# EXPERIENCES AND COPING STRATEGIES OF ADOLESCENTS LIVING WITH HIV IN KANYAMA COMMUNITY, LUSAKA PROVINCE: ZAMBIA

BY

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# DECLARATION

I, **Mukena Linyaku** declare that this dissertation submitted to the University of Zambia as partial fulfillment of the award of the degree of Master of Public Health (Health Promotion and Education) is my own work and has not been submitted either wholly or in part for another degree to this University or any other or Institute of higher education.

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# CERTIFICATE OF COMPLETION OF DISSERTATION

The undersigned certify that they have read the dissertation and are satisfied that it is the original work of the author under whose name it is being presented.

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# CERTIFICATE OF APPROVAL

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## ABSTRACT

### Background

HIV is a cross-cutting problem which does not only affect adults but also affects adolescents. The number of adolescents living with HIV is increasing due to the provision of Highly Active Antiretroviral Therapy (HAART) which enables them to live longer yet little is known about their experiences and the strategies they use to cope with their condition. Such knowledge could help HIV programs to better respond to their needs and help them to cope effectively.

### Methods

This qualitative study examined the experiences of adolescents living with HIV in Kanyama Community in Lusaka, Zambia. It used a phenomenological study design which focuses on the human experiences. The sampling approach which was used to select the sample of the study was purposive sampling. Data was collected using in-depth interviews with 24 adolescents living with HIV. Data was coded using NVIVO and analysed using thematic analysis. Thematic analysis was used to draw out adolescents' feeling and experiences of being HIV positive and to explore the coping strategies used by adolescents at Community level.

### Results

The three dimensions of the disclosure are disclosure to adolescents, adolescents disclosing to others and caregivers disclosing on behalf of the adolescents (third party disclosure). Most adolescents felt bad while a few felt good after knowing their status. Few disclosed to family members. All the girls and few boys were comfortable with third party disclosure and only a few boys were not comfortable with it. With regards to experiences with health services: all the girls appreciated the use of drugs. Both girls and boys had concerns about antiretroviral therapy services provided during weekdays. All participants were in good terms with health care providers. Regarding experiences with other people in society, some participants were taken care of by their family members while a few experienced stigma from peers and family members. Adolescents were able to cope using resilience, non-disclosure, spiritual intervention and the use of supportive systems.

### Conclusion

Adolescents had various experiences with regard to disclosure. Few girls and boys disclosed their status to biological parents and immediate caregivers. Some adolescents were not comfortable with third party disclosure while a few did not have problems with it. Health care services provided during the week when they were expected to be in class posed a challenge. Understanding adolescents’ experiences and what helps them to cope with their condition will help in adopting interventions that bring out positive experiences while mitigating negative ones. This would strengthen the provision of services tailored to the needs and circumstances of adolescents living with HIV in Zambia.

# DEDICATION

This dissertation is dedicated to my mother, Nambula and my late father Mr. Linyaku Imakumbili who made it possible for me to be who I am. To my beloved husband, Liwanga Simasiku, my children Monde, Nambula, Joseph and Nakubiana who were patient and understanding during the time that I was busy conducting this study.

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Above all, I thank Jehovah God for giving me the determination to undertake the research study successfully.

# LIST OF ABBREVIATIONS

AIDS : Acquired Immune deficiency Syndrome

ALWHIV : Adolescents living with HIV

ART : Anti-Retroviral Therapy

ARV : Antiretrovirals

CBO : Community Based Organisation

HIV : Human Immunodeficiency Virus

NGO : Non-Governmental Organisation

UNAIDS : United Nations Programme on HIV and AIDS

UNICEF : United Nations Children's Emergence Fund

UNZA : University of Zambia

WHO : World Health Organisation

# LIST OF TABLES

## TABLE OF CONTENTS

## CHAPTER THREE: METHODOLOGY ……………………………………………… 12

# CHAPTER ONE: INTRODUCTION

## 1.0 Introduction

Globally, about 3.2 million children were living with HIV and 120,000 adolescents aged 10-19 died of AIDS in 2013 (UNICEF, 2014). More than 60 per cent of all young people living with HIV are young women and 72 per cent of them are in sub-Saharan Africa. This shows that Africa has a burden of female young people living with HIV (UNICEF, 2011).

Recent information of mortality ratio among adolescents shows that there is an increase of 50per cent between 2005 and 2012. Adolescent boys aged 15-19 recorded 75per cent of Mortality rate which is much higher (UNICEF, 2014).

According to UNAIDS/UNICEF (2014), the Zambia Demographic Health Survey estimated a population of adolescents aged 10-19 to be 3,479,000 by 2013. Out of that number, 79,000 was an estimated number of adolescents living with HIV and 3,900 were estimated AIDS-related deaths.

Adolescents were not left out from the interventions provided to people living with HIV. They benefited from counselling and ART services provided in healthy facilities (Mburu *et al.*, 2014b). Sexually active adolescents also benefited from screening and treatment of opportunistic infection including condom distribution. However, these interventions provided for people living with HIV were not really tailored to meet the needs of the adolescents living with HIV in Zambia (Hodgson *et al.*, 2012).

## 1.1 Statement of the Problem

The number of adolescents living with HIV was 79,000 (UNICEF 2011 and 2014), who were living longer because of the provision of Highly Active Antiretroviral Therapy (HAART). Antiretroviral Therapy (ART) was an intervention which was given to expectant mothers in order to prevent Mother to Child Transmission of HIV. It was also given to people living with HIV for treatment purposes in order to reduce the viral load and increase the Cd4 count.

HIV-infected adolescents had a lot of issues which led them to depression. Some of them experienced stigma and discrimination from peers and family members (Martinez *et al.*, 2012b, Tanney *et al*., 2012). They were also at risk of unprotected sex and treatment to non-adherence (Steele *et al*., 2007).

In Zambia, the estimated number of adolescents aged 10-19 were 3,479,000 and out of that population, 79,000 were living with HIV (UNICEF, 2014). Despite having a large population of adolescents living with HIV, there was no policy for adolescents in Zambia.

A qualitative study was done in Zambia on adolescents to explore the experiences of adolescents living with HIV (ALWHIV) aged 10-19. It was done in three districts; Kalomo, Lusaka, and Kitwe. In Lusaka, it was done at Chelstone and University Teaching Hospital (UTH). Chelstone was a low-density population and medium income so their experiences and coping mechanism may differ from those in high density and low-income areas like Kanyama community where the study was conducted (Mburu *et al*., 2014b).

Most of the interventions provided for people living with HIV were planned and implemented without information on the situation of HIV-infected adolescents (Mburu *et al*., 2013). Less attention had been directed to understanding their experiences and how they cope with their circumstance so there was need to improve interventions by doing more studies on adolescents living with HIV. This study addressed the experiences and coping strategies of adolescents living with HIV in Kanyama Community.

### 1.2 Justification of the Study

The findings of the study will contribute to knowledge about the experiences and coping strategies of adolescents living with HIV. It will help to understand the experiences in order to develop practical interventions which will be effective for HIV-infected adolescent’s needs. Policy makers will be able to develop policies based on informed knowledge of ALWHIV. Health care providers will provide services tailored to the needs of adolescents living with HIV, therefore, contributing to health promotion.

### 1.3 Research Questions

The following were the research questions:

1. What are the experiences of adolescents living with HIV with regard to disclosure and significant others?
2. What are experiences of adolescents living with HIV with regard to health services and service providers
3. What coping strategies are available to HIV-infected adolescents?

## 1.4 Study Objectives

### 1.4.1 General Objectives

The general objective of the study was to explore experiences and coping mechanisms for adolescents living with HIV in Kanyama Community.

### 1.4.2 Specific Objectives

1. To explore adolescents’ feelings and experiences of being HIV positive at the community level.
2. To understand the experiences of adolescents living with HIV with regard to HIV services and service provider.
3. To explore the coping strategies used by adolescents living with HIV.

# CHAPTER TWO: LITERATURE REVIEW

## 2.0 Introduction

This chapter reviewed literature presenting qualitative evidence on experiences and coping strategies for adolescents aged 10-19 living with HIV in Zambia and elsewhere. There are two major themes which guided this review. The first theme was the experience that these adolescents had with regard to knowing and understanding their status. This helped in understanding how they experienced stigma and discrimination, social support, taking antiretroviral therapy and disclosure of their status. The other theme was the coping mechanisms which enabled them to endure their situation. Spiritual intervention, non-adherence, treatment, support and other relevant strategies were searched from literature.

## 2.1 Experiences of Adolescents Living with HIV

Adolescent period is a challenging time and this is even more for adolescents living with HIV. Although children with HIV are living longer, healthier lives and reaching adolescence as a result of increased access to Antiretroviral Therapy (ART), little has been done in Zambia to examine how they feel about being HIV positive (Hodgson *et al*., 2012).

### 2.1.1 Disclosure

Disclosure of one's HIV diagnosis may be one of the most challenging experiences for HIV-positive adolescents. It is common for adolescents to experience feelings of shame and guilt regarding their infection. The feelings of shame may result in isolation, fear, discrimination, and depression (Orban *et al*., 2010, Mason *et al*., 2011, Isaac and Fred, 2009). Adolescents need support and understanding of their condition for them to make a decision to disclose to family members, friends and sexual partners (Johnson and Neilands, 2007, Conner *et al*., 2006).

The people responsible for facilitating the disclosure of the adolescent's HIV status to important people in the youth's social and personal network must identify in advance benefits and barriers to disclosure. Most caregivers disclose inappropriately leading to internalised stigma and depression (BUSCH *et al*., 2007, Gourlay *et al*., 2013, Mburu *et al*., 2014b).This study ensures effective ways of handling disclosure process are documented.

The process of disclosure of HIV status is very important in people living with HIV. It is even more complex when children are involved because of concerns about children's emotion and ability to cope with the illness, stigma, family relations and concerns about social support. On the other hand, there are risks of disclosure which include loss of economic support, blame, abandonment, physical and emotional abuse, discrimination and disruption of family relationships (Seidenberg *et al*., 2012, UNICEF., 2011, Tanney *et al*., 2012).

World Health Organisation has developed guidance for healthcare workers on how to support children under 12 years of age and their caregivers on disclosure of HIV (Organisation, 2011).

Adolescents who have been told about their own HIV-positive status may be in a better position to access antiretroviral therapy (ART) from health facilities and adhere to treatment since they know the benefits of taking the drugs correctly. Finally, they are able to acquire psychosocial support from peer support groups (Hall *et al*., 2012).Explaining  to the adolescents that they have HIV fulfills their right to know about their own health and it may improve their adherence to ART, retention to care and prolong their life (Mason *et al*., 2011).

Adolescent's voluntary disclosure of HIV status can bring beneficial results for the individual, family and sexual partners (Wodi, 2005). Benefits like sharing of personal information and disclosing to a sexual partner for prevention purposes.

Other benefits are; an improvement in adherence to ART, access to health care and lower social related stigma (Berger *et al*., 2001).

The study done in Zambia by Mweemba focused on enablers, barriers, and processes of disclosure of HIV status by caregivers to adolescents in a rural district, it revealed that 17 out of 30 caregivers disclosed to adolescents (Mweemba *et al*., 2015).This shows that the disclosure rate to adolescents is low.

Another study was done in Kenya to determine the impact of paediatric antiretroviral therapy adherence, child well-being, and social relationship. It described the views of 120 parents and guardians of HIV-infected children aged 0-14. The findings revealed that out of the 120 parents and guardians, 118 of them did not disclose to adolescents. As much as they believed that disclosure might improve ART adherence and contribute to engagement to the social network, they were scared of negative psychological effects on children and negative social effects for their families which includes discrimination (Vreeman *et al.*, 2010). In this study, disclosure rate was very low.

### 2.1.2 Stigma and Discrimination

Challenges of living with HIV and AIDS were directly connected to the disease itself, such as adherence to antiretroviral therapy, resistance to medical treatment and mental ability to deal with the disease itself. Another challenge was stigma, which prevented adolescents from obtaining proper care (Conner *et al.*, 2006).

In Columbia, a study was done to explore personal and psychological experiences of ALWHIV from Burgess Clinic. The Clinic was dedicated to educating and treating adolescents to prevent the spread of HIVand AIDS. The researcher used Focus Group Discussions (FGDs) and semi-structured interviews to collect data from the participants. Themes used were social support, disclosure, HIV-related needs and challenges, and the role of spirituality in coping with their situation. The result of the study showed that youths need support from family, peers, teachers, health care providers and the clergy (Conner *et al.*, 2006).

Studies have shown that stigma and discrimination were something that affects people living with HIV. It was even worse with adolescents who need to deal with their changing bodies and developing sexuality. Stigma can either be internalised or imposed by significant others (peers, friends, and relatives). It could be related to receiving an HIV result which can even result in depression (Rao *et al.*, 2007, Tanney *et al.*, 2012, Martinez *et al.*, 2012b).

A qualitative study was done in Zambia on adolescents to explore the experiences of adolescents living with HIV (ALWHIV) aged 10-19 in Kalomo, Kitwe, and Lusaka. Focus group discussions and in-depth and semi-structured interviews were used to collect data from 111 participants. Participants aged 10-17 orally indicated their assent to participate while their parents signed consent forms. Those who were 18 and 19 years signed their own consent forms since the legal age of consent in Zambia is 18 years. The participants comprised of ALWHIV, health care providers and parents. Thematic analysis was used to draw out the experiences of ALWHIV at individual, family and peer, community and structural levels (Mburu *et al.*, 2014b)

Results revealed that the experiences of ALWHIV were determined by a range of factors located at the individual, family and peer, community and structural levels (Mburu *et al* 2014).

Individually, adolescents were affected by the resilience and internalised stigma. At family and peer, level-adolescents were supported by family members and friends to adjust to new drug taking routines though occasionally these people disclosed adolescents' HIV status inappropriately. It could be poor, delayed or disclosing to a third party without the consent of the adolescent involved. At the community level, school going adolescents' experiences were negatively affected by stigma and discrimination in schools. At the structural level, poor flexibility of clinic opening hours, staff shortage and a lack of health policies related to ALWHIV presented ongoing limitations to adolescents' ability to access relevant services (Mburu *et al.*, 2014b).

Out of the studies done in Zambia on adolescents aged 10-19, one focused on sexual reproductive health (Mburu *et al.*, 2013) and the other determined their experience of being HIV positive (Mburu *et al*., 2014b). The findings showed that adolescents had a lot of burning issues which needed to be sorted out. The studies further revealed that adolescents had different experiences at the individual, home, school, neighbourhood, community, and societal levels.

The above study concentrated on experiences of adolescents living with HIV but ignored the strategies which enabled them to cope with their condition. The study was done in Kalomo, Lusaka, and Kitwe. In Lusaka, it was done at Chelstone and University Teaching Hospital (UTH). Chelstone is a low-density population and medium income so their experiences and coping mechanism may differ from those in high density and low-income areas like Kanyama community where the current study was conducted.

### 2.1.3 Taking Antiretroviral Therapy and Side Effects

A qualitative study was done in Zambia to explore psychosocial, sexual and reproductive health (SRH) needs of ALWHIV aged 10-19 and to identify the gaps between the needs and existing services. Semi-structured interviews and FGDs were used to collect data from 111 participants. Results discovered that social networks had a significant impact on treatment adherence and assisted adolescents in coming to terms with an HIV diagnosis. Adolescents wanted to know SRH and HIV information, but service providers did not adequately meet these informational needs. ALWHIV require effective, targeted and sustainable HIV services to find the way safely through adolescence (Hodgson *et al*., 2012).

Antiretroviral therapy (ART) is a lifelong treatment which is not easy to adhere to, especially adolescents who still have a long way to go in life. It really takes courage and determination to continue taking drugs for life. The length of treatment worries them, as a result,they end up not adhering to treatment which leads to treatment failure and disease progression (Martinez *et al*., 2012b, Tanney *et al*., 2012).

Adolescents living with HIV were concerned about the side effects of ART which ended up disfiguring their bodies and this contributed to poor adherence (Johnson and Neilands, 2007)

### 2.1.4 Social Support

A supportive system is an expressed need of people living with HIV and AIDS. They need to get support from their families and peers, healthy, emotional attachments, and basic living necessities, spiritual and psychosocial outlets (Mburu *et al*., 2014b).

Adolescents living with HIV were concerned with social support which was significant to their survival, coping and general livelihood (Steele *et al*., 2007, Martinez *et al.*, 2012b). Positive results for many HIV-positive youths were attained with the presence of informed, non-judgmental understanding and reliable support systems. Negative results were associated with the absence of the support systems (Conner *et al*., 2006).Therefore, there is need to strengthen support systems at family and community levels.

In 2012, a qualitative study was done on the Latino youths living with HIV aged 16 -24 to determine the sources of stressors and how they cope with their stressors. In-depth interviews and FGDs were used to collect data from 30 participants. Themes developed were an initial psychosocial response to HIV diagnosis, disclosure, stigma, body image and concerns about the physical changes associated with HIV and ART, taking ART and side effects, disruption of future life goals and reproductive health concerns (Martinez *et al.,* 2012a).

Results revealed that anger and depression, struggle to disclose or not, HIV stigma, rejection by friends and relatives, changes in body image due to side effects, disruption of future goals and reproductive health worried the youths (Martinez *et al*., 2012b).

Mwai and Martinez acknowledge that adherence supporters play a major role in visiting people living with HIV to remind them of their clinical and pharmacy visit. This was achieved through the collaboration of Health facilities and Community Based Organisations (CBOs) which was working effectively in Zambia (Mwai *et al.*, 2013, Mburu *et al.*, 2014b).

A family which was the smallest unity in the community had a potential to support adolescents living with HIV effectively, especially if they were aware of the adolescents' HIV status. Family members helped in reminding the adolescent about adherence to treatment and care. They provided psychological and financial care in order to ease the burden of living with HIV (Rao *et al.*, 2007, Wodi, 2005).

### 2.2 Coping Strategies of Adolescents Living with HIV

HIVand AIDS are associated with social, psychological and behavioural stressors that really affect coping patterns and health status. It is common for people faced with a life-threatening illness to search for meaning, understanding and coping mechanisms to deal with their circumstances.

The Columbian study on Latino youths revealed that despite experiencing challenges, they gained an appreciation of what matters in life by adopting achievable goals in life and relying on religion and spiritual beliefs for health outcomes (Martinez *et al*., 2012b).

#### 2.2.1 Spiritual Intervention

The coping search for meaning often leads some to search for spiritual and religious answers. They rely on religion and spiritual beliefs for health outcomes. This enables them to pray to their God for divine direction and help to endure their condition. For some, their spirituality or religiosity serves as a protective factor and contributes to their ability to cope effectively with their HIV status (Abrahams and Jewkes, 2012).

Conner and others support the ideas of Abraham and Jewkes on the role of spirituality and religion as a coping mechanism of ALWHIV in Columbia. Individuals' attribution and faith had an impact on their mental health, disease progression and long-term survival (Conner *et al*., 2006), so there was need to talk to adolescents living with HIV in order to allow them to explore various coping strategies which could help them to live positively with their condition.

Most adolescents experienced stigma but had resources to resist and cope with the stigma which helped them to cope with their situation (Jena, 2014).They were strategic about who they disclosed to and who they  asked for help.

### 2.2.2 Non-disclosure

According to Fair and Albright (2012), some adolescents opted to keep their status as a secret in some situations in fear of rejection as a coping mechanism. Others used knowledge gained through treatment system to care for themselves and developed self-esteem that protects them against stigma (Wodi, 2005).

### 2.2.3 Treatment

Adherence counselling offered at the ART department empowered adolescents living with HIV with information on the effects of treatment like the capacity to prolong life. This became a source of comfort and enabled someone to cope with the situation especially those who would want to be parents in future (Hall *et al*., 2012, Jena, 2014).

### 2.2.4 Social Support

Open family conversations about HIV helped some adolescents to cope with individual and interpersonal stigma in order to live positively (Fielden *et al.*, 2011).

Family and peers supported HIV-infected adolescents to adhere to treatment and care and this helped adolescents to strive with their condition (Gitau Mburu *et al*., 2013).

The presence of Non-Governmental Organisation (NGO) enabled adolescents to cope with their situation through nutritional and psychosocial support (Mburu *et al.,* 2014b).

### 2.2.5 Other Coping Strategies

Adolescents varied in the way they coped with HIV. Some opted to listen to music, thinking of someone they care about, sleeping, trying on their own to deal with their problems, watching Television and daydreaming (Martinez *et al*., 2012b). A few preferred a low utilisation of alcohol and illicit drugs.

## 2.3 Summary of the chapter

The literature was reviewed to gain more understanding of experiences and coping strategies for ALWHIV. It revealed that adolescents living with HIV encountered a lot of issues like stigma and discrimination, depression, drug side effects, pill burden and the challenge of taking drugs for life. Despite encountering such problems, they were still able to cope with their circumstance through the use of spiritual intervention, non-disclosure, support and other coping strategies.

Thematic analysis was used to draw out the experiences of ALWHIV at individual, family, peer, community and structural levels (Mburu *et al.*, 2014b). Results revealed that the experiences of ALWHIV were determined by a range of factors located at the individual, family peer, community and structural levels (Mburu *et al., 2*014b).

Individually, adolescents were affected by the resilience and internalised stigma. At family and peer, level, adolescents were supported by family members and friends to adjust to new drug taking routines though occasionally these people disclosed adolescents' HIV status inappropriately. The disclosure could be poor, delayed or disclosing to a third party without the consent of the adolescent. At the community level, school going adolescents' experiences were negatively affected by stigma and discrimination in schools. At the structural level, poor flexibility of clinic opening hours, staff shortage and a lack of health policies related to ALWHIV presented ongoing limitations to adolescents' ability to access relevant services (Mburu *et al.,* 2014b).

The current study explored the experiences of adolescents after disclosure and the coping strategies applied in order to enable them to cope with their situation (Mburu *et al*., 2014b).

The two studies done in Zambia concentrated on experiences of ALWHIV and ignored how to deal with the effects of disclosure such as stigma from friends and family members.

# CHAPTER THREE: METHODOLOGY

## 3.0 Introduction

This was a qualitative study. Adolescents aged 10 to 19 living with HIV and aware of their HIV status were purposively selected. In-depth interviews were used to gather data on their lived experiences and coping mechanisms, regardless of whether they are on ART or not.

## 3.1 Study Design

It was a phenomenological study which focused on the experiences of adolescents living with HIV. Phenomenology includes discovering, analysing, clarifying and seeking patterns of certain phenomena based on individual's daily life experience. It emphasised on describing the meaning of several individual's perceptions, feelings and lived experiences in order to have a deep understanding of the phenomena (Lewis, 2015). Respondents were given an opportunity to discuss the topic in their own words. A phenomenological approach was relevant for this study because its major focus was to describe and to understand lived experiences and coping strategies of adolescents living with HIV (Zulu *et al.*, 2014).

## 3.2 Study Setting

The study was conducted in Kanyama Community. Kanyama community was purposively selected because it had a good number of adolescents living with HIV and belonged to a support group. Kanyama community had a catchment area of 161,151 people. The participants were drawn from Kanyama Clinic and Non- Governmental Organisation (NGO) known as Children International Zambia. Kanyama clinic offers voluntary counselling and testing to the general community. Those found to be HIV positive were referred to ART department, opened in April 2004, for further screening. Since inception, the ART department had enrolled 26,291 clients. Out of the enrolled clients, 1851 were children aged 0 to 14 years (PERFAR Quarterly, Facility-Based HIV Care/ART Reporting Form, 2014).

The ART department has a support group for people living with HIV known as Musayope (meaning do not be scared). The support group provided physical and emotional support to group members. The group members have meetings every Tuesday afternoon where they encourage each other through sharing their experiences and coping mechanisms.

The Clinic operates from Monday to Friday, On Wednesdays, a day specifically allocated to children, a meeting with the children is conducted as a support group to share their experiences and coping mechanisms, and afterward the children collect their ARVs. The support group comprises of children aged 18 and below as long as they are aware of their HIV status.

Children International Zambia is an NGO, which deals with vulnerable children (OVCs) aged 2-19 years. It provides food support and helps the children to find a sponsor for their education. Food is provided to children aged 2-12 while education sponsorship goes up to 19 years.Currently, 26 children living with HIV are on the Children International Zambia food support program.

### 3.3 Study Population and Target Group

The study population comprised of adolescents aged 10-19 living with HIV and were aware of their status. The adolescents were drawn from the support group of people living with HIV known as Musayope. Members of the support group met once weekly to share their experiences and coping strategies of living with HIV. They had disclosed their status and were able to talk about their condition within the support group without being ashamed. This reduced the risk of stigma. The interviews were conducted on the days that the support group meets to avoid attracting too much attention from other people if the meeting was called on a different day.

Adolescents belonging to the following categories were considered in the study; orphans and non–orphans, married and unmarried, school going and non-school going. In anticipation of experiences of girls and boys being different despite belonging to the same categories, four adolescents (two girls and two boys) were supposed to be selected from each category. This was not achieved because it was difficult to find an equal number of girls and boys in each category. Therefore, sex of the participants was limited to those available. Participants were drawn from two (2) identified points; facility level (Kanyama Clinic support group) and Community level (Children International Zambia).

### 3.4 Sampling Procedures

The sampling approach which was used to select the sample of the study was purposive sampling in which a predefined population was ideal because it was only going to cater for adolescents living with HIV and aware of their status.

The participants were selected from Kanyama ART department and the community-based organisation using maximum variation sampling which was a type of purposive sampling aiming at capturing the central themes that cut across participant variations like adolescents who are orphans and non-orphans, married and unmarried, school going and non-school going. Adolescents in each category had different experiences and coping mechanism which were vital to the study (Mburu *et al*., 2014b).

The researcher used the above categories for this study because the literature shows that ALWHIV had different experiences based on a range of factors located at the individual, family and peer, community and structural levels (Mburu *et al.*, 2014).

### 3.5 Sample Size

Adolescents belonging to the following categories were considered in the study; orphans and non–orphans, married and unmarried, school going and non-school going. Four adolescents (two girls and two boys) were supposed to be selected from each category. In anticipation that the experiences of young and older adolescents might differ, the two included young adolescents aged 10-14 and old adolescents aged 15-19. However, girls and boys had different experiences despite belonging to the same categories. The sample size was twenty-four (24) adolescents which was arrived at by selecting two boys and two girls from the six (6) categories.

### 3.6 Data Collection Methods

Data collection was done by the researcher, who had experience in qualitative data collection. In-depth interviews were used to collect data from adolescents living with HIV and a composite description of the essence of the experience for all of the individuals was developed. The description consisted of what and how they experienced the phenomena (Lewis, 2015).

#### 3.6.1 In-depth Interview

In conformity with the phenomenological approach, data was collected from adolescents living with HIV in Kanyama Community using in-depth interview guide (Zulu *et al*., 2014). Interviews were conducted at two places, Kanyama ART department, and Children International Zambia. Face-to-face in-depth interviews were conducted with adolescents living with HIV to determine their experience and coping strategies by using an in-depth interview guide. This data collection technique enabled adolescents living with HIV to tell their stories about their daily realities of life.

Interviews were conducted in English, Nyanja and Bemba which are common languages used in Lusaka. Interviews were recorded using a digital audio recorder. Nyanja and Bemba interviews were translated into English. In cases where the participants refused to have the interview recorded, detailed handwritten interview notes were taken and written in an interview notebook.

## 3.7 Data Analysis

A digital audio recorder was used to record the in-depth interviews and later transcribed the information into verbatim which was reviewed by all the authors involved in the study. Data was arranged and coded using NVIVO (version 10). Data was analysed using the thematic framework analysis which was a method used in identifying, analysing and reporting information in themes within the data collected from the participants. Thematic analysis was performed through the process of coding in six phases in order to create established, meaningful patterns. These phases were: familiarisation with data, generating initial codes, searching for themes among codes, reviewing themes, defining and naming themes, and finally producing the final report (Joffe and Yardley, 2004, Lewis, 2015).

### 3.7.1 Familiarisation with the Data

At this stage, the authors read and re-read the transcripts on experiences and coping patterns in order to understand the collected data while paying attention to patterns and occurrences.

### 3.7.2 Generation of Initial Codes

Initial codes were generated by documenting who (orphan or non-orphan) and how patterns occur in the various categories. The coding process was achieved by reducing data into labels in order to create categories for more efficient analysis. Here an inference on the meaning of the generated codes was done.

### 3.7.3 Searching for Themes among Codes

This stage involved combining codes into similar ideas that accurately depict the data and grouped together to form categories.

### 3.7.4 Reviewing Themes

The searched themes were later reviewed by critically looking at how the themes support the collected data when the analysis seemed incomplete.

### 3.7.5 Defining and Naming Themes

The categories were interpreted in order to determine the real meaning of the text. At the end of the analysis, the themes were cross-checked with the interview transcripts to check the validity of the data (Zulu *et al.*, 2014).

### 3.7. 6 Producing the Final Report

Finally, the report was written based on the data and relating themes.

## 3.8 Ethical Consideration

The purpose of the study was to explore the experiences and coping strategies of adolescents living with HIV in Kanyama community. HIV is a sensitive issue and it even became worse in this study because the focus was on adolescents. There were several ethical issues which were anticipated to be encountered during the study. The anticipated issues included approval, permission, informed consent, respect for participants and confidentiality, beneficence, autonomy, justice, and fairness. The issues were addressed as indicated below.

### 3.8.1 Approval

Ethical consideration was taken into account when conducting this research. The data collection only commenced after approval from ERES CONVERGE IRB (Ref.No.2015-June-021).

### 3.8.2 Permission

Permission to carry out the study was obtained from Lusaka District Health Office, Ministry of Community Development Mother and Child Health in charge of the study sites. Authority was also sought from Children International Zambia to carry out the study at their site in Kanyama community.

### 3.8.3 Informed Consent

The participants were informed about the purpose and nature of the study before the actual participation. The written informed consent was sought from the participants before they took part in the study. The participants, eighteen (18) years and above, were asked to sign a consent form based on rights of self-determination and full disclosure. Adolescents below the age of 18 signed an assent form while their caregivers signed a consent form.

Participants were not deceived or forced to take part in the study but they had a right to withdraw from the discussion at any stage. It was explained to them that whether they agreed or refused to take part in the study, their access to health care would not in any way be affected.

### 3.8.4 Respect for Participants and Confidentiality

Confidentiality was ensured throughout the entire research process. In the case of participants feeling uncomfortable to be seen by their peers participating in the study, privacy was maintained by talking to the participants in a room. The protection of participants' rights was a priority in the study. The participants were assured on the discussion that it would be conducted in a conducive environment. The information gathered was strictly confidential and the identity of the participants was anonymous as numbers were used instead of their real names.

To ensure anonymity and confidentiality of the participants, cryptogram (secret code) IDI and CI followed by a number were employed to present data. Codes starting with IDI represents participant drawn from the support group at Kanyama Clinic while CI represents participants from a Non-Governmental Organisation located in Kanyama Community.

### 3.8.5 Risks

HIV is a sensitive issue. In this study, it became more sensitive because the focus was on adolescents. Talking to them about their HIV status could have created anxiety and self-stigma. In order to reduce stigma, which could have resulted from participating in the study, interviews were conducted only on Wednesdays when children and adolescents met as a support group.

### 3.8.6 Beneficence

Participants were informed that there was no direct personal benefit for participating in the study. However, their responses were expected to generate information that would contribute to health care needs of adolescents living with HIV.

### 3.8.7 Justice and Fairness

All eligible research participants were given an equal chance to participate or decline. Those who opted out of the study were not subjected to unfair treatment on account of not taking part in the study.

## 3.9 Summary of the Chapter

It was a qualitative study which used phenomenological study design to explore lived experiences of adolescents living with HIV in Kanyama Community. Participants were purposively sampled from Kanyama ART department at Kanyama 1st level Hospital and Children International Zambia. In-depth interviews were used to collect data from adolescents aged 10-19 and the working sample was 24.

Data was audio recorded and transcribed into verbatim. NVIVO (version 10) was used to arrange and code the data.Thematic frame work was used to analyse the data.

# CHAPTER FOUR: REASERCH FINDINGS

## 4.0 Introduction

This chapter explores the experiences and coping strategies of adolescents living with HIV in Kanyama Community. It starts with a brief description of the participants followed by the presentation of the themes and sub-themes on experiences of adolescents living with HIV derived from the thematic analysis. In the presentation of the findings, verbatim quotations have been used to illustrate the themes and sub-themes.

## 4.1 Social-Demographic Characteristics

The researcher purposively included 24 adolescents who were living with HIV in Kanyama Community. The age of these participants ranged from 10 to 19. The 24 adolescents comprised of 15 males and 9 females, 14 were single orphans, 6 double orphans, 4 non-orphans, 21 School going, 3 non-schools going and none was married.

**Table 1: Characteristics and Sex of Adolescents**

| **Type of adolescents** | **Female** | **Male** | **Total** |
|---|---|---|---|
| Orphans | 7 | 13 | 20 |
| Non-Orphans | 2 | 2 | 4 |
| School Going | 8 | 13 | 21 |
| Non-School Going | 1 | 2 | 3 |
| Unmarried | 9 | 15 | 24 |

Table 1 indicates that more males (15) were interviewed than females (9). It also shows that all respondents were not married. Most of them (20) were orphans and (21) were still in school.

## 4.2 The Major and Sub-themes

The four major themes which emerged from the data were: experience with disclosure, relationship with significant others, experience with health services and coping strategies of adolescents living with HIV.

**Table 2: Selected Major Themes and Sub-themes**

| | **Major themes** | **Sub-themes** |
|---|---|---|
| **Experiences** | Experiences with disclosure | Disclosure to adolescents<br>Disclosure adolescents to others<br>Third party disclosure |
| | Relationship with significant others | Stigma from peers and family<br>Family support<br>Experience with teachers |
| | Experience of healthcare services | Experience with treatment<br>Health services<br>Healthcare, providers<br>Support group |
| **Coping strategies** | Resilience<br>Non-disclosure<br>Spiritual intervention | |
| | Social Support | Family members<br>Treatment<br>Healthcare, providers<br>Peers<br>Support group members<br>Teachers<br>Support from NGOs |

Table 2 above shows the major and sub-themes that were derived from the data.

Experience with disclosure included adolescents' feeling after knowing their status, adolescents' feeling after disclosing to others and their reaction to third party disclosure. Relationship with others includes adolescents 'relationship with peers, family and community members while experience with health services include adolescents' feelings with health care providers, drugs, and support group.

**Table 3: Major Themes by Sex**

| **Themes** | **Experience with Disclosure** | **Relationship with Significant others** | **Experience with Health Services** | **Coping Strategies** |
|---|---|---|---|---|
| **Girls** | Felt bad after knowing their status<br>Felt good after knowing their status<br>Felt good about the third person disclosure. | Stigmatised by peers and family members.<br>Cared by family members<br>Supported by teachers | Concerned with the provision of ART services during school days<br>Good terms with health care providers<br>Concerned about life-long treatment<br>Happy with the support group | Resilience<br>Treatment<br>Kept their status as a secret<br>Spiritual intervention<br>Support from family<br>Support from support group |
| **Boys** | Felt bad after knowing their status<br>Felt good after knowing their status<br>Disclosed to family members<br>Felt good about third party disclosure<br>Felt bad about third party disclosure | Stigmatised by peers and family members<br>Cared by family<br>Supported by teachers | Felt good about treatment<br>Concerned about drug fatigue<br>Happy with the support group | Resilience<br>Treatment<br>Kept their status as a secret<br>Spiritual intervention<br>Social support |

Table 3 shows the feelings of girls and boys with regard to their experiences and what helped them to cope with their negative feelings.

### 4.3 Experiences of Adolescents Living with HIV

The study revealed that adolescents had three major dimensions of experiences that emerged from the study. These include experience with disclosure, the experience of health services and experience with significant others.

### 4.3.1 Experience with Disclosure

Adolescents' experiences with disclosures reflected three sub-themes. These are disclosure to adolescents, adolescents disclosing to others and third party disclosure.

### Disclosure of HIV Status to Adolescents

Adolescents need to know their HIV status in order to take responsibility for their lives. It is only through disclosure that adolescents living with HIV can be aware of their status. Without disclosure, adolescents will continue experiencing adherence problems and end up progressing to AIDs.

The research findings show that adolescents had different feelings after they learned about their status. Some of the girls and boys were annoyed and cried after receiving the news of being HIV positive. They felt betrayed by their caregivers for denying them their right to information about their own life. Some of the adolescents had this to say:

> *… I was annoyed when my grandmother told me about my HIV status … (19 years old boy).*
>
> *… That day I cried, I felt like I can't move on with life… (I8-year-old girl).*

Other girls and boys felt good after disclosure due to the fact that they were already on treatment which can help them to live longer. Disclosure empowered them with knowledge which enabled them to understand their situation and live positively in life.

> *It did not pain me much, I felt good because the person who is not taking drugs may die while the one on drugs may live longer (12-year-old boy).*
>
> *… I felt good since I am already on treatment… (15-year-old girl).*

### Adolescents Disclosing their HIV Status to Others

Disclosure of HIV status to others is vital to adolescents living with HIV because this helps them to gain physical and psychosocial support. It is through disclosure that adolescents can share their experiences with others and encourage each other.

Few girls and boys disclosed to biological parents or immediate caregivers. Out of those who disclosed their status only one disclosed to his friends and class teacher. This is what he said about the benefits of disclosure:

> *I felt good to disclose to my friends and my teacher because they encourage me to continue with life… (19-year-old boy).*

### Third Party Disclosure

Most of the adolescents who were tested for HIV at a tender age experienced third party disclosure where their caregivers disclosed their status to other people without their consent.

The findings of the study show that some girls and boys who experienced third person disclosure were comfortable with it. They said that there was nothing wrong with caregivers disclosing adolescent's status to relatives. Family members are vested with the responsibility of taking care of anyone in the family who is sick so they need to know the status of adolescents. They considered disclosure as a means to get support from other people when need arises as stated below:

> *I felt good for my relatives to know my status because if I become sick they can help me (16-year-old girl).*
>
> *I felt good because if my mother is not around those relatives aware of my status can escort me to the clinic… (10-year-old boy).*

Few boys interviewed did not like the idea of disclosing their HIV status without their permission. They felt that it was only their biological parents or their immediate caregivers in case of orphans who have the right to know their HIV status. Some of the adolescents were depressed about the action of their caregivers of disclosing their HIV status without their consent or assent. A male double orphaned adolescent aged 14 narrated what happened when one of their relatives disclosed his status and that of his sister to neighbours. This is what he said:

> *I felt bad when I realised that some of my relatives are aware of my status. One of my relatives disclosed our status to neighbours and my sister heard, she cried. I am scared that they may reveal my status to others (14-year-old boy).*

Overall, adolescents experience with disclosure indicates that both girls and boys had positive and negative experiences on disclosure. Some felt good while others felt bad when they were told about their HIV status. Most of them were comfortable to disclose to biological parents or immediate caregivers while a few disclosed to friends and teachers. Some girls and boys were comfortable with third party disclosure while a few did not like it.

### 4.3.2 Relationship with Significant Others

This section deals with adolescents' experiences with people who have an influence on their life in society. Those with influence include peers, family, and teachers.

#### Stigma from Peers and Family Members

Adolescents living with HIV are likely to experience stigma in form of rejection and discrimination from peers and family members because of their condition.

This study revealed that few adolescents experienced stigma including those who didn't disclose their HIV status to their peers. Their peers were inquisitive about their health especially when they become sick often. This is elaborated by a girl, who was stigmatised by her peers as she had this to say:

> *You know in the village when I come back from school, some schoolmates would ask about my HIV status so that they know everything. Fortunately, my grandmother threatened them that my other relatives will beat them. You will see them; they will take you to the police station so that you can tell them where you got the information. That's how they stopped. I really felt bad about the reactions of my schoolmates (16-year-old girl).*

Adolescents expect support from the family members but unfortunately what is happening in some families is contrary to their expectation. Few adolescents experienced stigma from family members regardless of gender. This contributed to the stress and depression experienced by adolescents living with HIV. The quote below explains how adolescents were stigmatised:

> *I went for a holiday and then started school in Grade Five. They were shouting at me. I felt bad… That's what they were saying, I felt bad, and the following day I*

> *packed my clothes so that I can start off. Before starting off, I was told to return the clothes they gave me and I came back to my father (12-year-old boy).*

### Family Support

A family is the smallest unit in the society which is able to contribute to the well-being of adolescents living with HIV. With family support, the adolescent can adhere to treatment and live longer.

The findings of this study show that the majority girls felt supported by their family members. They interacted well with their families and found comfort and encouragement from the family circle. The quotes below prove this point:

> *I enjoy being with my family because they take good care of me… (18-year-old girl).*

Similar issues also came from the majority of the boys. They acknowledged the support from family members.

> *We lead a normal life. Other family members treat me well… (15-year old boy).*

### Experience with Teachers

Teachers play a role in the life of a school going adolescents. Teachers have a responsibility of taking care of the pupils at the school, this includes their health and educational well-being. Few girls and boys disclosed their status to their teachers. The teachers were able to support the adolescents after knowing their status. They were supported by allowing them to join their peers in class despite coming later after visiting the clinic. This is what one said:

> *He allows me to join my classmates in class after collecting drugs from the clinic (16-year-old girl).*

> *…They really treat me well… (19-year-old boy).*

In summary, the study proves that more girls and boys experienced stigma from their peers and family while others enjoyed family support. Teachers as part of the community had a positive impact on both girls and boys at school.

### 4.3.3 Experience of Health Services

The study identified three sub-themes with regard to adolescents' experience of health care services. The sub-themes were adolescents' experience with treatment and health care services, relationship with health care providers and experience with a support group.

#### Experience with Treatment

Taking Antiretroviral Therapy (ART) is vital to adolescents living with HIV because it reduces the progression of the disease and promotes health. All the girls and few boys appreciated the use of drugs which enabled them to be healthy despite being HIV positive. Adolescents reported that they were experiencing good health due to treatment compared to the way they were before starting drugs. No one experienced side effects of the drugs. The statement below shows the feelings of adolescents taking ART in Kanyama Community.

> *I am fine. I no longer get sick as I used to be before starting treatment… (18-year-old girl).*
>
> *I feel good to take drugs because I am now healthy. I no longer gets sick as I used to be… (12-year-old boy)*

Antiretroviral Therapy (ART) is a lifelong treatment which is not easy to adhere to, especially for adolescents who still have a long way to go in life. It was reported that it takes courage and determination to continue taking drugs for life. Some of the girls had concerns about treatment despite taking their drugs. They were concerned about lifelong treatment as stated by the quotes below:

> *…Treatment makes me become healthy and I feel good about it. The only challenge is to take drugs for life… (15-year-old girl).*

Some boys had their concerns too. They were worried about drug fatigue.

> *I am getting tired of taking drugs daily throughout my life… (15-year-old boy).*

Each person has the right to interact with other people but some adolescents living with HIV were denied this right by their caregivers. This was revealed by a 16 years old female adolescent who explained her worst experience in life since she knew her HIV status. This is what she said:

> *I feel bad for mom to deny me a chance to visit because she thinks that I won't take my drugs… (16-year-old girl).*

**Health Services**

As much as both girls and boys have appreciated the effects of treatment, most of them were concerned about the time the services were provided. The provision of ART services during weekdays when school going adolescents are expected to be in class posed a challenge of striking a balance between accessing health services and attending classes. This contributed to poor performance due to low-class attendance as adolescents could not go to school the days they go to the clinic for either clinical or pharmacy visit. The study revealed that both girls and boys had concerns about ART services provided during weekdays. This is confirmed by the quote below:

> *I am not happy with the provision of ART services during the week because I do not go to school when I have an appointment to collect my drugs from the clinic… (15-year-old girl).*

**Relationship with Health Care Providers**

Health care providers include nurses, doctors, adherence counsellors, pharmacy technicians and all supportive staff working at the clinic.

All adolescents were in good terms with health care providers. They appreciated the encouragement they got from health workers. Despite their busy schedule, health workers had time to counsel adolescents on the need to attend their clinical and pharmacy visits and how they should manage their situation in order to promote health and reduce infection. The quote below proves this point: *…They are friendly and encouraging. I was able to express myself freely… (18-year-old girl).*

### Support Group

A support group is a group of people who have one thing in common. In this case, the common thing is being HIV positive. They meet to share their experience of being HIV positive and what helps them to cope in order to encourage each other to live positively with their condition. This is done in the health facility set up. Health care providers coordinate the activities of the support group.

The study revealed that both girls and boys enjoyed being part of the support group where they were able to share information with their fellow HIV-positive adolescents. This was their source of comfort and encouragement in life. They no longer felt lonely as they realised that a lot of their peers had similar experiences in life and they were able to cope with their condition. This is confirmed by the following respondents who said:

> *I feel good to be among my fellow HIV positive people. I am no longer feeling lonely… (13-year-old girl).*
>
> *I felt very nice to be in the support group. I am no longer feeling lonely… (15-year-old boy).*

Issues coming out of experiences of adolescents with regard to health services were very important. All the girls and few boys felt good about taking drugs because it contributed to their good health. Some girls and boys were concerned about lifelong treatment and drug fatigue. The majority of them were concerned about the provision of ART services during weekdays when they were expected to be at school. They also have a good relationship with health care providers. Some girls and boys felt good about being members of the support group.

## 4.4 Coping Strategies of Adolescents Living with HIV

Coping strategies are ways adopted by adolescents to cope with their condition. The study revealed that adolescents living with HIV had negative experiences which include bad feelings after disclosure, stigma from peers and family. It is common for people faced with a life-threatening illness to search for meaning, understanding and coping mechanisms to deal with their circumstances. Despite adolescents experiencing challenges, they gained an appreciation for what matters in life by adopting various ways of coping with their situation. Adolescents were able to cope with their condition by adopting strategies such as resilience, non-disclosure, spiritual intervention and the use of supportive systems.

### 4.4.1 Resilience

Adolescents were able to cope with their situation of being HIV positive by accepting their status. Some girls and boys accepted their status to the extent that they were not bothered by what people said about them. They were able to talk about their status with anyone. This is proved by the quote below:

> *I have accepted my status. I do not complain about my condition because I cannot do anything to change my situation. No matter what people say about my status, I will live positively with it and encourage others to test for HIV… (18 years old girl).*

Boys had similar sentiments to that of girls.

> *I do not bother about what people say, I never mind about them… (19 years old boy)*

### 4.4.2 Non-disclosure

As much as disclosure is vital in HIV care, some adolescents opted to keep their status as a secret in some situations in fear of rejection from their peers, as a coping mechanism. They felt comfortable to be with friends who do not know their status. Five girls kept their status a secret. One of them only disclosed to the father of her child but decided not to disclose to her fiancée. This is exemplified by the following statement:

> *I will keep my status a secret because I might be rejected the same way the father to my child did. He married another woman who is negative like him… (19-year-old girl).*

Most boys felt that HIV was a sensitive issue, so they could not disclose to other people for fear of discrimination and rejection.

> *They might even leave me; I cannot have any friend so now I have kept this disease as a secret (15-year-old boy).*

### 4.4.3 Spiritual Intervention

The coping search for meaning often led some adolescents to search for spiritual and religious answers. They relied on religious and spiritual beliefs for health outcomes. This enabled them to pray to their God for divine direction and help to endure their condition. For some, their spirituality or religiosity serves as a protective factor and contributes to their ability to cope effectively with their HIV status. Most girls and some boys had similar sentiments. This can be confirmed from the following respondent who said:

> *I pray to God telling him that I am innocent as far as HIV transmission is concerned, I only found myself positive. He should make it possible for me to be healed (14-year-old girl).*
>
> *I pray to God. I communicate with God that he should safeguard my enemies. They should live to see my achievements. (16-year-old girl).*

### 4.4.4 Social Support

The study revealed that adolescents were able to cope with their condition through the support from family, community, health care providers, peers, support group and NGOs.

#### 4.4.4.1 Support from Family Members

Open family conversations about HIV helped some adolescents to cope with individual and interpersonal stigma in order to live positively and cope with their situation. Family played a very important part in the adolescents' life. Adolescents were able to cope with their condition through the encouragement from family members. Most girls and some boys were able to adhere to treatment because of the efforts of their relatives who acted as buddies and reminded them to take their drugs at the right time. A 16 years old orphan explained it this way:

> *My mother, my sister and all the people at home remind me to take my drugs (16-year-old girl).*

Some boys also appreciated the support they got from their parent through reminding them to take their drugs.

> *… Mom reminds me to take my drugs… (12-year-old boy).*

#### 4.4.4.2 Support from Healthcare Providers

Health care providers encourage adolescents during adherence counselling. This enabled all adolescents interviewed to cope with their situation because they wanted to continue living despite being HIV positive. This was confirmed by the following respondent who said Health Care Providers:

> *…tell us that we should continue taking drugs, we should not forget because if we forget we will be sick again and die then they will bury us. Even when your mother is not at home, you should take your drugs (10-year-old boy)*

#### 4.4.4.3 Support from Support Group Members

According to the findings of the study, adolescents encouraged each other during support group meetings on how they could cope with their situation. Peers support HIV-infected adolescents to adhere to treatment and care and this helps them to strive with their condition despite the hardships they encountered in life. They shared various coping strategies which empowered everyone with information to manage their situation as they proceed to adulthood. Some girls appreciated the support they received from their peers found in the support group. This was explained in the following way:

> *We share ideas on how we can continue taking ARVs with my fellow HIV positive adolescents, so that we should not stop because if we stop we won't achieve our goal in life such as becoming a nurse (19-years old girl).*

#### 4.4.4.4 Support from Non-Governmental Organisation

The escalating poverty levels in Zambia make it difficult for people to access food in most households, it is even worse for adolescents living with HIV since they need adequate food to boost their immunity and become health. The findings of the study showed that the presence of

Non-Governmental Organisation (NGO) enabled adolescents to cope with their situation through nutritional, psychosocial and educational support. An adolescent getting nutritional and educational support from an NGO (Children International Zambia) located in Kanyama Community had this to say:

> *The food I get from Children International Zambia helps me to be healthy and manage to take my drugs daily. It was going to be a challenge to take drugs without food. (12-years old boy).*

Adolescents were able to cope with their condition by using various strategies. Resilience, treatment, non-disclosure, spiritual intervention and support from family, community, support group and nutritional assistance provided by NGOs.

### 4.5 Summary of the Chapter

In summary, both girls and boys had a positive and negative feeling at community and facility level. Some felt good after knowing their status, after disclosing their status and after realising that their caregivers told other people without their consent. The majority of the adolescents were supported by family members and they felt well with treatment, enjoyed a good relationship with health care providers and within the support group.

Other adolescents felt bad after knowing their status and did not like the idea of their caregivers disclosing their status to other people without consent. Some experienced stigma from peers and family members. Despite adolescents' negative experiences; they managed to cope with their condition by acquiring coping strategies such as resilience, non-disclosure, treatment, spiritual intervention and social support.

# CHAPTER FIVE: DISCUSSION OF FINDINGS

## 5.0 Introduction

The study was aimed at exploring the experiences and coping strategies of adolescents living with HIV (ALWHIV) in Kanyama Community regardless of being on antiretroviral therapy.

In relation to the objectives, experiences of adolescents living with HIV were grouped into three main categories namely; experiences with disclosure experiences with significant others and experiences of health services. The fourth part was coping strategies, which enabled them to endure their condition despite experiencing unfavorable reactions in life. This chapter discusses how the results of this study compare with other studies in the three categories of experiences and what helped the adolescents to cope with their condition. It also provides an overall interpretation of the results in broader scientific-practical context.

## 5.1 Experiences with Disclosure

With regard to disclosure, this study found three dimensions in which adolescents experienced disclosure: disclosure of HIV status to adolescents, adolescents disclosing their status to others and third party disclosure (parents or caregivers disclosing adolescents' HIV status to other people).

Adolescents had different feelings after disclosure. Some felt sad while others felt good after being told that they were HIV positive. Those who felt bad felt betrayed by their caregivers for denying them their right to secrecy about their own life. As much as adolescents living with HIV were concerned about knowing their status, the caregivers involved in disclosure should have been equipped with knowledge and skill in order to do it effectively. Most caregivers disclosed inappropriately leading to internalised stigma and depression (Mburu *et al*., 2014a). Other caregivers had limited disclosure skills which made it difficult to disclose to adolescents under their care (Mweemba *et al*., 2015). Therefore, equipping caregivers with knowledge about disclosure will ensure effective ways of handling disclosure process.

Other adolescents felt well after disclosure due to the fact that they were already on treatment which could help them to live longer, similar findings were reported by Mason *et al*, 2011. Disclosure empowered adolescents with knowledge that enabled them to understand their situation and live positively in life. Studies show that explaining to the adolescents that they have HIV fulfilled their right to know their own health and improve their adherence to ART, retention to care and prolong their life (Mason *et al*., 2011, Vreeman *et al.*, 2010).

This study also found that gender had an influence on the experiences of adolescents after disclosure. The study found that more girls expressed their negative and positive feelings than boys. Masculinity seems to influence the boys not to express their feelings which could lead them to depression as time passes, so there is need to find ways of engaging boys in discussions so that they can bring out their concerns. More research needs to be done in order to explore why boys are not comfortable to disclose their status.

Regarding adolescents' disclosure of HIV status to others, girls were more comfortable to disclose their status to family members than boys. They narrated how the people whom they disclosed to, encouraged and helped them to take their drugs especially when they got sick and could not take the drugs on their own. These findings resonate with others such as Wodi, who reported that adolescent's voluntary disclosure of HIV status brought beneficial results like sharing of personal information and disclosing to a sexual partner for prevention purposes (Wodi, 2005). Bergers and others pointed out that improvement in adherence to ART, access to health care and lower social related stigma were benefits of disclosure (Berger *et al.*, 2001).

With regard to third party disclosure, the study findings suggested that some adolescents were comfortable with third-party disclosure as they expected family members to help them when they were in need. A study conducted in Nigeria on routine third party disclosure of HIV result to identifiable sexual partners in sub-Saharan Africa found that physicians had challenges in dealing with confidentiality, shared confidentiality, patient's right and third party right (Masiye and Ssekubugu, 2008).

Other adolescents did not like the idea of disclosing their HIV status without their permission. Adolescents realised that family members were aware of their status at a later stage in life, a situation which compromised confidentiality. They were only comfortable with their biological parents or their immediate caregivers in case of orphans, knowing their HIV status. Some of the adolescents were depressed about the action of their caregivers of disclosing their HIV status without their consent. These findings are consistent with the findings of Masiye, 2008, who reported that the majority of the respondents in the study conducted in Nigeria on third party disclosure wanted to know if their spouses had HIV infection through the physician while on the other hand, they did not allow their spouse to be told if they were infected (Masiye and Ssekubugu, 2008).

The study proposes the need for strengthening awareness programmes in order to promote confidentiality among care providers. It also calls for the need to design and implement effective disclosure strategies. Therefore, although third party disclosure was vital, the study suggested the need to handle it diligently especially when dealing with adolescents tested at a tender age to enable them to access health care in the absence of their parents.

### 5.2 Relationship with Significant Others

The following were the themes that emerged from the study: stigma from peers and family, family support, experience with teachers.

Regarding stigma from peers and family, the study found that few adolescents experienced stigma from peers and family. This was similar to the findings of Jena, 2014, who reported that most adolescents experienced stigma (Jena, 2014). Only 2 out of the 24 adolescents interviewed experienced stigma. It can thus be said that there is a reduction of stigma against adolescents living with HIV as shown by the findings of the study.

The study also showed that more boys were supported by their family members than girls. This could be due to society’s awareness of the attitude boys have of not expressing themselves, so family members took care of them to prevent them from being stressed by whatever they were concerned about in life. Boys needed to get support from family and peers, healthy, emotional attachments, and basic living necessities, spiritual and psychosocial outlets (Mburu *et al.*, 2014b).

Adolescents living with HIV were concerned about social support which was significant in their survival, coping and general livelihood (Steele *et al.,* 2007, Martinez *et al.*, 2012b).

Teachers as part of the community played a role in the life of school going adolescents. Teachers had a responsibility to take care of the pupils at school, which included their health and educational well-being. A few adolescents who disclosed their status to the teachers were being supported in various ways. Adolescents enjoyed the support they got from their teachers especially during the days they attended to clinical or pharmacy visits. Teachers understood the adolescent's situation and allowed them to join in class even if they came late after visiting the clinic (Conner *et al.*, 2006).

Issues that came out from a relationship with significant others showed that few adolescents experienced stigma from peers and friends while majority enjoyed the support from family members. It also showed that boys were more supported than girls which could be attributed to culture. Teachers also played a role in supporting the school going adolescents as long as they disclosed their status. Therefore, disclosure had an effect on social support.

## 5.3 Experiences of Adolescents Living with HIV with Regard to HIV Services and Service Providers

The following were the themes that emerged from the study: the experience of health service, experience with health care providers, experience with drugs and experience with a support group.

With regard to the experience of health services, the study discovered that adolescents complained of missing lessons at school whenever they were due for either clinical or pharmacy visits. Perhaps the situation called for the need to come up with a policy which would make it possible for Antiretroviral Therapy (ART) services to be provided during weekends and holidays so that school going children living with HIV can have free time to go to the clinic.

The findings of Mburu brought out the lack of a health policy related to adolescents living with HIV as factors which contributed to the ongoing limitation of adolescent's ability to access relevant services (Mburu *et al.,* 2014b). The limited access to HIV services by adolescents due to timing raised ethical questions about the right to health by adolescents, beneficence and the extent to which adolescents can exercise autonomy.

Despite the concerns raised on health services, we found that adolescents appreciated the encouragement they received from health care providers which enabled them to ask their caregivers about their HIV status that contributed to adolescents' ability to take medication independently. As adolescents grew into adulthood, there was need for them to independently start going to the clinic to get medical attention and take their drugs correctly instead of relying on their caregivers who may not always be available. This could only be possible if they were aware of their HIV status.

With regard to drugs, adolescents raised concerns about getting fed up of taking their drugs, especially that the drugs were to be taken for life. The study showed that most of the adolescents who disclosed their HIV status were able to adhere to treatment despite the concerns raised. They were adhering to treatment in order to improve their health condition and be able to live longer. Taking Antiretroviral Therapy (ART) was vital to adolescents living with HIV because it reduced the progression of the disease and promoted health. Berger and others stated benefits of disclosure as improvement in adherence to ART, access to health care and lower social related stigma (Berger *et al.,* 2001).

Regarding the support group, all adolescents regardless of gender, who were members of the support group enjoyed sharing information with their fellow HIV-positive peers. The interchange of information-empowered the adolescents with knowledge about their condition and that was a source of comfort and encouragement in their life. They no longer felt lonely but learned from their peer's experiences and coping strategies. Finally, they were able to acquire psychosocial support from peer support groups (Hall *et al.,* 2012).

Overall, the study suggested that as much as adolescents had positive experiences despite being HIV positive they also experienced negative feelings which included stigma from peers and family, drug fatigue and bad feelings associated with disclosure. Therefore, good experiences should be maintained while negative experiences should be mitigated in order to help adolescents living with HIV to cope with their condition.

## 5.4 Coping Strategies used by Adolescents Living with HIV

With regard to coping strategies, the following themes emerged from the study: resilience, non-disclosure, spiritual intervention and social support.

Concerning resilience, the study revealed that adolescents were able to cope with their situation by accepting their status to the point that they were not bothered by what people said about them. They did not focus on what people said about them but instead they concentrated on living positively with their condition so that they could be responsible adults. This is in relation to the Columbian study on Latino youths which revealed that despite experiencing challenges adolescents gained an appreciation for what mattered in life, they adopted achievable goals in life (Martinez *et al.,* 2012b).

The information adolescents acquired during adherence counselling enabled them to cope with their condition. They were given information on the effects and benefits of treatment which became a source of comfort and enabled adolescents living with HIV to cope with their situation. Wodi conquers with these findings by stating that "knowledge gained through treatment system helped adolescents to care for themselves and develop self-esteem that protected them against stigma" (Wodi, 2005, Hall *et al.,* 2012).

Despite being healthy because of the treatment adolescents were taking, some of them opted to keep their status as a secret as a coping strategy. These considered HIV to be sensitive in their life and that made them keep their HIV status as a secret for fear of rejection, stigma, and discrimination as noted in the study. Fair and Albright had similar findings (Fair and Albright, 2012).

Spiritual intervention was another strategy used by adolescents living with HIV to cope with their condition. The findings of the study showed that ALWHIV relied on God to help them to endure their situation. They poured out their hearts to God in prayer because they believed that it was only God who had the capacity to give them power beyond what was normal, which helped them to cope with their life situation. Abrahams and Jewkes (2012) had similar findings which stated that the coping search for meaning often led some to search for spiritual and religious answers. This enabled them to pray to their God for divine direction and helped them to endure their condition. Conner and others supported the ideas of Abraham and Jewkes on the role of spirituality and religion as a coping mechanism of ALWHIV in Columbia. Individuals' attribution and faith had an impact on their mental health, disease progression and long-term survival (Conner *et al.,* 2006).

The results of this study further indicated that ALWHIV were supported by their family members. Although almost all the respondents were orphans, they were staying with family members who supported them physically, psychologically and emotionally. The encouragement provided by family members enabled adolescents to cope effectively with their situation. The findings of Fielden was in agreement with the findings of this study which states that open family conversations about HIV helped some adolescents to cope with individual and interpersonal stigma in order to live positively (Fielden *et al.*, 2011). Families supported HIV-infected adolescents to adhere to treatment and care, and that helped adolescents to strive with their condition (Gitau Mburu *et al.*, 2013).

In addition to family support, adolescents also encouraged each other during support group meetings on how they could cope with their situation. Most of the adolescents appreciated the support they received from their peers. Peers supported each other to adhere to treatment and care, and this helped adolescents to strive with their condition (Gitau Mburu *et al.*, 2013). Adolescents who were aware of their own HIV-positive status were in a better position to access Antiretroviral Therapy (ART) from health facilities and adhere to treatment since they knew the benefits of taking the drugs correctly. Finally, they were able to acquire psychosocial support from peer support groups (Hall *et al.*, 2012).

Adolescents who disclosed their HIV status to their teachers had less challenges at school because they were able to go to school late after visiting the clinic for drug collection or clinical visit. The result of the Columbian study showed that youths needed support from family, peers, teachers, health care providers and the clergy (Conner *et al.*, *2*006). Therefore, one may argue that to effectively help adolescents cope with HIV, it was important to develop support networks or strategies that take an ecological perspective that focused or took into account the individual, group, family, community and societal level dynamics, opportunities and strengths.

Despite adolescents living with HIV experiencing challenges in lives, they were able to cope with their situation by using various strategies such as resilience, non-disclosure, spiritual intervention and social support.

## 5.5 Strengths and Limitations of the Study

### Strengths

The study had strength through the research process which included transcribing and reviewing all the interviews. The results were shared with the core authors and this led to clarification of certain issues and contributed to the credibility of the findings.

### Limitations

Firstly, generalisability of the findings of the study is a limitation in most studies and is not unexceptional to this study. The study was conducted in one setting with a small sample of respondents drawn from one health facility and one Non-Governmental Organisation located in Kanyama Community. The findings of the study may not be representative of other settings. Similar studies are, therefore, warranted in other settings for comparability of research findings.

Equal numbers of participants (two girls and two boys) were supposed to be drawn from six categories (orphans and non-orphan, school going and non-school going, married and unmarried). Equal numbers of girls and boys in each category was not achieved; therefore, sex of the participants was limited to those available.

Adolescents were sometimes disrupted and disturbed during the interview sessions. This was due to the noise generated by the children waiting to be attended to by Healthcare providers since the interviews were conducted during the paediatric day. Clerks sometimes knocked and entered the room during the interview process and this made some adolescents uncomfortable.

## 5.6 Summary of the chapter

The study suggested that most of the adolescents were supported by their families while a few experienced stigma and discrimination from peers and family members. They were also struggling with drug fatique and bad feeling associated to disclosure. Adolescents were able to cope with their condition by using resilience, non- disclosure, spiritual intervention and social support.

# CHAPTER SIX: CONCLUSIONAND RECOMMENDATIONS

## 6.0 Conclusion

The study revealed that adolescents had different experiences. They had both favourable and unfavourable experiences. The favourable experiences of adolescents living with HIV with regard to accessing HIV services included encouragement from support group members, treatment which resulted in good health and support from health care providers. The unfavourable experiences adolescents had to endure were life-long treatment resulting to drug fatigue, stigmatisation, being denied to visit friends in fear of poor adherence, the provision of antiretroviral services during weekdays and school time when they were expected to be in class. Despite the negative experiences adolescents living with HIV were experiencing, they managed to cope with their situation by adopting strategies such as resilience, treatment, non-disclosure, spiritual intervention and the use of supportive systems. This helped them to live positively with their condition. Therefore, in order to effectively help adolescents cope with HIV, it is important to develop support networks or strategies that take a holistic approach, that is, focus or take into account the individual, group, family, community, and societal level dynamics, opportunities and strengths.

## 6.1 Recommendations

Below are recommendations categorised into two: government and health workers.

**Recommendations for Government:**

- Come up with a policy which will make it possible for Antiretroviral Therapy (ART) services to be provided during weekends and holidays so that school going children living with HIV can have free time to go to the clinic. Currently, the adolescents are expected to attend their clinical and pharmacy visits on Wednesdays when they are also expected to be in class.
- Design and implement effective disclosure strategies in order to equip health workers with disclosure skills.

### Recommendations for Health Workers

- Strengthen their skills on disclosure strategies in order to help caregivers to disclose to adolescents effectively. Currently, caregivers are not equipped with adequate knowledge on how to disclose effectively to adolescents living with HIV under their care.
- Strengthen awareness programmes in order to promote confidentiality among care providers especially when third party disclosure is involved. This will help them to disclose to people who are rightly disposed to take care of the adolescents when need arises.

# REFERENCES

Abrahams, N. & Jewkes, R. 2012. Managing and resisting stigma: a qualitative study among people living with HIV in South Africa. *Journal of the International AIDS Society,* 15.

Berger, B. E., Ferrans, C. E. & Lashley, F. R. 2001. Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale¶. *Research in nursing & health,* 24**,** 518-529.

Busch, B., Wiener, L., Mellins, C. A., Marhefka, S. & Battles, H. B. 2007. Disclosure of an HIV diagnosis to children: History, current research, and future directions. Commentary. *Journal of developmental and behavioral pediatrics,* 28.

Conner, L., Wilson, A., Lyon, M. & D'angelo, L. 2006. The voices of teens living with HIV: How you can support us. *ME Lyon & LJ D" Angelo (Eds.), Teenagers, HIV and AIDS: Insights from youth living with the virus***,** 181-196.

Fair, C. & Albright, J. 2012. “Don't tell him you have HIV unless he's ‘the one’”: Romantic relationships among adolescents and young adults with perinatal HIV infection. *AIDS patient care and STDs,* 26**,** 746-754.

Fielden, S. J., Chapman, G. E. & Cadell, S. 2011. Managing stigma in adolescent HIV: silence, secrets, and sanctioned spaces. *Culture, health & sexuality,* 13**,** 267-281.

Gitau Mburu, M. R., Skovdal, M., Bitira, D., Hodgson, I., Mwai, G. W., Stegling, C. & Seeley, J. 2013. Resisting and challenging stigma in Uganda: the role of support groups of people living with HIV. *Journal of the International AIDS Society,* 16.

Gourlay, A., Birdthistle, I., Mburu, G., Iorpenda, K. & Wringe, A. 2013. Barriers and facilitating factors to the uptake of antiretroviral drugs for prevention of mother-to-child transmission of HIV in sub-Saharan Africa: a systematic review. *Journal of the International AIDS Society,* 16.

Hall, H. I., Gray, K. M., Tang, T., Li, J., Shouse, L. & Mermin, J. 2012. Retention in care of adults and adolescents living with HIV in 13 US areas. *JAIDS Journal of Acquired Immune Deficiency Syndromes,* 60**,** 77-82.

Hodgson, I., Ross, J., Haamujompa, C. & Gitau-Mburu, D. 2012. Living as an adolescent with HIV in Zambia–lived experiences, sexual health, and reproductive needs. *AIDS care,* 24**,** 1204-1210.

Isaac, K. & Fred, N. 2009. Factors influencing disclosure of HIV-positive status in Mityana district of Uganda. *African Health Sciences Journal*.

Jena, P. P. 2014. Exploring the lived experiences of adolescents living with vertically acquired HIV.

Joffe, H. & Yardley, L. 2004. 4 Content And Thematic Analysis. *Research methods for clinical and health psychology,* 56.

Johnson, M. O. & Neilands, T. B. 2007. Coping with HIV treatment side effects: conceptualization, measurement, and linkages. *AIDS and Behavior,* 11**,** 575-585.

Lewis, S. 2015. Qualitative inquiry and research design: Choosing among five approaches. *Health promotion practice***,** 1524839915580941.

Martinez, J., Harper, G., Carleton, R. A., Hosek, S., Bojan, K., Clum, G., Ellen & The Adolescent Medicine Trials Network, J. 2012a. The impact of stigma on medication adherence among HIV-positive adolescent and young adult females and the moderating effects of coping and satisfaction with health care. *AIDS patient care and STDs,* 26**,** 108-115.

Martinez, J., Lemos, D., Hosek & The Adolescent Medicine Trials Network, S. 2012b. Stressors and sources of support: The perceptions and experiences of newly diagnosed Latino youth living with HIV. *AIDS patient care and STDs,* 26**,** 281-290.

Masiye, F. & Ssekubugu, R. 2008. Routine third party disclosure of HIV results to identifiable sexual partners in sub-Saharan Africa. *Theoretical medicine and bioethics,* 29**,** 341-348.

Mason, M., Pate, P., Drapkin, M. & Sozinho, K. 2011. Motivational interviewing integrated with social network counseling for female adolescents: A randomized pilot study in urban primary care. *Journal of substance abuse treatment,* 41**,** 148-155.

Mburu, G., Hodgson, I., Kalibala, S., Haamujompa, C., Cataldo, F., Lowenthal, E. D. & Ross, D. 2014a. Adolescent HIV disclosure in Zambia: barriers, facilitators, and outcomes. *Journal of the International AIDS Society,* 17.

Mburu, G., Hodgson, I., Teltschik, A., Ram, M., Haamujompa, C., Bajpai, D. & Mutali, B. 2013. Rights-based services for adolescents living with HIV: adolescent self-efficacy and implications for health systems in Zambia. *Reproductive health matters,* 21**,** 176-185.

Mburu, G., Ram, M., Oxenham, D., Haamujompa, C., Iorpenda, K. & Ferguson, L. 2014b. Responding to adolescents living with HIV in Zambia: a social–ecological approach. *Children and youth services review,* 45**,** 9-17.

Mwai, G. W., Mburu, G., Torpey, K., Frost, P., Ford, N. & Seeley, J. 2013. Role and outcomes of community health workers in HIV care in sub-Saharan Africa: a systematic review. *Journal of the International AIDS Society,* 16.

Mweemba, M., Musheke, M. M., Michelo, C., Halwiindi, H., Mweemba, O. & Zulu, J. M. 2015. "When am I going to stop taking the drug?" Enablers, barriers and processes of disclosure of HIV status by caregivers to adolescents in a rural district in Zambia. *BMC public health,* 15**,** 1.

Orban, L. A., Stein, R., Koenig, L. J., Conner, L. C., Rexhouse, E. L., Lewis, J. V. & Lagrange, R. 2010. Coping strategies of adolescents living with HIV: disease-specific stressors and responses. *AIDS care,* 22**,** 420-430.

Organization, W. H. 2011. Guideline on HIV disclosure counselling for children up to 12 years of age.

Rao, D., Kekwaletswe, T., Hosek, S., Martinez, J. & Rodriguez, F. 2007. Stigma and social barriers to medication adherence with urban youth living with HIV. *AIDS care,* 19**,** 28-33.

Seidenberg, P., Nicholson, S., Schaefer, M., Semrau, K., Bweupe, M., Masese, N., Bonawitz, R., Chitembo, L., Goggin, C. & Thea, D. M. 2012. Early infant diagnosis of HIV infection in Zambia through mobile phone texting of blood test results. *Bulletin of the World Health Organization,* 90**,** 348-356.

Steele, R. G., Nelson, T. D. & Cole, B. P. 2007. Psychosocial functioning of children with AIDS and HIV infection: review of the literature from a socioecological framework. *Journal of Developmental & Behavioral Pediatrics,* 28**,** 58-69.

Tanney, M. R., Naar-King, S., Macdonnel, K. & Team, A. T. N. F. H. A. I. P. 2012. Depression and stigma in high-risk youth living with HIV: a multi-site study. *Journal of Pediatric Health Care,* 26**,** 300-305.

UNICEF. 2011. *Opportunity in Crisis: Preventing HIV from early adolescence to young adulthood*, UNICEF.

UNICEF.2014. Children and HIV & AIDS: *Key Statistics*- The Stephen Lewis Foundation

Vreeman, R. C., Nyandiko, W. M., Ayaya, S. O., Walumbe, E. G., Marrero, D. G. & Inui, T. S. 2010. The perceived impact of disclosure of pediatric HIV status on pediatric antiretroviral therapy adherence, child well-being, and social relationships in a resource-limited setting. *AIDS patient care and STDs,* 24**,** 639-649.

Wodi, B. E. 2005. HIV/AIDS Knowledge, Attitudes, and Opinions among Adolescents in the River States of Nigeria. *International Electronic Journal of Health Education,* 8**,** 86-94.

Zulu, J. M., Kinsman, J., Michelo, C. & Hurtig, A.-K. 2014. Hope and despair: community health assistants' experiences of working in a rural district in Zambia. *Hum Res Health,* 12**,** 10.1186.

# APPENDICES

## APPENDIX (I): INFORMATION SHEET

THE UNIVERSITY OF ZAMBIA

SCHOOL OF MEDICINE

DEPARTMENT OF PUBLIC HEALTH

INFORMATION SHEET FORM

**Study title:** Experiences and coping strategies of adolescents living with HIV in Kanyama Community

**Principle investigator:** Mukena Linyaku

### Purpose of research project

I am a Master of Public Health (MPH) student at the University of Zambia-Ridgeway campus. I also work for the Ministry of Community Development, Mother, and Child Health at Kanyama Clinic in Lusaka. I am doing a research on experience and coping strategies of adolescents living with HIV in Kanyama Community. The aim of the study is to understand the experiences of adolescents living with HIV, how they manage to cope with their circumstance and also to identify the gaps in health care needs assessment. I will be interviewing adolescents aged 10-19 living with HIV and are aware of their status. I am asking for your participation in this study.

### Why you are being asked to participate

You are being invited to take part in this research because I feel that your experience will help in the development of practical interventions which will be effective for HIV-infected adolescents' needs.

### Procedures

We will ask you to take part in an interview. This interview will take about one (1) hour. It will be done in a private place. If you permit us, we will tape record the interview to help pick all that you will say. If not, we will ask you if it is ok for us to write notes. The information from tape or notes will be typed in full, to help us fully understanding of what you will say. Your name will not be included in the tape and the typed documents.

### Benefits

There will be no direct and immediate material and financial benefits to you. In general, this study will help contribute towards the development of practical interventions which will be effective to meet the needs of adolescents living with HIV.

### Risks/discomforts

We do not expect you to have any major problems because of your participation in this study. But, some information you may tell us may be personal. In case of any emotional breakdown during the interview, you will be referred to psychosocial counsellors for counselling services to you. The interview will be conducted in a confidential manner and setting

### Protecting data confidentiality

We have put up steps to protect the information we will get from you. First, only members of the study team will be able to see the information. Second, we will not put names on any information. Instead, we will use numbers. The list of numbers and the information will be locked separately. The information you will provide will be strictly confidential and your identity will be protected. Third, we will destroy all tapes within 3 years after typing the information. We will keep copies of typed information on CDs in case we have a problem with the computer. This study has been approved by the Excellence in Research Ethics and Science (ERES) and permission has also been obtained from Ministry of Community Development, Mother and Child Health and Facility authorities. Should you have any questions or want clarification about the study, do not hesitate to get in touch directly with me. For any questions and concerns, you can call me on phone number, 0979-371050.

### What happens if I leave the study early?

I want you to know that your participation in this study is voluntary. You are free not to answer any questions that you are not comfortable with. You can also withdraw from the study at any time without any consequences for doing so.

### Who do I call if I have questions or problems?

Call the Principal Investigator, Mukena Linyaku on 0979-371050 if you have questions or complaints as a result of being in this study. You may also contact ERES Converge, 33 Joseph Mwila Road, Roads Park, Cell: 0955 155 633, 0955 155 634 and 0966 765 503. Email: eresconverge@yahoo.com.

## APPENDIX (II): INFORMED CONSENT ADOLESCENTS AGED 18 AND 19

THE UNIVERSITY OF ZAMBIA

SCHOOL OF MEDICINE

DEPARTMENT OF PUBLIC HEALTH

**Informed consent form for adolescents aged 18 and 19**

**Study title:** Experiences and coping strategies of adolescents living with HIV in Kanyama Community

**Principle investigator:** MUKENA LINYAKU

The purpose of this study has been explained to me and I understand the purpose, the benefits, risks and confidentiality of the study. I further understand that, if I agree to take part in this study, I can withdraw at any time without having to give an explanation and taking part in this study is purely voluntary.

I........................................................................................................................... (Names)

Agree to take part in this study designed to explore experiences and coping strategies of adolescents living with HIV in Kanyama Community.

**Signed/Thumbprint**.................................................Date......................................... (Participant)

**Signed/Thumbprint**.....................................................Date........................................ (Witness)

For more information you may contact the principal investigator Mukena Linyaku on 0979-371050 You may also contact ERES Converge, 33 Joseph Mwila Road Roads Park, Cell: 0955 155 633, 0955 155 634, 0966 765 503, Email: eresconverge@yahoo.com

## APPENDIX (III) ASSENT FORM FOR ADOLESCENTS AGED 10-17

### THE UNIVERSITY OF ZAMBIA

### SCHOOL OF MEDICINE

### DEPARTMENT OF PUBLIC HEALTH

**Assent form for adolescents aged 10-17**

**Study title:** Experiences and coping strategies of adolescents living with HIV IN Kanyama Community

**Principle investigator:** MUKENA LINYAKU

I am Mukena Linyaku from the University of Zambia. I am doing a study on experience and coping strategies of adolescents living with HIV in Kanyama Community. I am asking you to take part in the research study because I want to get information on experiences of adolescents living with HIV and how they manage with their circumstances.

For this research, I will ask some questions about your experiences of being HIV positive. We will keep all your answers private and will not show them to your guardian.

We don't think that any big problems will happen to you for being part of this study, but you might feel sad when we ask about bad things that happened to you. There are no physical risks involved in this study. However, you may feel uncomfortable answering some of the questions. You may refuse to answer any questions that you do not want to answer or questions that make you feel uncomfortable. You may stop the interview session at any time. Your responses or participation in this study will not affect you in any way.

There is no direct benefit to you personally for participating in this study. However, your responses will be expected to generate information that will not only be used to produce an academic paper but also contribute to health care needs of adolescents living with HIV.

You do not have to be in this study if you do not want to. You may stop being in the study at any time. If there is a question you don't want to answer, you are free to keep quiet. Your guardian was asked if it is OK for you to be in this study. Even if they say it's OK, it is still your choice whether or not to take part.

You can ask any questions you have, now or later. If you think of a question later, you or your guardian can contact me on 0979-371050.

Sign this form only if you have had all your questions answered and you have talked to your legal guardian about this research, and agree to take part in this study.

______________________________________________________________________

**Signature/Thumbprint** Printed Name Date

______________________________

Legal Guardian(s)

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Researcher explaining study

Signature Printed Name Date

## APPENDIX (IV): CONSENT FORM FOR PARENTS/GUARDIANS

### THE UNIVERSITY OF ZAMBIA

### SCHOOL OF MEDICINE

### DEPARTMENT OF PUBLIC HEALTH

**Informed Consent Form for Parents/ Guardians**

**Study title:** Experiences and coping strategies of adolescents living with HIV in Kanyama Community.

**Principle investigator:** Mukena Linyaku

THIS IS TO CERTIFY THAT I ____________________________________________ (name of parent/guardian) HEREBY agree to have my child __________________________________ (Child's name) participate in the above mentioned program.

I hereby agree to interview the child in relation to the study mentioned above. I fully understand that the information may be published but the names and identity will not be published or associated with the findings.

I understand that, I am free to deny permission to allow my child to participate in the study and free to withdraw the consent of my child at any time without penalty. I have been given an opportunity to ask questions, and all the questions have been answered to my satisfaction.

________________________ ________________________ _______

Name of parent/guardian **Signature/Thumbprint** of parent/guardians Date

________________________ ________________________ _______

Name of a researcher Signature of a researcher Date

For more information you may contact the principal investigator Mukena Linyaku on 0979-371050 You may also contact ERES Converge, 33 Joseph Mwila Road Roads Park, Cell: 0955 155 633, 0955 155 634, 0966 765 503, Email: eresconverge@yahoo.com

## Appendix (V): IN DEPTH INTERVIEW GUIDE

### SECTION A

**In depth guide on experiences and coping mechanism of adolescents living with HIV in Kanyama community, Lusaka District**

Date of interview………/………/……………….

Place/Community ………………

INSTRUCTION FOR THE INTERVIEWER

Consent form to be signed before the interview

Before starting the interview, the following should be read to the respondent.

You have already signed the consent, are you ready for the interview?

………………………….

Are you comfortable to be recorded?

………………………

### SECTION B

Exploring feeling of being HIV positive

- Can you tell me a brief introduction about yourself?
- Tell me a bit more on how you learnt about your status?

- How did you feel when you learnt that you are positive

- When did you learn that you are HIV positive?

- What did being positive mean to you? Probe more on their feelings both positive and negative)

- What does it mean now?

## SECTION C

Adolescent's experience with peers, family and community members.

- Tell me what you know about HIV.
- What has been your experience living with HIV?
- What was your experience with your peers?

- What was your experience with your family?

- What was your experience with community members?

- How have you been interacting with peers in a similar situation?

## SECTION D

Adolescent's experience with health facility.

- What was your familiarity with health care providers?
- What was your understanding of antiretroviral treatment?
- What was your familiarity with the counsellors? (Adherence and psychosocial counsellors)
- What has been your experience with the support group?

## SECTION E

Adolescent's coping with their HIV status.

- Tell me how you managed to live with HIV?
- Kindly explain how you are managing with your condition?

- What have been your good experiences?
- What is your waste experience?

## SECTION F

Adolescent’s disclosure of HIV status.

- Have you talked with someone about your HIV status?
- What has been your experience in disclosing your HIV status?
- How did you disclose to family members? Why did you disclose to these members?
- Tell me what you think about disclosing your status to your friends?
- What do you think about disclosing your status to community members?

## SECTION G

Closing remarks

- Do you have anything that you would like to tell me?
- Do you have any questions?

**Thank you for your participation**

## APPENDIX (I) INFORMATION SHEET

## THE UNIVERSITY OF ZAMBIA

## SCHOOL OF MEDICINE

## DEPARTMENT OF PUBLIC HEALTH

### IPEPALA LYA FYEBO

Umutwe we sambililo: Ifyakukumanya ne fyebo fibomba ku misepela ababa na HIV abekala mwa Kanyama.

**Kafwailisha mukalamba:** Mukena Linyaku

### Imifwaile ya mulimo wa ukukusokora

Ndi mubomfi mukalamba uwa fya bumi ku cintubwingi umusambi wa pa University of Zambia, Ridgway Campus. Na kabili mbomba ku Ministry of Community Development, Mother and Child Health pa kanyama Cliniki mu Lusaka. Ndasapika pafya kukumanya ne nshila shibomba ku misepela ababa ne HIV mwa Kanyama. Imifwaile ye sambililo lino ukumfwikisha ifya kukukamanya ifyo imisepela iyaba na HIV, ifyo bakumanisha no kubomba ne mibele babamo, na kabili ukwishiba kwaba pa kati ka kakusakama kwa fya bumi no kupimununa.

Inkala ipusha imisepela abali ne myaka 10 – 19 ababa na HIV e lyo nga balishiba ifyo baba. Ndemwipusha nga mwitemwa ukuibimbamo muli ili sambililo.

### Mulandu nshi twamipushisha ukuibimbamo

Tulemulalika ukubulamo imbali muli ukukusapika pantu ndeumfwa ukuti ifyakukumanya fyenu fikabe ifyakwafwa umukulundulula ifya kucilikila ifibomba bwino ne fyo bakabila nge imisepela iyambula HIV.

### Ifyocikaba

Tuklamipusha ukubulamo imbali mu uku kwipusha. Ukwipusha kukalasenda iawaala limo. Tukalacitila mu ncende yafisama. Nga mwatusuminisha tukalakopa ifyebo fyenu. Nga te ifyo, ifyebo tukalakopa nelyo ukulemba tukafitaipa fyonse mukukumanina, kukutwafwa ukumfwikisha ifyo mukalalanda. Amashina yenu tayakabimbwemo muli tepu na mu fyebo tukalemba.

**Ubunonshi**

Tukakwata mukulungatika fimo nelyo ukupelwa indalama kuli imwe. Mucikumbawile, limo isambililo likafwa ukusangwilako ku bunonshi bwingabomba kukwafwa imisepela ababa ne HIV ukukumanisha ififwaikwa.

**Amafya/ Ukukanayumfwa bwino**

Tatuleenekala imwe ukuba na mafia aya kalamba pa mulandu wakuibimba muli ili sambililo lelo ifyebo fimo ifyo wingatweba fikaba fya pa lwesu. Nga kwaba ukubipilwa kwa kutontonkany ilyo tulemwipusha, tukeba abafunda pa fya mutontonkanya ukuti bakakufunde. Ukwipusha kukalacitika mu nkama.

Ukusunga ifyebo twalashanya mu nkama: Natubikako intampulo ska kucingilila ifyebo fikafuma kuli iwe. Icakubalilapo, bekafya abali mwi bumba lya kusambilisha ebakamona mu fyebo. Icabubili, tatwakalebikapo amashina pa fyebo mu cifulo tukalabomfya ama namba. Umutande wa manamba capamo ne fyebo fikesalilwa pale pale. Ifyebo mukatupayanishisha fikasungwa mu nkama sana ne fya ku mishibilako fikacingililwa bwino. Icabutatu, ifyebo tukamikopa ifikaba mu matepu tukafyonaula mu ciputulwa ca myaka itatu. Tukasunga amakope ya fyebo fyataipwa pa CD pa mulandu wa kuti limbi kuti twakwata ubwafya na kompyuta. Ilisambililo nalisuminishiwa kuli ba Excellence in Research Ethics and Science (ERES) no kupelwa insambu kufuma ku Ministry of Community Development, Mother and Child Health and Facility Authorities. Ilyo mwakwata icipusho icili conse nelyo nga mulefwaya ukumilondolwela pa lwe sambililo, mwishimunuka ukulanda na ine mukulungatika pa mepusho ne fimikimine, kuti mwatuma foni pali iyi namba 0979 371050.

Finshi fingacitika nga naleka ukusambilila mukubangilila?

Ndefwaya iwe ukwishiba ukuti ukuibimba kobe muli lisambililo cakuitemenwa fye. Uli mutungwa ukukana-asuka amepusho ayo teti uyumfwe bwino ukulanda, nakabili kuti waleka ukusambilila pa nshita ili yonse ukwabula ubwafya pa kucita ifyo.

Nani mfwile ukutumina nga ndi na mepusho nelyo amafya

Tuminaba Principal Investigator, Mukena Linyaku pali iyi namba 0979 371050 nga uli na mepusho nelyo ifyakuilishanya pa mulandu wakuba muli lisambililo. Na kabili tumina ba ERES converge, 33 Joseph Mwila Road, Rhodes Park, Cell: 0955 155 633, 0955 155 634 na 0966 765 503, Email: eresconverge@yahoo.com

## APPENDIX (II): CONSENT FORM

### THE UNIVERSITY OF ZAMBIA

### SCHOOL OF MEDICINE

### DEPARTMENT OF PUBLIC HEALTH

## IPEPALA LYA KUSUMINISHANYA KWA MISEPELA ILI NE MYAKA 18 – 19

**Umutwe we sambililo:** Ifyo bakumanya ne nshila babomfya ku misepela ababa ne HIV mu bekashi ba mwa Kanyama.

**Kafwailisha mukalamba:** Mukena Linyaku

Imifwaile yaili sambililo nalilondololwa kuli ine, kabili ningufwikisha icilefwaikwa ukumwenamo amafya ne nkama ya ili sambililo kabili ningufwikisha ukuti, nga nasumina ukubula ilubali muli ili sambililo, kuti naleka inshita ili yonse ukwabula ukupela ubulondoloshi pantu ukubulamo ulubali muli ili sambili nacimoneka ukuti kuitemenwa fye.

Ine…………………………………………………………………………………..(Ishina) Ninsumina ukusendamo ulubali muli ili sambililo ilipekanishiwe ukulenga ukwishiba no kubomba ne nshila ku misepela iyaba ne HIV ukubekashi ba mwa Kanyama.

**Ukusaina ukufwatika…**…………….…………….Ubushiku…………… (Ababimilwemo)

**Ukusaina/ ukufwatika**……………………………..Ubushiku……………………… (Inte)

Ku fyebo na fimbi ifyalundwapo kuti mwatumina bakafwailisha Mukalamba ba Mukena Linyaku nangu ukwisatumona pa ERES Converge, 33 Joseph Mwila Road, Rhodes Park, Cell: 0955 155 633, 0955 155 634 na 0966 765 503, Email: eresconverge@yahoo.com

## APPENDIX (III) ASSENT FORM

### THE UNIVERSITY OF ZAMBIA

### SCHOOL OF MEDICINE

### DEPARTMENT OF PUBLIC HEALTH

## IPEPALA LYA KUSUMINISHANYA FYONSE MU KUMISEPELA ABALI NE MYAKA 10-17

Umutwe we sambililo: Ifya kukumanya ne nshila shibomba ku misepela ababa na HIV mwa Kanyama

**Kafwailisha Mukalamba:** Mukena Linyaku

Nine Mukena Linyaku ukufuma pa University of Zambia. Indecita amasambililo palwa fyakukumanya ne nshila shibomba ku misepela aba na HIV kubekala mwa Kanyama. Nde kwipusha ukuti ubulemo ulubali mu kusambilila kwa kusapika pantu ndeafwa kusanga ifyebo pa kukumanya ifya misepela ababa na HIV ne fyo bakumanisha pa mibele babamo.

Palwa ukukusapika, nkalaipusha amepusho yamo palwa fyakukumanya waba na fyo apo waliba HIV. Tukasunga amasuko yobe yonse mu nkama kabili tatwakayalange kubakusunga.

Tatuletontonkanya ukuti kukaba amafya ayakalamba ayakakucitikila pa kuba muli ili sambililo, lelo nalimo kuti waumfwa ububi ilyo twaipusha ifintu fyabipa ifyakucitikilapo. Takuli amafya yapa mubili ayalimo muli ili sambililo. Nangu cibe, teti uyumfwe bwino ukwasuka amepusho yamo.

Kuti wakana ukwasuka amepusho ayali yonse ayo taulefwaya ukwasuka nelyo amepusho ayo nalimo tawingayumfwa bwino. Kuti waleka iciputulwa cauleipusha pa nshita ili yonse. Ukusumina kobe ukwa kwakana muli ili sambililo takwakakukume mu nshila ili yonse.

Tamuli ukumwenamo kwa mukulungatika nga waibimba muli ili sambililo. Nangu cibe fyo ukwankulako kobe tukakwenekela kukusha ifyebo ifishakebe fye pa mapepala ya kusambilisha epela, lelo na kabili kukusangwilako kwa fikabilwa ifya kusakamana ubumi kumisepela ababa na HIV.

Tekuti ube mubili sambililo nga cakuti taulefwaya, kuti waleka ukusambilila inshita fye ili yonse. Nga kwaba icipusho ico taulefwaya ukwasuka, uli muntungwa ukwikala tondolo. Aba kusunga bakepushiwa inga cilifye bwino kuli iwe ukuba muli ili sambililo. Nangu cakuti balanda ukuti cili fye bwino, nalyo line.

Kuti mwaipusha amepusho mwakwata nomba nagu panuma. Nga mwatontonkanya ilipusho panuma imwe nelyo abamisunga muti mwatumina pa 0979 371050

Saineni ino formu lyeka nga cakuti fyasuko fyenu fyonse na fyasukwa e lyo namulanda ku bamisunga ba mwifunde pa lwa kuno kusapika no kusumina kubulamo ulubali muli lino isambililo.

______________________________________________________________________________

Ukusaina/ ukufwatika Ishina Lya Pulintwa Ubushiku

______________________________

Abamisunga aba mwi funde

______________________________________________________________________________

Kasapika ulelondolola Isambililo Ishina Lya Pulintwa Ubushiku
Ukusaina

## APPENDIX (IV): CONSENT FROM

### THE UNIVERSITY OF ZAMBIA

### SCHOOL OF MEDICINE

### DEPARTMENT OF PUBLIC HEALTH

## IPEPALA LYA KUSUMINISHANYA KWA BAFYASHI / ABAMUSUNGA

Umutwe we sambililo: Ifyakukumanya ne nshila shibomba ku misepela ababa na HIV kuabekala mwa Kanyyama

**Umukalamba wa balefwailisha (Principle Investigator): Mukena Linyaku**

Uku kuli kusuminishanya kwa kuti ine ________________________________________ (Ishina lya bafyashi nelyo abalemusunga) Ndesuminisha umwana wandi _________________________ (Ishina lya Mwana) ukuibimba muli programu ilumbwilwe pa mulu.

Ndesuminisha umwana wandi ukumwipusha mwisambililo ilumbwilwe pa mulu. Ningumfwikisha ukuti ifyebo nalimo kuti fyasabankanishiwa, lelo amashina ne fya kwishibilako umuntu tafyakasabankanishiwe ukulingana nefyo tukasanga.

Ningumfwisha ukuti: Indi muntungwa ukukanapela insambu sha kusuminisha umwana wandi ukuibimba muli ili sambililo kabili ndi no butungwa bwa kulesha ukwipusha umwana wandi ukwabula ukundipilisha. Nimpelwa ishuko lyakwipusha amepusho. Ne fipusho fyonse na fyasukwa ukulinga ne fyo ndefwaya.

| | | |
|---|---|---|
| ________________________ | _____________________ | ___________________ |
| Ishina lya bafyashi | **Ukusaina/ ukufwatika** kwa Bafyashi/ abalemusunga | Ubushiku |
| ________________________ | _____________________ | ___________________ |

Ishina Lya Ulesapika Ukusaina kwakwa Kasapika Ubushiku

Ku fyebo na fimbi ifyalundwapo kuti mwatumina bakafwailisha mukalamba ba Mukena Linyaku nangu ukwisatumona pa ERES Converge, 33 Joseph Mwila Road, Rhodes Park, Cell: 0955 155 633, 0955 155 634, 0966 765 503, Email: eresconverge@yahoo.com

## APPENDIX (V): IN DEPTH INTERVIEW GUIDE

### ICIPUTULWA – A

**Ubutungulushi bwashika pa fya kukumanya ne nshila shibomba ku misepela ababa ne HIV kubekala mwa Kanyama, mu Lusaka.**

Ubushiku bwa kwipusha:……………./…………/………….

Icifulo/ Incende……………………………….

**Amakambisho ya kwa Kepusha**

Ukusaina ipepala lya kusuminishanya ilyo tabalamwipusha

Ilyo tamulatendeka ukwipusha, ifyakonkapo fifwile ukubelengelwa uulea-asuka

Namusaina kale ipepala lya kwishiba, bushe mwaipekanya ku mepusho?

………………………………..

Bushe cili fye bwino kukopa ifyo mulelanda?

………………………………..

### ICIPUTULWA – B

Ukwishiba ifyo muyumfwa ifi mwakwata HIV

- Bushe kuti mwanondolwelako panono ifyo mwaba?
- Njebeniko na fimbi ifyo mwaishibe pa fyo mwaba mwebene?
- Mwayumfwile shani ilyo mwaishibe ukuti na mukwata HIV?
- Ni lilali mwaishibe ukuti namukwata HIV?
- Caba shani ifi mwalikwata akashishi ka HIV?
- Cinshi cilepilibula pali ino nshita?

### ICIPUTULWA – C

Ifyo imisepela yakumanya ku banabo, balupwa na mubwikashi

- Njebeniko ifyo mwaishiba palwa HIV
- Cinshi mwakumanya ifi mwakwata HIV?
- Cinshi abanenu bamyebele?
- Cinshi balupwa lwenu bamyebele?
- Cinshi abenamupalamano bamyebele?
- Abanenu abakwata HIV finshi mulanshanyapo nabo?

**ICIPUTULWA – D**

Imisepela ifyo ikumanya ne fya chipatala

- Mwaishibene shani na basakamana ifya bumi?
- Cali shani pa kuti mumfwikishe ukundapa kwa kubomfya ama antiretroviral (umuti bapela ababa na HIV)
- Mwaishibene shani na bafunda pa fya HIV? (Abomwacetekela, abasambilisha ifyakutontonkanya)
- Cakukumanya nshi mukwete ukufuma kwi bumba lya bafwailisha ifya HIV?

**ICIPUTULWA – E**

Imisepela iibomba nefyo baishiba ukuti baliba na HIV

- Njebeniko ifyo mukumanisha ifintu ifi mwaba na HIV?
- Mukwai njebeniko ifyo mukumanisha ifintu apo mwaliba muli iyi mibele?
- Cakukumanya nshi icisuma mwakwata?
- Cakukumanya nshi icabipa mwakwata?

**ICIPUTULWA – F**

Imisepela abasokolola ifi baba na HIV

- Mwalilandapo nabali bonse pali ifi mwakwata HIV?
- Cinshi cacitika ifi mwaisokolola ukuti mwalikwata HIV?
- Mwaebeko shani aba mu lupwa lwenu? Mulandu nshi mwaebeleko ba lupwa?
- Njebeni ifyo mutontonkanya ukwebako abanenu pali ifi mwakwata HIV?
- Finshi mutontonkanya ukwebako abantu ba mubwikashi pa fyo mwaba?

## ICIPUTULWA – G

Amashiwi yakulekelesha

- Bushe na mukwata ifili fyonse ifyo mwingatemwa kunjebako?
- Bushe
- na mukwata amepusho ayali yonse?

Natasha sana ukulandapo kwenu

## APPENDIX (I) INFORMATION SHEET

### THE UNIVERSITY OF ZAMBIA

### SCHOOL OF MEDICINE

### DEPARTMENT OF PUBLIC HEALTH

**Mutu wa phunziro:** Zomwe zimawacitikira ndi mmene amakhalira anyamata ndi atsikana a kwa Kanyama amene ali ndi HIV.

**Wofufuza Wamkulu: Mukena Linyaku**

**Colinga ca kufufuza**

Ndikuphunzira za umoyo wa Anthu (Master of Public Health – MPH) pa University of Zambia – Ridgeway Campus. Ndine wanchito wa Ministry of Community Development Mother and Child Health ku Kanyama Clinic mu Lusaka. Ndifuna kudziwa kuti moyo ulibwanji mwa Kanyama kwa anyamata ndi atsikana omwe ali ndi Kacilombo ka HIV. Colinga ca phunzilo lathu ndiko kudziwa kuti nanga anyamata ndi atsikana a HIV amakhala bwanji ndipo amacitapo ciani polimbana ndi matenda awo. Nanga zofunika ndi zotani pa moyo wawo. Ndidzafunsa ameni ali ndi HIV omwe anapimitsa kale azaka 10 mpaka 19.Ndipempha kuti ticitire pamodzi kufufuza kumeneku.

**Cifukwa cimene mufunikila pa phunziro lathu**

Cifukwa ncakuti zomwe mudziwa zidzathandizira kupeza momwe.

**Mmene Tidzachitira:** Tidzafuna kuti inunso mukambepo. Kufunsana kwathu kudzakhala kwa awala imodzi (one hour) basi. Kudzacitikira pa malo obisika. Ngati mutilola tidzacita record mawu anu kuti zones munena zimveke bwino. Ngati zocita record sizili bwino kwa inu, mungatilole kulemba manotsi. Mawu anu onse adzataipidwa bwino kuti uthenga wanu umveke bwino. Maina anu sadzapezeka pa tepu kapema pa manotsi.

**Mapindu**

Palibe malipilo alionse pa programu imeneyi. Koma maphunziro amenewa adzathandizira kudziwa thandizo lofunikira kwa anyamata ndi atsikana omwe ali ndi HIV.

**Mavuto omwe angabuke**

Sitiona kuti pangabuke vuto lililonse mukacita nafe maphunziro amenewa. Koma zina zomwe mungatiuze zingakhale cinsinsi canu.

Mukapwetekedwa mtima ndi kumvas cisoni pokufunsani ndiye kuti mudzalandira thandizo la aphungu okhazika mtima pansi ndi kukutonthozani. Sitidzakufunsirani pa gulu la anthu, koma panokha.

**Kuteteza cinsinsi**

Tapeza kale njira yosungira cinsinsi pa zones zomwe mudzatiuza. Choyamba ndife ofufuza okha omwe adzadziwa zomwe takambirana. Chaciwiri, maina a omwe afunsidwa sadzalembedwa pali ponse. Mmalo mwake, manambala ndi amene adzaimira maina. Manambala sadzasungidwa malo amodzi ndi zomwe mudzanenapo. Zomwe mudzatiuza zidzakhala cinsinsi cokwana ndipo maina anu sadzafalitsidwa. Cacitatu, matepu onse adzaonongedwa mkati mwa zaka zitatu, pambuyo pakuti zonse tazilemba bwino. Padzakhalanso ma CD a zomwe titzataipa, amene adzafunika pakakhala vuto la makopyuta. Chilolezo ca maphunziro amenewa chacokera kwa Excellence in Research Ethics and Science (ERES). Nawonso a Ministry of Community Development, Mother and Child Health and Facility apereka cilolezo cawo. Ngati pali funso kapena zimene simunamvetse, musataye nthawi kundifunsa kapena kunditumira foni pa 0979 371 050.

**Nanga ndikacoka phunziro lilimkati?**

Kucita nafe maphunziro amenewa nkodzifunira inu eni. Funso lililonse locititsa manyazi mungasankhe kusaliyankha. Mukafuna kucokapo ndi kusiya maphunziro ali mkati palibe adzakuimbani mlandu.

**Ngatu pali mafunso kapena zovuta ndiye kuti ndidzatumizira yani foni?**

Mukakhala ndi mafunso kapena dandaulo cifukwa copezeka kwanu pa maphunzirowa tumizani foni pa 0979 371 050 kwa wofufuza wamkulu (Principal Investigator), Mukena Linyaku. Thandizo lina mungalipeze ku ERES Converge, 33 Joseph Mwila Road, Rhodes Park, Cell: 0955 155 633, 0955 155 634 ndi 0966 765 503, Email: eresconverge@yahoo.com

## APPENDIX (II): CONSENT FORM

### THE UNIVERSITY OF ZAMBIA

### SCHOOL OF MEDICINE

### DEPARTMENT OF PUBLIC HEALTH

**Fomu yovomereza ya anyamata ndi atsikana a zaka 18 ndi 19**

**Mutu waphunziro:** Zomwe zimawacitikira ndi mmene amakhalira anyamata ndi atsikana a kwa Kanyama amene ali ndi HIV.

**Wofufuza Wamkulu:** Mukena Linyaku

Andifotokozera bwino colinga ca phunziro limeneli pamodzi ndi mavuto ndi cinsinsi cake. Ndikudziwanso bwino kuti ndikangolola kucita nawo maphunziro amenewa, ndingalekezere panjira popanda kupereka cifukwa cake popeza maphunziro ake ndi odzifunira kutengamo mbali.

Ine……………………………………………………………………………………… (Dzina)

Ndikuvomereza kucita nawo maphunzirowa ofuna kudziwa zomwe zimacitikira ndi mmene amakhalira anyamata ndi atsikana a kwa Kanyama amene ali ndi HIV.

Sainani/ Dindani Cala…………………………………….....Deti……………. (Wotengamo mbali)

Sainani/ Dindani Cala……………………………………..Deti………………. (Mboni)

Ngati mufuna kudziwa zambiri imbirani foni pa 0979 371 050 kwa wofufuza wamkulu Mukena Linyaku.

Thandizo lina mungalipeze ku ERES Converge, 33 Joseph Mwila Road, Rhodes Park, Cell: 0955 155 633, 0955 155 634 ndi 0966 765 503, Email: eresconverge@yahoo.com

## APPENDIX (III) ASSENT FORM

### THE UNIVERSITY OF ZAMBIA

### SCHOOL OF MEDICINE

### DEPARTMENT OF PUBLIC HEALTH

### FOMU YA MFUNDO ZOCHOKERA KWA ANA A ZAKA 10 MPAKA 17

**Mutu wa phunziro:** Zomwe zimacitikila anyamata ndi atsikana odwala AIDS kwa Kanyama ndi momwe amakhalira.

**Wofufuza Wamkulu:** MUKENA LINYAKU

Ndine Mukena Linyaku wa ku University of Zambia. Ndikufuna kudziwa kuti nanga moyo wa anyamata ndi atsikana odwala AIDS mwa Kanyama uli bwanji. Ndikupemphani kuti mutengemo mbali pa kufufuza kumeneku kuti ndidziwe kaya zimakhala bwanji kwa inu ndipo mumacita ciani ngati muli ndi HIV.

Pa kufufuza kwathu, ndidzafuna kudziwa kuti zinthu zili bwanji kwa inu amene munapezeka ndi kalombo ka HIV. Ndiponso zomwe mudzanena zidzakhala cinsinsi cathu, onse a kunyumba safunika kuwadziwitsa.

Nthawi zina simungakondwe kutiuzako zinthu zina zoipa zomwe zinakucitikirani koma palibe vuto lililonse lomwe mudzapeza ngati mwathandizira pa programu imeneyi. Zili kwa inu ngati simufuna kuyankha mafunso ena amene angakucititseni manyazi. Kuyankha kwanu mafunso sikudzabweletsa vuto lililonse ndipo munganene ngati simufuna kufunsidwa mafunso ena.

Ndi zoona kuti simudzapezapo malipilo pa programu imeneyi koma zomwe mudzanena zidzathandizira ambiri kudziwa zocita ngati ali ndi HIV.

Zili kwa inu ngati simufuna kupezekapo pa phunziro limeneli. Ndiponso ngati mwayamba kale, mungalekeze pomwe mwafunira. Simafunso onse omwe mufunika kuyankhapo. Tinakamba nawo kale amene mukhala nawo kuti inu mupezekepo pa programu imeneyi. Koma zili kwa inu ngati mufuna kupezekapo kapena ai.

Mungafunse mafunso omwe muli nawo nthawi iliyonse. Ngati mufuna kufunsa nthawi ina, mungatumize foni pa nambala iyi 0979371050. Mungasaine fomu ino ngati mwaimvetsa bwino ndipo mwagwirizana ndi amene amakusungani kuti mutengemo mbali pa phunzilo limeneli.

________________________________________________________________

**Saine/ cidindo ca Cala** Dzina Deti

____________________

Wosunga Mwana wa Lamulo

____________________

Phunziro La Kufufuza ________________ ______________

Saini Dzina Lotaipidwa Deti

## APPENDIX (IV): CONSENT FORM

**THE UNIVERSITY OF ZAMBIA**
**SCHOOL OF MEDICINE**
**DEPARTMENT OF PUBLIC HEALTH**

## FOMU YOVOMEREZA YA MAKOLO / WOSUNGA MWANA

**Mutu wa phunziro:** Zomwe timawacitikira ndi mmene amakhalira anyamata ndi atsikana a kwa Kanyama omwe ali ndi HIV.

**Wofufuza Wamkulu:** MUKENA LINYAKU

UWU NDI UMBONI WAKUTI INE ……………………………………………….. (Dzina la kholo/ wosunga mwana) ndikuvomereza kuti mwana wanga ……………………………………………… (Dzina la mwana) akhale ndi mbali pa programu imene yachulidwa pa mwambapa.

Ndivomereza kuti mwana wanga afunsidwe mafunso okhudza phunziro lomwe alisonyeza pamwambapa.

Ndamvetsa kuti zomwe zidzakambidwa pa phunziloli zingafalitsidwe pamene maina sadzafalitsidwa kapena kuwaikapo pa zotulukapo za kufufuza.

Ndikudziwa bwino kuti ndili ndi ufulu wakumletsa mwana wanga kukhala ndi mbali mu programuyi kapena kumuletsa nthawi iliyonse maphunziro atayamba kale popanda kuimbidwa mlandu.

Ndapatsidwa mpata wofunsa mafunso omwe ayankhidwa mondikhutiritsa.

| | | |
|---|---|---|
| ____________________ | __________________ | _______________ |
| Dzina la kholo/ wosunga mwana | **Saini** | Deti |
| ____________________ | __________________ | _______________ |
| Dzina la wofufuza | saini | deti |

Ngati mufuna kudziwa zambiri pa maphunzirowa tumizani foni pa 0979 371 050 kwa wofufuza wamkulu (Principal Investigator), Mukena Linyaku. Thandizo lina mungalipeze ku ERES Converge, 33 Joseph Mwila Road, Rhodes Park, Cell: 0955 155 633, 0955 155 634 ndi 0966 765 503, Email: eresconverge@yahoo.com

## APPENDIX (V): IN DEPTH INTERVIEW GUIDE

### CIGAWO A

**Mafunso okwana bwino pofufuza zimene zimawacitikira ndi mmene amakhalila anyamata ndi atsikana a HIV mwa Kanyama ku Lusaka.**

Tsiku la mafunso……..…/………………/………………

Malo…………………………………………………..…

**Malangizo Kwa wofunsa**

Fomu yovomereza iyenera kusaindwa kufunsa kusanayambe

Awerengereni zotsatirazi otengamo mbali musanayambe kuwafunsa

Mwasaina kale fomu yovomereza, kodi tiyambe kukufusani? ……………….

Kodi mudzalola kulekoda mau anu? …………………………..

### CIGAWO B

Kufufuza mmene amaonera zinthu munthu wa HIV

- Kodi mungandiuzeko dzina lanu, zaka ndi komwe mukhala?
- Mungandiuzeko mwacidule momwe munadziwira kuti muli ndi HIV?
- Unadzimva bwanji pamene unadziwa kuti uli ndi kacilombo ka HIV?
- Unadziwa bwanji kuti uli nako kacilombo kameneka?
- Ndi maganizo otani omwe unakhala nawo podziwa kuti uli ndi HIV?
- Nanga tsopano ukuona bwanji?

### CIGAWO C

Mmene anzake, acibanja ndi ena amaonera munthu wa HIV

- Umadziwapo ciani pa nkhani ya HIV?
- Mwapita muzotani kucokera pamene munakhala ndi HIV?
- Nanga anzako amakuona bwanji?
- Nanga am’banja lako anacita ciyani?
- Nanga anthu ena okudziwa anacita ciyani?

- Nanga mumakambitsirana ciani ndi a HIV anzanu?

## CIGAWO D

Zimene a Zacipatala acitapo

- Munagwirizana bwanji ndi anchito a zacipatala?
- Zinamveka bwanji kwa iwe za macilitso a HIV?
- Munagwilizana bwanji ndi alangizi (Alangizi a cikhalidwe)
- Munagwirizana bwanji ndi gulu lokucilikizani?

## CIGAWO E

Acicepere amene akulimbana ndi HIV?

- Nanga wakwanitsa bwanji kulimbana nayo HIV?
- Fotokoza mmene wakwanitsila kucita zinthu pokhala uli ndi vutoli?
- Tisimbireko zabwino zomwe zakucitikira.
- Nanga vuto limene sudzaiwala ndi lotani?

## CIGAWO F

Wacicepere auzako ena kuti ali ndi HIV

- Kodi pali amene unauzako kuti uli ndi HIV?
- Nciani cinacitika pamene unauzako ena kuti uli ndi HIV?
- Nanga am’banja lako unawadziwitsa bwanji? Nanga unawauziranji?
- Nanga ukuganizapo bwanji pouzako anzako za vuto limeneli?
- Uganizapo bwanji pa kudziwitsa anthu onse okudziwa?

## CIGAWO G

**Mau othera**

- Pangakhale zinanso zomwe ufuna kundiuza?
- Kodi pali mafunso ena amene ufuna kundifunsa

**Zikomo pa Kukhalapo kwako pa programu imeneyi.**