

**EVALUATION OF THE PSYCHOSOCIAL AND CLINICAL
OUTCOMES AFTER LIFE SKILLS PROVISION AMONG
PERINATALLY HIV-INFECTED OLDER ADOLESCENTS
RECEIVING CARE AT MBAGATHI HOSPITAL,
NAIROBI, KENYA**

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**Evaluation of the Psychosocial and Clinical Outcomes After Life Skills
Provision among Perinatally HIV-Infected Older Adolescents at
Mbagathi Hospital, Nairobi, Kenya**

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**A Thesis Submitted in Partial Fulfilment of the Requirements for the
Degree of Doctor of Philosophy in Public Health of the Jomo
Kenyatta University of Agriculture and Technology**

2022

DECLARATION

This thesis is my original work and has not been presented for a degree in any other university.

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This thesis has been presented for examination with our approval as the University supervisors

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KEMRI, Kenya

DEDICATION

To my children Angela, Daniel & Abigail, with love.

To my mother and father, Agnes & Paul Gitahi, I honour you, I am because you were.

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ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ALWHIV	Adolescents living with HIV
ART	Antiretroviral therapy
ERC	Ethics Review Committee
FGD	Focus Group Discussion
IDI	In-depth Interview
IG	Intervention Group
HIV	Human Immunodeficiency Virus
JKUAT	Jomo Kenyatta University of Agriculture and Technology
HIV-ASES	HIV-Adherence self-efficacy assessment survey
KDHS	Kenya Demographic and Health Survey
KEMRI	Kenya Medical Research Institute
NASCOP	National AIDS and Sexually Transmitted Infections Control Program
OR	Odds Ratio
RCTs	Randomized Controlled Trials
SCT	Social Cognitive Theory
SD	Standard Deviation

SLT	Social Learning Theory
SSA	Sub-Saharan Africa
UNAIDS	United Nations Programme on HIV/AIDS
USA	United States of America
VL	Viral Load
WHO	World Health Organization

OPERATIONAL DEFINITION OF TERMS

Adolescence	Transitional stage of physical and psychological development that generally occurs during the period from puberty to legal adulthood
Adolescent	An individual in the 10-19 years' age group
Adherence	The extent to which patients take medication as prescribed
ART	Antiretroviral therapy
ART adherence Self-efficacy	Confidence in one's ability to adhere to a treatment plan
Behavioural HIV acquisition	Transmission of HIV as a result of sexual relation or direct introduction into the blood stream as common in drug injection
HIV	Human Immunodeficiency Virus
HIV Disclosure	Knowledge of one's HIV status usually the process of incremental communication to a child of their HIV status.
Life skills	Life skills are abilities for adaptive and positive behaviour that enable humans to deal effectively with life's challenges
Late-adolescence	Transitional stage of physical and psychological development is characterised by the ability to think rationally, delay gratification, plan for the future, and gain a firm sense of identity between the ages of 17-19yrs.

Mid-adolescence	Transitional stage of physical and psychological development is characterised by a growing capacity for abstract thought and accelerating physical developments between the ages of 14-17 yrs.
Older adolescents	Individuals' aged between 15-19 years.
Perinatal HIV Acquisition	Transmission of HIV in utero or during the perinatal period
Self- efficacy	The extent or strength of one's belief in one's own ability to complete tasks and attain goals despite environmental and social barriers.
Self-esteem	Defined as our sense of worthiness as a person, our life objectives, our relationship with others, our social status and our emotional autonomy
Social support	Psychological adjustment from acceptance by family, peers and other social structures with an aim in improving health outcomes, increasing motivation for treatment, self-care behaviours, and also prevention of transmission of infection
HIV Stigma	HIV-related stigma refers to negative beliefs, feelings and attitudes towards people living with HIV
Transition	Process by which HIV-infected adolescents and young adults and their caregivers are empowered with knowledge and skills to independently manage their health
Younger adolescents	Individuals aged between 10-14 years of age
Viral load	Numerical expression of the quantity of virus in a given volume of fluid; sputum and blood plasma.

Suppression

Reduction of HIV RNA to an undetectable level with the implication of reduced viral replication and cellular invasion

ABSTRACT

HIV-related deaths account for the highest mortality among older adolescents and young people in Africa. Studies evaluating the most effective interventions to support disclosure in sub-Saharan Africa have not focused on life-skills provision aimed at empowering adolescents living with HIV (ALWHIV) to navigate the health system after transition to adult care. The overall objective of this study was to evaluate the effect of the introduction of a life skills curriculum as a transition to adult care support tool among perinatally infected adolescents receiving care at Mbagathi hospital, Nairobi, Kenya. The study employed a randomized clinical trial design and utilized a mix-methods approach to conduct the study in two phases between December 2018 and September 2019 among 140 ALWHIV aged 16-18 yrs. For the first phase of the study which utilized a formative qualitative approach, 58 adolescents were enrolled and eight focus group discussions (FGDs) and ten in depth interviews (IDIs) were conducted. Based on the qualitative data, the Baylor's curriculum was adapted and contextualized to include identified additional topics and exclude those that did not emerge as relevant to the adolescents. The curriculum was pilot tested among an additional 82 HIV positive adolescents randomized to an intervention arm (n=42); receiving the life-skills utilizing the modified curriculum and standard care) and a control arm (n=40); receiving standard of care consisting of psychosocial support for adolescents with virological failure and ad hoc unstructured support groups). Viral load, Antiretroviral therapy (ART) adherence self-efficacy and self-esteem were measured at baseline and 12 weeks post the intervention. Viral load suppression was the primary clinical outcome defined as ≤ 1000 copies (results abstracted from patient files from latest blood sample result within the past one year), while ART adherence self-efficacy (measured by the HIV-Adherence self-efficacy assessment survey (HIV ASES) utilizing ≥ 60 as cut-off) and self-esteem (measured by the Rosenberg scale; utilizing ≥ 35 as cut-off) were secondary outcomes. Data were also collected on sociodemographic and self-reported adherence to ART. Thematic analysis with an inductive-deductive approach was conducted for the analysis of qualitative data. Regression analysis was conducted to identify determinants of adherence while difference in difference analysis was utilized to analyse outcomes between the two study arms. The qualitative results revealed that adolescents' experiences challenges in antiretroviral adherence and struggled with psychosocial distress post-disclosure of their HIV status. They also expressed that they had many informational needs including how to set goals, reach their aspirations and utilize HIV prevention service such as Pre-exposure prophylaxis (PrEP). The RCT found that odds of increased self-reported adherence were 8.1 times higher among adolescents with higher ART Adherence self-efficacy (95% CI [2.31- 28.18]) and 3.8 times higher (95% CI [1.11-12.72]). The self-reported adherence $\geq 95\%$ had a high correlation with viral loads of < 1000 copies/ml (Kappa= 0.87). ART adherence self-efficacy was significantly higher among the adolescents in the intervention group ($p=0.012$). Viral suppression ($p=0.003$) and self-esteem ($p=0.04$) were also higher in the intervention group. The study reported unmet psychosocial needs among older ALWHIV, particularly during disclosure of their own HIV status and when they disclosed to others.

The contextualization of the life skills intervention in this study improved psychosocial and clinical outcomes among ALWHIV. The finds indicate a gap in tailored psychosocial support and psychosocial care training content targeting used older adolescents' unique needs. Further research into adherence self-efficacy as a potential indicator of transition readiness assessment to adult care for ALWHIV is warranted to meet the needs of older adolescents.

CHAPTER ONE

INTRODUCTION

1.1 Background

1.1.1 Adolescence stage in development

The World Health Organization (WHO) classifies adolescents as individuals between the ages of 10 to 19 (WHO, 2014). The adolescent phase is complex and is marked by psychosocial, behavioural, physiological and cognitive developmental changes. Adolescents are grouped into three overlapping developmental age groups: early adolescence ages 10 to 15, middle adolescence ages 14 to 17 and 16-19 years, defined as the late adolescence stage. There are often significant variations seen among populations and individuals' in the same populations; thus, the overlap of ages in these developmental groups is common (WHO, 2011).

1.1.2 Global and Sub-Saharan HIV prevalence and outcomes

The majority of the world's HIV (Human Immunodeficiency virus) infections occur in sub-Saharan Africa, where 85% of all adolescents living with HIV are located. The overall prevalence of HIV in the sub-Saharan African region (SSA) ranges between 3-15% (UNAIDS, 2018). Global data estimates indicate HIV-related deaths have halved in children and adults since 2010 but have only dropped by 5% in adolescents. Eastern and southern Africa remains the region most affected by the HIV epidemic, accounting for 45% of the world's HIV infections and 53% of people living with HIV globally (UNAIDS, 2018). A sustained effect of Antiretroviral therapy (ART) towards the optimal reduction of HIV viral load and consequently sustained immunity by HIV positive individuals depends on high levels of treatment adherence, the recommendation being ($\geq 95\%$) of daily oral dosing (Lima *et al.*, 2008). A growing body of evidence indicates poor clinical outcomes among adolescents compared to adults, including poor

viral load suppression and retention in treatment both in the western world and Africa (Bygrave *et al.*, 2012 ; Mwau *et al.*, 2018 ; Nachega *et al.*, 2009 ; Koech *et al.*, 2014; Slogrove *et al.*, 2018; Nglazi *et al.*, 2012; Lamb *et al.*, 2014).

1.1.3 HIV in adolescents; acquisition and outcomes

About half of adolescents (15-19) living with HIV reside in just six countries: South Africa, Nigeria, Kenya, India, Mozambique and Tanzania, with East and Southern Africa being home to 1.3 million HIV infected adolescents (UNAIDS, 2016). Studies from Ethiopia (Firdu, Enquselassie, & Jerene, 2017) and Kenya (Ngeno *et al.*, 2019) reported that adolescents were less likely to achieve viral suppression than children and adults. One possible reason for this is poor adherence to ART common among adolescents (UNAIDS, 2018). The majority of the 1.3 million adolescents living with HIV in sub-Saharan Africa acquired HIV perinatally and were diagnosed and initiated on ART as children (Hawkins, Evangeli, Sturgeon, Le Prevost, & Judd, 2016; Lowenthal *et al.*, 2014). These studies report lower adherence rates in adolescents compared to adults. Adolescents are not a homogenous group. They have evolving social needs in tandem with their physical and psychological development (Hawkins *et al.*, 2016). Studies suggest that older adolescents are particularly at risk of poorer HIV outcomes during their transition from paediatric to adult care particularly because they potentially undergo physical and psychosocial trauma as a result of HIV and environmental stressors among them death of caregivers and experienced stigma. (Mburu *et al.*,).

1.1.4 Adolescent HIV in Kenya

In Kenya, there are 300,000 adolescents and young people living with HIV (15-24yrs), with the highest morbidity and mortality mirroring with global picture and highest among older adolescents aged 15-19 years (NASCOP, 2014). The aim of HIV treatment using antiretroviral therapy is to suppress the HIV viral load thus reducing morbidity and

mortality among individuals' living with HIV. The reduction of viral load is referred to as viral suppression. According to the Kenya Population-based Impact Assessment in 2018, only 58% of adolescents living with HIV achieved viral suppression compared to 70% among adults. In Kenya, majority of adolescents acquire HIV through perinatal transmission. Sub-optimal clinical outcomes adolescents are twice more likely to occur among older adolescents between 15 and 19. (Apondi *et al.*, 2018) compared with younger adolescents. This has been attributed to poor or non-existing mechanisms in the transition of adolescents to adult-centred care that require them to take charge of their health-related behaviour (Koech *et al.*, 2014; Bygrave *et al.*, 2012). There are often no standardized practices such as psychosocial support care for the transition of these adolescents into adult clinics in Kenya and no structure psychosocial support systems tailored to older adolescents (Njuguna *et al.*, 2019).

1.2 Statement of the Problem

In addition to dealing with a chronic illness, HIV-infected adolescents have to confront psychosocial issues, maintain adherence to drugs, and learn to negotiate sexual relationships while undergoing rapid physical and psychological changes (UNAIDS, 2016; Mueller *et al.*, 2011; Agwu & Fairlie, 2013). Adolescents also often demonstrate poor virological suppression which results in mortality. The primary and most frequent cause for this increased mortality is poor adherence (Lima *et al.*, 2008; Bygrave *et al.*, 2012), (Mwau *et al.*, 2018; Nachega *et al.*, 2009 ; Koech *et al.*, 2014; Nglazi *et al.*, 2012; Ngeno *et al.*, 2019) to antiretroviral therapy. There is however a lack of understanding about the factors leading to poor adherence among older adolescents' transitioning to adult care.

Often, many psychological stressors associated with adherence, such as the adolescents' life events or living conditions, may not be modifiable. However, there are individual factors such as adherence self-efficacy that may be taught, enhanced and re-enforced

leading to better treatment outcomes. These have an influence on behavioural outcomes including adherence to drug therapies. (Bandura *et al.*, 1977)

More paediatric HIV infected populations survive from childhood, increasing the number of adolescents living with HIV and preparing to transition into adulthood (WHO, 2014; Lamb *et al.*, 2014). Without the necessary tools to engage in self-care and navigate health systems as adults, adolescents who transition into adulthood are more likely to have poor adherence and retention in care outcomes.

ART adherence self-efficacy is defined as the ability of an individual to continue with the treatment plan regardless of any challenges they may experience' (Mueller *et al.*, 2011; Johnson *et al.*, 2007) Among the few programs addressing adherence self-efficacy among adolescents, few have been evaluated for the effectiveness in improving virological and psychosocial outcomes, particularly adherence self-efficacy among older adolescents. Therefore, available evidence lacks the feasibility and effectiveness of life-skills provision within facility-based interventions and among these HIV-positive adolescents.

According to the social cognitive theory (SCT), external factors such as; social support and relational barriers are associated with modifiable cognitive factors such as; skills/learning, self-efficacy and individual goals in a reciprocal relationship (Figure 1.1) to affect health behaviour adherence (A Bandura, 1977).

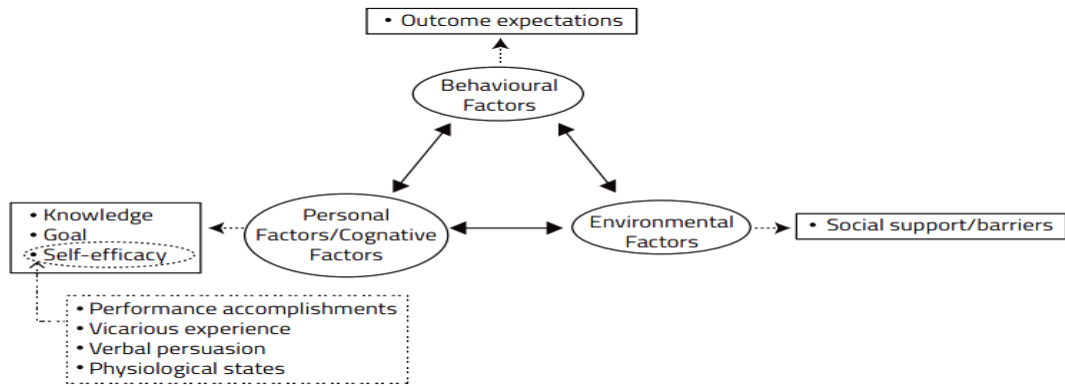


Figure 1.1: Adopted from Bandura A: Self-efficacy: Toward a unifying theory of behavioural change Psychol. Rev 84:191-215, 1977

Experts in child development agree that life skills among adolescents, regardless of their HIV status, are critical in guiding their navigation of the different social, environmental and behavioural transitional changes to adulthood. There is evidence of the effectiveness of patient support and education interventions intended to improve adherence to antiretroviral therapy. Unfortunately, majority of studies globally have evaluated life skills in the context of school-based programs (Srikala & Kishore Kumar, 2010; James, Reddy, Ruiter, McCauley, & Van Den Borne, 2006). In Kenya, few life-skills oriented programs have been implemented or evaluated specifically those that target adolescents living with HIV.

1.3 Justification

While all adolescents face the same difficulty during the developmental stage, data suggests adolescents presenting with behavioural HIV acquisition may have uniquely different psychosocial needs from those with perinatally acquired infection with regards to the recurrent and cumulative psychological stressors experienced. These include long periods of ill health, the death of caregivers and stigma. (Firdu *et al.*, 2017).

Kenya has almost 300,000 of the worlds' adolescents living with HIV. Older adolescents present with the poorest outcomes and this is detrimental as their transition into adult care requires all adolescents to be adept in navigating health systems and be self-motivated towards their care. There is need to improve these treatment outcomes but many interventions are created and developed by health workers and stakeholders and rarely meaningfully engage the beneficiaries, in this case, adolescents. There are tools and interventions required to improve adolescents' HIV outcomes. Evidence indicates that the transition process of adolescents to adult care, should provide a toolkit for coping with challenges related to the psychosocial stressors of living with HIV and the attainment of ART adherence self-efficacy (Cervia, 2013). The current World health guidelines focus on the first step of transition - disclosure of HIV status and provision of psychosocial support targeting children below the age of twelve (Cervia, 2013; WHO, 2011). There exists a lot of literature on how to address the needs of the younger adolescents (10-14) living with HIV as the transition to older adolescence and adulthood. However, most perinatally-infected children in Africa receive disclosure of their HIV status as adolescents (ages 12-19) (Hawkins *et al.*, 2016). This results in limited data and guidance on psychosocial needs and relevant support challenges among older perinatally infected adolescents who are of age to transition to adult care. This differs from adolescents with behaviourally acquired HIV who receive disclosure of their HIV status at the time of their HIV diagnosis. This study, therefore, focuses on adolescents between ages 15-19 who acquired HIV perinatally.

Although school-based life-skills training focusing on HIV prevention and mental health programs (Srikala & Kishore Kumar, 2010; Mwale & Muula, 2017) has been implemented among non-HIV-infected adolescents few interventions have focused on Africa ALWHIV. This study sought to incorporate adolescents' insights into modifying the life-skills curriculum to contextualize it to their needs. Few studies in SSA have focused on the impact of psychosocial interventions among adolescents that measure ART adherence self-efficacy. The Baylor School of Medicine HIV clinics in Botswana and Malawi employed a life skills curriculum in the setting of HIV positive adolescent

support groups (Appendix 44, 45) The life skills curriculum developed include areas such as communication and assertiveness skills, coping with stigma, life goals setting as and adherence to antiretroviral therapy. However, currently this life skills approach has not been implemented in Kenya. This study contributes to the knowledge gap in feasibility, acceptability and effectiveness of life-skills provision to HIV positive adolescents while using the socio-cognitive framework to observe the role of self-efficacy. The study will achieve this by piloting a modified Baylor's life-skills curriculum (Appendix 5) as a psychosocial intervention among older adolescents who are in preparation for transition to adult care. This study sought to contribute to policy formulation by providing evidence on psychosocial needs of adolescents that should be addressed within adolescent psychosocial care, the effects are on long term adherence motivation (ART self-efficacy) and their virological outcomes.

Mbagathi hospital has one of the oldest cohorts of children initiated on ART since 1995. It has transitioned approximately 800- paediatric patients (under 12 years of age) into adolescence. It is, therefore, an appropriate site with a sizeable cohort of perinatal-infected adolescents. Additionally, it is a catchment area to Dagoretti North and Kibera sub-counties that have the highest HIV prevalence in Nairobi county even among adolescents. Majority of these adolescents come from informal settlements whose poverty and violence rates further compound additional psychosocial.

1.4 Objectives

1.4.1 Broad Objective

The overall objective of the study was to evaluate the clinical and psychosocial outcomes of life-skills building among perinatally infected adolescents receiving care at Mbagathi Hospital Nairobi.

1.4.2 Specific Objectives

1. To identify the psychosocial support needs among perinatally HIV-infected adolescents at Mbagathi hospital.
2. To determine informational needs contextualised to the Kenyan setting that should be addressed in a modified Baylor's life skills curriculum targeting HIV positive adolescents in Mbagathi hospital.
3. To determine factors associated with ART adherence among HIV-infected adolescents at Mbagathi hospital.
4. To assess the effect of adapted Baylor's life skills curriculum on ART adherence self- efficacy, self-esteem and viral suppression among adolescents in Mbagathi hospital.

1.5 Hypotheses

HO: There is difference in the proportion of adolescents with high ART self –efficacy scores (≥ 60) as measured by the HIV-ASES scale among adolescents receiving life skills building compared to those who do not.

HO: There is no difference in the proportion of adolescents with a high self –esteem score (≥ 35) as measured by the Rosenberg test among adolescents receiving life skills building compared to those who do not.

HO: There is no difference in the proportion of adolescents with viral load suppression (≤ 1000 copies) among adolescents receiving life skills building compared to those who do not.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

Studies among paediatric and adolescent populations report delayed disclosure, low self-efficacy, depression, behavioural challenges, pill burden, younger age, stressful events and low levels of social support to be factors associated with poor ART medication adherence (UNAIDS, 2018); Hawkins *et al.*, 2016; Lowenthal *et al.*, 2014; Lima *et al.*, 2008; (Bygrave *et al.*, 2012), (Mwau *et al.*, 2018).

2.2 Psychosocial needs of adolescents

Disclosure is a critical component in initiating an individual's understanding of the disease, its implications and what treatment measures must be taken towards well-being and good health. HIV status disclosure often begins discussions that lead to better virological and psychosocial outcomes in HIV-infected children. Studies in Zambia (Haberer *et al.*, 2011), Uganda (Nabukeera-barungi *et al.*, 2015), and Namibia (Beima-Sofie *et al.*, 2017) have reported associations between delayed disclosure and poor clinical outcomes as demonstrated by an unsuppressed viral load in infected children and adolescents. One study in Uganda reported that where caregivers had not disclosed, HIV positive children and adolescents in the study were three times likely to be non-adherent to ART compared to their counterparts who were aware of their HIV status (Nabukeera-barungi *et al.*, 2015). The WHO guidelines on disclosure and post-disclosure psychosocial support in HIV infected children focus only on children below the ages of twelve (WHO, 2011). It is expected that in optimal health systems, disclosure of HIV status will have occurred incrementally in childhood and will be complete by early adolescence (WHO, 2011). A systematic review examining disclosure prevalence and correlates in twelve low and middle-income countries reported disclosure rates that ranged between 0.1% and 50% (Britto, Mehta, Thomas, & Shet, 2016). A large study

carried out in Kenya found a disclosure rate of 36% among HIV positive children and adolescents(Ngeno *et al.*, 2019). The available literature is, therefore, indicative of high rates of delayed disclosure. Globally, limited data and literature are available to inform guidelines on the psychosocial needs of perinatally infected adolescents who receive disclosure as adolescents. This, in turn, results in the provision of suboptimal post-disclosure support and inadequate information to adolescents as the current guideline are not tailored towards older adolescents.

2.3 Challenges in ART adherence among adolescents living with HIV(ALWHIV)

The primary aim of the provision of antiretroviral therapy is the reduction of viral load and improved quality of life. Studies in Kenya, (Mwau *et al.*, 2018 ; Koech *et al.*, 2014,) Zimbabwe, (Bygrave *et al.*, 2012), South Africa, (Nachega *et al.*, 2009), Ethiopia (Firdu *et al.*, 2017)), Uganda, and have found adolescents have significantly higher viral loads in perinatally infected adolescents compared adults. In addition, higher rates of loss to follow-up from clinical care among adolescents is reported. Numerous studies indicate that Adolescents are also among populations with the highest rate of loss to follow up from care (Lima *et al.*, 2008), (Mwau *et al.*, 2018), (Nachega *et al.*, 2009), (Nglazi *et al.*, 2012a), (Lamb *et al.*, 2014). A large multi-regional study reported that perinatally infected adolescents in Africa had the highest rate of loss to follow up compared to Asia, North & South America and the Caribbean (Slogrove *et al.*, 2018). A large cohort study from Kenya found that compared to adults, adolescents were three times more likely to be reported as a loss to follow up from HIV care clinics (Koech *et al.*, 2014).Often data on adolescents covers the entire spectrum of adolescents (10-19yrs) or more often older adolescents are lumped together with adults in the 15-24 years age band. Additionally, there are few studies that have focussed on older adolescents (15-19yrs of age) to establish unique determinants for the poor outcomes reported.

2.3.1 Adherence to ART and Psychological Correlates

Non-adherence is the single most significant challenge to the successful management of HIV-infected individuals, especially adolescents (UNAIDS, 2016) (Lowenthal *et al.*, 2014), (Mwau *et al.*, 2018) (Nachega *et al.*, 2009.). It may be due to any combination of structural, patient-related, provider-related, medication-related, disease-related, and psychological barriers (L. Li *et al.*, 2017). Psychological indicators associated with poor adherence include poor social support, low self-esteem, low self-efficacy and stressful life events (Ngeno *et al.*, 2019; Firdu *et al.*, 2017 ; Kasedde, Kapogiannis, McClure, & Luo, 2014; Williams *et al.*, 2006, Agwu & Fairlie, 2013, Adefolalu, Nkosi, Olorunju, & Masemola, 2014; Adefolalu *et al.*, 2014). Studies from both high-income and low-income countries with longstanding access to ART have indicated that HIV positive adolescents are at particularly high risk for experiencing stressful life events and emotional and behavioural problems. (Hawkins *et al.*, 2016; Petersen *et al.*, 2010; UNAIDS, 2016), Sohn & Hazra, 2013). Studies from sub-Saharan Africa report the following challenges: a perceived foreshortened future related to a lack of information about treatment as well as a sense of loss at not being able to lead a ‘normal’ life, having to cope with the loss of biological parents due to AIDS, and internalised stigma that was a barrier to disclosure to others outside the immediate family (Firdu *et al.*, 2017; Petersen *et al.*, 2010). In order to provide the lacking relevant psychosocial support understanding the psychosocial needs of adolescents within their contextualized setting is important. Even more useful is age-appropriate interventions which would be specific to older adolescent compared to children and younger adolescents.

2.3.2 Integrating self-efficacy within ART adherence interventions

Self-efficacy is described as the extent or strength of one’s belief in one’s own ability to complete tasks and attain goals despite environmental and social barriers (Swan & Kershaw, 1994), (Sedikides & Gress, 2003) (A Bandura, 1977). Self-efficacy has been

identified as a factor closely related to adherence. Higher self-efficacy was associated with better adherence (Le Prevost *et al.*, 2018),(Chen *et al.*, 2013), (Naar-King *et al.*, 2013), (Andrews, Skinner, & Zuma, 2006). Self-efficacy can be influenced by four determinants: - mastery of experiences, social modelling, social persuasion and psychological states. (Albert Bandura, 1998).

Compared to the other mentioned determinants of adherence, self-efficacy is modifiable and may be enhanced through appropriate cognitive-behavioural promoting influences offered as educational and information provision. Numerous studies within HIV positive adolescents and youth have identified self-efficacy as a key component in improved adherence and better treatment outcomes (Mueller *et al.*, 2011; Johnson *et al.*, 2007 ; Adefolalu *et al.*, 2014; Aregbesola & Adeoye, 2018) However, little research has focused on data exist on the acceptability, feasibility and impact of interventions aimed at increasing self-efficacy among HIV infected adolescents within sub-Saharan Africa.

2.3.3 Self -esteem as a potential correlate of ART adherence

Self-esteem includes our sense of worthiness as a person, our life objectives, our relationship with others, our social status, our emotional autonomy. Self-esteem, especially in adolescence, has many influences, from socializing with others to the results achieved by a person. The feeling of belonging in adolescence is exacerbated, not in relation to the family, but to the environment because social relations hold increasing importance in this period. At the same time, both self-esteem and self- efficacy are components of self-concept, Bandura's (1986 as cited in Bandura, 2007). Self-esteem interacts with environmental factors such as dysfunction in the family, peer relationships, and/or performance goals. Therefore, theoretically, self- esteem should interact with both the personal/cognitive component of SCT, with a focus on goals as well as the environment with the consequent contribution to behaviour under study, such as adherence to antiretroviral therapy. However, the relationship between efficacy to ART and self –esteem has not been well described.

2.3 Life-skills based Interventions Aimed at improving psychosocial and clinical outcomes among adolescents living with HIV

A systemic review of adherence interventions over a decade indicated that among numerous studies that have reported on adherence, few had reported virological outcomes (Amico, Harman, & Johnson, 2006). In a meta-analysis (74) that focused on virological outcomes (Simoni, Pearson, Pantalone, Marks, & Crepaz, 2006). The magnitude of the aggregated OR indicated that participants who received the intervention were 1.5 times as likely to report $\geq 95\%$ adherence and 1.25 times as likely to achieve an undetectable VL as participants in the control arm. There is a growing body of evidence that supports the premise that studies targeting those with poor adherence to ART had stronger effects than those intervening with groups of individuals who were mixed in terms of pre-test levels of adherence. The intervention effect was significantly stronger in studies that used a longer recall period (i.e., two weeks or one month) versus a shorter one (i.e., \leq seven days) for $\geq 95\%$ adherence. Additionally, the length of the interventions reported to be effective was variable. For example, in the study by (Remien *et al.*, 2005), a 4-session comprehensive intervention for couples delivered by a nurse practitioner demonstrated some success in increasing adherence. In contrast, in the studies by (Rathbun, Farmer, Stephens, & Lockhart, 2005) a single didactic session with a pharmacist was efficacious. A multisite national study carried out by the National Institutes of Health Adolescent Trials Network in the US reported significant drops in the viral log of newly initiated HIV positive adolescents after a computer-assisted motivational interviewing intervention (Naar-King *et al.*, 2013). This in contrast to other studies that indicate that interventions targeting practical medication management skills, those interventions administered to individual versus to groups, and those interventions delivered over 12 weeks or more were associated with improved adherence outcomes

However, little information exists on the effectiveness of interventions aimed at improving adherence among adolescents in low and middle-income countries and

particularly sub-Saharan Africa. Most studies include adolescents and adults. However out of 52 studies in a systematic review (Ridgeway *et al.*, 2018), only two studies focused on adolescents. One study offered an empowerment intervention to adolescents in Thailand offered as a five-session interactive didactic session improved $\geq 95\%$ adherence at $p < 0.001$ (80) (Kaihin, Kasatpibal, Chitreechuer, & Grimes, 2015). The other study offered ten didactic sessions to HIV positive adolescents in South Africa and reported significant improvements in mental health, knowledge of HIV and Adherence. (Bhana *et al.*, 2014).

Studies that report on the development and implementation of interventions focused on adolescents (Hodgson, Ross, Haamujompa, & Gitau-Mburu, 2012; Anitha Menon, Glazebrook, Campain, & Ngoma, 2007; Mburu *et al.*, 2013; Mimiaga *et al.*, 2019) report that the challenges of Adherence to ART and living with HIV among adolescents are often influenced by factors beyond the adolescents themselves. Literature reports that transition to adult care is a particularly critical period, and interventions should include voices of adolescents and young adults. Additional needs for successful transition plans should also include an assessment of the young adult's educational aspirations, with appropriate vocational and life skills training (Njuguna *et al.*, 2019). Adolescents living with HIV have also been found to have fewer Life skills mastery compared with HIV negative adolescents indicating that this approach should be a component of interventions towards improved adherence and within the context of transition to adult care (Lee & Hazra, 2015).

2.3.1 Life-skills based interventions improving Self –Efficacy and Self –Esteem

While data exists among adults and other populations on interventions that have reported on self-efficacy among pregnant women and adults (Johnson *et al.*, 2007; Adefolalu *et al.*, 2014; Aregbesola & Adeoye, 2018). Globally there are few studies that report on improving self- efficacy among HIV positive adolescent's interventions focusing on improving self -efficacy to ART adherence, particularly in sub-Saharan Africa. One pre-

and post-study that implemented an m-health intervention study -Mombasa among HIV positive adolescents, reported no significant changes in self-efficacy with the major limitation in the lack of a control group. However, in another study in South Africa that used art-based community for children and adolescents affected by HIV and AIDS, while self-esteem was not significantly improved; self-efficacy (Mueller, Alie, Jonas, Brown, & Sherr, 2011).

Though some HIV programs have incorporated life skills training as part of routine care to our knowledge, there are no published data on the evaluation of the use of life skills provision by these programs. Additionally, little is known about the acceptability, feasibility and effect of life skills training among adolescents receiving care in Kenya. Despite the robust body of data available on the importance of self-efficacy in promoting adherence to antiretroviral therapy by adolescents. To the best of our knowledge, the Baylor curriculum has not been evaluated for the impact on self-efficacy, perception of social support, coping with stigma and viral load reduction for the adolescent receiving HIV care. The core focus area of this study is, therefore, aimed at filling this knowledge gap. It focuses on evaluating the psychosocial needs of perinatally infected HIV positive adolescents.

2.3.2 Baylor's Life skills curriculum and incorporation sources of self-efficacy

Baylor's Life-skills curriculum is a life-skills curriculum that has been in use in Botswana and Tanzania within HIV program settings. To the best of our knowledge, there is no data on the evaluation of Baylor's curriculum as an intervention. This study hopes to answer the question of whether the adaptations of the curriculum that focus on enhancing adherence self-efficacy sources will result in a reduction of viral log load (The primary outcome) and increased self-esteem and adherence self-efficacy (secondary outcomes). One landmark study that focused on increasing self-efficacy by (Naar-King *et al.*, 2013) reported a randomized pilot trial of an intervention for youth initiating antiretroviral treatment. The intervention group showed an improvement in

viral load reductions and had a greater per cent of adolescents and youth with undetectable viral loads after six months.

2.4 Conceptual framework addressing life skills intervention in improving psychosocial and clinical outcomes

By leveraging on the social cognitive theory, which purports that increased information can affect the cyclic relationship between personal components, coping mechanisms by an individual (the self) to events in or the environment consequently affect behaviour change. The study hypothesizes that the provision of life skills would increase adherence self –efficacy (measured by the validated HIV-Adherence self-efficacy assessment survey (HIV ASES tool), increase self -esteem (measured by the Rosenberg test), which in turn would increase the ability to develop and maintain ART treatment goals. The conceptual framework illustrates incorporation of sources of self- efficacy and information on the adolescents psychosocial and informational needs in adapting the life skills curriculum. (Figure 2.1)

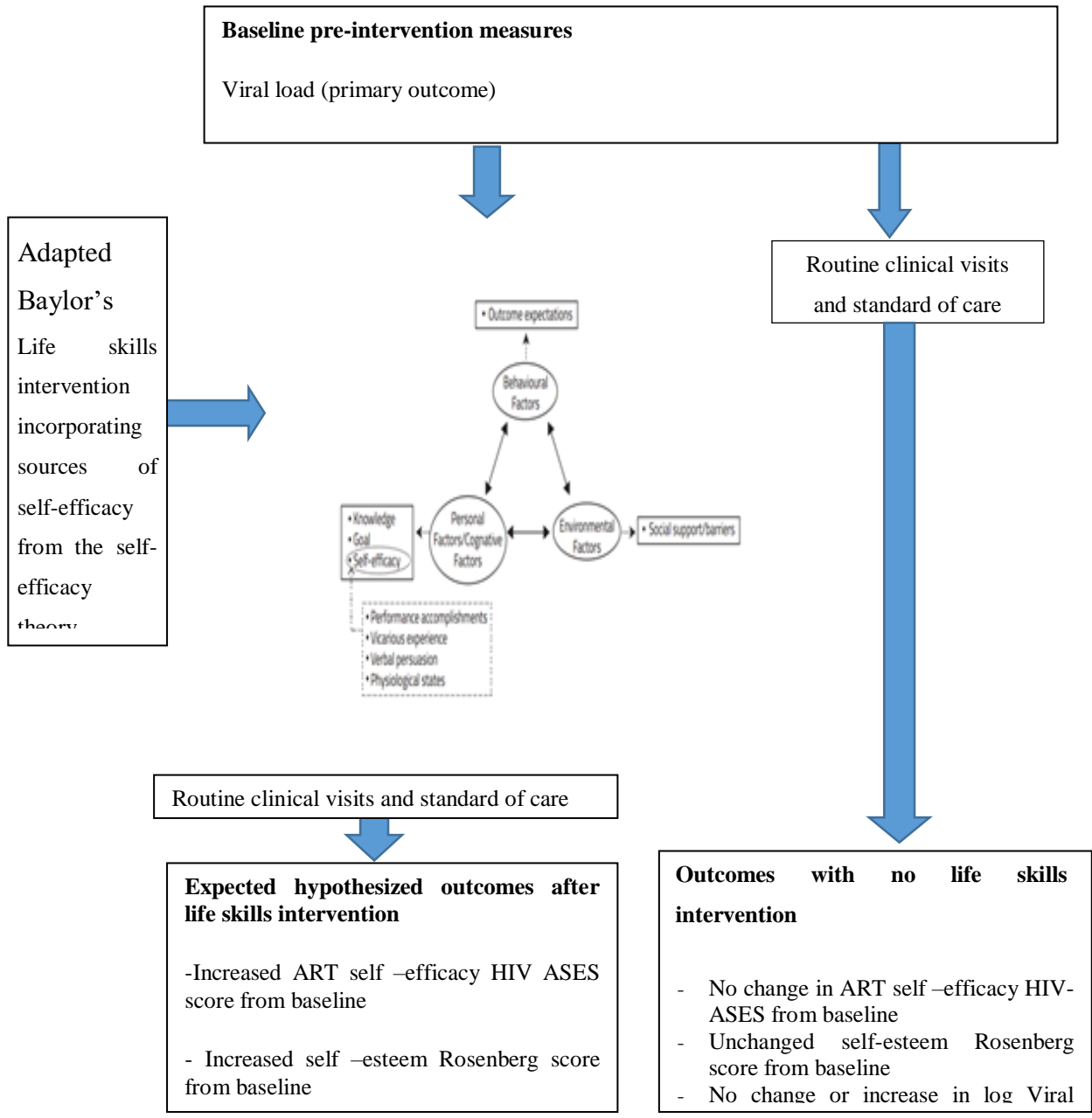


Figure 2.1: The hypothesized effects of the adapted Baylor life skills curriculum on the key study outcomes

CHAPTER THREE

MATERIALS AND METHODS

3.1 Study area

The study was carried out within the Nairobi county site within Mbagathi Hospital Comprehensive Care Centre. Nairobi has a total of 190,993 and has a total HIV prevalence of 3.8%. It however has the highest number of adolescents living with HIV within an urban setting in Kenya. It is a designated UNAIDS fast track city; an initiative that aims to ensure that 95% of individuals living with HIV achieve viral suppression (NASCO, 2014)



Figure 3.1: The map of Kenya depicting location of Nairobi county (source: open source Kenya country map)

Among its 15 sub-counties, the two with the highest HIV prevalence are Dagoretti North, with an HIV prevalence of 10-15% and Kibera with a prevalence of 15-16%. The latter consists primarily of an impoverished slum

HIV PREVALENCE BY SUB COUNTY

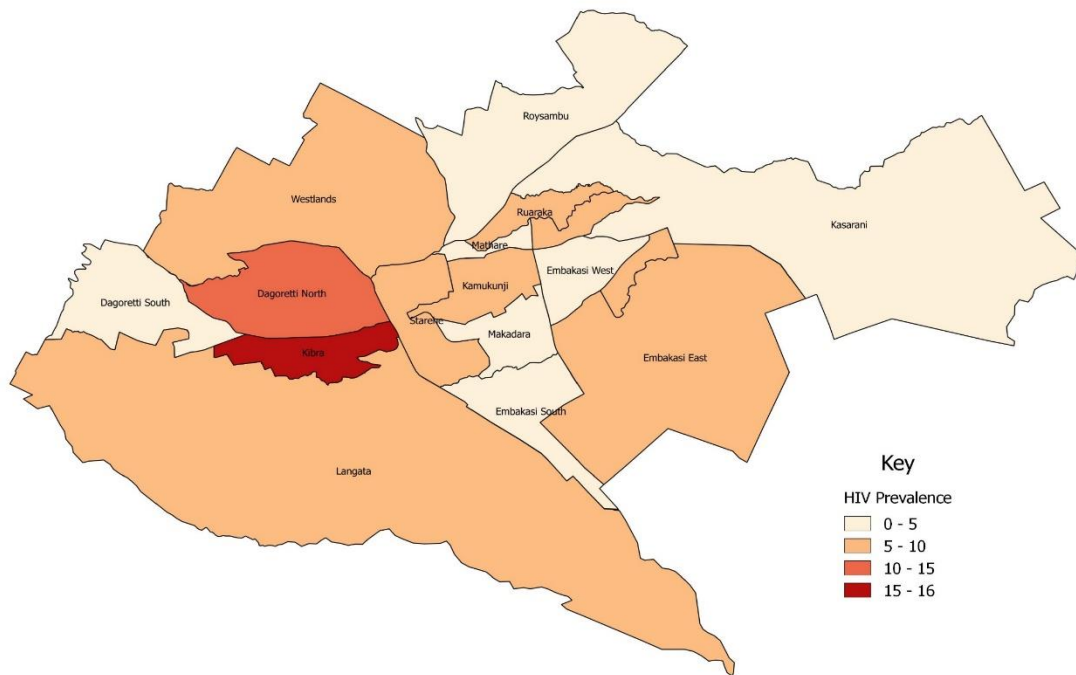


Figure 3.2: The HIV prevalence by Sub-County, Nairobi county (source: Kenya population estimates 2015)

The study was conducted in Mbagathi referral hospital located in Dagoretti-North sub-county, Nairobi county. Geographically, its catchment area serves the two sub-counties, Dagoretti North and Kibera, with the highest HIV prevalence at 10-15% and 15-16% respectively. However, as one of the first public sector HIV treatment centres in the country, it serves a population that resides within the whole county of Nairobi and its environs. It provides HIV care for over 6000 individuals living with HIV provide HIV services for individuals from the entire Nairobi county and its environs. Currently, 300

adolescents (ages 10-19) currently enrolled in care and on ART. Of these, 150 are between the ages of 15-19 yrs.

Operationally, clinic appointments for adolescents are scheduled every three months. Where poor adherence through viral load increment was identified, intensified one on one counselling are offered. This should ideally be on a monthly basis but may not occur in this manner as many school-going adolescents may not be able or are unwilling to miss school to attend the clinic. Clinical care was provided during an adolescent clinic that caters to adolescents 10-19 years of age on a designated day of the week(Wednesday). On this day, only the relevant age group was invited on an appointment basis to the clinic. They often present to the clinic without their guardians, although some may be accompanied. Support groups are held during the school vacation as many adolescents attend boarding schools. They usually occur three months apart and usually involve adolescents who are identified as biologically unsuppressed and who are willing and or receive caregiver support to do so. These support groups, however, are not regular and not all unsuppressed adolescents. Viral load tests are measured six months after initiation of ART with regular yearly follow up thereafter. They are at no cost to the patient. Plasma HIV-RNA levels using the branched DNA hybridisation technique (Versant™ HIV-1 RNA 3.0 branched-chain DNA assay, Roche Cobas Ampliprep/Cobas Taqman (CAP-CTM) detection range of 40copies/ml.

3.2 Study Design

This study employed an embedded mixed methods design- which constituted a randomized clinical trial with a formative qualitative phase.(Palinkas *et al.*, 2010)

The formative qualitative study was appropriate for exploring the adherence challenges and psychosocial needs and experiences of the adolescents. Focus group discussions and in-depth interviews were conducted to elicit in-depth discussions on the different life events and environments that contributed to the challenges faced by the adolescents as

well as to identify their information needs. The qualitative data findings from HIV positive adolescents were used to identify key areas/knowledge gaps required and adapt The Baylor's life-skill curriculum for use within the Kenyan context, specifically for the late adolescent period of HIV positive adolescents. Additionally, the focus of the adaptation sought to include aspects of the social cognitive theory with a focus on including components /sources of self-efficacy and self- esteem. The adaptation was focusing on the components of social modelling by other HIV positive adolescents in the areas that pertain to adherence towards ART, discussions on mastery of experiences, social persuasion by peers and discussions on coping mechanisms from psychological barriers identified during the qualitative study.

The second phase of the study utilized a randomized control trial to compare the effect of the life skills provision using this adapted Baylor life skills curriculum on psychosocial (Adherence self- efficacy and self-esteem) and clinical outcomes (viral load). Assessment of the life skills intervention required the collection of pre-intervention and post-intervention data from participants in both groups hence the choice of a randomized clinical trial.

3.3 Study Population

The study focussed on perinatally infected HIV-positive adolescents receiving care at Mbagathi Hospital comprehensive care centre. The centre provides care to 800 adolescents aged 10-19 years – of these, there are 140 older adolescents aged 16-19 years.

3.3.1 Inclusion Criteria

The following was the inclusion criteria for enrolment into the study: -

HIV- infected adolescents aged 16-19 years of age accessing HIV care services with More than three years' ART use) and proven perinatal infection either through

documented HIV DNA polymerase chain reaction (PCR) results or a documented antibody test in childhood and infancy (less than 5 years).

The use of the period of three years as a period of enrolment in care ensures that the adolescents included in the study were enrolled in early adolescence to reduce the likelihood of sexual behavioural transmission. The challenge of defining perinatally infected HIV infection in adolescents in a health system with poorly documentation has been included as a limitation of this study.

3.3.2 Exclusion Criteria

1. HIV positive adolescents ages 16-19 with documented sexual transmission of HIV
2. HIV positive adolescents ages 16-19 in whom disclosure is not started or was on-going
3. HIV positive adolescents ages 16-19 with perinatal infection who are currently experiencing WHO stage four disease manifestations.
4. HIV positive adolescents ages 16-19 with perinatal infection who do not give assent/consent to study participation
5. HIV positive adolescents with perinatal infection who have not commenced ART or have been initiated on ART less than six months at the time of study enrolment.
6. HIV positive adolescents ages 16-17 whose guardians decline to give consent

3.4. Sample size

Sample size determination during the qualitative part of the study: -

Convenience sampling was used to identify participants (based on the eligibility study criteria from adolescents attending the clinic on the clinic days designated to adolescent care into phase one of the study. Following the principles of Grounded Theoretical

approaches, the qualitative data was sampled to establish theoretical saturation, with an upper limit to sample size for feasibility within the study period. A total of 10 IDI and 6 FGDs with 8 individuals each in were conducted.

Sample size determination for the follow-up qualitative study phase: -

Sample size calculations for the intervention relied on the methods and assumptions described by (Wittes, 2002) and are based on the viral load change from baseline expected. The effect sizes were based on a study providing a psychosocial intervention with a similar viral log change outcome by (Naar-King et al., 2013) At a 95% confidence level, 39 adolescents in each arm, will have 90% power to estimate the change in viral load of at least 0.8 in the intervention arm.

Power	Effect size				
	0.2	0.4	0.6	0.8	1.0
90%	617	154	69	39	25
80%	462	116	51	29	18

$$N = 2 \times (Z_{(1-\alpha/2)} + Z_{(1-\beta)})^2 / (\delta^2 \times S^2)$$

N – Sample size per group

$Z_{1-\alpha/2}$ refers to the level of significance or confidence interval = 1.96 for 95% CI

$Z_{1-\beta}$ refers to the power of obtaining the difference between the two groups = 1.28 for 90% power

δ – the difference between the self-efficacy score means two treatment effect = 1.89

S – Pooled standard deviation of the parameter of interest in the two groups = 4.36

The calculated sample size required will be 26 in each group.

Taking into account an attrition rate of 50% (UNAIDS, 2016 ; NASCOP 2019) in each group, the sample size in each arm will be 39.

Assumptions

The populations in the two arms after randomization have equal standard deviations and similar variability

3.5 Sampling techniques

Qualitative phase

Participants were stratified based on gender and viral load. The rationale for this stratification was to decrease the inhibition of participating adolescents who often exhibit high self-awareness and self-consciousness, particularly in the presence of the opposite sex. Participants were also separated groups by viral load, i.e., those who had achieved viral load suppression (≤ 1000 copies/ml) and those who were unsuppressed (≥ 1000 copies/ml). Separating groups provided a safe environment for adolescents to speak about any psychosocial issues unique to them associated with poor adherence without fear of the potential judgement from peers who may not have experienced challenges resulting in poor adherence. FGDs were conducted in these four sub-categories. Data was collected on their psychosocial stressors as ALWHIV with a focus on the events such as disclosure of HIV status, stressors on a day to day, sources and needs of information, whether a skills imparting program would be relevant and recommendations for its implementation.

After a preliminary analysis of the data from the FGDs the IDI's were conducted with participants who were enrolled by did not take part in the FGDs to further explore the emergent themes in depth. This ensured attainment of saturation.

Prospective randomized control trial

Enrolled subjects previously not included in the qualitative part of the studies were enrolled during routine visits based on study criteria eligibility. A total of 82 adolescents were enrolled in the intervention part of the study. Randomisation using SPSS was used to place the eligible participants in the intervention and control groups. A sequence of random numbers was generated from SPSS with the allocation of participants to the intervention and control arms. (Arifin, 2012). Non-clinical research study staff allocated participants to the various groups following the sequence and automated allocation.

This was a pragmatic trial and thus the other elements were left as is in real-life situation. To reduce the potential for contamination we ensured that clinic staff were not aware of which were adolescents received the intervention. Additionally, adolescents from the two arms were separated for consequent clinic appointments by having bookings on specific days.

3.6 Study procedures

The study was conducted between December 2017 and December 2018 during the long school holidays as the majority of the adolescents were in boarding schools. After eligibility evaluation, consent was obtained from both adolescents and caregivers. The data collection tools and consent forms were pretested and adjustments made on the affected items.

3.6.1 Data collection

For the qualitative part of the study, the groups were stratified by sex for the FGDs and IDIs, which utilised structured topic guides for qualitative data collection. The study involved a single contact with each study participant, during the routine clinic visit on the same day as enrolment to the study. During the IDI or FDD the interviewer provided an overview of the study objectives and obtained informed consent from the participant

before proceeding with the FGD or IDI. Interviews and focus groups were audio-recorded. Focus groups lasted 60 to 90 minutes, while interviews lasted 30 to 45 minutes. The data was collected with the help of research assistants who were trained on data confidentiality and ethical issues regarding participant consent and data privacy/

During the randomized intervention study, data were collected at two time points; baseline and 12 weeks demographic data and clinical data such as duration of ART use, duration of enrolment in care, self-reported adherence, viral load and age at disclosure. Data was also collected data on stigma experiences, perceived social support system, ART adherence self-efficacy and reported self-esteem. Socio-demographic and psychosocial variables were collected using a structured computer-assisted self – interviewing survey and utilised chart abstraction for clinical data collection. Viral load results were considered valid if measured three months prior to the interview date. A blood sample was collected ONLY from study participants without a documented viral load result (within the previous three months of study start). The study was carried among adolescents within an urban setting; Nairobi city a cosmopolitan city– majority of whom received care in the English language and were from multiple ethnic communities. The commonly used language – Swahili also existed in many colloquial dialects that were difficult to merge. Hence in this study we utilized and retained English within all data collection tools.

3.6.2 Intervention

Following qualitative data analysis Baylors’ curriculum and themes were adapted derived from phase one of the study. The curriculum was offered through four sessions, each lasting three hours’ duration. It included topics such as sexuality, HIV knowledge, coping with stigma, pregnancy avoidance and contraception and Adherence to ART and self-care. The sessions were moderated by the PI and older HIV positive youth (young adults) and took place in a tent outside the clinic to allow for privacy. The sessions took place on two days of the week for two days. Each session consisted of a morning and

afternoon session with at least two topics covered on each day. The engagements had an interactive instruction approach through various platforms, including short movies, face to face instruction, role plays as well as a focus group approach to discuss responses and application of skills learnt in everyday life.

3.7 Measures

Various socio-demographic (age, sex, status of caregiver (alive /not), clinical (adherence and viral load) and psychosocial indicators (perception of social support, stigma, self-esteem adherence self-efficacy and perceived stigma) were collected at baseline and 12-week post-intervention. Their definition and scales/tools of measure are described below:-

3.7.1 ART Adherence Self-Efficacy

We measured self-efficacy using a previously HIV ASES tool (Johnson et al., 2007). consisting of a 12 item scale measuring the level of patient confidence to carry out relevant ART related behaviours Responses range from 1 (cannot do it at all) to 10 (absolute can do it). An optimal HIV-ASES cut-off for this study was determined through a benchmark of other studies validating the HIV-ASES score (Johnson et al., 2007) through assessing the performance (specificity and sensitivity) of different cut-off values in comparison with high levels of adherence. (APPENDIX I)

3.7.2 Adherence

A previously validated self –report adherence tool for adolescents and paediatric living with HIV that had previously been used in Paediatric AIDS Clinical Trials Group. (Van Dyke *et al.*, 2002) was the tool used in self-report. This tool utilised the number of missed doses. An adherence level of $\geq 95\%$ is recommended to achieve optimal viral suppression(World health organisation, 2006). Adherence of more than or equal to 95% was computed as no more than one dose a month- for those on a once a daily ART

regimen and no more than three doses a month for those on twice a day regimens. For this study, we also defined a treatment break as a period of three months or more of not taking any ART. (APPENDIX II)

3.7.3 Perception of social support:

Social support was measured using one question from the previously validated shortened social provisions scale. “Is there someone with whom you can discuss important decisions or challenges you face related to your HIV status?” (Caron, 2013) .The social provisions scale measures the level, type and perceived satisfaction with social support from one’s social network. This question was selected as it assesses the integration construct, an individual’s integration of their HIV status and treatment into social support circles- which was an area of exploration in this study. (APPENDIX II)

3.7.4 Stigma

Stigma was measured using the question, “Have you experienced stigma (people treated you differently) after learning of your HIV status?”. This is a question adapted from the 40-point HIV stigma scale. This question focuses on the assessment of experienced stigma, which was explored in this study. (APPENDIX II)

3.7.5 Self-esteem

Self –esteem was measured using the validated Rosenberg 10-point scale that measures global self-worth. All items are answered using a 4-point Likert scale format ranging from strongly agree to disagree (17). A score <25 indicated low self-esteem, whereas a score >35 indicates high self-esteem. (APPENDIX III)

3.8 Data analysis

Data analysis of qualitative data

After eight FGD's and ten IDIs were conducted, the information was transcribed into transcripts. The emergent themes were identified and coded using a codebook.

The codebook was developed a priori codes generated from the FGD and IDI guides, these codes were obtained from existing literature on adolescent needs. The codes were later supplemented by codes emerging from the transcripts themselves. Once the codebook was completed, coding was carried out independently by the research assistant and the principal investigator, with discussions held with the research team regarding any differences that emerged. Using a deductive and inductive approach, the process of transcription and reading of the transcripts provided an insight into emerging themes and was an essential part of preliminary data analysis. During the data collection period, the research team held biweekly meetings during which researchers compared notes and shared their understanding of the emerging themes.

To complement the coding process, socio-demographic profiles were reviewed to elicit the context of the participant's views. Transcripts and corresponding quantitative data were uploaded into Dedoose software version 8.2.27 to enable more systematic management, coding and retrieval of data. We considered questions on reflexivity throughout the study period, identifying and reflecting on our assumptions and preconceptions regarding the anticipated post-disclosure emotions. During analysis we explored comparisons by viral load, gender and time of disclosure. The comparisons did not come out clearly except for the time of disclosure and, therefore, have not presented the findings with these comparisons.

Quantitative Data Analysis

Descriptive analysis was conducted for the socio-demographic and clinical characteristics collected in the baseline survey and in the pre, and post-intervention questionnaires were conducted by summarising categorical and continuous variables into percentages and means/ medians, respectively. Binary outcomes of self-efficacy scores were created using a computed cut-off point defining a score of >90 as high or optimal self -efficacy. Self- esteem was classified according to validated Rosenberg cut-off measures >25 for normal and high self-efficacy. Viral load levels were determined, and change in viral load as measured by individuals attaining viral suppression <1000 copies/ml. The adherence self–efficacy scores, self-esteem scores were compared between the two groups pre-intervention, immediately after the intervention and at 12 weeks’ post-intervention using the difference in difference analysis. Analysis of data was carried out by Stata Corp. 2013. (Stata Statistical Software: Release 13. College Station, TX: Stata Corp LP. Stata version 13).

3.8 Ethical Considerations

Ethical approval was obtained from the university of Nairobi-Kenyatta National hospital ethics research committee prior to any study activity. (APPENDIX VIII) Approval was also sought from the Mbagathi Hospital administration (APPENDIX IX). De-identification of patient records was carried out by assigning each participant a study number to ensure confidentiality. A link log with patients’ identities was kept under storage at all times at a secure location by the principal investigator. Only study subjects in whom full disclosure had occurred were recruited into focus group discussions. Informed consent was sought from all adolescent study participants aged 18 and above. The study ensured all adolescents aged less than 18 years of age provided assent and their caregivers provided informed consent. The informed consent process addressed the following areas:

This study focussed on the optimisation of outpatient HIV care that the adolescents already receive and therefore posed minimal risk to the adolescent study participants as they would receive additional peer meeting sessions that they otherwise receive during normal adolescent support groups. Only laboratory data on the most recent viral load measure (within the last year) was obtained retrospectively, and no human blood samples were drawn.

Privacy and confidentiality

All identifiable data was kept as a link log in a secure location locked with a safe combination known only by the principal investigator. The study used unique patient identifiers for the period of the study. The database was encrypted and required password access. Confidentiality of participants' information and informed consent were ensured throughout the study.

CHAPTER FOUR

RESULTS

4.1 Introduction

This chapter describes the results of both the qualitative and quantitative phases of the research. It includes descriptive characteristics of the population under study and results study objective.

4.2 Psychosocial needs of adolescents

4.2.1 Socio-demographic characteristics qualitative component

A total of 58 adolescents were interviewed during the qualitative component of the study, and another eighty-one adolescents during the piloting of intervention. Fifty-eight (58) adolescents participated in either the FGDs (19 females and 29 males). A further ten participated in IDIs (6 females and four males). The median age of disclosure was 14 yrs. IQR (13-16).

Qualitative data thematic analysis results

Four major themes were identified: 1) Disclosure process- (Under the theme disclosure, there were identified three sub-themes; the role of peer and family support , barriers and facilitators of coping with HIV disclosure & post-disclosure perceptions among adolescents who experienced delayed disclosure versus those with timely disclosure and barriers and facilitators of coping after disclosure of HIV status) 2) Antiretroviral adherence 3)non-disclosure related psychosocial needs for older adolescents 4) Goals and aspirations. 5) Informational needs.

4.2.2 The Disclosure process

Adolescents reported that their status had been disclosed to them between the ages of 13 and 16. They shared that disclosure was generally unplanned and often triggered by an event such as the occurrence of an opportunistic infection due to poor adherence or because caregivers suspected that the adolescent was engaging in risky behaviour.

“I got sick and was taken to the hospital. I was almost 14 yrs. I don’t know what my mum was told, but I know we had to go to that hospital regularly. I was started on drugs. I didn’t take them. I think that’s when they knew they had to tell me” (FGD 1, male, participant 03, 17 yrs.).

‘I knew about my status in form one (15 years). I fell ill and had sores on my back and all over my body... I turned out HIV positive while my sister was negative... I remember asking her what that meant, and she told me to ask the doctor’ (FGD 2, participant 05 females, 17 yrs.).

“I was 15 years. How I found out was that one day I went out and came home late and my mum told me why are you disturbing me and yet you are HIV positive? Now at the time, I didn’t take it seriously...that’s how I got to know” (FGD 3, male, participant 04, 16 yrs.).

The adolescents also described self-discovery of their HIV status, usually associated with reading HIV-related posters or medical records during clinic visits. Interestingly, self-disclosure was more common among male participants. They expressed that they did not discuss their HIV status knowledge with their caregivers, who continued to accompany them to the clinic for routine care.

“I was walking around the hospital, and I would look at the posters...That’s how I knew.

I didn't tell them, though, that I knew. I was 13 years" (IDI 1, male, participant 05, 16 yrs.).

When I was 15 years, my dad left me with my medical file to hold, and I snooped and found that I was HIV positive... I confirmed some of the terms on Google and confirmed my status. I never told him I knew my status. Sometimes when he yelled at me, I felt like telling him that I know I am HIV positive... but I keep it to myself because I didn't want to look like I am snoop, so I kept it to myself" (FGD 1, male, participant 03, 17 yrs.,).

4.2.2.1 The role of peer and family support

Where present, family or caregiver support played a significant role in facilitating the transition from the first disclosure of HIV status to developing the internal drive to stay healthy by adhering to medication. ALWHIV who had a supportive adult in their home or school environment were better equipped to cope with their HIV status. Additionally, the presence of a caregiver or sibling with a similar HIV status resulted in increased openness in sharing their challenges.

These findings are illustrated by the quotes below: -

"I don't speak to my brothers about my status, I am close with my mum, and we talk about my status since we are both HIV positive" (FGD 3, male, participant 04, 16 yrs.).

4.2.2.2 Barriers and facilitators of coping after disclosure of HIV status

Spirituality and religion facilitated the acceptance of HIV status and provided coping and resilience among some adolescents. These adolescents attributed their perinatal infection as part of the supernatural event within their destiny and accepted the hardships as a part of events in life as illustrated in the quote below:-

No, I believe that in this world, many things happen, and this was what God thought I could handle, and that was my reasoning for this” (IDI 7 female, 17 yrs.).

Friends and peer support were facilitators towards coping with the post-disclosure period. Adolescents expressed that challenges faced in ART adherence and self-stigma were addressed during peer supports which allowed them to share experiences; however, these groups were not regular. The participants trusted their peers as sources of information and were more likely to enquire on matters they considered sensitive such as relationship and information on sex.

Participants also shared that they were able to cope thanks to the support and acceptance offered by their friends and other ALWHIV within support groups. Interestingly, participants who practised or believed in spirituality also felt that that had contributed to enabling them to cope with the knowledge of their HIV status. These findings are illustrated by the quotes below: -

“I learnt from the support group that I have been attending, and I listened to the information that was shared during those sessions by youth like me, and I realised that I have nothing to worry about and I can still live a healthy life regardless of my status” (FGD 5, female, Participant 18 16 yrs.).

There was consensus by the adolescents that being the only sibling within the family living with HIV was a major deterrent towards adherence and produced feelings of loneliness and isolations. Conversely, the adolescents gravitated towards HIV positive caregivers for support. Interestingly, these feelings of isolations were present even when there was a string of family support. Having a HIV positive status innately led to self-stigma and was a barrier towards self -acceptance. Another barrier to acceptance of HIV status that was expressed was related to poor information of the parents' own acquisition of the virus and onward transmission. Adolescents expressed that they craved to know

how their parents got infected and how they themselves had coped with the stigma. The participants reflected on the poor communication that existed between them and their caregivers that led to unwillingness on their part to share about their challenges even when they were struggling emotionally. A significant barrier to coping with the knowledge of one's HIV status was a lack of candid conversations about the circumstances of the adolescents' HIV acquisition and that of their parents as illustrated in the quote below:-

“Actually, I have always wanted to ask my dad what happened and how come my mum died as a result of HIV. It makes me sad we have never talked about” (female, 17 yrs.).

Adolescents who received timely knowledge of their HIV status (between ages 7 and 12) reported having coped well immediately after disclosure. However, they described feelings of anger and hopelessness arising in later years. These adolescents said that they often faced internal struggles with self-stigma and worried about the impact of HIV on their future relationships. These findings are illustrated by the quotes below: -

“I didn't feel bad because I didn't really understand much..., but gradually, after understanding what it meant to have HIV, I felt bad... I didn't tell anyone my feelings” (IDI 09, male, 18 yrs.).

“I was young; I just listened and took my meds; now I understand this thing. I wonder how I got it - was it my dad or my mum who brought it, and how other people will see it? What if other people know that I am HIV positive? What will be their reaction? Other youths or teens who do not know about my HIV status?” (FGD 3, male, participant 03, 17 yrs.).

4.2.2.3 Post-disclosure feelings among adolescents who experienced delayed disclosure

Participants who experienced delayed disclosure (after 12 years) reported immediately

feeling anger and disappointment about their status. These strong feelings took more than a year to resolve. Among those who reported delayed disclosure (after age 12), participants agreed that the process of self-acceptance was prolonged and that their ideal time of disclosure would have been when they were younger, as they felt it would have been easier to accept. Participants also expressed that acceptance of their HIV status was a significant barrier to adherence as illustrated by the quote below: -

“I would want to be told when I was like in class 3 (9 years), because that was when I would have accepted well, then she would have taken me through a process where I would have accepted myself how I am” (FGD 2, participant 06, female, 17 yrs.).

“If they told me early on about my status, it would not have taken me that long to accept my situation. I was told when I was in class 6 (12 years), and I took up to 2 years to accept myself, and I started feeling that my mother didn’t love me because if she did, then she would have told me earlier on” (FGD 4, participant 02, male, 16 yrs.).

A majority of participants expressed initial feelings of despair and hopelessness in the immediate post-disclosure period. One female respondent said: *“Truthfully.... it was painful. It was bad!”*. However, some exceptional participants reported that they coped well and appeared to accept the information. These participants reported that they did not experience strong emotional responses after learning about their HIV status. As illustrated below: -

“I knew it in 2014 when a certain doctor here told me not to be afraid, but he didn’t tell me anything else. Then when we got in, he talked to me and then told my mom to go outside, so when he told me I was not shocked because we had been taught that HIV was not the dangerous disease. After all, cancer was worse than HIV. So I didn’t panic” (FGD 6 male, participant 04 ,17 yrs.).

Respondents who experienced delayed disclosure (above 12 years) expressed the need to have a direct approach to discussions around their HIV status. During disclosure, adolescents reported a preference in shorter uninterrupted sessions that provided concise information on the chronic nature of HIV and the need to take lifelong medication. They also felt that they should have been affirmed and educated on the relatively healthy life one could live with regards to their dreams and aspirations despite being HIV positive.

4.2.3 Facilitators and barriers of Antiretroviral adherence

There was universal agreement among participants that knowledge of one's HIV status contributed to enhanced adherence to antiretroviral therapy. The adolescents reported that learning about their HIV status empowered them to understand the consequences of not adhering to medication. They also expressed that knowledge that a parent, relative, or peer died of HIV-related complications enhanced their resolve to adhere to medication and remain free of opportunistic infections. These findings are illustrated by the quotes below :-

“I prefer knowing my status because once you know your status, you have to work towards making sure you are okay, and you are healthy and so that you can be strong to move on.” (FGD 5, female, participant 011, 18 yrs.).

“My dad told me ‘there was something I want to tell you, but don’t be so shocked,’ I asked ‘What?’ “The drugs that you take are for HIV.” I said, “Me, I have HIV, and the way I am healthy?” He told me yes. I asked him where it came from. He told me that my mom had it, and you know my mom had died. I started taking drugs, and I have never stopped” (IDI 6, male 19 yrs.).

The disclosure process was not accompanied by standardised information on the importance of ART adherence, including among older adolescents. Even among ALWHIV who learned about their HIV status at a young age, adherence was still a challenge. They were only able to fully comprehend the importance of adherence in

ensuring good health outcomes as they grew older. These findings are illustrated by the quotes below: -

“I was told that I have to adhere to my medication, and I took it seriously after seeing that guy I was talking about ...who didn’t adhere to medication, and he ended up dying. So the doctor told me that I should adhere to my drugs. I don’t want to end up like him, that really scared me, and I decided to take my medication continually.” (IDI 3, female, 16 yrs.).

I: Was you told about adherence on the day they disclosed your status to you?

R1: Yes. I remember when I was young, my mum used to remind me constantly to take them on time. Initially, I didn’t understand why, but with time I got used to it.

I: Do you think such information should have been shared with you on the same day you were told about your status?

R1: Not all. It depends on the doctors you find on duty.

I: Anyone else?

R2: I was not told the same day; I was told later on.

I: Were you told immediately?

R2: Yes, I was told everything immediately. (FGD 2, Females)

4.2.4 Non-disclosure Psychosocial support needs for older adolescents

Adolescents expressed that they faced many challenges. This study found that anticipated stigma, a prolonged period of a negative perception of self, concerns about the future and suppression of post-disclosure feelings were challenges experienced by

these older adolescents. As illustrated by this quote below: -

“After my status was disclosed to me, I wanted to lock myself in the house, I didn’t feel like coming out of the house, and at that time, there was a lot of stigma that I didn’t want to hear about and that most people did not have the information. But now I feel better, and that was due to talking to several people over time” (IDI 8, female, 16yrs).

The adolescents often felt that despite knowledge of their HIV status when they were younger- it was during their current older adolescent stage that they were able to comprehend the implications of a HIV status and articulate the intense feelings that they experience. Often these feelings were intensely painful and full of despair. They often also chose not to voice these feelings. One typical unvoiced question was the genesis of their infection.

Participants hesitated to ask out of a desire to protect their caregivers emotionally. These questions largely remained unresolved until late adolescence.

“I felt that I was in another world, so when I look at my brother, I feel like they are in another world and I am in another world. So there are two worlds” (FGD 6, Male,16yrs) yrs.).”

“I have never asked her; there are many questions that I cannot just confront her about it, I look at her, and I don’t know what to ask her. I don’t want to confront her with how I contracted this disease. What did she do or didn’t do? I don’t know. Maybe she was innocent, and it’s my dad who had it and infected her, so there are many things that I am not sure I want to confront her. So I decided to keep quiet” (FGD 3, Participant 021, male, 17 yrs.).

4.2.5 Goals and aspirations

These adolescents were excited about the promise of their future and expressed relationship and career aspirations and goals. However, they also expressed that these

were areas that were never discussed at the clinic, and this made them doubt their attainability.

M: What would you like to be when you grow up?

R: Rich and successful, nice job, nice family ...just OK

M: That's nice ...are you looking forward to that?

R: yeah...but I don't know if I will live that long ...so I just enjoy life

M: What about you?

R: I want to be a doctor, so I can help young guys like with me with HIV

(FGD 6, Males)

“My future... When you were told that you are positive, you feel as if your future was coming to an end. I wish they told me that my future was going to be bright, and I will succeed. I wish they told us more about the drug. And how long I would have to be on treatment” (IDI 10, Participant 18, female. 16 yrs.).

Participants expressed concerns about the future, in particular regarding marriage, onward transmission and acceptance from peers and in their future relationships. Almost universally, they expressed the desire to be married, to have careers and to have normal, fulfilling lives. However, they expressed that often they lacked the confidence to face their future confidence as they felt it was uncertain based on their HIV status and acceptance by potential partners.

“What if my wife were to find out that I am HIV positive?” (FGD 4, Participant 027, male, 18 yrs.).

“Before, I didn't think about it. But now, it bothers me. What if my wife-to-be

found out that I am HIV positive? ... I will tell her when the time was right, but It was a concern. It's just that one question" (IDI 6,1male, 16 yrs.).

4.3 Informational needs for incorporation in adapted life-skills curriculum

The adolescents expressed that they needed more information on how to navigate relationships. Specifically, sexual relationships and how to prevent horizontal and vertical HIV transmission was a universal concern. Additionally, they wanted to find out about how to disclose their HIV status to sexual partners and peers. Coping with stigma, information on ART and prevention medication were areas the adolescents felt should be addressed during a counselling session or support groups. (Table 4.1)

Table 4.1: Informational needs of adolescents during qualitative study component

Theme	Quote
HIV Prevention	<p>"R: I heard that it's possible to have HIV negative children even if the parents are HIV positive. M: Yes, it's true. Do you know how it can happen? R: I don't know how that works out. M: Would you like to know how that happens? R: Yes, I would really love to know." (Female, FGD)</p> <p>"If I have a boyfriend and he is negative, and I am positive. I should come so that they run tests so that we can be counselled on the things we need to be aware of as we prepare to have children. (Female, 16yrs.,)"</p>
Stigma	<p>"I would like you to talk about stigma, especially in high school because once people know that you are infected, then it will be really bad because when people see you coming, they will be like "he is coming" or something of that nature and you might tell them to stop doing that not because you have it but because you don't want them to ever behave that way towards another person" (Female 18yrs.)</p>
Antiretroviral medication and Pre& Post-Exposure prophylaxis	<p>"When you have taken drugs at 7, and you forget, or you just ignore, you take a.m. in the morning, what can happen?" (Male, 16 yrs.,)</p> <p>"R: These drugs that are new, they are called Pepes, what are they? M: Do you mean PrEP or PEP R: Both.... what's the difference?" Male FGD)</p>

Theme	Quote
Love, marriage, relationships	<p>“I would like to get information on dating an HIV negative person and not infecting them and those HIV positive mothers who give birth to children what should be done so that their children do not end up being HIV positive.”</p> <p>Res: Is it bad to have a boyfriend when you are positive?</p> <p>M: do you mean like to engage in sex?</p> <p>Res: Yes.”</p>
How to disclose?	<p>(FGD, girls)</p> <p>“If you are HIV positive and your partner is HIV negative, then how you should check your HIV status to them so that they know earlier on in your relationship and how you can help each other to avoid hatred and blaming each other in the future.”</p>

4.3.1 Adaptation of the curriculum content from study data

We adapted the Botswana Baylor’s curriculum for adolescents living with HIV that was tailored to age group (ages 10-19) to reflect the needs of the Kenyan older adolescents transitioning to adult care. Table 4.1 indicates themes that emerged and the comparisons made between the themes of the original curriculum and the needs expressed by the adolescents in the study. Differences also emerged within themes that were similar in both groups. Specifically, in the content preferred by the older Kenyan adolescents. The curriculum had 13 sessions that were designed to be offered weekly; however, the adolescents felt that due to the short duration of the holidays and the expenses of attending the clinic that the sessions should be reduced to two sessions per week for two weeks. Each session would cover two three topics. Topics such as human rights and financial literacy from the original Baylor’s curriculum were excluded. Included instead were goal setting and HIV prevention information. The latter was evident in the adolescents expressed a need for more information on those topics. There were similarities; disclosure, ART adherence and relationships were key themes expressed by

the study participants and present in the original curriculum (Table 4. 2).

Table 4.2: Adaptation of adolescent HIV Botswana Baylors’ curriculum to the Kenyan adolescent living with HIV

Baylor’s curriculum themes Botswana BIPAI	Themes from qualitative data on adherence challenges psychosocial and informational needs
<p>Love, Sex, Relationships</p> <ul style="list-style-type: none"> • Condoms (proper usage and negotiation) • Female and male condoms <ul style="list-style-type: none"> ◦ Other birth control methods ◦ Myths about sex • STI Education and prevention • Family Planning • Multiple-concurrent partnerships 	<p>Love sex and relationships (Different content under theme – requested by adolescents)</p> <ul style="list-style-type: none"> • Condom Usage and negotiation • How PrEP works and the difference from PEP • Prevention services and accessibility to avoid vertical and horizontal transmission
<p>Disclosure</p> <ul style="list-style-type: none"> • To partners, parents, friends, public (differences between these) 	<p>Disclosure (Different content under theme – requested by adolescents)</p> <ul style="list-style-type: none"> • To partners, parents, friends, public (differences between these) • How to avoid violence related to disclosure
<p>Personal Safety</p> <ul style="list-style-type: none"> • Drugs and Alcohol • Road safety • Crime • Tuberculosis (TB) and HIV 	<p>Stigma [SUBSTITUTED]</p> <ul style="list-style-type: none"> • How to cope with anticipated stigma • How to cope with self-stigma • How to deal with enacted /experienced stigma
<p>Adherence</p> <ul style="list-style-type: none"> • Biologic HIV basis • Antiretroviral medications <ul style="list-style-type: none"> ◦ Biology ◦ Different types <p>Adherence barriers & strategies</p>	<p>Adherence (Different content under theme – requested by adolescents)</p> <ul style="list-style-type: none"> • Antiretroviral medications • How ART works? What is the viral load? • Differences between the second line and first-line regimens • What is viral suppression? • Does undetectable, mean I'm negative?
Baylor’s curriculum themes (Botswana BIPAI)	Themes from qualitative data on adherence challenges psychosocial and informational needs

<p>Confidence and Leadership/TL Elections</p> <ul style="list-style-type: none"> • Public Speaking • Leadership styles • Self-esteem building • Teen Leader Elections 	<p>Aspirations and future goals [SUBSTITUTED]</p> <ul style="list-style-type: none"> • Future • Family-related goals- discordancy and PMTCT • Goal setting • Identifying and growing one's talents • choosing Careers
<p>Self-care</p> <ul style="list-style-type: none"> • Stress • What is it? • How to manage stress • Mental health 	<p>Self-Care (DIFFERENT CONTENT UNDER THEME – REQUESTED BY ADOLESCENTS)</p> <ul style="list-style-type: none"> • Stress • How to identify stress • Coping with stress • Mental health <p>How to identify mental health symptoms</p>
<p>Human Rights</p> <ul style="list-style-type: none"> • Day of the African Child • Significance of Human rights • Universal Declaration of human rights. 	<p>EXCLUDED</p>
<p>Confidence and Leadership</p> <ul style="list-style-type: none"> • Public Speaking • Leadership styles • Self-esteem building 	<p>EXCLUDED</p>
<p>Physical activity and nutrition</p> <ul style="list-style-type: none"> • Physical activity • Nutrition • Hygiene 	<p>EXCLUDED</p>
<p>THEME: Gender Gender specific body discussions Gender norms and inequality Gender-based violence Sexual Orientation</p>	<p>EXCLUDED</p>
<p>Financial Literacy</p> <ul style="list-style-type: none"> • Spending and saving • Budgeting 	<p>EXCLUDED</p>

Enrolment

Following completion of qualitative component of the study, adolescents were enrolled for the pilot phase of the adapted modified curriculum. We screened 140 HIV positive adolescents (Figure 4.1). Of those screened, 40 participants aged <18 years of age were excluded due to the unavailability of the caregivers to provide informed consent, while 18 participants were excluded due to missing information about the perinatal infection. A total of 82 HIV positive adolescents were enrolled, data on demographic, psychosocial and clinical indicators was collected.

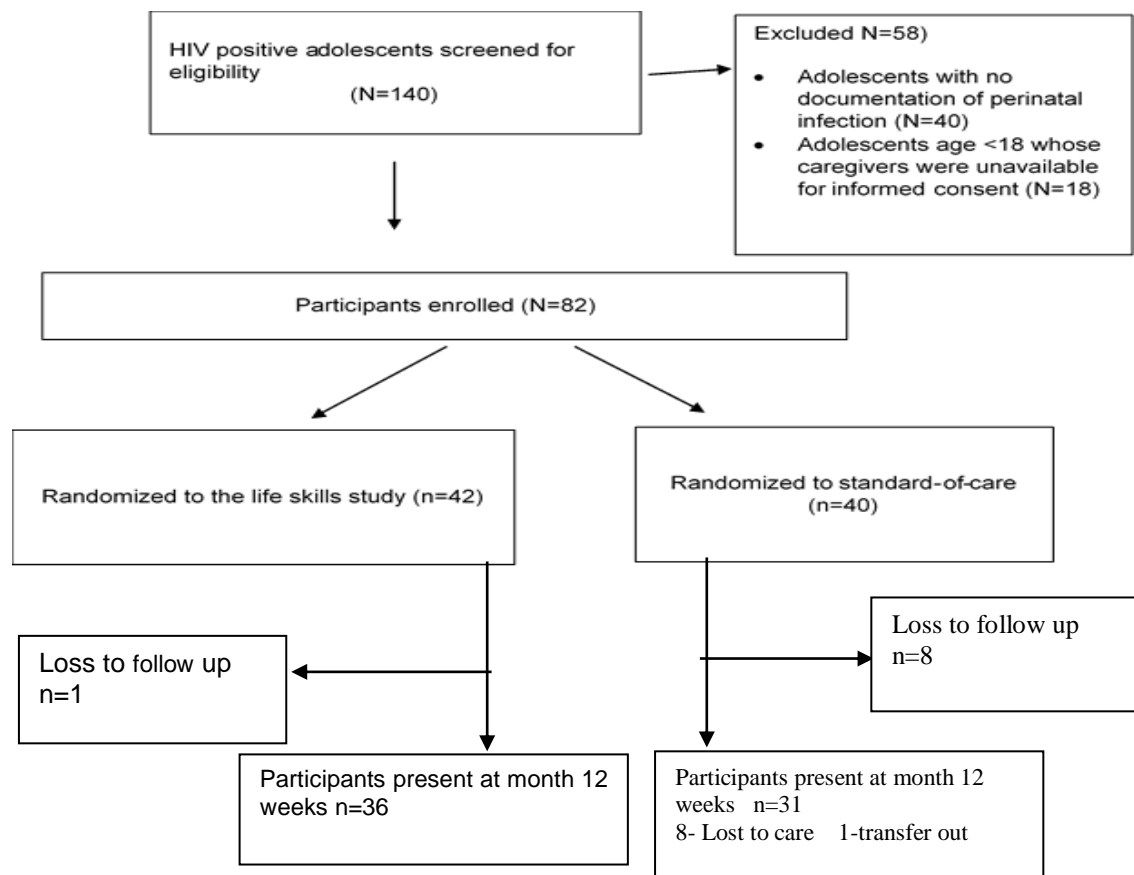


Figure 4.1: Study participant enrolment flow diagram

Socio-demographic characteristics of adolescents

The median age was 17 (IQR 11,14) and 61% of them being male. Sixty-one per cent were male. Most adolescents had been on ART for a median of 11 yrs. (IQR 7,13) while the median age at disclosure was 12yrs (IQR 11,14). Almost 65% of the adolescents had lost one or both parents or did not know their whereabouts, and 39% attended a boarding school. Using a cut off of >1000 viral copies/ml for viral suppression, 32% of the adolescents were virally suppressed and 15% reported at least one treatment break. Self-reported adherence of $\geq 95\%$ adherence was reported by 64% of the participants. Overall, 65% of the adolescents were on twice a day ART regimens compared to 34.6% (28) who were on once-a-day regimens.

Table 4.3: Demographic, clinical and psychosocial characteristics of HIV positive adolescents at enrolment

Characteristics	Total sample n=82 Frequency n (%)	Control n=40	Intervention n=42	P value
Age				
Median, IQR	17 (16,18)	17 (16,18)	17 (16,18)	0.616
Age at disclosure				
Median , IQR	12 (11,14)	12 (10,13)	12 (11,14)	0.061
Number of years on care				
Median , IQR	12 (8,13)	11 (7.5,13)	12 (8,14)	0.667
Number of years on ART				
Median , IQR	11 (7,13)	11 (6.5,13)	10.5 (7,12)	0.712
Gender				
Male	50 (61.0)	23 (57.5)	27 (64.3)	0.529
Female	32 (39.0)	17 (42.5)	15 (35.7)	
Viral load				
<1000 copies /ml	55 (67.9)	28 (71.8)	27 (64.3)	0.469
>1000 copies /ml	26 (32.1)	11 (28.2)	15 (35.7)	
Viral load group				
<400	53 (65.4)	26 (66.7)	27 (64.3)	0.427
400-1000	2 (2.5)	2 (5.1)	0 (0.00)	
1000-5000	6 (7.4)	2 (5.1)	4 (9.5)	
>5000	20 (22.12)	9 (23.1)	11 (26.2)	
Treatment break incidence				
Yes	12 (14.8)	7 (17.9)	5 (11.9)	0.444
No	69 (85.2)	32 (82.1)	37 (88.1)	
Reported ART adherence				
≥95% adherence	52 (64.2)	26 (66.7)	26 (61.9)	0.655
<95% adherence	29 (35.8)	13 (33.3)	16 (38.1)	
Self-efficacy score (mean)				
Low	97.4	102.3	92.83	0.424
High	14 (17.1)	11 (27.5)	15 (35.7)	
High	68 (82.9)	29 (72.5)	27 (64.3)	
Rosenberg Self-esteem score (mean)				
Normal	33.7	33.5	33.9	0.650
High	39 (47.6)	18 (45.0)	21 (50.0)	
High	43 (52.4)	22 (55.0)	21 (50.0)	

4.4 Factors associated with adherence

During bivariate analysis, factors significantly associated with self-reported of adherence of $\geq 95\%$ were ART self-efficacy ($p < 0.01$), self-esteem ($p = 0.04$) and attending boarding school ($p = 0.03$). There were no significant differences according to age or sex. (Table 4.4)

During analysis a high level of agreement (Kappa statistic = 0.087) between self-reported adherence and viral load (< 1000 copies/ml) was established. There was a high correlation indicated that the self-report used in this study was a reliable measure of adherence.

Table 4.4: Factors associated with adherence during bivariate analysis

	ART adherence <95% (n=29)	ART adherence $\geq 95\%$ (n=52)	95% CI	P value
SOCIO DEMOGRAPHIC FACTORS				
Age, years. (median(IQR))	17 (16-18)	17 (16-18)	1.24 (0.85-1.79)	0.25
Sex (n %)				
Male	19 (65.5)	30 (57.7)	Ref	
Female	10 (34.5)	22 (42.3)	1.39 (0.54-3.57)	0.49
Parental status (n,%)				
Both parents alive	11 (37.9)	17 (32.7)	Ref	
Only father alive	8 (27.6)	8 (15.4)	0.64 (0.18-2.23)	0.49
Only mother alive	5 (17.2)	16 (30.8)	2.07 (0.58-7.28)	0.25
Both parents not alive	4 (13.8)	9 (17.3)	1.45 (0.36-5.90)	0.59
At least one caregiver HIV positive	24 (82.7)	40 (76.9)	0.69 (0.22-2.21)	0.53
Schooling (n,%)				
Boarding	15 (53.6)	16 (32.7)	Ref	
College/university	3 (10.7)	3 (6.1)	0.93 (0.16-5.38)	0.94
Day school	8 (28.6)	27 (55.1)	3.16 (1.09-9.11)	0.03
Not in school	2 (7.1)	3 (6.1)	1.40 (0.20-9.61)	0.72

	ART adherence <95% (n=29)	ART adherence ≥95% (n=52)	95% CI	P value
CLINICAL FACTORS				
Age at disclosure of HIV status (median, IQR)	12 (12-14)	12 (13-13.5)	0.92 (0.76-1.09)	0.35
Duration on ART	10 (7-13)	11 (6.5-13)	1.02 (0.91-1.14)	0.74
Frequency of Treatment regimens (n,%)				
Once a day	12 (41.4)	16 (30.8)	1.24 (0.85-1.79)	0.33
Twice a day	17 (58.6)	36 (69.2)	Ref	
Disclosed to individual (n,%)				
Self	3 (10.3)	3 (5.8)	0.5 (0.03- 8.95)	0.63
Caregiver	11 (37.9)	29 (55.8)	1.31 (0.11-16.03)	0.82
Health worker	14 (48.3)	18 (34.6)	0.64 (0.05-7.83)	0.72
Other	1 (3.5)	2 (3.8)	Ref	
PSYCHOSOCIAL FACTORS				
Self-esteem score (median(IQR)	34 (30-37)	35 (33.5-37)	1.12 (1.00-1.26)	0.04
Self-efficacy score(median(IQR)	85 (70-105)	110 (100-115)	1.04 (1.01-1.06)	0.003
Reported experienced stigma (n,%)				
No	25 (86.2)	50 (96.2)	4(0.68-23.3)	0.12
Yes	4 (13.8)	2 (3.8)	Ref	
Perceived social support (n,%)				
No	9 (31.0)	16 (30.8)	Ref	
Yes	20 (69.0)	36 (69.2)	1.02 (0.38-2.70)	0.98
Support individual (n,%)				
Caregiver	13 (65.0)	24 (66.7)	0.37 (0.04-3.50)	0.38
Clinic counsellor	1 (5.0)	2 (5.5)	0.4 (0.02-10.01)	0.57
Sibling	5 (25.0)	5 (13.9)	0.2 (0.01-2.38)	0.20
Other relatives	1 (5.0)	5 (13.9)	Ref	

The multivariate model predicting self-reported adherence ≥95%

Factors with a reported p value ≤ 0.03 from the bivariate analysis were included in the multivariate model which indicated that ALWHIV with high ART adherence self-efficacy were eight times more likely to report high adherence [OR 7.9, 95% CI (2.23-28.08)], and those on a twice a day ART regimen were almost four times more likely to

report adherence [OR 3.8, 95% CI (1.11-12.72)]. Self-esteem, age, sex, schooling, perceived social support and experienced stigma were not found to be associated with adherence. (Table 4.5)

Table 4.5: Multiple regression model of factors associated with self-reported adherence

Multiple regression model of factors associated with Self-reported <95% adherence					
Variables	Unadjusted ORs (95%CI)	p-value	Adjusted (95%CI)	ORs	p-value
Age, years. median(IQR)	1.24 (0.85-1.79)	0.25	1.41 (0.88-2.26)		0.15
Sex					
Male	Ref		Ref		
Female	1.39 (0.54-3.57)		1.10 (0.36-3.39)		0.85
Schooling (n,%)					
Boarding	Ref		-		-
College/university	0.93 (0.16-5.38)	0.94	-		-
Day school	3.16 (1.09-9.11)	0.03	-		-
Not in school	1.40 (0.20-9.61)	0.72	-		-
Age at disclosure of HIV status (median, IQR)	0.92 (0.76-1.09)	0.35	0.94 (0.76-1.16)		0.56
Frequency of Treatment regimens (n,%)					
Once a day	Ref		Ref		
Twice a day	1.58 (0.62-4.08)	0.33	3.8 (1.11-12.72)		0.03
Self-esteem score					
Normal	Ref		Ref		
High	1.7 (0.67-4.19)	0.26	0.95 (0.29- 3.09)		0.93
Self-efficacy score					
Low	Ref		Ref		
High	6.8 (2.41-18.97)	<0.001	7.9 (2.23- 28.08)		0.001
Reported experienced stigma (n,%)					
No	4(0.68-23.3)	0.12	7.1 (0.59- 83.32)		0.12
Yes	Ref		Ref		
Perceived social support (n,%)					
No	Ref		Ref		
Yes	1.02 (0.38-2.70)	0.98	0.54 (0.15-1.92)		0.35

*Not all the proportion was based on the entire sample due to missing data for some variables.

From Factors with p-value ≤0.03 Three were selected for multivariate analysis

4.4.1 HIV treatment adherence self-efficacy Score

Overall, the study participants demonstrated high confidence in most of the areas related to the integration of treatment into their daily life, particularly on sticking to treatment even they were not feeling well or when the viral load increased. (APPENDIX I). The lowest score for self-reported efficacy on the use of medications in the presence of people unaware of their HIV status. Adolescents also scored low on ART adherence self-efficacy when their daily routine was disrupted. The composite score mean (SD) was 8.1 (1.8). Using computed ROC cut off (≥ 90), 68% of participants scored a high self-efficacy (Table 2). Cronbach's alpha was 0.832, which indicates a high level of internal consistency (reliability) for the self-efficacy scale.

4.5 Effect of life skills on viral load, adherence self-efficacy and self-esteem

4.5.1 Enrolment of ALWHIV

From the screened 140 HIV positive adolescents (Figure 1) and enrolment of 82 HIV positive adolescents' data on demographic, psychosocial and clinical indicators were collected. Further randomization was conducted to two arms (Control arm; standard of care; n=40) and intervention arm (n=42). Data were analysed after 12 weeks for the intervention (n=40 intervention group and n=37 control group). After randomization, as expected, the participants' characteristics were distributed evenly and did not have significant differences. (Table 8).

Following the life-skills intervention, ART adherence self-efficacy was significantly higher among the adolescents in the intervention group ($p=0.012$). Viral suppression was also significantly higher than the intervention group ($p=0.003$). There was no significant difference in self-esteem between the two arms ($p=0.593$).

Table 4.6: Effect of life skills intervention on psychosocial and clinical variables

Variables	Baseline (n=42) n%	End line (n=36) n%	Baseline (n=40) n%	End line (n=31) n%	OR (95%CI)	P- value
Self-esteem score²						
>35 high self-esteem	33 (79.07)	28(77.78)	21(67.74)	20(67.74)	6.75(1.05-43.2)	0.041
≤35 normal and low	9(20.93)	9(22.22)	9(32.26)	10(32.26)		
Adherence Self-efficacy score¹						
>60	37(88.37)	35(97.44)	38(97.44)	27(87.1)		
≤ 60	5 (11.63)	2(2.78)	2(2.56)	3(12.9)	66(19-2264)	0.010
Viral load ³						
Copies/ml						
<1000	26(62.7)	33(91.67)	28(71.8)	24(74.42)	9.3(12-24.70)	0.031
≥1000	16(37.2)	4(8.33)	12(28.2)	6(22.58)		

1 Controlled for adherence, disclosure age, regimen, social support, self-esteem,

2 Controlled for schooling, gender, stigma, regimen, social support, self-efficacy

3 Controlled for schooling, gender, stigma, regimen

The null hypotheses were therefore rejected: Adherence self–efficacy, self-esteem and viral suppression adherence changed after the provision of modified Baylor’s curriculum.

CHAPTER FIVE

DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 Discussion

The age of the adolescents living with HIV in this study population was different from studies that have explored psychosocial interventions. Most studies on ALWHIV have included adolescents with adults or focused on younger adolescents and children (Kidia *et al.*, 2014), (Woollett, 2016) (Dam lira *et al.*, 2019) . The median age of disclosure reported as 12yrs was relatively similar to that of other adolescent cohorts in sub-Saharan Africa but much higher than the recommendation by the WHO disclosure guidelines which was 7yrs.

5.1.1 Psychosocial needs of older adolescents

This study found that older adolescents possess unique unmet psychosocial needs, that the adopted curriculum is feasible to implement and incorporates additional informational and holistic areas as recommended by the adolescents.

5.1.1.1 Late disclosure as major area of psychological stress among older adolescents

This study presents new findings regarding the disclosure experiences, perceptions of the disclosure process, and post-disclosure psychosocial needs among perinatally HIV-infected adolescents. To the best of our knowledge, this is the first study that has attempted to document the views of older adolescents transitioning to adulthood. Additionally, this study brings new perspectives on the disclosure process by comparing the opinions of adolescents who had optimally timed disclosure versus those with delayed disclosure. The context of the study provides a unique opportunity to document arising issues when the delay in HIV disclosure occurs, as was often the case in sub-

Saharan Africa, as well as recommendations towards improvements in the post-disclosure psychosocial care package for during the transition of adolescents to adult care.

Overall, this study found that most participating adolescents had received disclosure between the ages of 13 and 16 years. Similar to the sentiments expressed by other adolescents in other African countries, including South Africa, Zambia and Zimbabwe, Kenyan adolescents described initial distress, then shock after disclosure. Similarly, they also desired accurate information about their illness (Woollett, 2016) (Kidia *et al.*, 2014) , (Hodgson *et al.*, 2012). In these studies, adolescents described having ‘coped’ with the knowledge of their status and having adjusted well clinically and emotionally.

A new finding from our research was that even in cases when disclosure was timely, adolescents had an initial apparent positive coping response, followed by a re-emergence of negative post-disclosure reactions during late adolescence. In contrast, studies among adolescents in sub-Saharan Africa (Anitha Menon, Glazebrook, Campain, & Ngoma, 2007) , (Woollett, 2016) reported post-disclosure initial distress followed positive coping in the immediate post-disclosure period among younger adolescents ages (11-13). These studies primarily focussed on younger adolescents (ages 10-14), in this study; as the adolescents grew older, they experienced a re-emergence of negative emotions and grave concerns about the impact of their HIV positive status on relationships with sexual partners and peers (Kidia *et al.*, 2014), (Woollett, 2016). The findings of our study are further supported by studies reporting the mental health and psychosocial issues experienced by Adolescents living with HIV who are aware of their status, which may include (Woollett, 2016) post-traumatic stress disorder, depression, and severe anxiety (Hawkins *et al.*, 2016), (Lowenthal *et al.*, 2014). While the psychosocial issues related to delayed disclosure are an expected finding, the re-emergence of post-disclosure negative emotions among those whose disclosure timing was optimal (before age 12), as recommended by current guidelines, was unexpected. A probable explanation for this was that most studies have focused on populations that had larger

numbers of their study participants in the early adolescence (10 to 14 years of age). Available literature indicates this difference in age may explain the findings of a re-emergence of post-disclosure feelings in this study, for developmental reasons. Often, there was also a higher level of self-awareness, coupled with the need to be accepted by peers in late adolescence (Anitha Menon, Glazebrook, Campain, & Ngoma, 2007), (Louthrenoo, 2018; Sharma & Agarwala, 2015). In our study, this finding was corroborated by the requests of older adolescents in the clinical setting for additional psychosocial support as they began to fully comprehend the implications of their HIV status, particularly with regard to their sexuality and relationships with peers and sexual partners (Okawa *et al.*, 2017). Another possible contributing reason for this phenomenon may be the lack of clear stepwise guidance for the provision of long-term post-disclosure support and the lack of knowledge regarding how to modify existing guidance to address the specific needs of adolescents who receive disclosure during mid- or late adolescence. In this study, adolescents described experiencing re-emergent negative post-disclosure feelings during late adolescence that interfered with their adherence. The occurrence seemed to dilute the expected effect of disclosure on adherence and positive living. This finding was consistent with the literature and indicates psychosocial stressors contribute to poor adherence in older adolescents. If not addressed, these psychosocial stressors result in poor outcomes after the transition to adult care despite the disclosure of HIV status (Britto *et al.*, 2016).

5.1.1.2 Role of peer support in psychological coping among older adolescents'

Peer support was identified as key in the acceptance of adolescents' HIV status. Existing literature indicates that strong social support was a facilitator of coping in the period after disclosure of HIV status to adolescents (WHO, 2011). Our findings indicate that peer influence in late adolescence was a strong facilitator in positive coping with the knowledge of one's HIV status. Available evidence describes the crucial importance of peer influence in this period as the drive for self-autonomy and independence emerges and the decisive role by peer-led interventions in providing adolescent responsive

psychosocial support (Brown, B. Bradford Bakken, Jeremy P. Ameringer, Suzanne W. Mahon, et al.).

These findings present a strong argument for the need to strengthen the current WHO disclosure guidelines with clear, concise guidance to health workers on the content of continuous post-disclosure psychosocial care. There was also a need to address specific psychosocial care content for adolescents who experience delayed disclosure by providing comprehensive information on HIV prevention, sexual reproductive health and life skills on coping with the HIV status. This finding was in keeping with the current guidelines, which recognise that disclosure was not a one-time event (WHO, 2011)..

5.1.2 Informational needs to be addressed in adaptation life skills curriculum

Adolescents in this study struggled with post-disclosure support and re-emergent negative emotions despite the timing of disclosure. They expressed the desire to acquire coping tools and skills in disclosure to others and dealing with self-stigma. This finding is consistent with the literature and indicates that these psychosocial stressors contribute to poor adherence in older adolescents (Okawa *et al.*, 2017; Ngeno *et al.*, 2019) and results in the observed poor outcomes after the transition to adult care despite the disclosure of HIV status (Britto *et al.*, 2016). Additionally, adolescents requested information on HIV prevention, ART literacy, adherence and sexual and reproductive health. They expressed that their preferred source of information were health workers. These have been documented in studies among older adolescents (Buseh, Glass, McElmurry, Mkhabela, & Sukati, 2002). The topics requested also aligned with other studies that carried out formative studies before curriculum development (Bhana *et al.*, 2014; Winskell, Miller, Allen, & Obong'o, 2016). However, in this study, a surprising finding was the need to discuss goals and aspirations as well goal setting. This points to the gap in holistic support of these adolescents, with the focus primarily remaining on the HIV status.

5.1.3 Factors associated with adherence

Social support and particularly caregiver relationships have been found to be a major contributor and influencer of health behaviours such as drug adherence (Damulira *et al.*, 2019). However, in our study, caregiver support was not significantly associated with better adherence. This was an interesting finding as the expected effect based on the SCT and literature would otherwise indicate an expected strong association. The study criteria of older adolescents in this study (16-19 yrs.), compared to the broader age range in other studies (10-19 yrs.), may have contributed to this difference as older adolescents often display a greater desire for autonomy and detachment from caregivers compared to younger adolescents (Daddis, 2006.). In this study, a single daily dose ART regimen was significantly associated with adherence. This was a finding supported by a previous study (Salou *et al.*, 2016). Guidelines for transitioning adolescents include switching to once a day regimens where possible. In this study, adolescents had been on ART for almost a decade, and factors such as adverse effects and ART resistance-associated treatment failure may have resulted in the reported twice a day dosing regimens (Salou *et al.*, 2016). Additionally, this study was conducted before the introduction of once a day dosing regimens that incorporate newer integrase inhibitors such as Dolutegravir to the Kenyan national guideline for use in transitioning ALWHIV.

Our findings indicate that reported adherence among older adolescents transitioning to adulthood was still suboptimal. In this study, high ART adherence self-efficacy and use of twice a day regimens were independently associated with high adherence. This was the first study to our knowledge that has explored modifiable psychosocial factors such as self-efficacy and self-esteem and their association to adherence among adolescents to sub-Saharan Africa. Only a little over two-thirds of the adolescents reported adherence $\geq 95\%$. We postulate that lack of privacy may have contributed to this finding and in particular, institutionalization such as living in boarding schools. Lack of privacy was a strong determinant of non-adherence in other studies in this region (Mutwa *et al.*, 2013), (Inzaule, Hamers, Kityo, Rinke De Wit, & Roura, 2016), (Lodico *et al.*, 2012),

(MacCarthy *et al.*, 2018). The data from the assessment of ART self –efficacy in our study supports this argument. Adolescents scored lowest during the assessment of their ability to adhere to ART in the presence of individuals who did not know their status.

Our findings that self-esteem was not associated with adherence were an interesting finding since in the adolescence developmental stage, self-esteem was an important component in decision making and behavioural outcomes (Mutwa *et al.*, 2013), (World health organization, 2006). There are scarce data on self-esteem in HIV positive adolescents in sub-Saharan Africa. However, (Educación, Falanga, Elvira De Caroli, & Sagone, 2012) studies in Indonesia (Purwaningsih, Asmoro, & Prastiwi, 2019), North America (Tyer-Viola *et al.*, 2014) and Pakistan (Kurniawan & fitrio deviantony2, 2019) among adults have found associations. There was data indicating that self –esteem may be a mediator of non-health self –efficacy (Nader Hajloo, 2014) and that both are components of self-concept; this interplay may have led to this variable being knocked out in the multiple regression model.

To the best of our knowledge, this is the first paper that describes the relationship between adherence ART self- efficacy and other psychosocial elements and particularly the effect of these factors in affecting adherence among older ALWHIV in sub-Saharan Africa. This study found that ART self -efficacy was strongly associated with self-esteem and that self-esteem mediated the expected effect of ART self-efficacy in optimal adherence positively. The findings of this study are important in providing insights into the development and implementation of psychosocial interventions.

Our study found that self-esteem was strongly associated with having social support. This finding is supported by other studies (Ebru Ikiz, Savi Cakar, & Prof, 2010) that describe a strong relationship between self-esteem during adolescence and perceived social support. We also found a strong association between ART self-efficacy and both adherence and viral load. While this is finding agrees with studies among adult populations (Johnson *et al.*, 2007), it was interesting to see the same among adolescents

transitioning to adult care. This finding indicates that ART self-efficacy could potentially act as a predictive tool during the adolescent transition to adult HIV care. Interestingly ART self-efficacy was not associated with stigma as has been reported in other studies (Katz *et al.*, 2013; X. Li *et al.*, 2011). We postulate that this difference may be due to the fact that these studies primarily looked at adult populations and seemed to focus on enacted stigma while our study focused on perceived stigma.

One study reports no association with self-efficacy (Education, 2016), while another found an association between self-esteem and better adherence (Chen *et al.*, 2013) among ALHIV. We argue that both of these studies did not primarily focus on adolescents, although one included adolescents in its sample size.

5.1.4 Effect of Life skills on Clinical and psychosocial factors

The finding in this study that a life-skills based intervention reduced viral load was an important finding due to the few studies available of interventions among older adolescents. To the best of our knowledge, this the first study in sub-Saharan Africa that has focussed on adherence self-efficacy in this population. Studies in resource-rich settings using a similar behavioural change approach with a focus on increasing self-efficacy have reported similar effectiveness (Whiteley, Brown, Mena, Craker, & Arnold, 2018; Naar-King *et al.*, 2013; L. Li *et al.*, 2017). Studies in resource-rich settings using similar behavioural change approach for improved adherence among adults living with HIV with a focus on increasing self-efficacy have reported similar effectiveness (Adefolalu *et al.*, 2014; Kim *et al.*, 2017; Ammassari *et al.*, 2002; Johnson *et al.*, 2007; Whiteley *et al.*, 2018; L. Li *et al.*, 2017) among adults. However, previous literature has been inconclusive on the effect on self-esteem (Mueller *et al.*, 2011; Purwaningsih *et al.*, 2019; Chen *et al.*, 2013). However, there is consensus that self-esteem is critical in this stage of life worth acceptance by peers (Louthrenoo, 2018; Sharma & Agarwala, 2015) described as a key component guiding behaviour among adolescents. This life skills intervention hypothesized that self-efficacy improvement would occur through the

intentional inclusion of the theoretical sources of self-efficacy such as verbal persuasion and vicarious learning (A. Bandura, 1977). Through peer involvement by well-adjusted young adults who had transitioned to adulthood, implementation utilized roleplaying and self-evaluation of past successes.

However, the improvement in viral suppression within 12 weeks is a landmark finding that motivates the intervention's scale-up in a larger sample size. We attribute this success largely to the human-centred design approach of modifying Baylor's curriculum (appendix 1) that incorporated contextualized psychosocial and informational needs as reported by adolescents during a formative study (Gitahi *et al.*, 2020). This further underscores the need for a participatory research approach during the development of interventions targeting adolescents. The development of the adapted life skills incorporated input from adolescents on their psychosocial and information needs (Gitahi *et al.*, 2020) Adolescents, as highlighted in numerous recommendations and studies. For example, the older adolescents in Kenya reported a need for information on HIV prevention, goal setting and career planning that were not included in the Baylor teen club curriculum. HIV prevention guidelines in Kenya are progressive, and at the time of the Baylor curriculums in other countries, there was little data and drive for adolescent PrEP access. The current W.H.O guidance incorporates most of the adolescent topics covered in this intervention (Appendix 11). Studies in resource-rich settings using similar behavioural change approach for improved adherence among adults living with HIV with a focus on increasing self-efficacy have reported similar effectiveness (Adefolalu *et al.*, 2014, Kim *et al.*, 2017, Ammassari *et al.*, 2002, Johnson *et al.*, 2007, Whiteley *et al.*, 2018) among adults. However, previous literature has been inconclusive on the effect on self-esteem (Mueller *al.*, 2011; Purwaningsih *et al.*, 2019; Chen *et al.*, 2013). However, there is consensus that self-esteem is critical in this stage of life worth acceptance by peers (Louthrenoo, 2018; Sharma & Agarwala, 2015), described as a key component guiding behaviour among adolescents. This life skills intervention hypothesized that self-efficacy improvement would occur through the intentional inclusion of the theoretical sources of self-efficacy such as verbal persuasion and

vicarious learning (A Bandura, 1977). Through peer involvement by well-adjusted young adults who had transitioned to adulthood, implementation utilized roleplaying and self-evaluation of past successes. However, it does not give guidance to health workers on how to engage adolescents on contextualize the defined topics to be addressed at transition. The public health impact of this study addresses older adolescents with perinatal infection. This population often have already experienced stressful psychosocial life events as children who would benefit the most from a robust psychosocial support system during the transition to adult care.

5.1.5 Study strengths and limitations

A strength of this study was that it did not restrict itself to adolescents who had either poor or optimal clinical outcomes as described by their viral load status. This inclusion was important, as self-management with adherence to ART was a key goal of adolescent transition to adult care. A limitation of this study was that our sample only selected adolescents with perinatal infection who would benefit the most from a robust psychosocial support system during the transition to adult care due to the often long duration of ART they have already experienced as children. The experiences of perinatally infected adolescents are distinct from those youths who acquired HIV from sexual transmission. However, with a majority of the HIV infections occurring among adolescents and young people, the experiences of those with the sexual acquisition of HIV would be useful and should comprise an important research question in future. A major limitation of this study was the possible risk of contamination. We attempted to mitigate this risk by ensuring that all scheduled visits post enrolment was made on separate adolescent days for those in the intervention group and control groups, therefore, minimizing their interaction. The implementers of the intervention were peer mentors and facilitators who were not known to the participants receiving HIV care in this facility. Additionally, health care workers were blinded to who was in the intervention.

5.2 Conclusions

In this study, we found that adolescents had many unmet psychosocial needs. These included suboptimal post-disclosure support. The emergence of psychological distress in older adolescence long after disclosure has been conducted is a pointer of the need to revisit this event and provide psychological support especially during transition to adult care. The study also points to a critical gap among current older adolescents who did not receive structured disclosure as recommended in the guidelines as part of the current guidelines. Transition to adulthood for this group must therefore have psychosocial support to cope with any traumatic life-event around initial disclosure.

Adolescents had many informational and psychosocial needs that they prefer addressed by health workers with a strong peer-support component. These informational needs should not be limited to ART-HIV related context but also holistic to extend to providing guidance on their goals and aspirations.

This study found that ART adherence self-efficacy and frequency of dosing were independent factors associated with adherence.

Lastly, life-skills building that focuses on increasing self-efficacy is effective in improving adherence and thereby reducing viral load.

The public health implications of this study are that it adds to the growing body of evidence that may influence the revision of the WHO HIV disclosure guidelines to include psychosocial support guidance for older adolescents. Additionally, adherence self-efficacy may have the potential to be a predictor or measure of optimal outcomes for adolescents after their transition to adult care.

5.3 Recommendations

From the findings of this study, we recommend that post-disclosure support should be included as part of psychosocial care offered to adolescents as a continuous process and therefore strengthening the current implementation of the World Health policy within HIV care facilities providing care for adolescents to ensure interventions among older adolescents transitioning to adult care include psychosocial care. The study recommends identifying older adolescents who did not have structured disclosure who may suffer from psychosocial trauma that may have occurred as a result of self-disclosure, accidental disclosure or circumstantial disclosure. The identification of these adolescents is critical to providing focussed post-disclosure support prior to transition to adult care.

The study recommends provision of an adolescent friendly HIV clinic environment that encourages adolescents to inquire for the information and services they require. Often, this may require addressing other area of the adolescents lives such as challenges at school and with relationship which are outside the realm of health but remain interconnected to their ability to adhere to ART and have psychological wellness.

This study recommends that as far as is possible single dose regimens are utilized as part of adolescents' treatment and that adherence and day to day management include aspects that increase adherence self-efficacy such as peer support and the opportunity to identify good clinical outcomes as a result of adherence

We recommend adoption of the use of this adopted Baylor's life-skills curriculum within routine clinical care and its incorporation into the guidelines as one among the potential curriculums for use in transition older adolescents to adult care. Peer facilitators should be used in engaging these adolescents. This could potentially provide much needed psychosocial impetus and increased ART adherence self-efficacy required at an individual –level to sustain ART adherence into adulthood.

This study recommends the consideration of routine use of ART adherence self-efficacy among adolescents as an indicator for predicting and monitoring successful transition to adulthood. This indicator has the potential to not only measure potential ability to continue ART adherence but also the likelihood of adherence during many challenging situations as the older adolescents often encounter as they transition to adulthood. It provides an opportunity for self-evaluation and an opportunity for empowerment before sub-optimal adherence occurs.

Additional research should be carried out in exploring the psychosocial and informational needs of older adolescents in rural settings as part of further contextualization and adaptation of the Baylor's curriculum to the Kenyan adolescent context; since this study was primarily carried out in an urban setting.

REFERENCES

- Adefolalu, A., Nkosi, Z., Olorunju, S., & Masemola, P. (2014). Self-efficacy, medication beliefs and adherence to antiretroviral therapy by patients attending a health facility in Pretoria. *South African Family Practice*, *56*(5), 281–285.
- Agwu, A. L., & Fairlie, L. (2013, June 18). Antiretroviral treatment, management challenges and outcomes in perinatally HIV-infected adolescents. *Journal of the International AIDS Society*, *16*.
- Amico, K. R., Harman, J. J., & Johnson, B. T. (2006). Efficacy of antiretroviral therapy adherence interventions: a research synthesis of trials, 1996 to 2004. *Journal of Acquired Immune Deficiency Syndromes (1999)*, *41*(3), 285–297.
- Ammassari, A., Trotta, M. P., Murri, R., Castelli, F., Narciso, P., Noto, P., ... Antinori, A. (2002). Correlates and predictors of adherence to highly active antiretroviral therapy: Overview of published literature. *Journal of Acquired Immune Deficiency Syndromes*, *31*(SUPPL. 3).
- Andrews, G., Skinner, D., & Zuma, K. (2006). Epidemiology of health and vulnerability among children orphaned and made vulnerable by HIV/AIDS in sub-Saharan Africa. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, *18*(3), 269–276.
- Apondi, E., Humphrey, J. M., Sang, E., Mwangi, A., Keter, A., Musick, B. S., ... Ayaya, S. (2018). Trends Over Time for Adolescents Enrolling in HIV Care in Kenya, Tanzania, and Uganda From 2001–2014. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, *79*(2), 164–172.
- Aregbesola, O. H., & Adeoye, I. A. (2018). Self-efficacy and antiretroviral therapy adherence among HIV positive pregnant women in South-West Nigeria: a mixed

- methods study. *Tanzania Journal of Health Research*, 20(4).
- Arifin, W. N. (2012). Random sampling and allocation using SPSS. *Education in Medicine Journal*, 4(1).
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84(2), 191–215.
- Beima-Sofie, K. M., Brandt, L., Hamunime, N., Shepard, M., Uusiku, J., John-Stewart, G. C., & O'Malley, G. (2017). Pediatric HIV disclosure intervention improves knowledge and clinical outcomes in HIV-infected children in Namibia. *Journal of Acquired Immune Deficiency Syndromes*, 75(1), 18–26.
- Bhana, A., Mellins, C. A., Petersen, I., Alicea, S., Myeza, N., Holst, H., ... McKay, M. (2014). The VUKA family program: piloting a family-based psychosocial intervention to promote health and mental health among HIV infected early adolescents in South Africa. *AIDS Care*, 26(1), 1–11.
- Britto, C., Mehta, K., Thomas, R., & Shet, A. (2016). Prevalence and Correlates of HIV Disclosure among Children and Adolescents in Low- and Middle-Income Countries: A Systematic Review. *Journal of Developmental and Behavioral Pediatrics*, 37(6), 496–505.
- Britto, C., Mehta, K., Thomas, R., & Shet, A. (2018). *Europe PMC Funders Group Prevalence and Correlates of HIV Disclosure Among Children and Adolescents in Low- and Middle-Income Countries : A Systematic Review*. 37(6), 496–505.
- Brown, B. B., Bakken, J. P., Ameringer, S. W., & Mahon, S. D. (2008). A comprehensive conceptualization of the peer influence process in adolescence. In M. J. Prinstein & K. A. Dodge (Eds.), *Understanding peer influence in children and adolescents*, (pp. 17–44). The Guilford Press.

- Brown, B. B., & Larson, J. (2009). Peer Relationships in Adolescence. In *Handbook of Adolescent Psychology*.
- Buseh, A. G., Glass, L. K., McElmurry, B. J., Mkhabela, M., & Sukati, N. A. (2002). Primary and preferred sources for HIV/AIDS and sexual risk behavior information among adolescents in Swaziland, Southern Africa. *International Journal of Nursing Studies*, 39(5), 525–538.
- Bygrave, H., Mtangirwa, J., Ncube, K., Ford, N., Kranzer, K., & Munyaradzi, D. (2012). Antiretroviral Therapy Outcomes among Adolescents and Youth in Rural Zimbabwe. *PLoS ONE*, 7(12).
- Caron, J. (2013). [A validation of the Social Provisions Scale: the SPS-10 items]. *Sante Mentale Au Quebec*, 38(1), 297–318. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/24337002>
- Cervia, J. S. (2013). Easing the transition of HIV-infected adolescents to adult care. *AIDS Patient Care and STDs*, 27(12), 692–696.
- Chen, W.-T., Wantland, D., Reid, P., Corless, I. B., Eller, L. S., Iiping, S., ... Webel, A. R. (2013). Engagement with Health Care Providers Affects Self-Efficacy, Self-Esteem, Medication Adherence and Quality of Life in People Living with HIV. *Journal of AIDS & Clinical Research*, 4(11), 256.
- Ebru Ikiz, F., Savi Cakar, F., & Prof, A. (2010). Perceived social support and self-esteem in adolescence. *Procedia Social and Behavioral Sciences*, 5, 2338–2342.
- Educación, F. Y., Falanga, R., Elvira De Caroli, M., & Sagone, E. (2012). Relationship between Self-Efficacy and Self-Concepts in University Students. *International Journal of Developmental and Educational Psychology INFAD Revista de Psicología*, N°1, 2.

- Education, J. P. (2016). *Implications of self-esteem in. XIV*(1), 90–99.
- Firdu, N., Enquselassie, F., & Jerene, D. (2017). HIV-infected adolescents have low adherence to antiretroviral therapy: A cross-sectional study in Addis Ababa, Ethiopia. *Pan African Medical Journal*, 27.
- Gitahi, N., Camlin, C., Mwanja, V., Ngure, K., Auerswald, C., & Bukusi, E. (2020). Psychosocial needs among older perinatally infected adolescents living with HIV and transitioning to adult care in Kenya. *PLOS ONE*, 15(7), e0233451.
- Haberer, J. E., Cook, A., Walker, A. S., Ngambi, M., Ferrier, A., Mulenga, V., ... Bangsberg, D. R. (2011). Excellent adherence to antiretrovirals in HIV+ Zambian children is compromised by disrupted routine, HIV Nondisclosure, and Paradoxical Income Effects. *PLoS ONE*, 6(4).
- Hawkins, A., Evangelini, M., Sturgeon, K., Le Prevost, M., & Judd, A. (2016). Episodic medication adherence in adolescents and young adults with perinatally acquired HIV: A within-participants approach. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, 28, 68–75.
- Hodgson, I., Ross, J., Haamujompa, C., & Gitau-Mburu, D. (2012). Living as an adolescent with HIV in Zambia-lived experiences, sexual health and reproductive needs. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, 24(10), 1204–1210.
- Inzaule, S. C., Hamers, R. L., Kityo, C., Rinke De Wit, T. F., & Roura, M. (2016). Long-term antiretroviral treatment adherence in HIV-infected adolescents and adults in Uganda: A qualitative study. *PLoS ONE*, 11(11).
- Johnson, M. O., Neilands, T. B., Dilworth, S. E., Morin, S. F., Remien, R. H., & Chesney, M. A. (2007). The role of self-efficacy in HIV treatment adherence:

- validation of the HIV Treatment Adherence Self-Efficacy Scale (HIV-ASES). *Journal of Behavioral Medicine*, 30(5), 359–370.
- Johnson, M. O., Neilands, T. B., Dilworth, S. E., Morin, S. F., Remien, R. H., & Chesney, M. A. (2007b). The role of self-efficacy in HIV treatment adherence: Validation of the HIV Treatment Adherence Self-Efficacy Scale (HIV-ASES). *Journal of Behavioral Medicine*, 30(5), 359–370.
- Kaihin, R., Kasatpibal, N., Chitreechuer, J., & Grimes, R. M. (2015). Effect of an Empowerment Intervention on Antiretroviral Drug Adherence in Thai Youth. *Behavioral Medicine*, 41(4), 186–194.
- Kasedde, S., Kapogiannis, B. G., McClure, C., & Luo, C. (2014). Executive summary: Opportunities for action and impact to address HIV and AIDS in adolescents. *Journal of Acquired Immune Deficiency Syndromes*, 66(SUPPL. 2).
- Katz, I. T., Ryu, A. E., Onuegbu, A. G., Psaros, C., Weiser, S. D., Bangsberg, D. R., & Tsai, A. C. (2013). Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. *Journal of the International AIDS Society*, 16.
- Kidia, K. K., Mupambireyi, Z., Cluver, L., Ndhlovu, C. E., Borok, M., & Ferrand, R. A. (2014). HIV status disclosure to perinatally-infected adolescents in Zimbabwe: A qualitative study of adolescent and healthcare worker perspectives. *PLoS ONE*, 9(1).
- Kim, M. H., Mazenga, A. C., Yu, X., Ahmed, S., Paul, M. E., Kazembe, P. N., & Abrams, E. J. (2017). High self-reported non-adherence to antiretroviral therapy amongst adolescents living with HIV in Malawi: barriers and associated factors. *Journal of the International AIDS Society*, 20(1), 21437.

- Koech, E., Teasdale, C. A., Wang, C., Fayorsey, R., Alwar, T., Mukui, I. N., ... Abrams, E. J. (2014). Characteristics and outcomes of HIV-infected youth and young adolescents enrolled in HIV care in Kenya. *AIDS*, 28(18), 2729–2738.
- Kurniawan1, D., & , Fitrio Deviantony2*, R. Y. (2019). Impact of hiv-Related Stigma: Self-Efficacy, Self-Esteem, and Social Isolation on ARV Medication Adherence among Persons Living With HIV in Turen, Malang. *Pakistan Journal of Medical and Health Sciences* Retrived from <https://www.researchgate.net/publication/339527275>
- Lamb, M. R., Fayorsey, R., Nuwagaba-Biribonwoha, H., Viola, V., Mutabazi, V., Alwar, T., ... Elul, B. (2014). High attrition before and after ART initiation among youth (15-24 years of age) enrolled in HIV care. *AIDS*, 28(4), 559–568.
- Le Prevost, M., Arenas-Pinto, A., Melvin, D., Parrott, F., Foster, C., Ford, D., ... Judd, A. (2018). Anxiety and depression symptoms in young people with perinatally acquired HIV and HIV affected young people in England. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, 30(8), 1040–1049.
- Lee, S., & Hazra, R. (2015, December 2). Achieving 90-90-90 in paediatric HIV: Adolescence as the touchstone for transition success. *Journal of the International AIDS Society*, 18.
- Li, L., Lin, C., Lee, S. J., Tuan, L. A., Feng, N., & Tuan, N. A. (2017). Antiretroviral therapy adherence and self-efficacy among people living with HIV and a history of drug use in Vietnam. *International Journal of STD and AIDS*, 28(12), 1247–1254.
- Li, X., Huang, L., Wang, H., Fennie, K. P., He, G., & Williams, A. B. (2011). Stigma mediates the relationship between self-efficacy, medication adherence, and quality of life among people living with HIV/AIDS in China. *AIDS Patient Care and STDs*, 25(11), 665–671.

- Lima, V. D., Harrigan, R., Murray, M., Moore, D. M., Wood, E., Hogg, R. S., & Montaner, J. S. G. (2008). Differential impact of adherence on long-term treatment response among naive HIV-infected individuals. *AIDS*, *22*(17), 2371–2380.
- Lodico, M. G., Spaulding, D. T., Voegtle, K. H., L, B., Berg, B. L., Idea, I. S., ... Xiaoshan, Z. (2012). [Http://Www.Edarticle.Com](http://www.edarticle.com). *RELC Journal*, *5*(1), 1–9.
- Louthrenoo, O. (2018). Evaluation of Psychosocial Adjustment and Self-Esteem in Perinatally HIV-Infected Adolescents. *Biomedical Journal of Scientific & Technical Research*, *2*(1).
- Lowenthal, E. D., Bakeera-Kitaka, S., Marukutira, T., Chapman, J., Goldrath, K., & Ferrand, R. A. (2014). Perinatally acquired HIV infection in adolescents from sub-Saharan Africa: A review of emerging challenges. *The Lancet Infectious Diseases*, *14*, 627–639.
- MacCarthy, S., Saya, U., Samba, C., Birungi, J., Okoboi, S., & Linnemayr, S. (2018). “how am i going to live?”: Exploring barriers to ART adherence among adolescents and young adults living with HIV in Uganda. *BMC Public Health*, *18*(1), 1158.
- Mburu, G., Ram, M., Oxenham, D., ... C. H.-C. and Y., & 2014, U. (2013). Responding to adolescents living with HIV in Zambia: a social–ecological approach. *Reproductive Health Matters*. Retrieved from <https://www.sciencedirect.com/science/article/pii/S019074091400139X>
- Menon, A, Glazebrook, C., ... N. C.-J. J. of, & 2007, U. (2007). Mental health and disclosure of HIV status in Zambian adolescents with HIV infection: implications for peer-support programs. *Journal of Acquired Immune Deficiency Syndromes*, *46*(3), 349–54. Retrieved from https://journals.lww.com/jaids/fulltext/2007/11010/mental_health_and_disclosure_of_hiv_status_in.16.aspx

- Menon, Anitha, Glazebrook, C., Campain, N., & Ngoma, M. (2007). Mental health and disclosure of HIV status in Zambian adolescents with HIV infection: Implications for peer-support programs. *Journal of Acquired Immune Deficiency Syndromes*, 46(3), 349–354.
- Menon, Anitha, Glazebrook, C., Campain, N., & Ngoma, M. (2007b). Mental health and disclosure of HIV status in Zambian adolescents with HIV infection: Implications for peer-support programs. *Journal of Acquired Immune Deficiency Syndromes*, 46(3), 349–354.
- Mimiaga, M. J., Bogart, L. M., Thurston, I. B., Santostefano, C. M., Closson, E. F., Skeer, M. R., ... Safren, S. A. (2019). Positive Strategies to Enhance Problem-Solving Skills (STEPS): A pilot randomized, controlled trial of a multicomponent, technology-enhanced, customizable antiretroviral adherence intervention for HIV-infected adolescents and young adults. *AIDS Patient Care and STDs*, 33(1), 21–24.
- Mueller, J., Alie, C., Jonas, B., Brown, E., & Sherr, L. (2011a). A quasi-experimental evaluation of a community-based art therapy intervention exploring the psychosocial health of children affected by HIV in South Africa. *Tropical Medicine and International Health*, 16(1), 57–66.
- Mueller, J., Alie, C., Jonas, B., Brown, E., & Sherr, L. (2011b). A quasi-experimental evaluation of a community-based art therapy intervention exploring the psychosocial health of children affected by HIV in South Africa. *Tropical Medicine and International Health*, 16(1), 57–66.
- Mutwa, P. R., Van Nuil, J. I., Asiimwe-Kateera, B., Kestelyn, E., Vyankandondera, J., Pool, R., ... Boer, K. R. (2013). Living Situation Affects Adherence to Combination Antiretroviral Therapy in HIV-Infected Adolescents in Rwanda: A Qualitative Study. *PLoS ONE*, 8(4).

- Mwale, M., & Muula, A. S. (2017, September 18). Systematic review: A review of adolescent behavior change interventions [BCI] and their effectiveness in HIV and AIDS prevention in sub-Saharan Africa. *BMC Public Health*, *17*.
- Mwau, M., Syeunda, C. A., Adhiambo, M., Bwana, P., Kithinji, L., Mwendu, J., ... Boeke, C. E. (2018). Scale-up of Kenya's national HIV viral load program: Findings and lessons learned. *PLoS ONE*, *13*(1).
- Naar-King, S., Outlaw, A. Y., Sarr, M., Parsons, J. T., Belzer, M., Macdonell, K., ... Adolescent Medicine Network for HIV/AIDS Interventions. (2013). Motivational Enhancement System for Adherence (MESA): pilot randomized trial of a brief computer-delivered prevention intervention for youth initiating antiretroviral treatment. *Journal of Pediatric Psychology*, *38*(6), 638–648.
- Nabukeera-barungi, N., Elyanu, P., Asire, B., Katureebe, C., Lukabwe, I., Namusoke, E., ... Tumwesigye, N. (2015). Adherence to antiretroviral therapy and retention in care for adolescents living with HIV from 10 districts in Uganda. *BMC Infectious Diseases*, 1–10.
- Nachega, J. B., Hislop, M., Nguyen, H., Dowdy, D. W., Chaisson, R. E., Regensberg, L., ... Maartens, G. (2009). Antiretroviral therapy adherence, virologic and immunologic outcomes in adolescents compared with adults in Southern Africa. *Journal of Acquired Immune Deficiency Syndromes*, *51*(1), 65–71.
- Nachega, J. B., Mills, E. J., & Schechter, M. (n.d.). Antiretroviral therapy adherence and retention in care in middle-income and low-income countries: current status of knowledge and research priorities. *Journals.Lww.Com*.
- Nader Hajloo. (2014). (PDF) Relationships Between Self-Efficacy, Self-Esteem and Procrastination in Undergraduate Psychology Students. *Iranian Journal of Psychiatry and Behavioral Sc*, *8*(3), 42–29. Retrieved from

https://www.researchgate.net/publication/273700586_Relationships_Between_Self-Efficacy_Self-Esteem_and_Procrastination_in_Undergraduate_Psychology_Students

National AIDS & STI Control, 2018 edition. . *Guidelines for Use of Art Kenya - Google Search*. Retrieved from http://cquin.icap.columbia.edu/wp-content/uploads/2017/04/ICAP_CQUIN_Kenya-ARV-Guidelines-2018-Final_20thAug2018.pdf

National AIDS and STI Control Programme (NASCO), K. (2014). Kenya AIDS Indicator Survey 2012: Final Report. *Nairobi, NASCO. June 2014*, 66, S3–S12.

Ngeno, B., Waruru, A., Inwani, I., Nganga, L., Wangari, E. N., Katana, A., ... Rutherford, G. W. (2019). Disclosure and Clinical Outcomes Among Young Adolescents Living With HIV in Kenya. *Journal of Adolescent Health*, 64(2), 242–249.

Nglazi, M. D., Kranzer, K., Holele, P., Kaplan, R., Mark, D., Jaspan, H., ... Bekker, L.-G. (2012a). Treatment outcomes in HIV-infected adolescents attending a community-based antiretroviral therapy clinic in South Africa. *BMC Infectious Diseases*, 12, 21.

Nglazi, M. D., Kranzer, K., Holele, P., Kaplan, R., Mark, D., Jaspan, H., ... Bekker, L. G. (2012b). Treatment outcomes in HIV-infected adolescents attending a community-based antiretroviral therapy clinic in South Africa. *BMC Infectious Diseases*, 12.

Njuguna, I., Beima-Sofie, K., Mburu, C., Mugo, C., Black, D. A., Neary, J., ... Wamalwa, D. (2019). Managing the transition from paediatric to adult care for HIV, Kenya. *Bulletin of the World Health Organization*, 97(12), 837–845.

- Okawa, S., Mwanza-Kabaghe, S., Mwiya, M., Kikuchi, K., Jimba, M., Kankasa, C., & Ishikawa, N. (2017). Adolescents' experiences and their suggestions for HIV serostatus disclosure in Zambia: A mixed-methods study. *Frontiers in Public Health, 5*.
- Palinkas, L. A., Aarons, G. A., Horwitz, S., Chamberlain, P., Hurlburt, M., & Landsverk, J. (2011). Mixed method designs in implementation research. *Administration and Policy in Mental Health and Mental Health Services Research, 38*(1), 44-53.
- Petersen, I., Bhana, A., Myeza, N., Alicea, S., John, S., Holst, H., McKay, M., & Mellins, C. (2010). Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: a qualitative investigation. *AIDS care, 22*(8), 970–978.
- Purwaningsih, P., Asmoro, C. P., & Prastiwi, Y. A. (2019). Self-esteem and motivation with adherence of people living with HIV/AIDS (PLWHA) in Indonesia with antiretroviral therapy: A cross-sectional study. *International Journal of Adolescent Medicine and Health, 1*(ahead-of-print).
- Rathbun, R. C., Farmer, K. C., Stephens, J. R., & Lockhart, S. M. (2005). Impact of an adherence clinic on behavioral outcomes and virologic response in treatment of HIV infection: a prospective, randomized, controlled pilot study. *Clinical Therapeutics, 27*(2), 199–209.
- Remien, R. H., Stirratt, M. J., Dolezal, C., Dognin, J. S., Wagner, G. J., Carballo-Diequez, A., El-Bassel, N., & Jung, T. M. (2005). Couple-focused support to improve HIV medication adherence: a randomized controlled trial. *AIDS (London, England), 19*(8), 807–814. <https://doi.org/10.1097/01.aids.0000168975.44219.45>.

- Ridgeway, K., Dulli, L. S., Murray, K. R., Silverstein, H., Dal Santo, L., Olsen, P., Darrow de Mora, D., & McCarraher, D. R. (2018). Interventions to improve antiretroviral therapy adherence among adolescents in low- and middle-income countries: A systematic review of the literature. *PloS one*, *13*(1), e0189770. <https://doi.org/10.1371/journal.pone.0189770>
- Sharma, S., & Agarwala, S. (2015). Self-Esteem and Collective Self-Esteem Among Adolescents: An Interventional Approach. *Psychological Thought*, *8*(1), 105–113.
- Simoni, J. M., Pearson, C. R., Pantalone, D. W., Marks, G., & Crepaz, N. (2006). Efficacy of interventions in improving highly active antiretroviral therapy adherence and HIV-1 RNA viral load. A meta-analytic review of randomized controlled trials. *Journal of Acquired Immune Deficiency Syndromes (1999)*, *43* (Suppl 1), S23-35.
- Slogrove, A. L., Schomaker, M., Davies, M. A., Williams, P., Balkan, S., Ben-Farhat, J., ... Leroy, V. (2018). The epidemiology of adolescents living with perinatally acquired HIV: A cross-region global cohort analysis. *PLoS Medicine*, *15*(3).
- Sohn, A. H., & Hazra, R. (2013, June 18). The changing epidemiology of the global paediatric HIV epidemic: Keeping track of perinatally HIV-infected adolescents. *Journal of the International AIDS Society*, *16*.
- Srikala, B., & Kishore Kumar, K. V. (2010). Empowering adolescents with life skills education in schools-School mental health program: Does it work. *Indian Journal of Psychiatry*, *52*(4), 344–349.
- Swan, A. R. H., & Kershaw, S. (1994). A computer model for skeletal growth of stromatoporoids. *Palaeontology*, *37*(2), 409–423.
- Tyer-Viola, L. A., Corless, I. B., Webel, A., Reid, P., Sullivan, K. M., & Nichols, P.

- (2014). Predictors of Medication Adherence Among HIV-Positive Women in North America. *JOGNN - Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 43(2), 168–178.
- UNAIDS, A. (2016). by the numbers: ending the AIDS epidemic by 2030 as part of the sustainable development goals. Geneva: Retrieved from <http://www.unaids.org/en/resources/documents/2016/ending-AIDS-epidemic-adolescents>
- United Nations Programme on HIV/AIDS (UNAIDS). (2018). *UNAIDS Data 2018*. 1, 1–376.
- Van Dyke, R. B., Lee, S., Johnson, G. M., Wiznia, A., Mohan, K., Stanley, K., Morse, E. V., Krogstad, P. A., Nachman, S., & Pediatric AIDS Clinical Trials Group Adherence Subcommittee Pediatric AIDS Clinical Trials Group 377 Study Team (2002). Reported adherence as a determinant of response to highly active antiretroviral therapy in children who have human immunodeficiency virus infection. *Pediatrics*, 109(4), e61. <https://doi.org/10.1542/peds.109.4.e61>
- Whiteley, L., Brown, L. K., Mena, L., Craker, L., & Arnold, T. (2018). Enhancing health among youth living with HIV using an iPhone game. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, 30(sup4), 21–33.
- WHO. (2011). *Guideline on HIV disclosure counselling for children up to 12 years of age*. 1–46. Retrieved from <http://www.who.int/about/>
- WHO. (2014). World Health Organization - Health for the world's adolescents a second chance in the second decade. Geneva: World Health Organisation, p. Online. Retrieved from <http://apps.who.int/adolescent/second-decade/>

- Williams, P. L., Storm, D., Montepiedra, G., Nichols, S., Kammerer, B., Sirois, P. A., ... PACTG 219C Team. (2006). Predictors of adherence to antiretroviral medications in children and adolescents with HIV infection. *Pediatrics*, *118*(6), e1745-57.
- Winskell, K., Miller, K. S., Allen, K. A., & Obong'o, C. O. (2016). Guiding and supporting adolescents living with HIV in sub-Saharan Africa: The development of a curriculum for family and community members. *Children and Youth Services Review*, *61*, 253–260.
- Wittes, J. (2002). Wittes J. (2002). Sample size calculations for randomized controlled trials. *Epidemiologic reviews*, *24*(1), 39–53. <https://doi.org/10.1093/epirev/24.1.39>
- Woollett, N. (2016). Adolescents Living with HIV: Emerging Issues in Public Health in South Africa. In: Liamputtong P. (eds) *Children and Young People Living with HIV/AIDS. Cross-Cultural Research in Health, Illness and Well-Being*. Springer, Cham.
- World health organization. (2006). From Access to Adherence: The Challenges of Antiretroviral Treatment - Studies from Botswana, Tanzania and Uganda, 2006: Factors that facilitate or constrain adherence to antiretroviral therapy among adults in Uganda: a pre-intervention study: Chapter 3: Retrieved from <https://apps.who.int/medicinedocs/en/d/Js13400e/10.6.1.html>

APPENDICES

Appendix I: Self Efficacy to Antiretroviral Adherence

HIV-ASES Items

I am going to ask you about situations that could occur during your treatment for HIV. Treatment can involve different things for different people. Sometimes, this might refer to taking medications, and other times it could refer to other things that you do to deal with HIV such as diet and exercise or taking vitamins. So, in these questions, when I ask you about your “treatment” or your “treatment plan,” I am talking not only about any medications that you might be taking for HIV, but also other things that make up your self-care. For the following questions I will ask you to tell me in the past month, including today, how confident you have been that you can do the following things. Use this response scale ranging from 0 (“cannot do at all”) to 10 (“completely certain can do”).

Note: The term “clinic” may be replaced by “doctor’s office” if participant does not receive care in clinic settings.]

Scoring:

Cannot do at all 00

01

02

03

04

Moderately certain can do 05

06

07

08

09

Completely certain can do 10

In the past month, how confident have you been that you can:

1. Stick to your treatment plan even when side effects begin to interfere with daily activities?
2. Integrate your treatment into your daily routine?
3. Integrate your treatment into your daily routine even if it means taking medication or doing other things
1. In front of people who don't know you are HIV-infected?
 4. Stick to your treatment schedule even when your daily routine was disrupted?
 5. Stick to your treatment schedule when you aren't feeling well?
 6. Stick to your treatment schedule when it means changing your eating habits?
 7. Continue with your treatment even if doing so interferes with your daily activities?
 8. Continue with the treatment plan your physician prescribed even if your T-cells drop significantly in the
2. Next three months?
 9. Continue with your treatment even when you are feeling discouraged about your health?
 10. Continue with your treatment even when getting to your clinic appointments was a major hassle?
 11. Continue with your treatment even when people close to you tell you that they don't think that it was doing
3. Any good?
 12. Get something positive out of your participation in treatment, even if the medication you are taking does
4. Not improve your health?

Appendix II: Post Life Skills Evaluation Data Collection Form

Immediate Follow up visit – (post- fifth life skills session)

ADHERENCE HISTORY:

Any breaks/Treatment interruptions of ART? Yes No

Self -reported Adherence:

- a) No missed doses in a month
- b) Maximum of three missed doses in a month
- c) More than three missed doses in a month but less than three missed doses in a week

At least three missed doses in a week

If yes to c and d -Reason for poor adherence: -

- Pill burden,
- Experiences Side effects
- Refusal due to lack of disclosure,
- Depression
- Improved health status does not see need
- Stigma
- substance abuse
- Challenges in school schedule
- Angry at parents /caregivers
- Forgot
- Other

STIGMA

Have you ever experienced stigma due to your HIV status?

Yes No

If yes from who? :-

School (classmates)

School (teachers)

Neighbours

Family members

Peers /Friends

How did you learn about your HIV Status?

Self-disclosure /discovery

Health worker

Caregiver

Siblings

Other relatives

Other

PERCEPTION OF SOCIAL SUPPORT

Was there any one with whom you feel you can discuss the challenges you face because of your HIV status?

Yes No

If yes whom?

Caregiver

- Sibling
- Friend
- Other relative
- Church leader
- Clinic counsellor
- Support group members at the clinic
- Other support group

CHALLENGES FACED IN COPING WITH HIV STATUS

- What are some of these challenges that affect you?
- Little motivation to take my ARV's
- Handling relationships with the opposite sex
- Wondering about my future and how it will be because of my status
- Stigma about my HIV status

Do you feel ready to join the adult clinic soon? Yes No Not sure

Do you feel you can face the future with confidence Yes No Don't know?

Please complete the self -efficacy on Appendix A

Please complete the Rosenberg self-esteem test

Appendix III: Post Life Skills Evaluation Data Collection Form

Second follow up visit – (Three months’ post life skills intervention)

ADHERENCE HISTORY:

Any breaks / Treatment interruptions of ART? Yes No

Self -reported Adherence:

- a) No missed doses in a month
- b) Maximum of three missed doses in a month
- c) More than three missed doses in a month but less than three missed doses in a week
- d) At least three missed doses in a week

If yes to c and d -Reason for poor adherence: -

- Pill burden,
- Experiences Side effects
- Refusal due to lack of disclosure,
- Depression
- Improved health status does not see need
- Stigma
- substance abuse
- Challenges in school schedule
- Angry at parents /caregivers
- Forgot
- Other

STIGMA

Have you ever experienced stigma due to your HIV status?

Yes No

If yes from who:-

School (classmates)

School (teachers)

Neighbours

Family members

Peers /Friends

How did you learn about your HIV Status?

Self-disclosure /discovery

Health worker

Caregiver

Siblings

Other relatives

Other

VIRAL LOAD

Blood sample drawn at this visit?

Yes No

If yes: viral copies/ml

PERCEPTION OF SOCIAL SUPPORT

Was there any one with whom you feel you can discuss the challenges you face because of your HIV status?

Yes No

If yes whom?

Caregiver

Sibling

Friend

Other relative

Church leader

Clinic counsellor

Support group members at the clinic

Other support group

CHALLENGES FACED IN COPING WITH HIV STATUS

What are some of these challenges that affect you?

Little motivation to take my ARV's

Handling relationships with the opposite sex

Wondering about my future and how it will be because of my status

Stigma about my HIV status

Do you feel ready to join the adult clinic soon? Yes No Not sure

Do you feel you can face the future with confidence Yes No Don't know?

Appendix III: Rosenberg Self-Esteem Scale

(computer assisted self -administered interview)

Scale:

Instructions

Below was a list of statements dealing with your general feelings about yourself. Please indicate how strongly you agree or disagree with each statement.

1. On the whole, I am satisfied with myself.

Strongly Agree Agree Disagree Strongly Disagree

2. At times I think I am no good at all.

Strongly Agree Agree Disagree Strongly Disagree

3. I feel that I have a number of good qualities.

Strongly Agree Agree Disagree Strongly Disagree

4. I am able to do things as well as most other people.

Strongly Agree Agree Disagree Strongly Disagree

5. I feel I do not have much to be proud of.

Strongly Agree Agree Disagree Strongly Disagree

6. I certainly feel useless at times.

Strongly Agree Agree Disagree Strongly Disagree

7. I feel that I'm a person of worth, at least on an equal plane with others.

Strongly Agree Agree Disagree Strongly Disagree

8. I wish I could have more respect for myself.

Strongly Agree Agree Disagree Strongly Disagree

9. All in all, I am inclined to feel that I am a failure.

Strongly Agree Agree Disagree Strongly Disagree

10. I take a positive attitude toward myself.

Strongly Agree Agree Disagree Strongly Disagree

Scoring:

Items 2, 5, 6, 8, 9 are reverse scored. Give “Strongly Disagree” 1 point, “Disagree” 2 points, “Agree” 3 points, and “Strongly Agree” 4 points. Sum scores for all ten items.

Keep scores on a continuous scale. Higher scores indicate higher self-esteem.

Appendix IV: Caregiver/Parental Informed Consent Form

Evaluation of clinical and psychosocial outcomes after life skills provision among perinatally HIV-infected adolescents receiving care at Mbagathi Hospital

Part 1: Information Sheet

Introduction:

I would like to tell you about a study being conducted by the above listed researchers. The purpose of this consent form was to give you the information you will need to help you decide whether or not your child should participate in the study. Feel free to ask any questions about the purpose of the research, what happens if your child participates in the study, the possible risks and benefits, the rights of your child as a volunteer, and anything else about the research or this form that was not clear. When we have answered all your questions to your satisfaction, you may decide if you want your child to be in the study or not. This process was called 'informed consent'. Once you understand and agree for your child to be in the study, I will request you to sign your name on this form. You should understand the general principles which apply to all participants in a medical research: i) Your child decision to participate was entirely voluntary ii) Your child may withdraw from the study at any time without necessarily giving a reason for his/her withdrawal iii) Refusal to participate in the research will not affect the services your child was entitled to in this health facility or other facilities.

May I continue? YES / NO

Purpose of the study

The study primarily aims to determine the outcomes of adolescents in care at KNH CCC. It also aims to determine if there was any association between their suppression of the HIV virus and various influences in their environment. It also aims to determine the challenges in addressing psychosocial challenges and needs they feel are not addressed. Lastly this study also aims to assess the role of a life skills intervention and its role in creating motivation to maintain and improve adherence to HIV medication.

Type of Research Intervention

This research will involve the adolescents' participation on a questionnaire interview with a qualified counsellor and will take about ten minutes of your time. In addition, there will be a pilot of the life skills curriculum which will be offered to randomly selected individuals

Participation Selection

Your child's participation in this research was entirely voluntary. It was their choice whether to participate or not. If he/she chooses not to participate all the services, you receive at this Centre will continue and nothing will change. She/he was free to decline participation of this study at any time.

Procedures

The study will have two parts

Part 1:

During our exploration of the challenges to ART adherence and psychosocial support needs of perinatally HIV-infected adolescents. These will be the procedures: -

Study visit one: -

1) After eligibility evaluation, consent will be obtained from both you and your child. Baseline demographic, disclosure, self –efficacy (using an existing validated tool; HIV-ASES [appendix 1]), perception of social support, viral load (copies/ml) and perception of the ability to cope with stigma will be evaluated using an interviewer-administered questionnaire. 2) A blood sample will be collected ONLY from study participants without a documented viral load result (within the previous six months of study start) if one will be available the blood sample will not be drawn,

Study visit two: -

We will then carry out focus group discussions composed of eight to twelve other adolescents. We will explore experiences faced, challenges in adherence to ART and unmet psychosocial needs.

Study visit three: -

You might also be included in in-depth interviews

Part 2: -

During the next part of the study we will pilot test the modified Baylor's life skills curriculum and measure its impact.

Study visit one: -

Enrolled subjects previously not included in the exploratory study in specific objective 1, will undergo eligibility review, informed consent and study enrolment.

During this visit the participants will be randomized into the control and intervention arm of the study through block randomization: -

- i. Control group Standard of care: - The usual care administered at the clinic will continue
- ii. Intervention arm: This will involve the provision of usual care administered at the clinic and inclusion of a HIV life skills training from the Baylor school of medicine (49). This training will be offered through four sessions each lasting four hours' duration. It included topics such as sexuality, HIV knowledge, coping with stigma, pregnancy avoidance and contraception and adherence to ART and self-care. The engagements will have an instruction approach through various platforms including short movies, face to face instruction as well as a focus group approach to discuss responses and application of skills learnt in everyday life.

Study visits two- five:

These study visits will involve continued provision of life skills training Each study visit will involve provision of a session of training until all four sessions are completed. At study visit five after the last session self- efficacy to ART will be assessed using HIV-ASES [appendix 1]).

Study visit six:

This study visit will occur 12 weeks after the completion of the life skills training intervention. At this visit, a final evaluation of the Self- efficacy to ART and viral load through drawing of 5-7 ml of blood

Control arm

Study visit two:

Study participants in the control arm will next be evaluated at the end of the study when all activities of the intervention arm are complete. Self – efficacy to ART (using an existing validated tool; HIV-ASES [appendix 1]) will be assessed.

Study visit three:

This study visit will occur 12 weeks after the completion of the life skills training intervention. At this visit, a final evaluation of the Self- efficacy to ART and viral load through drawing of 5-7 ml of blood

If you do not wish to answer any of the questions included in the survey, you may skip them and move on to the next question. The information recorded was confidential, your name was not being included on the forms, only a number will identify you, and no one else except the research investigators have access to your details. The interview will take place in the clinic Blood samples will be collected for this study (maximum 5-7ml). This will allow for a viral load test. You may decline if they do not want this done. You will be notified of the results as soon as they are available at a clinic visit or earlier if this was necessary.

If she/he do not wish to answer any of the questions included in the survey, he/she may skip them and move on to the next question. The information recorded was confidential, your name was not being included on the forms, only a number will identify you, and no one else except the research investigators have access to your details. The interview will take place in the clinic Blood samples will be collected for this study (maximum 5-7ml). This will allow for a viral load test. The adolescent may decline if they do not want this done. You and the adolescent will be notified of the results as soon as they are available at a clinic visit or earlier if this was necessary.

Duration

We will invite the adolescent for a focus group discussion in order to discuss challenges face during treatment, coping with stigma, sexuality and decision making and goal development. Transport re-imburement will be provided.

Risks

We will ask the adolescent to share with us some personal and confidential information, and he/she may feel uncomfortable talking about some of the topics. He/she does not have to give us any reason for not responding to any question or for refusing to take part in the interview.

Benefits

There will be a direct benefit to the adolescent with regards to finding out how well he/she have suppressed the virus as well as knowledge gained on HIV transmission, goal setting, coping with stigma, adherence and an opportunity to interact with other adolescents during the teen club.

Confidentiality

We will not be sharing information about your child to anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about will have a number on it instead of your name. Only the researchers will know what the number was and we will lock that information up with a lock and key. It will not be shared with or given to anyone except the research team who will have access to the information.

Part II: Certificate of consent.

- 1) I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. .

Print name of Care giver_____

Signature of caregiver _____

Date _____

- 2) I have explained the study to the participants and addressed any concerns about the study

Print Name of P.I /research assistant_____

Signature _____

Date_____

If you would like any further clarification please contact: -

Kenyatta National Hospital
Kamau

Dr. Nyawira Gitahi-

P. O. Box 20723 Code 00202. Nairobi OR

P.O Box 61968-00200

Tel. (254-020) 2726300-9 Ext 44355

Tel. 0765 709488

E-mail: uonknh_erc@uonbi.ac.ke

gnyawira@gmail.com

Appendix V: Adolescent- Assent/ Consent Form

Evaluation of clinical and psychosocial outcomes after life skills provision among perinatally HIV-infected adolescents receiving care at Mbagathi Hospital

Part 1: Information Sheet

Researchers: - Dr. Nyawira Kamau, Dr. P. Muiruri, Prof. E. Bukusi, Dr. K Ngure

Introduction:

I would like to tell you about a study being conducted by the above listed researchers. The purpose of this consent form was to give you the information you will need to help you decide whether or not you should participate in the study. Feel free to ask any questions about the purpose of the research

Purpose of the study

The study primarily aims to determine the psychosocial challenges and needs they feel are not addressed. Lastly this study also aims to determine the role of a life skills intervention and its role in creating motivation to maintain and improve adherence to HIV medication.

Type of Research Intervention

This research will involve the adolescents' participation on a questionnaire interview with a qualified counsellor and will take about ten minutes. After that the adolescents will be involved in focus group discussions lasting two hours. Some of the adolescents may be selected for in-depth interviews. Both the focus group discussions and in depth interviews will be seeking to explore challenges faced in adherence, difficulties experienced after disclosure and level of perceived preparedness to transition into the adulthood. In addition, there will be a pilot of the life skills curriculum which will be offered to randomly selected individuals

Participation Selection

Your participation in this research was entirely voluntary. It was your choice whether to participate or not. If you choose not to participate all the services, you receive at this Centre will continue and nothing will change. You are free to decline participation of this study at any time.

Procedures

The study will have two phases.

Phase 1:

During our exploration of the challenges to ART adherence and psychosocial support needs of perinatally HIV-infected adolescents. These will be the procedures: -

Study visit one: -

1) After eligibility evaluation, consent will be obtained from both you and your caregiver/guardian. Baseline demographic, disclosure, self –efficacy (using an existing validated tool; HIV-ASES [appendix 1]), perception of social support, viral load (copies/ml) and perception of the ability to cope with stigma will be evaluated using an interviewer-administered questionnaire. 2) A blood sample will be collected ONLY from study participants without a documented viral load result (within the previous six months of study start) if one will be available the blood sample will not be drawn,

Study visit two: -

We will then carry out focus group discussions composed of eight to twelve other adolescents. We will explore experiences faced, challenges in adherence to ART and unmet psychosocial needs.

Study visit three: -

You might also be included in in-depth interviews

Phase 2: -

During the next phase of the study we will pilot test the modified Baylor's life skills curriculum and measure its impact.

Study visit one: -

Enrolled subjects previously not included in the exploratory study in specific objective 1, will undergo eligibility review, informed consent and study enrolment.

During this visit the participants will be randomized into the control and intervention arm of the study through block randomization: -

- iii. Control group Standard of care: - The usual care administered at the clinic will continue
- iv. Intervention arm: This will involve the provision of usual care administered at the clinic and inclusion of a HIV life skills training from the Baylor school of medicine (49). This training will be offered through four sessions each lasting four hours' duration. It included topics such as sexuality, HIV knowledge, coping with stigma, pregnancy avoidance and contraception and adherence to ART and self-care. The engagements will have an instruction approach through various platforms including short movies, face to face instruction as well as a focus group approach to discuss responses and application of skills learnt in everyday life.

Study visits two- five:

These study visits will involve continued provision of life skills training Each study visit will involve provision of a session of training until all four sessions are completed. At study visit five after the last session self- efficacy to ART will be assessed using HIV-ASES [appendix 1]).

Study visit six:

This study visit will occur 12 weeks after the completion of the life skills training intervention. At this visit, a final evaluation of the Self- efficacy to ART and viral load through drawing of 5-7 ml of blood

Control arm

Study visit two:

Study participants in the control arm will next be evaluated at the end of the study when all activities of the intervention arm are complete. Self – efficacy to ART (using an existing validated tool; HIV-ASES [appendix 1]) will be assessed.

Study visit three:

This study visit will occur 12 weeks after the completion of the life skills training intervention. At this visit, a final evaluation of the Self- efficacy to ART and viral load through drawing of 5-7 ml of blood

If you do not wish to answer any of the questions included in the survey, you may skip them and move on to the next question. The information recorded was confidential, your name was not being included on the forms, only a number will identify you, and no one else except the research investigators have access to your details. The interview will take

place in the clinic Blood samples will be collected for this study (maximum 5-7ml). This will allow for a viral load test. You may decline if they do not want this done. You will be notified of the results as soon as they are available at a clinic visit or earlier if this was necessary.

Duration: We will invite the adolescent for five sessions of the life skills intervention each two hours long. The sessions will be held weekly for the duration of five weeks over the school vacation.

Risks: We will ask you to share with us some personal and confidential information, and you may feel uncomfortable talking about some of the topics. You do not have to give us any reason for not responding to any question or for refusing to take part in the interview.

Benefits: There will be a direct benefit to you with regards to finding out how well you have suppressed the virus as well as knowledge gained on HIV transmission, goal setting, coping with stigma, adherence and an opportunity to interact with other adolescents during the focus group.

Confidentiality

We will not be sharing information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about will have a number on it instead of your name. Only the researchers will know what the number was and we will lock that information up with a lock and key. It will not be shared with or given to anyone except the research team who will have access to the information.

Part II: Certificate of consent.

1) I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print Name of adolescent_____

Signature of adolescent _____

Date_____

2) I have explained the study to the participants and addressed any concerns about the study

Print Name of P.I /research assistant _____

Signature _____

Date _____

If you would like any further clarification, please contact: -

Kenyatta National Hospital
Kamau

Dr. Nyawira Gitahi-

P. O. Box 20723 Code 00202. Nairobi or

P.O Box 61968-00200

Tel. (254-020) 2726300-9 Ext 44355

Tel. 0765 709488

E-mail: uonknh_erc@uonbi.ac.ke

gnyawira@gmail.com

Appendix VI: Baylor School of Medicine Teen Club Curriculum

(Adopted with permission from the Botswana –Baylor children’s centre

Teen Club Curriculum

Overview: The Teen Club curriculum was a curriculum developed to address the needs of adolescents living with HIV (age 13-17) at Botswana-Baylor Children’s Clinical Centre of Excellence.

Curriculum and a guide: The Teen Club curriculum only designates a theme, topics that should be covered on that day, and takeaways that all the teens should leave the Teen Club with. The curriculum does not specify any activities that must be completed on that day. This flexibility year-to-year allows us to keep Teen Club interesting for our consistent participant population, adapt to the current needs of the Teen Club members, and leave room for Teen Leader input. It was the job of the Teen Club Coordinator to use to curriculum as a guide to create the facilitator guidelines for that day. Detailed below are the steps to take when developing facilitator guidelines:

- **Utilize designated resources:** On each curriculum guide, there was a section for designated resources. First, read past Teen Club curriculum in order to get an idea of what has been done in the past and how you can adapt or grow those activities. Then, utilize the expert resources indicated such as FHI 360’s Positive Connection and APC Project Positive Health Dignity & Prevention. Lastly utilize any additional resources indicated. If you ultimately take an activity directly from a designated resource, cite that resource in the curriculum.
- **Engage Teen Leaders:** Teen Leaders are the voice of Teen Club. Therefore, you should use Teen Leader meetings to run ideas by the Teen Leaders and get input and opinions on the upcoming Teen Club activities. You will then adjust the facilitator guidelines accordingly.

General structure of Teen Club Curriculum:

THEME: Overarching theme for the day
TOPICS: <ul style="list-style-type: none">• Subjects that should be covered in the activities that day
TAKEAWAYS: Things that all the teens should leave the Teen Club knowing or having done/discussed
RESOURCES: <ol style="list-style-type: none">1. Specially selected resources that should be utilized in order to development the Teen Club facilitator guidelines for the coming month

Facilitator Guidelines: Facilitator guidelines should do the following—

1. Address all topics designated in Teen Club curriculum
2. Should incorporate aspects of **creativity, physical activity, education,** and discussion
3. Should be easy to understand so that volunteers can facilitate sessions and that curriculum can be reviewed and understood in later years
4. Should be adaptable to the satellite site context

THEME: Love, Sex, Relationships

TOPICS:

- Safe Sex
 - Condoms (proper usage and negotiation)
- Female and male condoms
 - Other birth control methods
 - Myths about sex
- STI Education and prevention
- Family Planning
- Multiple-concurrent partnerships
- Disclosure
 - to partners, parents, friends, public (differences between these)

TAKEAWAYS:

After this Teen Club, teens should:

1. Know how to properly use both male and female condoms
2. Have strategies developed for negotiating condom use with a partner
3. Be able to explain why certain myths held about sex in Botswana are false
4. Know common STW as, symptoms, and how to seek medical attention

5. Know strategies to avoid unintended pregnancy and how to determine if you are ready for a child
6. Know that was possible to have a family while being HIV+ and the steps to take when you decide that was something you want
7. Understand the dangers of multiple concurrent partnerships
8. Have strategies for disclosing status to a partner, friend, or family member

RESOURCES:

1. Previous Teen Club curricula (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM)
2. APC Positive Health Dignity & Prevention: Risk Reduction Counselling (pg. 45-53), Disclosure of HIV status & partner notification (pg. 18)
3. Young Love—Multiple Concurrent Partnership curriculum
4. FHI 360 Positive Connections: Disclosure and developing trust in relationships (pg. 41), Sex and Relationships (pg. 80), Pregnancy: Planning and Prevention (pg. 91), Sexual Health and Positive Prevention (pg. 97)
5. Lesson Plans for Life Skills Education (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM > 01. Complete Botswana Life Skills Curriculum): Healthy Disclosure (pg. 37), Love, Sex, and Dating (pg. 48), Multiple Concurrent Partnerships (pg. 51), Relationships (pg. 67)

THEME: Personal Safety

TOPICS:

- Drugs and Alcohol
- Road safety
- Crime
- Tuberculosis (TB) and HIV

TAKEAWAYS:

After this Teen Club, teens should:

1. Know the dangers of drugs and alcohol, especially pertaining to being an adolescent living with HIV
2. Know the dangers of driving (i.e. high prevalence of road accidents in Botswana) and how to minimize those dangers
3. Know how and why alcohol impairs an individual's driving ability
4. Know strategies to minimize risk of being a victim of crime
5. Know the relationship between TB and HIV
6. Understand diagnosis and treatment procedures for TB

RESOURCES:

1. Previous Teen Club curricula (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM)
2. APC Positive Health Dignity & Prevention: The harms of alcohol use (pg. 55), TB and HIV (pg. 27)
3. Lesson Plans for Life Skills Education (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM > 01. Complete Botswana Life Skills Curriculum): Personal Safety (pg. 61)

THEME: Financial Literacy

TOPICS:

- Spending and saving
- Budgeting
- Banking and credit

TAKEAWAYS:

After this Teen Club, teens should:

1. Be able to evaluate how effectively they are controlling their money
2. Know how to create a budget for their personal use
3. Understand the concept of credit
4. Feel confident in their ability to open a bank account, if they so choose

RESOURCES:

1. Previous Teen Club curricula (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM)
2. Barclay's Ready to Work online resources (<https://readytowork.barclays/>)
3. Lesson Plans for Life Skills Education (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM > 01. Complete Botswana Life Skills Curriculum): Financial Literacy (pg. 31)

THEME: Confidence and Leadership / TL Elections

TOPICS:

- Public Speaking
- Leadership styles
- Self-esteem building

- Teen Leader Elections

TAKEAWAYS:

After this Teen Club, teens should:

1. Understand why public speaking was important in real life (i.e. school, job, expressing opinion in medical setting, etc.)
2. Gain practice speaking in front of peers
3. Feel supported and comfortable expressing their opinions in the Teen Clubs setting
4. Know that different leadership styles exist
5. Know which leadership style they possess
6. Know how to best work with people of differing leadership styles
7. Recognize the positive qualities that they possess and know that no one was perfect
8. Have strategies to improve their self-esteem if they are feeling down
9. Understand the commitment and role of Teen Leaders in Teen Club
10. Have been given the opportunity to run for Teen Leader, if they so choose
11. Have voted for the upcoming Teen Leaders

RESOURCES:

1. Previous Teen Club curricula (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM)
2. Youth Engaged in Leadership and Learning (YELL) (<https://gardnercenter.stanford.edu/publications/youth-engaged-leadership-and-learning-yell-handbook-program-staff-teachers-and>)
3. Lesson Plans for Life Skills Education (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM > 01. Complete Botswana Life Skills Curriculum): Teamwork and Leadership (pg. 90)

THEME: Self-care

TOPICS:

- Stress
 - What it was?
 - How to manage stress
- Mental health

TAKEAWAYS:

After this Teen Club, teens should:

1. Understand what stress was and how it manifests itself in your body
2. Be able to recognize the different triggers that can cause them to become stressed
3. Have explored different strategies for dealing with stress and know what strategies work best for them
4. Know common mental health illnesses for teens in Botswana
5. Know how to seek help for themselves or a friend if they are worried about mental health (i.e. resources)

RESOURCES:

1. Previous Teen Club curricula (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM)
2. Positive Connections: Exploring your emotions (pg. 121)
3. Baylor psychology department (Mama Phi)

THEME: Human Rights

TOPICS:

- Day of the African Child
 - History
 - Significance
- Human rights
 - Concept
 - Universal Declaration of human rights
 - BONELA
 - Human rights and HIV
- Laws and policies that affect adolescents living with HIV

TAKEAWAYS:

After this Teen Club, teens should:

1. Know the history of Day of the African Child
2. Understand the significance of Day of the African Child across the continent
3. Know the basic concept of human rights
4. Know the history of the Universal Declaration of Human Rights
5. Know the contents of the Universal Declaration of Human Rights—particularly the one adapted for adolescents
6. Understand BONELA and its role as a resource for the teens
7. Have discussed human rights as they particularly pertain to adolescents living with HIV (see poster)
8. Know the laws and policies in place in Botswana that effect their lives

RESOURCES:

1. Previous Teen Club curricula (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM)
2. Lesson Plans for Life Skills Education (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM > 01. Complete Botswana Life Skills Curriculum): Physical Activity (pg. 66)
3. Human rights day crafts (<https://humanrightswarrior.com/tag/human-rights-day-crafts/>)
4. Botswana Network on Ethics, Law, and HIV/AIDS (BONELA)

THEME: Adherence

TOPICS:

- Biologic HIV basis
- Antiretroviral medications
 - Biology
 - Different types
- Adherence barriers & strategies

TAKEAWAYS:

After this Teen Club, teens should:

1. Know the biologic basis of HIV
2. Understand what CD4 count and viral load mean
3. Understand what ARVs do biologically
4. Understand resistance
5. Understand the importance of taking ARVs consistently
6. Talk about common side effects of ART and what to do if experiencing side effects
7. Know that there are different types of ARVs and why certain people take different medications
8. Have discussed with peer's common barriers to adherence and ways to overcome those barriers
9. Have developed a personal adherence strategy for the upcoming year

RESOURCES:

1. Previous Teen Club curricula (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM)
2. APC Positive Health Dignity & Prevention: Adherence to antiretroviral treatment (pg. 39)

3. Positive Connections: Understanding HIV (pg. 30), Treatment and Adherence (pg. 49)
4. Lesson Plans for Life Skills Education (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM > 01. Complete Botswana Life Skills Curriculum): Adherence (pg. 7), Teamwork in adherence (pg. 86)

THEME: Physical activity and nutrition

TOPICS:

- Physical activity
- Nutrition
- Hygiene

TAKEAWAYS:

After this Teen Club, teens should:

1. Know the WHO recommended level of physical activity for adolescents
2. Know different ways to fulfil the daily physical activity recommendation (variety of types of physical activity to fit all preferences)
 - a. Yoga, sports, cardio, training, dancing, etc.
3. Have created a physical activity action plan for the next year
4. Understand what good nutrition for adolescents living with HIV was
5. Have discussed barriers to good nutrition and strategies to overcome those barriers
6. Be introduced to the clinics nutritionist and know that he was there as a resource for them.
7. Know the importance of hygiene as it pertains to nutrition, particularly for adolescents living with HIV

RESOURCES:

1. Previous Teen Club curricula (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM)
2. APC Positive Health Dignity & Prevention: Nutrition and HIV (pg. 55)
3. Positive Connections: Nutrition and Health Session (pg. 58)
4. http://www.who.int/dietphysicalactivity/factsheet_young_people/en/
5. Lesson Plans for Life Skills Education (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM > 01. Complete Botswana Life Skills Curriculum): Physical Activity (pg. 66)
6. Baylor nutritionist

THEME: Gender

TOPICS:

- Gender specific body discussions
- Gender norms and inequality
- Gender-based violence
- Female empowerment
- Sexual Orientation

TAKEAWAYS:

After this Teen Club, teens should:

1. Both males and females should understand the biological changes that happen in the bodies during adolescents (pre-puberty, puberty, and post-puberty)
2. Understand the health benefits of male circumcision (male specific)
3. Discuss gender norms in Botswana society and the possible problems that arise from these gender norms
4. Understand the prevalence of gender-based violence across the globe
5. Have identified what problematic gender norms lead to gender-based violence
6. Have discussed the ideas of female empowerment and gender equality
7. Have discussed different ways as individuals that they can help move towards gender equality
8. Know that sexual orientation was a spectrum
9. Understand the difficulties associated with stigma and discrimination for the LGBTQ community
10. Understand the importance of being a non-judgmental and supportive individual to any marginalized group

RESOURCES:

1. Previous Teen Club curricula (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM)
2. FHI 360 Positive Connections: Growing and Changing session (pg. 69)
3. <https://www.fhi360.org/media/videos/hear-me-stories-hurt-stories-heal-harim-mi-stori-blo-bagarap-stori-blo-kamapim-gutpla>
4. <https://www.fhi360.org/resource/empowering-women-and-girls-fact-sheet>
5. <https://www.fhi360.org/news/defying-odds>

THEME: Career Fair

TOPICS:

- Career Development

TAKEAWAYS:

After this Teen Club, teens should:

1. Know that their dream job should be a combination of something they love to do, something they are good at, and something they can get paid to do
2. Know that there are a variety of different career fields
3. Know roughly what it takes to get into different career fields
4. Have a better idea of their desired career field and feel as if they are equipped with the knowledge to pursue that field.

RESOURCES:

1. Previous Teen Club curricula (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM)
2. Lesson Plans for Life Skills Education (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM > 01. Complete Botswana Life Skills Curriculum): Career Development (pg. 12)
3. Citizen Entrepreneurial Development Agency (CEDA) (<http://www.ceda.co.bw/>)

THEME: Talent Show

TOPICS:

- Holiday Celebration
- Talent Show

TAKEAWAYS:

After this Teen Club, teens should:

1. Have been given the opportunity to sign up and perform for the entire Teen Club Group
2. Have felt comfortable and appreciated if they choose to perform
3. Have an appreciation for all of the different talents that Teen Club members have
4. Have an increased pride in being a Teen Club member

RESOURCES:

1. Previous Teen Club curricula (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM)

2. Lesson Plans for Life Skills Education (W://Teen Club > 0. Teen Club > FACILLITATOR GUIDELINES AND CURRICULUM > 01. Complete Botswana Life Skills Curriculum): Talent Show (pg. 86)

Appendix VII: Focus Group Discussion Guide

Focus Group Discussion Guide

Consent Process

Consent forms for focus group participants and assent forms for the care givers (appendix C and appendix E) will be completed in advance.

Thank you for agreeing to participate. We are very interested to hear your valuable opinion on challenges you face on adhering to ART and what you feel you struggle with as you think about becoming young adults while managing your HIV status.

- *The purpose of this study was to learn how after you learnt your status you felt supported or not by the health workers during your waists and the challenges and gaps you have experienced emotionally during this time as you have been dealing with disclosure and continuing to grow up with your HIV status. We hope to learn things that the clinic can do to provide better psychosocial support to you*
- *The information you give us was completely confidential, and we will not associate your name with anything you say in the focus group.*
- *We would like to tape the focus groups so that we can make sure to capture the thoughts, opinions, and ideas we hear from the group. No names will be attached to the focus groups and the tapes will be destroyed as soon as they are transcribed.*
- *You may refuse to answer any question or withdraw from the study at any time.*
- *We understand how important it was that this information was kept private and confidential. We will ask participants to respect each other's confidentiality.*
- *If you have any questions now or after you have completed the session, you can always contact a study team member like me whose names and phone numbers are on this form.*

Introduction:

1. Welcome

Introduce yourself and the note taker, and send the Sign-In Sheet with a few quick demographic questions (age, gender, cadre, yrs. at this facility) around to the group while you are introducing the focus group.

Review the following:

- Who we are and what we're trying to do

- What will be done with this information
 - Why we asked you to participate
 - If you are a supervisor, we would like to excuse you at this time
2. Explanation of the process: -Ask the group if anyone has participated in a focus group before. Explain that focus groups are being used more and more often in health and human services research.

About focus groups

- We learn from you (positive and negative)
- Not trying to achieve consensus, we're gathering information
- No virtue in long lists: we're looking for priorities
- In this project, we are doing both questionnaires and focus group discussions. The reason for using both of these tools was that we can get more in-depth information from a smaller group of people in focus groups. This allows us to understand the context behind the answers given in the written survey and helps us explore topics in more detail than we can do in a written survey.

Logistics

- Focus group will last about one hour
- Feel free to move around
- Where was the bathroom? Exit?
- Help yourself to refreshments

3. Ground Rules

Ask the group to suggest some ground rules. After they brainstorm some, make sure the following are on the list.

- Everyone should participate.
- Information provided in the focus group must be kept confidential
- Stay with the group and please don't have side conversations
- Turn off cell phones if possible
- Have fun

4. Turn on Tape Recorder

5. Ask the group if there are any questions before we get started, and address those questions.

6. Introductions :-*Discussion begins, making sure to give people time to think before answering the questions and don't move too quickly. We will Use the probes to make sure that all issues are addressed, but move on when the information becomes repetitive*

Questions:

1. Let's start the discussion by talking about your experiences here at this clinic. How long have you been coming to the clinic?

2. Now I'd like to ask about the experiences you had when you learnt about your HIV status, the first time.

How did you learn about your status?

3. Did you ever disclosure counselling at the clinic? Do you remember what the counsellor said to you? (please tell me about that)

-How did you feel, at that time?

-Do you remember what questions you had? If so, tell me, what questions did you ask the counsellor?

-Also please tell me, what questions did you have, that you didn't feel comfortable to ask?

Was there anything you wish was addressed during and after the disclosure counselling by the clinic counsellors?

4. Since then, how have you been coping emotionally with knowing your HIV status?

5. Now I want to ask you some questions about your sources of emotional support. Who do you rely on the most, for emotional support?

What about other kinds of support—who do you turn to?

Who do you tend to talk with the most, about your HIV status?

Let's talk about your support at home. How supportive are your family?

For those of you who feel support from your family, how do they support you?

Let's talk about friends at home or at school. Are you able to be open with your friends about your HIV status? Tell me about that.

7. Was there anyone who doesn't support you, but you wish they did?

-What makes it hard to talk with these people?

Has anyone here ever experienced HIV stigma? (raise hands) Tell me about it, please.

How did it make you feel?

8. What are some things that you do to cope with the stress that we feel because of stigma?

9. Now let's talk about ARVs. Tell me about what it was like for you to start taking ARVs.

What was hard about it?

What are some of the things that made you want to take your ARVs?

Are there times you feel like not taking your ART?

If so, when?

What makes you feel that way?

What do you think would make it easier for you?

10. How are you feeling about going to the adult clinic when the time comes?

What concerns do you have?

If it happened again do you feel equipped to handle it or do you feel you would like help in this area?

11. What do you feel you need to know more about, to be able to stay healthy?

Are there areas about your health ...you were discussed more at the clinic? If so which ones?

Are there areas about your health ...you wish were discussed more at the clinic? If so which ones?

12. Where do you see yourself 5 years from now?

Are there challenges you think you might face associated with your HIV status? Was so which are these? Can you tell me more?

13. Ok we are winding up now .do you think if we had a group discussion where we talked about the areas you brought over the holidays it would be helpful

If so how often would you like the sessions to be?

Any challenges you can think off that might prevent you from attending the sessions?

Probes for discussion:

- *Family member's HIV status and perceived support.*
- *Barriers to adherence*
- *Any discrimination and by whom*
- *Areas deficient in information*

That concludes our focus group. Thank you so much for coming and sharing your thoughts and opinions with us. We have a short evaluation form that we would like you to fill out if you time. If you have additional information that you did not get to say in the focus group, please feel free to write it on this evaluation form.

Appendix IX: Ethical Approval KNH/UON ERC



UNIVERSITY OF NAIROBI
COLLEGE OF HEALTH SCIENCES
P O BOX 19676 Code 00202
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KENYATTA NATIONAL HOSPITAL
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Ref: KNH-ERC/ Mod&SAE/388

19th November, 2018

Dr. Nyawira Gitahi-Kamau
INTROMID
KEMRI

Dear Dr. Nyawira

Re: Approval of modifications– study titled “Evaluation of clinical and psychosocial outcomes after life skills provision among perinatally-infected adolescents receiving care at Mbagathi Hospital Comprehensive Care Centre” (P766/10/2016)

Your response of 1st November 2018 refers.

Upon review of the revised document, the KNH-UoN ERC has **approved** the following modifications;

- 1) Change of study site from Kenyatta National Hospital to Mbagathi Hospital Comprehensive Centre.
- 2) Inclusion of self-esteem as a psychosocial measure (Appendix J).
- 3) Use of computer assisted self administered interview technique, instead of interviewer administered questionnaire.

Noted that Dr. Peter Muiruri is already a co-investigator in the above study.


The study tools are hereby endorsed and stamped for use.

Yours sincerely,

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

c.c. The Principal, College of Health Sciences, UoN
The Director CS, KNH
The Chair, KNH-UON ERC

Yours sincerely,



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

c.c. The Principal, College of Health Sciences, UoN
The Director, CS, KNH
The Chair, KNH- UoN ERC
The Assistant Director, Health Information, KNH
Supervisors: Prof. Elizabeth Bukusi (KEMRI), Dr. Kenneth Ngunjiri (J.K.U.A.T)

Protect to discover



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The study tools are hereby endorsed and stamped for use.

Yours sincerely,

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

c.c. The Principal, College of Health Sciences, UoN
The Director CS, KNH
The Chair, KNH-UON ERC

Appendix X: Nairobi County Approval

NAIROBI CITY COUNTY

Tel: 2724712, 2725791, 0721 311 808
Email: mbagathihosp@gmail.com



Mbagathi Hospital
P.O. Box 20725- 00202
Nairobi

COUNTY HEALTH SERVICES

25th June 2018

Dr. Nyawira Gitahi- Kamau
ITROMID KEMRI

Dear Madam,

RE: RESEARCH COMMITTEE VERDICT

This is in reference to your application for authority to carry out a research on *"Evaluation of clinical and psychosocial outcomes after life skills provision among perinatally HIV-infected adolescents receiving care at Mbagathi Hospital"*

Having gone through your protocol, the research committee has no objection provided that you capture Mbagathi Hospital as one of the sites in your study. The ethical approval should also capture the same information.

On completion of the research you are expected to submit one hard copy and one soft copy of the research report / thesis to this office.



Philip Mibei
For: Chairman – Research Committee
Mbagathi Hospital



Appendix XI: Publications from this work

PLoS One Published: July 29, 2020

<https://doi.org/10.1371/journal.pone.0233451>

Psychosocial needs among older perinatally infected adolescents living with HIV and transitioning to adult care in Kenya.

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ABSTRACT

Background: Little data is available on the long-term psychosocial effects of disclosure of HIV status that may occur in late adolescence, even when disclosure is timely. Moreover, few studies have described the post-disclosure psychosocial needs of older adolescents who experience delayed disclosure. This study sought to address existing knowledge gaps in the post-disclosure experiences and psychosocial needs of older adolescents living with HIV (ALWHIV).

Methods: We conducted focus group discussions (FGDs) and in-depth interviews (IDIs) among older perinatal infected adolescents aged 16-19 years. We collected socio-demographic data and baseline viral load (copies/ml) results for the preceding six months using interviewer-administered questionnaires and clinical notes abstraction. We analysed data inductively and deductively to identify themes related to the experiences and expectations of adolescents with the disclosure and post-disclosure period.

Results: Adolescents who reported having received timely disclosure expressed that as they grew older, they began to comprehend the lifelong repercussions of an HIV diagnosis and experienced a re-emergence of the negative feelings similar to those experienced during the post-disclosure period. Those who received the knowledge of their HIV status during late adolescence experienced prolonged periods of negative self-perception and anger at not receiving their HIV status earlier. They also expressed a need for more information during the disclosure process on the prevention of onward transmission of the virus, safe conception practices resulting in HIV negative children, and information on how to disclose their HIV status to sexual partners or peers. Anticipated stigma was experienced universally by these older adolescents and was a major barrier towards adherence and coping with an HIV status. Caregivers or siblings with a similar HIV status were a source of social support. Adolescents felt that the support of peers (ALWHIV) helped them to accept their HIV status and to learn how to develop a positive outlook on life.

Conclusion: Provision of psychosocial care in late adolescence during the transition to adult care is critical in ensuring the resolution of re-emergent negative emotions. Comprehensive information on HIV prevention and sexual reproductive health should be a crucial component of post-disclosure care for older adolescents. HIV Disclosure and adolescent transition guidelines should include these components to optimize psychosocial care for older adolescents.

Keywords: disclosure, Perinatal, HIV, adolescents, psychosocial care, transition

Introduction

There are 1.3 million adolescents aged 10 to 19 living with perinatally acquired HIV infection in the sub-Saharan African region (1),(2),(3),(4). They often have to balance coping with psychosocial challenges, maintaining adherence to ART and learning to negotiate sexual relationships (5),(6),(7). Studies report that the highest morbidity and mortality rates among PLWHIV are among older adolescents (15-24 years old) and young adults of the age to be transitioning to adult care (i.e., care for individuals >25 years old) (8).

The transition of adolescents has been described as a purposeful, planned process that addresses the medical, psychosocial, educational, and vocational needs of adolescents

and young adults with chronic medical conditions. to advance them from a pediatric and family-centered to an adult, individual-focused health care provider (9). This process is often hindered by the sub-optimal psychological preparation of the adolescents, which begins with the disclosure of their HIV status (10).

The WHO guidelines on disclosure and post-disclosure psychosocial support for HIV infected children recommend timely incremental disclosure beginning at age seven, a process which should be completed by age 12 (11). This guidance has not incorporated recommendations on post-disclosure support, where disclosure is delayed or on the content that should be addressed during the period of transition. A review of data from eleven countries, primarily from sub-Saharan Africa reported rates of disclosure by the age of 12 that ranged from 0.1% to 50% (12). A study from Kenya reported that 36% of adolescents knew about their HIV status by the age of 12 (13), which indicates that the disclosure of HIV status for the majority of adolescents and young adults currently in care occurred during mid to late adolescence (14-19)years of age (12,13). This is despite the existing evidence that timely disclosure improves adherence to ART (7,14 ,15) and facilitates the development of coping skills among adolescents living with HIV (16,17,18,19). With the current data suggesting that disclosure timing is often delayed (after the age of twelve), post-disclosure experiences and psychosocial needs of older adolescents are largely undescribed. This knowledge could guide recommendations on how to strengthen current guidelines on disclosure to suit the needs of older adolescents and young adults transitioning to adult HIV care. The objective of this study was to explore the circumstances surrounding the phenomena disclosure process, post-disclosure emotional experiences, expectations and informational needs of older ALWHIV during the transition to adult care.

METHODOLOGY

Study design

We carried out a cross-sectional qualitative study. The findings in this paper are part of a larger mixed-methods study that explored the psychosocial needs of adolescents during the transition to adult care. In this paper, we present the results of our analysis of data from focus groups (FGDs) and individual semi-structured interviews (IDIs) and describe the disclosure process, the post-disclosure feelings and unvoiced or voiced expectations of our adolescent participants.

Study setting

The study was conducted in two high-volume urban HIV clinics that were purposively selected: Mbagathi Hospital and Kenyatta National Hospital in Nairobi, the capital city of Kenya. We use the following selection criteria: 1) clinics that were well-established in

paediatric HIV care over the previous 15 years, and 2) clinics that were currently providing HIV treatment to large cohorts of perinatally infected ALWHIV.

Sampling and recruitment

During routine clinic visits, we screened ALWHIV for study eligibility. The study criteria included being 16 to 19 years of age, documented perinatal infection, and enrolment into HIV care and ART for at least three years. We explained the objectives of the study during the informed consent process.

As part of the larger mixed-methods study, during study enrolment we collected: 1) socio-demographic data, including the HIV status of the caregiver (primary caregiver indicated in the inpatient medical file) and of siblings; 2) medical history, time of disclosure (timely disclosure was defined as having occurred before the age of 12), duration of ART and viral load; and 3) psychosocial measures, such as the experience of stigma, ART self-efficacy, and self-esteem.

We collected these data with a combination of interviewer-administered questionnaires and chart abstraction. We confirmed perinatal infection through review of clinic records for a record of HIV DNA or antibody tests within the postnatal and infancy period or by using a composite proxy, i.e., clinic enrolment during early childhood and or duration of more than three years on ART and documented positive HIV status of the mother where available. These proxies were used to determine perinatal infection where there was no documentation of an infant PCR or HIV antibody testing in the clinical notes. Often in poor resource settings, paper-based medical records documenting an initial HIV diagnosis that occurred over a decade before may no longer be available, hence the need to include proxies.

We enrolled youth into FGDs based on sex and viral load. The rationale for stratification by sex was to decrease the inhibition of participating adolescents who often exhibit high self-awareness and self-consciousness, particularly in the presence of the opposite sex. We separated groups by viral load to provide a safe environment for adolescents to speak about any psychosocial issues or other factors related to poor adherence without fear of judgement from peers who may not have experienced these challenges. We conducted FGDs in these four sub-categories. After a preliminary analysis of the data from the FGDs, we held IDI's with participants who were enrolled by did not take part in the FGDs

Data collection

We collected data in December 2017 and December 2018 during the long school holidays as the majority of the adolescents were in boarding schools. Using pre-tested structured topic guides the FGDs provided a forum for participants to share, compare,

and contrast their experiences regarding their experiences with disclosure with their peers. In contrast, IDIs provided individual adolescents with an opportunity to reflect and provide rich, detailed descriptions of their disclosure experiences. We conducted 8 FGDs (n=48) and after a preliminary analysis to determine saturation, subsequently conducted 10 IDIs with ten additional participants.

Four social science graduate research assistants (three females and one male) trained in qualitative research and experienced in conducting interviews with adolescent's qualitative data collection), train. We employed non-clinically-trained research assistants who had not interacted with the adolescents to reduce the risk of social desirability bias. The study involved a single contact with each study participant, during which the interviewer provided an overview of the study objectives, and obtained informed consent from the participant before proceeding with the FGD or IDI. The study received ethical approval from the Kenyatta National Hospital /University of Nairobi Ethical and Research committee. We obtained written informed consent from all participants and their caregivers. No youth approached for participation refused to do so.

The FGD and IDI guides explored the adolescents' experiences during the disclosure process, any expectations they had, whether they had any unvoiced concerns or questions, and what emotions they experienced post the disclosure process. Using pre-tested structured topic guides the FGDs provided a forum for participants to share, compare, and contrast their experiences regarding their experiences with disclosure with their peers. In contrast, IDIs provided individual adolescents with an opportunity to reflect and provide rich, detailed descriptions of their disclosure experiences. Interviews and focus groups were audio-recorded. Focus groups lasted 60 to 90 minutes, while interviews lasted 30 to 45 minutes. Participants were reimbursed for their transport to the clinic and provided with snacks.

Data analysis

We conducted a thematic analysis of our data. Using a deductive and inductive approach, the process of transcription and reading of the transcripts provided an insight into emerging themes and was an essential part of preliminary data analysis. During the data collection period, the research team held biweekly meetings during which researchers compared notes and shared their understanding of the emerging themes. We used a codebook to define a priori codes generated from the FGD and IDI guides, which were later supplemented by codes emerging from the transcripts themselves. Once the codebook was completed, coding was carried out independently by two individuals with discussions held with the research team regarding any differences that emerged.

To complement the coding process, we reviewed socio-demographic profiles of the participants from the quantitative data to elicit the context of the participant's views. Transcripts and corresponding quantitative data were uploaded into Dedoose software

version 8.2.27, to enable more systematic management, coding and retrieval of data. We considered questions of reflexivity throughout the study period, identifying and reflecting on our assumptions and preconceptions regarding the anticipated post-disclosure emotions. During the analysis, we explored comparisons by viral load, gender and time of disclosure. These comparisons did not come out clearly except for the time of disclosure, and therefore, we have not presented the findings according to these stratifications. This study used the Consolidated criteria for reporting qualitative research (COREQ) (20)

RESULTS

Baseline data

Fifty-eight adolescents participated in either the FGDs (19 females and 29 males) or IDIs (6 females and 4 males), of whom 27 were virally suppressed, and 31 unsuppressed). Their median age at the time of disclosure was 13 years (IQR (13-16)). Only 9 participants reported having two living parents.

Qualitative findings

We identified five major themes: the adolescents' perception of the disclosure process, Antiretroviral adherence and disclosure, post-disclosure feelings, post-disclosure support needs for older adolescents and post-disclosure coping differences. Under the theme post-disclosure feelings, we identified sub-themes; the role of peer and family support, post-disclosure perceptions among adolescents who experienced delayed disclosure versus those with timely disclosure and barriers and facilitators of coping after disclosure of HIV status.

The Disclosure process

A majority of the adolescents reported that their status had been disclosed to them between the ages of 13 and 16. They shared that disclosure was generally unplanned and often triggered by an event such as the occurrence of an opportunistic infection due to poor adherence, or because caregivers suspected that the adolescent was engaging in risky behaviour.

“I got sick and was taken to the hospital. I was almost 14 yrs. I don't know what my mum was told, but I know we had to go to that hospital regularly. I was started on drugs. I didn't take them. I think that's when they knew they had to tell me” (male, 17 yrs.).

‘I knew about my status in form one (15 years). I fell ill and had sores on my back and all over my body... I turned out HIV positive while my sister was negative... I

remember asking her what that meant, and she told me to ask the doctor' (female, 17 yrs.).

"I was 15 years. How I found out is that one day I went out and came home late and my mum told me why are you disturbing me and yet you are HIV positive? Now at the time, I didn't take it seriously...that's how I got to know" (male, 16 yrs.).

The adolescents also described self-discovery of their HIV status, usually associated with reading HIV-related posters or medical records during clinic visits. Interestingly, self-disclosure was more common among male participants. They expressed that they did not discuss their HIV status knowledge with their caregivers who continued accompany them to the clinic for routine care.

"I was walking around the hospital, and I would look at the posters...That's how I knew. I didn't tell them, though, that I knew. I was 13 years" (male, 16 yrs.).

"When I was 15 years, my dad left me with my medical file to hold, and I snooped and found that I was HIV positive... I confirmed some of the terms on Google and confirmed my status. I never told him I knew my status. Sometimes when he yelled at me, I felt like telling him that I know I am HIV positive... but I keep it to myself because I didn't want to look like I am snoop, so I kept it to myself" (male, 18 yrs.).

Antiretroviral adherence and disclosure

There was universal agreement among participants that knowledge of one's HIV status contributed to enhanced adherence to antiretroviral therapy. The adolescents reported that learning about their HIV status empowered them to understand the consequences of not adhering to medication. They also expressed that knowledge that a parent, relative, or peer died of HIV-related complications enhanced their resolve to adhere to medication and remain free of opportunistic infections.

"I prefer knowing my status because once you know your status, you have to work towards making sure you are okay, and you are healthy and so that you can be strong to move on."

(female 18 yrs.).

"My dad told me 'there is something I want to tell you, but don't be so shocked,' I asked 'What?' "The drugs that you take are for HIV." I said, "Me, I have HIV, and the way I am healthy?" He told me yes. I asked him where it came from. He told me that my mom had it, and you know my mom had died. I started taking drugs, and I have never stopped" (male 19 yrs.).

“I was told that I have to adhere to my medication, and I took it seriously after seeing that guy I was talking about ...who didn’t adhere to his medication, and he ended up dying. So the doctor told me that I should adhere to my drugs. I don’t want to end up like Dennis, that really scared me, and I decided to take my medication continually.” (female, 16yrs.)-).

The disclosure process was not accompanied by standardised information on the importance of ART adherence, including among older adolescents. Even among ALWHIV who learned about their HIV status at a young age, adherence was still a challenge. They were only able to fully comprehend the importance of adherence in ensuring good health outcomes as they grew older.

I: Were you told about adherence on the day they disclosed your status to you?

R1: Yes. I remember when I was young, my mum used to remind me constantly to take them on time. Initially, I didn’t understand why, but with time I got used to it.

I: Do you think such information should have been shared to you on the same day you were told about your status?

R1: Not all it depends on the doctors you find on duty.

I: Anyone else?

R2: I was not told the same day; I was told later on.

I: Were you told immediately?

R2: Yes, I was told everything immediately.

(FGD, Females)

Post disclosure feelings

The role of peer and family support

Where present, family or caregiver support played a significant role in facilitating the transition from first disclosure of HIV status to developing the internal drive to stay healthy by adhering to medication. ALWHIV, who had a supportive adult in their home or school environment was better equipped to cope with their HIV status. Additionally, the presence of a caregiver or sibling with a similar HIV status resulted in increased openness in sharing their challenges.

“Since I have been getting the support, I am okay. I have accepted my status, and it’s okay. My aunty gives me support, and another matron in school also supports me. I love my parents and my dad and my sister, and they also give me support by making me strong” (female, 18yrs.).

“I don’t speak to my brothers about my status, I am close with my mum, and we talk about my status since we are both HIV positive” (male, 17yrs.).

Barriers and facilitators of coping after disclosure of HIV status

A significant barrier to coping with the knowledge of one’s HIV status was a lack of candid conversations about the circumstances of the adolescents’ HIV acquisition and that of their parents. Participants who did not have siblings who were living with HIV also struggled with accepting their HIV status.

Participants also shared that they were able to cope thanks to the support and acceptance offered by their friends and other ALWHIV within support groups. Interestingly, participants who practised or believed in spirituality also felt that this had contributed to enabling them to cope with the knowledge of their HIV status. (Table 1).

Table 1: Barriers and facilitators of coping after disclosure of HIV status

BARRIERS/ FACILITATORS TO ACCEPTANCE	PARTICIPANT QUOTES
FACILITATORS:	
Spirituality and religion	“No, I believe that in this world, many things happen and this is what God thought I could handle, and that is my reasoning for this” (female, 17 yrs.).
Perception of being in control of one owns health	“I prefer knowing my status because once you know your status, you have to work towards making sure you are okay, and you are healthy and so that you can be strong to move on” (female, 17 yrs.).
Friends, peer support groups and acceptance by other ALWHIV	“I learnt from the support group that I have been attending, and I listened to the information that was shared during those sessions by youth like me, and I realised that I have nothing to worry about and I can still live a healthy life regardless of my status” (female, 16 yrs.).
BARRIERS:	
Being the only HIV positive sibling	“I used to get stressed, in the past, but these days I am comfortable with my status. I was stressed just thinking why I was the only child in my family that was infected yet all my siblings are negative” (male, 17 yrs.).

Lack of information on how parents were infected and how HIV was transmitted to themselves “Actually, I have always wanted to ask my dad what happened and how come my mum died as a result of HIV. It makes me sad we have never talked about” (female, 17 yrs.).

Re-emergence of negative post-disclosure feelings by adolescents who received timely disclosure

Adolescents who received up-to-date knowledge of their HIV status (between ages 7 and 12) reported having coped well immediately after disclosure. However, they described feelings of anger and hopelessness arising in later years. These adolescents said that they often faced internal struggles with self-stigma and worried about the impact of HIV on their future relationships.

“I didn’t feel bad because I didn’t really understand much... but gradually, after understanding what it meant to have HIV, I felt bad... I didn’t tell anyone my feelings” (male, 18 yrs.).

“I was young; I just listened and took my meds; now I understand this thing. I wonder how I got it - was it my dad or my mum who brought it, and how other people will see, what if other people know that I am HIV positive? What will be their reaction? Other youths or teens who do not know about my HIV status?” (female, 17 yrs.).

Post-disclosure feelings among adolescents who experienced delayed disclosure

Participants who experienced delayed disclosure (after 12 years), reported immediately feeling anger and disappointment about their status. These strong feelings took more than a year to resolve. Among those who reported delayed disclosure (after age 12), participants agreed that the process of self-acceptance was prolonged and that their ideal time of disclosure would have been when they were younger, as they felt it would have been easier to accept. Participants also expressed that acceptance of their HIV status was a significant barrier to adherence.

“I would want to be told when I was like in class 3 (9 years) because that is when I would have accepted well, then she would have taken me through a process where I would have accepted myself how I am” (female, 17 yrs.).

“If they told me early on about my status, it would not have taken me that long to accept my situation. I was told when I was in class 6 (12 years), and I took up to 2 years to accept myself, and I started feeling that my mother didn’t love me because if she did, then she would have told me earlier on” (male, 16 yrs.).

Participants expressed concerns about the future, in particular regarding marriage, onward transmission and acceptance from peers and in their future relationships.

“What if my wife were to find out that I am HIV positive?” (male, 18 yrs.).

“I would like to have been told more about marriage. How you can live with your wife and the children not get infected and how you can get a negative family” (male, 17 yrs.).

Disclosure was often delayed due to anticipated stigma by the caregivers or parents towards the child. The adolescents agreed that this constant fear of stigma further fuelled their feeling of low self-worth and anticipated lack of acceptance by peers (Table 2). Participants eventual acceptance was facilitated by access to knowledge about HIV and its life-long management. Often, respondents chose to keep their feelings and questions to themselves upon discovering their HIV status. One typical unvoiced question was the genesis of their infection. Participants hesitated to ask out of a desire to protect their caregivers emotionally. These questions largely remained unresolved until late adolescence. Participants often also hid their despair even from immediate family or caregivers.

Table 2: Post-disclosure negative feelings among adolescents with delayed disclosure (illustrative notes)

Anticipated stigma
“After my status was disclosed to me, I wanted to lock myself in the house, I didn’t feel like coming out of the house, and at that time there was a lot of stigma that I didn’t want to hear about and that most people did not have the information. But now I feel better, and that is due to talking to several people over time” (female, 16yrs).
“No, because when you are young, you can talk and disclose your status, so they lied to me that I was taking drugs to cure a cold” (female, 17yrs.).
“I felt that I was in another world, so when I look at my brother, I feel like they are in another world and I am in another world. So there are two worlds” (male, 16 yrs.)”
A prolonged period of a negative perception of self
“It was not good, and I kept thinking about this life of having to take medicine the rest of my life, but after counselling, I went back home pretending to be happy but deep inside I was not happy. Before I was told I was social, and I had no fear, but after being told my status, I became less social and quieter. It took me like three years to cope and be able to take medicine without feeling anything” (male, 18 yrs.).
Concerns about the future
“Before I didn’t think about it. But now, it bothers me. What if my wife-to-be found out that I am HIV positive? ... I will tell her when the time is right, but It is a concern. It’s just that one question” (male, 16 yrs.).
Suppression of post-disclosure feelings

“I have never asked her, there are many questions that I cannot just confront her about it, I look at her, and I don’t know what to ask her. I don’t want to confront her with how I contracted this disease, what did she do or didn’t do? I don’t know maybe she was innocent, and it’s my dad who had it and infected her, so there are many things that I am not sure I want to confront her. So I decided to keep quiet” (male, 17 yrs.).

Post-disclosure coping differences

Participants reported distinctly different reactions to how they coped and expressed their emotional responses to the post-disclosure experience. A majority of participants expressed initial feelings of despair and hopelessness in the immediate post-disclosure period. One female respondent said: “Truthfully.... it was painful. It was bad!”. However, some exceptional participants reported that they coped well and appeared to accept the information. These participants reported that they did not experience strong emotional responses after learning about their HIV status.

“I knew it in 2014 when a certain doctor here told me not to be afraid, but he didn’t tell me anything else. Then when we got in, he talked to me and then told my mom to go outside, so when he told me I was not shocked because we had been taught that HIV is not the dangerous disease. After all, cancer is worse than HIV. So I didn’t panic” (male, 17 yrs.).

Disclosure and post-disclosure support needs for older adolescents

Respondents who experienced delayed disclosure (above 12 years) expressed the need to have a direct approach to discussions around their HIV status. During disclosure, adolescents reported a preference in shorter uninterrupted sessions that provided concise information on the chronic nature of HIV and the need to take lifelong medication. They also felt that they should have been affirmed and educated on the relatively healthy life one could live with regards to their dreams and aspirations despite being HIV positive.

Additionally, participants across time of disclosure expressed the need to continue receiving information updates and counselling sessions during routine clinic appointments. They felt that this would provide an opportunity for them to voice their concerns, questions and dynamic challenges as they emerge. Information requested included HIV prevention methods.

“I think when we come for our results, they should not make the counselling session too long. It tortures me more. They should make it short and to the point. Like she was told, it was chest problems while it was not. It’s better you tell me straight up, then I figure out how to cope with it” (female, 17 yrs.).

“My future... When you were told that you are positive, you feel as if your future is coming to an end. I wish they told me that my future is going to be bright, and I will succeed. I wish they told us more about the drug. And how long I would have to be on treatment” (female, 16 yrs.).

DISCUSSION

This article presents new findings regarding the disclosure experiences, perceptions of the disclosure process, and post-disclosure psychosocial needs among perinatally HIV-infected adolescents. To the best of our knowledge, this is the first paper that has attempted to document the views of older adolescents transitioning to adulthood. Additionally, this study brings new perspectives on the disclosure process by comparing the opinions of adolescents who had optimally-timed disclosure versus those with delayed disclosure. The psychosocial issues among ALWHIV as a result of delayed HIV disclosure, have been described in the literature (21,22,23). This paper provides a unique opportunity to document arising issues from the perspective of older adolescents when a delay in HIV disclosure occurs and recommendations towards improvements in the post-disclosure psychosocial care package during the transition of adolescents to adult care.

Overall, this study found that most participating adolescents had received disclosure between the ages of 13 and 16 years. Similar to the sentiments expressed by other adolescents in other African countries, including South Africa, Zambia and Zimbabwe, Kenyan adolescents described initial distress, then shock after disclosure. Similarly, they also desired accurate information about their illness (23,24,25,26). In these studies, adolescents described having ‘coped’ with the knowledge of their status and having adjusted well clinically and emotionally.

A new finding from our research was that even in cases when disclosure was timely, adolescents had an initial apparent positive coping response, followed by a re-emergence of negative post-disclosure reactions during late adolescence. In contrast, studies among adolescents in sub-Saharan Africa (27,23,25) reported post-disclosure initial distress followed positive coping in the immediate post-disclosure period among younger adolescents ages (11-13). These studies primarily focussed on younger adolescents, in this study, as the adolescents grew older, they experienced a re-emergence of negative emotions and grave concerns about the impact of their HIV positive status on relationships with sexual partners and peers (24,23). The findings of our study are further supported by studies reporting the mental health and psychosocial issues experienced by adolescents living with HIV who are aware of their status. These psychosocial issues include post-traumatic stress disorder, depression, and severe anxiety (2,3).

While the psychosocial issues related to delayed disclosure are an expected finding, the re-emergence of post-disclosure negative emotions among those whose disclosure timing was optimal (before age 12), as recommended by current guidelines, was unexpected. A probable explanation for this is that most studies have focused on populations that had larger numbers of their study participants in the early adolescence (10 to 14 years of age). Available literature indicates this difference in age may explain the findings of a re-emergence of post-disclosure feelings in this study, for developmental reasons. Often, there is also a higher level of self-awareness, coupled with the need to be accepted by peers in late adolescence (25,26,28). In our study, this finding was corroborated by the requests of older adolescents in the clinical setting for additional psychosocial support as they began to comprehend the implications of their HIV status fully, particularly concerning their sexuality and relationships with peers and sexual partners (28). Another possible contributing reason for this phenomenon may be the lack of clear stepwise guidance for the provision of long-term post-disclosure support, and the lack of knowledge regarding how to modify existing guidance to address the specific needs of adolescents who receive disclosure during mid-or late adolescence.

In this study, adolescents described experiencing re-emergent negative post-disclosure feelings during late adolescence that interfered with their adherence. The occurrence seemed to dilute the expected effect of disclosure on adherence and positive living. This finding is consistent with the literature and indicates psychosocial stressors contribute to poor adherence in older adolescents (28, 13)

If not addressed, these psychosocial stressors result in poor outcomes after the transition to adult care despite the disclosure of HIV status (12).

Peer support was identified as key in the acceptance of adolescents' HIV status. Existing literature indicates that perceived social support was a facilitator of coping in the period after disclosure of HIV status to adolescents (11). Our findings suggest that peer influence in late adolescence was a strong facilitator in positive coping with the knowledge of one's HIV status. Available evidence describes the crucial importance of peer influence in this period as the drive for self-autonomy and independence emerges (28,31,32) and the decisive role by peer-led interventions in providing adolescent responsive psychosocial support (32).

These findings present a strong argument for the need to strengthen the current WHO disclosure guidelines with clear, concise guidance to health workers on the content of continuous post-disclosure psychosocial care. There is also a need to address specific psychosocial care content for adolescents who experience delayed disclosure by providing comprehensive information on HIV prevention, sexual reproductive health and life skills on coping with the HIV status. This finding is in keeping with the current guidelines, which recognises that disclosure is not a one-time event(11). We recommend

that any guidance developed for health workers regarding continued psychosocial support for adolescents transitioning to adult care include a strong peer-support component.

A strength of this study is that it did not restrict itself to adolescents who had either reduced or optimal clinical outcomes as described by their viral load status. This inclusion is essential, as self-management with adherence to ART is a crucial goal of adolescent transition to adult care. A limitation of this study is that our sample only selected adolescents with perinatal infection who would benefit the most from a robust psychosocial support system during the transition to adult care due to the often long duration of ART they have already experienced as children. The experiences of perinatally infected adolescents are distinct from those youths who acquired HIV from sexual transmission. However, with a majority of the HIV infections occurring among adolescents and young people, the experiences of those with the sexual acquisition of HIV would be useful. They should comprise an important research question in future. Another limitation was that our study only focused on adolescents within urban settings and may not be generalizable to those in rural settings. The perceptions and experiences of the caregivers would also have been useful in collaborating and enhancing our understanding of the re-emerging psychological issues of the adolescents and what environmental factors were present. Due to limited resources, we were not able to include caregivers in our study.

CONCLUSION

In this study, we found that post-disclosure support is a psychosocial need that extends long after the actual disclosure has occurred. As most disclosure takes place beyond the recommended age, there is a need for the current guidelines to address knowledge and disclosure of HIV status during late adolescence. The content should include comprehensive HIV knowledge, life skills training that emphasizes self-acceptance, and a focus on empowering the adolescents to undertake disclosure within relationships. Interventions focussing on adolescents' transition to adult care should address re-emergent negative emotional responses and include a strong peer component.

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AUTHORS

NG, CC, CA, EB, and conceptualized the manuscript, NG-and CC developed the methodology and tools, NG and VM collected data and analysed the data and wrote the manuscript & EB, KN, CC and CA provided input and critically reviewed the manuscript.

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AUTHORS' COMPETING INTERESTS

All the authors declare that they have no conflicts of interest. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

REFERENCES

1. UNAIDS. Ending the AIDS epidemic for adolescents, with adolescents. 2016; Available from: <http://www.unaids.org/en/resources/documents/2016/ending-AIDS-epidemic-adolescents>
2. Hawkins A, Evangelic M, Sturgeon K, Le Prevost M, Judd A. Episodic medication adherence in adolescents and young adults with perinatally acquired HIV: A within-participants approach. *AIDS Care - Psyche Socio-Medical Asp AIDS/HIV*. 2016 Mar 24; 28:68–75.
3. Leventhal ED, Bakeera-Kitaka S, Marukutira T, Chapman J, Goldrath K, Ferrand RA. Perinatally acquired HIV infection in adolescents from sub-Saharan Africa: A review of emerging challenges. Vol. 14, *The Lancet Infectious Diseases*. Lancet Publishing Group; 2014. p. 627–39.
4. WHO. World Health Organization - Health for the world's adolescents a second chance in the second decade [Internet]. Geneva: World Health Organisation. 2014. p. Online. Available from: <http://apps.who.int/adolescent/second-decade/>
5. Sohn AH, Hazra R. The changing epidemiology of the global paediatric HIV epidemic: Keeping track of perinatally HIV-infected adolescents. Vol. 16, *Journal of the International AIDS Society*. 2013.

6. Petersen I, Bhana A, Myeza N, Alicea S, John S, Holst H, et al. Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: A qualitative investigation. In: *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*. 2010. p. 970–8.
7. Rudy BJ, Murphy DA, Harris DR, Muenz L, Ellen J, Adolescent Trials Network for HIV/AIDS Interventions. Patient-related risks for nonadherence to antiretroviral therapy among HIV-infected youth in the United States: a study of prevalence and interactions. *AIDS Patient Care STDS* [Internet]. 2009 Mar [cited 2019 Sep 9];23(3):185–94. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/19866536>
8. UN Joint Programme on HIV/AIDS (UNAIDS). The Gap Report. Geneva: UNAIDS [Internet]. 2014; Available from: <https://www.refworld.org/docid/53f1e1604.html>
9. Carrizosa J, An I, Appleton R, Camfield P, Von Moers A. Models for transition clinics. *Epilepsia* [Internet]. 2014 Aug 1 [cited 2020 Feb 26];55(s3):46–51. Available from: <http://doi.wiley.com/10.1111/epi.12716>
10. Lam PK, Fidler S, Foster C. A review of transition experiences in perinatally and behaviourally acquired HIV-1 infection; same, same but different? Vol. 20, *Journal of the International AIDS Society*. International AIDS Society; 2017.
11. WHO. Guideline on HIV disclosure counselling for children up to 12 years of age. 2011 [cited 2019 Sep 9];1–46. Available from: <http://www.who.int/about/>
12. Britto C, Mehta K, Thomas R, Shet A. Prevalence and Correlates of HIV Disclosure among Children and Adolescents in Low- and Middle-Income Countries: A Systematic Review. *J Dev Behav Pediatr*. 2016 Aug 1;37(6):496–505.
13. Ngeno B, Waruru A, Inwani I, Nganga L, Wangari EN, Katana A, et al. Disclosure and Clinical Outcomes Among Young Adolescents Living With HIV in Kenya. *J Adolesc Heal*. 2019 Feb 1;64(2):242–9.
14. Spicer N. *Global Health : SCIENCE AND PRACTICE*. 2015;42(3):89–99.
15. Nglazi MD, Kranzer K, Holele P, Kaplan R, Mark D, Jaspán H, et al. Treatment outcomes in HIV-infected adolescents attending a community-based antiretroviral therapy clinic in South Africa. *BMC Infect Dis*. 2012 Jan 25;12.
16. Brown LK, Lourie KJ, Pao M. Children and adolescents living with HIV and AIDS: a review. *J Child Psychol Psychiatry* [Internet]. 2000 Jan [cited 2019 Sep 9];41(1):81–96. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/10763677>
17. Schenk KD, Michaelis A, Sapiano TN, Brown L, Weiss E. Improving the lives of vulnerable children: Implications of horizons research among orphans and other children affected by AIDS. Vol. 125, *Public Health Reports*. Association of Schools of Public Health; 2010. p. 325–36.
18. Mburu G, Hodgson I, Teltschik A, Ram M, Haamujompa C, Bajpai D, et al. Rights-based services for adolescents living with HIV: Adolescent self-efficacy and implications for health systems in Zambia. *Reprod Health Matters*. 2013 Jun;21(41):176–85.

19. Midtbø V, Shirima V, Skovdal M, Daniel M. How disclosure and antiretroviral therapy help HIV-infected adolescents in sub-Saharan Africa cope with stigma. *African J AIDS Res.* 2012;11(3):261–71.
20. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups | The EQUATOR Network [Internet]. [cited 2019 Oct 4]. Available from: <http://www.equator-network.org/reporting-guidelines/coreq/>
21. Vranda MN, Mothi SN. Psychosocial issues of children infected with HIV/AIDS. Vol. 35, *Indian Journal of Psychological Medicine.* Wolters Kluwer -- Medknow Publications; 2013. p. 19–22.
22. Santamaria EK, Dolezal C, Marhefka SL, Hoffman S, Ahmed Y, Elkington K, et al. Psychosocial implications of HIV serostatus disclosure to youth with perinatally acquired HIV. *AIDS Patient Care STDS.* 2011 Apr 1;25(4):257–64.
23. Woollett N. Adolescents Living with HIV: Emerging Issues in Public Health in South Africa. In 2016. p. 65–88.
24. Kidia KK, Mupambireyi Z, Cluver L, Ndhlovu CE, Borok M, Ferrand RA. HIV status disclosure to perinatally-infected adolescents in Zimbabwe: A qualitative study of adolescent and healthcare worker perspectives. *PLoS One.* 2014 Jan 27;9(1).
25. WHO | IMAI one-day orientation on adolescents living with HIV. WHO. 2011;
26. Hodgson I, Ross J, Haamujompa C, Gitau-Mburu D. Living as an adolescent with HIV in Zambia-lived experiences, sexual health and reproductive needs. *AIDS Care - Psychol Socio-Medical Asp AIDS/HIV.* 2012 Oct 1;24(10):1204–10.
27. Menon A, Glazebrook C, Campain N, Ngoma M. Mental health and disclosure of HIV status in Zambian adolescents with HIV infection: Implications for peer-support programs. *J Acquir Immune Defic Syndr.* 2007;46(3):349–54.
28. Okawa S, Mwanza-Kabaghe S, Mwiya M, Kikuchi K, Jimba M, Kankasa C, et al. Adolescents' experiences and their suggestions for HIV serostatus disclosure in Zambia: A mixed-methods study. *Front Public Heal.* 2017;5.
29. Mburu G, Ram M, Oxenham D, ... CH-C and Y, 2014 U. Responding to adolescents living with HIV in Zambia: a social–ecological approach. *Reprod Health Matters* [Internet]. 2013 [cited 2019 Sep 9]; Available from: <https://www.sciencedirect.com/science/article/pii/S019074091400139X>
30. Britto C, Mehta K, Thomas R, Shet A. Europe PMC Funders Group Prevalence and Correlates of HIV Disclosure Among Children and Adolescents in Low- and Middle-Income Countries : A Systematic Review. 2018;37(6):496–505.
31. Brown BB, Larson J. Peer Relationships in Adolescence. In: *Handbook of Adolescent Psychology.* John Wiley & Sons, Inc.; 2009.
32. Brown, B. Bradford Bakken, Jeremy P. Ameringer, Suzanne W. Mahon SD. A comprehensive conceptualization of the peer influence process in adolescence. books.google.com [Internet]. [cited 2019 Oct 9]

Supporting information

S1_File.Compressed folder., S1_File.pdf

Appendix XII: Publications from this work

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Full Length Research Paper



Journal of AIDS and HIV Research

Determinants of antiretroviral therapy adherence among older adolescents living with HIV in Kenya during the transition to adult care: An observational study

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Lower levels of adherence to antiretroviral therapy (ART) among older adolescents as compared to adults are influenced by individual, psychosocial, and treatment-related factors. Successful transition of older adolescents into HIV adult care from paediatric & adolescent focused care requires an understanding of barriers to ART adherence. This study aimed at determining individual factors affecting ART adherence among older HIV positive adolescents transitioning to adult care. Between December 2018 and January 2019, we conducted a cross-sectional study among 82 perinatally infected adolescents aged 16-19 years in an HIV care and treatment clinic in Nairobi, Kenya. We used completed structured questionnaires and abstracted data from clinical charts. We

performed multivariate logistic regression to identify factors independently associated >95% self-reported ART adherence (7-day recall). The study participants had a median age of 17 (IQR 16,18) on ART for a median duration of 11 years (IQR 7,13). Sixty-four per cent (52) of the adolescents reported optimal adherence was of >95%, and 15% reported missing doses for three or more months. Self-reported adherence had a high correlation with viral loads of <1000 copies/ml (Kappa= 0.087). Adolescents with high self-efficacy were eight times more likely to report adherence of >95% [OR 8.1, 95% CI (2.31- 28.18)]. Once a day, dosing was also independently associated with adherence [OR 1.58, 95% CI [0.62-4.08].

Conclusions: The reduction of ART pill burden and the inclusion of assessment of ART self-efficacy may contribute to transition preparedness among adolescents.

Key words: Transition, adolescents, HIV, adherence, antiretroviral therapy, self-efficacy.

INTRODUCTION

There are approximately 1.3 million adolescents (10-19 years) living with HIV (ALWHIV) in Eastern and Southern Africa (UNAIDS 2016) and nearly 300,000 adolescents and young adults (15-25 years) are living with HIV in Kenya majority of whom acquired HIV during the perinatal period (UNAIDS, 2016). To achieve the UNAIDS goal of ensuring 95% of people living with HIV (PLWHIV) achieve viral suppression, older adolescents must remain motivated to continue adherence to ART as they gain independence and begin to practice self-management (UNAIDS, Nations, & UN Joint Programme on HIV/AIDS (UNAIDS) 2014).

Psychosocial, socio-demographic, individual, and treatment-related factors, (Adejumo et al., 2005) influence optimal adherence and consequent virological suppression and decreased mortality.

Conversely, poor adherence can lead to poor clinical outcomes, increased chances of transmission and a higher probability for the development of drug resistance (Haberer et al., 2011), (Slogrove et al., 2017). Globally, viral suppression, retention to care and adherence to antiretroviral therapy (ART) among older adolescents (15-19 years) is lower than that of adults and children (Lamb et al., 2014) (Carrizosa et al., 2014).

HIV care services in many sub-Saharan African countries are distributed between specialised paediatric and adult clinics (Adejumo et al., 2015). A successful transition of the adolescent to adult care (defined as 'the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems) (Carrizosa et al., 2014) often means that the adolescents must possess the

motivation to continue to adhere to life-long ART.

Despite the large numbers of older adolescents living with HIV, compared to data on adults, there is a lack of data on adolescent patient factors, such as self-efficacy (Naar-King et al., 2006), medication-related factors (Biadgilign et al., 2009) (Adejumo et al., 2015), and social factors, such as social support and their influence on adherence (Reda and Biadgilign, 2012) (Van Dyke et al., 2002).

Understanding these modifiable individual clinical, psychosocial and socio-demographic factors could provide valuable insights during the development of interventions aimed at improving adherence among transitioning adolescents. This study aimed at determining the individual-level, socio-demographic, clinical and psychosocial factors affecting adherence to ART among older HIV positive adolescents transitioning to adult care.

METHODOLOGY

Study site and design

A cross-sectional study was conducted between December 2018 and January 2019 within a large urban HIV care and treatment outpatient clinic that currently

provides treatment to approximately 300 adolescents. This facility was purposively selected as it provides HIV care to a large cohort of paediatrics who were in the process of transitioning to adult care.

This process of transition in this clinic

includes the identification of adolescents between the ages of 16 and 19 years, followed by an assessment of their readiness by

evaluating viral load measures in the past year and a psychosocial support counselling session. If considered ready, the adolescents

progress from the adolescent clinic days to receiving clinical reviews on adult clinic days. The goal of the transition is that the adolescents should be able to navigate the pharmacy, phlebotomy and clinician interactions without the aid of a caregiver.

Inclusion criteria for the study were: a) Perinatal HIV infection, b) Ages 16-19 years, c) ART use for at least three years. Perinatal infection was confirmed through 1) review of clinic records for HIV DNA results within the postnatal and infancy period or 2) by using proxies such as duration of more than three years on ART and documented HIV status of the mother where available. Proxies were used to determine perinatal infection where documentation of infant PCR or child HIV antibody testing confirmation was lacking in the clinical notes.

Study procedure and data collection

140 adolescents were screened. Out of these, 18 adolescents did not fit the study criteria as there was no documentation of perinatal infection. An additional 40 could not be enrolled as their caregivers were unavailable for obtained consent. Therefore, 82 study participants who met the study inclusion criteria during their routine clinic appointments were identified. After enrolment to the study,

data were collected through abstraction of patient hospital records, including lab results and questionnaires collected using computer-assisted self-interviewing. Blood samples of 5 ml were collected from adolescents who did not have a recent viral load result recorded in the previous three months in the patient records. Research assistants were non-clinical and had not interacted with the study participants before.

Data collection

Baseline demographic data and clinical data such as duration of ART use, duration of enrolment in care, self-reported adherence, viral load and age at disclosure were collected. Data on stigma experiences, perceived social support system, ART adherence self-efficacy and reported self-esteem were also collected. Demographic and psychosocial variables

ART adherence self-efficacy

Self-efficacy was measured using a previously validated HIV-Adherence self-efficacy assessment survey (HIV-ASES) tool consisting of a 12 item scale measuring the level of patient confidence to carry out relevant ART related behaviours (Johnson et al., 2007)(Johnson et al. 2007). Responses range was from 1 (cannot do it at all) to 10 (absolute can do it). HIV-ASES cut-off for this study was determined by assessing the performance (specificity and sensitivity) of different cut-off values using Receiver Operating Characteristics (ROC) analyses.

Self-esteem

Self-esteem was measured using the

were collected using a structured computer-assisted self-interviewing survey and utilised through chart abstraction for clinical data collection. Viral load results were valid if measured three months prior to the interview date.

Measures

Adherence

A previously validated self-report adherence tool was used for adolescents and paediatric living with HIV previously used in the *Paediatric AIDS Clinical Trials Group*. (Van Dyke et al., 2002)(Van Dyke et al. 2002)(Van Dyke et al. 2002). This tool utilised the number of missed doses. An adherence level of $\geq 95\%$ is recommended to achieve optimal viral suppression (World health organization, 2006). 95% adherence was computed as no more than one dose a month

validated Rosenberg 10-point scale that measures global self-worth. All items are answered using a 4-point Likert scale format ranging from strongly agree to disagree (ROSENBERG SELF-ESTEEM SCALE, 1965). A score < 25 indicated low self-esteem, whereas a score > 35 indicates high self-esteem.

Perception of social support

Social support was measured using one question from the previously validated shortened social provisions scale. "Is there someone with whom you can discuss important decisions or challenges you face related to your HIV status?" (Perera, 2016), (Caron, 2013). The social provisions scale measures the level, type and perceived satisfaction with social support from one's social network. This

question was selected as it assesses the integration construct; an individual's integration of their HIV status and treatment into social support circles which was an area of exploration in this study.

Stigma

Stigma was measured using the question, "Have you experienced stigma (people treated you differently) after learning of your HIV status?". This is a question adapted from the 40-point HIV stigma scale. This question focuses on the assessment of experienced stigma, which was explored in this study.

Data analysis

Descriptive statistics were used to characterise study variables. Four factors associated with adherence were assessed and Chi-square was utilised for categorical variables and Kruskal Wallis test for difference in means during bivariate analysis. Regression analysis was then used for variables found to have a significance of $p \leq 0.3$ and regression models were used to examine the independent associations between self-reported adherence and 1) clinical (age at disclosure, frequency of ART regimen), 2) psychosocial (stigma, social support, adherence self-efficacy and self-esteem) and 3) socio-demographic (age, sex, schooling, caregiver status) variables. The Kappa statistic measure was used to examine agreement between self-reported adherence and viral load. For adherence of self-efficacy, area under ROC curve of 89.5 had a sensitivity of 74% and

specificity of 67%. Therefore, a cut-off score of <90 was used to describe low self-efficacy. Cronbach's alpha reliability coefficient was conducted to measure the internal consistency of the items (variables) in the HIV-ASES and Rosenberg self-esteem scales.

Regression analysis was used to determine independent associations between adherence and the clinical, psychosocial and demographic variables. All analyses were conducted using StataCorp. 2013. (Stata Statistical Software: Release 13. College Station, TX: StataCorp LP. Stata version 13).

RESULTS

Baseline characteristics

The adolescents in the study had a median age of 17 (IQR 11, 14) and 61% of them being male. Sixty-one per cent were male. Most adolescents had been on ART for a median of 11 years (IQR 7, 13) while the median age at disclosure was 12 years (IQR 11, 14). Almost 65% of the adolescents had lost one or both parents or did not know their whereabouts, and 39% attended a boarding school. Using a cut off >1000 viral copies/ml for viral suppression, 32% of the adolescents achieved viral suppression and 15% reported at least one treatment break. Self-reported adherence of $\geq 95\%$ adherence was reported by 64% of the participants. Overall, 65% of the adolescents were on twice a day ART regimens compared to 34.6% (28) who were on once-a-day regimens (Table 1).

HIV treatment adherence self-efficacy

score

Overall, the study participants demonstrated high confidence in most of the areas related to the integration of treatment into their daily life, particularly on sticking to treatment even they were not feeling well or when the viral load increased (Table 2). The lowest score was self-reported efficacy on the use of medications in the presence of people unaware of their HIV status. Adolescents also scored low on ART adherence self-efficacy when their daily routine was disrupted. The composite score mean (SD) was 8.1 (1.8). Using computed ROC

cut off (≥ 90), 68% of participants scored a high self-efficacy (Table 2). Cronbach's alpha was 0.832, which indicates a high level of internal consistency (reliability) for the self-efficacy scale.

Self-esteem

Most of the study participants demonstrated high confidence in most of the areas related to their adherence to ART, particularly on capability do things as well as most other people, inclination towards the feeling of being a failure and the perception of having a number of good qualities.

Table 1. Sociodemographic, clinical and psychosocial characteristics of study participants.

Characteristics	Frequency n (%)
Age Median, IQR	17 (16,18)
Gender	
Male	50 (61.0)
Female	32 (39.0)
Age at disclosure (Median, IQR)	12 (11,14)
Number of years, on ART (Median, IQR)	11 (7,13)
School enrolment	
Boarding secondary school	32 (39.0)
College/University	6 (7.3)
Day school	35 (42.7)
Not enrolled in school	5 (6.1)
Apprenticeship/Employed	4 (4.9)
Parental status	
Both parents alive	29 (35.4)
Only father alive	16 (19.5)
Only mother alive	21 (25.6)
Both parents not alive	13 (15.9)
Either parent's status Not known	3 (3.7)

Care-giver living with HIV	
Yes	65 (79.3)
No	17 (20.7)
Viral load (copies/ml)	
<400	53 (65.4)
400 to 999	2 (2.5)
1000 to 5000	6 (7.4)
>5000	20 (24.7)
Reported ART adherence	
≥95% adherence	52 (64.2)
<95% adherence	29 (35.8)

The lowest score was related to the perception of respect for self (Table 3). a high internal consistency of the self-esteem items in the scale (Cronbach's alpha= 0.714) was reported. Self-esteem composite mean (SD) was 3.4 (0.4).

Adherence

There was a high level of agreement (Kappa statistic = 0.087) between self-reported adherence and viral load (<1000 copies/ml). This high correlation indicated that self-report used in this

study was a reliable measure of adherence.

The most common regimen was Zidovudine/Lamivudine/Nevirapine combination (41.4%), followed by Tenofovir/Lamivudine/Efavirenz at (24.3%) (Figure 1).

During bivariate analysis, factors significantly associated with self-reported of adherence of >95% were ART self-efficacy (p<0.01), self-esteem (p=0.04) and attending boarding school (p=0.03). There were no

Table 2. Responses to individual questions on the 12-point HIV ASES tool.

HIV adherence self-efficacy	Mean (SD)
Stick to treatment even with side effects Interfering.	8.3 (3.1)
Integrate treatment into a daily routine.	8.4 (2.5)
Take medication in front of people unaware of your status.	4.3 (4.4)
Stick to treatment even when the daily routine is disrupted.	7.7 (3.3)
Stick to treatment even when you are not feeling well	8.8 (2.7)
Stick to treatment even if it means changing eating habits.	8.5 (2.5)

Continue treatment even if interferes with daily activities.	8.4 (2.9)
Continue treatment plan from physician even T-Cell drops or viral load increases.	8.8 (2.4)
Continue treatment even when discouraged about health.	8.4 (2.8)
Continue treatment even when getting to the clinic is a hassle.	8.8 (2.3)
Continue treatment if close people say it is not doing good.	8.1 (3.4)
Positive about treatment even without health Improvement.	8.4 (2.9)

Table 3. Assessment of self-esteem Rosenberg.

Rosenberg Test questions	Mean (SD)
On the whole, I am satisfied with myself.	3.7 (0.5)
At times I think I am no good at all.	2.9 (1.2)
I feel that I have a number of good qualities.	3.7 (0.6)
I am able to do things as well as most other people.	3.7 (0.6)
I feel I do not have much to be proud of.	3.4 (0.9)
I certainly feel useless at times.	3.5 (0.8)
I feel that I'm a person of worth, at least on an equal plane with others.	3.6 (0.7)
I wish I could have more respect for myself.	1.5 (0.7)
All in all, I am inclined to feel that I am a failure.	3.7 (0.5)
I take a positive attitude toward myself.	3.6 (0.7)

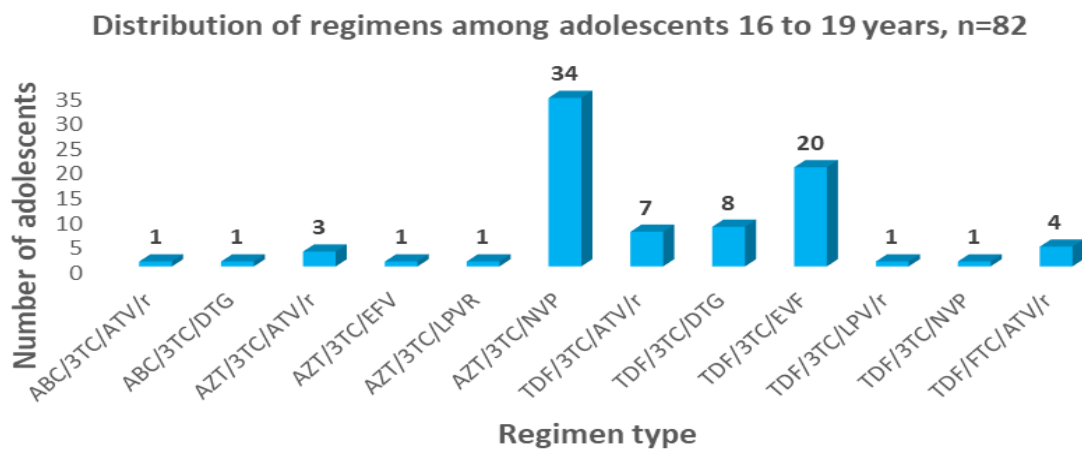


Figure 1: Study participants ART regimen distribution.

Table 4: Factors associated with adherence during bivariate analysis.

Factor	ART adherence <95% (n=29)	ART adherence ≥95% (n=52)	95% CI	P value
Socio demographic factor				
Age, years, median(IQR)	17 (16-18)	17 (16-18)	1.24 (0.85-1.79)	0.25
Gender (n, %)				
Male	19 (65.5)	30 (57.7)	Ref	
Female	10 (34.5)	22 (42.3)	1.39 (0.54-3.57)	0.49
Parental status (n, %)				
Both parents alive	11 (37.9)	17 (32.7)		
Only father alive	8 (27.6)	8 (15.4)	0.64 (0.18-2.23)	0.49
Only mother alive	5 (17.2)	16 (30.8)	2.07 (0.58-7.28)	0.25
Both parents not alive	4 (13.8)	9 (17.3)	1.45 (0.36-5.90)	0.59
Mother status NK	1 (3.5)	2 (3.8)	1.29 (0.10-16.0)	0.84
At least one caregiver HIV positive	24 (82.7)	40 (76.9)	0.69 (0.22-2.21)	0.53
Schooling (n, %)				
Boarding	15 (53.6)	16 (32.7)	Ref	
College/university	3 (10.7)	3 (6.1)	0.93 (0.16-5.38)	0.94
Day school	8 (28.6)	27 (55.1)	3.16 (1.09-9.11)	0.03
Not in school	2 (7.1)	3 (6.1)	1.40 (0.20-9.61)	0.72
Clinical factor				
Age at disclosure of HIV status (median, IQR)	12 (12-14)	12 (13-13.5)	0.92 (0.76-1.09)	0.35
Duration on ART	10 (7-13)	11 (6.5-13)	1.02 (0.91-1.14)	0.74
Frequency of treatment regimens (n, %)				
Once a day	12 (41.4)	16 (30.8)	1.24 (0.85-1.79)	0.33
Twice a day	17 (58.6)	36 (69.2)	Ref	
Disclosure individual (n, %)				
Self	3 (10.3)	3 (5.8)	0.5 (0.03- 8.95)	0.63
Caregiver	11 (37.9)	29 (55.8)	1.31 (0.11-16.03)	0.82
Health worker	14 (48.3)	18 (34.6)	0.64 (0.05-7.83)	0.72
Other	1 (3.5)	2 (3.8)	Ref	
Psychosocial factor				
Self-esteem score (Mean,SD)	34 (30-37)	35 (33.5-37)	1.12 (1.00-1.26)	0.04
Self-efficacy score	85 (70-105)	110 (100-115)	1.04 (1.01-1.06)	0.003
Reported experienced stigma (n, %)				
No	25 (86.2)	50 (96.2)	4(0.68-23.3)	0.12
Yes	4 (13.8)	2 (3.8)	Ref	
Perceived social support (n, %)				
No	9 (31.0)	16 (30.8)	Ref	
Yes	20 (69.0)	36 (69.2)	1.02 (0.38-2.70)	0.98
Support individual (n, %)				
Caregiver	13 (65.0)	24 (66.7)	0.37 (0.04-3.50)	0.38
Clinic counsellor	1 (5.0)	2 (5.5)	0.4 (0.02-10.01)	0.57
Sibling	5 (25.0)	5 (13.9)	0.2 (0.01-2.38)	0.20
Other relatives	1 (5.0)	5 (13.9)	Ref	

significant differences according to age or sex (Table 4).

The multivariate model predicting self-reported adherence >95%

Older ALWHIV with high ART adherence self-efficacy were eight times more likely to report high adherence [OR 7.9, 95% CI (2.23-28.08)] and those on a twice a day

ART regimen were almost four times more likely to report adherence [OR 3.8, 95% CI (1.11-12.72)]. Self-esteem, age, sex, schooling, perceived social support and experienced stigma were not found to be associated with adherence among these older adolescents (Table 5).

DISCUSSION

The findings indicate that reported adherence among older adolescents transitioning to adulthood is still suboptimal. In this study, high ART adherence self-efficacy and use of twice a day regimens were independently associated with high adherence. This is the first study to our knowledge that has explored modifiable psychosocial factors such as self-efficacy and self-esteem and their association to adherence among adolescents to sub-Saharan Africa.

Only a little over two-thirds of the adolescents reported adherence $\geq 95\%$. It was postulated that lack of privacy may have contributed to this finding and in particular, institutionalisation such as living in boarding schools. Lack of privacy is a strong determinant of non-adherence in other studies in this region ((MacCarthy et al., 2018) (Damulira et al., 2019). The data from the assessment of ART self-efficacy in our study supports this argument. Adolescents scored lowest during the assessment of their ability to adhere to ART in the presence of individuals who did not know their status.

Social support and particularly caregiver

relationships is a significant contributor and influencer of health behaviours such as drug adherence ((Damulira et al., 2019). However, in our study, caregiver support was not significantly associated with better adherence. The study criteria of older adolescents in this study (16-19 years), compared to the broader age range in other studies (10-19 years) may have contributed to this difference as older adolescents often display a greater desire for autonomy and detachment from caregivers compared to younger adolescents (Daddis, n.d.). In this study, the number of doses was significantly associated with adherence. This is a finding supported by previous studies (World Health Organization - HIV and Adolescents from Guidance to Action," n.d). Guidelines of transitioning of adolescents include switching to once a day regimens where possible. In this study, adolescents had been on ART for almost a decade, and factors such as adverse effects and ART resistance-associated treatment failure may have resulted in the reported twice a day dosing regimens (Purwaningsih, Asmoro, and Prastiwi 2019)(Purwaningsih et al., 2019a), (Tyer-Viola et al., 2014). Additionally, this study was conducted before the introduction of once a day dosing regimens that incorporate newer integrase inhibitors such as Dolutegravir to the Kenyan national guideline for use in transitioning ALWHIV (National AIDS & STI Control, 2018)(National AIDS & STI Control 2018)(National AIDS & STI Control 2018).

Our findings that self-esteem was not associated with adherence were an exciting finding since in adolescence developmental stage, self-esteem is a critical component in decision making

and behavioural outcomes Educación, et al., 2012). There are scarce data on self-esteem in HIV positive adolescents in sub-Saharan Africa. However, studies (Educación et al., 2012) in Indonesia (Purwaningsih, Asmoro, and Prastiwi 2019)(Purwaningsih et al., 2019b), North America (Tyer-Viola et al., 2014) and Pakistan (Kurniawan and Fitrio 2019) have found associations. There is data indicating that self-esteem may be a mediator of non-health self-efficacy (Nader, 2014) and that both are components of self-concept this interplay may have led to this variable being knocked out in the multiple regression model.

There is a wealth of research (33-36) indicating that self-efficacy (one's sense of being able to adhere to ART and adhering to clinic appointments) is a significant contributor to improved adherence and better treatment outcomes in Adults living with HIV. (Aregbesola and Adeoye, 2018). The finding that ART self-efficacy was independently associated with self-reported adherence is significant. It indicates that this may be a key indicator to be considered in the readiness assessment of adolescents during the transition to adult care. Older adolescents require sufficient motivation to continue with self-care regardless of external factors/circumstance;

Table 5. Multiple regression model of factors associated with self-reported adherence.

Variable	Self-reported >95% adherence		Self-reported ≥95% adherence	
	Unadjusted ORs (95%CI)	p-value	Adjusted ORs (95%CI)	p-value
Age, years, median (IQR)	1.24 (0.85-1.79)	0.25	1.41 (0.88-2.26)	0.15
Gender				
Male	Ref		Ref	
Female	1.39 (0.54-3.57)		1.10 (0.36-3.39)	0.85
Schooling (n, %)				
Boarding	Ref		-	-
College/University	0.93 (0.16-5.38)	0.94	-	-
Day school	3.16 (1.09-9.11)	0.03	-	-
Not in school	1.40 (0.20-9.61)	0.72	-	-
Age at disclosure of HIV status (median, IQR)	0.92 (0.76-1.09)	0.35	0.94 (0.76-1.16)	0.56
Frequency of treatment regimens (n, %)				
Once a day	Ref		Ref	
Twice a day	1.58 (0.62-4.08)	0.33	3.8 (1.11-12.72)	0.03
Self-esteem score				
Normal	Ref		Ref	
High	1.7 (0.67-4.19)	0.26	0.95 (0.29- 3.09)	0.93
Self-efficacy score				
Low	Ref		Ref	
High	6.8 (2.41-18.97)	<0.001	7.9 (2.23- 28.08)	0.001

Reported experienced stigma (n, %)				
No	4(0.68-23.3)	0.12	7.1 (0.59- 83.32)	0.12
Yes	Ref		Ref	
Perceived social support (n, %)				
No	Ref		Ref	
Yes	1.02 (0.38-2.70)	0.98	0.54 (0.15-1.92)	0.35

*Not all the proportion was based on the entire sample due to missing data for some variables. Factors with p-value ≤ 0.3 were selected for multivariate analysis.

hence the importance adherence of self-efficacy.

Prioritisation of the development of interventions that focus on promoting adherence self-efficacy and building self-esteem during the preparation of transition to adult care was recommended. This could potentially provide much needed psychosocial impetus and motivation required at an individual-level to maintain ART adherence into adulthood.

A limitation of this study was that it focused perinatally on infected adolescents in an urban setting. The findings may not be generalisable to adolescents with sexually acquired HIV infection or those in semi-urban and rural settings. Perinatal infection results in a longer duration of ART use (in this study the adolescents had been on ART for almost a decade) and exposure to psychosocial stressors, which makes this population distinct in clinical and psychosocial HIV care. Additionally, a vast majority of adolescents transitioning to adult care-acquired HIV in the perinatal period. Another limitation is that this study used self-reported adherence as an adherence measure which may lead to inaccurate reporting due to recall bias and social desirability. While the viral load is the goal standard of adherence, in many

low resource settings, self-adherence is often used as a routine measure during

clinic visits. In contrast, viral load measures are assessed periodically (usually twice a year). There was an acceptable level of agreement in this study between the viral suppression cut off and self-reported. However, there are studies including a systematic review (Dachew, et al., 2014) that report self-reported adherence to be an accurate adherence measure (Profile et al., 2001), mainly when short durations as the case in this study (Nieuwkerk and Oort, 2005).

Conclusions

Assessing and developing interventions focusing on individual-level modifiable factors associated with adherence such as self-efficacy may contribute to adherence self-efficacy and potentially promote a successful transition to adult care for ALWHIV.

Ethical considerations

Written informed consent was obtained to participate and publish from adolescents above 18 years age, and for adolescents aged below 18 years. We obtained both assent and caregiver consent. The University of Nairobi-Kenyatta National

Ethical and Research Committee granted ethical approval for this study.

Data availability

All data generated or analysed during this study are included in this published article and its supplementary information files.

CONFLICT OF INTERESTS

The authors have not declared any conflict of interests.

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REFERENCES

UNAIDS (2016). Ending the AIDS epidemic for adolescents, with adolescents;
<http://www.unaids.org/en/resources/documents/2016/ending-AIDS-epidemic-adolescents>
UNAIDS, Nations JU, UN Joint Programme on HIV/AIDS (UNAIDS). Fast-Track Targets [Internet]. 2014. Available from: https://www.unaids.org/sites/default/files/media_asset/JC2686_WAD2014report_en.pdf
Adejumo OA, Malee KM, Ryscavage P, Hunter SJ, Taiwo BO (2015).

Contemporary issues on the epidemiology and antiretroviral adherence of HIV-infected adolescents in sub-Saharan Africa: a narrative review. *Journal of the International AIDS Society* 18(1): 20049.

Haberer JE, Cook A, Walker AS, Ngambi M, Ferrier A, Mulenga V (2011) Excellent adherence to antiretrovirals in HIV+ Zambian children is compromised by disrupted routine, HIV Nondisclosure, and Paradoxical Income Effects. *PLoS One* 6(4):e18505

Slogrove AL, Mahy M, Armstrong A, Davies MA (2017). Living and dying to be counted: What we know about the epidemiology of the global adolescent HIV epidemic. *Journal of the International AIDS Society* 20:21520.

Lamb MR, Fayorsey R, Nuwagaba-Biribonwoha H, Viola V, Mutabazi V, Alwar T, Casalini C, Elul B (2014). High attrition before and after ART initiation among youth (15-24 years.. of age) enrolled in HIV care. *AIDS*.28(4):559.

Carrizosa J, An I, Appleton R, Camfield P, Von Moers (2014). A Models for transition clinics. *Epilepsia* 55:46-51. Available from: <http://doi.wiley.com/10.1111/epi.12716>

Naar-King S, Templin T, Wright K, Frey M, Parsons JT, Lam P (2006). Psychosocial factors and medication adherence in HIV-positive youth. *AIDS Patient Care STDS* 20(1):44-7.

Biadgilign S, Deribew A, Amberbir A, Deribe K (2009). Barriers and facilitators to antiretroviral medication adherence among HIV-infected paediatric patients in Ethiopia: A qualitative study [Internet]. *Journal of Social Aspects of HIV/AIDS* Vol. 6. Available from:

- <https://www.ajol.info/index.php/saharaj/article/view/50639>
- Adejumo OA, Malee KM, Ryscavage P, Hunter SJ, Taiwo BO (2015) Contemporary issues on the epidemiology and antiretroviral adherence of HIV-infected adolescents in sub-Saharan Africa: A narrative review. *Journal of the International AIDS Society* 16:18(1).
- Reda AA, Biadgilign S (2012). Determinants of adherence to antiretroviral therapy among HIV-infected patients in Africa. 2012.
- Van Dyke RB, Van Dyke RB, Lee S, Johnson GM, Wiznia A, Mohan K, Stanley K, Morse EV, Krogstad PA, Nachman S (2002). Reported Adherence as a Determinant of Response to Highly Active Antiretroviral Therapy in Children Who Have Human Immunodeficiency Virus Infection. *Pediatrics* 109(4)e61-e61. [Available from: <http://www.pediatrics.org/cgi/content/full/109/4/>]
- World Health Organisation (2006). From Access to Adherence: The Challenges of Antiretroviral Treatment - Studies from Botswana, Tanzania and Uganda, Factors that facilitate or constrain adherence to antiretroviral therapy among adults in Uganda: a pre-intervention study: Chapter 3: [Internet]. 2006 [cited 2020 Mar 26]. Available from: <https://apps.who.int/medicinedocs/en/d/Js13400e/10.6.1.html>
- Johnson MO, Neilands TB, Dilworth SE, Morin SF, Remien RH, Chesney MA (2007). The role of self-efficacy in HIV treatment adherence: validation of the HIV Treatment Adherence Self-Efficacy Scale (HIV-ASES). *Journal of behavioral medicine* 30(5):359-70. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/17588200>
- Perera HN (2020). Construct Validity of the Social Provisions Scale: A Bifactor Exploratory Structural Equation Modeling Approach. *Assessment*. 23(6):720-33. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/26063712>
- Caron J (2013). A validation of the Social Provisions Scale: the SPS-10 items. *Sante Ment Que* 38(1):297-318. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/24337002>
- Mutwa PR, Van Nuil JI, Asiimwe-Kateera B, Kestelyn E, Vyankandondera J, Pool R, Ruhirimbura J, Kanakuze C, Reiss P, Geelen S, van de Wijgert J (2013). Living Situation Affects Adherence to Combination Antiretroviral Therapy in HIV-Infected Adolescents in Rwanda: A Qualitative Study. *PLoS One* 8(4): e60073.
- Inzaule SC, Hamers RL, Kityo C, Rinke De Wit TF, Roura M (2016). Long-term antiretroviral treatment adherence in HIV-infected adolescents and adults in Uganda: A qualitative study. *PLoS One* 11(11):e0167492. Not cited
- MacCarthy S, Saya U, Samba C, Birungi J, Okoboi S, Linnemayr S (2018). “how am i going to live?”: Exploring barriers to ART adherence among adolescents and young adults living with HIV in Uganda. *BMC Public Health* 18(1):1-11. <https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-018-6048-7>
- Damulira C, Mukasa MN, Byansi W,

- Nabunya P, Kivumbi A, Namatovu P, (2019). Examining the relationship of social support and family cohesion on ART adherence among HIV-positive adolescents in southern Uganda: baseline findings. *Vulnerable children and youth studies* 14(2):181-190.
- Daddis C. Desire for Increased Autonomy and Adolescents' Perceptions of Peer Autonomy: "Everyone Else Can; Why Can't I *Child Development* 82(4):1310-1326. Available from: <https://www.jstor.org/stable/41289844>
- World Health Organization (2020). HIV and Adolescents from Guidance to Action Available from: https://apps.who.int/adolescent/hiv-testing-treatment/page/Improving_adherence
Not cited
- Salou M, Dagnra AY, Butel C, Vidal N, Serrano L, Takassi E, Konou AA, Houndenou S, Dapam N, Singo-Tokofaï A, Pitche P (2016). High rates of virological failure and drug resistance in perinatally HIV-1-infected children and adolescents receiving lifelong antiretroviral therapy in routine clinics in Togo. *J Int AIDS* 27;19(1). Not cited
- National AIDS & STI (2020). Control M of H. Guidelines on Use of Antiretroviral Drugs for Treating and Preventing HIV Infection in Kenya. Available from: <https://www.nascop.or.ke/new-guidelines/>
- Educación FY, Falanga R, Elvira De Caroli M, Sagone E (2012). relationship between self-efficacy and self-concepts in university students. *International Journal of Developmental and Educational Psychology* 2(1):227-233.
- Purwaningsih P, Asmoro CP, Prastiwi YA (2019). Self-esteem and motivation with adherence of people living with HIV/AIDS (PLWHA) in Indonesia with antiretroviral therapy: A cross-sectional study. *International Journal of Adolescent Medicine and Health* 1. (ahead-of-print). Not cited
- Tyer-Viola LA, Corless IB, Webel A, Reid P, Sullivan KM, Nichols P (2014). Predictors of Medication Adherence Among HIV-Positive Women in North America. *JOGNN - Journal of Obstetric, Gynecologic & Neonatal Nursing* 43(2):168-178.
- Kurniawan D, Fitri DRY (2019). Impact of HIV-Related Stigma: Self-Efficacy, Self-Esteem, and Social Isolation on ARV Medication Adherence among Persons Living With HIV in Turen, Malang Pakistan *Journal of Medical and Health Sciences*. https://www.researchgate.net/publication/n/339527275_Impact_of_HIV-Related_Stigma_Self-Efficacy_Self-Esteem_and_Social_Isolation_on_ARV_Medication_Adherence_among_Persons_Living_With_HIV_in_Turen_Malang
- Nader H (2020) Relationships Between Self-Efficacy, Self-Esteem and Procrastination in Undergraduate Psychology Students. *Iranian journal of psychiatry and behavioral sciences* 8(3):42. https://www.researchgate.net/publication/n/273700586_Relationships_Between_Self-Efficacy_Self-Esteem_and_Procrastination_in_Undergraduate_Psychology_Students
- Firdu N, Enquesselassie F, Jerene D (2017). HIV-infected adolescents have low adherence to antiretroviral therapy: A cross-sectional study in Addis Ababa, Ethiopia. *Pan African Medical Journal* 27(1):31.

Aregbesola OH, Adeoye IA (2018). Self-efficacy and antiretroviral therapy adherence among HIV positive pregnant women in South-West Nigeria: a mixed-methods study. *Tanzania Journal of Health Research* 20(4).

<http://search.ebscohost.com/login.aspx?direct=true&AuthType=cookie,ip,shib&db=awn&AN=thrb-170709&site=ehost-live>

Dachew BA, Tesfahunegn TB, Birhanu AM (2014). Adherence to highly active antiretroviral therapy and associated factors among children at the University of Gondar Hospital and Gondar Poly Clinic, Northwest Ethiopia: a cross-sectional institutional based study. *BMC Public Health* 14(1):875. <http://www.ncbi.nlm.nih.gov/pubmed/25155293>

Profile S, Hays RD, Maldonado T, Liu H, Golin CE, Miller LG, (2001). A Comparison of Multiple Measures of Adherence to HIV Protease Inhibitors A Comparison Study of Multiple Measures of Adherence to HIV Protease Inhibitors Background: Poor adherence to HIV protease inhibitors may]. *annals.org*. <https://www.researchgate.net/publication/11984476>. Not cited

Nieuwkerk PT, Oort FJ (2005). Self-Reported Adherence to Antiretroviral Therapy for HIV-1 Infection and Virologic Treatment Response. *JAIDS JAIDS Journal of Acquired Immune Deficiency Syndromes* 38(4):445-8. Available from: <http://journals.lww.com/00126334-200504010-00010>

Appendix XII: Publications from this work

VULNERABLE CHILDREN AND YOUTH STUDIES

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The role of self-efficacy in HIV treatment adherence and its interaction with psychosocial factors among HIV positive adolescents in transition to adult care in Kenya

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ABSTRACT

Adolescents and young adults (15–24 yrs.) have poorer HIV clinical outcomes than adults. Despite this, there is minimal data on individual-level factors such as self-efficacy towards antiretroviral adherence among perinatally infected adolescents living with HIV in sub-Saharan Africa. Our study examined the interaction between antiretroviral treatment adherence self-efficacy and other psychosocial factors among adolescents receiving care in Nairobi, Kenya. We enrolled perinatally infected Adolescent Living with HIV (ALWHIV) 16–19 yrs. who were accessing care routinely at the HIV clinic. We measured self-reported ART adherence (7-day recall) and defined optimal adherence as >95%, and conducted a regression analysis to identify independently associated factors. Mediation analysis explored interactions between the psychosocial variables. We enrolled 82 ALWHIV median age 17 (IQR 16,18) who had been on ART for a median age of 11 yrs. (IQR 7,13). Sixty-four per cent (52) of the ALWHIV reported optimal adherence of >95%, and 15% reported missing doses for three or more months. After controlling for the other covariates, self-esteem, high viral load and an adherence level > 95% were significantly associated with adherence self-efficacy. Self-esteem was significantly associated with adherence self-efficacy and social support ($p < 0.001$ and $p = 0.001$), respectively. The paramed test indicated that the association between self-efficacy and adherence was mediated by self-esteem with a total effect of OR 6.93 (bootstrap 95% CI 1.99–24.14). Adherence self-efficacy was also mediated by self-esteem in developing adherence behavior. Interventions focused on increasing adherence among ALWHIV should include self-esteem building components. Key words : Adolescents, Adherence self -efficacy, Transition , perinatal,

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Introduction

HIV is the leading cause of morbidity and mortality among adolescents (10–19 yrs.) in Africa. Existing literature extensively describes non-modifiable factors associated with non-adherence in adolescents, which include age, gender, (Berihun Assefa Dachew, 2014; Nabukeera-barungi et al., 2015), distance from the treatment centre (Getachew Arage, 2014) and past traumatic events/stressors like loss of a family member (Nyandiko et al., 2006). However, there is little documentation on modifiable behavioural/psychosocial barriers. One of these critical modifiable factors includes ART adherence self-efficacy (defined as the extent or strength of one's belief in one's own ability to complete tasks and attain goals despite environmental and social barriers)(Bandura, 1977) (Farmer et al., 2001)(Sharma & Agarwala, 2015) is associated with improved adherence and better treatment outcomes (Firdu et al., 2017), (Mueller et al., 2011), (Johnson et al., 2007), (Adefolalu et al., 2014), (Aregbesola & Adeoye, 2018). While all adolescents living with HIV (ALWHIV) face the same difficulty during the developmental stage, data suggests adolescents presenting with behavioural HIV acquisition are uniquely different from those with perinatal acquired infection with regards to the persistent and cumulative psychological stressors experienced (Petersen et al., 2010) (Kasedde et al., 2014). Transition by these ALWHIV to adult care aims at supporting them to continue ART adherence and to navigate the health systems during clinic appointment as independent individuals. Understanding factors that potentially produce long-term motivation towards adherence to ART and clinic attendance are crucial for establishing adolescent transition.

There is little data on the interaction between self-efficacy and factors such as perceived social support, the experience of HIV related stigma and self-esteem. (Lee & Hazra, 2015). Despite the role of self-esteem in decision making in older adolescents (World health organization, 2006), there is no consensus (Education, 2016) (Le et al., 2018), with some studies indicating self-esteem is not associated with poor adherence. In contrast, other studies among ALWHIV have found associations with better ART adherence and higher self-esteem (Naar-King et al., 2013). In sub-Saharan Africa, the role of self-esteem has not been described extensively in the literature. Understanding drivers and mediators of self-efficacy among older ALWHIV can provide much-needed data useful in developing interventions that would motivate them towards optimal selfmanagement and optimal outcomes as they transition to adult care. This study aimed at investigating self-efficacy and other associated factors among older ALWHIV

transitioning to adult care.

Methods

Study design and site

We conducted a cross-sectional study at the Mbagathi Comprehensive Care Centre (CCC), an HIV care and treatment outpatient clinic in Nairobi, Kenya, to determine the interaction between ART adherence self-efficacy and other psychosocial variables among older ALWHIV. The clinic provided HIV care and treatment to ~300 adolescents aged 10–19 and was purposively selected as it provides HIV care to a large cohort of adolescents in the process of transition to adult care.

The data analyzed and presented in this paper were collected between December 2018 and March 2019 among perinatally infected ALWHIV as part of a more extensive mixed methods study evaluating psychosocial and clinical outcomes of ALWHIV.

Study population

We enrolled ALWHIV, who presented for routine HIV clinic visits between December 2018 and March 2019. Participants eligible for enrolment were between the ages of 16–19 years, were perinatally HIV infected, and had been using Antiretroviral Treatment (ART) for at least three years. We confirmed perinatal infection using either: 1) clinic records for HIV DNA results within the postnatal and infancy period, or 2) proxies such as duration of >3 years on ART and documented HIV status of the mother. Adolescents who were unaware of their HIV status were not eligible for participation. We received ethical approval from the Kenyatta National Hospital/ University of Nairobi Ethics and Research Committee.

Measurements ART adherence self-efficacy

We measured self-efficacy using an unmodified HIV-Adherence self-efficacy assessment survey (HIV-ASES), a previously validated tool (Johnson et al., 2007) consisting of a 12 item Likert scale measuring the level of patient confidence to carry out relevant ART related behaviours. We determined the optimal HIV-ASES cut-off by assessing the performance (specificity and sensitivity) of different cut-off values using. The optimal cut-off was 89.5, and this cut-off had a sensitivity of 74% and specificity of 67%. We computed the area under the ROC curve at a cut-off point of 70% correctly classified 72.8% of all the participants based on whether they had treatment breaks or not. According to this cut-off, 67.5% of the participants had scores ≥ 89.5 . A score of < 90 was the cut-off for defining low self-efficacy, with >90 defining high self-efficacy.

Self-esteem

We measured self-esteem using the validated unmodified Rosenberg 10-point scale that measures global self-worth. All items are answered using a 4-point Likert scale format ranging from strongly agree to disagree strongly. (Rosenberg self-esteem scale, 1965) A score <25 indicated low adherence self-esteem, whereas a score >35 showed a higher adherence self-esteem

Adherence

Adherence was measured as self-reported missed doses. An adherence level of >95% has been recommended to achieve optimal viral suppression. (World health organization, 2006) 95% adherence was documented as no more than one dose a month for those on a once a daily ART regimen and no more than three doses a month for those

on twice a day regimens

Perception of social support

We measured social support using a modified question, ‘There is someone with whom I could discuss important decisions or challenges I face related to my HIV status. The validated shortened social provisions scale (Perera, n.d.)(Caron, 2013) measured level type and perceived satisfaction with social support from one’s social network. We selected this specific question as it measured the construct of integration, similar to ART adherence self-efficacy (the primary outcome).

Stigma

We measured experienced stigma using one modified question from the component that measured personalized stigma from the validated 12 points shortened HIV stigma scale (Berger, Ferrans & Lashley, 2001) (Reinius et al., 2017). ‘Have you experienced stigma (people treated you differently) after learning of your HIV status?’

Data analysis

We computed descriptive statistics of demographic characteristics and the variables of interest. We examined various characteristics (age, gender, disclosure, adherence, treatment break, social support and stigma) with self-efficacy and self-esteem using non-parametric tests, Spearman correlation coefficients for continuous variables and Wilcoxon-Mann-Whitney test and Kruskal Wallis test for categorical variables as appropriate. Next, we developed two multiple linear regression models by incorporating variables with statistical significance ($p < 0.2$) during bivariate analysis. Standardized regression beta coefficients and their significance levels were reported. Lastly, mediation analysis was employed following the following steps (MacKinnon et al., 2007). One multivariate linear regression model (model 1) and two multivariate logistic regression models (model 2 and model 3) were used to test the effect of the mediator (self-esteem, M). In the first model, the mediation variable (self-esteem, M) was regressed on the independent variable (self-efficacy, X) with a regression coefficient a. In the second model, the dependent variable (adherence ART, Y) was regressed on the independent variable (self-efficacy, X) with a regression coefficient c. In the third model, the dependent variable (Y) was simultaneously regressed on the independent variable (X) and the mediation variable (M) with regression coefficients c’ (Y on X) and b (Y on M). The paramed package in STATA (Emsley & Liu, 2020) was used to confirm the mediation effect. All analyses were conducted using Stata version 13 Stata Corp Texas. (Stata Statistical Software: Release 13. College Station, TX: StataCorp LP. Stata version 13).

We screened 140 HIV positive adolescents for eligibility according to the study criteria. Out of those screened, 20 participants aged <18 years of age were excluded due to the unavailability of the caregivers to sign the consent, while 28 participants were excluded due to missing information on perinatal infections. A total of 82 HIV positive adolescents were enrolled, Figure 1.

Baseline characteristics

Participants median age was 17 years [IQR; 16 to 18]. Approximately half (61%) were male. Eighty-one per cent of the adolescents were schooling and enrolled in high school

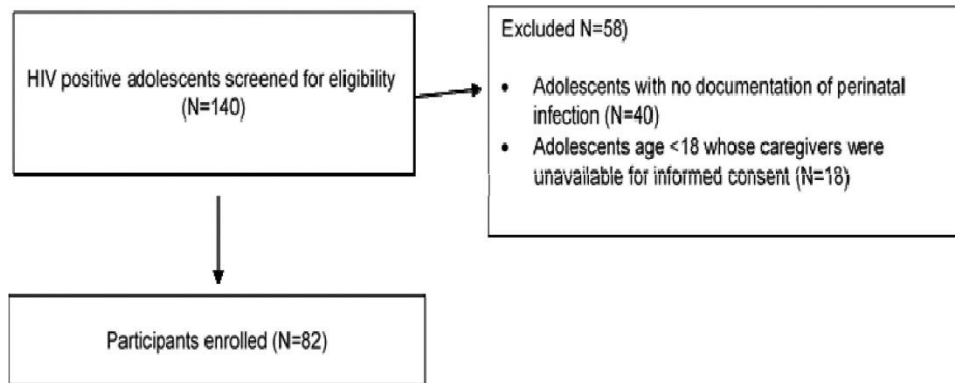


Figure 1. Study enrolment schema.

at the time of the study. Most adolescents have been on ART for a median of 11 years [IQR 8,13]. Sixty-one per cent of the adolescents had lost at least one or both parents. Self-reported adherence of >95% was reported by 52 adolescents (64.2%), while 15% reported taking a treatment break in the three months before enrolment to the study. (see Table)

A high proportion of adolescents, 68.3%, showed a high (>89.5) ART adherence self-efficacy (Table 1). Most participants (85.4%) demonstrated high confidence in most areas related to their adherence to ART, particularly on sticking to treatment even when you are not feeling well (appendix 1). Only 42 (51.2%) reported that they would use ART in the presence of people unaware of their HIV status. (appendix 1)

Using the Rosenberg scale, slightly less than half of the adolescents (45%) had normal self-esteem (<35 > 25), 52.4% reported having high self-esteem (≥35), and only 2.5% had a low self-esteem score (<25). Almost a third (32.1%) of the participants had an elevated viral load, while 65% and 2.5% had viral suppression (<400 copies/ml) and low-level viremia (400 copies/ml-1000 copies/ml), respectively.

Adherence

ART adherence self-efficacy

Bivariate analysis showed that adherence self-efficacy was significantly associated with self-esteem score, adherence and categorized viral load ($p = 0.05$). (Table 2).

Self-esteem

Bivariate analysis for psychosocial and clinical factors and self-esteem score, as shown in

Table 3 Table 2. ART self-efficacy and social support were associated with self-esteem with a significant impact ($p = <0.05$)

Table 1. Baseline characteristics of study participants (N = 82)

Characteristics	Frequency n (%)
Age	17 (16,18)
Median, IQR	
Age at disclosure Median, IQR	12(11,14)
Number of years on care Median, IQR	12(8,13)
Number of years on ART Median, IQR	11 (7,13)

Gender Male	50 (61.0)
Female	32 (39.0)
School enrollment Boarding school	32 (39.0)
College/ university	6 (7.3)
Day school	35 (42.7)
Not enrolled in school	5 (6.1)
Other	4 (4.9)
Parental status	29 (35.4)
Both parents alive	
Only father alive	16 (19.5)
Only mother alive	21 (25.6)
Both parents not alive	13 (15.9)
Mother status NK	3 (3.7)
Care giver HIV status Yes	65 (79.3)
No	17 (20.7)
Viral load (copies /ml) <400	53 (65.4)
400 to 1000	2 (2.5)
1000 to 5000	6 (7.4)
>5000	20 (24.7)
Treatment break incidence Yes	12 (14.8)
No	69 (85.2)
Reported ART adherence >95% adherence	52 (64.2)
<95% adherence	29 (35.8)
Self-efficacy score	26 (31.7)
Low	
High	56 (68.3)
Rosenberg Self-esteem score	2 (2.50)
Low	
Normal	37 (45.1)
High	43 (52.4)
Social support Yes	57 (69.5)
No	25 (30.5)
Source of support Caregiver	38 (66.7)
Sibling	10 (17.5)
Clinic counsellor	3 (5.3)
Other relative Stigma	6 (10.5)
Yes	6 (7.3)
No	76 (92.7)

Table 2. Association between psychosocial and clinical variables and ART adherence self-efficacy

	HIV ASES SCORE \geq 90	HIV ASES SCORE < 90	p-value
Self-esteem score (median IQR)	30 (28–35)	37 (34–37)	0.002
Adherence			
≤95% adherence	17 (65.4)	12 (21.8)	0.002
>95% adherence	9 (34.6)	43 (78.2)	
Age at disclosure (median IQR)	12 (11–15)	12 (10.5–13.5)	0.23

No of yrs on ART (median IQR)	10 (7–13)	10.5 (6–13)	0.50
Viral load categories			
Age at disclosure (median IQR)	12 (11–15)	12 (10.5–13.5)	0.23
No of yrs on ART (median IQR)	10 (7–13)	10.5 (6–13)	0.50
Viral load categories <400			
	13 (50.0)	40 (72.7)	0.06
400–1000	0 (0.0)	2 (3.6)	
1000–5000	4 (15.4)	2 (3.6)	
>5000	9 (34.6)	11 (20.0)	
Treatment break Yes			
	18 (69.2)	51 (92.7)	0.005
No	8 (30.8)	4 (7.3)	
Social support Yes			
	10 (38.5)	15 (26.7)	0.28
No	16 (61.5)	41 (73.3)	
Stigma Yes			
	22 (84.6)	54 (96.4)	0.05
No	4 (15.4)	2 (3.6)	

Table 3. Bivariate analysis Association between psychosocial and clinical variables and self-esteem

	Normal Self-esteem (n = 39)	High self-esteem (n = 43)	P value
Self-efficacy score (median IQR)	94 (70–110)	110 (100–115)	0.002
Age at disclosure (median IQR)	12 (11–14)	12 (11–14)	0.86
ART years (median IQR)	11 (7–12)	10 (6–13)	0.79
Viral load categories <400			
	23 (58.9)	30 (71.4)	0.64
400–1000	1 (2.6)	1 (2.4)	
1000–5000	4 (10.3)	2 (4.8)	
>5000	11 (28.2)	9 (21.4)	
Treatment break Yes			
	30 (78.9)	39 (90.7)	0.13
No	8 (21.1)	4 (9.3)	
Social support Yes			
	17 (43.6)	8 (18.6)	0.01
No	22 (56.4)	35 (81.4)	
Stigma Yes			
	35 (89.7)	41 (95.4)	0.33
No	4 (10.3)	2 (4.6)	

Mediation analysis

Mediation analysis indicated that self-esteem significantly mediated the effect of self-efficacy on adherence (Table 4 and Figure 2). In Model 1, self-esteem was associated with self-efficacy (regression coefficient = 1.56, SE = 0.56, $p < 0.001$) after controlling for key demographic and psychosocial factors (treatment break, social support and stigma experience). Model 2 showed that adherence was significantly associated with self-efficacy (regression coefficient = 1.93, SE = 0.56, $p = 0.001$). In Model 3, adherence was associated with self-

Table 4. A mediation analysis

	Model 1: (X → M)	Model 2: (X → Y)	Model 3: (X, M → Y)
	DV = Self-esteem (a)	DV = Adherence (c)	DV = Adherence (c') (b)
Treatment break (No)	0.29 (0.74)	-0.04 (0.73)	0.04 (0.73)
Social support (Yes)	1.22 (0.54)*	-0.27 (0.56)	-0.25 (0.58)
ART self-efficacy score	1.56 (0.56)*	1.93 (0.56)***	1.93 (0.60)***
Self-esteem	-	-	-0.07 (0.58)
Total effect	6.93 (8.45)***	-	-

Note: Numbers in the cells are unstandardized coefficients (SE).

X: self-esteem; M: self-efficacy; Y: Adherence to ART.

*p < 0.05; *** p < 0.001

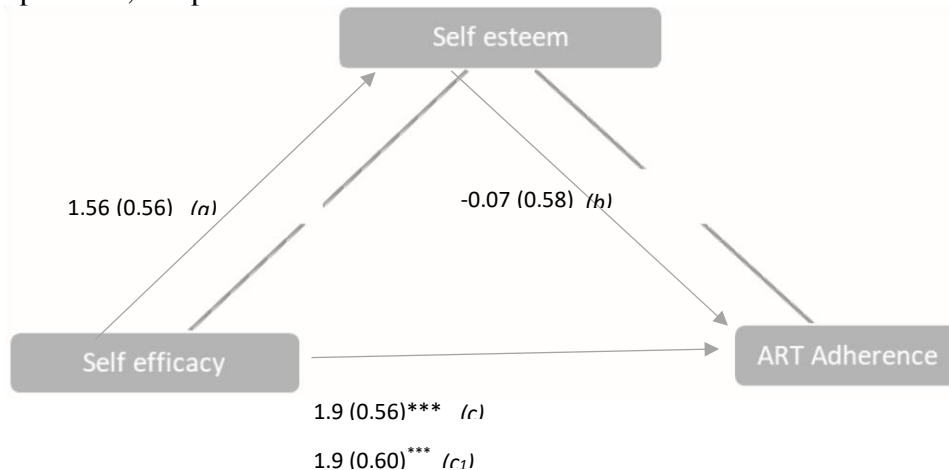


Figure 2. Mediation analysis. Note: Numbers are unstandardised coefficients and standard errors are given inside the brackets. paramed total effect = 6.93 (8.45)***p < 0.05

esteem when both adherence self-efficacy and self-esteem were included (regression coefficient = 0.07, SE = 0.58, p = 0.479). In contrast, the significant direct effect of self-efficacy on adherence remained constant (regression coefficient at 1.9 resulting in a complete mediation.). The paramed test indicated that the association between self-efficacy and adherence was mediated by self-esteem with a total effect of OR 6.93 (bootstrap 95%CI 1.99–24.14) with a natural indirect effect (nie) of OR 0.97 (bootstrap 95%CI 0.49–1.59).

Discussion

To the best of our knowledge, this is the first paper that describes the relationship between adherence ART self-efficacy and other psychosocial elements and particularly the mediation effect of these factors in affecting adherence among older ALWHIV in subSaharan Africa.

This study found that ART self-efficacy was strongly associated with self-esteem and that self-esteem mediated the expected effect of ART self-efficacy in optimal adherence.

Our study found that self-esteem was strongly associated with having social support, which aligns with other studies (Ebru Ikiz et al., 2010) that describe a strong relationship between self-esteem during adolescence and perceived social support.

Higher ART adherence self-efficacy was associated with increased self-reported adherence and a higher proportion of adolescents achieving viral load suppression. This finding agrees with studies among adult populations (Johnson et al., 2007). This finding further indicates that higher ART self-efficacy could potentially act as a predictive tool for optimal clinical outcomes during the adolescent transition to adult HIV care. ART self-efficacy was not associated with stigma reported in other studies (Katz et al., 2013) (X. X. Li et al., 2011) we postulate this may be due to the fact that other reported studies primarily looked at adult populations and seemed to focus on enacted stigma while our study focused on perceived stigma. However, the association between individual characteristics, particularly adherence self-efficacy and adherence, is comparable to similar findings in adult studies (Aregbesola & Adeoye, 2018) (L. L. Li et al., 2017) (Johnson et al., 2007) and therefore significant because this study focussed on older adolescents in whom HIV disclosure had occurred and who were in the process of transition to adult HIV clinic. The transition process (Cervia, 2013) focuses on equipping adolescents to practice self-management, including self-administration of antiretroviral drugs.

Our study found a strong association between adherence efficacy and self-esteem among adolescents. The relationship of self-esteem and self-efficacy within the realm of self-concept are well described (Human Nature and the Social Order – Charles Horton Cooley – Google Books, n.d.)

One study reports no association with self-efficacy (Education, 2016), while another found an association between self-esteem and better adherence (Chen et al., 2013) among ALHIV. We argue that these studies did not primarily focus on adolescents, although one included adolescents in its sample size. Our main finding was the partial mediation of self-esteem on ART adherence self-efficacy resulting in improved adherence. This finding has not been reported in literature among ALWHIV in sub-Saharan Africa. The implications of this finding are mainly the potential effect of including self-esteem building activities within interventions focusing on improving adherence among ALWHIV. It also underscores the role of self-esteem in this population and the resultant effect on health behavior such as ART adherence.

A limitation of this study is that it did not include adolescents with non-perinatal HIV infection acquisition. While developmentally, all ALWHIV face the same challenges, the length of ART use and the life events and stressors provides a unique combination of environmental factors affecting adherence in perinatal HIV acquisition; the scope of this study. The greatest contributor if new infections in Kenya through sexual transmission remain the older adolescents and young adults, and there is still an inherent need to explore this population. Another limitation is that this study focused on urban adolescents, and therefore the results may not be generalizable.

Conclusion

In conclusion, the expected gains of ART adherence self-efficacy may be mediated by low self-esteem. The findings of this study are important in providing insights into the

development and implementation of psychosocial interventions. Interventions focusing on adolescents transitioning to adult care should include a component that evaluates individuals' self-esteem and providing cognitive, psychosocial care or life skills required to ensure that adherence to ART

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Disclosure statement

No potential conflict of interest was reported by the author(s).


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Notes on contributor

NGK, and EB, developed the research concept, NGK, BA, and VM collected data, SM analyzed the data, NGK, EB, PM and SM provided input and EB, NGK and PM critically reviewed the manuscript.

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References

- Adefolalu, A., Nkosi, Z., Olorunju, S., & Masemola, P. (2014). Self-efficacy, medication beliefs and adherence to antiretroviral therapy by patients attending a health facility in Pretoria. *South African Family Practice*, 56(5), 281–285.
- Arage, G., Tessema, G. A., & Kassa, H. (2014). Adherence to antiretroviral therapy and its associated factors among children at South Wollo Zone Hospitals, Northeast Ethiopia: a cross-sectional study. *BMC public health*, 14, 365.
- Aregbesola, O. H., & Adeoye, I. A. (2018). Self-efficacy and antiretroviral therapy adherence among HIV positive pregnant women in South-West Nigeria: A mixed-methods study. *Tanzania Journal of Health Research*, 20(4), 4
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84(2), 191–215. <https://doi.org/10.1037/0033-295X.84.2.191>
- Berger, B. E., Ferrans, C. E., & Lashley, F. R. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Research in Nursing & Health*, 24(6), 518–529
- Berihun Assefa Dachew, T. B. T. A. M. B., 1*. (2014). Adherence to highly active antiretroviral therapy and associated factors among children at the University of Gondar Hospital and Gondar PolyClinic, Northwest Ethiopia: A cross-sectional institutional based study. *BMC Public Health*.
- Caron, J. (2013). [A validation of the social provisions scale: The SPS-10 items]. *Sante Mentale Au Quebec*, 38(1), 297–318. <http://www.ncbi.nlm.nih.gov/pubmed/24337002>

- Cervia, J. S. (2013). Easing the transition of HIV-infected adolescents to adult care. *AIDS Patient Care and STDs*, 27(12), 692–696.
- Chen, W.-T., Wantland, D., Reid, P., Corless, I. B., Eller, L. S., Ipinge, S., . . . Webel, A. R. (2013). Engagement with health care providers affects self-efficacy, self-esteem, medication adherence and quality of life in people living with HIV. *Journal of AIDS & Clinical Research*, 4(11), 256.
- Education, J. P. (2016). Implications of self-esteem. *XIV*(1), 90–99.
- F. Ebru Ikiz, Firdevs Savi Cakar, Perceived social support and self-esteem in adolescence, *Procedia Social and Behavioral Sciences*, Volume 5, 2010, Pages 2338–2342, ISSN 1877–0428,
- Farmer, R. F., Jarvis, L. R. L., Berent, M. K., & Corbett, A. (2001). Contributions to global self-esteem: The role of importance attached to self-concepts associated with the five-factor model. *Journal of Research in Personality*, 35(4), 483–499.
- Firdu, N., Enquoselassie, F., & Jerene, D. (2017). HIV infected adolescents have low adherence to antiretroviral therapy: A cross sectional study in Addis Ababa, Ethiopia. *Pan African Medical Journal*, 27
- Human Nature and the Social Order - Charles Horton Cooley - Google Books. (n.d.). Retrieved June 4, 2020, from https://books.google.co.ke/books/about/Human_Nature_and_the_Social_Order.html?id=-pORAAAAIAAJ&redir_esc=y
- Johnson, M. O., Neilands, T. B., Dilworth, S. E., Morin, S. F., Remien, R. H., & Chesney, M. A. (2007). The role of self-efficacy in HIV treatment adherence: Validation of the HIV Treatment Adherence Self-Efficacy Scale (HIV-ASES). *Journal of Behavioral Medicine*, 30(5), 359–370.
- Kasedde, S., Kapogiannis, B. G., McClure, C., & Luo, C. (2014). Executive summary: Opportunities for action and impact to address HIV and AIDS in adolescents. *Journal of Acquired Immune Deficiency Syndromes*, 66((SUPPL)), 2. <https://doi.org/10.1097/QAI.0000000000000206>
- Katz, I. T., Ryu, A. E., Onuegbu, A. G., Psaros, C., Weiser, S. D., Bangsberg, D. R., & Tsai, A. C. (2013). Impact of HIV-related stigma on treatment adherence: Systematic review and meta-synthesis. *Journal of the International AIDS Society*, (Vol), 16.
- and depression symptoms in young people with perinatally acquired HIV and HIV affected young people in England. *AIDS Care*, 30(8), 1040–1049.
- Lee, S., & Hazra, R. (2015, December 2). Achieving 90- 90-90 in paediatric HIV: Adolescence as the touchstone for transition success. *Journal of the International AIDS Society*, 18, 20257
- Li, L., Lin, C., Lee, S. J., Tuan, L. A., Feng, N., & Tuan, N. A. (2017). Antiretroviral therapy adherence and self-efficacy among people living with HIV and a history of drug use in Vietnam. *International Journal of STD & AIDS*, 28(12), 1247–1254.
- Li, X., Huang, L., Wang, H., Fennie, K. P., He, G., & Williams, A. B. (2011). Stigma mediates the relationship between self-efficacy, medication adherence, and quality of life among people living with HIV/AIDS in China. *AIDS Patient Care and STDs*, 25(11), 665–671.
- MacKinnon, D. P., Fairchild, A. J., & Fritz, M. S. (2007). Mediation Analysis. *Annual*

- Review of Psychology*, 58(1), 593–614.
- Mueller, J., Alie, C., Jonas, B., Brown, E., & Sherr, L. (2011). A quasi-experimental evaluation of a community-based art therapy intervention exploring the psychosocial health of children affected by HIV in South Africa. *Tropical Medicine and International Health*, 16(1), 57–66.
- Naar-King, S., Outlaw, A. Y., Sarr, M., Parsons, J. T., Belzer, M., & Macdonell, K., & Adolescent Medicine Network for HIV/AIDS Interventions. (2013). Motivational Enhancement System for Adherence (MESA): A randomized pilot trial of a brief computer-delivered prevention intervention for youth initiating antiretroviral treatment. *Journal of Pediatric Psychology*, 38(6), 638–648.
- Nabukeera-barungi, N., Elyanu, P., Asire, B., Katureebe, C., Lukabwe, I., Namusoke, E., . . . Tumwesigye, N. (2015). Adherence to antiretroviral therapy and retention in care for adolescents living with HIV from 10 districts in Uganda. *BMC Infectious Diseases*, 1–10.
- Nyandiko, W. M., Ayaya, S., Nabakwe, E., Tenge, C., Sidle, J. E., Yiannoutsos, C. T., . . . Tierney, W. M. (2006). Outcomes of HIV-infected orphaned and non-orphaned children on antiretroviral therapy in Western Kenya. *Journal of Acquired Immune Deficiency Syndromes*, 43 (4), 418–425.
- Perera, H. N. (n.d.). *Running head: The social provisions scale and bi-factor-eseem construct validity of the social provisions scale: A bifactor exploratory structural equation modeling approach*. <https://doi.org/10.1177/1073191115589344>
- Petersen, I., Bhana, A., Myeza, N., Alicea, S., John, S., Holst, H., . . . Mellins, C. (2010). Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: A qualitative investigation. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, 22(8), 970–978.
- Reinius, M., Wettergren, L., Wiklander, M., Svedhem, V., Ekström, A. M., & Eriksson, L. E. (2017). Development of a 12-item short version of the HIV stigma scale. *Health and Quality of Life Outcomes*, 15(1), 1.
- ROSENBERG SELF-ESTEEM SCALE. (1965).
- Sharma, S., & Agarwala, S. (2015). Self-esteem and collective self-esteem among adolescents: An interventional approach. *Psychological Thought*, 8(1), 105–113.
- Valente, M. J., Rijnhart, J., Smyth, H. L., Muniz, F. B., & MacKinnon, D. P. (2020). Causal Mediation Programs in R, Mplus, SAS, SPSS, and Stata. *Structural equation modelling: a multidisciplinary journal*, 27(6), 975–984.
- World health organization. (2006). *From access to adherence: The challenges of antiretroviral treatment - studies from Botswana, Tanzania and Uganda, 2006: Factors that facilitate or constrain adherence to antiretroviral therapy among adults in Uganda: A pre-intervention study: Chapter 3*. Retrieved March 26, 2020, from <https://apps.who.int/medicinedocs/en/d/Js13400e/10.6.1.html>