

**KNOWLEDGE, SEXUAL BEHAVIOURS, PREGNANCY EXPERIENCES AND HIV
PREVENTION AMONG ADOLESCENTS LIVING WITH HIV FROM EARLY
CHILDHOOD IN DAR ES SALAAM, TANZANIA**

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MMed (Paediatrics and child health) dissertation

Muhimbili University of Health and Allied Sciences

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By

Irene Kokushubila Rweyemamu

**A dissertation Submitted in (partial) Fulfillment of the Requirements for the Degree
of Master of Medicine (Paediatrics and Child Health) of
Muhimbili University of Health and Allied Sciences**

Muhimbili University of Health and Allied Sciences

November, 2013

CERTIFICATION

The undersigned certify that they have read and hereby recommend for acceptance by Muhimbili University of Health and Allied Sciences a dissertation entitled *Knowledge, Sexual behaviours, pregnancy experiences and HIV prevention among adolescents living with HIV from early childhood in Dar es salaam, Tanzania* in (Partial) fulfillment of the requirements for the degree of Master of Medicine (Pediatrics and Child Health) of Muhimbili University of Health and Allied Sciences.

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Date: _____

DECLARATION AND COPYRIGHT

I, **Irene Kokushubila Rweyemamu**, declare that this **dissertation** is my own original work and that it has not been presented and will not be presented to any other university for a similar or any other degree award.

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Date.....

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DEDICATION

This work is dedicated to my lovely sons Ivan and Brian who had missed me during my busy schedules.

Sons you occupy a very special place in my heart.

You are a gift that God has granted me with and

You are the reason why I put so much effort in everything that I do.

ABSTRACT

Background:

Due to the widespread use of antiretroviral therapy, most children who have been living with HIV/AIDS from a young age are healthy and reach their adolescence and early adulthood. While most of these adolescents have started exploring their sexuality, their preventive practices are reported to be inadequate thus increasing the risk for onward transmission of the infection.

In Tanzania not much has been done on this subject and hence there is no enough data to inform the intervention programmes targeting this population.

Objective:

This study aimed at assessing knowledge, sexual behaviours, pregnancy experiences and HIV preventive practices of adolescents who have been living with HIV from early childhood. The results that have been obtained will be channelled to programmes providing care to these adolescents in order to institute appropriate interventions.

Methodology:

This was a cross sectional study which was carried out at five Care and Treatment Centres (CTC) led by the Management and Development for Health (MDH) programme for a period of 9 months. The study population included adolescents of 10-19 years of age who have been living with HIV from early childhood. The study used both quantitative and qualitative methods. Quantitative data was collected using structured questionnaires while qualitative data was gathered through indepth interviews. Analysis of quantitative data was done using SPSS while that for qualitative data was done through content analysis.

Results:

The study enrolled 300 adolescents. Over 80% of them could correctly identify the means through which HIV can be transmitted and prevented. Thirty nine percent of these adolescents had had penetrative sex and 22% reported to have had unprotected sex at least once. The only significant risk factor for unprotected sex was having lost a mother. About 10 % of the female adolescents reported to have ever been pregnant with about a third of these having living children.

The main findings from the qualitative data were that the poor preventive practices were a consequence of fear of disclosure of HIV status to sexual partners, fear of rejection by the partners and sense of powerlessness shown by the women in negotiating safer sex.

Conclusion:

Adolescents who have been living with HIV from early childhood have good knowledge on HIV transmission and prevention. Penetrative sex among them is common however their preventive practices are poor thus posing a risk for secondary transmission of HIV.

Recommendation:

There is a need for programmes dealing with HIV infected adolescents to concentrate their care on the issues regarding sexual and reproductive health especially on promotion of safer sex, disclosure of HIV status to sexual partners and women empowerment in order to prevent secondary transmission of HIV/AIDS.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
CTC	Care and Treatment Centers
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
IDC	Infectious Disease Centre
MNH	Muhimbili National Hospital
MDH	Management and Development for Health
PMTCT	Prevention of Mother to Child Transmission of HIV
SSA	Sub Saharan Africa

1.0 INTRODUCTION AND LITERATURE REVIEW

1.1 Background

With continued use of antiretroviral therapy (ART) more children who are infected with Human Immunodeficiency Virus (HIV) get a chance to survive to their adolescence and early adulthood.^{1, 2, 3} Although the exact number of the survivors is hard to establish, evidence from a number of studies has shown a trend of a slow but steadily growing population. One of the HIV/AIDS care and support centres in Uganda has recorded some 5000 young people living with HIV since infancy the oldest being 23 years old.⁴

Ninety percent of the estimated 2.1 million children under 15 years of age who were living with HIV in 2009 resided in sub Saharan Africa. In Tanzania there were 160,000 children living with HIV.⁵ Most of these had acquired the disease from their mothers during pregnancy, delivery or breastfeeding.⁶ In many settings, children with access to highly active antiretroviral therapy (HAART) have markedly reduced HIV associated morbidity and mortality and are surviving through childhood, entering adolescence and increasingly transferring to adult care. As a result HIV has become a chronic condition of childhood.^{7, 8} In Tanzania the roll out of ART began 10 years back. As of the year 2011 over three hundred thousand adults and children were on treatment with ARVs.

Adolescence is a phase of physical growth and development accompanied by sexual maturation, often leading to intimate relationships. It is a period of increased vulnerability to risk taking predisposing adolescents to various adverse outcomes including HIV/AIDS. This is because of a gap which exists between arousal and sensation seeking both of which increase significantly at puberty and the development of self-regulatory capability which does not fully mature until early adulthood.

Adolescents are therefore more vulnerable to risky behaviors that predispose them to HIV/AIDS. On top of that they face the peer pressure leading to unsafe sex, casual sex, experimentation with sexuality, drug abuse including intravenous drugs, all directing towards increased exposure to risk for HIV transmission.

The response and attitude of family, teachers and society toward adolescents also adds to the challenges faced by adolescents. Most of these supportive structures do not give adolescents the basic information about sex, sexuality and HIV/AIDS, making them more vulnerable.⁹

Adolescents living with HIV are no different from other adolescents. However the difficulties of working with adolescents in general on issues of sexual and reproductive health are more complicated for adolescents living with HIV. This group of adolescents is compelled to deal with two major challenges at the same time. They must cope not only with adolescent developmental issues, but also with a chronic, socially stigmatizing and sexually transmittable illness.

Although it is recommended that disclosure of HIV status to children should begin from 6 years of age.¹⁰ Most of them learn of their HIV status during adolescence a time during which they also have to face a number of risk taking behaviors including sexual behaviors. Because of delays in disclosure acting responsibly even after knowing their HIV status becomes a big challenge and this poses a threat to the control of HIV transmission.

1.2 Knowledge on HIV transmission and prevention

A number of studies have revealed that knowledge on HIV transmission and prevention is not a problem among adolescents who have been living with HIV from childhood. Most of them know of the means through which HIV can be transmitted and are knowledgeable about the means to prevent it. This was reported in previous studies done in Canada¹⁴ and the USA.²⁵

In these studies the proportion of adolescents who could correctly identify the means through which HIV can be transmitted and prevented was over 80%. In the study done in USA 95% of the participants could identify sex as a mode of HIV transmission, 82% correctly identified that HIV can be transmitted from mother to child and 77% of them knew that condoms can be used as preventive measures for HIV.

1.3 Sexual behaviours

Studies have shown that adolescents living with HIV have started to explore their sexuality, by dating and some of them are involved in intimate relationships.^{4, 11, 12, 13, 14} A study done in Uganda¹⁵ revealed that 41% of these boys and girls have ever had a boyfriend or girlfriend and 52% of them were in relationships during the time of the study. In a study done in USA²⁵ 79% of the participants reported to have ever had a boyfriend or girlfriend. More males have been reporting to have ever been in sexual relationships compared to the females. In Uganda significantly more males (45.7%) reported to have ever been in a sexual relationship compared to the females (32.9%).¹⁵

Published data from various studies further suggested that 27- 46% of them have already been sexually active.^{4, 13} The mean age of first sexual intercourse among those who were found to be sexually active was 14⁴ for girls and 13⁴ to 15¹³ for boys and the median number of lifetime sexual partners was found to be 3. Having multiple sexual partners in this population of adolescents is considered as a risk factor for secondary transmission of HIV.

Apart from penetrative sex several other sexual behaviours have been reported among these adolescents including kissing, touching, fondling and masturbation. Studies done in Kenya and Uganda have shown that about one out of three of these adolescents have ever engaged in all these other sexual behaviours.^{4,15}

1.4 HIV preventive practices

HIV preventive practices have been reported to be poor among this population of adolescents who have been living with HIV from early childhood. Risky sexual behaviours have in that matter been shown to be highly prevalent among them although less common compared to the general population. The Ugandan study revealed that despite knowing their HIV status 61% of these children reported not to have used any protection the first time they had penetrative sex.¹⁶ This poses a great hindrance in the global efforts of achieving a 50% reduction in sexual transmission of HIV by 2015.^{17, 18} What remained unknown is how many of those

who were sexually involved with these adolescents and were HIV negative were infected during those sexual acts.

In addition to that over half of those who had used protection the first time they had sex, had taken risks in subsequent relationships.¹³ More than one third of those who were in a relationship with recent sexual partners who were HIV negative or of unknown serostatus had engaged in at least one unprotected sexual act with them.⁴ The median number of lifetime sex partners among them was three. This gives more evidence for the risk of onward transmission of HIV and possible secondary infection of HIV among these adolescents.

Only two studies determined the barriers for condom use in this population. A common explanation given was the risk of exposing their HIV status to a partner which could result into rejection by the partners as well as social stigma.^{19,20} Condom use was also shown to act as a reminder of the infection and a barrier to intimacy. Knowledge on HIV transmission and prevention was shown to have no impact on risky behaviour.²⁰ However these studies did not find out if these adolescents were aware of the risk for secondary HIV transmission to themselves and how this could impact on their sexual behaviour.

HIV status disclosure to sexual partners is described as one of the means of prevention of HIV transmission. However disclosure rates to sexual partners among these adolescents has been shown to be low ranging between 20 and 40 percent.^{4,21} Most of them reported to have been scared of disclosing their status because of fear of rejection, harassment, unauthorized disclosure to others and parental influence.^{22, 23} This is a challenge to the existing programmes that deal directly with these children and is a setback to the global efforts of cutting down the sexual transmission of HIV/AIDS.

1.5 Predictors for risky sexual behaviours

Only a few studies have determined the factors associated with risky sexual behaviour among adolescents who have been living with HIV from childhood.

The determinants for initiation of sex were assessed in a few studies. The likelihood for having initiated sex was significantly increased in those who were older,^{4, 12, 15} in poorer health, less likely to be on antiretroviral therapy, with undetectable viral loads, live on their own or were involved in drug or alcohol use.^{4, 16}

A study done in USA showed that the odds of having unprotected sex were higher in adolescents who were living with a relative other than their biological mother.²⁷ Among youth who did not report history of sexual intercourse at baseline non-adherence to ART was associated with initiation of sexual intercourse during follow up.²⁷

1.6 Pregnancy experiences

It has been shown through previous studies that most of these adolescents have dreams and intentions of having children.^{15, 25} In the studies done in Uganda and Kenya more than 80% of those who did not have children intended to have one in future.^{4, 15}

Issues of reproduction are becoming serious for this population. A number of them have reported being pregnant or having impregnated others and most of these are unplanned pregnancies. The proportion of female participants who reported to have ever been pregnant ranged between 13 and 24 percent some of them reporting up to three pregnancies.^{14, 16} The high rate of unplanned pregnancies further indicates that these adolescents are having unprotected sex which puts them at risk for transmission and re-infection with HIV.

The youngest age at which pregnancy was reported was 13 years.¹⁹ Those who reported to have ever been pregnant were much older than their counterparts,¹⁹ with much lower viral loads and with much better CD4 counts¹⁶. Most of these pregnancies resulted in live births and a few had abortions both spontaneous and induced. The rate of perinatal transmission among those who had live births was 3.3% which is very low.¹⁶

In Tanzania we still have scarcity of data regarding the sexual behaviors, pregnancy experiences and HIV prevention among this group of adolescents therefore carrying out appropriate interventions is still a challenge.

2.0 PROBLEM STATEMENT

With the widespread use of ART more children who are infected with HIV are surviving and have a chance to live to their adolescence and early adulthood. On reaching adolescence most of adolescents start having desires for sex. Previous studies have shown that more than a third of them become sexually active and some of them become pregnant by this age ^{4, 11, 12, 13.}

Despite being involved in sexual activities their preventive practices are still inadequate hence posing a risk for further transmission of the infection and possible re infection with a different strain of the virus. In the absence of appropriate interventions this may in turn set back the efforts of the United Nations to reduce the sexual transmission of HIV by 50% by the year 2015 ^{17, 18.}

Currently information regarding this topic in our country is scarce and hence we have limited data to inform the various programmes dealing with adolescents living with HIV/AIDS. We therefore lack evidence to institute appropriate measures. Only a few of the previous studies determined the factors which were associated with risky sexual behaviours among this population and most of these studies were done out of Africa.

Therefore the proposed study seeks to assess knowledge, sexual behaviours, pregnancy experiences and HIV prevention among these adolescents. It also aims to determine factors that are associated with risky sexual behaviours in this population in order to set up appropriate preventive measures.

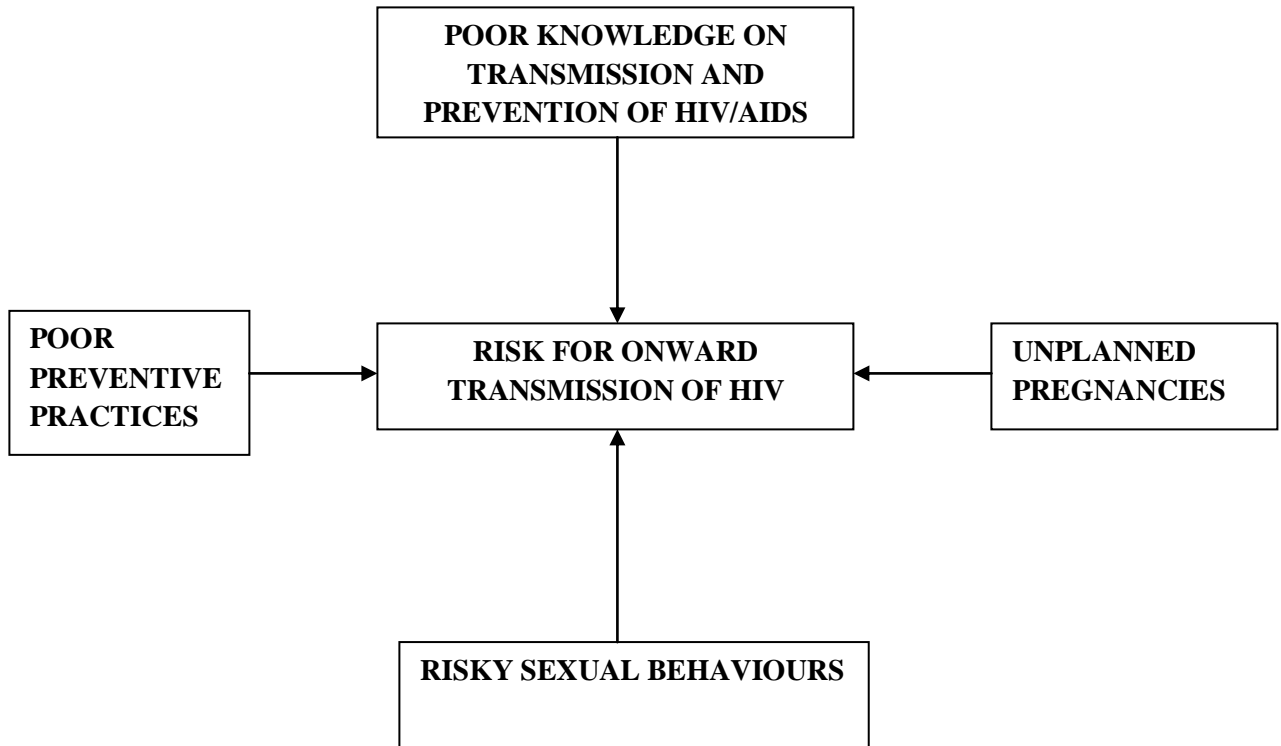
3.0 RATIONALE

This study is worth conducting at this time because we have a big enough number of children who have survived with HIV to adolescence due to widespread use of ART. In Tanzania programmes supporting ART have been there for over 10 years promoting the survival of these adolescents. Currently there is inadequate data to inform the programmes addressing this population group regarding their sexual behaviours and HIV prevention.

This population is chosen because during adolescence is when most people start to develop sexual urges and may become sexually active. Adolescents are also more likely to engage in risky sexual behaviours due to the difference in timing that exists between development of sexual maturity and the capability to control sexual desires. Apart from that most of them learn of their HIV status during this time. Because of this acting responsibly even after knowing their HIV status becomes a big challenge and this poses a threat to the control of HIV transmission.

Results that will be generated by this study will be used by the responsible programmes to institute appropriate interventions

4.0 CONCEPTUAL FRAMEWORK



5.0 RESEARCH QUESTIONS

1. What is the level of knowledge on HIV transmission and prevention among HIV infected adolescents living with HIV from early childhood?
2. What are the sexual behaviours of these HIV infected adolescents?
3. What are the HIV preventive practices of HIV infected adolescents?
4. What are the pregnancy experiences of HIV infected adolescents living with HIV from early childhood?
5. What are the factors associated with risky sexual behaviour among these HIV infected adolescents?

6.0 OBJECTIVES

6.1 BROAD OBJECTIVE

To assess knowledge, sexual behaviours, pregnancy experiences and HIV preventive practices of adolescents who have been living with HIV from early childhood in Dar es salaam, Tanzania

6.2 SPECIFIC OBJECTIVES

1. To assess knowledge on HIV transmission among HIV infected adolescents by age and sex
2. To assess knowledge on HIV prevention among HIV infected adolescents by age and sex
3. To assess sexual behaviour of HIV infected adolescents by age and sex
4. To assess the HIV preventive practices of HIV infected adolescents by age and sex
5. To describe the pregnancy experiences of HIV infected adolescents
6. To determine factors associated with risky sexual behaviour among HIV infected adolescents

7.0 METHODOLOGY

7.1 Study area:

The study was conducted in Dar es Salaam, Tanzania at Care and Treatment Centers (CTC) for HIV led by the Management and Development for Health (MDH) program. Dar es Salaam is selected conveniently out of the 28 regions of Tanzania.

The MDH program supports HIV Care and Treatment, integration of TB services and Prevention of Mother to Child Transmission (PMTCT) in public and private health facilities in the Dar es Salaam region. HIV Care and Treatment is supported in 47 health facilities in the region the biggest number of patients being seen at the major centres of Mwananyamala, Amana and Temeke in the municipal hospitals, Muhimbili National Hospital (MNH) and Infectious disease centre (IDC). The rest are minor centres found in health centres, dispensaries and private hospitals.

Up to June 2012 the programme had enrolled 3270 adolescents in total in all its centres, 73% of these being in the major centres. The number of adolescents who were enrolled in these major centres by the end of June 2012 included 573 at Amana, 456 at IDC, 624 at Mwananyamala, 532 at Temeke and 226 at MNH.

7.2 Study design:

A descriptive cross sectional study which employed both quantitative and qualitative methods

7.3 Study duration:

The study was conducted between July 2012 and March 2013

7.4 Study population:

Adolescents aged between 10 and 19 years who have been living with HIV from early childhood attending CTC clinics at the major centres led by MDH. Adolescence was chosen because it is a period of heightened vulnerability to various risky behaviours including risky sexual behaviours.

7.5 Sample size for quantitative data:

Was computed from the following formula;

$$N = Z^2 P (1-P)/E^2$$

Where;

Z is percentage point corresponding to significance level. If significance level is 5%, **Z** is 1.96
P stands for proportion which is derived from the following previous studies basing on the study objectives;

1. Proportion of adolescents who had knowledge on common ways of preventing HIV which was 66% ⁴.
2. Proportion of adolescents who reported use of HIV preventive methods which was 37% ⁴.
3. Proportion of adolescents who had ever been pregnant or impregnated others which was 24% ¹⁴.

E corresponds to maximum likely error which was 6%

Therefore 3 sample sizes were calculated as follows basing on the different proportions and the biggest value was considered to be the sample size;

1. $N_1 = 1.96^2/0.06^2 \times 0.66 (1-0.66) = 239$
2. $N_2 = 1.96^2/0.06^2 \times 0.37 (1-0.37) = 248$
3. $N_3 = 1.96^2/0.06^2 \times 0.24 (1-0.24) = 194$

Hence the sample size **N= 248** adolescents

Addition of 10% was done to accommodate for missing data.

Hence **280** was the minimum sample size however **300** adolescents were recruited to increase the power of the study.

7.6 Sampling Procedure for quantitative data:

Multistage sampling was done in order to select the study participants. All the five major CTC centres were included in this study. Since there were variations in the number of adolescents in each of the centres, proportional sampling was done from the selected centres depending on the total number of adolescents present in each centre and on the sample size using the following formula;

$$\frac{\text{Number of adolescents found in one of the selected centres}}{\text{Total number of adolescents found in all the five centres}} \times \text{Sample size}$$

Total number of adolescents found in all the five centres

Therefore the number of adolescents from each centre was;

1. Muhimbili National Hospital
 $226/2411 \times 300 = 28$
2. Infectious Disease centre
 $456/2411 \times 300 = 57$
3. Amana Municipal hospital
 $573/2411 \times 300 = 71$
4. Mwananyamala Municipal Hospital
 $624/2411 \times 300 = 78$
5. Temeke Municipal Hospital
 $532/2411 \times 300 = 66$

Adolescents were then recruited consecutively from each centre until when the calculated samples were reached.

7.7 Recruitment of study participants:

Recruitment of participants was done during clinic hours (9am to 2pm) on all the days in which the pediatric clinics are conducted in each of the centres except during the public holidays. These days included Monday to Friday at the IDC and MNH; Fridays only at mwananyamala, temeke and amana hospitals. Identification of eligible individuals was done by the attending nurses as they arrive to the clinic. Identification was done by looking for the age at diagnosis of HIV in the patients' files and seeking for clarification from the adolescents

or their caretakers when the files were missing. Only those who were diagnosed at five years or below were included in this study. Disclosure status was determined by questioning the caretakers or the adolescents themselves in case the caretaker was not around before enrollment. Those who were aware of their HIV status were then referred to either the research assistants or the investigator for enrollment into the study.

7.8 Inclusion criteria:

- Confirmed HIV positive adolescents aged 10-19 years who have been living with HIV from early childhood
- Adolescents to whom disclosure of HIV status had already been done.
- Adolescents of 18 years or above who gave a written consent to take part in the study
- Parents/caretakers of adolescents below 18 years who gave a written consent to take part in the study and adolescents who gave assent to take part in the study

7.9 Exclusion criteria:

- Adolescents who were unaware of their HIV status i.e disclosure was not yet done
- Parents/Caretakers who did not give a written consent for adolescents below 18 years to take part in the study
- Adolescents of 18 years and above who did not give a written consent to take part in the study
- Adolescents below 18 years who did not assent to take part in the study

7.10 Data collection instruments:

Quantitative data was collected through structured questionnaires while qualitative data was gathered through in depth interviews

7.11 Questionnaires:

Interviewer administered questionnaires were used for data collection. The questionnaires were divided into 5 main sections made of both closed and open ended questions. The first section included questions on socio demographic and clinical characteristics, second section on knowledge on HIV/AIDS transmission and prevention, third section on sexual behaviours, fourth section on HIV preventive practices and the final section on pregnancy experiences. Clinical stage of the disease and records of the most recent CD4 count were retrieved from the patients' files. (Appendix 1) Interviews were done in private rooms and each of them lasted for about half an hour. Each centre had two research assistants who were trained by the investigator after pretesting of the questionnaire. All ambiguities were cleared before data collection began.

7.12 In depth interviews:

These were done to 10 adolescents half of whom were females and half males, 2 from each of the centres with the purpose of complementing the quantitative data. The first two participants from each centre who were sexually experienced in case of males and those with pregnancy/sexual experiences in case of females were identified and requested to participate in the interview. The next adolescent with sexual experience was taken for the interview when the requested adolescent was not ready to participate in the interview. The interviews were carried out in private rooms for a period of 45-60 minutes in order to maintain confidentiality. A semi structured interview guide was used to lead the interview. A voice recorder was used to record the conversations. All the interviews were done by the principal investigator.

7.13 Pre testing of the questionnaire:

This was done 2 weeks prior to the beginning the study using HIV infected adolescents attending CTC clinic at MNH. Five percent of the sample size i.e 16 questionnaires were used for pilot testing and those subjects who were involved were not included in the analysis.

7.14 Analysis of quantitative data:

Questionnaires were coded before entering into the computer using Statistical package for social sciences (SPSS) version 16. Data cleaning was done by using consistence checks. Continuous variables were expressed as mean \pm SD if they were normally distributed. Medians and interquartile ranges were used to express continuous variables which were skewed. Categorical variables were expressed as proportions. Differences in proportions were tested using the chi square (χ^2) test. Fisher's exact test was used in situations where the expected value in one of the cells was less than 5. Logistic regression analysis was used to determine the predictors for risky sexual behaviours.

7.15 Analysis of qualitative data:

First a verbatim transcript of the entire discussion was produced anonymously and translated into English. The principal investigator and two other people who are experienced with analysis of qualitative data identified, discussed and agreed on the central themes. Content analysis was then used to identify several categories of answers related to each theme and subtheme respectively.

7.16 Ethical consideration:

The aims and benefits of the study were explained to the parents/guardians as well as the study participants. Parents/guardians of respondents aged 10–17 years were asked to provide written permission for their children to participate in the study. Subsequently, the respondents were asked to indicate their own willingness to participate by assenting to the study. Individual written consent only was solicited from adolescents of 18 years and above.

Participants' information which was filled in the questionnaires or audio recorded was kept confidential with no any identifying information. Access to the data was limited to the principal investigator.

7.17 Ethical clearance:

Ethical clearance to carry out this study was sought from Muhimbili University of Health and Allied Sciences (MUHAS) higher degree research and publication committee. Permission to conduct the study was obtained from the Directors of Clinical Services of Muhimbili national hospital and District Medical officers (DMO's) of Ilala, Mwananyamala and Temeke municipal councils.

DEFINITION OF TERMS

- 1. Adolescence:** Adolescence is defined as the period between 10 and 19 years of age. It is a continuum of physical, cognitive, behavioural and psychosocial change. It is often a period of increased vulnerability to various risky behaviors which may predispose adolescents to adverse outcomes including HIV/AIDS. For the purpose of this study adolescents of the defined age group i.e 10-19 years are going to be recruited.
- 2. Childhood:** This is a developmental stage between infancy and adulthood. It includes all individuals below the age of 18 years. Early childhood is defined as the period before the age of normal schooling which is regarded as below 5 years of age which will be referred to in this study.
- 3. Sexual behaviour:** Sexual behaviour stands for any activity which can be solitary, between two persons, or in a group that induces sexual arousal or response of the body. It can be divided into acts which involve one person, such as masturbation, or two, or more, people, such as sexual intercourse, oral sex, or mutual masturbation. For the purpose of this study sexual behaviour includes activities like kissing, touching/fondling and sexual intercourse.
- 4. Risky behaviours:** Risky behaviours refer to activities that place an individual or group directly or indirectly at risk for contracting HIV. Direct risk behaviours include activities such as unprotected vaginal and anal sex, multiple sexual partners and sharing drug needles. Indirect risks include drinking alcohol, smoking, the use of illicit drugs, and other such activities that may lead to impaired judgment. According to UNAIDS (2004), the main mode of transmission in Sub-Saharan Africa is heterosexual unprotected sex. Therefore, for the purpose of this study, the focus was specifically on sexual risk behaviours that place individuals at risk for contracting HIV which include unprotected anal sex, vaginal sex, oral-genital sex, and having multiple sexual partners.

8.0 RESULTS

8.1 RESULTS FOR QUANTITATIVE SURVEY

8.11 Background characteristics of the HIV infected adolescents

The study enrolled 300 adolescents with females (54.0%) outnumbering males (46.0%). They ranged between 10 and 19 years with a median age of 15 years. Most of them were in early adolescence (39.7%) and were predominantly in primary and secondary schools. About three quarters of them were orphans either double or single orphans. Almost all of them (97.0%) were already on treatment with antiretroviral drugs with 54.4% having stage 3 of HIV/AIDS.

Table 1: Background characteristics

Characteristics	Male n (%)	Female n (%)	Total n (%)
Sex	138(46.0)	162(54.0)	
Age distribution			
10-14	53 (38.4)	66 (40.7)	119 (39.7)
15-16	41 (29.7)	42 (25.9)	83 (27.7)
17-19	44 (31.9)	54 (33.3)	98 (32.7)
	138	162	300
Level of education			
Primary	61 (44.2)	79 (48.8)	140 (46.7)
Secondary	71 (51.4)	79 (48.8)	150 (50.0)
College/University	3 (2.2)	2 (1.2)	5 (1.7)
No formal education	3 (2.2)	2 (1.2)	5 (1.7)
	138	162	300
Status of the parents			
Both alive	33 (23.9)	40 (24.7)	73 (24.3)
Father deceased	23 (16.7)	24 (14.8)	47 (15.7)
Mother deceased	36 (26.1)	35 (21.6)	71 (23.7)
Both deceased	46 (33.3)	63 (38.9)	109 (36.3)
	138	162	300
On ART treatment			
Yes	135 (97.8)	156 (96.3)	291 (97.0)
No	3 (2.2)	6 (3.7)	9 (3.0)
HIV/AIDS stage			
Stage 1	6 (4.4)	11 (7.3)	17 (5.9)
Stage 2	40 (29.4)	39 (25.8)	79 (27.5)
Stage 3	74 (54.4)	91 (60.3)	165 (57.5)
Stage 4	16 (11.8)	10 (6.6)	26 (9.1)
	136	151	287
Median duration of ARV treatment (yrs)	6 (4-7)	6 (3-7)	7 (3-7)
CD4 count			
< 350 cells/mm ³	53 (41.1)	58 (38.7)	111 (39.8)
> 350 cells/mm ³	76 (58.9)	92 (61.3)	168 (60.2)
	129	150	279

8.12 Knowledge on HIV transmission

Most of the participants knew of the common ways through which HIV can be transmitted with their proportion ranging between 84 and 100% in all the categories of knowledge on HIV transmission. Despite the differences seen in some of the categories both in terms of age as well as sex, none of them were statistically significant.

Table 2; Knowledge on HIV transmission among HIV infected adolescents by age and sex

Mode of Transmission	Male	Female	p value	10-14	15-16	17-19	P value
Blood transfusion							
Yes	133(97.1)	153(99.4)	0.19*	109(97.3)	80(97.6)	97(100)	
No	4(2.9)	1(0.6)		3(2.7)	2(2.4)	0(0.0)	
Unprotected sex							
Yes	134(99.3)	150(98.7)	0.21*	107(98.2)	80(98.8)	97(100)	
No	1(7.0)	2(1.3)		19(1.2)	2(2.4)	0(0.0)	
Hugging							
Yes	6(4.4)	9(5.7)	0.79	6(5.4)	4(4.1)	15(5.1)	0.82*
No	129(95.6)	148(94.3)		106(94.6)	94(95.9)	277(94.9)	
Kissing							
Yes	14(10.7)	18(11.9)	0.78	17(15.5)	6(7.6)	9(9.7)	0.20
No	117(89.3)	133(88.1)		93(84.5)	73(92.4)	84(90.3)	
Mother to child							
Yes	111(91.0)	132(84.6)	0.15	90(84.1)	73(93.6)	80(86.0)	0.14
No	11(9.0)	24(15.4)		17(15.9)	5(6.4)	13(14.0)	
Sharing needles							
Yes	134(99.3)	156(98.7)	0.56	113(98.3)	79(98.8)	98(100)	0.44
No	1(0.7)	2(1.3)		2(1.7)	1(1.2)	0(0)	

N: B; * Fisher Exact test was used

8.13 Knowledge on HIV prevention

Over 80% of the adolescents knew about the common ways in which HIV can be prevented. Differences observed between males and females and between the age groups were not statistically significant. About a third of both females and males thought that taking and adhering to ART can prevent the transmission of HIV and their proportion increased as the age decreased. This finding was highly statistically significant.

Table 3; Knowledge on HIV prevention among HIV infected adolescents by age and sex

Mode of prevention	Male	Female	p	10-14	15-16	17-19	P
	N (%)	N (%)	value	N (%)	N (%)	N (%)	value
Abstinence							
Yes	107(82.3)	119(81.5)	0.88	88(83.0)	66(83.5)	72(88.8)	0.70
No	23(17.7)	27(18.5)		18(17.0)	13(16.5)	19(11.2)	
Condom use							
Yes	110(88.7)	124(86.1)	0.58	86(81.9)	67(91.7)	81(90.0)	0.09
No	14(11.3)	20(13.9)		19(18.1)	6(8.3)	9(10.0)	
Taking/Adhering to							
ART	43(34.7)	45(30.8)	0.88	48(46.2)	19(25.0)	21(23.3)	0.001
Yes	81(65.3)	101(69.2)		56(53.8)	57(75.0)	69(76.7)	
No							

8.14 Sexual behaviour of HIV infected adolescents by sex

About four out of ten of the adolescents had ever been in a sexual relationship with the proportion of males being higher compared to that of females and this difference was statistically significant. Two thirds of those who had ever had a sexual relationship had had penetrative sex. Most of them had also been involved in other sexual behaviours with almost all behaviours being more common in males as compared to the females.

Table 4; Sexual behaviour of HIV infected adolescents by sex

	Male N (%)	Female N (%)	Both N (%)	p value
Ever been in a sexual relationship				
Yes	63(45.7)	53(32.9)	116(38.8)	
No	75(54.3)	108(67.1)	183(61.2)	0.03
Currently in a sexual relationship				
Yes	48(34.8)	41(25.3)	89(29.7)	
No	90(65.2)	121(74.7)	211(70.3)	0.07
Median age at 1 st sex (yrs)	15(14-16)	15(14-17)	15 (14-16)	
Ever engaged in				
Kissing (% Yes)	63(100)	49(92.5)	112(96.6)	0.04
Light petting (% Yes)	56(88.9)	39(73.6)	95(81.9)	0.03
Heavy petting (% Yes)	45(71.4)	31(58.5)	76(65.5)	0.14
Oral sex (% Yes)	9(14.3)	13(24.5)	22(19.0)	0.16
Vaginal sex (% Yes)	42(66.7)	30(56.6)	72(62.1)	0.27
Median number of lifetime sexual partners (Median {IQR})	2 (1-3)	2 (1-3)	2 (1-3)	

8.15 Sexual behaviour of HIV infected adolescents by age

The proportion of adolescents who reported to have ever been in sexual relationships increased as the age of the respondents increased. This was highly statistically significant. Similar findings were obtained in all the sexual behaviours except for heavy petting. The differences in these proportions were all statistically significant except for kissing.

Table 5; Sexual behaviour of HIV infected adolescents by age

	10-14	15-16	17-19	Total	p value
Ever had a sexual relationship					
Yes	22(18.5)	28(33.7)	66(67.3)	116(38.8)	0.001
No	97(81.5)	55(66.3)	32(32.7)	183(61.2)	
Currently in a relationship					
Yes	18(15.1)	24(28.9)	47(48.0)	89(29.7)	0.001
No	101(84.9)	59(71.7)	51(52.0)	211(70.3)	
Ever engaged in Kissing (% Yes)	20(90.9)	27(96.4)	65(98.5)	112(96.6)	0.13
Light petting (% Yes)	14(63.6)	22(78.6)	59(89.4)	95(81.9)	0.02
Heavy petting (% Yes)	10(45.5)	16(57.1)	16(24.2)	76(65.6)	0.02
Oral sex (% Yes)	0(0)	4(14.3)	18(27.3)	22(19.0)	0.007*
Vaginal sex (% Yes)	8(36.4)	16(57.1)	48(72.7)	72(62.1)	0.008

N:B; *Fischer Exact test was used

8.16 HIV preventive practices of the study participants:

Most of the study participants who had ever had penetrative sex had used condoms during sexual intercourse; nevertheless about 9 out of 10 had had at least one unprotected sexual act with the proportion being higher in males. Only 27% of those who had sex had disclosed their HIV status to their sexual partners.

Table 6; HIV preventive practices of HIV infected adolescents who have ever had sex

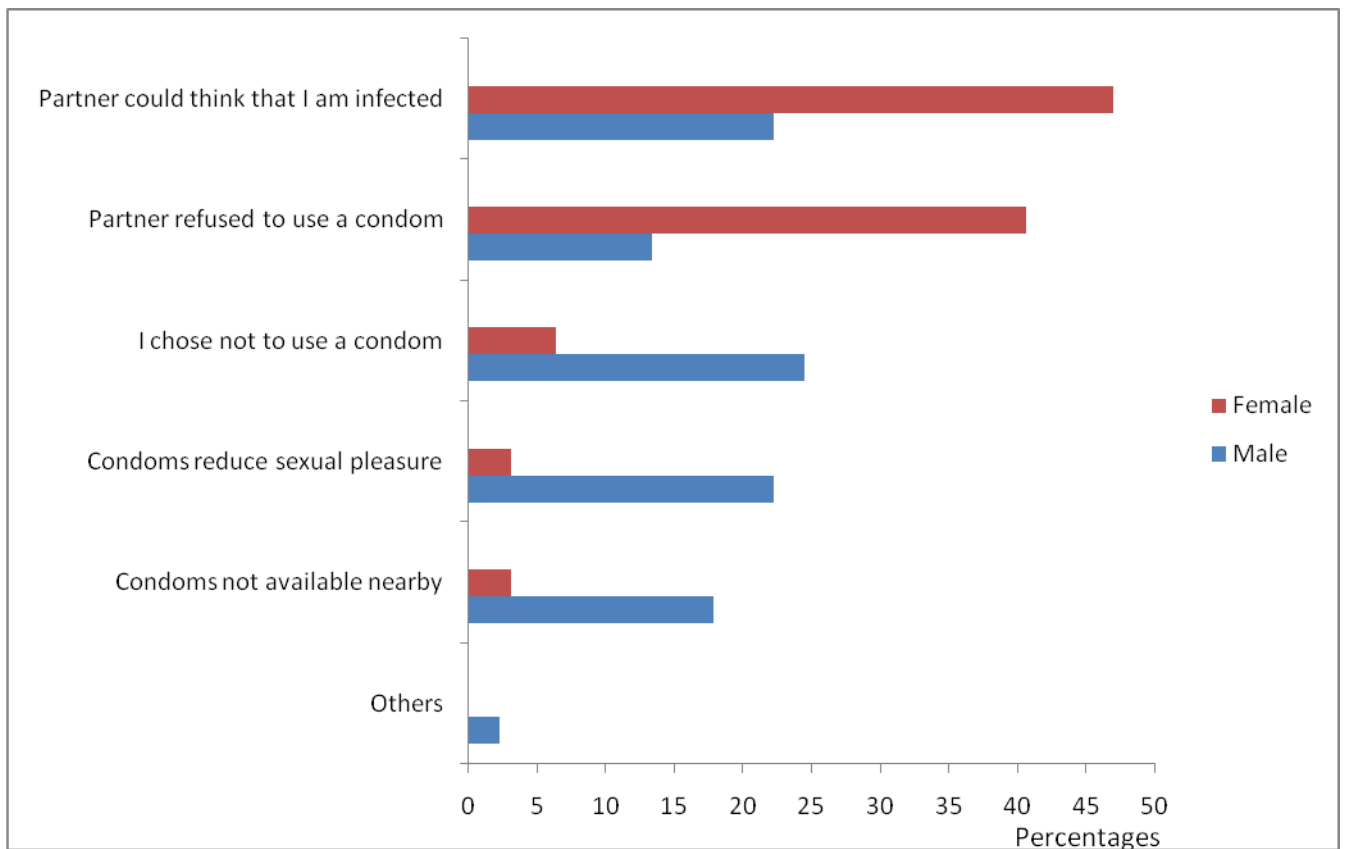
	Male	Female	Total	p value
Ever used a condom during sexual intercourse				
Yes	31(72.1)	29(93.5)	60(81.1)	0.002*
No	12(27.9)	2(6.5)	14(18.9)	
Ever had sex without a condom				
Yes	40(93.0)	28(90.3)	68(91.9)	0.69*
No	3(7.0)	3(9.7)	6(8.1)	
Ever disclosed HIV status to sexual partner				
Yes	9(20.9)	11(35.5)	20(27.0)	
No	34(79.1)	20(64.5)	54(73.0)	0.38
Sexual partners to whom disclosure was done				
Some of them	9(22.0)	11(35.5)	20(27.8)	
None of them	32(78.0)	20(64.5)	52(72.2)	
HIV status of current sexual partner				
Positive	0(0.0)	3(10.7)	3(4.3)	
Negative	2(4.9)	5(17.9)	7(10.1)	
I don't know	38(92.7)	20(71.4)	58(84.1)	
Sex with HIV negative or of unknown status				
Yes	37(97.4)	27(100.0)	64(98.5)	
No	1(2.6)	0(0.0)	1(1.5)	

N:B; *Fischer Exact test was used

8.17 Reasons given for having had unprotected sex

Most of the adolescents chose to have unprotected sex because they thought that if they insisted about condom use their partners could suspect that they are HIV infected and this was more evident in females. Another common reason given was partner refusal to use a condom and this was also reported more by the female participants.

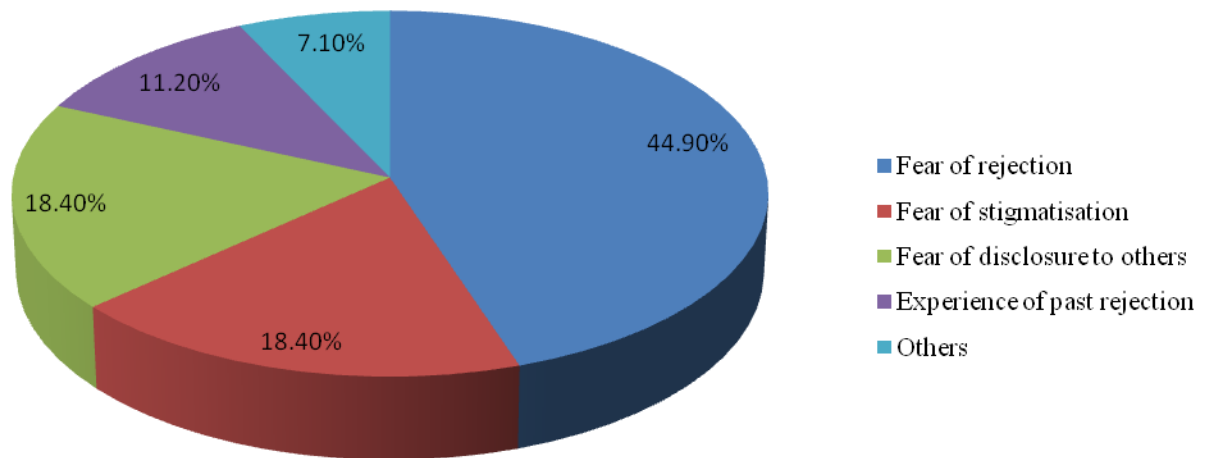
Fig 1: Reasons for having unprotected sex



8.18 Reasons for nondisclosure of HIV status to sexual partners

A number of reasons were given for non disclosure of HIV status to sexual partners. The most common reason was fear of rejection by the sexual partner which was given by almost half of the respondents. Other common reasons were fear of stigmatization and fear that the sexual partners could disclose their HIV status to others.

Fig 2: Reasons for nondisclosure of HIV status



8.19 Predictors for unprotected sex

Males were 1.4 times more likely to have unprotected sex compared to females but this was not statistically significant. Having lost a mother was the only significant risk factor for unprotected sex.

Table 7; Univariate analysis for factors associated with unprotected sex among HIV infected adolescents

	Unadjusted OR (95% CI)	P value
Sex		
Male	1	
Female	0.32(0.02-4.83)	1.43
Age group		
10-14	1	
15-16	0.99(0.03-14.27)	1.50
17-19	0.08(0.16-32.13)	0.98
Status of the parents		
Both alive	1	
Father deceased	0.75(0.04-14.27)	0.99
Mother deceased	11.25(1.41-89.25)	0.02
CD4 count		
< 350 cells/mm ³	1	
> 350 cells/mm ³	0.32(0.02-5.86)	1.67

N: B; 1 in the column of unadjusted OR stands for the reference category

8.20 Pregnancy experiences of HIV infected female adolescents

Only 9.72% of the female participants who had ever had sex had ever been pregnant with one of them being pregnant during the study period. Two out of seven had live births and their children were still alive. Over half of them had received PMTCT services.

Table 8; Pregnancy and child bearing experiences among HIV infected females

	N=150	%
Ever been pregnant	7	9.72%
Outcome of the pregnancy		
Live birth	2	28.57%
Spontaneous Abortion/Miscarriage	2	28.57%
Induced abortion	2	28.57%
Currently pregnant	1	14.29%
Received PMTCT services		
Yes	4	57.14%
No	3	42.86%
Any living children (Yes)	2	28.57%

8.2 RESULTS FOR QUALITATIVE SURVEY

8.2.1 Sociodemographic characteristics of the participants

There were a total of 10 participants, 5 females and 5 males. Their ages ranged between 15 and 19 years with 6 of them being above 16 years and 4 of them of between 15 and 16 years. Two of the females were married. Three of them had primary education, 6 had secondary education and one of them had no formal education.

8.2.2 Themes

Several themes came out of this survey and these were fear of disclosure, sense of powerlessness, fear of rejection and unawareness of HIV status

8.2.2.1 Fear of disclosure

A number of participants felt that using condoms is a challenge especially when it is a risk for disclosure of their HIV status. One of the participants reported;

“If it was my choice then I could have used condoms every time I had sex but with this situation it is really hard for me. I told my boyfriend to use a condom the first time we did it but as time goes by I lose grounds for insisting on condom use because I am sure if I do so he will ask for an explanation and I am really scared of exposing my status to him....” (15 years old female)

This participant was ready to use condoms however she had a challenge in using them consistently since she had fear that her partner would suspect that she is HIV infected.

Another one had this to tell;

“I have dated a couple of women because I never stay with women for long... I prefer short term relationships. If I stay with someone for a long time we can become very close and I may be forced to reveal my status something that I am not prepared for at the moment....” (17 years old male)

According to this participant it is the fear of disclosing his status to his sexual partners that forces him to have unstable relationships.

Other participants were afraid that if they reveal their status then the sexual partners will spread the information to other people who will start discriminating them. This is illustrated by the following statements which were given by some of them;

“I have not told any of my sexual partners that I am HIV infected. I am sure you are aware of the current situation... if I tell someone the truth everyone else will know and I will just regret it. There are a lot of stories amongst us.... you will just hear people saying that so and so has HIV... I usually just keep quiet and continue keeping my secret.....Stigma is still there” (19 years old female)

Another one had this to reveal;

“To tell a sexual partner that I am HIV infected is not an easy thing, most of the times I hesitate to do it because I am not sure of how he is going to react. I am scared that he might leave me.....if I tell him he might also go and tell other people about my condition and they will start talking badly about me and make me feel terrible.....” (15 years old female)

According to these participants they are scared that upon revealing their status to sexual partners other people may be told who may in turn start to discriminate them.

8.222 Sense of powerlessness

Three out of the five female participants felt that they are not strong enough to negotiate condom use during sex if a man is not ready to do so. This is demonstrated by the following statements;

“Using a condom in every sexual act is possible but it’s not easy especially for us women we don’t have enough confidence to do so and we usually hesitate to tell men to put on condoms or put them on ourselves....”(19 years old female)

Another one said;

“I wanted to use a condom but it was he who refused to use it and I could not force him... I felt sorry for him but what could I do? He said condoms reduce sexual pleasure.....”(18 years old female)

Another participant reported;

“I have had sex with two men but I have never used a condom....most of the times men are the ones who decide whether to use a condom or not. I am usually not strong enough to tell a man to put on a condom.....and with my condition I feel like he is going to suspect me....” (15 years old female)

Hence these participants felt that they do not have power to decide about condom use during sex simply because they are women.

A sense of powerlessness was also felt by one of the female participants who was married but had not revealed her status to her husband. She had this to share;

‘I am married and I am living with my husband, I don’t see the possibility of me using a condom every time I have sex with him. After all because I am married people expect me to have children, how I can continue using a condom if I want to have kids? It is really difficult. I know I was wrong not to let him know before we got this far, may be one day I will have the strength to do so.’ (19 years old female)

8.223 Fear of rejection

Most of these adolescents were scared of being rejected if they reveal their status. This is exemplified by the following statement which was given by one of them;

“If I tell the truth nobody will accept me....who would want to be with a person who is already infected and leave so many others who are not infected? I will just continue keeping my secret” (16 years old male)

Some of these adolescents were strong enough to reveal their HIV status however they experienced rejection upon doing that which has continued to act as a barrier for further disclosure. One of the participants had this to tell;

“Mmmh, that issue about disclosing to sexual partners I will never try it again. I told my first boyfriend that I am infected and I will never forget what he did to me. He told several of his

friends in school and he also left me. I felt very bad and I also had an argument with my mother because she usually discourages me to tell anyone the truth. I had to move to another school because of that....” (18 years old female)

Another one reported;

“I was dating a certain man; we were so close I thought I had found the right man. One day I decided to tell him the truth....this man pretended to be ok with the situation...one day I caught him cheating with another woman, when I asked him he said he cannot be with a woman like me... that I am nothing to him and being with me is like signing his own death sentence....I felt very very bad but I learnt my lesson. I will never do it again.... (17 years old female)

8.224 Unawareness of HIV status

Some of them were not aware that they are infected with HIV when they began to have sex. This was stated by two of the participants as follows;

“I did not tell her. Previously I did not know that I am infected with HIV. I was using ARVs for a long time and every time I asked I was told that I have a heart problem. As I grew up I started suspecting that I have HIV because every time I went to the clinic I would see posters talking of either TB or HIV. I did my own research and just a few months ago they were forced to tell me the truth....” (15 years old Male)

Another one had this to report;

“Yes I have used condoms during sex but not all the times. In the beginning I never knew that I am HIV infected so I was having sex without a condom....” (16 years old male)

Therefore in accordance to the statements given by these adolescents it is the unawareness of their HIV status that made them have unprotected sex.

9.0 DISCUSSION

The main aim of this study was to assess knowledge on HIV transmission and prevention, sexual behaviours, HIV preventive practices and pregnancy experiences of adolescents who have been living with HIV from early childhood.

9.1 Knowledge on HIV transmission and prevention

Most adolescents could correctly identify the means through which HIV can be transmitted and prevented. Over 90% knew that HIV can be transmitted by unprotected sexual intercourse equivalent to what was reported by Ezeanolue et al in USA²⁵ and Fernet et al¹⁴ in Canada who conducted studies among adolescents of similar nature. More than 80% knew that HIV can be prevented by abstaining and by correct and consistence use of condoms. This has been the trend in most of the studies that examined knowledge among this group of adolescents.

This is expected because HIV has been there for a while, in Tanzania for close to 30 years. Information about it is widespread and it is even provided in schools from the primary level where most of these adolescents have gone through. These adolescents have also been attending CTC clinics and some of them are involved in HIV positive youth support groups where information on HIV transmission and prevention is provided on a regular basis.

Apart from correctly identifying the modes of HIV transmission and prevention, 30% of these adolescents thought that taking and adhering to ART can help prevent HIV transmission. They believed that once you start using ARV's you cannot transmit HIV. This could be so because once they start using ARVs they become healthier and get less opportunistic infections. This is one of the common misconceptions surrounding HIV/AIDS. It is ranked as the 7th common misconception among the 10 most common misconceptions about HIV/AIDS²⁶. It is rather a negative misconception especially among the group of adolescents that were included in this study as it encourages them to continue having unprotected sexual intercourse and thus increasing the risk for secondary transmission of HIV.

9.2 Sexual behaviour

The overall proportion of HIV infected adolescents who had ever been in sexual relationships was found to be 38.8%. This finding was lower than 66% and 41% which were reported by Birungi et al in studies of similar nature done in Kenya and Uganda respectively^{4, 15}. It is also lower than 79% found by Ezeanolue et al in USA²⁵. These differences could be the result of differences in study populations between these studies. The Kenyan and Ugandan studies included older participants of 15 and 19 years only while that of USA incorporated those of 13 to 19 years. Evidence has demonstrated that in adolescents as the age increases the likelihood of engaging in sexual relationships increases as well.

More males (45.7%) reported to have ever been in sexual relationships compared to females (32.9%) and this finding was statistically significant. This concurs with a study done by Birungi et al in Uganda¹⁵ where 46% of males reported to have ever been in sexual relationships compared to 37% of females which was also statistically significant. This has been a common finding in most studies assessing sexual behaviour in males and females. This could be so because in most societies including ours it is regarded as a prestige for a man to be involved in sexual relationships as well as other sexual behaviours while for a female it is regarded as a disgrace.

The proportion of adolescents who had ever been in sexual relationships increased as the age increased and this was statistically significant. A study done in USA by Koenig et al¹² and Canada by Wiener et al¹³ had similar findings. This has been a norm globally in terms of sexual relationships and sexual activities, older adolescents are more likely to engage in them compared to younger adolescents. The older ones have more time and hence more likelihood of being exposed to risks for initiating sexual relationships as well as sexual activity.

Out of those who had ever been in sexual relationships 62.1% had had vaginal sex which constituted 24% of the overall proportion. This was comparable to 27% reported by Fielden et al in Canada²¹ but was lower than 33%, 41% and 46% reported by Birungi et al in Uganda¹⁵, Wiener et al in USA¹³ and Koenig et al¹² respectively. The higher proportion reported in

other studies could be a result of incorporating both adolescents and young adults in their studies which increases their likelihood of having engaged in sex.

Early sexual debut i.e before 15 years has been listed as a risk factor for HIV transmission since with early sexual debut the likelihood of having multiple lifetime sexual partners increases. In this study one out three adolescents (39.2%) reported to have had early sexual debut. This proportion is slightly higher compared to that of 26.3% obtained by Ezeanolue et al in USA²⁵. The initiation of sex at an earlier age in this population increases the possibility of having multiple sexual partners and hence the chances for onward transmission and reinfection with HIV.

9.3 HIV preventive practices

Over 80 percent of adolescents who were sexually active had used condoms at least once during sexual intercourse, nevertheless only 8.1% of these had used them consistently. Despite most of them knowing that unprotected sex is one of the major means of HIV transmission, 91.9% of those who were sexually active reported to have had unprotected sex at least once with an overall proportion of 22.6%. This is similar to what was reported by Koenig et al¹² in a study done in USA where 28% of the participants reported to have had unprotected sex. In a study done by Fernet et al¹⁴ more than half of participants who reported condom use at first sex had unprotected sex subsequently. This poses a challenge in terms of prevention of HIV transmission because with every act of unprotected sex there is a potential risk for HIV transmission and hence limiting the global efforts against the spread of HIV.

The proportion of females who reported to have had engaged in sexual intercourse in which a condom was used was higher (93.5%) compared to that of males (72.1%) and this was highly statistically significant. This concurs with the findings of Birungi et al in Uganda¹⁵ but has not been a consistent finding in other studies. This could probably be explained by the fact that females usually have a sense of responsibility over their actions as compared to males thus even in this situation they probably chose not to put their partners at risk of transmission of HIV.

In spite of the fact that most of the adolescents who had ever been in sexual relationships were dating partners of unknown HIV status (84.1%) or HIV negative (10.1%), almost all them had had unprotected sex with these partners. This finding is in accordance with that of Koenig et al¹². This furthermore underlines the possibility for secondary transmission of HIV and hence counteracting the efforts to curb HIV transmission.

Several reasons were provided for having chosen to have unprotected sex both in qualitative as well as quantitative surveys. Most of the adolescents expressed fear that their partners could suspect that they are HIV infected if they insisted about condom use and this was more evident in females. This finding concurs to what was previously published by Fernet et al in a study done in Canada among adolescents living with HIV since birth²⁰. Condom use has been linked with the likelihood of exposure of HIV status to sexual partners and these youths are not ready to take that risk because it could jeopardize their relationships. This feeling however puts at risk the sexual partners who are not HIV infected and the HIV infected adolescents as well because they are also at risk of being infected with a different strain of HIV.

Another common reason given was partner refusal to use a condom and this was also reported more by the female participants. The qualitative data revealed sense of powerlessness that is linked with this reasoning. A couple of women conveyed lack of power in negotiating condom use during sex and thought that it is the men that have to decide. This was also evident in the study done by Fernet et al²⁰ that was cited above. For ages this has been a norm globally but more so in the less developed world including Tanzania where women empowerment is still a challenge and the cultural norms regard men as being superior. Women have been considered to have less gender power thus the primary decision makers for condom use thought to be the men. With this attitude going on the efforts to prevent sexual transmission of HIV are laid on the line.

Disclosure rate to sexual partners among adolescents living with HIV from childhood has been reported to be low. In this study only 27% adolescents who have ever had sex had disclosed their HIV status to their sexual partners and less than five percent had done it to all of their partners. This corresponds to findings of Birungi et al in Uganda¹⁵, Michaud et al in

Switzerland²² and Koenig et al¹². Disclosure of HIV status is regarded as one of the preventive interventions since once it is done then the uninfected individual will be able to make an informed decision in terms of sexual practices as well as be more cautious when engaging in any sexual encounter with the partner. The low disclosure rate among this population is a great risk because they stand a great chance of transmitting the infection to others.

Both quantitative as well as qualitative data suggested that nondisclosure was not done purposely but came about as a consequence of a number of reasons. The most common reason given was fear of rejection by the partner which was also well narrated in the qualitative survey. Most of them were not sure of their partners' reactions once disclosure is done and some of them had experienced rejection when they had decided to do so. This fear has been shown to act as a big obstacle to HIV status disclosure to sexual partners. Childs et al²³, Leonard et al²⁴, Birungi et al¹², Fernet et al¹⁴ and Michaud et al²² had similar findings in studies done in USA, Uganda, Kenya, Canada and Switzerland respectively among adolescents perinatally infected with HIV.

Other common reasons that were given in both qualitative as well as quantitative surveys were fear of partners disclosing to others without their authorization and fear of stigmatization or discrimination. These reasons were also given in the studies that were cited above. Stigma in HIV is still a problem despite the disease being around for more than two decades. With the persistence of stigma disclosure will remain a challenge. Rejection or acceptance by sexual partners is hard to predict but in the face of stigma the probability of rejection is high and hence limiting the chances of HIV status disclosure to sexual partners which is one of the landmarks in HIV prevention.

9.4 Risk factors for unprotected sex

The only significant risk factor for unprotected sex was having lost a mother. Those who had no mothers were found to be eleven times more likely to have unprotected sex. This is similar to the findings of Tassiopoulos et al in a study done in USA²⁷ who found that youth living

with a relative other than their biological mother had higher odds of engaging in unprotected SI than those living with a nonrelative. This has been a norm in most situations. The presence of parents but more so of a mother is an important element in the fight against HIV/AIDS. Mothers usually help shape and modulate the behaviour of their children and help them make correct decisions in case they are faced with challenges including those concerning issues of sexuality. Mothers have also shown to be ready to care for their children in whatever circumstance and in that way protecting them from risky situations that could encourage them to engage in risky behaviours.

The rest of the risk factors had very small samples thus it was hard to conclude about the significance of the findings.

9.5 Pregnancy experiences

Only 9.72% of the sexually active female adolescents had ever been pregnant. This is a smaller proportion compared to 17.9% which was reported by Ezeanolue et al in USA but slightly higher than 5.9% which was reported by Brogly et al also in USA¹⁹. Birungi et al in Uganda¹⁵ had pregnancies reported by 41% of all the adolescents. All of these studies were done among adolescents who have survived with HIV from childhood.

The explanation for the higher proportion documented in the Ugandan study could be because it also included the males who had reported to have had impregnated some women while the rest of the proportions were for females who had ever been pregnant only. The lower proportion in this study could have been because it only included the adolescents who were attending the adolescent clinics during the time of the study and did not involve those who could have been attending PMTCT clinics.

All of these pregnancies were unplanned and the fact that they did occur also increases the risk for further HIV transmission and re-infection.

10.0 STUDY LIMITATIONS

1. This was a strictly hospital based study done in public care and treatment centres thus its findings may not be generalizable to the whole population of adolescents who have been living with HIV from early childhood.
2. Data concerning pregnancy experiences could have been an under estimation because not all adolescents who were attending PMTCT clinics while the study was being conducted were involved in the study.

11.0 STUDY STRENGTHS

1. This study incorporated both quantitative as well as qualitative methods. The qualitative data complemented the quantitative....
2. Adolescents of all ages i.e from 10 to 19 years were included in this study different from most other studies which included only the older adolescents. In that way it was possible to make comparison of various factors between different age groups.
3. Analysis for predictors of risky sexual behaviour were determined which was also not done in most other studies.

12.0 CONCLUSION

1. Knowledge on HIV transmission and prevention among adolescents living with HIV from early childhood is high (>80% and >90%) respectively.
2. Penetrative sex among these adolescents is common.
3. HIV preventive practices among them are poor.
4. Having lost a mother was the only significant risk factor for risky sexual behaviours.

13.0 RECOMMENDATIONS

1. Programmes caring for these adolescents should strengthen patient education on issues concerning sexual and reproductive health. These include promotion of safe sex, disclosure of HIV status to sexual partners and discourage the misconception that antiretroviral drugs have a role in preventing transmission of HIV. This is in order to prevent secondary transmission of HIV/AIDS as well as reinfection.
2. Female adolescents need to be empowered in order to be able to negotiate safer sex and in that manner prevent secondary transmission of HIV
3. Disclosure of HIV status to the HIV infected adolescents needs to be done early preferably during pre-adolescence in order to allow them to make informed decisions when they start engaging in sexual behaviours.
4. A follow up study is recommended with a bigger sample size in order to be able to determine risk factors for all the risky sexual behaviours as well as the pregnancy and child bearing experiences of these adolescents.

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APPENDICES:**APPENDIX 1; QUESTIONNAIRE (ENGLISH VERSION):****Questionnaire No.:** _____**Date:** **Day** **Month** **Year** **Study Site:**

SECTION 1:

1.1 Sex of the respondent

 Male Female1.2 Age of the respondent Years old

1.3 Level of education

 Primary Secondary Vocational training College/University No formal education

1.4 Marital status

 Single Married Divorced/Separated Cohabiting Widowed

1.5 Status of the parents

 Both alive Father alive Mother alive

Both parents deceased

1.6 Current head of the respondent's household

- Father
 Mother
 Aunt/Uncle
 Grandfather/Grandmother
 Others _____
 Living alone

1.7 Age at diagnosis of HIV Years Months

1.8 Age at disclosure of HIV status Years Old

1.9 The most recent CD4 count _____ Cells/mm³

1.10 Time during which the CD4 count was taken _____ Year _____ Month

1.11 Clinical stage of HIV/AIDS

- Stage 1
 Stage 2
 Stage 3
 Stage 4

1.12 Already on ART treatment? Yes No

1.13 Duration of ART treatment? Months Years

SECTION 2: Knowledge on HIV transmission and prevention

2.1 Can HIV be transmitted through transfusion of infected blood to an uninfected individual?

- Yes No I don't know

2.2 Can HIV be transmitted through unprotected (without a condom) sexual intercourse with an infected partner?

- Yes No I don't know

2.3 Can a person have HIV and not show signs of any disease?

- Yes No I don't know

2.4 Can a person who looks healthy, but has HIV pass the virus on to other people through unprotected sexual intercourse?

Yes No I don't know

2.5 Can a person get HIV by hugging someone who has this virus?

Yes No I don't know

2.6 Can HIV be transmitted by deep kissing?

Yes No I don't know

2.7 Can a HIV positive mother transmit the infection to her baby?

Yes No I don't know

2.8 Can HIV be transmitted by sharing needles with infected individuals?

Yes No I don't know

2.9 Can a HIV positive person get re infected with the virus by having unprotected sexual intercourse?

Yes No I don't know

2.10 Can a HIV positive person on ART treatment transmit the infection through unprotected sexual intercourse?

Yes No I don't know

2.11 One way of preventing HIV is not having sexual intercourse at all

Yes No I don't know

2.12 Can correct and consistent use of condoms during sexual intercourse prevent HIV transmission?

Yes No I don't know

2.13 Can the use of contraceptive pills or injections prevent HIV transmission?

Yes No I don't know

2.14 Can taking and adhering to ART prevent HIV transmission?

Yes No I don't know

SECTION 3: Sexual behavior

- 3.1 Have you ever had a boyfriend/girlfriend? Yes No
- 3.2 Do you currently have a boyfriend/girlfriend? Yes No
- 3.3 Have you ever kissed a boy/girl? Yes No
- 3.4 Have you ever engaged in light petting (fondling each other's upper body)?
 Yes No
- 3.5 Have you ever engaged in heavy petting (fondling each other's private parts)?
 Yes No
- 3.6 Have you ever had vaginal sexual intercourse? This means intimate contact with someone during which the penis enters the vagina (female private parts)
 Yes No
- 3.7 Have you ever had oral sex? This means intimate contact during which the penis is in the mouth or mouth to anus or mouth to vagina
 Yes No
- 3.8 Have you ever had anal sex? This means sexual intercourse during which the penis enters the anus
 Yes No
- 3.9 If you have never had sex, at what age do you expect to first have your sexual intercourse?
 Yes No
- 3.10 If you have had sexual intercourse, how old were you when you did so for the first time?
 Years old
- 3.11 With how many different people have you had sexual intercourse in the past 6 months?
_____ Partners
- 3.12 With how many different people have you had sexual intercourse in your life?
_____ Partner

SECTION 4: HIV preventive practices (To be filled only by those who have had sexual intercourse i.e vaginal/anal sex)

4.1 Have you ever used a condom during sex? Yes No

4.2 The first time you had sexual intercourse, did you use a condom? Yes No

4.3 The last time you had sexual intercourse, did you use a condom? Yes No

4.4 Have you ever had sex without using a condom? Yes No

4.5 If you have ever had sex without using a condom, what are the reasons why you did not use a condom? (Mark all that apply)

- My partner refused to use a condom
- I chose not to use a condom
- My partner may think I have a disease
- Condoms were not available anywhere nearby
- Condoms reduce pleasure
- Others _____

4.6 If you have ever used a condom during sexual intercourse what are the reasons for having used a condom? (Mark all that apply)

- To prevent self re infection
- To prevent infecting the partner
- To prevent pregnancy
- To avoid contracting other STI's
- Others _____

4.7 Have you ever disclosed your HIV status to any of your sexual partners? Yes No

4.8 To how many of your sexual partners have you disclosed your status?

- All of them
-

Some of them

None of them

4.9 If you had not disclosed your status to some or all of your sexual partners what are the reasons for non disclosure?

Fear of rejection by partner

Fear of stigmatization by the partner

Fear of partner disclosing to others

Others _____

4.10 What is the HIV status of your current partner?

HIV positive

HIV negative

I don't know

I am not currently in a relationship

4.11 If your partner is HIV negative or you are not aware of his/her HIV status have you ever engaged with him/her in sexual intercourse?

Yes No

SECTION 5: Pregnancy experiences

5.1 Have you ever been pregnant or impregnated someone?

Yes No I don't know

5.2 If yes how many times have you ever been pregnant or impregnated someone?

_____ Times

5.3 Were the pregnancies/pregnancy planned?

Yes No

5.4 If you have ever been pregnant how old were you when you first became pregnant?

Years old

5.5 What have been the outcome/outcomes of your pregnancy/pregnancies?

Live birth

Still birth

Abortion/Miscarriage

5.6 Did you carry out any interventions to prevent transmitting HIV infection to your baby?

Yes No

5.7 At what stage did you carry out interventions to prevent transmitting HIV to your baby?

During pregnancy

During delivery

During breastfeeding

5.8 Do you have any living children? Yes No

5.9 If yes how many living children do you have? Yes No

5.10 What is the HIV status of your child/children?

HIV positive

HIV negative

Both

I don't know

QUESTIONNAIRE (SWAHILI VERSION)

Namba ya dodoso.: _____

Tarehe: **Siku** **Mwezi** **Mwaka** **Jina la Kliniki:**

SEHEMU YA KWANZA: Weka alama ya pata kwenye boksi lililo pembeni ya jibu ambalo umechagua

1.1 Jinsia

Msichana Mvulana

1.2 Umri; Miaka

1.3 Kiwango cha elimu

Elimu ya msingi

Sekondari

Shule ya ufundi

Chuo kikuu

Sijasoma

1.4 Hali ya ndoa

Sijaoa/Sijaolewa

Nimeoa/Nimeolewa

Nimeachwa/Nimeachika

Nimewekwa kinyumba

Mjane

1.5 Hali ya wazazi

- Wote wako hai
- Baba amefariki
- Mama amefariki
- Wote wamefariki

1.6 Nani ni mkuu wa nyumba unayoishi sasa hivi?

- Baba
- Mama
- Mjomba/Shangazi
- Bibi/Babu
- Wengineo _____
- Mimi mwenyewe

1.7 Ulikuwa na umri gani ulipogundulika kuwa una virusi vya ukimwi? Miaka Miezi

1.8 Ulikuwa na umri gani ulipoelezwa kwa mara ya kwanza kuwa una virusi vya ukimwi?

Miaka

1.8 Kiasi cha CD4 kilichopimwa ndani ya miezi 6; _____ Seli/mm³

1.9 Steji ya ugonjwa (Ukimwi)

- Steji 1
- Steji 2
- Steji 3
- Steji 4

1.10 Umeshaanza kutumia dawa za ARV? Ndiyo Hapana

1.11 Ni muda gani umepita tangu ulipoanza kutumia dawa za ARV? Miezi Miaka

SEHEMU YA PILI: Ufahamu kuhusu maambukizi na kujikinga na virusi vya UKIMWI

2.1 Je mtu anaweza kuambukizwa ukimwi kwa kuongezewa damu yenye virusi vya ukimwi?

Ndiyo Hapana Sifahamu

2.2 Je mtu anaweza kupata virusi vya ukimwi kwa kufanya mapenzi bila ya kutumia kondomu na mtu aliyeathirika?

Ndiyo Hapana Sifahamu

2.3 Je kuna uwezekano wa mtu kuwa na virusi vya ukimwi ila asionyeshe dalili za ukimwi?

Ndiyo Hapana Sifahamu

2.4 Je mtu mwenye virusi vya ukimwi ambaye haonyeshi dalili za ukimwi anaweza kusambaza virusi vya ukimwi kwa kufanya mapenzi bila ya kutumia kinga?

Ndiyo Hapana Sifahamu

2.5 Je mtu anaweza kupata virusi vya ukimwi kwa kumkumbatia mtu aliyeathirika?

Ndiyo Hapana Sifahamu

2.6 Je virusi vya ukimwi vinaweza kuambukizwa kwa njia ya kubusiana?

Ndiyo Hapana Sifahamu

2.7 Je mwanamke mjamzito mwenye virusi vya ukimwi anaweza kumuambukiza mtoto wake virusi hivyo?

Ndiyo Hapana Sifahamu

2.8 Je mtu anaweza kupata virusi vya ukimwi kwa kushirikiana kutumia sindano za madawa ya kulevya na mtu mwenye virusi vya ukimwi?

Ndiyo Hapana Sifahamu

2.9 Je mtu ambaye ana virusi vya ukimwi anaweza kupata maambukizi mengine ya virusi vya ukimwi kwa kufanya mapenzi bila ya kutumia kinga?

Ndiyo Hapana Sifahamu

2.10 Je mtu mwenye ukimwi aliyeanza kutumia dawa za ARV anaweza kusambaza virusi vya ukimwi kwa kufanya mapenzi bila ya kutumia kinga?

Ndiyo Hapana Sifahamu

2.11 Njia mojawapo ya kuzuia maambukizi ya virusi vya ukimwi ni kutofanya mapenzi kabisa

Ndiyo Hapana Sifahamu

2.12 Je matumizi ya kondomu kwa usahihi kila mara wakati wa kufanya mapenzi yanaweza kuzuia maambukizi ya virusi vya ukimwi?

Ndiyo Hapana Sifahamu

2.13 Je matumizi ya vidonge vya majira (vidonge vya kuzuia mimba) yanaweza kuzuia maambukizi ya virusi vya ukimwi?

Ndiyo Hapana Sifahamu

2.14 Je matumizi ya dawa za ARV yanaweza kuzuia maambukizi ya virusi vya ukimwi?

Ndiyo Hapana Sifahamu

SEHEMU YA TATU: Mahusiano ya kimapenzi

3.1 Je umeshawahi kuwa na mpenzi?

Ndiyo Hapana

3.2 Je kwa sasa hivi una mpenzi?

Ndiyo Hapana

Swali la 3.6 mpaka 3.15 yajibiwe na wale waliowahi kuwa na mpenzi/wapenzi tu. Kama hujawahi kuwa na mpenzi/wapenzi nenda sehemu ya nne ya dodoso.

3.3 Je umeshawahi kumbusu mpenzi wako?

Ndiyo Hapana

3.4 Je umewahi kushikwa au kumshika mpenzi wako sehemu za juu za mwili kama matiti?

Ndiyo Hapana

3.5 Je umewahi kushikwa au kumshika mpenzi wako sehemu za siri za mwili?

Ndiyo Hapana

3.6 Je umewahi kufanya mapenzi kwa kuingiza/ kuingiziwa uume kwenye uke?

Ndiyo Hapana

3.7 Je umewahi kufanya mapenzi kwa kunyonya/kunyonywa sehemu za siri za mwili?

Ndiyo Hapana

3.8 Je umewahi kufanya mapenzi kwa kuingiza/kuingiziwa uume sehemu ya haja kubwa?

Ndiyo Hapana

3.9 Kama hujawahi kufanya mapenzi unategemea kuanza kufanya hivyo ukiwa na miaka mingapi?

Miaka

3.10 Kama umewahi kufanya mapenzi ulikuwa na umri gani ulivyofanya mapenzi kwa mara ya kwanza?

Miaka

3.11 Je umefanya mapenzi na watu wangapi katika kipindi cha miezi sita iliyopita

Watu _____

3.12 Je umeshawahi kufanya mapenzi na watu wangapi tangu uzaliwe?

Watu _____

SEHEMU YA NNE: Matumizi ya njia za kujikinga na UKIMWI

Maswali yote ya sehemu ya nne yajibiwe na wale tu waliowahi kufanya mapenzi; kama hujawahi kufanya mapenzi endelea na sehemu ya tano ya dodoso

4.1 Je umewahi kutumia kondomu wakati wa kufanya mapenzi?

Ndiyo Hapana

4.2 Je ulitumia kondomu ulipofanya mapenzi kwa mara ya kwanza?

Ndiyo Hapana

4.3 Je ulitumia kondomu ulipofanya mapenzi mara ya mwisho?

Ndiyo Hapana

4.4 Je umeshawahi kufanya mapenzi bila ya kutumia kondomu?

Ndiyo Hapana

4.5 Kama umewahi kufanya mapenzi bila ya kutumia kondomu ni kwa nini ulifanya hivyo (Unaweza kujaza jibu zaidi ya moja)

Mpenzi wangu alikataa kutumia kondomu

Niliamua kutotumia kondomu

Mpenzi wangu angehisi nina virusi vya ukimwi

Kutokupatikana kwa kondomu maeneo ya jirani

Kondomu zinapunguza utamu wa mapenzi

Mengineo _____

4.6 Kama umewahi kutumia kondomu wakati wa kufanya mapenzi ni kwa nini ulifanya hivyo? (Unaweza kujaza jibu zaidi ya moja)

Kuepuka kupata maambukizi mapya ya virusi vya ukimwi

Kuepuka kumuambukiza mwenzangu

- Kuepuka kupata/kumpa mtu mimba
- Kuepuka kupata magonjwa mengine ya zinaa
- Mengineo _____

4.7 Je umewahi kumwambia mtu yeyote kati ya uliowahi kufanya nao mapenzi kuwa una virusi vya ukimwi?

- Ndiyo Hapana

4.8 Uliwaambia wangapi kati ya wote uliowahi kufanya nao mapenzi kuwa una virusi vya ukimwi?

- Wote
- Baadhi yao
- Sikumwambia yeyote kati yao

4.9 Kama hukuwaambia wapenzi wako wote au baadhi yao kuwa una virusi vya ukimwi kwa nini ulifanya hivyo? (Unaweza kujaza jibu zaidi ya moja)

- Niliogopa kuwa mpenzi wangu angenikataa kama ningemwambia ukweli
- Nimewahi kukataliwa na mpenzi wangu wa mwingine nilipomwambia kuwa nimeathirika
- Niliogopa kunyanyapaliwa
- Niliogopa kuwa mpenzi wangu atawaambia watu wengine kuwa nimeathirika
- Mengineo _____

4.10 Kama una mpenzi sasa hivi, je mpenzi wako ana virusi vya ukimwi?

- Ndiyo Hapana Sifahamu

4.11 Kama mpenzi wako hana virusi vya ukimwi au haufahamu kama ameathirika umewahi kufanya nae mapenzi?

- Ndiyo Hapana

SEHEMU YA TANO: Afya ya uzazi

5.1 Je umewahi kupata mimba au kumpa mtu mimba?

Ndiyo Hapana

5.2 Kama ndiyo ni mara ngapi umewahi kupata au kumpa mtu mimba?

Mara _____

Kama wewe ni mvulana nenda kwenye swali namba 5.8; kama ni msichana na umewahi kupata mimba endelea na maswali yanayofuata chini; kama ni msichana na hujawahi kupata mimba asante kwa kushiriki umefikia mwisho wa maswali.

5.3 Kama umewahi kupata mimba je ulipanga kupata mimba hiyo/hizo?

Ndiyo Hapana

5.4 Je ulikuwa na miaka mingapi ulipopata mimba kwa mara ya kwanza?

Miaka

5.5 Je ulipata matokeo gani baada ya kupata mimba? (unaweza kuchagua jibu zaidi ya moja)

- Mtoto alizaliwa mzima
- Mtoto alikuwa amefariki wakati wa kuzaliwa
- Mimba ilitoka kabla ya kufikisha miezi saba
- Mimba ilitoka baada ya kufikisha miezi saba

5.6 Je ulipata huduma yoyote ya kuzuia maambukizi ya virusi vya ukimwi kwenda kwa mtoto?

Ndiyo Hapana

5.7 Kama ndiyo ni wakati gani ulipata huduma ya kuzuia maambukizi ya virusi vya ukimwi kwenda kwa mtoto? (unaweza kuchagua jibu zaidi ya moja)

- Wakati wa ujauzito
- Wakati wa kujifungua
- Wakati wa kunyonyesha

5.8 Je una watoto walio hai kwa sasa?

Ndiyo Hapana

5.9 Kama ndiyo una watoto wangapi walio hai?

Watoto _____

5.10 Je watoto wako pia wameathirika na virusi vya ukimwi?

Ndiyo, wote wameathirika

Hapana

Ndiyo baadhi yao

Sifahamu

Umefikia mwisho wa dodoso, asante sana kwa ushiriki wako.

APPENDIX 2: IN DEPTH INTERVIEW GUIDE FOR ADOLESCENTS LIVING WITH HIV FROM EARLY CHILDHOOD (ENGLISH VERSION)

THEME 1: KNOWLEDGE ON HIV TRANSMISSION AND PREVENTION

1. I am sure by now you know a lot about HIV/AIDS; how do people become infected with HIV/AIDS?
 - a. PROBE: What are the behaviors that put people at risk for HIV transmission? (Unprotected sex, multiple sexual partners, alcohol/drug use, sharing needles)
 - b. PROBE: What are the various misconceptions surrounding HIV/AIDS transmission? (Hugging, eating/drinking, use of ARV, looking healthy)
2. Do you think that HIV adolescents still need to protect themselves against HIV?
 - a. PROBE: Why is it important to continue protecting yourself against HIV?
 - b. PROBE: What would be the consequences of dual infection with HIV?
3. What do you know about mother to child transmission of HIV?
 - a. PROBE: How can a mother transmit HIV to her baby? (pregnancy, delivery, breastfeeding)
 - b. PROBE: What can be done to prevent mother to child transmission of HIV?
4. What can be done to prevent HIV/AIDS transmission?
 - a. PROBE: What is your opinion about abstinence as a means of HIV/AIDS prevention?
 - b. PROBE: How is the practicability of this method to you and other adolescents living with HIV?
 - c. PROBE: What is your opinion about condom use as a means to prevent HIV/AIDS?
 - d. PROBE: What is your opinion about the use of ARV in prevention of HIV/AIDS transmission?

THEME 2: SEXUAL BEHAVIOR

1. What is your opinion about sex among HIV infected adolescents?
 - a. PROBE: What prompted you to have sex the first time you had it?
 - b. PROBE: Do you have any other ways to satisfy your sexual desires other than sexual intercourse?
 - c. PROBE: Do you think it is possible to overcome your desires for sex?
2. Which sexual partner do you prefer in terms of HIV status?
 - a. PROBE: What is the reason for your preference?
3. How many sexual partners have you had in your lifetime?
 - a. PROBE: How many have you had in the past 6 months?
 - b. PROBE: What is the reason for having multiple sexual partners?

THEME 3: HIV PREVENTIVE PRACTICES

1. We have talked about condom use as a means for HIV prevention; have you ever used a condom during sex?
 - a. PROBE: Did you use a condom the first time you had sex?
 - b. PROBE: What about in the rest of the times?
 - c. PROBE: Have you ever had sex without using a condom?
 - d. PROBE: What was the reason for not using a condom?
2. What is your opinion about disclosure of HIV status to your sexual partners?
 - a. PROBE: Why would you choose not to disclose your status?
 - b. PROBE: Have you ever disclosed your status any of your sexual partners?
 - c. PROBE: What was the response of your partner after disclosure?
 - d. PROBE: How did his/her response affect you?
3. Have you ever had sex with a HIV negative partner or whom his/her status you didn't know?
 - a. PROBE: Did you/your partner use any protection during that sexual encounter?

- b. PROBE: Did you disclose your status to such partner/partners?
- c. PROBE: Who made the choice not to use a condom?

THEME 4: PREGNANCY AND CHILD BEARING EXPERIENCES

1. What is your opinion about pregnancy in HIV infected adolescents?
 - a. PROBE: Do you think it is proper for HIV infected adolescents to get pregnant?
2. Have you ever been pregnant/impregnated someone?
 - a. PROBE: Did you plan for this/these pregnancy/pregnancies?
3. Did you use any prophylaxis to prevent mother to child transmission of HIV/AIDS?
 - a. PROBE: If you did not what was the reason?
 - b. PROBE: If you did at what stage did you use the prophylaxis?
4. What was the outcome of your pregnancy?

IN DEPTH INTERVIEW GUIDE FOR ADOLESCENTS LIVING WITH HIV FROM EARLY CHILDHOOD (SWAHILI VERSION)

SEHEMU YA KWANZA: UFAHAMU KUHUSU UKIMWI NA MAAMBUKIZI YA UKIMWI

1. Nina uhakika unafahamu mengi kuhusu UKIMWI; Je ni kwa njia gani virusi vya UKIMWI vinaweza kuambukizwa?
 - a. Ni tabia gani zinaweza kumuweka mtu katika hatari ya kuambukizwa virusi vya UKIMWI? (Kufanya mapenzi bila kinga, kuwa na wapenzi wengi, kutumia vilevi, kutumia sindano)
 - b. Je kuna imani gani potofu kwenye jamii yako kuhusu maambukizi ya UKIMWI? (Kukumbatiana, kula pamoja, kutumia dawa za ARV, muonekano wa mtu)
2. Je unadhani vijana wenye virusi vya UKIMWI/UKIMWI bado wanahitaji kujikinga na virusi hivyo?
 - a. Kuna umuhimu gani wa kuendelea kujikinga?
 - b. Ni nini madhara ya kuwa na maambukizi ya virusi vya UKIMWI vya aina zaidi ya moja?
3. Unafahamu nini kuhusu maambukizi ya virusi vya UKIMWI kutoka kwa mama kwenda kwa mtoto?
 - a. Je ni kwa njia zipi mama anaweza kumuambukiza mwanae virusi vya UKIMWI?
 - b. Ni njia zipi zinaweza kutumika kuzuia maambukizi ya virusi vya UKIMWI toka kwa mama kwenda kwa mtoto?
4. Ni njia zipi zinaweza kutumika kuzuia maambukizi ya virusi vya UKIMWI toka kwa mtu mmoja kwenda kwa mwingine?
 - a. Ni nini maoni yako kuhusu kutofanya mapenzi kabisa kama njia mojawapo ya kuzuia maambukizi ya virusi vya UKIMWI?
 - b. Unaonaje kuhusu mafanikio ya njia hii katika kuzuia maambukizi ya UKIMWI kwa vijana ambao wanaishi na virusi vya UKIMWI?
 - c. Nini maoni yako kuhusu matumizi ya kondomu kama njia ya kuzuia maambukizi ya virusi vya UKIMWI? (Matumizi ya kila mara, mpenzi wa muda mrefu)
 - d. Ni nini maoni yako kuhusu matumizi ya ARV na kinga dhidi ya maambukizi ya virusi vya UKIMWI?

SEHEMU YA PILI:

1. Nini maoni yako kuhusu ufanyaji wa mapenzi kwa vijana wanaoishi na virusi vya UKIMWI?
 - a. Ni kitu gani kilikupelekea kufanya mapenzi mara ya kwanza ulipoamua kufanya hivyo?
 - b. Kuna njia zozote nyingine unazotumiaga ili kupata sexual satisfaction other than kufanya mapenzi?
 - c. Je unadhani inawezekana kuzishinda hisia zako za kimwili za kutaka kufanya mapenzi?
2. Je unapendelea kuwa na mpenzi wa aina gani kwa kuzingatia hali yake ya kiafya? (Mwenye virusi au ambae hana)
 - a. Kwa nini unapendelea kuwa na mpenzi wa aina hiyo?
3. Je umewahi kuwa na wapenzi wangapi tangu ulipoanza mahusiano ya kimapenzi?
 - a. Umekuwa na wapenzi wangapi katika kipindi cha miezi sita iliyopita?
 - b. Ni sababu zipi zimekufanya kuwa na mpenzi zaidi ya mmoja?

SEHEMU YA TATU: UZUIAJI WA MAAMBUKIZI YA VIRUSI VYA UKIMWI

1. Tumeshaongea kuhusu matumizi ya kondomu kama njia mojawapo ya kuzuia maambukizi ya virusi vya UKIMWI, umeshawahi kutumia kondomu wakati unafanya mapenzi?
 - a. Je ulitumia kondomu ulipofanya mapenzi kwa mara ya kwanza?
 - b. Vipi kuhusu mara nyingine ulizofanya mapenzi?
 - c. Je umeshawahi kufanya mapenzi bila ya kutumia kondomu?
 - d. Ni sababu zipi zilikupelekea kufanya mapenzi bila ya kutumia kondomu?
2. Nini maoni yako kuhusu kuwaambia watu ambao unafanya nao mapenzi kuwa una virusi vya UKIMWI?
 - a. Kwa nini umeamua kutowaambia wapenzi wako kuwa umeathirika?
 - b. Je umewahi kumwambia yeyote kati ya wapenzi wako kuwa umeathirika?
 - c. Je nini kilitokea baada ya kumwambia mpenzi/wapenzi wako kuwa umeathirika?
 - d. Je ulichukuliaje mtazamo wa mpenzi/wapenzi wako?
3. Je umeshawahi kufanya mapenzi na mtu ambaye hana virusi vya UKIMWI au ambaye hufahamu kama ameathirika?
 - a. Je mlitumia kondomu mlipofanya mapenzi?
 - b. Ulimwambia/uliwaambia kuwa una virusi vya UKIMWI?
 - c. Nani alichagua kufanya mapenzi bila ya kutumia kinga?

SEHEMU YA NNE:

1. Nini maoni yako kuhusu vijana wenye virusi vya UKIMWI kupata mimba au kuwapa watu wengine mimba?
 - a. Je unafikiri ni sahihi kwa msichana mwenye virusi vya UKIMWI kupata mimba?
2. Je ulitumia njia zozote za kuzuia maambukizi ya virusi vya UKIMWI kwenda kwa mtoto?
 - a. Kama hapana ni kwa nini hukufanya hivyo?
 - b. Kama ndiyo ulitumia njia hizo wakati gani?
3. Je watoto uliowapata uliweza kuwakinga na virusi vya UKIMWI?

APPENDIX 3 ; CONSENT FORMS

Parental consent Form (English version)

Serial no _____

Dear Parent/guardian,

This is to inform you about the research that will be conducted at the Care and treatment centre (CTC) for HIV which your child is attending.

My name is Irene Rweyemamu a postgraduate student at Muhimbili University of health and allied sciences (MUHAS) doing a study among HIV infected adolescents aged 10 to 19 years at various CTC clinics in Dar es salaam

The purpose of the study is to assess knowledge, sexual behavior, pregnancy experiences and HIV prevention among HIV infected adolescents in Dar es salaam

What participation involves:

If you allow your child to participate in the study, he/she will have to fill a questionnaire inquiring about issues of sexual behavior, pregnancy experiences and HIV prevention. Some of the adolescents will also be asked to participate in focused group discussions made of 6-8 adolescents and in depth interviews involving only one adolescent in order to get more detailed information.

Will anyone know that my child was in the study?

Names or any other identifying features will not be included in the questionnaires, notes taken during the individual interviews or focused group discussions. All the information that will be obtained from the study participants will be kept confidential.

Right to withdraw from the study:

Taking part in this study is completely voluntary. Adolescents will be told that they can choose not to participate in the study and may withdraw at any point. There will be no penalty

for withdrawing and he/she will continue to receive the services that are normally provided in the hospital.

Are there benefits and risks?

The information obtained from your child will help me and the region at large understand whether these adolescents are taking any risks that could compromise the control of HIV infection. This information will help us set appropriate interventions in order to prevent further transmission of the infection to others and re infection of these adolescents with new strains of the HIV virus.

The risks from this study are minimal given the fact that all the information obtained will be kept confidential.

Who to contact:

If you ever have questions about this study, you may contact the following people:

The chairperson of Research and Publication Committee at Muhimbili University of Health and Allied Sciences (Tel: 2150302); P. O. Box 65001, Dar-es-salaam.

Study Supervisors: Ms. Lusajo Kajula, Dr Mangi Ezekiel or Dr Edward Kija of Muhimbili University of Health and Allied Sciences,P.O BOX 65001,Dar es Salaam.

Principal investigator: Dr Irene Rweyemamu of the same address and mobile no.0713 552186.

I hope that you will permit your child to participate in this study.

I have read the content of this form. My questions have been answered and I agree/Disagree to participate in this study.

Signature of parent.....

Signed at.....

On..... (date)

Relationship with the adolescent (eg. Father, mother, aunt, etc).....

Parental consent form (Swahili version)

Fomu ya ridhaa ya mzazi

Namba ya usaili _____

Mpendwa mzazi,

Hii ni kukufahamisha kuhusu utafiti utakaofanyika katika vituo vya afya hapa mjini Dar es salaam ambapo mtoto wako amekuwa akitibiwa.

Mimi naitwa Irene Rweyemamu, ni mwanafunzi wa shahada ya uzamili Chuo Kikuu cha Sayansi za Afya na tiba Muhimbili. Nafanya utafiti kwa vijana wenye umri kati ya miaka 10 na 19 wanaoishi na virusi vya UKIMWI wanaopata matibabu katika vituo vya afya vya hapa Dar es salaam.

Dhumuni la utafiti huu ni kujua kuhusu ufahamu wao juu ya maambukizi na kujikinga na maambukizi mapya ya virusi vya UKIMWI, mahusiano yao kimapenzi na afya ya uzazi.

Jinsi ya kushiriki

Kama utakubali mtoto wako ashiriki katika utafiti huu, atapewa fomu ya kujaza yenye maswali machache yanayotokana na madhumuni ya utafiti huu. Baadhi ya vijana wataombwa pia kushiriki katika mahojiano ya kijana mmoja mmoja au vikundi vya vijana 6 mpaka 8 kuhusu hoja hizo hizo ili kupata maelezo kwa undani zaidi.

Je kuna mtu yeyote anaweza kujua kama mtoto wangu ameshiriki katika utafiti huu?

Taarifa za mtoto wako zitatunzwa kwa siri kwa kutumia namba badala ya jina la mgonjwa. Ishara zozote zinazoweza kumtambulisha kijana hazitajumuishwa katika dodoso au fomu zitakazotumika katika mahojiano.

Uhuru wa kutoshiriki katika utafiti;

Kushiriki kwenye utafiti huu ni hiari. Mtoto anaweza kujitoa wakati wowote akijisikia kufanya hivyo. Kama utachagua kutoshiriki, mtoto wako ataendelea kupata huduma katika kituo chake cha afya kama kawaida.

Faida na madhara ya utafiti huu

Utafiti huu utakuwa msaada mkubwa kwangu mimi binafsi na kwa jamii kwa ujumla. Maelezo yatakayopatikana kutoka kwa vijana hawa yatasaidia kujua kama wanashiriki katika vitendo vyovyote vinavyoongeza hatari ya kupata maambukizi mapya ya virusi vya UKIMWI au kuambukiza vijana wengine. Hii itasaidia katika kupanga mipango itakayosaidia katika kupunguza maambukizi hayo ikiwemo kutoa elimu kwa vijana hao.

Nani wa kumtafuta kama unahitaji maelezo zaidi?

Endapo unahitaji kupata maelezo zaidi kuhusu utafiti huu unaweza kuwasiliana na wafuatao:

Mwenyekiti wa kamati ya utafiti ya chuo kikuu cha afya cha muhimbili kwenye sanduku la barua 65001 Dar es salaam au namba ya simu 2150302.

Wasimamizi wa utafiti huu ambao ni Ms Lusajo Kajula, Dr Mangi Ezekiel au Dr Edward Kija wote wa sanduku la barua 65001 Dar es salaam.

Mkuu wa utafiti Dr Irene Rweyemamu wa sanduku la barua hilohilo hapo juu au namba ya simu 0713552186

Ni matumaini yangu kuwa utamruhusu mwanao kushiriki katika utafiti huu.

Natanguliza shukrani

Nimesoma maelezo yote yaliyoandikwa hapo juu na kuyaelewa vizuri na hivyo nimeamua kumruhusu/kutomruhusu mwanangu kushiriki.

Sahihi ya mzazi/mlezi

Imesainiwa (mahali)

Tarehe

Uhusiano na mgonjwa (mzazi/mlezi).....

Adolescent consent form (English version)

Dear Adolescent,

This is to inform you about the research that will be conducted at the Care and treatment centre (CTC) for HIV which you are attending.

My name is Irene Rweyemamu a postgraduate student at Muhimbili University of health and allied sciences (MUHAS) doing a study among HIV infected adolescents aged 13 to 19 years at various CTC clinics in Dar es salaam

The purpose of the study is to assess knowledge, sexual behavior, pregnancy experiences and HIV prevention among HIV infected adolescents in Dar es salaam

What participation involves:

If you agree to participate in the study, you will have to fill a questionnaire inquiring about issues of sexual behaviour, pregnancy experiences and HIV prevention. Some of the adolescents will also be asked to participate in in depth interviews involving only one adolescent in order to get more detailed information.

Will anyone know that you were a part of this study?

Names or any other identifying features will not be included in the questionnaires, notes taken during the individual interviews or focused group discussions. All the information that will be obtained from the study participants will be kept confidential.

Right to withdraw from the study:

Taking part in this study is completely voluntary. **You can choose** not to participate in the study and may withdraw at any point. There will be no penalty for withdrawing and you will continue to receive the services that are normally provided in the hospital.

Are there benefits and risks?

The information obtained from you will help me and the region at large understand whether adolescents living with HIV are taking any risks that could compromise the control of HIV infection. This information will help us set appropriate interventions in order to prevent further transmission of the infection.

The risks from this study are minimal given the fact that all the information obtained will be kept confidential.

Who to contact:

If you have any further questions regarding the study you may contact the following;

The chairperson of Research and Publication Committee at Muhimbili University of Health and Allied Sciences (Tel: 2150302); P. O. Box 65001, Dar-es-salaam.

Study Supervisors: Ms. Lusajo Kajula, Dr Mangi Ezekiel or Dr Edward Kija of Muhimbili University of Health and Allied Sciences,P.O BOX 65001,Dar es Salaam.

Principal investigator: Dr Irene Rweyemamu of the same address and mobile no.0713 552186.

I hope that you will agree to be part of this important study.

I have read the content of this form. My questions have been answered and I agree/Disagree to participate in this study.

Signature of adolescent.....

Signed at.....

On..... (date)

Adolescent consent form (Swahili version)

Fomu ya ridhaa ya kijana

Namba ya usaili _____

Mpendwa kijana,

Hii ni kukufahamisha kuhusu utafiti utakaofanyika katika vituo vya afya hapa mjini Dar es salaam ambapo umekuwa ukitibiwa.

Mimi naitwa Irene Rweyemamu, ni mwanafunzi wa **digrii ya uzamili ya** Chuo Kikuu cha Sayansi za Afya na tiba Muhimbili. Nafanya utafiti kwa vijana wenye umri kati ya miaka 10 na 19 wanaoishi na virusi vya UKIMWI wanaopata matibabu katika vituo vya afya vya hapa Dar es salaam.

Dhumuni la utafiti huu ni kujua kuhusu ufahamu wako juu ya maambukizi na kujikinga na maambukizi mapya ya virusi vya UKIMWI, mahusiano yako kimapenzi na afya ya uzazi.

Jinsi ya kushiriki

Kama utakubali kushiriki katika utafiti huu, utapewa fomu ya kujaza yenye maswali machache yanayotokana na madhumuni ya utafiti huu. Baadhi ya vijana wataombwa pia kushiriki katika mahojiano ya kijana mmoja mmoja au vikundi vya vijana 6 mpaka 8 kuhusu hoja hizo hizo ili kupata maelezo kwa undani zaidi.

Je kuna mtu yeyote anaweza kujua kama mtoto wangu ameshiriki katika utafiti huu?

Taarifa zako zote zitatumizwa kwa siri kwa kutumia namba badala ya jina lako. Ishara zozote zinazoweza kumtambulisha kijana hazitajumuishwa katika dodoso au fomu zitakazotumika katika mahojiano.

Uhuru wa kutoshiriki katika utafiti;

Kushiriki kwenye utafiti huu ni hiari. Unaweza kujitoa wakati wowote ukijisikia kufanya hivyo. Kama utachagua kutoshiriki, utaendelea kupata huduma katika kituo chako cha afya kama kawaida.

Faida na madhara ya utafiti huu

Utafiti huu utakuwa msaada mkubwa kwangu mimi binafsi na kwa jamii kwa ujumla. Maelezo yatakayopatikana kutoka kwako na vijana wengine yatasaidia kujua kama mnashiriki katika vitendo vyovyote vinavyoongeza hatari ya kupata maambukizi mapya ya virusi vya UKIMWI au kuambukiza vijana wengine. Hii itasaidia katika kupanga mipango itakayosaidia katika kupunguza maambukizi hayo ikiwemo kutoa elimu kwenu kuhusu kujikinga na maambukizi mapya.

Nani wa kumtafuta kama unahitaji maelezo zaidi?

Endapo unahitaji kupata maelezo zaidi kuhusu utafiti huu unaweza kuwasiliana na wafuatao;

Mwenyekiti wa kamati ya utafiti ya chuo kikuu cha afya cha muhimbili kwenye sanduku la barua 65001 Dar es salaam au namba ya simu 2150302.

Wasimamizi wa utafiti huu ambao ni Ms Lusajo Kajula, Dr Mangi Ezekiel au Dr Edward Kija wote wa sanduku la barua 65001 Dar es salaam.

Mkuu wa utafiti Dr Irene Rweyemamu wa sanduku la barua hilohilo hapo juu au namba ya simu 0713552186

Ni matumaini yangu kuwa utakuwa tayari kushiriki katika utafiti huu.

Natanguliza shukrani

Nimesoma maelezo yote yaliyoandikwa hapo juu na kuyaelewa vizuri na hivyo nimeamua kwa hiari yangu kushiriki katika utafiti huu.

Sahihi ya mshiriki

Imesainiwa (mahali)

Tarehe