

**THE PRESBYTERIAN UNIVERSITY OF EAST AFRICA**

**A STUDY TO DETERMINE THE PERCEIVED IMPACT OF  
DISCLOSURE OF PEDIATRIC HIV POSITIVE STATUS IN KIBAGARE  
VILLAGE ON DECEMBER 2012**

**MUSAU SALOME NDETO**

**A10/2017/10**

**A DISSERTATION TO THE DEPARTMENT OF CLINICAL MEDICINE  
AS PARTIAL FULFILLMENT FOR THE AWARD OF DIPLOMA IN  
CLINICAL MEDICINE, SURGERY AND COMMUNITY HEALTH OF  
THE PRESBYTERIAN UNIVERSITY OF EAST AFRICA**

**PRESBYTERIAN UNIVERSITY OF EAST AFRICA**

**P.O BOX 389-00902**

**KIKUYU**

**DECLARATION**

I declare that this is my original work and has not been presented for examination purposes in any university or institution of higher learning.

Signature ..... ..

Musau Salome Ndeto

Date

This research project has been submitted for examination with my approval as the supervisor.

Signature ..... ..

Alphonse Miyawa

Date

Presbyterian University of East Africa

Department of Health Sciences

Kikuyu Campus

P.O Box 389-00902

Kikuyu

## **ABSTRACT**

The aim of this research is to determine the perceived impact on pediatric HIV status disclosure. HIV is one of the most feared diseases in Africa. It can be contracted through exchange of blood or body transmission. The most common mode of transmission is through unprotected sexual intercourse. In children, they mostly acquire from the mother during pregnancy or delivery.

In this project it aims at determining the perceived impacts, both positive and negative upon disclosing the child's HIV status either to the child or community at large. These impacts include: isolation, discrimination, excommunication and some are also killed. On the positive side disclosure results to adherence to ARV therapy, the child will be able to manage complications associated with HIV and the child can join social groups which are helpful to them.

In this paper therefore, will evaluate and determine who should disclose this information to the child, at what age should the disclosure be made, and what are the perceived impacts upon disclosing this information either to the child or to the community at large.

## **ACKNOWLEDGEMENTS**

My sincere gratitude to the following persons, each of whom helped me in one way or another to bring this research project into completion.

First and foremost, I give all glory to Almighty God for giving me sound mind, good health and strength to come this far.

Mr. Miyawa, my research coordinator, who was very instrumental in helping me initiate this whole project by teaching me the fundamentals it entails.

My dearest family and friends for the support they offered.

My closest and dearest friend Francis who has been a great inspiration in each and every day of my life.

Thank you and may the Lord bless you abundantly.

## **DEDICATIONS**

I dedicate this research project to all African children who are sero-reactive; it is not what happened to you that matters, but how you react to it.

## TABLE OF CONTENTS

DECLARATION .....	ii
ABSTRACT .....	iii
ACKNOWLEDGEMENTS.....	iv
DEDICATIONS.....	v
TABLE OF CONTENTS .....	vi
LIST OF ABBREVIATION.....	x
LIST OF TABLE .....	xi
LIST OF FIGURES .....	xii
CHAPTER ONE.....	1
1.0 DEFINITION.....	1
1.1 EPIDEMIOLOGY.....	1
1.3 CLINICAL FEATURES .....	2
1.3.1 Symptoms .....	2
1.3.2 Signs .....	2
1.3.3 Importance of HIV Testing.....	2
1.4 PROVIDER INITIATED TESTING AND COUNSELLING .....	3
1.4.1 Consent .....	3
1.4.2 Confidentiality.....	3
1.4.3 Counseling .....	3
1.4.4 Correct Test Results .....	3
1.4.5 Connection to HIV Prevention, Treatment Care and Support .....	3
1.5 HIV TESTING.....	4
1.5.1 Specimen.....	4
1.5.2 Sample Collection .....	4
1.5.3 Sample Collection Procedure.....	4
1.5.3.1 Finger Prick Sample .....	4
1.6 LABORATORY DIAGNOSIS.....	5
1.6.1 Diagnosis in Adults .....	5
1.6.2 Diagnosis in Children .....	5

1.7 ROUTES OF TRASMISSION .....	6
1.7.1 In Adults .....	6
1.7.2 In Infants and Children .....	6
1.8 WHO STAGING OF HIV .....	7
1.8.1 Revised Clinical Staging of HIV/AIDS in Adults .....	7
1.8.2 Revised Clinical Staging of HIV/AIDS for Infants and Children.....	8
1.9 ANTIRETRO VIRAL THERAPY .....	9
1.9.1 ARV Drug Class.....	9
1.9.2 WHO Recommendation on who to Start ARV Therapy .....	10
1.10 COMPLICATIONS OF HIV .....	10
1.10.1 Drug Toxicity .....	10
1.11 HIV PREVENTION.....	10
1.11.1 Sexual Transmission.....	11
1.11.2 Transmission through Blood.....	11
1.11.3 Mother to Child Transmission .....	11
1.12 RESEARCH PROBLEM.....	11
1.13AIM OF THE STUDY .....	11
1.14 RESEARCH OBJECTIVES .....	12
1.15 RESEARCH QUESTIONS .....	12
CHAPTER TWO .....	13
2.0 INTRODUCTION.....	13
2.2 LITERATURE REVIEW .....	13
CHAPTER THREE: RESEARCH METHODOLOGY.....	18
3.1 INTRODUCTION.....	18
3.2 STUDY AREA .....	18
3.2.1 Geographical Area.....	18
3.2.2 Topography and Vegetation.....	18
3.2.3 Climatic Conditions.....	18
3.2.4 Administrative Boundaries .....	18
3.2.5 Communication .....	18
3.2.6 Educational Facilities .....	19

3.2.7 Social Economic Status .....	19
3.3 RESEARCH POPULATION.....	19
3.4 RESEARCH DESIGN.....	19
3.5 SAMPLING PROCEDURES .....	19
3.5.1 Sample Method and Technique.....	19
3.5.2 Sampling Size Determination .....	20
3.6 DATE COLLECTION .....	21
3.6.1 Data Collection Methods and Techniques .....	21
3.6.2 Data Collection Procedure .....	21
3.7 DATA ANALYSIS AND REPORTING .....	21
3.8 LIMITATIONS.....	21
3.9 ETHICAL CONSIDERATION .....	21
3.10 ASSUMPTION .....	21
CHAPTER FOUR: DATA PRESENTATION AND ANALYSIS .....	22
4.1 INTRODUCTION.....	22
4.2 QUANTITATIVE DATA ANALYSIS .....	22
4.3 BACKGROUND DATA ANALYSIS .....	22
4.3.1 Gender of the Respondents .....	22
4.3.2 Age of the Respondents .....	23
4.3.3 HIV Status of Respondents.....	24
4.3.4 Marital Status of the Respondents.....	25
4.3.5 The number of children of the respondents .....	26
4.3.6 Level of Education of the Respondent .....	27
4.3.7 Occupation .....	28
4.3.8 The Number of Children Infected with HIV.....	29
4.3.9 The Child’s Awareness.....	30
4.3.10 Who made the Disclosure .....	31
4.3.11 The Age of Disclosure .....	32
4.3.12 The Child’s Reaction after Disclosure.....	33
4.3.13 The well being of the child after disclosure.....	34
4.3.14 Benefits of Disclosure to the child .....	35



4.3.15 Risks to the Child upon Disclosure .....	36
4.3.16 Benefits to Others .....	37
4.3.17 Risks of disclosing a child’s HIV status to others.....	38
CHAPTER FIVE: STUDY FINDINGS AND RECOMMENDATIONS .....	40
5.1 INTRODUCTION.....	40
5.2 DISCUSSION.....	40
5.3 RECOMMENDATIONS.....	41
5.3 CONCLUSION.....	41
SCHEDULE OF RESEARCH ACTIVITY .....	42
BUDGET.....	43
THE PERCEIVED IMPACT OF DISCLOSURE OF PEDIATRIC HIV POSITIVE STATUS QUESTIONNAIRE .....	45
REFERENCES: .....	47

## LIST OF ABBREVIATION

HIV	–	Human Immunodeficiency Virus
AIDS	-	Acquired Immunodeficiency Syndrome
WHO	-	World Health Organization
UNAIDS	–	United Nations Programme on HIV Aids
UNODC	–	United Nations Office on Drugs and crime
ARV	-	Anti Retro Viral
ARVT	–	Antiretroviral Therapy
STI	-	Sexually Transmitted Infections
EDTA	–	Ethylenediaminetetraacetic acid
EIA	–	Enzyme Immune Assay
MTCT	–	Mother to child Transmission
TB	–	Tuberculosis
CD <sub>4</sub>	–	Cluster of Differentiation 4
USA	–	United States of America
Mm <sup>3</sup>	–	Millimeters cubed
DRC	–	Democratic Republic of Congo
NNRTI	–	Non-nucleoside Reverse Transcriptase
NRT	–	Nucleotide Reverse Transcriptase

**LIST OF TABLE**

Table4.3.1 Gender of the respondents.....22

Table4.3.2 Age of the respondents.....23

Table4.3.3 HIV status of the respondents.....24

Table 4.3.4 Level of education of the respondents.....25

Table 4.3.5 Occupation of the respondents.....26

Table 4.3.6Marital status of the respondents.....27

Table4.3.7 Number of children.....29

Table 4.3.8Number of the infected children.....31

Table 4.3.9 Child’s awareness.....33

Table 4.3.10Who made the disclosure.....34

Table 4.3.11At what age was the disclosure made.....35

Table 4.3.12 Child’s reaction after disclosure.....36

Table 4.3.13Change in the well being of the child.....37

Table 4.3.14Benefits of disclosure to the child.....36

Table 4.3.15Risks of disclosure to the child

Table 4.3.16Benefits of disclosing to others

Table 4.3.17Risks of disclosing to others

## **LIST OF FIGURES**

- Figure 4.3.1 Gender of the respondents
- Figure 4.3.2 Age of the respondents
- Figure 4.3.3 HIV status of the respondents
- Figure 4.3.4 Level of education of the respondents
- Figure 4.3.5 Occupation of the respondents
- Figure 4.3.6 Marital status of the respondents
- Figure 4.3.7 Number of children
- Figure 4.3.8 Number of the infected children
- Figure 4.3.9 Child's awareness
- Figure 4.3.10 Who made the disclosure
- Figure 4.3.11 At what age was the disclosure made
- Figure 4.3.12 Child's reaction after disclosure
- Figure 4.3.13 Change in the well being of the child
- Figure 4.3.14 Benefits of disclosure to the child
- Figure 4.3.15 Risks of disclosure to the child
- Figure 4.3.16 Benefits of disclosing to others
- Figure 4.3.17 Risks of disclosing to others

RESEARCH STUDY: A STUDY TO DETERMINE THE PERCEIVED IMPACT OF  
DISCLOSURE OF PEDIATRIC HIV POSITIVE STATUS IN  
KIBAGARE VILLAGE ON DECEMBER 2012

RESEARCHER: MUSAU SALOME NDETO  
A10/2017/10

BROAD OBJECTIVE: TO DETERMINE THE PERCEIVED IMPACTS ON  
DISCLOSURE OF PEDIATRIC HIV STATUS

SPECIFIC OBJECTIVES: - TO DETERMINE WHO SHOULD DISCLOSE THE HIV  
STATUS TO THE CHILD  
- TO DETERMINE AT WHAT AGE OF THE CHILD  
SHOULD THE DISCLOSURE BE MADE  
- TO EXPLORE ON THE POSITIVE AND NEGATIVE  
PERCEIVED IMPACTS ON DISCLOSURE OF PEDIATRIC  
HIV STATUS.

## **CHAPTER ONE**

### **1.0 DEFINITION**

HIV According to USAID (2010) HIV stands for Human Immunodeficiency Virus. HIV is a virus (Of the type called retro virus) that infects cells of the human immune system mainly CD4 positive t cells and macrophages and destroy or impair their function. Infection with this virus results in progressive deterioration of the immune system leading to “immune deficiency”.

AIDS -This stands for acquired immunodeficiency syndrome. It is a surveillance definition based on signs, symptoms and infections associated with the deficiency of the immune system that stems from infection with HIV.

### **1.1 EPIDEMIOLOGY**

Globally 34.0 million (31.4 -35.9 million) people were living with HIV at the end of 2011 .an estimated 0.08% of adults aged 15 -49 years worldwide are living with HIV although the burden of epidemic continues to vary between countries and regions.( WHO, 2012).

Sub Saharan Africa remains the mostly affected with 23.3 million people infected. Nearly 1 in every 20 adults (4.9%) living with HIV are in Africa accounting for 69% of infected persons worldwide. Female are more affected than male and the prevalence rates are much higher in urban areas. In Africa at large, the number of people (adults and children) that acquired HIV in 2011 was (2.5 million) 20% lowers than in 2001, (WHO, 2012). In Africa, HIV prevalence trend among population group at higher risk of contracting the infection. This includes; sex workers, people who inject drugs, men who have sex with other men, prisoners and migrants.

According to UNODC, Eastern Africa is the second most affected region by HIV and AIDS in Africa after the southern Africa. Although general prevalence has been reducing during the past 2 decades new areas of concern with regard to infection among the most at risk population are emerging. . in Kenya, it is estimated that 1.6 million people are living with HIV. Adult age (15-49) prevalence rate is 6.2 % amounting to 1.4 million, women aged 15-49 infected with HIV are 800,000 and children aged 0-14 years amount to 220,000. Deaths due to AIDS were 62,000 and orphans due to AIDS aged 0-17 were 1.1 million. (UNAIDS HIV and AIDS estimates, 2012).

In provinces, HIV prevalence range from a high of 13.9% in Nyanza province, to a low of 0.9% in North Eastern province. Women account for 59.1% of adults living with HIV and their prevalence is twice that among men, (Kenya National Bureau of Statistic, 2012).

### **1.3 CLINICAL FEATURES**

The symptoms of HIV vary depending on the stage of infection. Though people living with HIV tend to be most infectious in the first few months, many are unaware of their status until later stages.

The first few weeks after initial infection, individuals may experience no symptom or influenza like illness including fever, headache and rash of sore throat. As the infection progressively weakens the person's immune system, the individual develop other signs and symptoms.

#### **1 .3.1 Symptoms**

Patient reports:

- Swollen neck
- Weight loss
- Increased body temperature
- Diarrhea
- Cough

#### **1.3.2 Signs**

- Swollen lymph nodes
- Cachexia
- Fever

At this state, in case the health practitioner at hand suspects HIV infection, blood screening for HIV should be conducted.

#### **1.3.3 Importance of HIV Testing**

To know the HIV status of a person

In case one is infected, to the all necessary precautions to prevent the spread of HIV to others

If tested positive, to access treatment, care and support services

In case of a pregnant HIV mother, to protect the transmission of HIV to the unborn child

Those tested HIV negative to continue protecting themselves from acquiring the disease

## **1.4 PROVIDER INITIATED TESTING AND COUNSELLING**

WHO defines 5 key components “the 5 C’s” that must be respected and adhered to by all HIV Testing and counseling services. These include;

1. Consent
2. Confidentiality
3. Counseling
4. Correct test results
5. Connection to prevention, care and treatment

### **1.4.1 Consent**

People being tested for HIV must give informed consent in order to be tested. They must be informed of the process of testing and services available depending on the results of the test and they have a right to refuse testing.

### **1.4.2 Confidentiality**

Testing services must be confidential meaning that the content of discussion between the person tested and the health provider as well as the results should not be disclosed to anyone else without the consent of the person tested.

### **1.4.3 Counseling**

Testing must be accompanied by appropriate and high quality pre- test and post-test counseling.

### **1.4.4 Correct Test Results**

Testing must be performed and quality measures followed. Results must be communicated to the person tested unless that person refuses the results.

### **1.4.5 Connection to HIV Prevention, Treatment Care and Support**

Patient should be supported through concrete and well resourced patient referral depending on the results of the test.



WHO recommend that HIV testing should be done voluntary on individual in public health ground. Mandatory testing should only be done in case of;

- ✓ Screening HIV and other blood borne infections of all blood destined for transfusion or for manufacture of blood products.
- ✓ Screening for donors prior to all procedures involving transfer of bodily fluids or body parts

## **1.5 HIV TESTING**

### **1.5.1 Specimen**

Many types of specimen can be used with HIV testing technologies. These include;

- ❖ Whole blood
- ❖ Plasma
- ❖ Serum
- ❖ Oral fluids (saliva)
- ❖ Urine

Blood (whole blood, plasma and serum) is the most preferred specimen for testing because it has a high concentration of HIV antibodies than urine or oral fluids.

### **1.5.2 Sample Collection**

Blood needed for HIV testing can be collected by venipuncture or by finger prick or ear lobe prick.

### **1.5.3 Sample Collection Procedure**

#### **1.5.3.1 Finger Prick Sample**

In African set up this is the mostly preferred method in sample collection. It is used to perform a rapid test or to make a dried blood spot on a filter paper. The procedure entails;

1. Massage the finger (preferably the middle or ring finger) .this will case blood to accumulate at the tip of the finger.
2. Cleanse the finger pad with 70% isopropyl alcohol
3. Wipe away the alcohol with sterile gauze
4. Use a sterile lancet to firmly prick the finger pad

5. Wipe the first drop of blood off the finger with sterile gauze before collecting the subsequent blood
6. If the original puncture is inadequate, the same site should not be punctured again. Use another site
7. Avoid squeezing the puncture site as this may cause blood hemolysis
8. Collect about 10 mls of blood

## **1.6 LABORATORY DIAGNOSIS**

The current HIV testing technologies are:

- Antibody test – detects antibodies to HIV
- Virological test – detect specified HIV antigens
- Viral nucleic acid – detect polymerase chain reaction
- Viral culture – grows the virus

The most commonly used technologies are the antibody test and the virological tests since they are cheap and are associated with low laboratory errors.

In antibody test the technologies used are;

- ✓ EIA rapid test
- ✓ Western blot
- ✓ Immunofluorescent assay

In Kenya, rapid test is the most preferred.

Virologic test technologies include;

- ✓ EIA
- ✓ Antigen testing

### **1.6.1 Diagnosis in Adults**

The diagnosis is confirmed by antibody test. This detects the antibodies produced by the body to fight against HIV antigens.

### **1.6.2 Diagnosis in Children**

Recommendation by WHO

1. HIV antibody serology assay used for clinical diagnostic testing in children entails;
  - ❖ <18 months of age – used as a screening assay to determine HIV exposure
  - ❖ >18 months of age – used as a diagnostic assay
2. Virologic assay test is used for children below 18 months. The viral assay recommended for use entail; HIV DNA on whole blood specimen, HIV RNA on plasma and P24 antigen in plasma.
3. HIV exposed infants should have HIV virological testing at 4-6 weeks of age or at the earliest opportunity thereafter.
4. Infants with initial positive virological test results ARVT should be started without delay.
5. In breastfeeding infants or children should not be discontinued in order to perform any kind of diagnostic HIV test.
6. Children 18 months or older with suspected HIV infection or exposure should have an antibody test performed.

## **1.7 ROUTES OF TRASMISSION**

### **1.7.1 In Adults**

This is broadly classified to sexual and non sexual routes.

#### Sexual

- Unprotected sex which could be;
- Anal
- Oral
- Vaginal

#### Non – Sexual

- Injection drug use - sharing of needles and syringes
- Contact between infectious fluids and bleeding cuts or open sores
- Tattoos and piercing - sharing of piercing tools
- Mother to infant transmission

### **1.7.2 In Infants and Children**

This can be as result of maternal transmission to the child or other routes.

Mother to Child Transmission

- ✓ During pregnancy – new born is exposed to vaginal fluids
- ✓ During labor and delivery – exchange of maternal and newborn blood in the placenta
- ✓ After delivery – in breast milk

Other routes

- ✓ Blood transfusion (unscreened blood)
- ✓ Use of contaminated needles and syringes
- ✓ Child abuse (sexual abuse)

## **1.8 WHO STAGING OF HIV**

### **1.8.1 Revised Clinical Staging of HIV/AIDS in Adults**

Stage 1

- Asymptomatic
- Persistent generalized lymphadenopathy

Stage 2

- Moderate unexplained weight loss (10% of the measured body weight)
- Recurrent respiratory tract infections
- Herpes zoster
- Angular cheilitis
- Recurrent oral ulcerations
- Popular pruritis eruption
- Seborrhoeic dermatitis
- Fungal nail infection of the fingers

Stage 3

- Severe weight loss (>10% of measured body weight)
- Unexplained chronic diarrhea for longer than 1 month
- Unexplained persistent fever
- Oral candidiasis
- Oral hairy leukoplekia
- Pulmonary TB

- Severe presumed bacterial infection
- Acute necrotizing ulcerative stomatitis gingivitis or periodontitis

#### Stage 4

- HIV wasting syndrome
- Pneumocystic pneumonia
- Recurrent severe bacterial pneumonia
- Esophageal candidiasis
- Chronic herpes simplex infection
- Extra pulmonary TB
- Kaposi sarcoma
- CNS toxoplasmosis
- HIV encephalopathy

### **1.8.2 Revised Clinical Staging of HIV/AIDS for Infants and Children**

#### Stage 1

- ✓ Asymptomatic
- ✓ Persistent generalized lymphadenopathy

#### Stage 2

- ✓ Hepatosplenomegally
- ✓ Popular pruritic eruptions
- ✓ Seborrhoeic dermatitis
- ✓ Extensive human papilloma virus infection
- ✓ Extensive molluscum contagiosum
- ✓ Fungal nail infection
- ✓ Recurrent oral ulcerations
- ✓ Lineal gingival erythema
- ✓ Angular cheilitis
- ✓ Herpes zoster
- ✓ Recurrent chronic respiratory tract infections

### Stage 3

- ✓ Moderate unexplained malnutrition not adequately responding to treatment
- ✓ Unexplained persistent diarrhea >14 days
- ✓ Unexplained persistent fever
- ✓ Oral candidiasis
- ✓ Oral hairy leukoplekia
- ✓ Acute necrotizing ulcerative gingivitis
- ✓ Pulmonary TB
- ✓ Severe recurrent presumed bacterial infection

### Stage 4

- ✓ Unexplained severe wasting or malnutrition
- ✓ Pneumocystic pneumonia
- ✓ Recurrent severe presumed bacterial infection
- ✓ Chronic herpes simplex
- ✓ Extra pulmonary TB
- ✓ Kaposi sarcoma
- ✓ Esophageal candidiasis
- ✓ CNS toxoplasmosis
- ✓ HIV encephalitis

## **1.9 ANTIRETRO VIRAL THERAPY**

### **1.9.1 ARV Drug Class**

#### Nucleoside Reverse Transcriptase Inhibitor (NRTI)

- ✓ Zidovudine
- ✓ Stavudine
- ✓ Lamivudine
- ✓ Abacavir
- ✓ Tenofovir

#### Non Nucleoside Reversed Transcriptase (NNRTI)

- ✓ Efavirenz

- ✓ Nevirapine

### **1.9.2 WHO Recommendation on who to Start ARV Therapy**

1. Treat all patients with CD4 count less than or equal to 350 cells/mm cubed irrespective of WHO clinical staging
2. All patients with clinical stage 1 and 2 should have access to CD4 test to decide when to initiate treatment
3. All patients with clinical stage 3 and 4 should be started on ARV therapy irrespective of their CD4 count

WHO recommend that first line therapy should include 2 drugs from NRTI AND 1 drug from NNRTI

### **1.10 COMPLICATIONS OF HIV**

Most complications occur when one is diagnosed with AIDS. These complications may be due to ARV toxicity or opportunistic infections.

#### **1.10.1 Drug Toxicity**

- ❖ Lipodystrophy
- ❖ Neuropathy
- ❖ Lactic acidosis
- ❖ Anemia
- ❖ Neuropaenia
- ❖ Renal dysfunction
- ❖ Tetragenicity
- ❖ Psychiatric illness
- ❖ Hepato toxicity

### **1.11 HIV PREVENTION**

There are three broad methods of preventing HIV/AIDS. These include;

1. Sexual transmission
2. Transmission through blood

### 3. Mother to child transmission

#### **1.11.1 Sexual Transmission**

- Abstinence
- Being faithful to your partner
- Use of condoms (male and female)
- Circumcision
- Avoid anal or oral sex

#### **1.11.2 Transmission through Blood**

- ✓ Avoid use of contaminated needles and syringes
- ✓ Avoid sharing of needles and syringes among patients
- ✓ Wear protective gears eg. Gloves when handling body fluids
- ✓ Use of pre and post exposure HIV prophylaxis

#### **1.11.3 Mother to Child Transmission**

- ❖ Provision of ARV drugs to HIV positive mothers during pregnancy and labor
- ❖ Avoid unwanted pregnancies among HIV infected women
- ❖ Ensure HIV testing of pregnant women and timely access to effective ARV therapy
- ❖ Keep women of reproductive age and their partners HIV negative

### **1.12 RESEARCH PROBLEM**

According to Vreeman C, M Winstone et al, (2010) in Africa, due to cultural belief and HIV stigma, disclosing a child's HIV status and the subsequent impacts of disclosure have not been well studied.

In Kibagare village, no community health activity has ever tackled the issue of pediatric HIV status disclosure.

This research on pediatric HIV status disclosure is worth of academic researching to determine who should disclose, at what age should the disclosure should be made and what are the perceived positive and negative impacts of disclosing the child's HIV status.

### **1.13 AIM OF THE STUDY**

The aim of the study is to determine the perceived impacts of pediatric HIV status disclosure in Kibagare Village.



### **1.14 RESEARCH OBJECTIVES**

The researcher will be guided by the following objectives:

**Broad Objective:**

To determine the perceived impacts on disclosure of pediatric HIV status

**Specific Objectives:**

To determine who should disclose the HIV status to the child

To determine at what age of the child should the disclosure be made

To explore on the positive and negative perceived impacts on disclosure of pediatric HIV status

### **1.15 RESEARCH QUESTIONS**

1. Who should disclose the child's HIV status to that child?
2. At what age of the child should the disclosure be made?
3. What are the perceived impacts of HIV status disclosure to the child?

## CHAPTER TWO

### 2.0 INTRODUCTION

Despite the progress in expanding access to ART in the recent years, progress in pediatric HIV counseling and disclosure – The gateway to successful treatment – has lagged. In 2009, an estimated 2,500,000 children under 4 years of age were living with HIV. Of these, 2,300,000 live in Sub-Saharan Africa. Of the estimated 1,276,000 children under 15 years of age in need of ART, just 356,400 i.e. 28% are on treatment. This was as a result of failure to the disclosure of the child's HIV diagnosis and also drops out on ART adherence (WHO, 2009).

### 2.2 LITERATURE REVIEW

World wide, AIDS is estimated to be the 8<sup>th</sup> leading cause of death among adolescent ages 15-19 years and the 6<sup>th</sup> leading cause of death among those aged 10-14 years. In countries with high HIV prevalence, AIDS take a relative toll. This is because children with HIV disease have been called 'The Missing Face of AIDS' because they lack basic healthcare including HIV disclosure; which is the core factor contributing to ART adherence (WHO, 2009).

Recent research documents the complex psychosocial issues related to disclosure of a child's HIV status. Research on disclosure of a child's HIV status including who should disclose, at what age of the child should the disclosure be made and what are the perceived impacts upon disclosure has been 'A vital part of research' on families affected with HIV/AIDS.(USAID – AMPATH, 2001)

ART saves the lives of HIV infected children. For 2.3 million children around the world, currently living with HIV, disclosing the child's status, initiating and maintaining ART is crucial to showing the progression to AIDS and preventing death. The caregivers of HIV infected children, whether parents, relative or guardian play a casual role in the initiation of discussing the child's HIV status and also provision of ART to the child.

As the disclosure of HIV test results play an important role in the way forward, many HIV infected children have not been explicitly told of their diagnosis.

According to WHO, an extensive review of literature on effects of disclosure was conducted to support the developmental guidance on HIV disclosure. This focused on patterns of disclosure,

the difference between disclosure and non disclosure, the experience of caregivers with HIV, their decision on whether to disclose or not to disclose, the reason behind their decision on disclosure and the child's perceived impacts on post disclosure period.

Studies point to the contextual challenges facing the parent or caregiver as there were associated complications upon disclosure. This included: Feeling of shame on the parent or care givers on disclosing their own HIV status, explaining the route at which HIV was transmitted to the child, and the reason why they had not disclosed this information. Caregivers also feared the stigma associated with disclosure exacerbated depression and negative mental health that could affect the child (UNAIDS, 2009).

Many researchers argue that disclosure comes with added responsibilities. This includes: the child's illness management; including medication, initiation and adherence and coping with HIV symptoms and treatment side effects. These responsibilities often increase parental stress.

Disclosure is a process of many conversations over time and may call for information reassurance and planning. The act of disclosure include a number of specific steps of explanations including naming the condition, how it was transmitted to the caregiver or the child, are there other family members that are infected, what will happen to the child in the course of their own disease and incase the caregiver dies, who will take care of the child (USAIDS-AMPATH, 2001).

In a study from Maryland, children who were aware of their HIV status were significantly less likely to be categorized as adherent. Another study from New York, children's knowledge of their HIV status also associated with lower CD<sub>4</sub> count and higher viral load. This study also indicated among pediatric care systems, many HIV infected children were not aware of their diagnosis. One study from Thailand reported that 1 in 5 HIV infected children age 5-16 years (mean age 9 years) had been told f their HIV diagnosis by their parents. Parents involved in this study raised concerns about disclosure as it could cause psychological harm to the child and probably the child was too young to keep a secret to themselves.

The Sub-Saharan Africa, studies from South Africa using semi structured interviews suggested that disclosure on pediatric HIV status could impact medication initiation and adherence. In DRC a qualitative study with 19 youths and 42 caregivers found that the median age at disclosure was 15 years and one of the most common reasons for disclosure was to improve the child's adherence to their treatment regimen as well as the child to stay healthy.

In eastern Africa a qualitative study in Uganda involving 50 pediatric caregivers argued that disclosure on HIV status should start as early as 5 years of age and complete disclosure should be made by the time the child reaches 17 years of age. In a larger cross-sectional study from Ethiopia, it was found that children who were not aware of their own HIV status and that of their caregivers were actually more likely to adhere to ART than their counterparts; even when adjustment for other characteristics such as age was done.

In Western Kenya, USAID-AMPATH conducted a study in collaboration with Moi University School of Medicine and Moi Teaching and Referral Hospital on how pediatric caregivers revealed the disclosure of a child's HIV status. These caregivers described that disclosure had some negative and positive impacts. Benefits included sustaining the child's ART adherence through addressing the child's developmental needs to understand why they are taking ART. However, they were simultaneous risks involved with disclosing HIV status.

This included: the risk of the child could be negatively be affected in their social life and also school performance since majority of them were school goers. Upon disclosing this information to other persons e.g. relatives, they could respond negatively by stigmatizing, isolating, discouraging or discriminating the affected child or the family at large. In this study, only 2 caregivers out of 40 had informed the child on HIV diagnosis. This was as results of some children were too young or developmentally unready for disclosure.

In Kibagare village, which is located in Kangemi slums Westlands constituency, no research had been conducted on the impacts of disclosing pediatric HIV status. There has been a neglected of this issue because parents and caregivers were greatly afraid of the negative impacts associated with disclosure. Only 15% of HIV infected children were aware of their HIV diagnosis. For

example in Kangemi Health Centre which serves the people of Kibagare village the ratio of adult to children (aged 5-12 years) enrolled in ART programme was 9.2. the most challenging task on disclosure according to Kangemi Health Care staff members was: who should disclose this information to the child, at what age of the child should the disclosure be made and what are the impacts of disclosing this information to the child and the community at large. (Kangemi Health Centre).

WHO recommendation of pediatric HIV status disclosure indicates that:

Children of school age should be told their status; the younger should be told their status incrementally to accommodate their cognitive skills and emotional maturity in preparation for full disclosure.

The decision on who should or will disclose to the child should be guided by the intent to improve the child's welfare and minimize the risk to his/her well being and to the quality of the relationship between the child and the parent/caregiver

Initiatives should be put in place to enforce privacy protection discrimination and promote tolerance and acceptance of people (in this case children) living with HIV. This can help create environments where disclosure of HIV status is easier.

According to WHO publication on Disclosure of Pediatric HIV status, child age in relation to disclosure always intertwine: the older the child, the more likely the child will develop emotional or behavioral problems upon disclosure and if the child is not on treatment, the more neurocognitive delay they will develop. Studies suggest that parents/caregivers who are distressed (HIV positive) see more distress in their children and thus there's fear of disclosing this information to the child.

A study was done to compare between outcomes for HIV positive children (0 – 12 years) who were disclosed to and those who were not and outcome of HIV positive children before and after disclosure. This study was conducted in different WHO member states. It was found that in a Romanian study health outcome indicate that there was CD<sub>4</sub> count decline, later on drug adherence was improved and thus less than half of the risk of death over a 3 year period among children who had been disclosed to compared with their counterparts. In Togo, Uganda and

DRC, a nearly 20% greater rate of drug adherence was reported in those children who were aware of their status. On comparing effects before and after disclosure a prospective, longitudinal, multicity USA study followed pediatric cases (0-12 years) 3 years before and 3 years after disclosure. Butler et al found no significant change on health measure, mental health and social behaviour of the child. Conclusively it was learnt that disclosure had positive impacts on the child and those disclosing this to the child, should consider the child's cognitive development.

In Africa researches indicate that the negative impacts of disclosure outway the positive impacts. This was particularly the stigma associated with HIV disease. In Africa at large, HIV is considered as one of the most dangerous disease of human kind and thus upon disclosure of a pediatric HIV status to other persons, the risk include isolation, stigmatization, discrimination and excommunication of the child or family affected from the community. Luckily with the new technology of social networks such as Face book, Twitter, My Space and Internet access new and positive information has been conveyed about HIV/AIDs. Many people particularly youths are changing their mindset towards the positive response upon HIV infection.

## **CHAPTER THREE: RESEARCH METHODOLOGY**

### **3.1 INTRODUCTION**

This chapter aims at identifying the research method appropriate for the study. It aims at identifying the research technique that will be appropriate for the researcher in order to determine the perceived impact of disclosure of pediatric HIV positive status. This will also enable the researcher to identify a sample that will at most represent the entire population at Kibagare Village.

### **3.2 STUDY AREA**

#### **3.2.1 Geographical Area**

Kibagare village is situated in Kangemi sub location Nairobi County in Kenya. Its geographical co-ordinates are 1<sup>0</sup>16'0 North and 36<sup>0</sup>43'60" East.

#### **3.2.2 Topography and Vegetation**

Kibagare is located 1,816 meters above sea level. The landscape type of soil is lixisol, with clay-enrichment, low horizon and high saturation of bases. It is mostly covered with buildings and man-made objects. The land is cultivated and some natural vegetations are still preserved.

#### **3.2.3 Climatic Conditions**

Kibagare has a humid of > 0.65 p/per climate. Its climate is classified as marine west (No dry season, warm summer) with sub tropical dry forest biozone. Average temperatures are 23.30C and average rainfall 986mm annually.

#### **3.2.4 Administrative Boundaries**

The study was carried out in Kibagare village Kangemi Sub-location, Westlands Constituency, Nairobi County.

#### **3.2.5 Communication**

The main roads in the area are Nairobi-Nakuru highway commonly known as Waiyaki way, Mukabi road and Kibagare village (Kibagare lane) is not tarmac.

### **3.2.6 Educational Facilities**

Kangemi is the home of well known schools such as Nairobi School and Kianda School. Public schools include Loresho and Kangemi primary. It also boasts to be home to Jomo Kenyatta University of agriculture and Technology Nairobi Campus.

### **3.2.7 Social Economic Status**

Majority of people in Kibagare village do not have permanent jobs. They mostly do casual work in order to earn a living. Trade is prevalent in Kangemi open market. It entails selling of foodstuff. More than 50% of Kibagare population lives in absolute poverty.

## **3.3 RESEARCH POPULATION**

The research population was approximately 400 adults in Kibagare village who had children aged between 1 and 18 years.

## **3.4 RESEARCH DESIGN**

The research design is a descriptive cross-sectional study design. This will provide an accurate portrayal of a group of subjects (both parents and guardians with HIV positive children aged between 1 and 18 years. It will entail the precise measurement of phenomena on perceived impacts of pediatric HIV positive status disclosure. The availability of subjects and time will not be expensive. The descriptive study and time will be utilized to determine who should disclose the HIV status to that child at what age should the disclosure be made and what are the perceived impacts both negative and positive upon HIV status disclosure to the child.

## **3.5 SAMPLING PROCEDURES**

### **3.5.1 Sample Method and Technique**

Sampling is the process of selecting a number of individual study unit in such a way that they represent the entire population (Mugenda and Mugenda 1999). In this study non-probability method will be adopted since the study is judgmental.



### 3.5.2 Sampling Size Determination

The sample size was calculated using the Fisher's et al 1998 formula. It estimates the population proportion with a specified absolute precision.

$$n = \frac{z^2 p Q}{d^2}$$

Where;

N = sample size

Z = Confidence interval/Standard deviation. It's usually taken as being 1.96

P = Prevalence of the population of 50% of the population is unknown P = 0.5

Q = 1-P It's usually constant

D = Design effect used to minimize errors = 1

d<sup>2</sup> = Precision of confidence interval or degree of accuracy and can be 5% or 2%.

This Fisher's et al 1998 formula is used in population > 10,000; substituting.

$$n = \frac{z^2 p Q}{d^2}$$

i.e.

$$\frac{(1.96)^2 \times 0.5 \times (1 - 0.5)}{0.05^2} = \frac{(1.96)^2 \times 0.5 \times 0.5 \times 0.5}{0.05^2}$$

$$\frac{0.9604}{0.0025} = 384.16 \approx 384$$

For a target population <10,000

$$Nf = \frac{n}{1 + \left(\frac{n}{N}\right)}$$

Where Nf= Sample size

n = constant figure i.e. 384 adults

N = Estimated target population i.e. 400 adults

$$Nf = \frac{384}{1 + \left(\frac{384}{400}\right)}$$

$$= 384 \times \frac{196}{100}$$

$$= 195.92 \approx 196$$

### **3.6 DATE COLLECTION**

#### **3.6.1 Data Collection Methods and Techniques**

The researcher intends to use one method of collecting data, primary method. Primary data method is where data is collected from the source. The researcher also intends to collect both quantitative and qualitative data.

#### **3.6.2 Data Collection Procedure**

The researcher will develop instruments such as questionnaire. These questionnaires will be both structured and unstructured with both open and closed ended questions. The researcher will also do several interviews with the administrative management of the Kibagare village.

### **3.7 DATA ANALYSIS AND REPORTING**

The researcher will analyze both the dependent and independent variables. In order to meaningfully describe the distribution of the core, the researcher will use a descriptive analysis. Graphical presentation will be used, as the researcher aims at adequately exhausting the study questions to a concise analysis of the research.

### **3.8 LIMITATIONS**

The researcher anticipated hindrance especially because of time, finance and unwillingness from the respondents.

### **3.9 ETHICAL CONSIDERATION**

According to Mugenda and Mugenda (1999) ethics is defined as a branch of philosophy which deals with one's conduct and serves as a guide to ones behaviour. In this study, the researcher will require an introductory letter to the people under study. Any data that will be obtained will be treated as confidential and only for academic purposes.

### **3.10 ASSUMPTION**

The sample used represented the study population. The information/data collected was correct.

## CHAPTER FOUR: DATA PRESENTATION AND ANALYSIS

### 4.1 INTRODUCTION

This chapter presents a summary and study finding of data collected from the study through the questionnaires. It analyzes the data in tabular formats and gives presentation in form of graphs and pie charts.

### 4.2 QUANTITATIVE DATA ANALYSIS

The researcher collected data from parents and guardians in Kibagare village. These were caregivers of HIV positive children aged between 1 to 18 years. The questionnaire was designed to incorporate the close ended questions. The data collected was analyzed to get clear picture of results. The questions used in the study were carefully checked and edited for errors, to ensure competencies, consistency and accuracy. This was to make sure that the information given by respondents was accurate and valid.

### 4.3 BACKGROUND DATA ANALYSIS

In order to analyze the research study, the researcher submitted a total of 196 questionnaires of which 26 questionnaires were not answered as required. The remaining questionnaires were 170, each with a total of 17 questions were answered well. The researcher used tables and determined cumulative frequency and the percentage and degree on the response in reference to the data codes.

#### 4.3.1 Gender of the Respondents

The study sought to establish the gender of the respondents since both genders were caregivers to HIV infected children.

The table 4.3.1 Shows gender of the respondents.

<b>Gender</b>	<b>Frequency</b>	<b>Cumulative frequency</b>	<b>Percentage %</b>
Male	50	50	29.41
Female	120	170	70.59

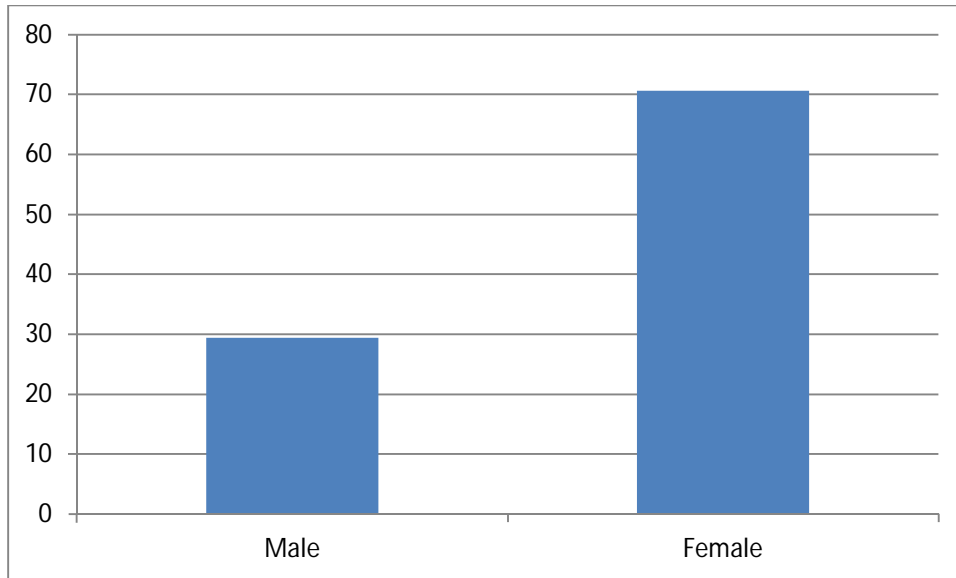


Fig.4.3.1 shows the gender of the respondents

According to this data it shows that most of the caregivers were female with 70.59% compared to the males who were 29.41%.

#### 4.3.2 Age of the Respondents

The study sought to establish the age of the respondents. This was sought in terms of age brackets.

The table 4.3.2 shows the age of the respondents

Age	Frequency	Cumulative Frequency	Degrees
0-20	20	20	42.35
21-30	30	50	105.88
31-40	50	100	63.53
>40	70	170	148.24

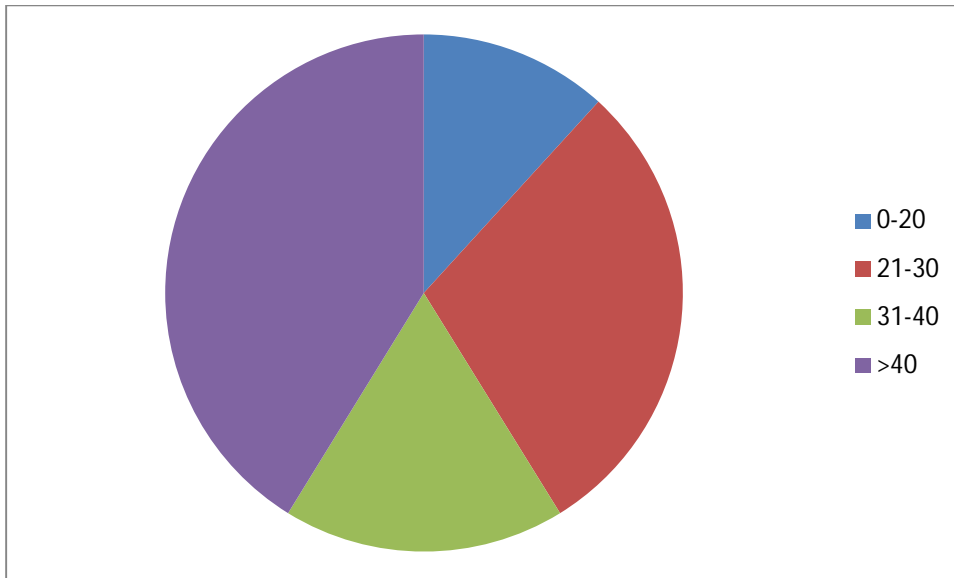


Fig.4.3.2 shows the age of the respondents

According to this data it shows the commonest age group of the respondents was above 40 years of age i.e. 148.24<sup>0</sup> while the least age group was between 0-20 years with 42.35<sup>0</sup>.

### 4.3.3 HIV Status of Respondents

The study sought to know the HIV status of the respondents; indicated as positive or negative.

HIV Status	Frequency	Cumulative Frequency	Percentage
Positive	110	110	64.71
Negative	60	170	35.29

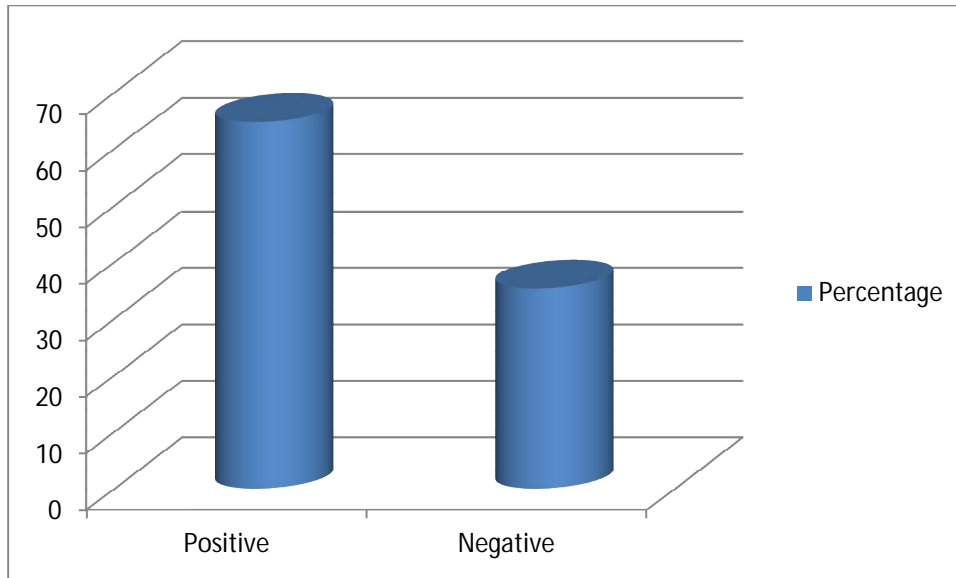


Fig.4.3.3 shows the HIV status of the respondents

According to this data most of the caregivers were HIV positive amounting to 64.71% while the negative caregivers were 35.21%.

#### 4.3.4 Marital Status of the Respondents

The study sought to know the marital status of the respondents. This was rated as single, married and others.

The table 4.3.5 shows the marital status of the respondents

Marital status	Frequency	Cumulative Frequency	Percentage
Single	40	40	23.53
Married	60	100	35.29
Others	70	170	41.18

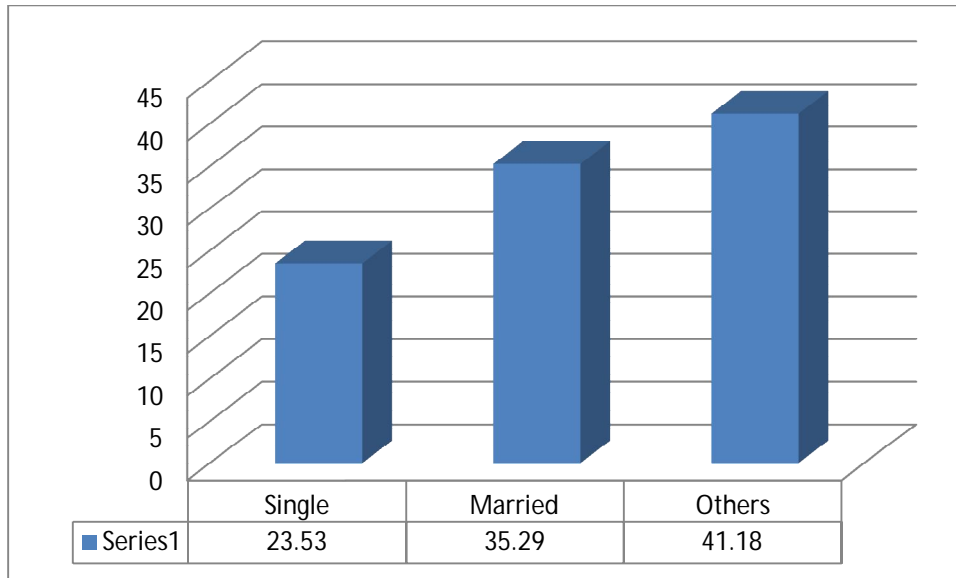


Fig.4.3.5 shows the marital status of the respondents

According to this data there was a high percentage of 41.18% of respondent who lied in the class of others. This class included the divorced, widowed, widowers. The married class came second with 35.29%. It was followed by single class which amounted to 23.53%.

#### 4.3.5 The number of children of the respondents

The study sought to establish the number of children the respondent had. This was the total number of children.

The table 4.3.6 shows the number of children the respondent had

Number of children	Frequency	Cumulative Frequency	Percentage
0	10	10	5.88
1	20	30	11.76
2	60	90	35.29
>2	80	170	47.06

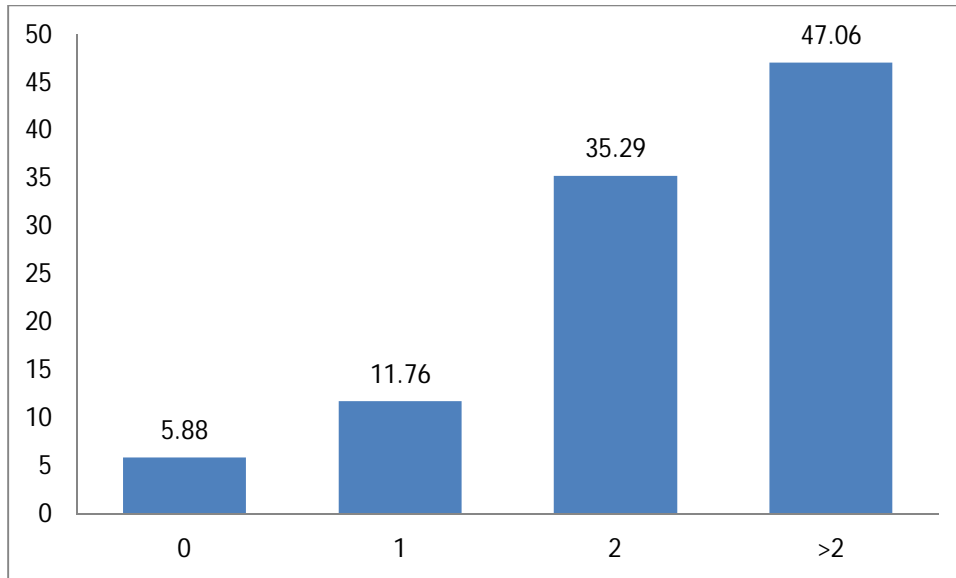


Fig.4.3.6 shows the number of children

According to this data, most of the respondents had more than 2 children. This amounted to 47.06%. The least was 5.88% which represented the percentage of respondent who did not have children.

#### 4.3.6 Level of Education of the Respondent

The study sought to establish the level of education of the respondents. This would influence the perceived impact of disclosure.

The table 4.3.4 shows the level of education of the respondents

Level of Education	Frequency	Cumulative Frequency	Percentage
Primary	20	20	11.76
Secondary	50	70	29.41
Tertiary	40	110	23.53
Graduates	20	130	11.76
Others	40	170	23.53



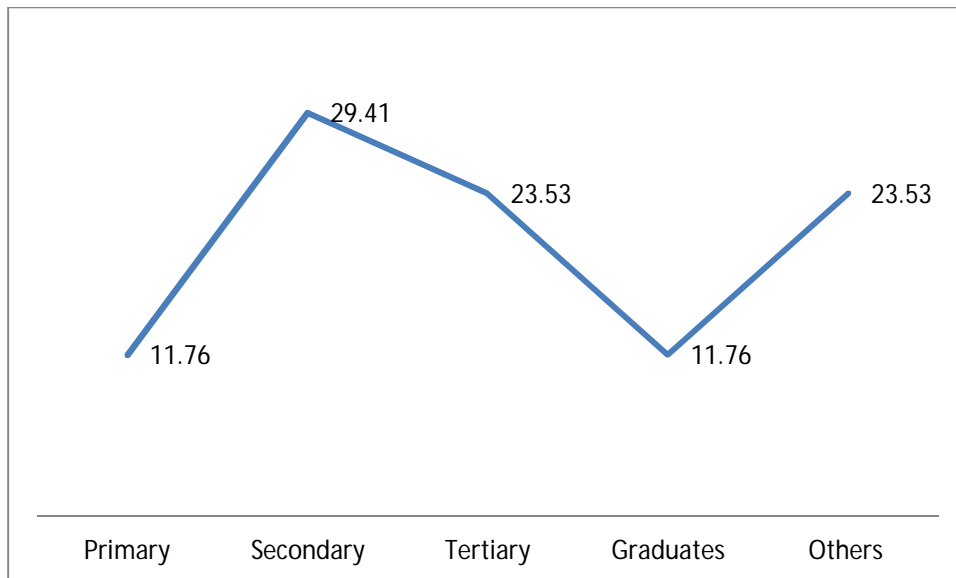


Fig.4.3.4 shows the level of education of the respondents

According to this data majority of the caregivers had reached secondary level of education with 29.41%. Those who reached primary and the graduates had some percentage of 11.76%. The tertiary and others had 23.53%.

#### 4.3.7 Occupation

The study sought to know the occupation of the respondent.

The table 4.3.17 showed the occupation of the respondent.

Risks	Frequency	Cumulative Frequency	Percentage
Occupation	50	50	29.41
Self employed	40	90	23.53
Unemployed	80	170	47.06

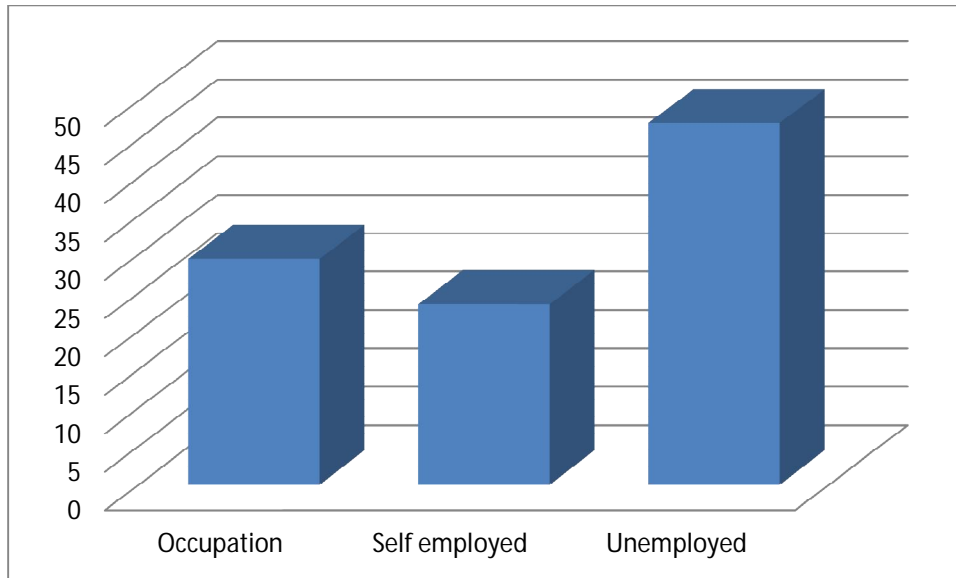


Fig.4.3.5 shows the occupation of the respondents

From the data obtained it showed that majority of the respondents were unemployed accounting for 47.06%. Only 23.53% were employed.

#### 4.3.8 The Number of Children Infected with HIV

The study sought to know the number of children who are infected with HIV were being taken care of by the respondent

The table 4.3.7 shows the number of children infected with HIV

Number of children	Frequency	Cumulative Frequency	Percentage
0	40	40	23.53
1	80	120	47.06
2	30	150	17.65
>2	20	170	11.76

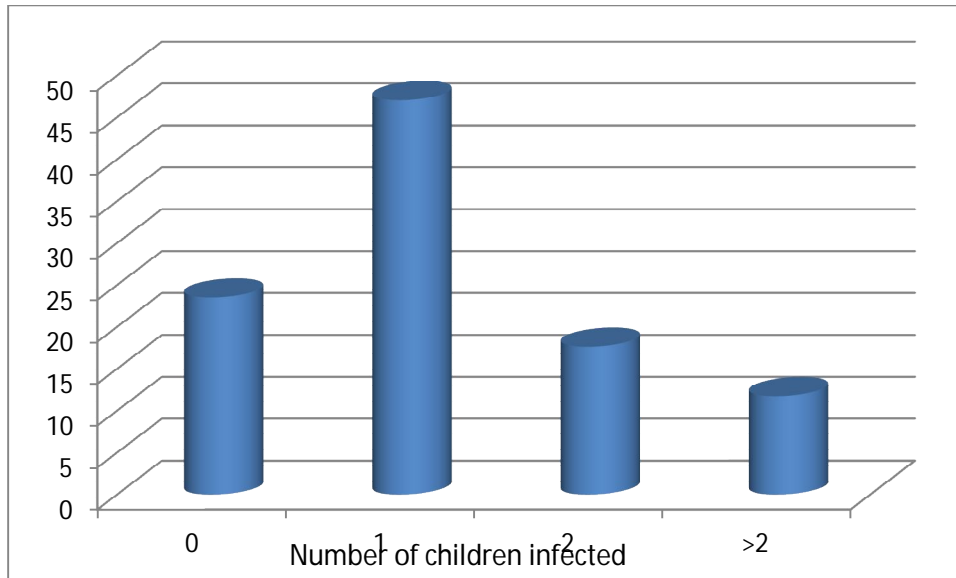


Fig.4.3.7 Shows the number of children infected

According to this data, majority of caregivers were taking care of 1 child who was HIV infected. The least of caregivers were taking care of more than 2 children.

#### 4.3.9 The Child's Awareness

The study sought to know where the children infected knew about their status.

The table 4.3.8 shows the child's awareness of their HIV status

Child's Awareness	Frequency	Cumulative frequency	Degree
Yes	20	20	42.35
No	150	170	317.67

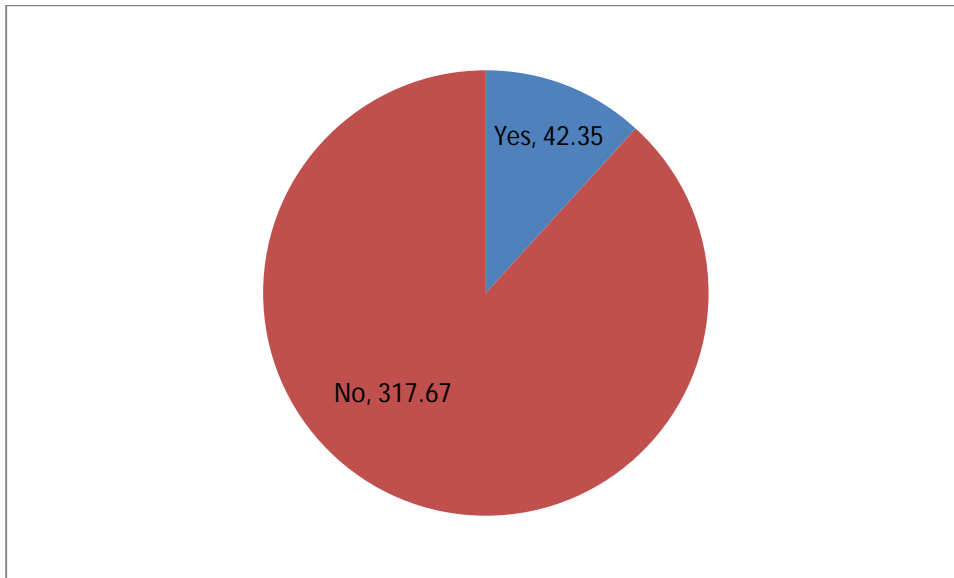


Fig 4.3.8 shows the child's awareness

According to this data, only 42.35<sup>0</sup> i.e. 20 out of 170 children taken care of by the caregivers knew their HIV status. The other 377.65 children were not aware of their HIV status.

#### 4.3.10 Who made the Disclosure

The study sought to know who made the disclosure to his children.

Who made disclosure	Frequency	Cumulative frequency	Percentage
Parent	20	20	11.76
Guardian	30	50	17.65
Relative	50	100	29.47
Health worker	70	170	41.18

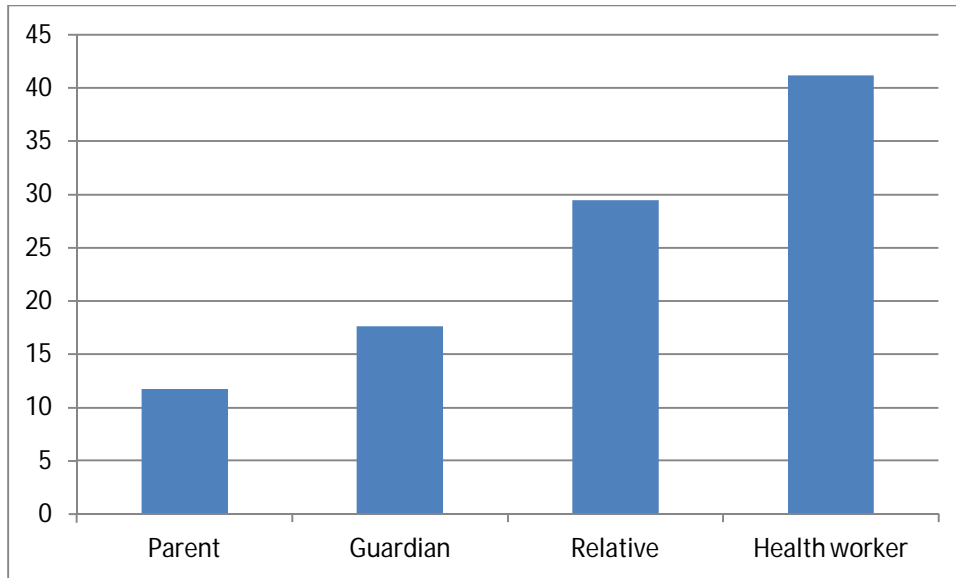


Fig.4.3.9 shows who made the disclosure

According to this data most of disclosure was made by the health workers. The least disclosure was made by parents.

#### 4.3.11 The Age of Disclosure

The study sought to know at what age was the disclosure made.

Number of children	Frequency	Cumulative Frequency	Percentage
0-5	0	0	0
6 - 11	60	60	35.29
12 - 17	80	140	47.06
>18	30	170	17.64

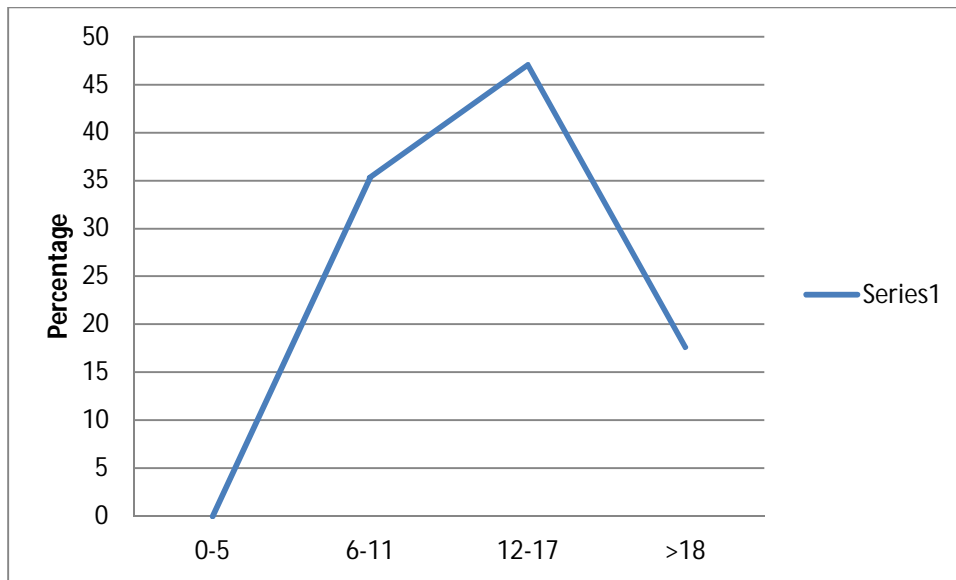


Fig.4.3.10 shows the age of disclosure

According to this data most disclosure was made at the age of (12-17). No disclosure was made at the age bracket between 0-5 yrs.

#### 4.3.12 The Child's Reaction after Disclosure

The study sought to know what the child's reaction was soon after disclosure of their status.

The table 4.3.11 shows the child's reaction after reaction

Child's Reaction	Frequency	Cumulative Frequency	Percentage
Happy	0	0	0
Sad	60	60	35.29
Confused	110	170	64.71

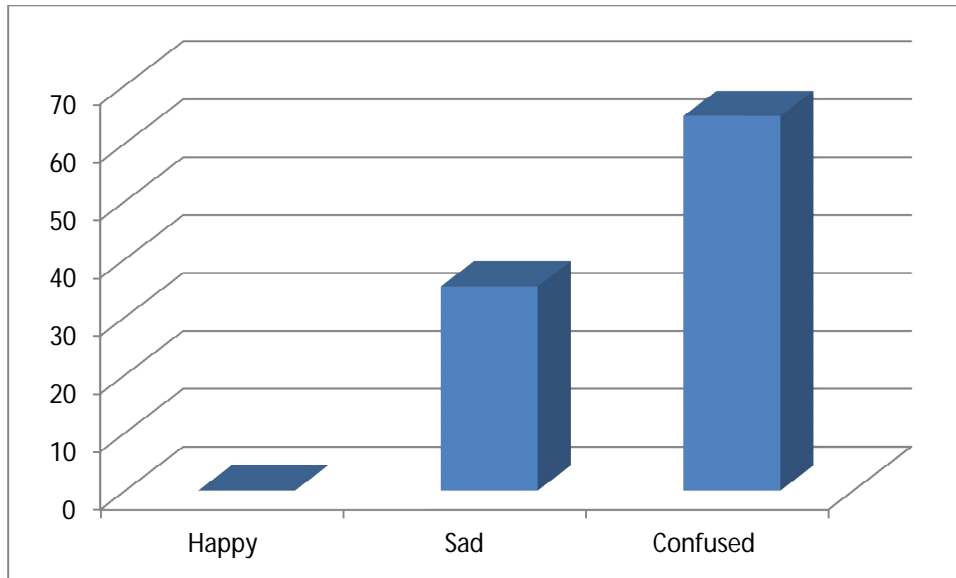


Fig.4.3.11 shows the child's reaction after disclosure

From the data above it showed that most of the children were confused with 64.71% immediately after disclosure was made. Only 35.29% were used upon disclosure.

#### 4.3.13 The well being of the child after disclosure

The study sought to establish the child's wellbeing after disclosure.

The table 4.3.12 show if there were changes to the well being of the child after the disclosure was made.

Change	Frequency	Cumulative Frequency	Degree
Yes	120	120	254
No	50	170	106

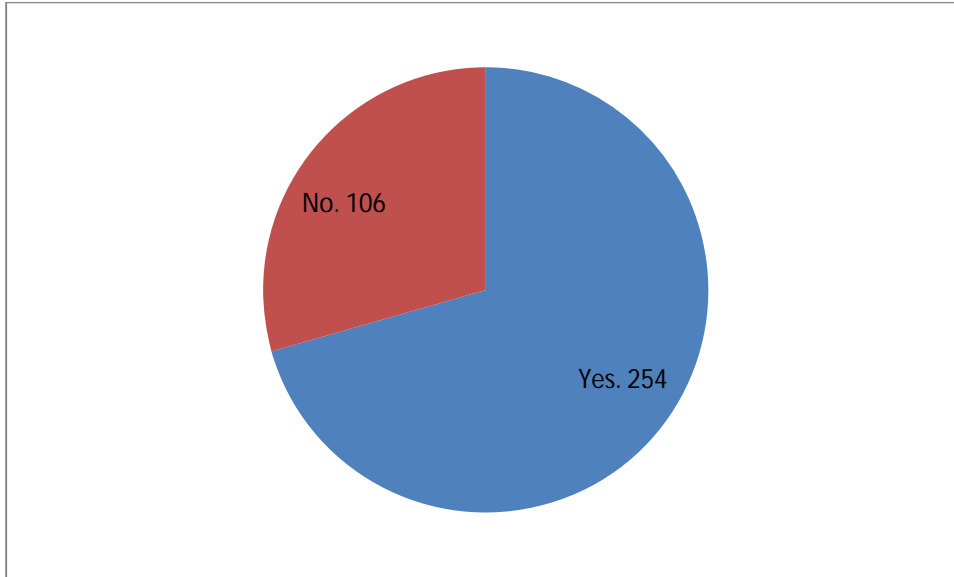


Fig.4.3.12 shows the well being of the child after disclosure

From the data obtained, it indicated that the well being of the child was interfered with on subsequent days after disclosure. This was amounted to 254<sup>0</sup> out of 360<sup>0</sup>. The respondents who felt that the well being of the child was not affected were 106<sup>0</sup> out of 360<sup>0</sup>.

#### 4.3.14 Benefits of Disclosure to the child

The study sought to know if there were benefits to the child upon disclosure.

Benefits	Frequency	Cumulative Frequency	Percentage
Yes	90	90	52.94
No	80	170	47.06



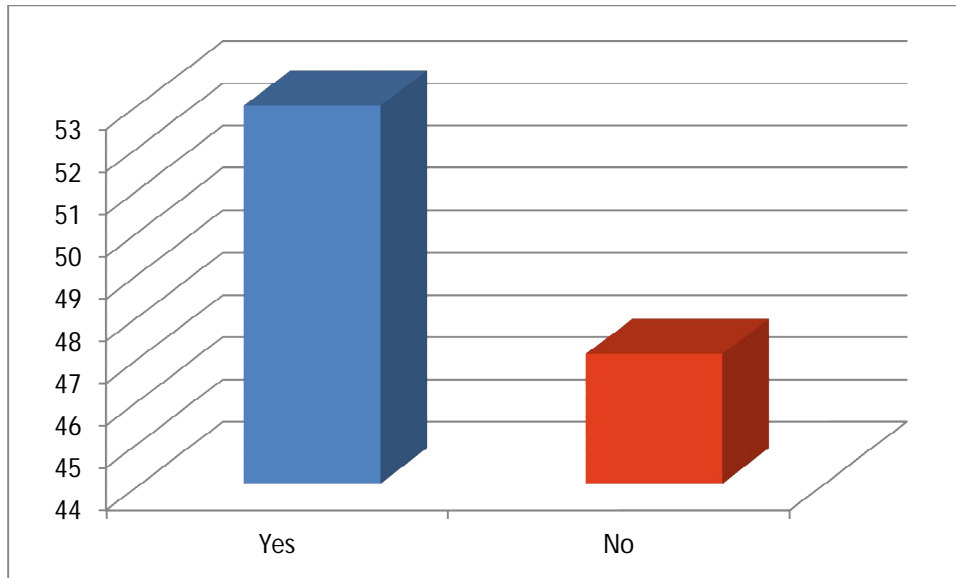


Fig.4.3.13 shows the benefits of disclosure to the child

From the data obtained it showed that the benefits to the child outweigh the risks anticipated. Benefits were 52.94% while risks amount to 47.06% according to the respondents.

#### 4.3.15 Risks to the Child upon Disclosure

The study sought to know if there were any risks to the child upon disclosure

The table 4.3.14 shows the risks of disclosing HIV positive status to a child

Benefits	Frequency	Cumulative Frequency	Percentage
Yes	80	50	164.91
No	90	170	190.59

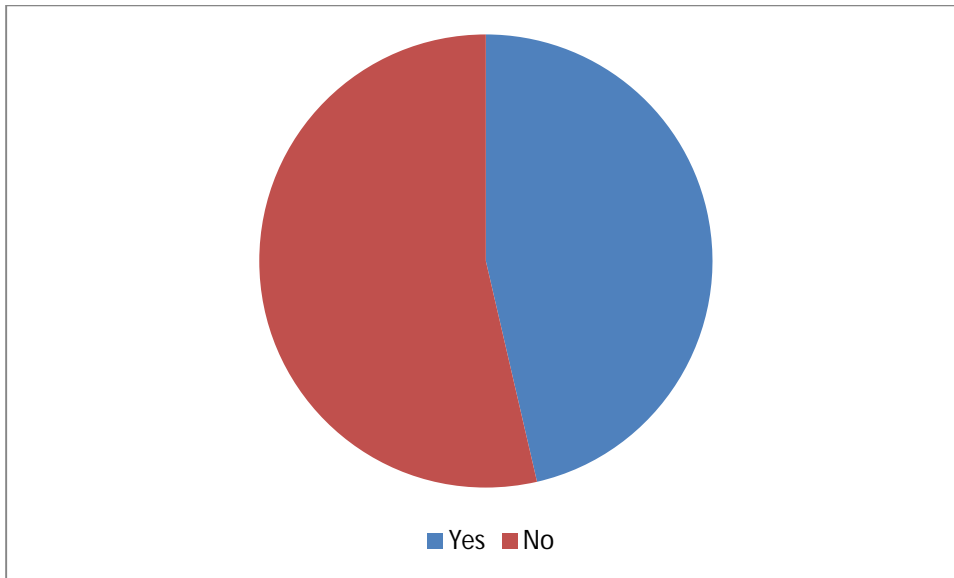


Fig.4.3.14 shows the risks of disclosure to the child

From the data obtained there was a minimal risk to the child upon disclosing their HIV positive status. This amounted to 190.59<sup>0</sup>.

#### 4.3.16 Benefits to Others

The study sought to know if there were any benefits upon disclosing the child's HIV positive status to others such as the community, relatives and school staff.

The table 4.3.15 shows the benefits of disclosing a child's HIV status to others

<b>Benefits</b>	<b>Frequency</b>	<b>Cumulative Frequency</b>	<b>Percentage</b>
Yes	50	50	21.41
No	120	170	70.59

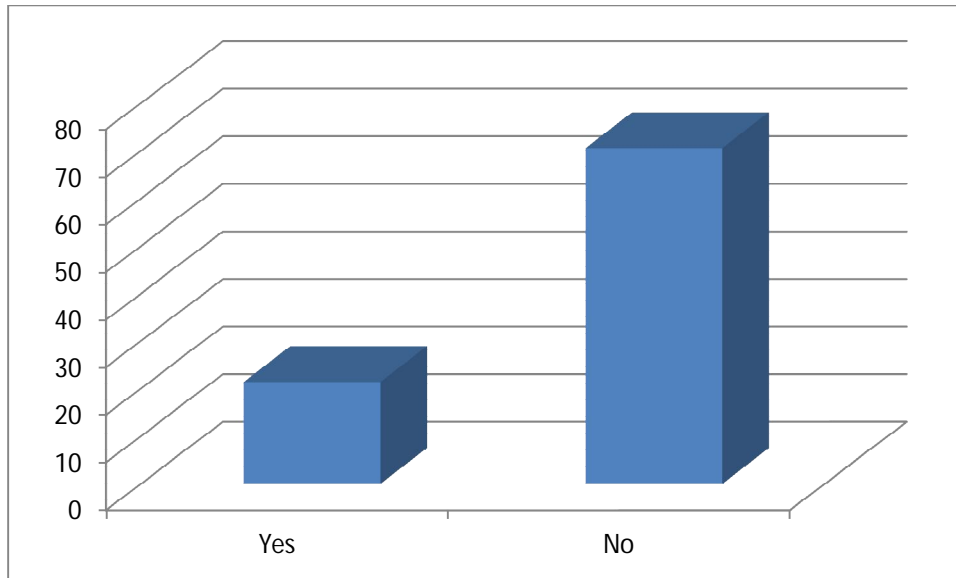


Fig.4.3.15 shows the benefits of disclosing to others

From the data obtained it showed that benefits were well with 29.41%. The risks were a bit higher with 70.59%.

#### 4.3.17 Risks of disclosing a child's HIV status to others

The study sought to know if there were risks upon disclosing a child's HIV status to others.

The table 4.3.16 shows the risks

Risks	Frequency	Cumulative Frequency	Percentage
Yes	120	120	254.12
No	50	170	105.88

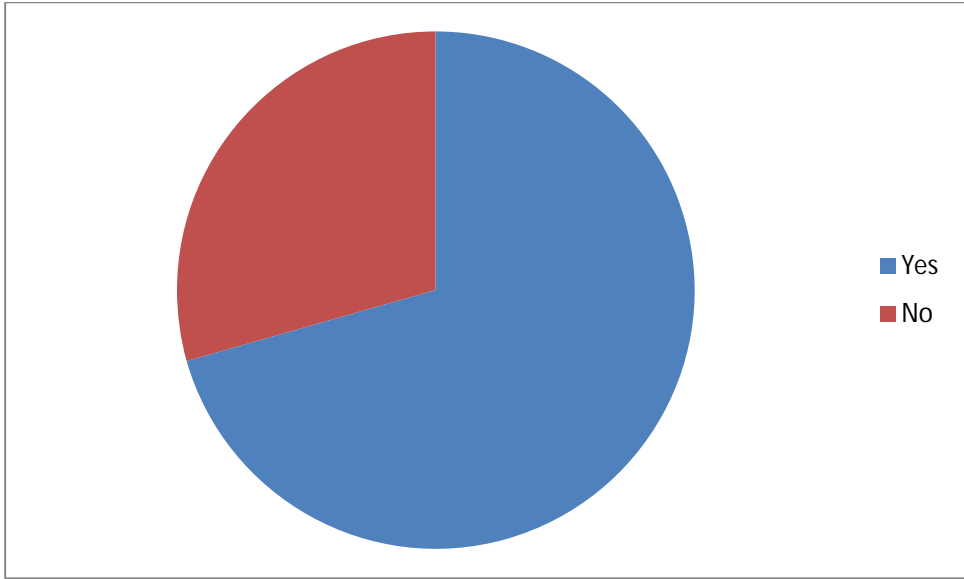


Fig.4.3.17 shows the risks of disclosing

From the data obtained it indicated that the risks were high with 254.120. The benefits were 105.88<sup>0</sup>.

## **CHAPTER FIVE: STUDY FINDINGS AND RECOMMENDATIONS**

### **5.1 INTRODUCTION**

This study highlights the findings of the study and the discussion on the findings of the study.

The study was done to determine the perceived impacts of disclosure of pediatric HIV positive status.

### **5.2 DISCUSSION**

Most of the caregivers were female with 70.59% compared to males who were 29.41%. The study showed that the commonest age group of caregivers was >40 years which amounted to 148.240. The least age group was 0-20 years with 42.350. Most of them had attained a secondary level of education. There was a least of the respondents who had reached primary and graduate level. Most of them were among the other group in their marital status. This group entailed the divorced, widowed, widowers and orphans. The single group was least accounting to 23.53%.

Most of the respondents had more than 2 children accounting to 47.06% only 5.88% did have children of their own. Majority of the care givers i.e. 47.06% were taking care of one child who was HIV infected. Least of the caregivers were looking after more than 2 children accounting for 11.76%. Among this HIV infected children, only 42.35% were aware of their HIV status compared to 317.650 who did know what they were HIV infected. In this case, most of disclosure was made by health workers accounting for 41.18%. The least people who made disclosure were parents amounting for 11.76%.

None of the disclosure was done at the age between 0-5 years. Most of disclosure was made at age of 12-17 years accounting for 47.06%. This was followed by age group 6-11 which accounted for 35.29%. Most of the HIV infected children were confused upon disclosure of their HIV status. This accounted for 64.71%. Others were sad amounting to 35.29%. None of them was happy about their HIV status.

Majority of the children experienced some changes in their well being accounting for 254°. Only 106° did not experience some changes. Benefits of disclosing HIV status of a child to that child amounted to 52.94% while the risks were 47.06%. benefits upon disclosing this information to others was 29.41% while the risks were high accounting for 70.59%.

### **5.3 RECOMMENDATIONS**

As the disclosure of HIV testing results plays an important role in the way forward caregivers need to disclose this information to the children infected. It should be done to:

- ✓ School age children who have already attained cognitive skills and emotional maturity
- ✓ For the younger children, this process of disclosing should be incremental in preparation of full disclosure
- ✓ By the age of 17 years full disclosure should have already be made.
- ✓ Disclosure should be made by the person who is more close to the child such as a guardian/parent.
- ✓ Disclosure should be made early enough before the child is sexually active as this will prevent the spread of HIV.
- ✓ Disclosure of this information improves the child's adherence to ARV.
- ✓ Disclosure will prepare the infected child to manage HIV related complications such as AIDS and opportunistic diseases.
- ✓ These HIV infected children should be encouraged to join helping social networks so as to improve their self esteem.

### **5.3 CONCLUSION**

The researcher acknowledges that most of the HIV infected children are not aware of their HIV status and when disclosure is made majority of these children do not comprehend. Most of caregivers fear disclosing their children's HIV status to others as this would result to stigmatization, discrimination and isolation. Most of disclosures are made at the age between 12-17 as by this time the child has acquired cognitive skills and full emotional maturity. Most of the caregivers are of the female gender at the age >40 years and HIV positive. Majority of them are widowed or divorced with > 2 children and most of them were unemployed.

## SCHEDULE OF RESEARCH ACTIVITY

<b>Defense</b>	<b>December 2012</b>	<b>January 2013</b>	<b>February 2013</b>
Questionnaire design	√		
Pre-testing questionnaire	√		
Data collection	√		
Data analysis		√	
Report writing			√
Report submission and presentation			√

**BUDGET**

<b>Expenditure</b>	<b>Cost. Kshs.</b>
Printing	400.00
Internet	-
Transport	500.00
Stationery	1,000.00
<b>Total</b>	<b>5,500.00</b>



Musau Salome Ndeto  
Presbyterian University of East Africa  
P.O Box 387-00902  
Kikuyu – Kenya

19<sup>th</sup> November 2012

Kangemi Chief Officer  
St. Martin's Primary School,  
P.O BOX 68291-00200  
Nairobi-Kenya

Dear Sir/Madam

Ref: PERMISSION TO CARRY OUT A RESEARCH STUDY IN KIBAGARE VILLAGE ON  
DECEMBER 2012

I am a student in Presbyterian University of East Africa undertaking a course in Diploma in Clinical Medicine, Surgery and community Health. Currently, I am in 3<sup>rd</sup> Year semester.

I am required to carry out a research project on determining the perceived impact on disclosure of pediatric HIV positive status as a partial fulfillment of my course.

I am therefore requesting for permission to carry out my project which will bring out the perceived impact of pediatric HIV positive status disclosure in Kibagare community.

I am looking forward to your response. Thank you in advance.

Yours Faithfully,

**Musau Salome Ndeto**

# THE PERCEIVED IMPACT OF DISCLOSURE OF PEDIATRIC HIV POSITIVE STATUS QUESTIONNAIRE

## Introduction

This questionnaire seeks to gather information from the caregivers of pediatric HIV positive children aged between 1 and 18 years. It is in regard to who should disclose a child's HIV positive status to that child, at what age should the disclosure be made and what are the perceived impacts (both positive and negative) upon disclosure of pediatric HIV positive status.

Please spare your 5 minutes to respond to these questions. Information that you will provide will be treated as confidential and for academic purposes.

Many thanks ad regards

## Section A: Biodata (Please tick [] where appropriate)

1. Gender

Male [] Female []

2. Age

0-20 [] 21-30 [] 31-40 [] >40 []

3. HIV Status

Positive [] Negative []

4. Marital Status

Single [] Married [] Others Pleas indicate.....

5. Number of children

0 [] [ ] 1 2 [] >2 []

6. Level of education

Primary [] Secondary []  
Tertiary [] Graduate []

7. Occupation

Employed [] Self employed [] Unemployed []

### **Section B: HIV Status of a child**

1. How many of your children are HIV infected?  
1 [ ]      2 [ ]      > 2 [ ]
2. Is the child aware of their HIV status?  
Yes [ ]      No [ ]
3. If yes, who made the disclosure?  
Parent [ ]      Guardian [ ]      Relative [ ]      Health worker [ ]
4. At what age was the disclosure made?  
0-5 yrs [ ]      6-11 yrs [ ]      12-17 [ ]      > 18 [ ]
5. What was the child's reaction upon disclosure?  
Happy [ ]      Sad [ ]      Confused [ ]
6. Did the disclosure change the child's well being?  
Yes [ ]      No [ ]

### **Section C: Impact of Disclosure**

1. Are there benefits to the child upon discussing their HIV positive status?  
Yes [ ]      [ ] No
2. Are there risks of disclosing HIV positive status to a child?  
Yes [ ]      [ ] No
3. Are there benefits of disclosing a child's HIV positive status to the community?  
Yes [ ]      [ ] No
4. Are there risks upon disclosing a child's HIV positive status to the community?  
Yes [ ]      [ ] No

## REFERENCES:

1. Rachel C, Vreeman,et al; (2010) perceived impact of disclosure of pediatric HIV status on pediatric ARV therapy adherence, child well being and social relationship in resource limited setting, AIDS patient care and STDS, VOL 24, Children's Health Services Research, Indianapolis
2. WHO, (2001) Guidelines for Using HIV Testing Technologies in Surveillances, WHO Press, Geneva
3. WHO, (2010) Antiretroviral Therapy for HIV Infection in Adults and Adolescent, WHO Press, Geneva
4. UNAIDS (2010) Operational Guidelines on HIV Testing and Therapy of Infants, Children and Adolescent for Service Providers in African Region, UNAIDS Press centre, Geneva
5. WHO, (2011) HIV in the WHO African region, WHO Press, Geneva
6. WHO, (2011) Guideline on HIV disclosure and counseling for children up to 12 years of age, WHO Press, Geneva

