or widowed did not aspire to re-marry but were keen on ensuring the welfare of their children. Only twenty two percent (22\%) of respondents who were divorced, separated and widowed mentioned their intention to get into a marital union by remarrying. Three percent ( $3 \%$ ) of them were however undecided on whether to re-marry or remain single. Respondents who had never married had more ambitions to get into a marital union than those who had married but separated, divorced or widowed. This shows that every
individual in the society desires to fulfil the roles of starting and bringing up a family as socially expected by the society. More male respondents who had been widowed and those who had never married expressed their intention to re-marry and to marry respectively. Forty percent $(40 \%)$ of the male respondents who had been widowed, separated or divorced had desires to re-marry as compared to nineteen percent (19\%) of the female respondents in the same category.

In most African communities, social status of men depends on their marital status. A polygynous man in the African societies earns more respect from people than a monogamous man. It is therefore more important for a man to re-marry after losing his partner in order to be respected in the society, than it is for a woman to do the same. A woman who decides to remain unmarried after separation or widowhood is perceived to be moral. From the narratives given by informants, it was evident that sero-positivity did no impact negatively on parenthood and family building ambitions of people living with HIV and that of their partners as also found by Undie et al. (2009).

According to the findings of this study, it became evident that respondents who were below the age of 28 years had more desire to fulfil marital aspirations than those who were older. It was also shown that marriage provided social status and security for both men and women. Through marriage, both men and women earned respect from the society. A young woman who is not married is likely to be stigmatized (than is a single man) and treated as a social misfit, immoral or a prostitute. This could be the reason why younger women had the desire to get into a stable sexual relationship after regaining health and strength from ART as illustrated in table 5.2.

Table 5.2: Decisions on Marriage

| Decision to marry/re-marry | Frequency | Percent (\%) |
| :--- | :--- | :--- |
| To marry/re-marry | 16 | 22.0 |
| Not to marry/re-marry | 55 | 75.0 |
| Not decided to marry/re-marry | 2 | 3.0 |
| Total | $\mathbf{7 3}$ | $\mathbf{1 0 0 . 0}$ |

Magdalene, 32 years and a widow when asked if she had plans to re-marry after her husband died of AIDS reported:
"I don't want to re-marry because the demands in a marriage are too many. I don't know if my knew partner will accept my condition and the challenges that come with it such as the consistent use of condom and avoidance of regular sexual activities. A new husband may expect me to bear him other children which will be a burden to me both financially and physically. My body cannot bear the changes that come with child bearing without worsening my condition." (Source: female participant, 32 years, in depth-interview)

Maureen, 27 years and widowed did not want to re-marry and she narrated as follows:
"I don't want to re-marry after losing my husband. The new marriage may be stressful than the previous one. This will not be good for me. It is very important that if one wants to live a positive life, they have to avoid stress. If a person living with HIV is under continuous stress, the body grows weaker. If I get married, the man will most likely want to have a child with me which I am not ready for. The three children I have are enough for me. The cost of living has gone up and it is very demanding and costly to feed many children. The most important thing for me would be to look after the children I already have and give them the best quality of life according to my level of income" (Source: female informant, 27 years, married)

It was clear from the study that there were other individuals who wanted to get into a marital union after regaining health and strength from ART. Annette, 33 years and single wanted to get another partner for marriage after the demise of her husband and she stated:
"Marriage is very important for a woman. A married woman earns respect from relatives, friends and even neighbours. When a woman is single and lives alone, the neighbours despise and sometimes get very confrontational with her. But if they see a man who comes to stay in her house regularly like a husband, they treat her with respect. A married woman has dignity in the society and that is why it is my prayers to re-marry." (Source: Female informant, 33 years, single)

Another female informant also stated:
"My dream is to get married in future. It is respectable for a woman to be married. Those who die without marrying are considered a curse in my community and treated with no respect at all both in life and death. Marriage also gives stability to a person because it is important to have someone with whom to share ones' emotional problems as well as economic responsibilities." (Source: Female informant, 26 years, single)

The above extracts from study participants show that marriage in African communities gives status to an individual. Both men and women who are married in the society are regarded highly than their unmarried counterparts. This is why divorce in the traditional African societies was non-existent. Individuals whose marriages failed were considered failures by the society and were in some instances subjected to mockery.

From the findings of this study, it was concluded that childbearing and marriage were important aspirations that each individual wanted to achieve. Those who had no children and those who had never been married were keener on having children and getting married than those who had children and those who had been divorced or widowed. That was why people living with HIV and AIDS whose general health had been rejuvenated by ART and had fulfilled these ambitions in life earlier were no longer enthusiastic about them.

This study concluded that ART had a positive influence on the physical, social and sexual health of individuals who had deteriorated from the effects of HIV and AIDS. After starting on the ART, such individuals were able to lead normal lives once again. They gained physical health and could engage in economic activities such as weaving, pottery, carvings, doing small trade of fruits and vegetables, being domestic workers in the neighbouring estates such as Langata, Woodley and Jonathan Ngeno in order to generate an income for their families.

Such individuals were also able to engage in social life in the society as a result of the regained physical health. Consequently, they were once again able to participate in usual societal lives which include living an active sexual life, having sexual partners, bearing children and even starting and bringing up families.

## CHAPTER SIX

## CONCLUSIONS AND RECOMMENDATIONS

### 6.1 Introduction

The general objective of the study was to investigate the sexual behaviour of people living with HIV and AIDS after regaining health through ART. The specific objectives of the study were to examine the challenges faced by people living with HIV and AIDS in expressing their sexuality; to explore practices that influence sexual pleasure and desires of people living with HIV and AIDS and finally; to determine the reproductive goals of people living with HIV and AIDS such as marrying, re-marrying and having children after revitalization to health by ART. The findings in regard to each specific objective is then summarized and conclusions drawn. Finally, recommendations are also spelled out.

### 6.2 Conclusions

The study established that people living with HIV and AIDS encounter difficulties when seeking partners for a long time relationship. Society stigmatizes those who are living with HIV and AIDS does not expect them to have a sexual relationship because people associate them with propagating the spread of HIV. It is this kind of stigma that leads to people living with HIV and AIDS to avoid disclosing their HIV status to other people.

Adhering to protective sex was also found to be challenging among people living with HIV and AIDS. Use of condom was hindered by social cultural beliefs that condom was for partners who were not intimate or had several other sexual partners. This hampered the use of condom further in committed relationships and marriages. It was also found from the study that women's engagement in protective sex was largely dependent on the willingness of the man to use protection. Female condoms which could empower women to engage in protected sex were however not readily available and affordable as the male condoms were. Discordant relationships were found to be more challenging than when both partners are HIV positive.

When it was the man who was HIV positive in such relationships, it was more likely not to break up than when it was the woman who was the HIV positive partner.

It was further found that ART created an increase in the desire for sexual activity among people living with HIV and AIDS due to its wide components that includes but not limited to nutrition, counselling and sometime ARVs. From this study, it was concluded that in as much as ARVs rejuvenates the physical body, its use alone without the other components of the ART was not enough to resurrect fully the sexual lives of its recipients. Penetrative genital sex was also found to be the ultimate source of sexual pleasure for most people. Non-penetrative sexual pleasures were not thought to gratify sexual desires. The appreciation of the later could however be realized through cultural change by the youth generation.

It was further revealed that childbearing and marriage were aspirations held by some individuals who had benefited from ART. These are notably life aspirations that each person would desire to fulfil in a lifetime despite their HIV status. However, those who had children and had been married at one time in life no longer aspired to have more children or to get into a marital relationship despite having a renewed health from the use of ART.

Despite the challenges facing people living with HIV and AIDS in expressing their sexuality, they still have ways of keeping their sexuality alive by forming social support systems through which they can exchange ideas on various problems they encounter from a stigmatizing society. As agents, they have coined their own social arenas which are the support groups where they can talk freely on issues of sexuality without being condemned by HIV negative people who know their status.

### 6.3 Recommendations

Based on the study findings, the following recommendations are made:

- Further investigation should be carried out to explore the challenges faced by discordant couples in their marital life. The study should find out how discordances are handled across gender among couples. This should shade more light on why women
whose sexual partners are HIV positive chose to stay in their relationships while men are likely to abandon the same.
- A study should be done to find out how people living with HIV and AIDS think they can help in sensitizing the general public and how they can be integrated in HIV control and prevention programs.
- Support groups that target the youth should also be established to cater for the sexuality education for these young adults whose experience of sexuality is quite different from that of older people.
- Investigation should be done on the process and procedure of disclosing a person's HIV status. This should shade more light on who is the first person to be disclosed to and how do they respond? How does the other partner react upon disclosure of the HIV status of their partner? How does this vary across gender?


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## APPENDICES:

## APPENDIX I: QUESTIONNAIRE FOR SEXUALITY OF ART CLIENTS IN KIBERA, NAIROBI

Good Morning/Afternoon,

My name is Milka Nyariro from the University of Nairobi. I am conducting a study on sexuality of people on antiretroviral therapy in Kibera, Nairobi. This is in partial fulfilment for my Master of Arts in Anthropology degree at the Institute of Anthropology, Gender and African Studies of the University of Nairobi. This study aims to establish how people living with HIV/AIDS in Kibera slums and are on ART express their sexuality as a way of promoting a healthy and responsible sexuality among the people living with HIV and AIDS in this informal settlement. This is as a strategy for promoting responsible sexuality in Kibera slums as one of the ways of fighting HIV and AIDS in the area. The study findings will be recommended to the relevant Non-Governmental Organizations, Faith Based and Community Based Organizations who work toward the control of the spread of HIV/AIDS and promotion of responsible and pleasurable sexuality within the Kibera slums. I kindly request if you could participate in the study.

Do I have your consent?

1. Yes
2. No

## SECTION 1: DEMOGRAPHIC INFORMATION

Date-

Questionnaire no

1. Name (optional)
2. Age
3. Gender
(a) Male
(b) Female
4. Area of residence-
5. Marital status
a) single
b) married
c) separated/divorced
d) widowed

## SECTION 2: SOCIO-ECONOMIC INFORMATION

6. What is your highest level of Education?
(a) Primary
(b) Secondary
(c) College/Tertiary
(d) University
7. What is your occupation?
8. What is your income per month? Ksh $\qquad$

## SECTION 3: CHALLENGES FACED BY PEOPLE LIVING WITH HIV/AIDS

## AND ARE ON ART IN EXPESSING THEIR SEXUALITY

10. How many children do you have? $\qquad$
11. Would you like to have children in the future?
a) Yes
b) No
12. Please give your reasons for the answer above.
13. Have you discussed with your partner about having children in future?
a) yes
b) no
14. What did you agree on?
a) to have children
b) not to have
c) not agreed
15. What method would you prefer to use to have children putting into consideration your HIV status?
a) natural method
b) Caesarean method
c) not decided
d) adoption
16. What measures do you have to take before having children as a person living with HIV and is now on ART?
17. What challenges do you face in your sexual life due to your HIV status?
$\qquad$
$\qquad$
$\qquad$
$\qquad$
$\qquad$
18. Please state some of the reproductive goals that you find challenging to fulfil because of your HIV status?
$\qquad$
$\qquad$
$\qquad$
19. Is there any type of sexual conduct that you cannot engage in with your partner as a result of your HIV status?
(a) Yes
(b) No
20. If yes above, please state below.
$\qquad$
$\qquad$
$\qquad$
$\qquad$
21. Are there any challenges that you face when choosing a long time partner?
(a) Yes
(b) No
22. If yes, please state.
$\qquad$
$\qquad$
$\qquad$
$\qquad$
23. Are you aware of the HIV status of your current partner?
(a) Yes
(b) No
24. Give your reasons for the answer above
$\qquad$
$\qquad$
$\qquad$
$\qquad$
25. In your opinion, what are the challenges of having a HIV negative partner?
$\qquad$
$\qquad$
$\qquad$
$\qquad$
26. Give suggestions on how to handle the above challenges.
$\qquad$
$\qquad$
$\qquad$
$\qquad$
27. How often do you engage in protective sex?
(a) Never
(b) Rarely often
(c) Often
(d) Quiet often
(e) Always
28. Which of the following do you practice to protect yourself against contracting new strains of the virus?
(a) Use of condoms
(b) Having one partner
(c) Abstaining from sexual conduct
(d) Other (specify)

## SECTION 4: SEXUAL PLEASURES, DESIRES AND REPRODUCTIVE GOALS OF PEOPLE LIVING WITH HIV AND AIDS

28. What can you rate your sexual desire to be after being put on ART?
(a) Low
(c) Moderate
(d) High
29. As a person living with HIV, how can you get sexual pleasure and satisfaction without exposing yourself to re-infection?
$\qquad$
$\qquad$
$\qquad$

30a. Is a person's HIV status of importance when looking for a long time partner?
(a) Yes
(b) No

30b. What would you prefer your prospective partners' status to be?
(a) HIV positive
(b) HIV Negative
(c) Either positive or Negative
(d) Not decided
31. In what ways has your HIV status affected the way you experience sexual desire and pleasure?
$\qquad$
$\qquad$
$\qquad$

32 In your opinion, has ART increased your sexual desire?
(a) Yes
(b) No

32(b) Give your reasons for the answer above
$\qquad$
$\qquad$
$\qquad$
33. What are some of the reproductive ambitions that you wish to achieve after regaining health through ART?
$\qquad$
$\qquad$
$\qquad$
34. Given that you are HIV positive, would you wish to have children in the future?
(a) Yes
(b) No

34b. If yes, please state your reasons.
$\qquad$
$\qquad$
35. What step would you take if you lost your long term partner?
(a) To remarry
(b) To remain single
(c) Other (specify)
36. Give reasons for your answer above
37. How can you achieve your sexual and reproductive goals without exposing yourself to reinfections? (Explain)
38. What are your sexual and reproductive rights that you feel the society does not allow you to express as a result of your HIV status? (State)

## THANK YOU

## APPENDIX II: NARRATIVE GUIDE FOR (PLWHA) AND ARE ON ART

1. As person living with HIV, what are the ambitions that you would like to fulfil especially after regaining health and strength from the antiretroviral therapy?
2. What are the positive effects of ART on your sexual and reproductive life?
3. What sexual and reproductive activities are you able to engage in as a result of the health benefit of ART?
4. What measures do you take to ensure that you do not get infected with new strains of the virus?
5. How did you learn about such measures?
6. As a person on antiretroviral therapy, how do you experience sexual pleasure and desire without getting re-infected?
7. What effects have the ART had on your sexual desires?
8. What are some of the ways that one can use to give/receive sexual pleasure to their partner?
9. What part of your sexual and reproductive rights do you think you are not able to exercise due to your HIV status?

## THANK YOU

## APPENDIX III: INTERVIEW GUIDE FOR KEY INFORMANTS

1. In your opinion, what are the effects of Anti retroviral therapy on the patients' sexual and reproductive desires?
2. In your own experience what are the reported changes in the sexual and reproductive life of a patient that are thought to be a result of antiretroviral therapy?
3. What are some of the life aspirations that people living with HIV pursue after regaining health through ART?
4. What are the challenges posed by these aspirations to the health of the patients?
5. Is sexuality education part of the Anti retroviral therapy?
6. How do you advice the discordant couples on how to get children if they so desire and at the same time practice safe sex?

THANK YOU

## APPENDIX IV: FOCUS GROUP DISCUSSION GUIDE

1. Briefly discuss the life aspirations that one is able to pursue after regaining health because of ART.
2. What is your view on having children by HIV positive people who are on ART?
3. What different kinds of discrimination is one likely to face as a result of being HIV positive?
4. What is the importance of protective sex as a person on ART?
5. Marriage is an important social function an individual is expected to fulfil in the society, what is your view on marriage for people living with HIV/AIDS?
6. Do you think the task of procreation of procreation is worth pursuing for people on ART?
7. Discuss the general challenges in the daily sexual and reproductive lives of people living with HIV/AIDS.

## THANK YOU



