



UNIVERSITY OF NAIROBI

**PSYCHOSOCIAL CHARACTERISTICS AND DISCLOSURE STATUS OF HIV
INFECTED ADOLESCENTS ATTENDING CLINIC AT KENYATTA
NATIONAL HOSPITAL**

Principal Investigator: Dr. Douglas Kinuthia Gaitho

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**Department of Paediatrics and Child Health,
University of Nairobi P.O. Box 30197 – 00100, Nairobi.**

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DECLARATION

I declare that this dissertation is my original work and has not been presented for the award of a degree in any other university or published elsewhere.

Signed.....Date.....

Dr Douglas Kinuthia Gaitho (M.B.Ch.B)

Department of Paediatrics and Child Health, University of Nairobi

This dissertation has been submitted to the University of Nairobi with our full approval as supervisors:

Signed.....Date.....

Prof. Ruth Nduati (MB ChB, M. Med, MPH)

Professor of Paediatrics

Department of Paediatrics and Child Health, University of Nairobi

Signed..... Date.....

Prof. Dalton Wamalwa (MB ChB, M.Med, MPH)

Associate Professor

Department of Paediatrics and Child Health, University of Nairobi

Signed.....Date.....

Dr.Manasi Kumar (MSc, PhD, C.Psychol.)

Senior Lecturer in Clinical Psychology

Department of Psychiatry, University of Nairobi

DEDICATION

To the almighty God who gave me strength and wisdom to accomplish this work

To all the adolescents who made this work possible, for their resilience, determination and inspiration.

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ABBREIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ALHIV	Adolescent/s living with HIV
ART	Antiretroviral Treatment
CCC	Comprehensive Care Centre
DSMV	Diagnostic and Statistical Manual of Mental Disorders
HIV	Human Immunodeficiency Virus
KNH	Kenyatta National Hospital
LTFU	Loss to follow up
MHP	Mental Health Problems
PMTCT	Prevention of Mother to Child Transmission
QOL	Quality of Life
SDG'S	Sustainable Development Goals
STI's	Sexually Transmitted Infections
UNAIDS	Joint United Nations Program on HIV/AIDS
UNICEF	United Nations Children's Fund
WHO	World Health Organization

DEFINITIONS:

- Adolescent** – WHO definition of any person between the ages of 10 - 19 years.
- Psychosocial** – This refers to one’s psychological development in, and interaction with, a social environment.
- Disclosure** – For purposes of this study, Disclosure referred to an adolescent gaining knowledge on his/her own HIV status.
- Full Disclosure – Child was aware that the illness they have was HIV and/or AIDS, and had disease specific information on HIV such as how it is transmitted and how it can be prevented.
- Perinatal HIV infection** – This refers to HIV transmission from mother to child.
- Caregiver** – a person who provides direct care to an adolescent.
- Stigma** – Refers to the shame or disgrace attached to something regarded as socially unacceptable.
- Adherence** – adolescent’s capability to strictly follow the prescribed treatment plan
- HEADSS tool** - A tool used to assess psychosocial characteristics of adolescents. Assessing their **H**ome environment, **E**ducation and **E**mployment, **A**ctivity, **S**exuality, **S**uicide and depression traits.

ABSTRACT

Background

Globally mortality due to AIDS related illnesses among adolescents remains unacceptably high. Kenya is among six countries that contribute nearly half of the adolescent AIDS related deaths worldwide. Adolescence is a period of rapid physical growth, sexual maturation and great cognitive and psychological changes. In order to reverse the incidence and mortality trends there is an urgent need to determine the drivers of this problem and the possible interventions.

Objectives

The study sought to describe psychosocial characteristics of HIV infected adolescents, the HIV disclosure status and in a sub-analysis determine the association between psychosocial characteristics and disclosure of HIV status.

Study Methods

Study participants were recruited from among adolescents in long-term follow-up in the HIV CCC at KNH. The psychosocial characteristics were elucidated using the **H**ome environment, **E**ducation and **E**mployment, **A**ctivity, **S**exuality, **S**uicide and **D**epression traits (HEADSS) a standard tool whose validity had been established in different populations. In addition information was sort on HIV infection disclosure status. The study was carried out between August and December 2016.

Results

A total of 270 adolescents aged 10-19 years were recruited and they form the study population. The mean age was 14.75 years (SD=2.65) and 53.7% (n=145) were males. Almost all of the participants 99.6% (n=269) were still in school, 18.5% (n=50) had experienced bullying, 18.1% (n=49) reported dropping school performance, 33.7% (n=91) had repeated a class, 31.5% (n=85) had changed school in the last 2 years, 44.1% (n=119) reported being sent away from school due to lack of fees, 12.6% (n=34) reported missing meals in the preceding 2 weeks and 29.6% (n=80) were not involved in extracurricular activities. Among 229 adolescents aged 12 years and above 13.6% (n=31) reported having had a sexual encounter of whom 64.5% (n=20) shared that they did not consistently use a

condom. Overall 52.6% of the adolescents had symptoms of depression. Older adolescents aged between 15-19 years had a higher prevalence of symptoms of depression compared to those aged 10-14 years. Three factors on univariate analysis were significantly associated with symptoms of depression and included repeating a class ($p=0.018$), being sent away from school due to lack of tuition fees ($p=0.005$) and involuntary missing of meals ($p=0.009$). Full disclosure of HIV status occurred among 174 (64.4%) of the adolescents. These included 58 (46.4%) of 125 and 116 (80%) of 145 of the 10-14 and 15-19 years olds respectively and this difference was significant ($P<0.001$). There was a lower HIV disclosure rate among adolescents those who had not achieved sexual debut compared to those who had 70.6% ($n=139$) versus 90.3% ($n=28$), a significant difference ($P= 0.021$).

Conclusions

One in two of the adolescents interviewed had depression symptoms which was significantly associated with poverty – lack of school fees and missing meals. Disclosure rates were higher in older adolescents.

1. INTRODUCTION:

There is a growing population of HIV infected adolescents and worldwide is the only age group experiencing rising incidence and mortality. Their needs are specific but least served by health services(1). There are two categories of HIV infected adolescents, those who were infected in the perinatal period and those who have acquired the infection beyond that period mostly through horizontal transmission. Majority of HIV infected adolescents acquired it perinatally. According to the current treatment guidelines, all HIV infected adolescents should be on ART however this goal has not been fully achieved because of previous treatment eligibility criteria that would have delayed ART initiation among the slow progressors and failure to access diagnosis due to loss to follow up or suboptimal coverage of prevention of mother to child transmission (PMTCT) programs (2).

Horizontal Transmission of HIV is largely sexual and may follow consensual or non-consensual sex. In most parts of the world sexual debut occurs during adolescence, with varying age and conditions. Risk of acquiring HIV includes unprotected sex, early forced sex with or without violence. Non sexual transmission among adolescents includes use of injecting drug, sharing of blades during circumcision or female genital mutilation, traditional scarification, and poor hygiene practices in health provision leading to exposure to poorly sterilized equipment or transfusion with contaminated blood and blood products.

Several factors increase the risk of sexual transmission of HIV among adolescents, these include – age and sex, gender, social and cultural norms and value systems about sexual activity, residence, socioeconomic status, sexual orientation and education level. Vulnerable adolescents include those who are orphans, from key populations and those affected by humanitarian crises (2).

Global Epidemiology of Adolescent HIV

Worldwide there are about 1.2 billion adolescents of whom 2.1 million are HIV infected, among them 83% live in sub Saharan Africa (2). Kenya is among the six countries that contribute nearly half of all HIV infected adolescents globally, the others being South Africa, Nigeria, Tanzania, Ethiopia and India. HIV is the second most common cause of death among adolescents globally, and the number one cause of death in Africa(1,2). In 2013, a quarter of a million new HIV infections were reported among adolescents of whom about 67% were in girls

and of those adolescents aged 15-19 years. It was estimated that there was a new adolescent HIV infection every 2 minutes. In the same year about 120,000 adolescents died of an AIDS related illness. Adolescents are the only population in which AIDS related deaths have not decreased in the period 2005-2013. In contrast there has been a cumulative 38% reduction in AIDS related deaths in other age groups(2). There is very low scale up and treatment of HIV infected adolescents. There is emerging evidence that HIV infected adolescents seeking treatment face stigma, discrimination, lack of disclosure and minimal support to help them remain in care (3).

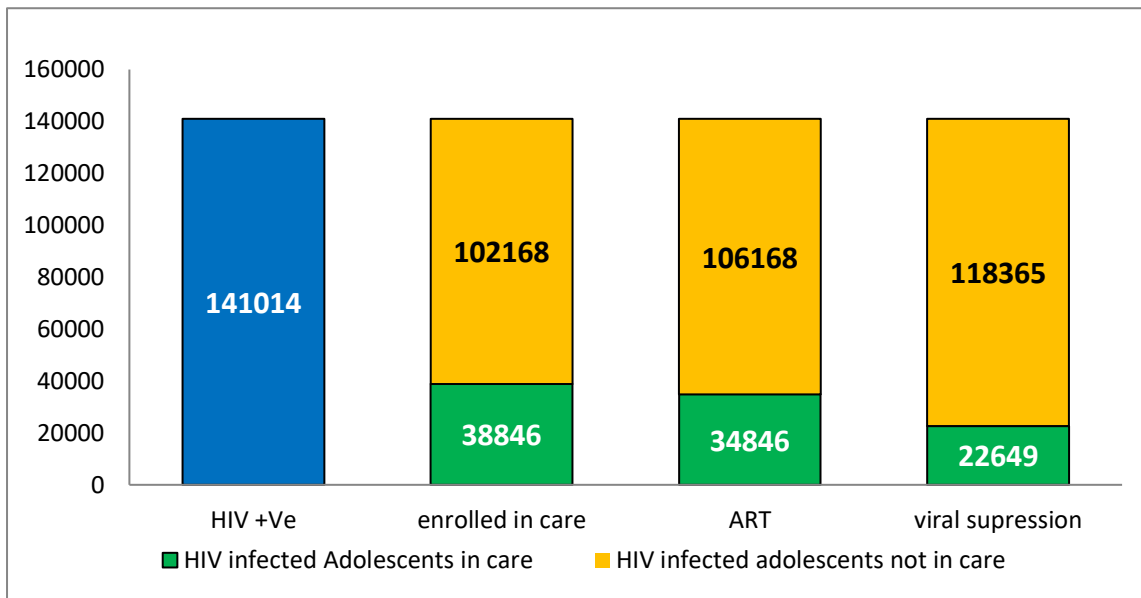
In an effort to address these gaps globally, a collaboration platform named '*ALL IN - #EndAdolescentAIDS*' has been established by several global organizations (2). The plan is to use this platform to create a social movement that will lead to improved results for adolescents through key changes in policies & programs. It is expected that this will result in a significant reduction in deaths due to AIDS related illnesses and new HIV infections among adolescents by the year 2020 and ending the AIDS epidemic by the year 2030.

These strategies are congruent with the United Nations Sustainable development goals (SDGs) goal number three that aims at ensuring healthy lives and promoting wellbeing for all ages. This includes ending the AIDS epidemic by the year 2030 (4).

Adolescent HIV in Kenya

Complications arising from HIV infection are the number one cause of mortality among adolescents in Kenya. About 10,000 10-24 year olds died of AIDS related illnesses in 2014. HIV testing and ART coverage among adolescents remains low. Less than a third of adolescents aged 15-19 years know their HIV status. It is estimated that there are 105,679 adolescents in need of ART as of the year 2014(5). The cascade of engagement in HIV care among adolescents shows that in 2014, 141,014 were known to be HIV positive, of these 38,717 were enrolled in a HIV care program representing 27.5%. Of whom 34,846 were on ART and only 22,649 had achieved viral suppression representing about 65% (5). This is far from the 90-90-90 targets described in the Kenya AIDS strategic plan, which aims to have 90% of infected individuals identified, 90% linked to care, 90% put on anti-retroviral therapy and 90% achieve viral suppression.

Figure 1: Kenya Adolescent HIV cascade 2014 (5)



The global *All In campaign to end adolescent AIDS* was officially launched in Kenya in February 2015. Kenya then released a *Fast Track Plan to End Adolescent AIDS* in September 2015. The plan has midterm targets by the year 2017 to reduce new HIV infections by 40% among adolescents and young people, to reduce AIDS related deaths among adolescents and young people by 20% and reduce stigma and discrimination among the same age group by 25%. To achieve these, the plan aims to use evidence based interventions, committed leadership both at county and national level, use of young people as stewards and champions and coordination of multisector initiatives for results (5).

Kenya country guidelines on use of ART state that all adolescents with confirmed HIV infection are eligible for ART irrespective of immunosuppression status, WHO clinical staging, age, pregnancy or breast feeding status, co-infection status, risk group or any other criteria. First line ART regimen for adolescents weighing below 35 kilograms is a combination of Abacavir, Lamivudine & Efavirenz and those weighing more than 35 kilograms is Tenofovir, Lamivudine & Efavirenz (6). The guidelines also recommend gradual disclosure of HIV infection status from the age of 8 years and full disclosure by 14 years. Issues around disclosure are complex due to stigma, lack of stable social support to the adolescent, challenges around family relations, weak adolescent parenting skills and concern about a child's emotional and maturation ability to understand the illness and cope with it. Lack of disclosure ultimately negatively affects the wellbeing of a child, including accessing paediatric HIV care and treatment and adherence to it (7). This study sort to further elucidate the psychosocial issues among adolescents attending an urban HIV clinic in a tertiary institution.

2. LITERATURE REVIEW

Adolescence is a period of physical, cognitive, emotional, social and behavioral maturation. WHO in 2001 did an analysis from six cross national studies to assess the risk and protective factors on sexual initiation, substance use and depression among adolescents. They concluded that peers, families, schools and communities played a crucial role in determining individual adolescent health outcomes. Parenting had a strong association to the development of risk or protective factors (8). Parents' role in an adolescent is divided into five dimensions and each has been shown to specifically influence adolescent health outcomes.

- Connection – A good emotional bond between parents and adolescents is one of the identified protective factors influencing individual adolescent health outcomes.
- Behavior control – This involves parents' actions to influence adolescent behavior. It includes establishing rules that govern the adolescents' behavior and consequences for misbehavior.
- Respect for individuality – Adolescents should be allowed to develop a healthy sense of self apart from his / her parents.
- Modelling of appropriate behavior – Parents are role models to adolescents influencing attitude and behavior.
- Provision and protection – Parents may not be able to meet all the needs of a growing adolescent. These includes mentoring, guidance, opportunity for education, life experiences and employment that aid in full maturation.

To be able to understand adolescents psychosocial characteristics one needs a tool that broadly looks at issues faced by adolescents. HEADSS assessment tool in the form of a structured questionnaire has been used to assess the **H**ome environment, **E**ducation and **E**mployment, **A**ctivity, **D**rug use, **S**exuality, **S**uicide and depression traits among adolescents.

Validation of the HEADSS assessment tool for analysis of psychosocial characteristics has been done in outpatient departments in the United States of America and found to be a very useful in screening for possible mental health problems (MHP). There is currently limited data on its use among adolescents living with HIV in Sub Saharan Africa. Capelli et al used the tool in assessing mental health in paediatric patients in the emergency department. A total of 313 patients were recruited with a mean age of 14.3 years. The study provided evidence to support

the psychometric properties of the tool. It had a sensitivity of 82% and a specificity of 87% in predicting psychiatric consult and admission to in patients psychiatry(9).

Psychosocial support of HIV infected Adolescents

Psychosocial support has emerged as a key pillar of HIV care and indeed any chronic illness requiring chronic medication. Psychosocial support enable the adolescent develop effective mechanisms of coping with the day to day challenges (10). Mutumba et al (2015) and Petersen et al (2011) respectively found that perinatally HIV infected (PHIV +) adolescents faced numerous psychosocial problems that included stigma and discrimination, relationship challenges such as HIV status disclosure, difficulties with their medication, loss of biological parents in cases of orphans, denial and ambivalence towards HIV. In the same studies caregiver's were found to have challenges with disclosing HIV infection status to the adolescent, financial constraints and lack of family and social support. The adolescents who remained in care had developed coping strategies to the challenges which included, adhering to their medication, limiting disclosure of HIV status, seeking social support, and engaging in religious activities (11–13).

Challenges faced by ALHIV have a major impact in the quality of life and end up being barriers to clinic attendance and poor outcomes. Enimil et al in 2015 demonstrated that food insecurity was associated with poor adherence to ART. In this study there were 40 participants half of whom were female with a mean age of 15.5 years (age range 12 – 19 years) of whom 53% reported death of at least one parent. Viral suppression rate was at 33% (14).

Mental Health Status of ALHIV

Suicide the most severe manifestation of depression ranks third as the leading cause of death among adolescents globally (15). Mental health problems (MHP) are common among ALHIV. Kamau et al in 2010 in a study of 162 children and adolescents from a poor resource setting and attending the Kenyatta National Hospital HIV clinic found the prevalence of psychiatric disorders to be 48.8%. (16).

Scorza et al (2014) used a case control study to compare mental health status in children who were HIV infected or affected with those who were HIV unaffected. They enrolled 683 children aged between 10 – 17 years. HIV infected and affected children showed higher prevalence rates of depression, anxiety, conduct and functional disorders compared to HIV unaffected children (17). These were similar to findings of a study done by Louw et al (2016) who used a case control study that had 78 HIV infected youth who were compared with a demographically

matched 30 non infected youth. This study among other outcomes looked at the psychosocial effects of caring for a HIV infected youth, which revealed significant depression rates among caregiver's with HIV infected adolescents (18).

One study however that screened for emotional and behavioral problems and quality of life (QOL) of ALHIV showed that majority of the children scored within normal ranges.

Effect of mental Health problems on HIV treatment among adolescents

Mental health problems have a negative impact on the ALHIV. Dow et al (2016) showed that depression, emotional and behavioral difficulties impacted negatively on adherence to ART (19).

Factors associated with increased risk of Mental Health problems among HIV infected adolescents

Care-taker characteristics and individual attributes contribute towards risk of mental health problems among adolescents living with HIV. Kapetanovic et al (2012) in a study of perinatally infected adolescents found psychiatric disorder and health related functional limitations of the care-takers to be associated with increased MHPs among ALHIV (20). In a study of 562 HIV infected adolescents, Kim et al (2015) found the prevalence of depression to be 18.9% (19). In this study depression was associated with female gender, fewer years of schooling, death in the family / household, failing a school term / class, having a boyfriend or girlfriend, not disclosed to or not sharing one's HIV status with another person, severe immunosuppression and bullying in school for taking medication. These studies show that mental health services and stigma reduction for the adolescents and their care-giver may help improve treatment outcomes (21).

Manifestation of mental health disorders are influenced by the stage of development and even within the adolescent period there are big differences between early and late adolescence. Perinatally infected adolescents maybe quite different from those infected as adolescents in terms of their cognitive functioning and ability to deal with everyday stresses. The chronic stress of living in a family with HIV may mold a different adolescent from one who is acutely infected. Success in treating the perinatally infected children means there are increased numbers of adolescents who are long-term survivors of HIV and the continued high incidence of HIV among adolescents, there is a need to further study psychosocial issues in adolescents so as to improve the quality of care provided.

Drug Use and Sexuality among ALHIV

Adolescence is a period where risky sexual and drug use behavior is very common. Access to reproductive health services in both HIV infected and uninfected adolescents remain a big challenge. Biddlecom et al (2008) carried out a survey in Burkina Faso, Malawi, Ghana and Uganda and identified barriers to access of sexual and reproductive health services. These were mainly psychosocial reasons such as embarrassment / fear and financial cost(22). ALHIV do engage in sexual activity and are at risk of HIV re-infection or contracting a Sexually Transmitted Infection (STI). In one study by Mbalinda et al (2015) carried out a cross sectional survey among PHIV+ adolescents. The study recruited 624 ALHIV. The mean age of sexual debut was 15.8 years, 16.2% reported symptoms of sexually transmitted infections. More than a third reported ever having sex. Of these 76.5% used condoms inconsistently and 49.3% had been pregnant or had impregnated someone. Those who were currently in a relationship, 56.3% did not disclose their HIV status neither did they know their partners' HIV status. Adolescents aged 15 – 19 years were six times likely to have been sexually active compared to those 10 – 14 years. Adolescents living alone were more likely to be sexually active compared to those who lived with one or both parents. Those who were not in school were more likely to be sexually active, have been treated for an STI and ever drank alcohol compared to those who were in school(23).

Disclosure of HIV status is associated with safer sex practices according to Toska et al (2015). In this study 850 ALHIV were recruited of whom 52% were female and 68.1% had acquired the infection vertically. Adolescents who reported ever having sex were 14.9% of whom 85% had a boyfriend/girlfriend. Adolescents expressed fear of stigma and rejection if they revealed their HIV status to their partners. The study identified a need to mitigate the effects of disclosure at the same time equipping the adolescents with the necessary skills on safe sex practices(24).

Drug use has been associated with risky sexual behavior. Dolezal et al (2011) recruited 193 ALHIV aged 9 – 16 years and 127 perinatally HIV exposed but were HIV uninfected. Though there was no difference in terms of sexual risk behavior and substance use among the two groups, adolescent mental health was significantly associated with risky sexual behavior and substance use (25).

Commonly used substances are alcohol, tobacco and marijuana. Alperen et al (2015) showed that the risk factors for alcohol use among PHIV+ adolescents included higher severity of

emotional and conduct problems and alcohol and marijuana use at home by caregivers or others. Risk factors for marijuana use among those PHIV+ adolescents included stressful life event and marijuana use at home(26).

Education for ALHIV

ALHIV just like their uninfected counterparts, despite the challenges faced, require good education with subsequent good school performance. Souza et al (2010) looked at data for the period 1987 – 2007. These included 49 PHIV+ adolescents with a mean age of 12.5 years and mean follow up of 9 years of whom 89.8% were attending school, 38.6% of those attending school had their HIV status disclosed to school staff, 51% were reported to have school failure whereas 28.6% had dropped out of school. Problems with school functioning need early detection and intervention in this age group (27).

Disclosure of HIV status and Adherence to ART

Disclosure rates of HIV status to HIV infected children remains low in sub-Saharan Africa. A systematic review done by Vreeman et al (2013) looking at disclosure in resource limited settings identified that it was influenced by child's age and perceived ability to understand the meaning of HIV infection whereas for the caregivers was influenced by among other things education level (28). Prevalence of disclosure is higher with advancing age. A study by Vreeman et al (2013) of 285 child& caregiver dyads showed 41% of caregivers reported that the child was aware of their own HIV status compared to 31% of self-reported HIV disclosure by children (29,30). A similar study by John-Stewart et al (2014) recruited 271 child & caregiver dyads whom were aged 6-16 years. Seventy nine percent of caregivers believed that the child should know their HIV status. However the prevalence of disclosure was a low 19%. Ten percent of those who knew their HIV status learnt about it accidentally. Reasons for disclosure included among others adherence to medication while for non-disclosure included age and fear for inadvertent disclosure (31).

Disclosure of HIV status has been found to be beneficial on treatment outcome and overall psychosocial wellbeing of ALHIV. O'Malley et al conducted a qualitative interview with 35 health care workers (HCW) and 46 caregivers. Both the HCW and caregiver reported benefits of disclosure among others to include improved understanding by the child on how HIV medication works, increased child hopefulness of their future and improved adherence to treatment (32).

Psychosocial factors play a key role in influencing adherence to medication. In a study by Nabukeera-Barungi et al (2015) looked at adherence to ART and retention in care of HIV infected adolescents. The study recruited 1824 adolescents, of whom 90.4% self-reported good adherence and 90% were still enrolled in care 1 year after initiating ART. The most outstanding barriers to adherence were stigma, discrimination and disclosure of HIV status. Other factors include poverty, fatigue, side effects of medication, pill burden and depression. Facilitators of good adherence included peer support groups, counseling, supportive HCW's and provision of food and transport(33).

Validation of Patient Health Questionnaire (PHQ-9)

Various tools are available for assessing depression (34). Patient Health Questionnaire (PHQ-9) has been used to screen for depression among adolescents. A PHQ-9 score of >11 has a sensitivity of 89.5% and specificity of 77.5% for detecting youth who are HIV negative meeting DSM-IV criteria for major depression in validation studies done in Western countries. These cutoffs are similar for adult population(35). In Kenya, PHQ-9 has been validated among adult population living with HIV as a reliable tool for assessing DSM-IV depressive disorders (36). The tool has however not been validated among Adolescents living with HIV in our setting.

3. STUDY JUSTIFICATION AND UTILITY

Kenyan adolescents living with HIV face numerous challenges; key amongst them being HIV status disclosure, stigma & discrimination, and adherence to medication. HIV infected adolescents engage in risky sexual behaviors, poly-substance abuse and have been shown to have higher prevalence of depression compared to their HIV uninfected counterparts.

Tracking psychosocial adversities and associated outcomes among adolescents living with HIV provide us with unique insight into developing curative and preventative interventions and allow us to rethink pathways to various services and outreach implementation gaps.

4. STUDY OBJECTIVES

a. Primary Objectives

1. To describe psychosocial characteristics of HIV infected adolescents attending clinic at KNH ascertained using HEADSS framework.

Hypothesis: There are unique emotional and psychosocial barriers in lives of HIV infected adolescents that can be discerned through HEADSS framework.

2. To determine the prevalence of HIV disclosure status among adolescents attending clinic at KNH.

Hypothesis: Half of the adolescents do not know their HIV status.

b. Secondary Objective

To determine the association between psychosocial characteristics and disclosure of HIV status among adolescents attending clinic at KNH.

Hypothesis: Adolescents who are HIV infected and aware of their HIV status might have favorable psychosocial characteristics.

5. METHODOLOGY

5.1. Study Design

We conducted a descriptive cross sectional study.

5.2. Study Population

The study population was HIV infected adolescents aged 10 – 19 years.

5.3. Study Location

The study was conducted at the Comprehensive Care Centre at Kenyatta National Hospital.

5.4. Study period

The study was carried out from August 2016 to December 2016.

5.5. Study Outcomes

The study provided a description of the psychosocial characteristics of HIV infected adolescents attending care at KNH. These were obtained using a HEADSS assessment tool in the form of a structured questionnaire. This tool assessed the **H**ome environment, **E**ducation, **A**ctivity, **S**exuality, **D**rug use, **S**uicide and depression traits among adolescents. The questionnaire used had questions derived from already pre-existing structured and validated questions. The screen for depression used questions obtained from the Patient Health Questionnaire (PHQ-9). The study outcomes were as follows:

- Socio-demographic characteristics – age, sex, education level, relation to the caregiver.
- Home environment – relationships with other household members, changing homes in the last one year, missing meals and physical violence.
- Education – school performance, bullying, repeating classes, inability to pay school fees, change of schools in the last 2 years and reasons for missing school.
- Activity and routine – involvement in extracurricular activities and religious activities.
- Drugs – use of drugs and substances of abuse.

- Sex – involvement in sexual activity, practice of safe sex and worry about pregnancy / sexually transmitted diseases.
- Suicide and depression –Any adolescent with a score of 1 or more was considered to have a depressive symptom.

Description of disclosure status of HIV infected adolescent. A structured questionnaire with validated questions was administered to the adolescent to assess the level of disclosure. Disclosure status was described as either fully disclosed or non-disclosure.

5.6. Inclusion Criteria

Each of the adolescent recruited fulfilled the following criteria so as to be included in the study.

- An adolescent who was HIV infected and gave assent and the caregiver gave an informed consent.

5.7. Exclusion Criteria

We excluded adolescents not on ART.

5.8. Sample Size Determination

This was calculated using Fischer's Formulae;

$$n = \frac{Z_{\alpha}^2 p (1-p)}{d^2}$$

$$Z_{\alpha} = 1.96$$

$$n = \frac{(1.96)^2 0.2 (1-0.2)}{(0.05)^2}$$

$$n=246$$

- n = estimated sample size

- Z_{α} = standard normal deviate for 95% CI (1.96)
- $p = 0.2$
- d = level of precision (set at 5%)

This was calculated using an estimated P value of 0.2 that was determined from Kim et al study that showed the prevalence of depression among ALHIV to be 18.9% (21).

5.9. Study Procedure

The research assistant recruited for the study was a clinical Psychologist with a Master's degree in Clinical psychology. She had prior worked in the clinic and interacted with the adolescents. This ensured that most of the adolescents were comfortable being interviewed by someone who was familiar to them increasing on accuracy of responses given. The research assistant received training on how the study was to be carried out and familiarization with the data collection tool. The principal investigator carried out follow up supervision throughout the study period.

Study participants were identified from registers in the Comprehensive Care Centre. Consecutive sampling technique was used. The principal investigator or the research assistant approached both the adolescent and caregiver on arrival at the clinic. The principal investigator or the research assistant then proceeded to explain the purpose and usefulness of the study to the pair and the methods to be used to obtain the information. An assent was then obtained from the adolescent and an informed consent from the guardian / caregiver for those aged 10-17 years. For adolescents aged 18 and 19 years, an informed consent from the adolescent sufficed. Consent and assent were both administered in written forms. This was done in either English or Kiswahili languages according to the caregiver / adolescents preference. The pre-designed consent / assent form which was given to the caregiver / adolescent at this point respectively described the purpose of the study as well as the study procedures to be followed. The principal investigator / research assistant conducted the consent / assent discussion and ensured that the caregiver and adolescent respectively understood the information provided in the form. Any questions concerning the study that emerged from either the caregiver or the adolescent were addressed at this point. Consent / assent given was voluntary and free of any coercion. A copy of the signed consent was given to those who agreed to enrol in the study. No adolescent or caregiver declined to participate in the study.

Data was then collected from eligible participants, both the caregiver and the adolescent in the form of a structured pre-tested questionnaire. The caregiver and adolescent interview was carried out individually in the absence of the other, maintaining privacy and high level of confidentiality. The caregiver was interviewed first alone, where disclosure status of HIV to the adolescent was determined to avoid changing this status during the adolescent interview which was done in the absence of the caregiver. Adolescents were interviewed using the same questionnaire irrespective of their disclosure status. This is because the questions were structured in a way that would assess status of disclosure and not disclose the HIV status to an adolescent who did not know his or her HIV status. Those adolescents found to have psychosocial adversities were linked with a psychiatrist or a psychosocial worker in the clinic for closer follow up and appropriate intervention. None of the caregivers or adolescents opted out of the interview before it was complete. The caregiver interview lasted about five minutes and the adolescent interview lasted about half an hour.

5.10.Data Collection

The pre- tested questionnaire administered to the guardian / parent provided information on:

- Who the caregiver was to the adolescent and if they were orphans?
- Level of Education
- Caregiver HIV status
- Number of children under their care
- If the adolescent knew his / her own HIV status

The pre-tested questionnaire administered to the adolescent provided the following information:

- A description of the home environment that the adolescent lives in. This includes relationship with other household members, physical violence at home and food insecurity.
- A detailed perspective of the adolescent current and past education experiences.
- Activities that the adolescent being interviewed is engaged in.
- The prevalence of drug / substance use among HIV infected adolescents.
- Described sexual activity of the HIV infected adolescent.

- Suicidal or depression traits that were present.
- HIV disclosure status.
- Adherence to ART.

5.11.Data Management and Analysis

Data was entered onto SPSS version 23.0. Descriptive statistics were computed for continuous variables and frequency and proportions for categorical variables were determined. Chi square tests were used to determine the association between psychosocial characteristics and disclosure. We had a priori determined the critical risk factors determining disclosure and adjustment problems based on published research evidence. We therefore carried out a univariate analysis on variables thought to have an association with disclosure. The variables were age, gender, currently in school, level of education, been bullied in school, dropping school performance, involvement in extracurricular activities, repeating a class, change of school, lack of school fees, change in school, missing meals, ever had sex and depression score.

Variables that had a p value of <0.05 in univariate analysis were entered into a multivariate regression to determine the association between the variable and the outcome.

5.12.Ethical Considerations

Ethical approval was obtained from Kenyatta National Hospital and University of Nairobi Ethics and Research Committee approval number P217/03/2016.

6. RESULTS

We enrolled 270 adolescents after obtaining consent and assent from the caregiver and adolescents respectively. Results are presented in a format representing the HEADSS tool.

6.1. Sociodemographic characteristics of the adolescents

The mean age of adolescents enrolled into the study was 14.75 years (SD=2.65) including 125 aged 10-14 years and 145 aged 15-19 years of whom 53.7% (n=145) were male.

Home Environment

Fifty-nine (21.9%) adolescents had changed homes in the previous year. Challenges encountered at home included physical violence in 4.1% (n=11) with 6.7% (n=18) of adolescents interviewed reported running away from home. In the preceding two weeks 29.6% (n=80) reported missing meals.

When faced with a problem at home majority of the adolescents 58.1% (n=157) talked to their mothers' about it. This was regardless of their age or gender. Table 3 below summarizes whom the adolescents prefer to talk to when they have a problem at home.

Education

Majority of the adolescents 99.6% (n=269) were in school. Half of them 50.7% (n=137) were in primary school, 36.3% (n=98) were in secondary school and the remainder 12.6% (n=34) were in tertiary or vocational training institutions. The commonest reason for missing school was attributed to sickness 98.1% (n=265). Those in school 18.5% (n=50) had experienced bullying. Bullying was more common in those aged 10-14 years 25.6% (n=32) compared to those aged 15-19 years 12.4% (n=18). About a third of the adolescents interviewed were not happy with their school performance (n=77) and 18.1% (n=49) reported that their school performance was dropping. However majority of the adolescents 96.3% (n=260) were ready to further and continue their education. Some of the challenges experienced in school was being sent away from school due to lack of tuition fees among 44.1% (n=119) of the adolescents and having to repeat a class 33.7% (n=91).

When faced with a problem in school, majority of the adolescents talked to their teacher 64.8% (n=175) or a friend 24.4% (n=66). Table 3 summarizes the adolescents' response when asked whom they preferred to talk to at school when faced with a problem.

Table 1: Home and Education characteristics of the adolescent

Category	Overall (N=270)	10-14 years (N=125)	15-19 years (N=145)	P – Value
	n(%)	n(%)	n(%)	
Changed homes in the last one year	59(21.9)	25(20)	34(23.4)	0.5
Ever run away from home	18(6.7)	3(2.4)	15(10.3)	0.009
Physical violence at home	11(4.1)	5(4)	6(4.1)	0.9
Currently in school	269(99.6)	125(100)	144(99.3)	0.4
Current level of education				
Primary	137(50.7)	117(93.6)	20(13.8)	<0.001
Secondary	98(36.3)	8(6.4)	90(62.1)	
Postsecondary	34(12.6)	0(0.0)	34(23.4)	
Missing	1(0.4)	0(0.0)	1(0.7)	
Bullied in school	50(18.5)	32(25.6)	18(12.4)	0.01
School performance dropping	49(18.1)	23(18.4)	26(17.9)	0.9
Happy with school performance	193(71.5)	92(73.6)	101(69.7)	0.5
Plan to continue with education	260(96.3)	125(100)	135(93.1)	0.003
Changed schools in the past 2 years	85(31.5)	41(32.8)	44(30.3)	0.7
Ever Repeated a class	91(33.7)	46(36.8)	45(31.0)	0.3

Activity

Some adolescents, 29.6% (n=80) were not involved in any extracurricular activities which included sports and other hobbies. However majority of them 93% (n=251) attended religious activities.

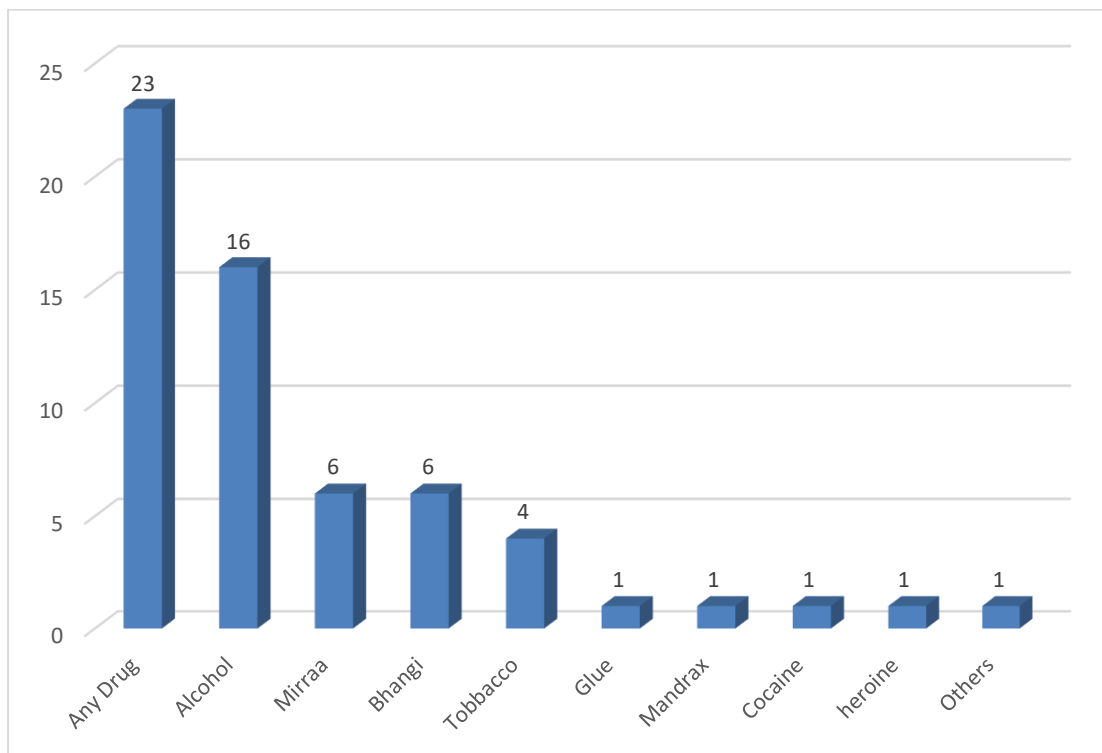
Table 2: Whom the adolescents prefer to talk to when faced by a problem at home & in school and their source of knowledge on reproductive health

	Overall N=270 n(%)	10-14 years N=125 n(%)	15-19 Years N=145 n(%)	P - Value	Male N=147 n(%)	Female N=123 n(%)	P - Value
Person to talk to if having problem at home							
Mother	157(58.1)	84(67.2)	73(50.3)	0.006	81(55.9)	76(60.8)	0.3
Father	61(22.6)	34(27.2)	27(18.6)	0.1	39(26.9)	22(17.6)	0.09
Relative	38(14.1)	20(16)	18(12.4)	0.4	23(15.9)	15(12)	0.4
Sibling	34(12.6)	9(7.2)	25(17.2)	0.01	17(11.7)	17(13.6)	0.6
no one	21(7.8)	5(4)	16(11)	0.03	15(10.3)	6(4.8)	0.1
Friend	7(2.6)	0(0)	7(4.8)	0.01	3(20.7)	4(3.2)	0.5
God	1(0.4)	0(0)	1(0.7)	0.4	0(0)	1(0.8)	0.3
Person to talk to when having a problem in school							
Teacher	175(64.8)	103(82.4)	72(49.7)	<0.001	96(65.3)	79(64.2)	0.9
Counselor	12(4.4)	3(2.4)	9(6.2)	0.1	5(3.4)	7(5.7)	0.4
Friend	4(1.6)	18(14.4)	48(33.1)	<0.001	33(22.4)	33(26.8)	0.4
Parents	10(3.7)	3(2.4)	7(4.8)	0.3	6(4.1)	4(3.3)	0.7
No one	31(11.5)	8(6.4)	23(15.9)	0.02	20(13.6)	11(8.9)	0.2
Adolescents source of information on Sexual and Reproductive Health							
School	178(69.5)	89(79.5)	89(61.8)	0.002	96(70.1)	82(68.9)	0.8
Parents	35(13.7)	13(11.6)	22(15.3)	0.4	18(13.1)	17(14.3)	0.8
Friends	4(1.6)	2(1.8)	2(1.4)	0.8	4(2.9)	0(0.0)	0.06
Church	2(0.8)	0(0.0)	2(1.4)	0.2	1(0.7)	1(0.8)	0.9
Television	1(0.4)	0(0.0)	1(0.7)	0.4	0(0.0)	1(0.8)	0.3
Media	15(5.9)	2(1.8)	13(9.0)	0.01	10(7.3)	5(4.2)	0.3
Clinic	113(44.1)	34(30.4)	79(54.9)	<0.001	64(46.7)	49(41.2)	0.4
Others	2(0.8)	0(0.0)	2(1.4)	0.2	1(0.7)	1(0.8)	0.9

Drugs / Substance use

The overall prevalence of drug / substance use among participants was 8.5% (n=23) and family or friends to the adolescent who used drugs were 35.6% (n=96). Figure 3 below illustrates the most commonly used drugs by the adolescents.

Figure 2: The most commonly used drugs by adolescents



Sexuality

Of the 229 adolescents who were 12 years and above 13.6% (n=31) reported having had a sexual encounter of whom 64.5% (n=20) shared that they did not consistently use a condom. Of all the adolescents interviewed 3% (n=8) had a forced sexual encounter. Most adolescents who were sexually active got condoms from health facilities 95.65% (n=22). Majority had their first sexual encounter at the age of 18 years 35.7% (n=10) and overall 73% (n=19) had one sexual partner.

Most of the adolescents obtain information about HIV and reproductive health from school 69.5% (n=178) and healthcare workers 44.1% (n=113). Table 3 above summarizes the source of information on reproductive health by the adolescents.

Mental Health Assessment

Suicide and depression was assessed using PHQ – 9. The presence of any one of the above symptoms included in the screening tool was classified as having a depression symptom.

Overall 52.6% (n=142) adolescents had at least one symptom of depression. The mean depression score was 1.78 (SD=2.81). Twelve (4.4%) of the adolescent ever had symptoms of suicide in the preceding two weeks among them 3 felt this way all the time and this was the first time these symptoms were picked up.

6.2. Univariate analyses of disclosure and psychosocial risk factors

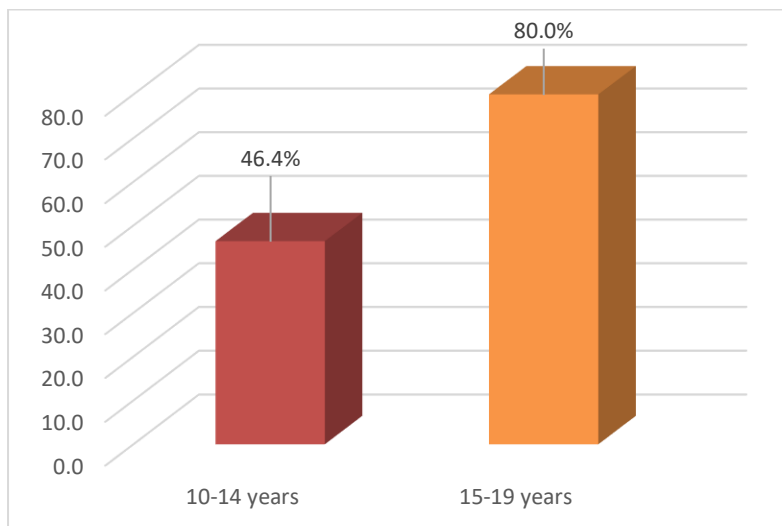
The prevalence of HIV disclosure to the adolescents was 64.4% (n=174). Rates of disclosure were higher among adolescents aged 15-19 years compared to the 10-14 age group at 80% (n=116) versus 46.4% (n=58) O.R= 4.6 [95% CI 2.7,7.9], $p < 0.001$. Put in another way the younger teens had an 80% less likelihood of having disclosure of their HIV status O.R 0.2 (95% CI 0.1, 0.4). Boys and girls were equally likely to have had disclosure ($p > 0.05$).

Table 5 below summarizes the prevalence of disclosure among study participants.

Table 3; Prevalence of HIV status disclosure among study participants

Group	Frequency	Percentage (%)	95% C.I.	
			Lower	Upper
Overall	174	64.4	58.5	70.0
10-14 years	58	46.4	37.6	55.2
15-19 years	116	80.0	73.8	86.2
Male	90	61.2	53.1	68.7
Female	84	68.3	60.2	76.4

Figure 3; Prevalence of HIV status disclosure by age



Those who had experienced bullying in school were 50% less likely to have had disclosure of their HIV status compared to those who hadn't reported bullying, 26/174 (14.9%) versus 24/96 (25%) respectively, OR = 0.5 [(95% CI (0.3, 0.9) p = 0.04].

Table 4; Factors associated with HIV status disclosure

Parameter	Overall (N=270)	Disclosure		O.R (95% C.I)	P - value
		Yes (n=174)	No (n=96)		
10-14 years	125(46.3)	58(33.3)	67(69.8)	Ref.	<0.001
15-19 years	145(53.7)	116(66.7)	29(30.2)	4.6 (2.7-7.9)	
Male	145(53.7)	88(51.5)	57(59.4)	Ref.	0.2
Female	122(45.2)	83(48.5)	39(40.6)	1.4(0.8-2.3)	
School performance dropping	49(18.1)	29(16.7)	20(20.8)	0.8(0.4-1.4)	0.4
Ever repeated class	91(33.7)	53(30.5)	38(39.6)	0.7(0.4-1.1)	0.1
Ever been bullied	50(18.5)	26(14.9)	24(25.0)	0.5(0.3-0.9)	0.04
Changed schools	85(31.5)	53(30.5)	32(33.3)	0.9(0.5-1.5)	0.6
Change homes	59(21.9)	41(23.6)	18(18.8)	1.3 (0.7-2.5)	0.4
Depression score(Mean; SD)	1.38(2.8)	2.18(3.22)	1.05(1.63)	1.2 (1.1-1.4)	0.001
Presence of Depression	142(52.6)	96(55.2)	46(47.9)	1.3 (0.8-2.2)	0.3
Ever had sex	31(11.5)	28(16.8)	3(4.9)	3.9(1.1-13.3)	0.02
Physical violence at home	11(4.1)	4(2.3)	7(7.3)	0.3(0.09-1.0)	0.05

Drug use	23(8.5)	18(10.3)	5(5.2)	2.1(0.8-5.9)	0.1
Family or friend uses drugs	96(35.6)	73(42.0)	23(24.0)	2.3(1.3-4.0)	0.003
Primary Level Education	137(50.7)	67(38.5)	70(73.7)		<0.001
Secondary	98(36.3)	75(43.1)	23(24.2)	3.4 (1.9-6.1)	
Post-secondary	34(12.6)	32(18.4)	2(2.1)	16.7 (3.9-72.5)	
Missing	1(0.4)				
Sent away from school due to lack of fees	119(44.1)	73(42.0)	46(47.9)	0.8(0.5-1.3)	0.3
Meals Missed	34(12.6)	19(10.9)	15(15.6)	0.7(0.3-1.4)	0.3
Involved in extracurricular activities	190(70.4)	124(71.3)	66(68.8)	1.1 (0.7-1.9)	0.7

Adolescents who had experienced sexual debut had an almost fourfold increased likelihood of full disclosure compared to those without prior sexual encounter 28/174 (16.8%) versus 3/96 (4.9%), O.R = 3.9 [(95% CI 1.1, 13.3) p=0.04].

Since half of the study participants had depression symptoms, we carried out a secondary analysis to determine factors that were associated with these symptoms. Looking at differences between participants' ages of 10-14 and 15-19 years on their depression scores, we found that 50/125 (40%) of the younger group had more depressive symptoms versus 90/145 (63.4%) of older adolescents, OR = 2.6 [(95% CI 1.59, 4.26) p<0.001].

Repeating a class was associated with almost a two fold increase in depression symptoms in 57/142 (62.6%) adolescents compared to those who had not repeated a class 34/128 (37.4%), OR = 1.9 [(95% CI 1.11, 3.11) p=0.02] while being sent away from school due to lack of school fees among 74/142 (62.2%) was associated with twice the likelihood of depression compared to adolescents who didn't have difficulty with school fees 45/128 (37.8%) OR = 2 [(95% CI 1.23, 3.28) p=0.005]. Missing meals in the preceding two weeks for 25/142 (17.6%) of the adolescents was associated with almost thrice the likelihood of depression symptoms compared to those who had not missed a meal 9/128(7%) OR = 2.8 [(95% CI 1.27, 6.31) p = 0.009].

Multivariate analysis of association between Disclosure and other variables.

In the multivariate analysis we carried over factors that were significantly associated with disclosure on univariate analyses to generalized linear model as shown in Table 7.

Being ages 15-19 years and having experienced physical violence at home had odds of 1.94 (CI 0.95 – 3.96) and 0.17 (CI 0.03 – 0.82) respectively of having full HIV status disclosure done.

We also carried out a multivariate analysis of factors that were significantly associated with depression symptoms on univariate analyses to generalized linear model. These factors were age, repeating classes, change of schools in the last 2 years and missing meals due to lack of food in the preceding two weeks. Being of ages 15-19 years and missing meals due to food insecurity had odds of 2.88 (CI 1.72, 4.82) and 2.62 (CI 1.09, 6.28) respectively of developing depression symptoms.

Table 5; Multivariate generalized linear model on factors associated with disclosure

Parameter	β	S.E	Odds ratio	95% C.I		P-Value
				Lower	Upper	
15-19Years	0.7	0.4	1.9	1.0	4.0	0.07
10-14Years	Ref.		1			
Ever been bullied	-0.2	0.4	0.9	0.4	2.0	0.7
Ever had sex	1.1	0.7	3.0	0.8	11.9	0.1
Physical violence at home	-1.8	0.8	0.2	0.03	0.8	0.03
Family or friend uses drugs	0.5	0.4	1.7	0.9	3.3	0.1

Table 6; Multivariate generalized linear model on factors associated with depression

Parameter	β	S.E	Odds ratio	95% C.I		P - Value
				Lower	Upper	
Age 15-19 Years	1.06	0.3	2.88	1.72	4.82	<0.001
10-14 Years	<i>Ref.</i>		1			
Changed schools	0.4	0.3	1.56	0.89	2.72	0.1
Ever repeated a class	0.6	0.3	1.87	1.07	3.24	0.03
Ever been sent away for lack of School fees	0.6	0.3	1.81	1.07	3.06	0.03
Missed meals cause of lack of food	1.0	0.5	2.62	1.09	6.28	0.03

7. DISCUSSION

Just over six of ten adolescents had full disclosure of their HIV status. Age was the only independent predictor of disclosure, with 4 of 10 adolescents aged 10-14 years knowing their status compared to 8 of 10 among those aged 15-19 years. This finding that was similar to publication by Vreeman et al based on studies conducted in Western Kenya which found a disclosure prevalence of 31% on self-report (30). These findings are an improvement over earlier status as reported in a study at KNH where prevalence of full disclosure was 19% (31). This could be attributed to a clear policy and increased efforts to fully disclose HIV status by the age of 14 years. Observational studies seem to suggest disclosure of HIV status is associated with better drug adherence and improved health outcomes (32).

This is among the first study in Kenya to comprehensively assess psychosocial issues that are faced by adolescents living with HIV using a standardized tool. We addressed psychosocial and mental health issues among ALHIV which are not routinely assessed during regular clinic visits. Majority of adolescents were in school, which was encouraging. A study done by Souza et al had a higher dropout rate, with 89.8% not in school (27). For those in school some faced various challenges which included being sent away from school due to lack of school fees, concerns about dropping school performance, repeating a class and bullying. A systematic review done showed that problems with school functioning need early detection and intervention (27).

One in every two adolescents enrolled in this study had symptoms of depression and 4.4% had suicidal ideation. The independent predictors for depression was age, repeating a class and poverty measured by the surrogate markers that included missing meals and being sent away from school due to lack of fees. Surprisingly depression was not associated with disclosure in univariate analysis. This is probably the first time adolescents enrolled in this clinic were evaluated using the HEADSS tool and thus enabling a comprehensive assessment of their status. Prior to this study age was usually the only indicator for starting disclosure in our clinic. This finding of very high prevalence of depression symptoms is important and raises questions regarding timing and criteria for disclosure and whether it affects drug adherence. This was a cross-sectional study and therefore the causal relationship between disclosure and depression could not be evaluated.

This study used PHQ-9 to screen for depression symptoms and did not go further to differentiate the severity of depression despite the identification of 12 participants with suicidal ideation who were referred for emergency mental health care. In published literature this tool has been validated among non- HIV infected adolescents in the USA (35). In Africa this tool has been used among HIV infected adults in Western Kenya (36) and among adolescents living with HIV in Tanzania. In the latter study severity of depression was computed as score of 10 or greater based on the validation studies done in adults in Western Kenya (19). The authors of these studies did not give a clear justification of using an adult criteria on adolescents. Our study had many young adolescents whose cognitive development was still far away from that of an adults and therefore would manifest mental illness in a different way. In further studies there is need to go further and make a DSMV diagnosis of depression as part of the strategy to develop more refined criteria for diagnosis of major depression among ALHIV. Some of this work would include validation against other criteria for diagnosis of depression such as Beck Depression Inventory version II (BDI-II) and The Children's Depression Rating Scale – Revised (CDRS-R). Important questions are does disclosure trigger or worsen depression, and further to this does it have an impact on drug adherence.

There is emerging evidence on the negative impact of depression on adolescent HIV treatment. Our study shows older adolescent and repeating a class was associated with depressive symptoms. A study done in Malawi by Kim et al found bullying because of being on medication, severe immunosuppression and having a boyfriend / girlfriend were associated with depression (21).

Among those adolescents interviewed who were 12 years and older, 13.6% reported ever having sex. These was more common among those aged 15-19 years. According to Kenya Demographic and Health Survey 2014, 37.3% of the older adolescents reported sexual debut (37). This represented a higher prevalence nationwide compared to our study suggesting that HIV infected adolescents maybe postponing sexual debut or they have delays in their adolescent development because of chronic illness. There is considerable variability in proportion of HIV infected adolescent who have achieved sexual debut. In Uganda Mbalinda et al found a prevalence of a third (23) while in South Africa Toska et al found a prevalence of 14.9% (24). These difference may reflect variability in the age composition of the study population and also the prevalent norms on adolescent sexuality.

In this study the majority of the adolescents who had achieved sexual debut reported inconsistent condom use similar to a Ugandan study that found 76.5% of ALHIV inconsistently used condoms (12). Inconsistent use of condoms poses important challenges including reinfection of a HIV infected partner with risk of transmitting resistant strains, and of course transmission of HIV to their uninfected partners. They also run the risk of acquisition and transmission of sexually transmitted diseases. There was poor knowledge of HIV preventive strategies. In our study a third of adolescents did not think that condoms reduce HIV transmission while another third did not know if condoms reduced transmission of HIV. The majority of adolescents in our study obtained condoms from health facilities however healthcare workers did not feature as a key source of information about HIV and other reproductive health issues. This maybe an indication of limited contact between adolescents and health workers or missed opportunities within the health facilities.

One in ten of the adolescents interviewed reported drug abuse with alcohol being the most commonly used drug. These findings are very key because other studies have found a strong association between mental health and risky sexual behavior & substance use (25).

Strengths

This study has several strengths that include a validated adolescent evaluation tool. The interview was conducted by a clinical psychologist who was closely supervised by the investigator and Dr. Kumar a mental health expert in clinical psychology.

The study was conducted in a well-established clinic that had followed many of the adolescents since childhood. All the adolescents were on anti-retroviral drugs. The study was conducted during the school holidays so that adolescents in boarding school had an equal opportunity to participate similar to those in day schools. All the adolescents approached for the study accepted to participate and so did their guardians. This means there is minimal non-participation bias. In order to ensure informed consent and respect for the relationship between the adolescent and the parent / guardian, the researchers first approached the guardian for permission before assent by the adolescent. This overwhelming participation probably reflect the stage of adolescent development where they desire to conform with peers. The HEADSS tool enabled the identification of 12 adolescents with suicidal ideation. This was 4.4% of the study population. This finding alone is a strong justification for routine use of this tool in assessing HIV infected adolescents.

Limitations

The major limitation to this study was that it was cross-sectional, meaning that exposure and outcome were measured at the same time therefore causal relationships could not be ascertained. Other limitations were that the adolescents were engaged in face to face interviews, which would have led to under reporting or socially acceptable responses. Future studies could benefit from probably an Audio – Computer Assisted Self Interviews especially in reporting sensitive information. The study did not have a comparison group of adolescents with a different chronic illness and therefore cannot establish whether the depression symptoms are unique to HIV infected adolescents or a feature of adolescents struggling with chronic illness. The site of the study is a tertiary health facility that receives referrals from all over the country and hence have a sicker population. Further to this the study relied on self-reported information from caregivers and adolescents and there was no way to ascertain the accuracy of the information.

8. CONCLUSION

The overall prevalence of full HIV disclosure among adolescents interviewed was 64.4% (n=174). This was higher in the older adolescents.

The HEADSS tool revealed that;

Home – 12.6% of adolescents reported missing meals in the preceding two weeks

Education - Schooling difficulties encountered included lack of school fees in 44.1%, dropping school performance in 18.1% and repeating a class among 33.7% of the adolescents interviewed.

Activity – A third (29.6%) of the study participants were not involved in extracurricular activities.

Drugs – 8.5% of adolescents had used drugs of abuse most common being alcohol.

Sexuality - Of those adolescents aged 12 years and above 13.6% (n=31) reported having had a sexual encounter of whom 69% (n=20) shared that they did not consistently use a condom. Majority of the adolescents obtained information on reproductive health from schools.

Suicide / Depression symptoms – Half (52%) of the adolescents in this study had symptoms of depression including 12 who were suicidal. Missing meals, repeating a class and being sent away from school due to lack of school fees were associated with depression symptoms.

9. RECOMMENDATIONS

- HEADSS tool should be institutionalized as an assessment tool for the adolescents. Further research is needed to determine optimal administration of the tool and whether self-administration is equally valid. The latter would be helpful in busy understaffed clinics.
- The KNH adolescent clinic needs to establish links with existing government poverty eradication programs for vulnerable children that include cash transfers, emergency food aid and school bursaries.
- The KNH clinic needs to strengthen reproductive health services including health education for the ALHIV enrolled into their clinic.
- Validation studies ought to be carried out on the PHQ-9 among HIV infected adolescents to determine the cut-off points that would be diagnostic of DSMV major depression disorder.

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11. APPENDICES

11.1. ETHICAL APPROVAL



UNIVERSITY OF NAIROBI
COLLEGE OF HEALTH SCIENCES
P O BOX 19676 Code 00202
Telegrams: varsity
Tel: (254-020) 2726300 Ext 44355

KNH-UON ERC
Email: uonknh_erc@uonbi.ac.ke
Website: <http://www.erc.uonbi.ac.ke>
Facebook: <https://www.facebook.com/uonknh.erc>
Twitter: [@UONKNH_ERC](https://twitter.com/UONKNH_ERC) https://twitter.com/UONKNH_ERC

KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726300-9
Fax: 725272
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/170

23rd May, 2016

Dr. Douglas Kinuthia Gaiho
H58/75022/2014
Dept. of Paediatrics & Child Health
School of Medicine
College of Health Sciences
University of Nairobi

Dear Dr. Kinuthia

REVISED RESEARCH PROPOSAL- PSYCHOSOCIAL CHARACTERISTICS AND DISCLOSURE STATUS OF HIV INFECTED ADOLESCENTS ATTENDING CLINIC AT KENYATTA NATIONAL HOSPITAL (P217/03/2016)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH-UoN ERC) has reviewed and **approved** your above proposal. The approval period is from 23rd May 2016 – 20th May 2017.


This approval is subject to compliance with the following requirements:

- Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH-UoN ERC before implementation.
- Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
- Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
- Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (Attach a comprehensive progress report to support the renewal).
- Submission of an executive summary report within 90 days upon completion of the study.
This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

For more details consult the KNH- UoN ERC website <http://www.erc.uonbi.ac.ke>

Protect to discover

Yours sincerely,



PROF. M.L. CHINDIA
SECRETARY, KNH-UoN ERC

c.c. The Principal, College of Health Sciences, UoN
The Deputy Director, CS, KNH
The Assistant Director, Health Information, KNH
The Chair, KNH- UoN ERC
The Dean, School of Medicine, UoN
The Chair, Dept. of Paediatrics and Child Health, UoN
Supervisors: Prof. Ruth Nduati, Prof. Dalton Wamalwa, Dr. Manasi Kumar

11.2. CAREGIVERS QUESTIONNAIRE

Initials of the care Giver _____ Date _____

Age _____

Sex _____

1. What is your relation to the child?
 1. *Father*
 2. *Mother*
 3. *Sibling*
 4. *Relative*
 5. *Friend*
 6. *Others* _____

2. Are you the primary caregiver?
 1. *Yes*
 2. *No*

3. What is your marital status?
 1. *Single*
 2. *Married*
 3. *Widowed*
 4. *separated*

4. Are both parents of the adolescent alive?
 1. *Yes*
 2. *No*
 3. *None*

5. Do people living in the household know the adolescent HIV status?
 1. *Yes*
 2. *No*

6. Are you HIV positive?
 1. *Yes*
 2. *No*

7. If answer *yes* to the above, are you on antiretrovirals drugs?
 1. *Yes*
 2. *No*

8. Does the adolescent know that he/she is HIV infected?
 1. *Yes*
 2. *No*
 3. *Not sure*
 4. *Others* _____

11.3. ADOLESCENT QUESTIONNAIRE

Questionnaire No. _____ Initials _____ Age _____ Date _____

Instructions

Please Circle the number with the appropriate answer/s.

Module 1: Education and Home

1. Do you go to school?

1. *Yes* 2. *No*

If no to Question 1 move to Question Number 5

2. What class are you in?

3. What is the highest level of education achieved?

4. Reasons for missing school?

5. Whom do you talk to at home when you have a problem? _____

6. Have you changed homes recently in the last 1 year?

1. *Yes* 2. *No*

7. Have you ever run away from home?

1. *Yes* 2. *No*

8. Is there any physical violence at home?

1. *Yes* 2. *No*

9. Have you been bullied at school?

1. *Once* 2. *Sometimes* 3. *Severally* 4. *Never*

10. Is your school performance dropping?

1. *Yes* 2. *No*

11. Are you happy with your school performance?

1. *Yes* 2. *No*

12. Whom do you talk to in school when you have a problem? _____

13. Do you plan to continue with your education?

1. *Yes* 2. *No*

14. Are you working?

1. *Yes* 2. *No*

15. Do you earn salary?

1. *Yes* 2. *No*

16. Are you involved in extra-curriculum activities in school?

1. *Yes* 2. *No*

17. Have you changed schools in the past 2 years?

1. *Yes* 2. *No*

18. Have you ever had to repeat a class?

1. *Yes* 2. *No*

19. Have you ever been:

1. *Suspended*
2. *Expelled*
3. *Considered dropping out*
4. *None of the above*

20. Have you ever been sent away from school for fees?

1. *Once* 2. *Sometimes* 3. *Severally* 4. *Never*

Module 2: Exercise routine

21. Do you miss meals because of lack of enough food?

1. *Once* 2. *Sometimes* 3. *Severally* 4. *Never*

22. Do you go to school hungry?

1. *Once* 2. *Sometimes* 3. *Severally* 4. *Never*

23. How many times in the last week? _____

24. How many meals do you have in a day (breakfast, lunch and dinner)? _____

25. Do you regularly attend religious or spiritual activities?

1. *Yes* 2. *No*

Module 3: Drugs

26. Do any of your friends or family members use?

1. *Tobacco*
2. *Alcohol*
3. *Other Drugs* _____

27. Have you ever tried:

- Alcohol 1. Once 2. Sometimes 3. Severally 4. Never
- Miraa / Khat 1. Once 2. Sometimes 3. Severally 4. Never
- Glue 1. Once 2. Sometimes 3. Severally 4. Never
- Bhangi 1. Once 2. Sometimes 3. Severally 4. Never
- Mandrax 1. Once 2. Sometimes 3. Severally 4. Never
- Cocaine 1. Once 2. Sometimes 3. Severally 4. Never
- Heroin 1. Once 2. Sometimes 3. Severally 4. Never
- Tobacco 1. Once 2. Sometimes 3. Severally 4. Never
- Any other 1. Once 2. Sometimes 3. Severally 4. Never

Module 4: Sexuality

28. Have you ever been forced or pressured into doing something sexual that you didn't want to do?

1. Yes 2. No

10-11 years not eligible from here. Only 12 year olds and above. If 10 – 11 years move to Question 45

29. Have you ever had sex?

1. Yes 2. No. 3. Don't know 4. Refused

If NO / Don't Know or Refused to answer in the above question 29, move to question number 45

30. What was the main reason you had sex for the first time?

31. How old were you when you had sex for the first time? _____

1. Don't know 2. Refused

32. Was the first person you had sex with younger, same age or older than you?

33. How were you related to the first person whom you had sex with? _____

34. Did you use a condom the first time you had sex?

35. Do you know where to get a condom?

36. If yes to Qn. 38 where would you get a condom?

1. Health facility
2. Friends
3. Parents/Guardians

4. *Public places/Toilets*
5. *Girlfriend/Boyfriend*

37. Have any of your relationships been violent?

1. *Yes*
2. *No*

38. How many sexual partners have you had altogether _____

39. (Girls) Have you ever been pregnant or worried that you may be pregnant?

1. *Yes*
2. *No*

40. (Boys) have you ever gotten someone pregnant or worried that they might have been?

1. *Yes*
2. *No*

41. When you have sex do you use a condom?

1. *Once*
2. *Sometimes*
3. *Severally*
4. *Never*

42. Have you ever had a sexually transmitted infection or worried that you had an infection?

1. *Once*
2. *Sometimes*
3. *Severally*
4. *Never*

43. Have you ever heard of an infection called HIV?

1. *Yes*
2. *No*
3. *Don't know*

44. Where do you get information concerning HIV infection?

1. *School teacher*
2. *Parents /Guardians*
3. *Friends*
4. *Religious leaders*
5. *Internet*
6. *Mobile phones*
7. *Television*
8. *Radio*
9. *Health providers*
10. *Other*_____

Module 5: Suicide /Depression

45. Do you feel “stressed” or anxious more than usual?

1. *Once*
2. *Sometimes*
3. *Severally*
4. *Never*

46. Do you feel sad or down more than usual?

1. *Once* 2. *Sometimes* 3. *Severally* 4. *Never*

47. Are you having trouble falling sleep?

1. *Once* 2. *Sometimes* 3. *Severally* 4. *Never*

48. Have you thought about hurting yourself or someone else?

1. *Once* 2. *Sometimes* 3. *Severally* 4. *Never*

49. Does it seem that you've lost interest in things that you used to really enjoy?

1. *Once* 2. *Sometimes* 3. *Severally* 4. *Never*

50. Do you find yourself spending less time with friends?

1. *Once* 2. *Sometimes* 3. *Severally* 4. *Never*

51. Have you ever tried to kill yourself?

1. *Once* 2. *Sometimes* 3. *Severally* 4. *Never*

Any adolescent with suicidal ideation should immediately be referred to a psychiatrist

Module 7: Disclosure and Adherence

DO NOT READ OPTIONS, THIS IS AN OPEN ENDED QUESTION

52. Why do you come for visits at this clinic?

1. *HIV* 2. *Other illness* 3. *Does not know* 4. *Other*_____

DO NOT READ OPTIONS, THIS IS AN OPEN ENDED QUESTION

53. If answer to Qn. 59 is due to illness, do you know what your illness is called?

1. *HIV* 2. *Other illness* 3. *Does not know* 4. *Other*_____

DO NOT READ OPTIONS, THIS IS AN OPEN ENDED QUESTION

54. Why do you have to take medicines?

1. *HIV* 2. *Other illness* 3. *To stay healthy* 4. *Does not know* 5. *I wonder about this* 6. *Other:* _____

55. Do you ever refuse to take the medicines that you are supposed to take?

1. *Once* 2. *Sometimes* 3. *Severally* 4. *Never*

56. Do you ever miss taking the medicines that you are supposed to take?

1. *Once* 2. *Sometimes* 3. *Severally* 4. *No*

57. Do you ever **not** take the medicines because you do not want to take them in front of other people?

1. *Once*

2. *Sometimes*

3. *Severally*

4. *Ne*

58. Do you ever have problems with taking the medicines because you do not know why you are taking them?

59. Do you ever have problems taking the medicines every day?

60. Do you ever have problems taking the medicines on time?

END

1.3. CONSENT FORM

ADOLESCENTS PSYCHOSOCIAL CHARACTERISTICS STUDY.

CARE GIVERS CONSENT FORM:

Patient's Study Identification Number: _____

Date: _____

Study Title: PSYCHOSOCIAL CHARACTERISTICS AND DISCLOSURE STATUS
OF HIV INFECTED ADOLESCENTS ATTENDING CLINIC AT
KENYATTA NATIONAL HOSPITAL

Investigator: Dr. Douglas Kinuthia Gaitho (MB ChB)
Paediatric Resident, University of Nairobi
Tel Number:- 0723- 431945

Supervisors: Prof. Ruth Nduati (MB ChB, M. Med, MPH)
Professor Department of Paediatrics and Child Health,
University of Nairobi

Prof. Dalton Wamalwa (MB Ch B, M.Med, MPH)
Associate Professor Department of Paediatrics and Child Health,
University of Nairobi

Dr. Manasi Kumar(MSc, PhD, C.Psychol.)
Senior Lecturer in Clinical Psychology Department of Psychiatry
University of Nairobi

Investigator's Statement:

We are requesting you and your child to kindly participate in this research study. The purpose of this consent form is to provide you with the information you will need to help you decide whether to participate in the study or not. This process is called 'Informed Consent'. Please read this consent information carefully and ask any questions or seek clarification on any matter concerning the study.

Introduction:

Adolescents living with HIV are faced with numerous psychosocial challenges that affect their overall wellbeing and treatment outcome. Understanding these psychosocial factors will aide in developing high impact interventions to help them cope with the challenges.

Benefits:

The results of the study will be shared with the doctor for any intervention required to assist your child. The results will as well help other adolescent facing similar challenges.

Risks:

There will be no risks to you or your child during the study. There will be no invasive procedures carried out in the study. Refusal to participate will in no way jeopardize the treatment of your child in any way.

Voluntariness:

The study will be fully voluntary. There will be no financial rewards to you for participating in the study. One is free to participate or withdraw from the study at any point. Refusal to participate will not compromise your child's care in any way.

Confidentiality:

The information obtained about you, your child and your family will be kept in strict confidence. No specific information regarding you, your child or your family will be released to any person without your written permission. We will, however, discuss general overall findings regarding all children assessed but nothing specific will be discussed regarding you or your child. We will also, not reveal the identity of you or your child in these discussions.

Problems or Questions:

If you ever have any questions about the study or about the use of the results you can contact the principal investigator, **Dr. Douglas Kinuthia Gaitho** by calling **0723-431945**.

If you have any questions on your rights as a research participant you can contact the **Kenyatta National Hospital Ethics and Research Committee (KNH- ESRC)** by calling **2726300 Ext. 44355**.

Consent Form: Participant's Statement:

I _____ having received adequate information regarding the study research, risks, benefits hereby **AGREE / DISAGREE** (Cross out as appropriate) to participate in the study with my child. I understand that our participation is fully voluntary and that I am free to withdraw at any time. I have been given adequate opportunity to ask questions and seek clarification on the study and these have been addressed satisfactorily.

Parents Signature: _____ Date _____

I _____ declare that I have adequately explained to the above participant, the study procedure, risks, and benefits and given him /her time to ask questions and seek clarification regarding the study. I have answered all the questions raised to the best of my ability.

Interviewers Signature _____ Date _____