HIV Status Disclosure, Stigma and Viral Suppression among Adolescents and Young Adults Living With HIV

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Abstract

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Introduction: Viral suppression remains the gold standard in determining success in HIV treatment. Adolescents and young adults with HIV (AYHIV) have poorer adherence and viral suppression than adults. Several factors have been associated with viral non-suppression among AYHIV through their influence on adherence. Individual level factors include younger age and male sex, sub-optimal dosing, and HIV-related stigma; interpersonal factors include low social support while health system factors include having treatment support cadre of staff and dedicated adolescent spaces in facilities. There is mixed evidence regarding the influence of social processes (including how one knew their HIV status [i.e., disclosure], stigma, and social support) on viral suppression in AYHIV. The WHO recommends that children between ages 6-12 years are informed of their HIV status through a planned and structured disclosure process involving their caregivers and providers. Few studies have described the disclosure experiences of AYHIV and their preferences especially following the roll out of disclosure guidelines and wider availability of disclosure tools in SSA countries since 2014.

Methods: The aims of the dissertation address the following questions: Chapter 1) what is the prevalence and severity of HIV stigma among AYHIV, the co-occurrence of different stigma domains, and modifiable factors associated with HIV stigma? We used cross-sectional survey data from an observational study, Data-Informed Stepped Care (DiSC) to improve Adolescent HIV outcomes, among youth ages 15-24 years. Generalized linear models (GLM) were utilized to estimate the associations between modifiable factors and HIV stigma. Chapter 2) what is the impact of HIV stigma on mental health, treatment adherence and viral suppression? We used the longitudinal survey and routine data from the DiSC study to conduct longitudinal analyses, utilizing GLM for the analysis for viral suppression, and generalized estimating equations (GEE) for the analyses for depressive symptoms and treatment adherence. Chapter 3) what are the adolescent perspectives on the disclosure process, their experiences, preferences and perception of the impact disclosure had on their treatment and other aspects of life? We utilized cross-sectional survey data from the Adolescent Transition to Adult Care for HIV-infected Adolescents in Kenya (ATTACH) study for AYHIV ages 10-24 years, in addition using GLM to assess associations between modifiable factors associated with the disclosure process and satisfaction with disclosure.

Results: Chapter 1: The mean overall stigma score for the 1,011 AYHIV was 25 (range: 10-50). The majority (88%) reported anticipated stigma, 48% perceived community stigma, 36% experienced stigma and 24% internalized stigma. Factors associated with higher stigma levels were AYHIV attending general/adult clinics compared to those in adolescent clinics, AYHIV having dropped out of school, being in a sexual relationship, exposure to violence. Some caregiver involvement in HIV care, and being in a support group were associated with lower mean stigma levels.

Chapter 2: Among the 1,011 AYHIV, there were significant increments in risk of depressive symptoms, non-adherence and having a detectable viral load (>50 copies/ml) for every 1 standard deviation increase in stigma scores. Experienced and anticipated stigma were associated with detectable VL , while internalized and perceived community stigma were associated with depressive symptoms.

Chapter 3: Majority of the 375 AYHIV enrolled were disclosed to by providers, although 53% preferred that caregivers performed disclosure. Three-quarters preferred disclosure to be completed by age 12 years. Nearly three-quarters of AYHIV reported they were ready for disclosure when it happened, and 83% were satisfied with the process. Majority also reported that they felt supported by the clinic and caregivers pre-and post-disclosure. Lower support was associated with lower disclosure satisfaction. AYHIV reported that disclosure positively influenced their ART adherence.

Conclusions: The studies in this dissertation identify key factors that may predict HIV stigma, and are likely amenable to interventions. This includes clinic structures that favor provision of adolescent friendly care, the school environment, and caregiver involvement in HIV care. The significant impact of HIV stigma on mental health, health behaviors and treatment outcomes demonstrated is an important catalyst for development of anti-stigma interventions. Lastly, we identified ways to improve the disclosure experience for AYHIV, especially through enhanced caregiver and clinic support throughout the process.

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INTRODUCTION

Sub-Saharan Africa (SSA) bears the greatest burden of HIV among adolescents and young adults (AYA), with 75% of the more than 4 million adolescents and young adults (10-24 years) living with HIV (AYHIV) living in East and South Africa, and Nigeria.(1) The burden of HIV among AYHIV has increased over the last decade in part due to the high incidence (though now reducing) of new infections among young people ages 15 to 24 years. In 2019, 1 in 4 HIV infections in SSA was among adolescent girls and young women,(1) while in Kenya, close to half of all new HIV infections are among young people ages 15-24 years.(2) The other reason for the growing burden is the increase in perinatally-infected children (many of whom acquired HIV before the full scale-up of prevention of mother to child transmission ([PMTCT] programs across the region) entering adolescence. The survival of HIV-infected children has increased over time due to improved access to antiretroviral therapy (ART) and provision of more efficacious ART.(3, 4) There are however emerging challenges in HIV care for AYHIV. In the UNAIDS 90-90-90 targets (2020),(5) compared to adults, AYHIV were further away from achieving the targets of starting ART (2nd 90), and much further in achieving viral suppression targets (3rd 90).(6) In the 2030 UNAIDS 95-95-95 targets,(5) the aim is to have at least 86% of <u>all</u> HIV-infected persons achieving viral suppression. Studies across SSA show that AYHIV have poorer adherence to treatment, retention in care, viral suppression and higher HIV-related mortality.(7-10)

Viral suppression is now recognized globally as a key outcome of HIV treatment.(11) It is also one of the key HIV prevention strategies with the ‘undetectable=untransmissible’ (U=U) mantra gaining prominence in recent years after studies showed that virally suppressed HIV-infected individuals cannot transmit to their sexual partners.(12) Understanding the drivers of viral suppression is therefore crucial to enable development of relevant interventions for people living with HIV. The literature on drivers of viral suppression is diverse, with a few factors consistently shown to be associated with viral suppression. Adherence to treatment may mediate the impact of majority of factors on viral suppression. This is demonstrated by studies that have separately looked at factors associated with -or- interventions that have an impact on ART adherence(13-17) and viral suppression(14, 18, 19) showing similarity in factors, and studies looking at the impact of adherence on viral suppression.(20-22) However, the strength of association between these factors and either outcomes is different, likely because the levels of adherence required to achieve viral suppression has a wide range, estimated to be as low as 54% in some patients and certain ART regimens, and due to uncertainty in the measurement of adherence. To achieve non-detectable levels of viremia however may still require very high levels adherence (>95%).(23, 24) Categories of HIV-related stigma include community stigma (discriminatory attitudes by persons in the community against people living with HIV), anticipated stigma (expectation that one will be discriminated against due to one's HIV status), experienced stigma (lived experience of discrimination) and internalized stigma (acceptance of negative characterization).(25) The categorization allows for specific measurement and development of interventions targeting the individual, their support system and the community. Other categorizations include structural (e.g. criminalizing laws) and intersectional (across HIV, mental health, disability, sexuality, gender etc.) stigma.(26) Previous studies hypothesized that community stigma which is perceived or experienced by individuals affects those living with HIV through internalization of that stigma, resulting in anticipated stigma from the community, which in turn influences treatment adherence and mental health.(25) Counter-intuitively, efforts towards adherence may also be seen as competing with stigma avoidance efforts where full adherence requires disclosure of HIV status to others.(27) Multiple studies among adults (including in SSA) show that internalized and enacted stigma are associated with viral non-suppression.(28-30) This however is not always replicated in the few studies among AYHIV.(31, 32) More research work is required to understand the inter-play between various forms of stigma, mental health and adherence, and the impact of stigma on viral suppression among AYHIV in SSA.

Disclosure of HIV status to perinatally infected adolescents has been associated with improved retention in care, ART adherence, viral suppression, and mental health.(33, 34) From a public health perspective, disclosure before sexual debut improves chances of preventing onward transmission.(35) Challenges affecting the disclosure process in SSA include caregiver reluctance to disclose,(36) poor access to appropriate disclosure tools(37) and heavy workload among healthcare workers (HCW) in facilities.(38) The World Health Organization (WHO) guidelines recommend that children advance through a planned and structured disclosure process between ages 6 and 12 years involving both caregivers and HCWs in the process.(39) However, in SSA, full disclosure typically occurs at a later age, with sub-optimal caregiver involvement.(33, 40) While multiple studies have examined HCW and caregiver preferences and practices to inform these guidelines on disclosure,(41) fewer studies have examined the adolescent perspective and preferences on these practices.(42) Understanding the adolescent perspective on the impact of the disclosure process on treatment adherence, post-disclosure coping and provision of support is essential for improving the disclosure experience and incorporating patient-centered care approaches.

In Chapter 1 of this dissertation, we assess the prevalence and severity of HIV stigma among AYHIV, the co-occurrence of different stigma domains, and identify modifiable factors associated with HIV stigma. In Chapter 2, we estimate the effect of HIV stigma on mental health, treatment adherence and viral suppression. Chapter 3 fills gaps in literature on the adolescent perspectives on the disclosure process, providing a historical account of their experiences with the disclosure process, and its impact on their treatment and other aspects of life.

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CHAPTER 1: Individual-, interpersonal- and institutional-level factors associated with HIV stigma among youth in Kenya

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Abstract

HIV stigma remains a barrier in achieving optimal HIV treatment. We studied the prevalence and multilevel predictors of HIV stigma among adolescents and young adults with HIV (AYHIV) ages 15-24 years in Western Kenya. Of 1,011 AYHIV, 69% were female with a median age of 18 years. Most (59%) attended adolescent clinic days, and 40% attended support groups. One-quarter (27%) had experienced physical, 18% emotional, and 7% sexual violence. The majority of AYHIV (88%) reported anticipated stigma, 48% perceived community stigma, 36% experienced stigma, and 24% internalized stigma. Compared to AYHIV attending adolescent clinics, those in general/adult clinics had higher internalized stigma. Similarly, having dropped out of school was associated with higher internalized stigma. AYHIV in sexual relationships had higher experienced and anticipated stigma. Lastly, exposure to violence was associated with higher experienced, internalized, anticipated and perceived community stigma. The factors could be considered when developing anti-stigma interventions.

Key words: HIV stigma; Stigma types; Adolescent; Youth; Violence; Sexual behavior

Introduction

Stigma is a socially damaging phenomenon where people living with HIV (PLHIV) are considered socially undesirable, lose their social standing, lose power when relating with people in their communities, and are denied certain benefits and freedoms enjoyed by other members of their communities.(1) Functioning as a multi-level process consisting of intrapersonal, interpersonal, community, institutional and structural domains,(2) stigma is an important driver of the HIV pandemic, and remains a barrier in achieving optimal HIV treatment targets.(1, 3, 4) The experience of stigmatizing attitudes and actions from others (*experienced stigma*) may result in PLHIV feeling less valued (*internalized stigma*). How close family and friends, community members and institutions treat PLHIV shapes their perception of the community's tolerance (*perceived community stigma*) and influences their expectation of how they may be treated in future (*anticipated stigma*).

HIV stigma is associated with poor HIV outcomes including antiretroviral therapy (ART) non-adherence, viral non-suppression, and poor mental health.(5) Among adolescents and young adults with HIV (AYHIV), stigma has also been associated with lowered quality of life(6), and increased use of alcohol and tobacco.(7) The four HIV stigma types described in the health stigma and discrimination framework (experienced, internalized, anticipated, and perceived community stigma)(3, 8) are hypothesized to impact specific aspects of physical and mental health, health-seeking behaviors, social self-concept, and interpersonal relationships.(3, 4, 9-15) Interventions to reduce HIV stigma have been developed for diverse contexts. However, in systematic reviews(16-23) most stigma intervention studies were considered to be of low quality, non-specific, and few interventions demonstrated a direct effect on HIV stigma reduction. The complex, multi-layered nature of HIV stigma is likely a key reason for lack of intervention effectiveness. Interventions that focused on more than one stigma type and on multiple levels (individual to structural levels) showed higher effectiveness in reducing stigma.(24, 25) Structural interventions like the scale up of antiretroviral treatment, decriminalizing HIV,(26) and poverty reduction have also been shown to significantly reduce stigma among adults living with HIV.(18) Few stigma interventions have been developed specifically for AYHIV,(24, 27) particularly those living in sub-Saharan Africa.(24) Improved understanding of factors that predict or co-occur with HIV stigma could enhance the development of stigma interventions. Previously identified upstream factors that were associated with HIV stigma include self-disclosure of HIV status, healthcare setting and judgement by providers, lower education, violence and poor HIV-related health.(28-31) None of these studies were among AYHIV, and most did not evaluate specific stigma types.(31) Understanding co-occurrence of different HIV stigma types may also inform intervention development. We determined the prevalence of HIV stigma and HIV stigma types, and determined correlates of HIV stigma and types among AYHIV.

Methods

Study design

This was a nested cross-sectional analysis within a prospective cohort study of AYHIV conducted in nine facilities in Western Kenya between April 2019 and March 2020.(32) The primary goal of the parent study, Data-Informed Stepped Care (DiSC) to improve Adolescent HIV outcomes, was to conduct formative work towards the development of a data-driven, health systems intervention to improve engagement in care among AYHIV ages 10-24 years in Kenya. In this analysis, we included participants aged 15-24 years.

Theoretical model

In this project, we seek to expand the health stigma and discrimination framework, which proposes relationships between HIV stigma types and health/behavioral/interpersonal outcomes.(3, 33) We hypothesize that individual, interpersonal, community, institutional and structural level factors predict the severity of HIV stigma types. These relationships between upstream factors and the stigma types in turn have a bearing on the impact HIV stigma types have on specific patient outcomes (Figure 1).

Study procedures

Recruitment and enrollment

Recruitment was conducted in HIV clinics and maternal and child health (MCH) clinics serving pregnant or parenting AYHIV commonly referred to prevention of mother to child transmission of HIV (PMTCT) clinics. Those who consented completed an enrollment questionnaire with socio-demographic information including age, sex, education, income, and food security. They provided HIV-related information including age at diagnosis, process of knowing their HIV status, perception of mode of HIV acquisition, participation in peer support groups, clinic type (adolescent, general/adult, PMTCT), self-disclosure of one's HIV status, and information related to sexual activity.

Measures

HIV stigma was assessed using a 10-item Youth HIV Stigma Scale,(34) an abbreviation of the 40-item Berger's stigma scale.(35) Each question was assessed on a 5-item Likert scale (strongly disagree to strongly agree). The scale assessed four HIV stigma types – experienced/personalized stigma, internalized stigma/negative self-image, perceived community stigma/public attitudes towards people with HIV, and anticipated stigma/disclosure concerns. We assessed the reliability of the scale using the Cronbach's alpha:(36) overall stigma scale - $\alpha = 0.79$; experienced stigma (3 questions) – $\alpha = 0.70$; internalized stigma (3 questions) - $\alpha = 0.80$; perceived community stigma (2 questions) - $\alpha = 0.74$; anticipated stigma (2 questions) – $\alpha = 0.44$. Social support was assessed using the 12-item Multidimensional Scale of Perceived Social Support (MPSS)(37) - $\alpha = 0.78$, while the 2-item Connor Davidson Resilience Scale was used to assess resilience(38) - $\alpha = 0.59$. Independence in care was measured using two questions assessing the AYHIV’s ability to adhere to clinic schedules, and ability to adhere to medication without involvement of a caregiver. Experience of violence (physical, sexual, and emotional) was assessed using three questions derived from the WHO Violence Against Women Instrument.(39) Questions were gender-neutral and asked about ever, and recently (last 6 months) having experienced physical, emotional or sexual violence, with examples provided for each type of violence.

Definition of key variables

We dichotomized the HIV stigma and the HIV stigma types variables as follows: overall stigma – answering ‘strongly agree’ or ‘agree’ to any of 10 questions among those who answered all the 10 questions for overall and for the subset of questions for the specific stigma type. We defined mode of HIV infection as vertical if the ART start date was <15 years of age, and behavioral if ≥15 years. For those with missing ART start date information, we classified those who knew their HIV status before age 15 years in the vertical category and at or after age 15 in the behavioral category.(40) We included those previously married (divorced/widowed) and those currently married or cohabiting or in a relationship in the marriage variable as ‘ever married’. The school enrollment variable was dichotomized into a) those who were still in school (primary or secondary) or had completed secondary school, and b) those who had dropped out of primary or secondary school and were currently out of school. The point of care in the facility was either a) adolescent/pediatric clinic, b) adult or general clinic, or c) PMTCT clinic. No independence in care was defined as requiring caregiver support in clinic attendance and medication adherence, full independence was if support was not required for either, while partial independence was if either was required. The three categories for experiencing any violence (physical/sexual/emotional) were no violence, past violence (experienced but not in the last 6 months) and recent violence (experienced in the last 6 months). Sexual relationships were categorized as never, previously, and current.

Ethical considerations

The DiSC study was approved by the Maseno University Ethics Review Committee (MUERC/00642/18), and the University of Washington Institutional Review Board (#STUDY00005767). Participants ≥18 years and emancipated minors (<18 years) provided informed written consent at the time of recruitment. We received a waiver allowing AYHIV ages 15-17 attending clinic alone to self-consent. Caregivers for the other minors provided parental consent with the minors providing assent.

Statistical Analysis

We summarized the sociodemographic and HIV-related characteristics, and other measures using counts, proportions, median and interquartile range (IQR) as appropriate, and calculated mean (standard deviation [SD]) overall stigma across the variable categories. We reported the mean (SD) and prevalence of overall HIV stigma and the four stigma types, and described the co-occurrence of different HIV stigma types across individuals.

We estimated the association between overall HIV stigma and sociodemographic, HIV-related characteristics and other measures. Guided by the multilevel stigma model,(17) we included modifiable factors at the interpersonal level (example: sexual relationships, experience of violence, self-disclosure and being in a support group) and institutional levels (example: type of clinic, school). Overall stigma (outcome) was included in the generalized linear models (family = ‘gaussian’) as a continuous variable. We reported mean differences (MD) from bivariate analyses, and adjusted mean differences (aMD) after adjusting for age and gender. Previous literature demonstrated intersectionality between HIV stigma and age, and gender.(41) Similar analyses were conducted to estimate the associations between the four HIV stigma types and the factors in the overall stigma models with a significant association in the bivariate analyses. Lastly, we conducted stratified analyses to determine whether the associations between overall

HIV stigma and the selected factors were different across age groups (15-19 years and 20-24 years). The 95% confidence intervals (95%CI) for the mean differences and p values (p) were computed using bootstrapping to account for clustering of participants by facility. Power calculations were done with the assumption of a sample size of ~1000 AYHIV and a standard deviation of 10 for the overall HIV stigma score. We had >80% power to detect a mean difference in overall stigma levels of 5 (out of a maximum possible score of 40) between groups for factors with a prevalence of 3%, and mean difference of 2 between groups for factors with a prevalence of 50%. All analyses were completed using R studio (R Foundation for Statistical Computing, Vienna, Austria).

Results

Description of the study population

Of 1,011 AYHIV included in this analysis, 701 (69%) were female with a median age of 18 years (interquartile range [IQR]: 16-21). The majority 534 (57%) knew their HIV status before they were 15 years old and 564 (58%) were classified as having acquired HIV vertically. Fifty-nine percent received care at the adolescent/pediatric clinic, 31% at the adult or general HIV clinic, and 10% at the PMTCT clinic. Overall, 405 (40%) were in a support group. The majority (52%) of those in adolescent/pediatric clinics, 28% of those in adult/general clinics and 10% of those in PMTCT clinics were in a support group; 920 (92%) were independent in care. Majority of AYHIV, 647 (64%) had ever had sex, and 328 (51%) of those with a sexual partner had disclosed their status to their partner. Further, 280 (27%) had experienced physical violence, 178 (18%) emotional violence, and 68 (7%) sexual violence. The median social support score (range: 10-60) was 43 (IQR: 38-48), while the median resilience score (range: 2-10) was 8 (IQR: 6-9) (Table 1).

Prevalence of overall, experienced, internalized, perceived community and anticipated stigma

The overall stigma score was normally distributed with a median of 25 (IQR: 21-29) and mean 25 (SD: 7). Of 890 AYHIV with an overall stigma score (all stigma questions answered), 817 (92%) had any stigma; 350 (36%) had experienced stigma, 241 (24%) had internalized stigma, 478 (48%) had perceived community stigma, and 871 (88%) had anticipated stigma. Only 83 (9%) had all four stigma types. There was high co-occurrence of all stigma types with the lowest being the proportion of AYHIV with anticipated stigma who also had internalized stigma (25%), and the highest being the proportion of AYHIV with experienced stigma who also had anticipated stigma (97%). Female and older youth (20-24 years) had higher prevalence of all four HIV stigma types (Figure 2).

Predictors of overall HIV stigma (Figure 3)

Institutional-level factors associated with overall HIV stigma were the clinic type and school enrollment status. Compared to AYHIV attending adolescent/pediatric clinics, those in general/adult clinics had a higher mean stigma level (aMD: 1.58 [0.13-3.04], p=0.042). Only 4% of the mean difference in stigma levels between those in adolescent and general/adult clinics was explained by being in a support group. AYHIV who had dropped out of school reported higher stigma levels compared to those who had completed or were still in school (aMD: 2.04 [0.44-3.64], 0.027) (Table 2).

Interpersonal-level factors associated with overall HIV stigma were being in a sexual relationship, self-disclosure to a sexual partner, experiencing violence, and independence in care. Those who had a past sexual relationship (aMD: 2.87 [0.10-5.65], p=0.048) or were in a current relationship (aMD: 2.61 [1.28-3.93], p=0.001) had higher stigma levels compared to those who have never been in one. AYHIV who had ever self-disclosed to a sexual partner tended to have higher stigma levels (aMD: 1.16 [-0.27-2.59], p=0.07). Those who had experienced past violence (aMD: 2.51 [-0.12-5.13], p=0.058) and recent violence (aMD: 2.91 [1.38-4.44], p=0.002) also had higher stigma levels compared to those with no experience of violence. There was a trend towards significance in the analysis for independence in care. Compared to AYHIV without any caregiver involvement in their HIV care (fully independent), those with some involvement (partial independence) had lower mean stigma levels (aMD: -1.90 [-4.10-0.31], p=0.07) (Table 2). Social support was not associated with HIV stigma (Supplementary table 1).

Individual-level factors assessed included mode of HIV acquisition, process of learning ones HIV status, age of knowing their HIV status and resilience. Unlike resilience, the first three had an association with HIV stigma on bivariate analysis but not after adjusting for age and gender (Supplementary table 1).

In the age-stratified analysis, the factors that were associated with overall stigma for those ages 20-24 years were being in the adult/general clinic (aMD: 3.05 [1.01-5.10], p=0.012), dropping out of school (aMD: 2.00 [0.20-3.81], 0.043), having partial independence (aMD: -3.49 [-6.78-(-0.20)], p=0.041), and experiencing recent violence (aMD: 3.45 [1.27-5.62], p=0.008). For those 15-19 years, cofactors were being in a sexual relationship in the past (aMD: 2.64 [0.02-5.26], p=0.048) and currently (aMD: 2.71 [1.20-4.22], p=0.005). There was a trend towards significance for those who experienced recent violence (aMD: 2.42 [-0.53-5.62], p=0.083) and dropping out of school (aMD: 2.33 [-0.20-4.85], 0.060). While not significant, those receiving care at PMTCT (aMD: 2.05 [-1.94-6.04], p=0.265) and those who had self-disclosed to a sexual partner (aMD: 1.93 [-0.64-4.51], p=0.104) had higher stigma levels (Supplementary table 1).

Predictors of stigma types

Factors that were associated with *experienced stigma* were being in a sexual relationship in the past (aMD: 1.14 [0.39-1.90], p=0.005) and currently (aMD: 1.02 [0.44-1.61], p=0.009), and experiencing violence in the past (aMD: 0.89 [0.04-1.75], p=0.046) and recently (aMD: 0.81 [0.26-1.36], p=0.013). Dropping out of school (aMD: 0.76 [0.02-1.50], 0.049), being served in the adult/general clinic (aMD: 0.78 [0.09-1.47], p=0.033), partial independence (aMD: -0.82 [-1.55-(-0.10)], p=0.029), and experiencing violence recently (aMD: 0.65 [0.26-1.05], p=0.014) were associated with *internalized stigma*. There was a trend to significance for the association between internalized stigma and experiencing violence in the past (aMD: 0.60 [0-1.21], p=0.056) and being in a support group (aMD: -0.58 [-1.29-0.11], p=0.071). Experiencing violence in the past (aMD: 0.66 [0.24-1.08], p=0.008), and recently (aMD: 1.13 [0.49-1.77], p=0.010) were associated with *perceived community stigma*. The association between being in a support group and perceived community stigma trended towards significance (aMD: -0.16 [-0.33-0.01], p=0.059). Factors associated with *anticipated stigma* were being in a current sexual relationship (aMD: 0.50 [0.06-0.94], p=0.034), with a trend to significance for recent experience of violence (aMD: 0.46 [-0.05-0.97], p=0.073) (Table 2). Results of the bivariate analysis for all factors and the four stigma types are in supplementary table 2.

Discussion

Nearly all youth included in this study reported at least one form of stigma. Anticipated stigma was the most prevalent while a quarter of the youth reported internalized stigma, and about 10% reported experience of all four stigma types. School attendance and clinic type were institutional level factors associated with HIV stigma, while interpersonal level factors included independence in care (involvement of a caregiver in care), sexual relationships, self-disclosure to a sexual partner, and experiencing violence. The health stigma and discrimination framework proposes relationships between HIV stigma types and health/behavioral/interpersonal outcomes. In this study, we shift the focus more proximally to identify modifiable multilevel factors that either cause or co-occur with specific HIV stigma types, and therefore are important to include in the anti-stigma interventions.

A variety of stigma scales and approaches to computation of scores have been used in the literature, making comparisons of prevalence or levels of HIV stigma across studies and populations challenging.(34, 42-46) Previous studies in settings similar to ours have reported higher prevalence of internalized stigma and experienced stigma, with a mixed picture for anticipated stigma among AYHIV.(29, 46-48) While a few other studies reported lower prevalence of internalized and experienced stigma,(49, 50) it is clear that there is a significant stigma burden among youth with HIV. In our study, older age was associated with higher stigma levels, consistent with higher levels of stigma observed in adult studies.(45, 51, 52) The marginalizing experiences by PLHIV likely stack up across the life span. Except for the much higher prevalence of anticipated stigma we reported in our study, previous studies with adults reported higher prevalence of experienced and internalized stigma levels.(44, 53-56) Overall, our data suggest a need to incorporate interventions to reduce stigma in clinics and communities.

The multi-level manifestation of HIV stigma where structural, institutional, community, interpersonal and intrapersonal factors contribute to its propagation is fairly well understood.(17) However, to develop effective interventions and policies that reduce stigma and mitigate its effects, we need to contextualize these factors across the different population groups and regions. In our study, we highlight the influence of clinic type. While some clinics serve their youth in separate spaces or days, others serve them together with adults.(57) We found significantly lower stigma levels among youth attending adolescent clinics. Youth have previously reported their discomfort with attending HIV clinics with adults. The reactions include shame of being seen by older members of their communities in the HIV clinics, expectation of being looked down upon, ambivalence and complex emotions around the chronicity of the illness seen as one sees older unwell/disease afflicted individuals, expectation not to be understood by providers in the adult clinics among others.(58, 59) From this study, we could infer that these activate pathways for HIV stigma, especially internalized stigma. These challenges informed the roll-out of youth responsive clinics in region.(60-62) Providers in these clinics were also trained on provision of youth friendly services.(63, 64)

On the other hand, pregnant or parenting adolescent girls and young women with HIV served in PMTCT clinics reported high stigma levels. Though we did not have power to detect statistically significant differences with those in the adolescent clinics, it is possible that the associations are from a combination of the stigmatization, unmet socioemotional needs around unplanned, early pregnancy, their HIV status, how and what services are offered or not in these PMTCT clinics. Unlike youth who were served in general/adult and PMTCT clinics, majority of those in adolescent clinics had joined support groups. Though being in a support group only marginally explained the differences in HIV stigma between those in adolescent and general/adult clinics, the support groups by themselves could be important interventions to reduce stigma. Being in a support group was associated with lower internalized and anticipated stigma through their empowerment and living positive messaging. The support groups likely prepare the adolescents and young adults to counter some stigmatizing situations and bolster their confidence and sense of self-worth leveraging peer support. Expanding the reach of youth responsive clinics and peer support groups, which are highly advocated for to enhance HIV treatment outcomes,(65-67) could be effective ways to mitigate internalized stigma for youth.

HIV stigma manifests in the interpersonal relationships youth are involved in. We found that youth who had ever been in sexual relationships, and especially if they were currently in one, reported higher experienced stigma. Likely due to their lived experiences, including the need for disclosure to their partners, they also had higher anticipated stigma. Development of relationships is a key part of development during adolescence and young adulthood.(68, 69) Ensuring that these relationships are healthy is a challenge especially for adolescents,(70) which is worsened by mixed messaging around the need for partnerships for support and the equally important message for them to delay sexual debut.(71-73) For AYHIV, the complexity is heightened by disclosure of their HIV status, which may lead to emotional and physical intimate partner violence and rejection.(74-76) Violence however does not only affect those in sexual relationships. Youth with HIV in general are disproportionately affected by physical, emotional and sexual violence, which negatively affects their mental health and treatment adherence.(77-81) We found a strong relationship between experience of violence and HIV stigma through all types. It is highly likely that HIV stigma is one of the main pathways through which violence impacts treatment outcomes for AYHIV. Interventions focused on mitigating the impact of HIV stigma and eventually improving treatment outcomes would be strengthened by the inclusion of measures to address violence against AYHIV.

We assessed the role of caregivers in the HIV care for AYHIV. We found that youth whose caregivers were involved in their care- especially in clinic attendance (partially or not independent), had lower levels of internalized stigma independent of their age. Interestingly, the association was stronger for the older age group (20-24 years), which counter-intuitively may support the continued involvement of caregivers into early adulthood of their youth with HIV. It was also worth noting that self-disclosure to family was not associated with higher stigma levels unlike disclosure to partners, a trend highlighted in previous literature.(82) In summary, these results support increased involvement of caregivers in the HIV care for adolescents and young adults, including into their early adulthood, which has been shown to improve their treatment outcomes.(83)

It is plausible that dropping out of school may heighten internalization of stigma by cutting these youth from sources of support, information and oversight of key individuals like teachers, social workers and peers. In this case, supporting AYHIV to remain in school could be an important structural and institutional anti-stigma intervention. The reverse interpretation, that HIV stigma may result in AYHIV dropping out of school suggests that the support for the AYHIV to remain in school should include measures that mitigate the impact of HIV stigma in the school environment. Measures already tested in our setting include increasing HIV literacy among school staff, specific HIV treatment support measures in school like confidential treatment storage, linkages between schools and health facilities and psychosocial support.(84)

A strength of this analysis is that the study population resembled the population of youth with HIV in care in Kenya with majority being female, having acquired HIV vertically, being in school, and already debuted sexual relationships. The large sample size, collection of a wide range of variables, basing the analysis on an established theoretical framework, and using validated scales for key measures including the HIV stigma scale validated for AYHIV are strengths of this study. The cross-sectional design of this study is a key limitation that makes it challenging to explain the direction of associations.

Conclusion

This exploratory multilevel analysis leverages the health stigma and discrimination framework to demonstrate a strong positive relationship between HIV stigma types and behaviors and their impact on HIV treatment and mental health outcomes. This study added proximal factors to the existing framework and assessed their proposed relationship with the stigma types. The identified institutional, interpersonal and individual level assessed influence the experience, internalization, anticipation of stigma and perception of their communities differently. While violence towards adolescents and young adults with HIV had an effect on all four HIV stigma types, being in sexual relationships largely influenced their experience and anticipation of stigma. On the other hand, school enrollment, caregiver involvement, being in a support group and clinic type influenced their internalization of HIV stigma. These factors could be considered among other structural factors when developing anti-stigma interventions.

Tables and Figures

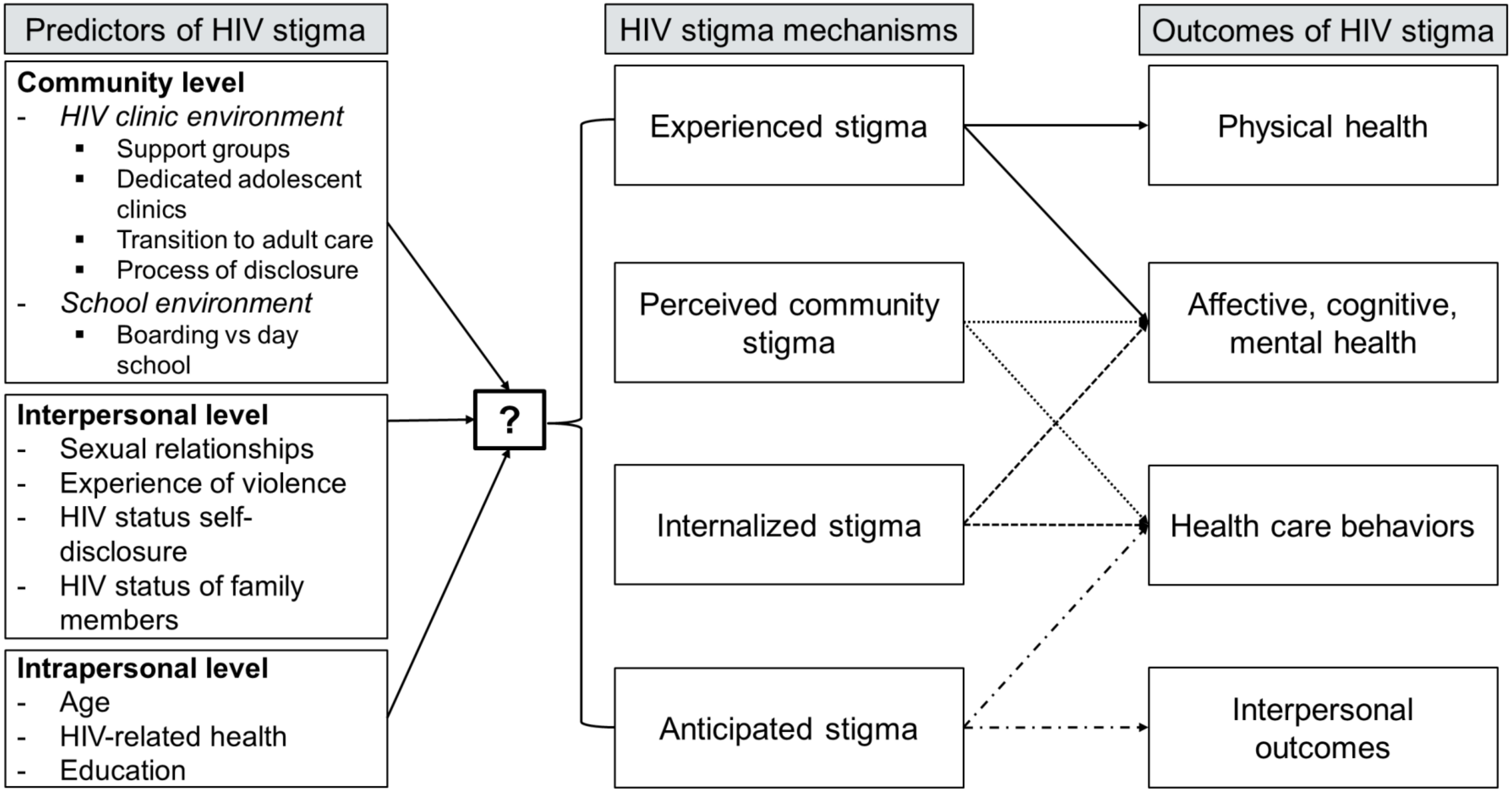
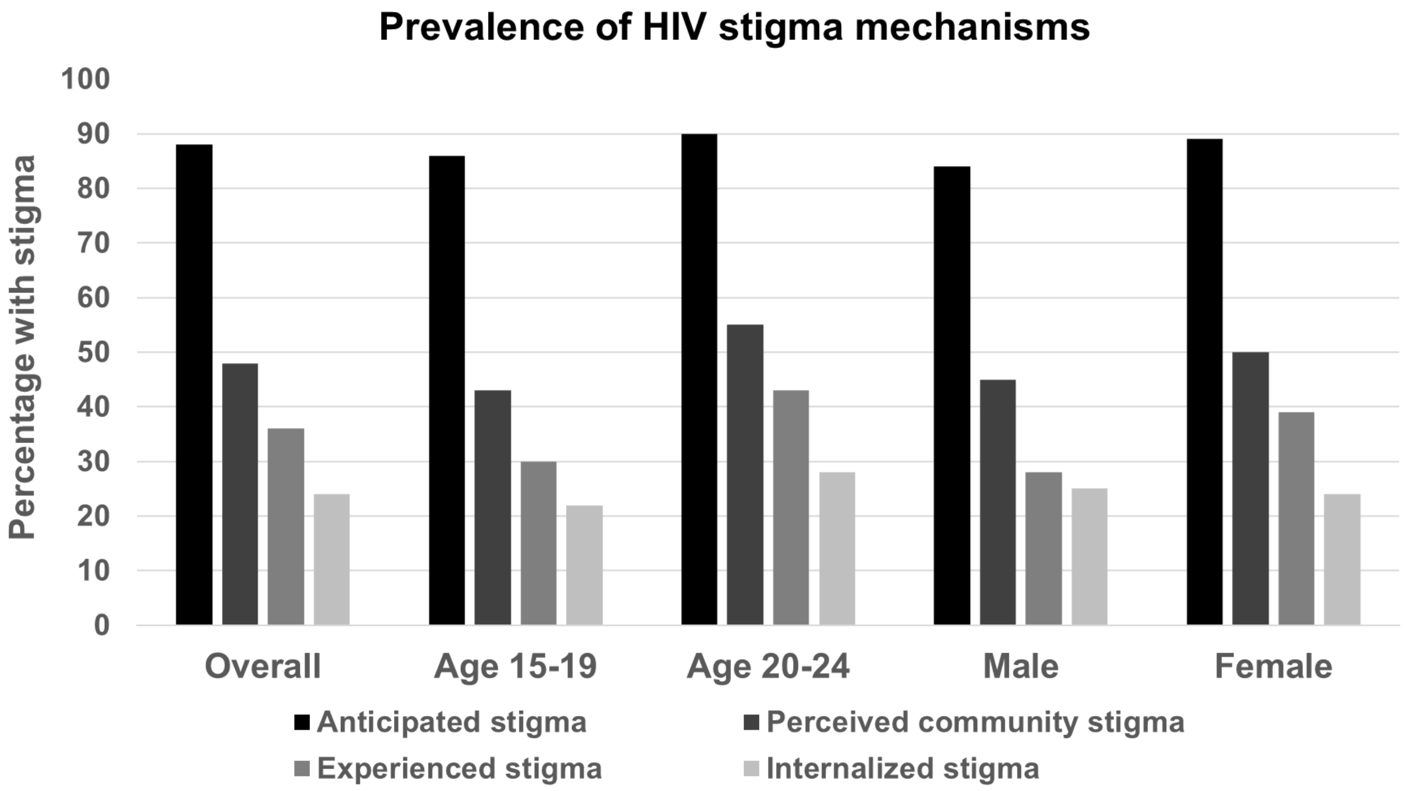


Figure 1: Health stigma and discrimination framework with hypothesized predictors of HIV stigma



Co-occurrence of stigma mechanisms *(column %)*

	Experienced	**Internalized**	**Perceived community**	**Anticipated**
Experienced		53%	50%	39%
Internalized	35%		35%	25%
Perceived	67%	70%		51%
Anticipated	97%	96%	96%	

Figure 2: Co-occurrence of HIV stigma types and the prevalence by age and gender

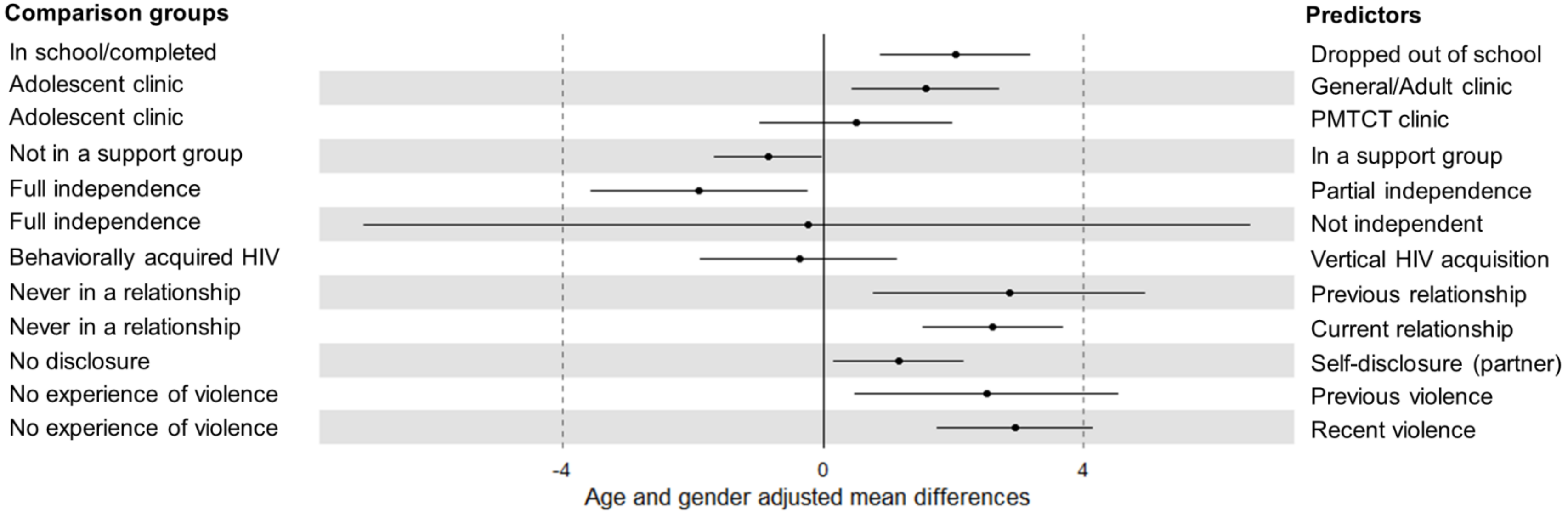


Figure 3: Predictors of HIV stigma among adolescents and young adults with HIV

Table 1: Characteristics of adolescents and young adults living with HIV

Factor	**N**	**Overall n (%)**	**Mean (SD) HIV stigma score**
Age (years)	1011		
15-19		597 (59)	24 (6.6)
20-24		414 (41)	27 (7.2)
Gender	1011		
Female		701 (69)	26 (7.0)
Male		310 (31)	24 (6.9)
School enrollment	1005		
In school		607 (60)	24 (6.5)
Completed secondary		180 (18)	26 (6.7)
Dropped out of school		218 (22)	28 (7.6)
In boarding school (Those in school)	603		
No		443 (73)	24 (6.1)
Yes		160 (27)	25 (7.4)
Relationship status	992		
Never married		681 (69)	25 (6.7)

[a] Ever married		311 (31)	27 (7.2)
Point of care	1005		
Adolescent/pediatric clinic		595 (59)	24 (6.5)
General/adult clinic		311 (31)	27 (7)
Maternal and Child Health Clinic		99 (10)	26 (7.6)
Process of learning HIV status	989		
Told by parent/provider/others		424 (43)	24 (6.6)
Underwent HIV testing		565 (57)	26 (7.1)
Perception of mode of HIV infection	990		
Vertical		441 (44)	24 (6.9)
Sexual		217 (22)	28 (7.3)
Other		77 (8)	25 (7.6)
Don’t know		255 (26)	25 (6.1)
Age at knowing HIV status (years)	929		
<15		534 (57)	24 (6.8)
≥15		395 (43)	27 (7.0)
Mode of HIV infection	969		
Vertical		564 (58)	24 (6.9)

Behavioral		405 (42)	26 (6.9)
In a peer support group	1003		
No		598 (60)	26 (6.9)
Yes		405 (40)	24 (7.0)
Independent in care	1002		
No		15 (1)	24 (8.3)
*Partial		67 (7)	23 (5.7)
Full		920 (92)	25 (7)
Ever experienced physical violence	1011		
No		731 (72)	25 (6.8)
Yes (but not in last 6 months)		146 (14)	27 (7.5)
Yes (including last 6 months)		134 (13)	27 (6.6)
Ever experienced emotional violence	1011		
No		833 (82)	25 (6.6)
Yes (but not in last 6 months)		83 (8)	27 (8)
Yes (including last 6 months)		95 (10)	29 (7.1)
Ever experienced sexual violence	1011		
No		943 (93)	25 (6.8)

Yes (but not in last 6 months)		42 (4)	27 (8.8)
Yes (including last 6 months)		26 (3)	30 (7.1)
Ever had sex			
No	1011	364 (36)	23 (6.1)
Yes		647 (64)	26 (7.1)
Self-disclosed to family members	1005		
No		467 (46)	25 (7.2)
Yes		538 (54)	26 (6.7)
Self-disclosed to sexual partner	646		
No		318 (49)	26 (7.1)
Yes		328 (51)	27 (7.0)
Self-disclosed to others	1005		
No		840 (84)	25 (7.0)
Yes		165 (16)	25 (7.0)

Table 2: Correlates of HIV stigma from multivariate analysis (adjusted for age and gender)

Factor	*Age and gender adjusted mean difference (95% confidence interval), p value*				
	Overall stigma	**Experienced stigma**	**Internalized stigma**	**Perceived community stigma**	**Anticipated stigma**
School enrollment					
In school/completed	Reference	Reference	Reference	Reference	Reference
Dropped out	**2.04 (0.44-3.64), 0.027**	0.23 (-0.25-0.71), 0.226	**0.76 (0.02-1.50), 0.049**	0.51 (-0.11-1.13), 0.094	0.31 (-0.19-0.82), 0.196
Point of care					
Adolescent clinic	Reference	Reference	Reference	Reference	Reference
General/adult clinic	**1.58 (0.13-3.04), 0.042**	0.21 (-0.22-0.64), 0.286	**0.78 (0.09-1.47), 0.033**	0.17 (-0.25-0.60), 0.328	0.25 (-0.35-0.85), 0.253
Maternal and Child Health Clinic	0.51 (-1.86-2.88), 0.513	-0.10 (-0.51-0.32), 0.610	**0.53 (-0.11-1.16), 0.080**	-0.26 (-1.58-1.05), 0.669	0.18 (-1.06-0.21), 0.759
In a peer support group					
No	Reference	Reference	Reference	Reference	Reference

Yes	-0.84 (-2.06-0.39), 0.126	0.04 (-0.32-0.39), 0.797	**-0.58 (-1.29-0.11), 0.071**	**-0.16 (-0.33-0.01), 0.059**	0.03 (-0.35-0.41), 0.812
Independence in care					
Full	Reference	Reference	Reference	Reference	Reference
Partial	**-1.90 (-4.10-0.31), 0.07**	-0.04 (-0.99-0.90), 0.920	**-0.82 (-1.55-[-0.10]), 0.029**	-0.52 (-1.52-0.47), 0.112	-0.39 (-1.29-0.51), 0.340
Not independent	-0.24 (-18.82-18.34), 0.950	1.16 (-4.83-7.15), 0.462	0.06 (-2.16-2.27), 0.949	-0.14 (-4.01-3.72), 0.869	-1.09 (-8.39-6.21), 0.469
Mode of HIV infection					
Vertical	Reference	Reference	Reference	Reference	Reference
Behavioral	0.37 (-2.94-3.67), 0.642	0.04 (-0.76-0.84), 0.883	0.21 (-0.76-1.18), 0.515	-0.02 (-0.42-0.367), 0.901	0.11 (-0.92-1.14), 0.644
Sexual relationships					
None	Reference	Reference	Reference	Reference	Reference
Yes but not currently	**2.87 (0.10-5.65), 0.048**	**1.14 (0.39-1.90), 0.005**	0.42 (-0.39-1.23), 0.275	0.47 (-0.41-1.34), 0.200	0.31 (-0.51-1.14), 0.321
Currently in a relationship	**2.61 (1.28-3.93), 0.001**	**1.02 (0.44-1.61), 0.009**	0.28 (-0.32-0.87), 0.295	0.38 (-0.25-1.02), 0.129	**0.50 (0.06-0.94), 0.034**

Self-disclosed to sexual partner					
No	Reference	Reference	Reference	Reference	Reference
Yes	**1.16 (-0.27-2.59), 0.070**	0.40 (-0.13-0.93), 0.124	0.23 (-0.35-0.81), 0.397	0.22 (-0.21-0.66), 0.176	0.23 (-0.30-0.76), 0.293
Ever experienced violence (physical/emotional/sexual)					
No	Reference	Reference	Reference	**Reference**	Reference
Yes (but not in last 6 months)	**2.51 (-0.12 -5.13), 0.058**	**0.89 (0.04-1.75), 0.046**	**0.60 (0-1.21), 0.056**	**0.66 (0.24-1.08), 0.008**	0.43 (-0.24-1.09), 0.177
Yes (including last 6 months)	**2.91 (1.38-4.44), 0.002**	**0.81 (0.26-1.36), 0.013**	**0.65 (0.26-1.05), 0.014**	**1.13 (0.49-1.77), 0.010**	**0.46 (-0.05-0.97), 0.073**

Bolded and black font color: Significant association between factor and overall HIV stigma/stigma type

Bolded and gray font color: Association between factor and overall HIV stigma/stigma type has a trend towards significance (0.1<p>0.05)

Supplementary table 1: Overall and age-stratified correlates of overall HIV stigma

	Overall (Bivariate)		**Overall (Age and gender adjusted)**		**Age 15-19 years (Gender-adjusted)**		**Age 20-24 years (Gender-adjusted)**	
Factor	**Mean difference (95%CI)**	**P value**	**Mean difference (95%CI)**	**P value**	**Mean difference (95%CI)**	**P value**	**Mean difference (95%CI)**	**P value**
Age (years)	0.47 (0.27-0.68)	0.001						
Gender								
Female	Reference		Reference					
Male	-1.99 (-4.31-0.34)	0.078	-1.19 (-3.98-1.60)	0.223				
School enrollment								
In school/completed	Reference		Reference		Reference		Reference	
Dropped out	3.18 (1.11-5.26)	0.018	**2.04 (0.44-3.64)**	**0.027**	**2.33 (-0.20-4.85)**	**0.060**	**2.00 (0.20-3.81)**	**0.043**
In boarding school								
No	Reference		Reference		Reference		Reference	

Yes	0.84 (-1.78-3.47)	0.324	0.62 (-2.24-3.48)	0.424	0.52 (-1.54-2.59)	0.542	0.52 (-1.54-2.59)	0.542
Point of care								
Adolescent clinic	Reference		Reference		Reference		Reference	
General/adult clinic	2.46 (0.64-4.29)	0.013	**1.58 (0.13-3.04)**	**0.042**	0.52 (-1.42-2.45)	0.479	**3.05 (1.01-5.10)**	**0.012**
Maternal and Child Health Clinic	2.16 (0.17-4.14)	0.046	0.51 (-1.86-2.88)	0.513	2.05 (-1.94-6.04)	0.265	1.14 (-0.57-2.85)	0.169
Process of learning HIV status								
Told by parent/provider/others	Reference		Reference		Reference		Reference	
Underwent HIV testing	1.69 (-0.02-3.41)	0.051	0.12 (-1.20-1.44)	0.806	0.38 (-0.79-1.54)	0.433	-0.59 (-2.39-1.22)	0.438
Perception of mode of HIV infection								
Vertical	Reference		Reference		Reference		Reference	

Sexual	3.09 (-0.11-6.29)	0.057	1.33 (-1.97-4.63)	0.376	**3.92 (-0.50-8.34)**	**0.058**	0.28 (-4.51-5.08)	0.904
Other	0.47 (-2.96-3.91)	0.732	0.12 (-3.28-3.51)	0.926	0.13 (-3.31-3.57)	0.926	-0.19 (-4.67-4.30)	0.921
Don’t know	0.30 (-1.71-2.31)	0.677	-0.36 (-2.84-2.12)	0.592	0.04 (-1.49-1.58)	0.931	-1.28 (-7.50-4.94)	0.511
Mode of HIV infection								
Vertical	Reference		Reference		Reference		Reference	
Behavioral	2.11 (0.46-3.76)	0.015	0.37 (-2.94-3.67)	0.642	1.33 (-1.17-3.82)	0.250	-0.55 (-5.47-4.37)	0.643
Age at knowing HIV status (years)	0.22 (-0.02-0.46)	0.070	0.04 (-0.24-0.31)	0.765	-0.01 (-0.31-0.30)	0.954	-0.01 (-0.41-0.39)	0.956
In a peer support group								
No	Reference		Reference		Reference		Reference	
Yes	-1.83 (-3.62-[-0.04])	0.046	-0.84 (-2.06-0.39)	0.126	-0.87 (-2.31-0.56)	0.168	-1.25 (-5.18-2.68)	0.455
Social support	-0.02 (-0.08-0.05)	0.581	-0.03 (0.15-0.10)	0.593	-0.06 (-0.16-0.05)	0.186	0.00 (-0.26-0.26)	0.975

Resilience	-0.13 (-0.38-0.11)	0.292	-0.11 (-0.55-0.34)	0.500	-0.18 (-0.85-0.51)	0.397	-0.01 (-0.41-0.39)	0.937
Independent in care								
Full	Reference		Reference		Reference		Reference	
Partial	-2.34 (-4.50-[-0.18])	0.044	**-1.90 (-4.10-0.31)**	**0.07**	-1.10 (-3.29-1.09)	0.223	**-3.49 (-6.78-[-0.20])**	**0.041**
Not independent	-1.41 (-5.37-2.55)	0.722	-0.24 (-18.82-18.34)	0.950	-0.08 (-21.16-21.00)	0.980	-	
Ever experienced violence (physical/emotional/sexual)								
No	Reference		Reference		Reference		Reference	
Yes (but not in last 6 months)	2.94 (0.17-5.71)	0.043	**2.51 (-0.12 -5.13)**	**0.058**	2.54 (-0.62-5.46)	0.104	**2.49 (-0.67-5.65)**	**0.097**
Yes (including last 6 months)	3.38 (1.78-4.97)	0.006	**2.91 (1.38-4.44)**	**0.002**	**2.42 (-0.53-5.62)**	**0.083**	**3.45 (1.27-5.62)**	**0.008**
Sexual relationships								
None	Reference		Reference		Reference		Reference	

Yes but not currently	3.37 (0.54-6.20)	0.033	**2.87 (0.10-5.65)**	**0.048**	**2.64 (0.02-5.26)**	**0.048**	2.09 (-2.65-6.84)	0.419
Currently in a relationship	3.55 (1.82-5.28)	0.006	**2.61 (1.28-3.93)**	**0.001**	**2.71 (1.20-4.22)**	**0.005**	1.56 (-2.60-5.72)	0.304
Self-disclosed to sexual partner								
No	Reference				Reference		Reference	
Yes	1.56 (-0.05-3.17)	0.053	**1.16 (-0.27-2.59)**	**0.084**	1.93 (-0.64-4.51)	0.104	0.71 (-2.18-3.60)	0.479
Self-disclosed to family members					N/A			
No	Reference		Reference				Reference	
Yes	0.91 (-0.21-2.03)	0.083	0.21 (-0.82-1.24)	0.566			-0.01 (-1.61-1.59)	0.988
Self-disclosed to others					N/A			
No	Reference		Reference				Reference	
Yes	-0.25 (-1.41-0.90)	0.656	-0.04 (-1.35-1.27)	0.947			-0.20 (-2.39-1.99)	0.399

Bolded and black font color: Significant association between factor and overall HIV stigma/stigma type

Bolded and gray font color: Association between factor and overall HIV stigma/stigma type has a trend towards significance (0.1<p>0.05)

95%CI: 95% confidence interval

Supplementary table 2: Bivariate analysis of select individual, interpersonal and institutional characteristics and HIV stigma types

Factor	***Bivariate analysis: mean difference (95% confidence interval), p value***			
	Experienced stigma	**Internalized stigma**	**Perceived community stigma**	**Anticipated stigma**
Age (years)	0.14 (0.06-0.21), 0.007	0.08 (0-0.18), 0.063	0.15 (0.04-0.26), 0.019	0.10 (-0.02-0.23), 0.076
Gender				
Female	Reference	Reference	Reference	Reference
Male	-0.71 (-1.46-0.04), 0.064	-0.20 (-0.76-0.36), 0.394	-0.39 (-1.26-0.47), 0.138	-0.41 (-1.18-0.36), 0.234
School enrollment				
In school/completed	Reference	Reference	Reference	Reference
Dropped out	0.65 (0.19-1.11), 0.010	0.86 (0-1.71), 0.049	0.89 (0.12-1.65), 0.027	0.58 (-0.47-1.63), 0.174
Point of care				
Adolescent clinic	Reference	Reference	Reference	Reference

General/adult clinic	0.51 (-0.03-1.05), 0.066	0.85 (-0.05-1.76), 0.059	0.50 (0.03-0.96), 0.038	0.44 (0-0.89), 0.051
Maternal and Child Health Clinic	0.48 (0.05-0.91), 0.032	0.65 (-0.03-1.33), 0.056	0.34 (-1.05-1.73), 0.506	0.53 (-0.57-1.64), 0.319
In a peer support group				
No	Reference	Reference	Reference	Reference
Yes	-0.29 (-0.73-0.15), 0.154	-0.68 (-1.47-0.10), 0,072	-0.46 (-0.81-0.12), 0.031	-0.21 (-1.04-0.62), 0.411
Independence in care				
Full	Reference	Reference	Reference	Reference
Partial	-0.19 (-1.10-0.72), 0.650	-0.88 (-1.49-[-0.28]), 0.013	-0.66 (-1.69-0.37), 0.102	-0.48 (-1.40-0.45), 0.250
Not independent	0.79 (-5.04-6.61), 0.568	-0.15 (-2.21-1.91), 0.840	-0.51 (-4.18-3.17), 0.564	-1.33 (-7.48-4.82), 0.410
Mode of HIV infection				
Vertical	Reference	Reference	Reference	Reference
Behavioral	0.57 (0.01-1.13), 0.047	0.43 (-0.18-1.05), 0.129	0.55 (-0.15-1.24), 0.100	0.47 (-0.79-1.72), 0.178

Sexual relationships				
None	Reference	Reference	Reference	Reference
Yes but not currently	1.20 (0.61-1.80), 0.002	0.56 (-0.20-1.33), 0.120	0.72 (-0.30-1.74), 0.111	0.43 (-0.33-1.19), 0.218
Currently in a relationship	1.20 (0.67-1.72), 0.005	0.51 (0.03-0.98), 0.033	0.81 (0.03-1.60), 0.045	0.72 (-0.04-1.49), 0.06
Self-disclosed to sexual partner				
No	Reference	Reference	Reference	Reference
Yes	0.45 (-0.12-1.01), 0.089	0.36 (-0.33-1.05), 0.255	0.42 (0.02-0.81), 0.037	0.29 (-0.53-1.10), 0.341
Ever experienced violence (physical/emotional/sexual)				
No	Reference	Reference	Reference	Reference
Yes (but not in last 6 months)	1.00 (0.06-1.95), 0.045	0.68 (0.04-1.31), 0.042	0.60 (0.24-1.36), 0.017	0.53 (-0.34-1.40), 0.172
Yes (including last 6 months)	0.94 (0.49-1.39), <0.001	0.73 (0.35-1.11), 0.007	1.28 (0.55-2.01), 0.007	0.56 (-0.04-1.17), 0.062

CHAPTER 2: Effect of HIV stigma on depressive symptoms, treatment adherence, and viral suppression among youth with HIV

This work is under revision at the journal AIDS.

Abstract

Objective

We estimated the effects of HIV stigma on mental health and treatment outcomes for youth with HIV (YWHIV).

Design

Secondary analysis of longitudinal data for YWHIV ages 15-24 years in Western Kenya.

Methods

Participants completed a survey assessing socio-demographics, antiretroviral therapy (ART) adherence, depressive symptoms (PHQ-9), and HIV stigma (10-item Wright scale). First viral load (VL) after enrollment was abstracted from records. We estimated risk of depressive symptoms (score>4), non-adherence (missing ≥2 days of ART in a month), and detectable VL (≥50 copies/ml) for each standard deviation (SD) increase in HIV stigma score, adjusted for age and gender (and regimen in VL model).

Results

Of 1,011 YWHIV, 69% were female with a median age of 18 years; 24% were on dolutegravir-based regimens. Frequency of non-adherence, depressive symptoms and detectable VL was 21%, 21% and 46%, respectively. Mean stigma score was 25 (SD=7.0). Each SD stigma score increment was associated with significantly higher risk of depressive symptoms (adjusted relative risk [aRR] 1.31 [95% confidence interval [CI]: 1.20-1.44]), non-adherence (aRR 1.16 [CI: 1.05-1.27]) and detectable VL (aRR 1.20 [CI: 1.08-1.32]). Experienced and anticipated stigma were associated with detectable VL (aRR 1.16 [CI: 1.10-1.22] and aRR 1.23 [CI: 1.12-1.35] respectively). Internalized and perceived community stigma were associated with depressive symptoms (aRR 1.31 [CI: 1.21-1.40] and aRR 1.24 [CI: 1.13-1.36] respectively).

Conclusions

Stigma levels were associated with depressive symptoms, non-adherence and detectable VL. Interventions to decrease stigma may improve virologic and mental health outcomes in YWHIV.

Key words: HIV stigma; adherence; viral suppression; adolescents; depression; mental health

Introduction

HIV stigma is the discrediting and stereotyping of persons living or associated with HIV (PWHIV) resulting in a loss of power within close social circles, communities, and institutions. Stigmatizing beliefs and behavior remain important barriers to achieving HIV prevention, testing, and treatment targets.(43)

Previous studies have been conducted to evaluate the relationship between HIV stigma and mental health, treatment adherence, viral suppression and quality of life.(25, 27-29, 43-47) Some of these studies showed a high prevalence of HIV stigma among PWHIV and associations between stigma and poor mental health and treatment outcomes; findings supported by qualitative studies.(27, 44, 45) In systematic reviews,(44, 45) the majority of the studies reviewed utilized cross-sectional study designs, which made it difficult to determine what factor preceded the other. Only five of 64 studies included in the systematic review by Rueda et al.,(45) and four of 41 by Katz et al.,(44) utilized a longitudinal design. Further, among the 92 different studies included in the two reviews, only one was among Youth with HIV (YWHIV), and four were conducted in sub-Saharan Africa (SSA). The sole longitudinal study among YWHIV showed no significant effect of HIV stigma on utilization of health services, an outcome closely associated with the outcomes assessed in our study.(48) YWHIV are disproportionately affected by poor mental health compared to adults with HIV and their counterpart youth without HIV,(47, 49) have poorer health behaviors,(7) and experience worse treatment outcomes compared to adults with HIV.(9) They are also at a stage where relationships with peers, family and authorities are shaped,(50, 51) and are more likely to be affected by the attitudes and behaviors those they interact with have toward them. This makes research on factors that contribute to poor mental health, health behaviors and treatment outcomes particularly important for YWHIV.

HIV stigma is a complex phenomena with several domains that describe different mechanisms through which PWHIV experience and respond to the attitudes and actions towards PWHIV. The health stigma and discrimination framework lists four domains - experienced stigma, internalized stigma, anticipated stigma, and perceived community stigma, and provides a theoretical framework to study their impact on health behaviors, mental health, interpersonal and treatment outcomes.(52, 53) Several studies have provided some evidence for the hypothesized relationships between specific HIV stigma domains and these outcomes.(27, 45) Limitations in the current literature include inconsistent associations between stigma and outcomes and few longitudinal analyses that would allow causal interpretation of the relationships.(44) Further, few of these studies were conducted in Eastern and Southern Africa (ESA)(27, 44) and among YWHIV.(54) This has resulted in the under-representation of YWHIV in ESA in interventions targeting HIV stigma.(55) Understanding the relationship between different stigma domains and health behaviors/outcomes will facilitate the development of interventions for YWHIV that address their immediate and longer-term needs to achieve a higher quality of life. In this study, we aimed to determine the effect of HIV stigma and specific stigma domains on depressive symptoms, antiretroviral treatment (ART) adherence and viral suppression among YWHIV.

Methods

Study design

This longitudinal analysis utilized data from the Data-Informed Stepped Care (DiSC) to improve Adolescent HIV outcomes, a prospective study in Western Kenya conducted between April 2019 and March 2020 among YWHIV ages 10-24 years. The primary aim of the DiSC observational study was to identify predictors of non-retention and develop the intervention and platform for a cluster randomized clinical trial of the data-informed stepped care intervention (DiSC RCT). In this study, we utilized longitudinal data from the DiSC observational study in the subset of YWHIV ages 15-24 years. Younger adolescents were excluded due to frequent lack of disclosure in this age group, which was a requirement for answering HIV-related questions in the surveys.

Theoretical model

Our study was informed by the health stigma and discrimination framework.(43, 56) In this framework, different HIV stigma domains are hypothesized to influence different health outcomes- experienced stigma affects physical health and affective, cognitive and psychological domains, internalized stigma and anticipated community stigma both affect affective/cognitive/mental health and health care behaviors, and anticipated stigma affects health care behaviors and interpersonal outcomes. We sought to assess the strength of some of these proposed relationships in our population of YWHIV (Figure 1A).

Ethical considerations

The study was approved by the Maseno University Ethics Review Committee (MUERC/00642/18), and the University of Washington Institutional Review Board (#STUDY00005767). Participants ≥18 years and emancipated minors (<18 years) provided informed written consent at the time of recruitment, while caregivers for the other minors provided parental consent with the minors providing assent. Youth ages 15-17 attending care without a parent were approved by the IRB to independently consent for participation.

Study procedures

Recruitment and enrollment procedures, and a description of the measures including their reliability have been detailed in a different manuscript (manuscript under review). In brief, YWHIV were recruited in HIV clinics and maternal and child health (MCH) clinics in nine facilities. A survey was administered assessing socio-demographic information, HIV stigma, depressive symptoms, and ART adherence at enrollment and two follow up visits at 6 and 12 months after enrollment. Electronic medical data containing ART regimen and viral load (VL) information for the enrolled participants were abstracted from a national VL data repository.

Measures

The primary exposure of interest was HIV stigma. HIV stigma was measured using a 10-item Youth HIV Stigma Scale.(57) Each question was assessed on a 5-item Likert scale (strongly disagree to strongly agree), with combinations of different questions in the scale measuring four stigma domains: experienced (3 questions), internalized (3 questions), anticipated (2 questions) and perceived community stigma (2 questions). Only surveys with all questions completed received an overall stigma score, while those surveys limiting answers to questions assessing a specific stigma domain, received a score for only that domain. The stigma scale had a Cronbach's score (α) of 0.79. Outcomes of interest including depressive symptoms, ART adherence and viral suppression. Depressive symptoms were assessed using the Patient Health Questionnaire-9 (PHQ-9), α = 0.70. Participants reported the number of days they missed an ART dose in the last 30 days to assess ART adherence. For the VL analysis, we selected the first VL done 0-12 months after the participant completed the enrollment survey.

Definition of key variables

ART regimens were categorized as follows: regimens that included efavirenz or nevirapine were categorized as non-nucleoside reverse transcriptase inhibitor (NNRTI)-based, atazanavir or lopinavir as protease inhibitor (PI)-based, dolutegravir (DTG)-based, and 'other' if a regimen did not include an antiretroviral drug from one of these categories. Participants with a score >4 (range: 0-27) on the PHQ-9 were classified as having depressive symptoms. Another variable with additional categories classified those with a score of 5-9 as having mild depressive symptoms and ≥10 as having moderate-severe depressive symptoms. Participants who missed ART doses for 2 or more days in the prior month were classified as non-adherent. A VL of ≥50 copies/ml was classified as detectable.(58)

Statistical Analysis

Descriptive analysis

We summarized the baseline sociodemographic and HIV-related information, depressive symptoms, and ART adherence using counts, proportions, median and interquartile range (IQR) as appropriate. We also reported the mean (standard deviation [SD]) of the scores for overall HIV stigma and the four stigma domains, and counts (proportions) for depressive symptoms and ART adherence in the three visits. The proportion of participants with a detectable VL was also reported.

Analysis of the effect of HIV stigma or stigma domains and outcomes

In the primary analyses, we conducted longitudinal analyses to estimate the effect of overall HIV stigma and the four stigma domains separately on depressive symptoms and ART adherence. Time-varying stigma variables (exposures of interest) were included in the generalized estimating equations models (family = binomial, link=log) as continuous variables. Depressive symptoms and ART adherence outcome variables were included as binary variables. The effect of stigma (overall and domains assessed at baseline) on having a detectable VL (one binary measure) was assessed using generalized linear models (family = binomial, link=log).

Missing data: Missingness in the stigma variables ranged from 2% to 12%, while 8% and 7% were missing data on ART adherence and depressive symptoms respectively. Missingness for the VL and ART regimen was 35% and 25% respectively. There were no differences between those with and missing a VL except in age, where those missing a VL were slightly older (median age of 19 versus 18 years, p=0.003). Imputation of missing data was done separately for the analyses involving ART adherence/depressive symptoms and the analyses involving VL measures using multiple imputation by chained equation (MICE) (5 imputations each). For each analysis, we selected one of the 5 imputed datasets whose mean stigma measures were closest to the original dataset. Sensitivity analyses using the other four imputed datasets and complete case analyses for the three outcomes was done. Additional sensitivity analyses done for the ART adherence and depressive symptoms models included using only baseline stigma measures, excluding the baseline outcome measures, and cross-sectional analyses involving only baseline stigma and outcome measures.

We reported adjusted relative risks (aRR) or adjusted prevalence ratios (aPR) as appropriate after adjusting estimates for age and gender(18, 26) in all models, and ART regimen in the model for having a detectable VL (as a precision variable).(19) The 95% confidence intervals (95%CI) and p values (p) in the longitudinal analyses were derived from model parameters. In the VL analysis and the cross-sectional analyses for ART adherence and depressive symptoms, we utilized clustered standard errors (by facility) to compute the 95%CI and p values for the adjusted relative risks and prevalence ratios.

<u>Power calculations</u> were done with the assumption of a sample size of ~1000 YWHIV. We had >80% power to detect an odds ratio of at least 1.26, 1.34 and 1.48 for an outcome with a prevalence of 50%, 20% and 10% respectively at the mean of the HIV stigma scores. In our case, the odds ratio is the change in log odds for the outcome at the mean of the HIV stigma scores and at one standard deviation above the mean. All analyses were completed using R studio (R Foundation for Statistical Computing, Vienna, Austria).

Results

Description of study population

Total number of participants was 1,011 in visit 1 (baseline/enrollment), 767 in visit 2, and 522 in visit 3. Only 460 participants had all three visits. Of the 1,011 YWHIV included in this analysis, 701 (69%) were female with a median age of 18 (IQR: 16-21) years and 24% (181/756) were on a dolutegravir-containing regimen (Table 1). At baseline, the mean score for overall, experienced, internalized, anticipated and perceived community stigma were 25 (SD: 7.0), 7 (SD: 2.7), 6 (SD: 2.6), 7 (SD: 2.0), and 5 (SD: 2.4) respectively. At baseline, 21% (190/926) had missed ≥2 days of ART doses, 3% (27/938) had moderate to severe depressive symptoms, 18% (167/938) had mild depressive symptoms. The proportion of YWHIV with non-adherence and depressive symptoms in visit 2 and 3 are shown in table 2. Close to half (46%, [306/662]) had a detectable VL at their first VL after enrollment (eligible VL in this analysis).

Effect of overall HIV stigma

Bivariate and adjusted analyses showed that overall HIV stigma was significantly associated with having depressive symptoms, ART non-adherence and having a detectable VL (Table 3). An increment of one standard deviation in overall HIV stigma increased the risk of depressive symptoms by 31% (aRR: 1.31 [95%CI: 1.20-1.44], p<0.001), the risk of non-adherence by 16% (aRR: 1.16 [95%CI: 1.05-1.27], p=0.003), and the risk of having a detectable VL by 20% (aRR: 1.20 (95%CI: 1.08-1.32), p=0.003) (Figure 2).

Effect of specific stigma domains

The four stigma domains had an effect on at least one of the three outcomes (Figure 2), confirming the hypotheses derived from the health stigma and discrimination framework (Figure 1B). Experienced stigma had an effect on depressive symptoms (aRR: 1.09 [95%CI: 1.01-1.18], p=0.036), ART non-adherence (aRR: 1.09 [95%CI: 1.00-1.19], p=0.039) and having a detectable VL (aRR: 1.16 [95%CI: 1.10-1.22], p<0.001). Internalized stigma had an effect on depressive symptoms (aRR: 1.31 [95%CI: 1.21-1.40], p<0.001). Anticipated stigma had an effect on ART non-adherence (aRR: 1.20 [95%CI: 1.10-1.31], p<0.001) and having a detectable VL (aRR: 1.23 [95%CI: 1.12-1.35], p<0.001). Perceived community stigma had an effect on depressive symptoms (aRR: 1.24 [95%CI: 1.13-1.36], p<0.001) and having a detectable VL (aRR: 1.16 [95%CI: 1.04-1.30], p=0.001), (Table 3).

Sensitivity, complete case and cross-sectional analyses

Analyses utilizing the imputed datasets not selected for the primary analyses produced adjusted point estimates for overall stigma within +/- 0.02 of those from the selected dataset. Differences between the analyses using imputed data and complete cases were the statistically significant effects of internalized and perceived community stigma domains on ART adherence, and anticipated stigma on depressive symptoms in the complete case analyses that were not significant in the imputed datasets (Table 3). The effects of overall stigma and stigma domains on depressive symptoms and ART adherence in the primary analyses were generally more attenuated than the point estimates from the longitudinal analyses with only baseline stigma measures (Supplementary table 1) and in the cross-sectional analyses (Supplementary table 2).

Discussion

In this longitudinal analysis, we found that HIV stigma was associated with depressive symptoms, ART non-adherence and having a detectable VL among YWHIV. There were some differences in impact of stigma domains on outcomes. For example, all domains except anticipated stigma had an effect on depressive symptoms; while all domains except internalized stigma had an effect on either ART non-adherence or having a detectable VL. Comparison of the intensity of stigma reported in our study and other studies among YWHIV and adults in SSA is challenging due to the different scales used to assess stigma. Therefore, we may not accurately establish whether constructs in the different scales measured the same thing. In two systematic reviews focusing on HIV stigma with a combined 92 studies,(44, 45) only one study conducted in multiple SSA countries among adults reported mean stigma scores. A direct comparison with our study was not possible due to the use of different scales and scoring methods with our study. The study reported a mean stigma score of 0.43 [range: 0-3].(59) The prevalence of depressive symptoms in this study (21%) on the other hand is within the range reported from other studies conducted in SSA.(47, 60-64) Recent studies in Kenya,(65) and

SSA(66, 67) reported similarly high prevalence of non-adherence (>20%) and detectable VL (>40%).(65, 68)

Our study is among the few longitudinal studies that have assessed and found evidence of an effect of HIV stigma on outcomes among YWHIV in SSA. Previous cross-sectional studies(44, 45) suggest a cyclical relationship between HIV stigma, and adherence/depression. However, many researchers favor considering HIV stigma as the exposure and mental health and health behaviors as outcomes. A few studies have investigated the reverse relationship, for example demonstrating that poor mental health was associated with higher HIV stigma.(69, 70) In this study we investigated this ‘reverse’ relationship using baseline data and showed that YWHIV with depressive symptoms had higher overall stigma scores than those without depressive symptoms.(71) In a longitudinal study from a cohort of adults from multiple SSA countries, good treatment adherence was associated with a steeper decline in mean HIV stigma over time.(59) The impact of HIV stigma on viral suppression is less studied. Most studies evaluating this relationship have been conducted in the United States among adults,(28, 29, 72) with a few among adolescents and young adults.(32) In one study among adults in Zambia and South Africa, internalized stigma was associated with poor viral suppression.(30) Poor ART adherence is the most important cause for poor viral suppression,(73, 74) which together with the fact that routine viral load measurements started less than 6 years ago in most SSA countries,(75) may explain the paucity in data. We reported effects of stigma on both undetectable VL and on adherence measures, with slightly higher effect sizes for viral detectability than ART adherence, likely due to misclassification of adherence status, which is measured through a self-report. Viral detection is a more accurate marker for ART adherence than self-report, except in instances where non-suppression is due to resistance or dosing challenges where the patient receives non-effective doses of ART (usually due to lack of adjustment of doses with increases in weight) even when they are adherent.(9) We also reported higher effect sizes for HIV stigma and depression, an important predictor for non-adherence. Though we did not conduct formal mediation analysis, our findings suggest HIV stigma first impacts poor mental health, which in turn partly affects non-adherence and viral suppression (Figure 2).(29)

A strength of this study was that we provided evidence for the effect of HIV stigma (overall), and specific HIV stigma domains on depressive symptoms, ART adherence and viral suppression in an understudied population (YWHIV). The results provide researchers designing stigma interventions with a basis for the expected impact of their interventions on mental health and treatment outcomes. The differential impact of various stigma domains on both mental and physical health outcomes may inform intervention design. For example, interventions with strong components to reduce internalized stigma may be more likely to impact mental health outcomes, while those thought to reduce anticipated stigma (for example assisted disclosure of HIV status) would be expected to impact health behaviors (like ART adherence). Addressing the direct environment or external factors that perpetuate the actual experience of stigma would impact both mental health and health behaviors. Studies in global mental health have underscored the need to develop robust stigma measurement and mitigation strategies as stigma continues to add considerable psychosocial burden.(76) Lastly, these results show that the efforts to achieve the UNAIDS 95-95-95 goals(77) will benefit from increased investment to tackle HIV stigma across the HIV care cascade, especially for YWHIV who lag behind adults in all targets.(78, 79) Of note, HIV stigma interventions may be crucial in this population to achieve the last 95, which targets to have 95% of those on treatment virally suppressed. Our study evaluated proportion with undetectable VL. Using a VL cut-off of 1000 c/ml, 88% of YWHIV would be considered suppressed in our study, higher than reports from recent studies among YWHIV in Kenya,(18, 65, 80) though still below the goal of 95%. The association between HIV stigma and viral non-suppression (>1000 c/ml) was similar to that found between HIV stigma and having a detectable VL (aRR=1.20). Other strengths of this study were the longitudinal design, which allowed for causal interpretation of our finding, and having a large sample size, which allowed us to detect modest effect sizes. The study was conducted in a high HIV prevalence region, where stigma interventions are needed most. The high data missingness was a weakness occasioned by missed visits following the COVID-19 pandemic, and utilization of viral load data abstracted from routine clinic records, which while making the study feasible to conduct, has previously been shown to have many gaps.(80) We addressed the missingness to the best possible extent using imputation and sensitivity analyses.

Conclusion

In this study, we provided evidence of the negative effect of HIV stigma on mental health, treatment adherence, and viral suppression. We established the effect of specific stigma domains on depressive symptoms and ART adherence, confirming the hypotheses underlying the health stigma and discrimination framework. The results provide a guide on the expected effect sizes for in the designing stigma interventions with a basis for the expected impact of their interventions on mental health and treatment outcomes.

Tables and Figures

Table 1: Characteristics of youth living with HIV

Factor	**N**	**Overall** **Median (IQR)/n (%)**
Age (years)	1011	
15-19		597 (59)
20-24		414 (41)
Gender	1011	
Female		701 (69)
Male		310 (31)
School enrollment	1005	
In school/Completed secondary		787 (78)
Dropped out of school		218 (22)
Point of care	1005	
Adolescent/pediatric clinic		595 (59)
General/adult clinic		311 (31)
Maternal and Child Health Clinic		99 (10)

Age at knowing HIV status (years)	929	13 (10-18)
Years since knowing HIV status	929	5 (2-8)
ART regimen	756	
NNRTI-based		387 (51)
DTG-based		181 (24)
PI-based		180 (24)
Other		8 (1)

IQR: Interquartile range

Table 2: Summary of longitudinal HIV stigma, adherence and depressive symptom measures

	Visit 1		Visit 2		Visit 3	
Factor	**[1]N**	**n (%)/ Mean (SD)**	**[2]N**	**n (%)/ Mean (SD)**	**[2]N**	**n (%)/ Mean (SD)**
Overall stigma	890	25 (7.0)	623	25 (6.6)	456	25 (5.5)
Experienced stigma	924	7 (2.7)	669	7 (2.7)	478	7 (2.4)
Internalized stigma	975	6 (2.6)	733	6 (2.5)	509	6 (2.3)
Perceived community stigma	986	5 (2.4)	723	5 (2.3)	508	5 (2.1)
Anticipated stigma	967	7 (2.0)	727	7 (2.0)	502	7 (1.9)
Non-adherence	926	190 (21%)	720	72 (10%)	509	39 (8%)
Depressive symptoms	938	194 (21%)	631	55 (9%)	436	36 (8%)

[1]N<1011 due to missing responses by participants when completing the questionnaire

[2]N<1011 due to missed visits and missing responses by participants when completing the questionnaire

SD: Standard deviation

Table 3: Effect of HIV stigma on depressive symptoms, adherence, and viral suppression

A. USING IMPUTED DATASETS			
	Depressive symptoms	**Non-adherence**	***Detectable viral load**
Adjusted relative risk (95% confidence interval), p value			
Overall stigma	**1.31 (1.20-1.44), <0.001**	**1.16 (1.05-1.27), 0.003**	**1.20 (1.08-1.32), 0.003**
Experienced stigma	**1.09 (1.01-1.18), 0.036**	**1.09 (1.00-1.19), 0.039**	**1.16 (1.10-1.22), <0.001**
Internalized stigma	**1.31 (1.21-1.40), <0.001**	1.06 (0.97-1.16), 0.175	1.01 (0.92-1.10), 0.874
Anticipated stigma	1.04 (0.95-1.14), 0.411	**1.20 (1.10-1.31), <0.001**	**1.23 (1.12-1.35), <0.001**
Perceived community stigma	**1.24 (1.13-1.36), <0.001**	1.01 (0.93-1.11), 0.755	**1.16 (1.04-1.30), 0.001**
B. COMPLETE CASE ANALYSIS			
Overall stigma	1.48 (1.33-1.64), <0.001	1.26 (1.12-1.42), <0.001	1.18 (1.09-1.28), <0.001
Experienced stigma	1.31 (1.17-1.47), <0.001	1.16 (1.04-1.30), 0.009	1.10 (1.03-1.17), 0.004
Internalized stigma	1.34 (1.23-1.47), <0.001	1.14 (1.01-1.28), 0.027	1.04 (0.97-1.10), 0.260
Anticipated stigma	1.20 (1.07-1.36), 0.003	1.23 (1.08-1.39), 0.001	1.22 (1.09-1.38), <0.001
Perceived community stigma	1.34 (1.20-1.51), <0.001	1.15 (1.02-1.30), 0.020	1.14 (1.02-1.26), 0.014

Estimates from longitudinal analysis compare outcomes for persons with a one standard deviation difference in HIV stigma level

Estimates are adjusted for age, gender (*and regimen)

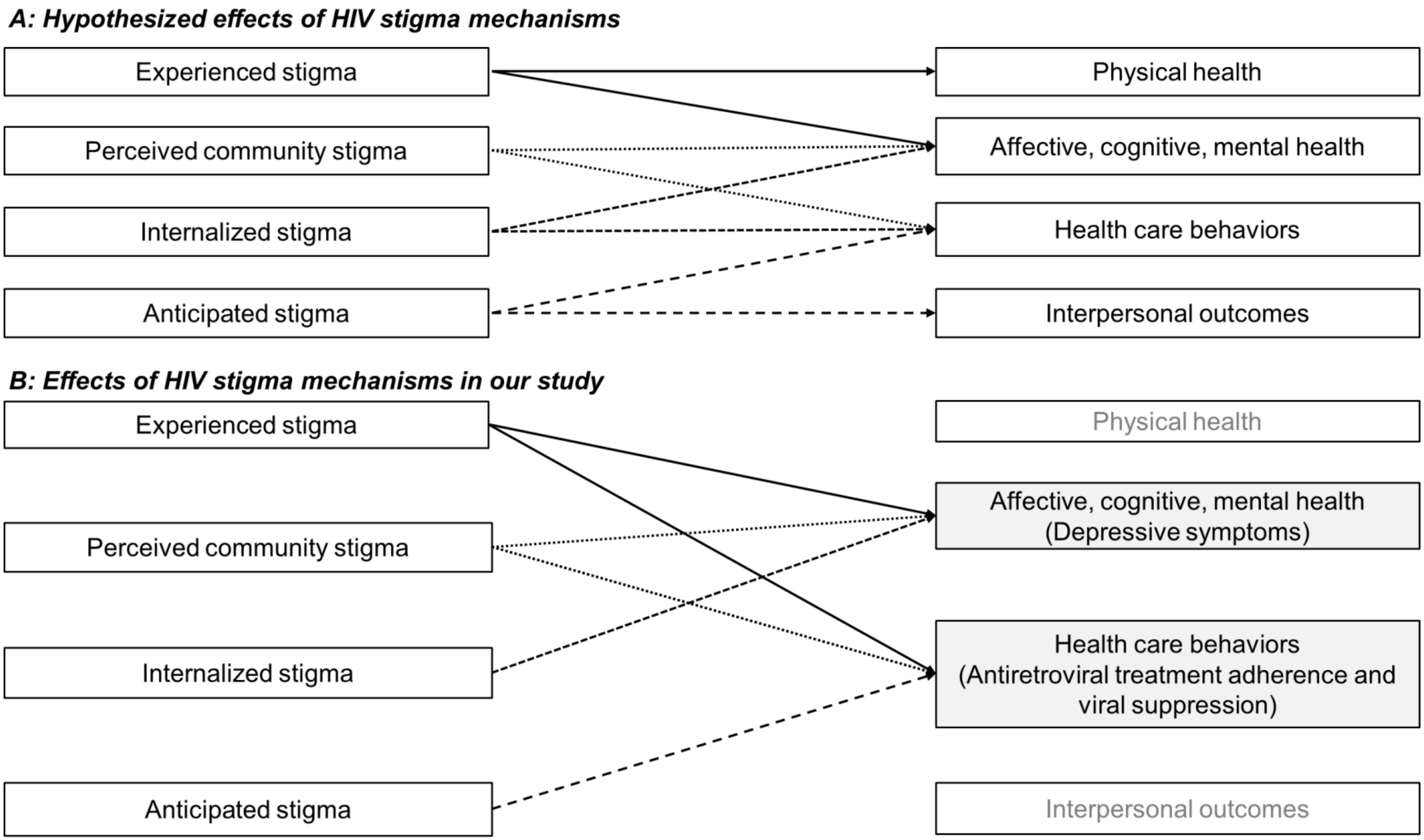


Figure 1: HIV stigma framework showing hypothesized and measured effects of stigma domains

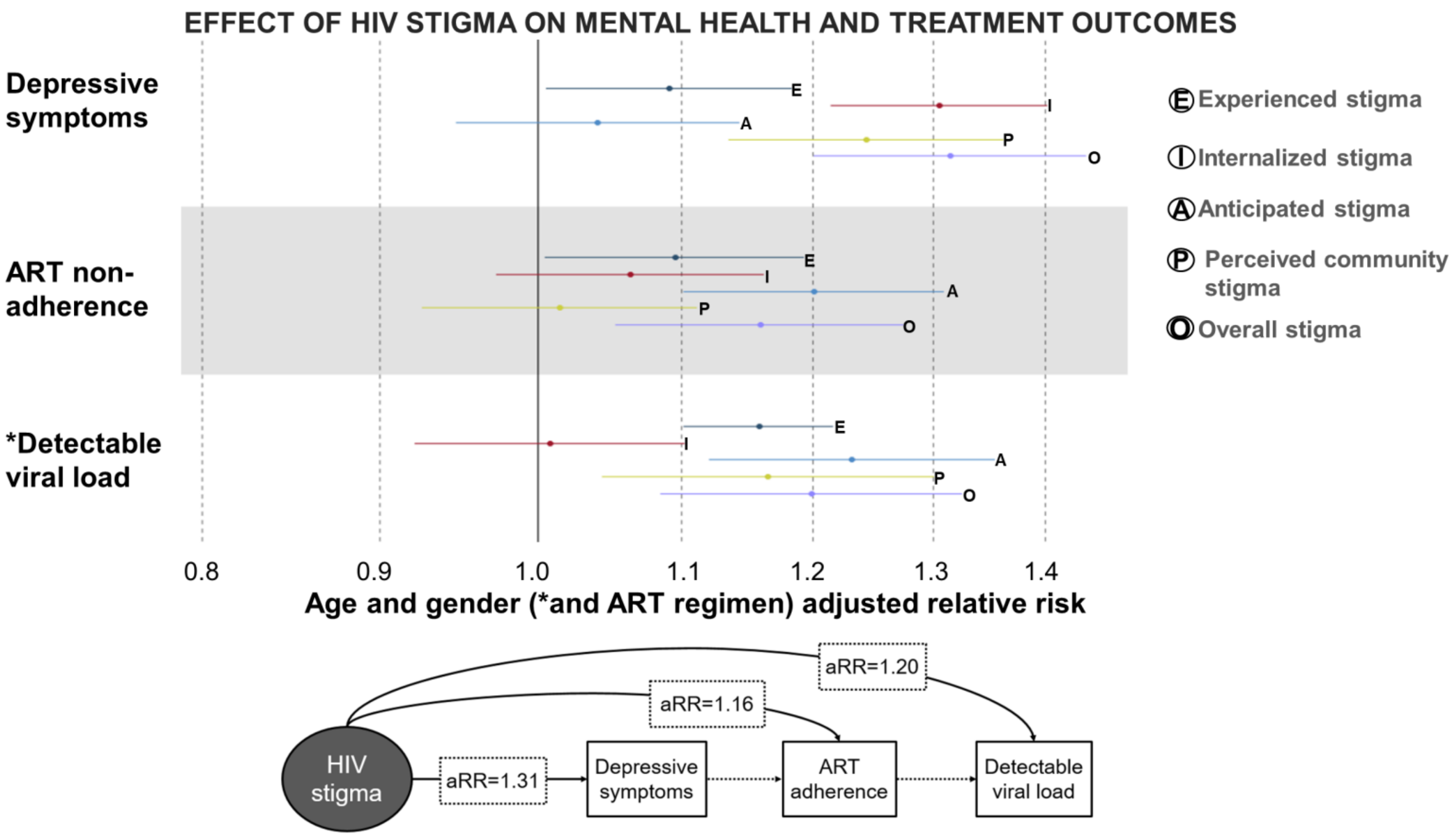


Figure 2: Effect of HIV stigma on depressive symptoms, treatment adherence and viral suppression

Estimates are from longitudinal analysis and compare outcomes for persons with a one standard deviation difference in HIV stigma levels

aRR: adjusted relative risk

Supplementary table 1: Effect of HIV stigma on depressive symptoms and adherence using baseline stigma measures only from imputed datasets

A. INCLUDING BASELINE OUTCOME MEASURES		
	Depressive symptoms	**Non-adherence**
	Age and gender-adjusted relative risk (95% confidence interval), p value	
Overall stigma	**1.44 (1.31-1.57), <0.001**	**1.27 (1.15-1.40), <0.001**
Experienced stigma	**1.33 (1.21-1.45), <0.001**	**1.17 (1.06-1.29), 0.002**
Internalized stigma	**1.27 (1.18-1.38), <0.001**	**1.17 (1.07-1.28), <0.001**
Anticipated stigma	**1.19 (1.08-1.32), <0.001**	**1.20 (1.08-1.33), <0.001**
Perceived community stigma	**1.30 (1.18-1.43), <0.001**	**1.12 (1.02-1.24), 0.019**
B. EXCLUDING BASELINE OUTCOME MEASURES		
Overall stigma	**1.41 (1.23-1.62), <0.001**	**1.18 (1.03-1.34), 0.014**
Experienced stigma	**1.39 (1.22-1.58), <0.001**	**1.12 (0.99-1.26), 0.081**
Internalized stigma	**1.21 (1.08-1.36), 0.001**	**1.12 (1.00-1.26), 0.041**
Anticipated stigma	**1.21 (1.04-1.41), 0.013**	1.08 (0.95-1.22), 0.240
Perceived community stigma	**1.23 (1.07-1.42), 0.004**	**1.11 (0.99-1.26), 0.082**

Estimates from longitudinal analysis compare outcomes for persons with a one standard deviation difference in HIV stigma level

Supplementary table 2: Cross-sectional analysis to estimate associations of HIV stigma and depressive symptoms and adherence

A. USING IMPUTED DATASETS		
	Depressive symptoms	**Non-adherence**
Age and gender-adjusted prevalence ratio (95% confidence interval), p value		
Overall stigma	**1.49 (1.27-1.75), <0.001**	**1.28 (1.15-1.43), <0.001**
Experienced stigma	**1.36 (1.18-1.56), <0.001**	**1.15 (1.01-1.31), 0.043**
Internalized stigma	**1.31 (1.15-1.49), <0.001**	**1.15 (1.07-1.23), <0.001**
Anticipated stigma	**1.16 (1.02-1.31), 0.021**	**1.32 (1.14-1.53), <0.001**
Perceived community stigma	**1.40 (1.30-1.50), <0.001**	**1.15 (1.03-1.28), 0.010**
B. COMPLETE CASE ANALYSIS		
Overall stigma	**1.50 (1.26-1.80), <0.001**	**1.30 (1.12-1.50), <0.001**
Experienced stigma	**1.36 (1.17-1.58), <0.001**	1.16 (0.97-1.37), 0.102
Internalized stigma	**1.33 (1.17-1.51), <0.001**	**1.17 (1.09-1.26), <0.001**
Anticipated stigma	1.16 (0.99-1.37), 0.073	**1.30 (1.11-1.51), <0.001**
Perceived community stigma	**1.37 (1.27-1.49), <0.001**	**1.17 (1.06-1.29), 0.002**

Estimates from cross-sectional analysis of enrollment data compare outcomes for persons with a one standard deviation difference in HIV stigma level

CHAPTER 3: Adolescent perspectives on HIV status disclosure based on their own experience of disclosure in Kenya; a cross-sectional study

This work is being revised for re-submission to JANAC

Abstract

There are limited data regarding perceptions and preferences for disclosure of HIV status among adolescents and young adults living with HIV (AYHIV). AYHIV from 20 HIV clinics in Kenya completed an anonymous survey on their HIV disclosure experience and preferences. Over half (57%) of the 375 AYHIV enrolled were disclosed to by HCWs, although 53% preferred caregivers perform disclosure. Most (75%) preferred full disclosure by age 12 years. Overall, 275 (73%) AYHIV reported they were ready for disclosure when it happened, and 83% were satisfied with the process. They felt supported by clinic and caregivers pre-disclosure (64% and 68% respectively) and post-disclosure (>75% for each). Lower pre-disclosure clinic support and caregiver support were associated with lower disclosure satisfaction. Older age and disclosure by a caregiver were associated with a preference for a caregiver to disclose. AYHIV reported that disclosure positively influenced their ART adherence (77%).

Key words

Caregiver; disclosure readiness; observational study; satisfaction; young people

Introduction

Adolescents and young adults living with HIV (AYHIV) are a growing population in sub-Saharan Africa (SSA) (1). The increase in AYHIV is due to the transition of a large population of survivors of perinatally transmitted HIV into adolescence in the last decade, following improved access to antiretroviral treatment (ART) (3). In addition, adolescents and young adults aged 15-24 years have high HIV incidence when compared to other age groups (1).

Despite progressive improvement in HIV care, including improved treatment options and implementation of adolescent friendly care, AYHIV have poorer viral suppression and high HIV-related mortality when compared to adults (10). Poorly optimized treatment due to dose adjustment challenges and development of resistance contribute to this disparity (35). Poor outcomes in this age group are also linked to poor adherence to treatment, stemming from a variety of factors including lack of or inappropriate HIV status disclosure for perinatally-infected adolescents, living situation, school schedules, stigma, adolescent rebellion, and poor mental health (7, 25, 81, 82).

Disclosure of HIV status to perinatally-infected adolescents has been associated with improved retention in care, ART adherence, viral suppression, and mental health (33, 34). From a public health perspective, disclosure before sexual debut improves chances of preventing onward transmission (35). Challenges affecting the disclosure process in SSA include caregiver reluctance to disclose,(36) poor access to appropriate disclosure tools (37) and heavy workload among healthcare workers (HCW) in facilities (38).

The World Health Organization (WHO) guidelines recommend that children advance through a planned and structured disclosure process (39). Various tools have been developed to guide the process for AYHIV in SSA (83, 84). Recommended disclosure practices include conducting disclosure for children between ages 6 and 12 years, and involving both caregivers and HCWs in the process (39). However, in SSA, full disclosure typically occurs at a later age, with 50% taking place after age 13 (33, 41, 85). The involvement of caregivers is also sub-optimal due to fears of caregivers regarding their competency to lead the process, and ability to support the emotional needs of the child after disclosure (40, 41). Studies examining the impact of lower age of disclosure and caregiver involvement in the disclosure process on adolescent adherence, and disease progression, show a positive impact (86). While multiple studies have examined HCW and caregiver preferences and practices to inform these guidelines on disclosure,(41) fewer studies have examined the adolescent perspective on these practices. Understanding the adolescent perspective on the impact of the disclosure process on treatment adherence, post-disclosure coping and provision of support is essential for improving the disclosure experience and incorporating patient-centered care approaches.

In this study, we determined AYHIV's preferences on when disclosure should happen, who should be involved, whether they felt prepared and supported to know their status, and their satisfaction with the disclosure process. Further, we determined AYHIV's perception on the impact disclosure had on their adherence, clinic attendance, sexual behavior and self-disclosure.

Materials and methods

Study design

This cross-sectional analysis is nested in the ongoing Adolescent Transition to Adult Care for HIV-infected Adolescents in Kenya (ATTACH) study, a cluster randomized clinical trial (RCT) (NCT03574129) assessing the impact of an adolescent transition package developed in Kenya on transition outcomes for AYHIV. Data for this analysis was collected from AYHIV age 12-24 years enrolled in 20 large HIV clinics in 4/47 counties in Kenya between October and November 2019, prior to RCT start.

Participant recruitment

The recruiting study nurse screened a sample of AYHIV attending clinic (at most 20 per clinic) to ascertain their age, disclosure status and willingness to participate in the study. Those who confirmed that they received HIV care (fully disclosed to) provided oral consent to complete an anonymous survey.

Data collection and measures

Based on a theoretical disclosure framework (Figure 1) adapted from earlier work by the authors,(87) we assessed AYHIV's disclosure experience, perspectives and preferences and their perceived impact of disclosure on health outcomes. The 30-minute survey was administered by a study nurse to individual AYHIV after their routine clinic visit, with the data collected using mobile (tablet-based) REDCap, stored and managed using the same secure web-based platform hosted at the University of Washington.

Socio-demographic information including age of the participant, sex, education level, County of residence and living companion were collected. We also collected HIV-related information including duration since start of ART and duration since they were disclosed to.

To describe their disclosure experience, AYHIV provided information on who disclosed their HIV status to them (caregiver, HCW, self-discovery, HIV testing), whether they perceived that the disclosure was planned, and whether they already suspected being HIV infected before disclosure was done. To assess disclosure readiness, they were also asked whether at the time of disclosure they felt prepared to receive that information (yes, no, not sure). They also rated the support they received from HCW and caregivers on Likert scales before disclosure (always, usually, sometimes, never) and after disclosure (a lot, some, a little, not at all). Satisfaction was assessed using one question asking AYHIV to rate their with the disclosure process on a Likert scale (very satisfied, satisfied, somewhat satisfied, not satisfied).

We assessed AYHIV's preferences for the disclosure process with the following questions: Who do you think should tell children that they have HIV? (Caregiver, HCW, do not know), at what age should children living with HIV be told that they have HIV? When should your disclosure have happened (earlier, later, never, do not know). Finally, we assessed the AYHIV's perceived impact of disclosure on sexual behavior, adherence, and clinic attendance. AYHIV were asked: Do you feel that knowing you have HIV helped you? If yes, how was it helpful? Choices included: taking medication on time, to abstain from sex, to practice safer sex, to talk freely with healthcare workers, and to communicate better with the caregivers.

Ethical considerations

The ATTACH study was approved by the University of Washington institutional review board (IRB), and the University of Nairobi/ Kenyatta National Hospital ethics and research committee (ERC). To conduct the anonymous pre-trial surveys, the IRB and ERC waived parental consent for minors (12-17 years) since majority were unaccompanied to clinic and the study required that they knew their HIV status to be enrolled. The survey was considered low risk with participants only required to provide oral consent.

Analysis

Descriptive statistics (counts and proportions) were used to characterize sociodemographic characteristics including age, gender, education (primary, secondary and tertiary), living companion (family, partner and other), duration on ART (<1, 1-4, 5-10 years and since childhood), and HIV prevalence of County of residence (classified as hyper-endemic [>11%], high prevalence [>5% and <11%] and low-medium prevalence [<5%]) (88). We also described disclosure practices including duration since disclosure (<1, 1-4, ≥5 years), who disclosed (caregiver, HCW, adolescent figured out), whether the disclosure was planned, and whether the

AYHIV suspected being HIV positive before disclosure. AYHIV's disclosure preferences described included preferred time for disclosure (classified as earlier, later, never and don't know) and preferred person to disclose (caregiver, HCW, other persons). We further described adolescent satisfaction with the disclosure process (Likert scores: 1- very satisfied, 2- satisfied, 3- somewhat satisfied and 4- not satisfied.), preparation by clinic (1-a lot, 2-some, 3-a little, and 4-not at all), and pre and post disclosure support (1-always, 2-usually, 3-sometimes, 4-never). Further, we described their readiness for disclosure (classified as no, yes, not sure) and the impact of disclosure on adherence, sexual behavior and self-disclosure using counts and proportions. Perinatally-infected AYHIV were defined as meeting any one of the 3 following criteria: 1) currently aged 15 years or younger, 2) disclosure was done by caregiver or family member, or 3) they were on ART before age 15 years.

Linear regression was used to assess factors associated with satisfaction with the disclosure process for perinatally-infected AYHIV. Satisfaction was included in the model as a continuous outcome variable. Predictor variables assessed included age (assessed as a continuous variable), gender, education level, duration on ART, duration since disclosure, preferred time for disclosure, disclosure readiness, person involved in disclosure, whether disclosure was planned, and suspicion of HIV status pre-disclosure as categorical variables. Additionally, preparation by clinic, clinic and caregiver pre- and post-disclosure support were included in the model as continuous predictor variables. Accounting for clustering within facility, we report unadjusted and age-adjusted mean differences (aMD), 95% confidence interval (95%CI) from bootstrapped t-statistics and bootstrapped p values (89).

We used binomial regression to determine factors associated with disclosure readiness, and AYHIV's preference for disclosure by a caregiver for perinatally-infected AYHIV. The "no" and "don't know" responses for disclosure readiness were combined to create the binary outcome variable (0-not ready, 1-ready). Similarly, we combined the "HCW" and "other persons" responses for preferred person to disclose to create a binary outcome variable (0-not caregiver, 1-caregiver). Similar predictor variables as in the satisfaction models were assessed in the two analyses excluding AYHIV's preferences on time to disclose and where the variable was an outcome. Accounting for clustering within facility, we report unadjusted and age-adjusted prevalence ratios (aPR), 95%CI from bootstrapped t-statistics and bootstrapped p values. We adjusted for age in all models due to the differences in understanding of the disclosure process by adolescents at different ages (90). Analyses used R Studio (Version 1.1.456, 2009-2018).

Results

Of 375 enrolled AYHIV, 228 (60%) were from regions with a HIV prevalence ≥5%, 258 (69%) were female, and the median age was 18 years (IQR: 15-21). All AYHIV were on ART and 252 (67%) reported ART use for ≥5 years, and 293 (78%) were living with family. Overall, 265 (71%) were classified as having perinatally acquired HIV, and 193 (52%) reported knowing their HIV status for ≥5 years (Table 1).

The majority of AYHIV were informed of their status by a HCW (214 [57%]) or caregiver (145[39%]). Only 15 (4%) discovered their positive HIV status on their own. Slightly over half (53%) preferred that caregivers disclose, 151 (44%) preferred disclosure by HCWs, and 266 (75%) preferred disclosure occur by 12 years of age. The majority (197 [67%]) thought the disclosure was planned. Only few, 37 (10%) suspected being HIV positive pre-disclosure. Overall, 180 (57%) felt the clinic prepared them adequately for disclosure, 189 (64%) felt supported adequately by the clinic pre-disclosure, and 206 (68%) felt supported by caregivers pre-disclosure (Table 2).

Overall, 275 (73%) AYHIV reported being ready to be disclosed to at the time disclosure was done, and 274 (83%) reported being satisfied or very satisfied with the disclosure process. After disclosure, 90 (24%) AYHIV reported improved communication with HCWs while 65 (17%) reported improved communication with caregivers. Regarding sexual behavior, 55 (15%) AYHIV reported that disclosure helped them abstain from sexual activity, while 67 (18%) reported practicing safer sex after disclosure. The majority (290 [77%]) reported improved medication adherence and almost half (158 [42%]) reported improved clinic attendance after disclosure, and (212 [57%]) subsequently personally disclosed their status to someone else. Most (304 [81%]) felt supported by the clinic, and caregivers 293 (78%) post-disclosure (Table 3).

Lower perception of having support from the clinic before disclosure was associated with lower satisfaction with the disclosure process (aMD: 0.19 [0.06-0.33]). Similarly, lower caregiver support before and after disclosure was associated with lower satisfaction with the disclosure process (aMD: 0.19 [0.06-0.32] and 0.17 [0.02-0.32] respectively). Further, AYHIV who suspected they were HIV positive before they were disclosed to had lower satisfaction than those who never suspected (aMD: 0.37 [0.00-0.75]). Lastly, compared to AYHIV who preferred an earlier disclosure, those who felt that they should never have been disclosed to had lower satisfaction with the disclosure process (aMD: 1.02 [0.22-1.82]). Age, gender, education level, duration on ART, duration since disclosure, person who disclosed, and whether disclosure was planned were not associated with satisfaction with disclosure (Table 4).

Preparation for disclosure by the clinic had a significant association with disclosure readiness for perinatally-infected adolescents and young adults. Each decrease in reported level of preparation (example: some preparation compared to a lot of preparation) was associated with a 14% lower likelihood of being ready for disclosure (aPR: 0.86 [0.78-0.96]). Further, AYHIV who suspected they were HIV positive before disclosure were 19% more likely to report readiness for disclosure compared to those who did not suspect (aPR: 1.19 [1.00-1.43]) .

One-year older age was associated with a 4% higher likelihood of AYHIV’s preference for a caregiver to disclose (aPR: 1.04 [1.01-1.08]). Compared to AYHIV disclosed to by a caregiver, those who were disclosed to by a HCW were 38% less likely to report preference for a caregiver (aPR: 0.62 [0.44-0.87]). Further, AYHIV who reported being ready for disclosure were 43% more likely to prefer a caregiver than those who were not ready for disclosure (aPR: 1.43 [1.13-

1.81]). Lastly, compared to AYHIV disclosed to <1 year before the study, those disclosed to 1-4 years ago and ≥5 years ago tended to prefer disclosure by caregivers (aPR: 2.05 [0.82-5.12] and 2.23 [0.90-5.53] respectively) (Table 5). No significant associations were found for other variables assessed for association with disclosure readiness and preference for caregiver to perform disclosure.

Discussion

In this treatment experienced group of AYHIV, the majority were perinatally-infected and had known their HIV status for >5 years. The majority preferred an early age of disclosure (12 years or less), and that a caregiver discloses. Over 80% of AYHIV were satisfied with the disclosure process, with the majority reporting being adequately prepared by the clinic and supported by the clinic and caregivers before and after disclosure. Clinic and caregiver support were strong determinants of satisfaction with the disclosure process, disclosure preparation by the clinic was associated with disclosure readiness, while older age, longer duration since disclosure, disclosure readiness and disclosure by a caregiver were associated with AYHIV's preference for disclosure by a caregiver.

Preferences of age at full disclosure have been previously studied among 31 AYHIV in Zimbabwe (90) and 37 AYHIV in South Africa, and as in this study, AYHIV preferred early disclosure (42). While HCW also advocate for early age at disclosure, citing improving adherence and child's right to know as major motivators, caregivers favor disclosure when the child is older (91-93). Fears expressed by caregivers on disclosure at an early age include social rejection, worry by the child, doubt on the child understanding the HIV diagnosis, and the child keeping the diagnosis a secret (91, 92). Caregivers were preferred by a majority of AYHIV in this study to lead the disclosure process, despite a majority reporting to have been disclosed to by a HCW, either in a HIV care setting or during HIV testing. Older age of the adolescent, and longer duration since disclosure were associated with the preference for a caregiver to disclose. These findings highlight the evolution in the appreciation of the disclosure process and the HIV diagnosis that AYHIV go through as they age (90). Disclosure practitioners and policymakers should appreciate that the AYHIV's preferences and the impact disclosure has could change as they grow older. On the other hand, AYHIV disclosed to by a HCW were less likely to prefer disclosure by a caregiver, when compared to those disclosed to by a caregiver, indicating that the adolescent's preference was informed by their own disclosure experience. The adolescent's relationship with their caregivers could also determine their preference. A previous qualitative study showed that adolescents preferred disclosure in a healthcare setting, where HCW can provide accurate information, and due to the belief that HCW would be more straightforward (90). This study brings out a related point by showing that AYHIV's disclosure readiness-, which is determined by their preparation in clinic-, was strongly associated with the preference for a caregiver to disclose. Many studies with HCW and caregivers advocate for either the caregiver to take the leading role or to be actively involved together with a HCW,(90) though caregivers have previously been reluctant to lead the process citing lack of skill on how to disclose appropriately (92). The caregivers however appreciate the benefits of disclosure on adherence, and report feeling relieved after the disclosure happens (33). The preference of a majority of AYHIV on age at full disclosure (≤12 years), and caregivers involvement in the disclosure process in this study, is in agreement with disclosure guidelines (39). Supporting caregivers to overcome their fears of early disclosure, and interventions to increase their disclosure skills are necessary to ensure their meaningful involvement.

We demonstrated that the support AYHIV received in clinic, and from caregivers during and after disclosure was key in their satisfaction with the process, amplifying the need for broad, purposeful engagement of both during the disclosure process. Delay in disclosure contributed to lower satisfaction where participants that suspected they were HIV positive before they were formally disclosed to were more dissatisfied with the disclosure process. Notably, those AYHIV who suspected they were HIV positive were more likely to report being ready for disclosure. This reinforces the need for disclosure before the children attain an age where they find out their HIV status by themselves. There was no difference in satisfaction between AYHIV disclosed to by a caregiver versus by a HCW, which supports the practice of having both fully involved. While preparation in clinic was important in the AYHIV being ready for disclosure, it was interesting to note that it was not decisive in improving their satisfaction with the disclosure experience. In the last 5 years, several tools have been developed to guide HCW in preparing adolescents for disclosure in SSA, and have been found to be effective in increasing their knowledge of HIV and improving clinical outcomes (37, 83, 84). The tools however offer little guidance on caregiver roles, and their assessments rarely include implementation outcomes including satisfaction by adolescents and caregivers with the disclosure process. Development and scale-up of disclosure tools targeting caregivers to increase their knowledge of HIV, adolescence and the disclosure process as envisioned in disclosure guidelines,(39) and assessing whether the tools improve adolescent's disclosure experience are important next steps.

This study added to the body of knowledge of the potential benefits of disclosure. The majority of AYHIV in our study reported improved adherence to treatment and clinic schedules. A few also reported improved communication with caregivers and HCW and improved sexual behavior. Only 38% reported being happier after knowing their HIV status, highlighting the need for immediate post-disclosure support. While AYHIV in our study reported benefits of disclosure, evidence is mixed on the impact of disclosure on adherence to treatment,(33, 94) mental health (95) and sexual behavior which may impact onward transmission (96).

The strength of this study included the representation of a broad age range (12-24 years) of AYHIV, with wide geographical representation and HIV epidemic diversity. The cross-sectional design of the study and recall limitations for adolescents who may have undergone disclosure many years before the study were limitations.

Conclusions

Adolescents and young adults living with HIV advocated for an appropriately timed disclosure process involving caregivers and healthcare workers as envisioned in disclosure guidelines. Support from the caregivers and HCW during and after disclosure is important in improving disclosure experience.

Tables and Figures

Table 1: Sociodemographic characteristics and HIV treatment history

Characteristic, N=375	**n (%)/ median (IQR)**
County of residence (HIV prevalence)	
Homa Bay (Hyper-endemic [>11%])	118 (31)
Nairobi (High prevalence >5% and <11%)	110 (29)
Nakuru (Low-medium prevalence <5%)	70 (19)
Kajiado (Low-medium prevalence <5%)	77 (21)
Female gender	258 (69)
Age	
12-14	87 (23)
15-19	158 (42)
20-24	130 (35)
Education level	
Primary	163 (43)
Secondary	184 (49)
Tertiary	28 (8)
Duration on ART	
<1 year	33 (9)
1-4 years	89 (24)
5-10 years	90 (24)
Since childhood	162 (43)
Living companion	

Family (Parent/ grandparent/uncle/aunt/sibling)	293 (78)
Partner	51 (14)
Other (Lives alone/ friends)	31 (8)
Mode of HIV acquisition	
Perinatally acquired	265 (71)
Behaviorally acquired	110 (29)
Duration since disclosure (N=372)	
<1 year	41 (11)
1-4 years	138 (37)
≥5 years	193 (52)

Table 2: Disclosure practices and pre-disclosure support to adolescents and young adults

Characteristic	**n (%)**
Who disclosed HIV status (N=374)	
Caregiver	145 (39)
Healthcare worker	214 (57)
Adolescent figured out	15 (4)
Who should disclose (N=342)	
Caregiver	182 (53)
Healthcare worker	151 (44)
Other persons	9 (3)
Preferred age for disclosure (N=356)	
<10 years	68 (19)
10-12 years	198 (56)
13-15 years	56 (16)
>15 years	34 (9)
Preferred time for disclosure (N=362)	
Earlier	193 (53)
Later	59 (16)
Never	13 (4)
Don't know	97 (27)
Planned disclosure (N=290)	
Yes	194 (67)
No	61 (21)

Don’t know	35(12)
Adolescent suspected being HIV positive (N=372)	
Yes	37 (10)
No	325 (87)
Don’t know	10 (3)
Clinic prepared adolescent (N=316)	
A lot	180 (57)
Some	58 (18)
A little	56 (18)
Not at all	22 (7)
Pre-disclosure clinic support (N=298)	
Always	189 (64)
Usually	44 (15)
Sometimes	31 (10)
Never	34 (11)
Pre-disclosure caregiver support (N=302)	
Always	206 (68)
Usually	27 (9)
Sometimes	30 (10)
Never	39 (13)

Table 3: Post-disclosure outcomes and support for adolescents and young adults

Characteristics (N=375)	**n (%)**
Was ready to be disclosed to	
Yes	275 (73)
No	88 (24)
Not sure	12 (3)
Satisfaction with disclosure (N=329)	
Very satisfied	105 (32)
Satisfied	169 (51)
Somewhat satisfied	31 (10)
Not satisfied	24 (7)
Adolescent happier after disclosure	141 (38)
Improved communication with health worker	90 (24)
Improved communication caregiver	65 (17)
Disclosure helped me abstain	55 (15)
Disclosure helped me practice safer sex	67 (18)
Disclosure improved adherence	290 (77)
Disclosure improved clinic attendance	158 (42)
**Self-disclosure*	
To anyone	212 (57)
To family	167 (45)
To friends	33 (9)
To intimate partners	57 (15)

Supported by clinic (N=374)	
A lot	304 (81)
Some	41 (11)
A little	24 (7)
Not at all	5 (1)
Supported by caregiver (n=373)	
A lot	293 (78)
Some	21 (6)
A little	37 (10)
Not at all	22 (6)

*Non-exclusive categories

Table 4: Factors associated with adolescents and young adults' satisfaction with disclosure

Factor	**Satisfaction (N=229)** ***Mean (range)***	**Mean Difference (95%CI), p value**	**Age-adjusted Mean Difference (95%CI), p value**
Pre-disclosure clinic support	*1.89 (1-4)	**0.19 (0.04-0.34), 0.02**	**0.19 (0.06-0.33), 0.01**
Always	1.73 (1-4)		
Usually	2.07 (1-4)		
Sometimes	2.39 (1-4)		
Never	2.00 (1-4)		
Pre-disclosure caregiver support		**0.18 (0.06-0.30), 0.01**	**0.19 (0.06-0.32), 0.01**
Always	1.75 (1-4)		
Usually	2.05 (1-4)		
Sometimes	2.22 (1-4)		
Never	2.21 (1-4)		
Post-disclosure clinic support		0.14 (-0.08-0.36), 0.17	0.14 (-0.10-0.38), 0.20
A lot	1.85 (1-4)		
Some	1.89 (1-4)		
A little	2.00 (1-4)		
Not at all	3.50 (1-4)		

Post-disclosure caregiver support		**0.17 (0.03-0.31), 0.03**	**0.17 (0.02-0.32), 0.04**
A lot	1.82 (1-4)		
Some	2.00 (1-4)		
A little	2.03 (1-4)		
Not at all	2.67 (1-4)		
Clinic prepared adolescent		0.07 (-0.10-0.25), 0.35	0.07 (-0.11-0.26), 0.38
A lot	1.82 (1-4)		
Some	1.96 (1-4)		
A little	1.95 (1-4)		
Not at all	2.07 (1-4)		
Suspected HIV positive status			
No	1.86 (1-4)	Reference	Reference
Yes	2.23 (1-4)	**0.37 (0.00-0.74), 0.05**	**0.37 (0.00-0.75), 0.05**
Don’t know	1.50 (1-2)	-0.36 (-2.04-1.32), 0.35	-0.36 (-2.06-1.35), 0.36
Preferred time for disclosure			
Earlier	1.85 (1-4)	Reference	Reference
Later	1.65 (1-4)	-0.20 (-0.65-0.25), 0.31	-0.20 (-0.13-0.34), 0.31
Never	2.88 (2-4)	**1.03 (0.21-1.84), 0.03**	**1.02 (0.22-1.82), 0.03**

Don’t know	1.95 (1-4)	0.11 (-0.13-0.34), 0.36	0.11 (-0.13-0.34), 0.35
Age		0.00 (-0.03-0.04), 0.85	
10-14	1.83 (1-4)		
15-19	1.92 (1-4)		
20-24	1.90 (1-4)		
Gender			
Male	1.91 (1-4)	Reference	Reference
Female	1.87 (1-4)	-0.03 (-0.35-0.28), 0.79	-0.04 (-0.33-0.25), 0.78
Education level			
Primary	1.86 (1-4)	Reference	Reference
Secondary	1.92 (1-4)	0.06 (-0.18-0.30), 0.60	0.06 (-1.31-1.14), 0.65
Tertiary	1.78 (1-4)	-0.08 (-1.95-1.78), 0.82	-0.08 (-0.05-0.05), 0.80
Duration on ART			
<1 year	1.83 (1-2)	Reference	Reference
1-4 years	1.94 (1-4)	0.11 (-0.55-0.77), 0.65	0.12 (-0.52-0.75), 0.65
5-10 years	1.86 (1-4)	0.03 (-0.58-0.64), 0.92	0.03 (-0.65-0.72), 0.90
Since childhood	1.88 (1-4)	0.04 (-0.47-0.56), 0.80	0.05 (-0.55-0.65), 0.82

Duration since disclosure			
<1 year	2.08 (1-4)	Reference	Reference
1-4 years	1.97 (1-4)	-0.12 (-1.02-0.78), 0.74	-0.12 (-1.06-0.83), 0.75
≥5 years	1.85 (1-4)	-0.24 (-1.22-0.74), 0.54	-0.24 (-1.28-0.80), 0.56
Was ready to be disclosed to			
No	1.87 (1-4)	Reference	Reference
Yes	1.88 (1-4)	0.01 (-0.44-0.46), 0.96	0.01 (-0.41-0.44), 0.93
Not sure	2.17 (1-4)	0.30 (-3.74-4.34), 0.70	0.30 (-3.75-4.34), 0.67
Who disclosed HIV status			
Caregiver	1.87 (1-4)	Reference	Reference
Healthcare worker	1.90 (1-4)	0.03 (-0.30-0.37), 0.84	0.03 (-0.30-0.36), 0.82
Self-discovery	2.00 (1-4)	0.13 (-0.70-0.96), 0.74	0.12 (-0.70-0.95), 0.75
Planned disclosure			
Yes	1.85 (1-4)	Reference	Reference
No	1.88 (1-4)	0.03 (-0.34-0.63), 0.86	0.03 (-0.42-0.48), 0.87
Don’t know	2.00 (1-4)	0.15 (-0.32-0.63), 0.41	0.15 (-0.33-0.63), 0.34

*Overall satisfaction

Bolded: Significant association with satisfaction with disclosure process

Supplementary table 1: Characteristics of adolescents and young adults that were ready for disclosure when it was completed

Factor	**Not ready (N=67)** ***n (%)/ mean (range)***	**Ready (N=198)** ***n (%)/ mean (range)***	**Prevalence ratio (95%CI), p value**	**Age-adjusted prevalence ratio (95%CI), p value**
Clinic prepared adolescent for disclosure	2.14 (1-4)	1.66 (1-4)	**0.86 (0.77-0.97), 0.03**	**0.86 (0.78-0.96), 0.02**
A lot	23 (35)	111 (60)		
Some	17 (26)	35 (19)		
A little	18 (28)	27 (15)		
Not at all	7 (11)	11 (6)		
Suspected HIV positive status				
No	62 (93)	165 (84)	Reference	Reference
Yes	4 (6)	26 (13)	**1.19 (1.00-1.43), 0.05**	**1.19 (1.00-1.43), 0.06**
Don't know	1 (1)	6 (3)	1.18 (0.58-2.42), 0.48	1.18 (0.56-2.47), 0.52
Age	17 (12-24)	16 (12-24)	0.99 (0.97-1.02), 0.40	
10-14	20 (30)	67 (34)		
15-19	32 (48)	97 (49)		

20-24	15 (22)	34 (17)		
Female gender	36 (54)	126 (64)	1.11 (0.93-1.34), 0.26	1.12 (0.95-1.33), 0.20
Education level				
Primary	33 (49)	95 (48)	Reference	Reference
Secondary	32 (48)	96 (48)	1.01 (0.88-1.17), 0.89	1.06 (0.89-1.25), 0.49
Tertiary	2 (3)	7(4)	1.05 (0.04-29.56) , 0.81	1.13 (0.00-451), 0.68
Duration on ART				
<1 year	2 (3)	5 (3)	1.06 (0.71-1.59), 0.78	1.05 (0.02-57), 0.82
1-4 years	6 (9)	17 (9)	1.01 (0.72-1.42), 0.89	1.01 (0.02-40), 0 .97
5-10 years	20 (30)	52 (26)	1.03 (0.63-1.68) , 0.89	1.01 (0.67-84), 0 .94
Since childhood	39 (58)	123 (62)	Reference	Reference
Duration since disclosure				
<1 year	6 (9)	11 (5)	Reference	Reference
1-4 years	16 (24)	5 (29)	1.20 (0.78-1.84), 0.40	1.20 (0.82-1.77), 0.35
≥5 years	45 (67)	129 (66)	1.15 (0.74-1.77), 0.53	1.17 (0.80-1.72), 0.41
Who disclosed HIV status				
Caregiver	36 (55)	109 (55)	Reference	Reference

Healthcare worker	29 (44)	79 (40)	0.97 (0.82-1.15), 0.73	0.97 (0.83-1.14), 0.71
Self-discovery	1 (1)	10 (5)	1.21 (0.82-1.79), 0.31	1.23 (0.83-1.81), 0.28
Planned disclosure				
Yes	45 (74)	121 (68)	Reference	Reference
No	10 (16)	33 (18)	1.05 (0.90-1.24), 0.52	1.08 (0.92-1.27), 0.31
Don’t know	6 (10)	25 (14)	1.11 (0.92-1.34), 0.24	1.10 (0.93-1.30), 0.29
Pre-disclosure clinic support	1.66 (1-4)	1.57 (1-4)	0.98 (0.88-1.08), 0.62	0.98 (0.89-1.07), 0.58
Always	41 (64)	128 (69)		
Usually	9 (14)	24 (13)		
Sometimes	9 (14)	20 (11)		
Never	5 (8)	14 (7)		
Pre-disclosure caregiver support	1.75 (1-4)	1.58 (1-4)	0.96 (0.87-1.07), 0.34	0.96 (0.89-1.04), 0.36
Always	42 (66)	132 (71)		
Usually	5 (8)	18 (10)		
Sometimes	6 (10)	21 (11)		
Never	10 (16)	16 (8)		
Supported by clinic post-disclosure	1.28 (1-4)	1.29 91-4)	1.01 (0.89-1.13), 0.88	1.00 (0.89-1.12), 0.98
A lot	54 (81)	158 (80)		

Some	8 (12)	21 (11)		
A little	4 (6)	17 (9)		
Not at all	1 (1)	1 (0)		
Supported by caregiver post-disclosure	1.32 (1-4)	1.40 (1-4)	1.03 (0.98-1.08), 0.19	1.04 (0.97-1.11), 0.26
A lot	54 (81)	155 (79)		
Some	5 (8)	12 (6)		
A little	5 (8)	24 (12)		
Not at all	2 (3)	6 (3)		

Bolded: Significant association with disclosure readiness

Supplementary table 2: Characteristics of adolescents and young adults that preferred disclosure by a caregiver

Factor	**Not preferred caregiver (N=127)** ***n (%)/ mean (range)***	**Preferred Caregiver (N=138)** ***n (%)/ mean (range)***	**Prevalence ratio (95%CI), p value**	**Age-adjusted prevalence ratio (95%CI), p value**
Age (years)	16 (12-24)	17 (12-24)	**1.04 (1.01-1.08), 0.03**	
10-14	46 (36)	41 (30)		
15-19	66 (52)	63 (46)		
20-24	15 (12)	34 (25)		
Who disclosed HIV status				
Caregiver	56 (44)	89 (65)	Reference	Reference
Healthcare worker	67 (53)	41 (30)	0.62 (0.42-0.89), 0.01	**0.62 (0.44-0.87), 0.01**
Self-discovery	4 (3)	7 (5)	1.04 (0.58-1.86), 0.86	0.98 (0.51-1.89), 0.94
Was ready to be disclosed to				
No	36 (28)	24 (17)	Reference	Reference

Yes	87 (69)	111 (81)	1.40 (1.10-1.78), 0.01	**1.43 (1.13-1.81), 0.01**
Not sure	4 (3)	3 (2)	1.07 (0.00-194), 0.92	1.10 (0.02-79), 0.88
Duration since disclosure				
<1 year	13 (10)	4 (3)	Reference	Reference
1-4 years	37 (30)	35 (26)	2.07 (0.82-5.18), 0.08	**2.05 (0.82-5.12), 0.08**
≥5 years	76 (60)	98 (71)	2.39 (0.92-6.23), 0.06	**2.23 (0.90-5.53), 0.06**
Female gender	70 (55)	92 (67)	1.27 (1.00-1.62), 0.05	1.23 (0.93-1.61), 0.13
Education level				
Primary	69 (54)	59 (43)	Reference	Reference
Secondary	54 (43)	74 (53)	1.25 (1.01-1.56), 0.04	1.11 (0.83-1.48), 0.40
Tertiary	4 (3)	5 (4)	1.21 (0.00-13524), 0.61	1.01 (0.00-6288), 1.00
Duration on ART				
<1 year	5 (4)	2 (1)	0.54 (0.00-128104), 0.31	0.50 (0.00-1018661), 0.25
1-4 years	13 (10)	10 (7)	0.83 (0.57-1.22), 0.33	0.91 (0.62-1.32), 0.67
5-10 years	31 (25)	41 (30)	1.09 (0.76-1.56), 0.63	1.10 (0.84-1.46), 0.47

Since childhood	77 (61)	85 (62)	Reference	Reference
Planned disclosure				
Yes	77 (69)	89 (69)	Reference	Reference
No	16 (15)	27 (21)	1.17 (0.85-1.62), 0.32	1.15 (0.82-1.60), 0.40
Don't know	18 (16)	13 (10)	0.78 (0.45-1.37), 0.38	0.80 (0.44-1.47), 0.44
Suspected HIV positive status				
No	111 (88)	116 (85)	Reference	Reference
Yes	13 (10)	17 (12)	1.11 (0.79-1.56), 0.50	1.13 (0.78-1.58), 0.54
Don't know	3 (2)	4 (3)	1.12 (0.04-30.50), 0.80	1.13 (0.03-39.50), 0.79
Clinic prepared adolescent for disclosure	1.85 (1-4)	1.73 (1-4)	0.94 (0.82-1.07), 0.31	0.93 (0.80-1.07), 0.24
A lot	56 (48)	78 (59)		
Some	29 (25)	23 (17)		
A little	23 (20)	22 (17)		
Not at all	8 (7)	10 (7)		
Pre-disclosure clinic support	1.59 (1-4)	1.59 (1-4)	1.00 (0.91-1.10), 0.97	0.99 (0.91-1.07), 0.67
Always	79 (67)	90 (68)		
Usually	16 (14)	17 (13)		
Sometimes	13 (11)	16 (12)		

Never	9 (8)	10 (7)		
Pre-disclosure caregiver support	1.60 (1-4)	1.63 (1-4)	1.01 (0.91-1.13), 0.76	0.98 (0.89-1.07), 0.61
Always	99 (68)	95 (71)		
Usually	15 (13)	8 (6)		
Sometimes	11 (9.5)	16 (12)		
Never	11 (9.5)	15 (11)		
Supported by clinic post-disclosure	1.33 (1-4)	1.26 (1-3)	0.93 (0.68-1.27), 0.57	0.95 (0.74-1.23), 0.67
A lot	99 (78)	113 (82)		
Some	15 (12)	14 (10)		
A little	10 (8)	11 (8)		
Not at all	2 (2)	0		
Supported by caregiver post-disclosure	1.44 (1-4)	1.32 (1-4)	0.91 (0.73-1.12), 0.34	0.90 (0.75-1.09), 0.26
A lot	95 (75)	114 (83)		
Some	12 (10)	5 (4)		
A little	14 (11)	15 (11)		
Not at all	5 (4)	3 (2)		

Bolded: Significant association with disclosure readiness

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