Supporting Adherence and Viral Suppression Goals for Adolescents and Young Adults Living with HIV in Kenya

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ABSTRACT

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Background: Achieving viral suppression goals for adolescents living with HIV (ALHIV) requires individual adherence to ART and efficient and effective health systems to monitor viral load (VL) and coach adolescents when adherence falters. The purpose of this three-study dissertation is to understand individual and health systems drivers of adherence and VL monitoring among ALHIV in Kenya. **Aim 1** sought to assess if VL results are available in EMR and ALHIV knowledge of their VL results**. Aim 2** sought to identify factors impacting the return of VL information to clinics and clients and how healthcare providers make decisions on when to repeat confirmatory VL testing. **Aim 3** measured adherence self-efficacy to ART at an individual level and evaluated the relationship between ART adherence self-efficacy, viral suppression, and its predictors.

Methods: 1. We compared VL results of ALHIV aged 15-19 available in the National Database and compared them to clinic-based electronic medical records (EMR) for accuracy and completeness at six facilities in Kiambu and Nakuru counties. Additionally, ALHIV attending care at these facilities participated in exit surveys, and the modified Poisson regression model assessed the relationship between ALHIV characteristics and knowledge of VL results. **2.** We conducted focus group discussions and in-depth interviews with purposively selected healthcare providers from various phases of VL information flow. **3.** We further analyzed baseline data from a longitudinal cohort of Kenyan ALHIV enrolled in the Data-informed Stepped Care study to assess correlates of ART adherence self-efficacy and HIV viral suppression. Mixed effects regression models, clustering for facility, assessed associations between HIV adherence self-efficacy scores, viral suppression, and predictors of interest.

Results: **1.** Of 207 charts that were randomly selected, 86% (n=179) of the VL matched National Database source records; however, ≥ 10% of VL results were missing in the EMR or incongruent with the National Database source. Out of 132 ALHIV who participated in the survey, only half (52%) reported receiving their last VL result, and older ALHIV (18-19 years) were more likely to receive their test results than younger ALHIV (15-17 years).

2. Identified themes from facility staff were: (1) individual and family level challenges and (2) facility-level challenges to obtaining VL samples, (3) facility-developed strategies to improve sample collection, (4) supply chain constraints affecting laboratory-related delays, (5) lack of VL information affecting treatment decisions, (6) client-specific factors impacting return of VL results, and (7) first healthcare providers to address non-suppressed VL were adherence counselors (8) reluctance to repeat VL until adherence challenges are resolved and (9) measuring adherence through subjective means.

3. Among 1,033 ALHIV, those with no or mild depressive symptoms had higher HIV-adherence self-efficacy (HIV-ASES) scores than those with moderate-to-severe depressive symptoms. ALHIV with high perceived social support scores had higher odds of suppressed viral loads than those with low social support. Although not statistically significant, ALHIV with high adherence self-efficacy scores more frequently had suppressed viral loads compared to those with low levels of adherence self-efficacy scores.

Conclusion: To meet viral suppression goals, interventions that support ALHIV VL knowledge and mental health, combined with efficient health systems processes such as mobile tools, are necessary.

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Chapter 1

Introduction

Among 39 million people living with HIV (PLHIV) in 2022, roughly 1.6 million were adolescents ages 10-19 years of age.[1,2] Adolescents and young adults represent the growing share of individuals living with HIV.[1] In 2022 alone, 480,000 young people between the ages of 10-24 were newly infected, with adolescent girls (10-18 years old) accounting for 80% of all new HIV infections among this age group.[1] With the development and distribution of antiretroviral therapy (ART), significant improvement in mortality has been achieved in different age groups globally; however, the progress in mortality among adolescents lags behind.[3] Approximately 27,000 adolescents died of AIDS-related causes in 2022.[4] Even with knowledge and tools to save lives, HIV remains one of the leading causes of infectious mortality among adolescents and young people in sub-Saharan Africa.[5]

Adolescents and young adults living with HIV (ALHIV) have low viral suppression compared to adults living with HIV. The benefits of achieving viral suppression include a low risk of transmission to sexual partners and mitigation of the progression of the disease.[17] To end the HIV epidemic, the Joint United Nations Programme on HIV/AIDS (UNAIDS) has set 95:95:95 targets to be achieved by 2030.[18] This strategy calls for 95% of all people living with HIV to receive HIV diagnosis, 95% of those who are diagnosed to be on ART, and 95% of those who are on ART to be virally suppressed across all sub-populations and age groups.[18] However, in Kenya, a population-based survey in 2018 reported that among ALHIV, only 56% had achieved HIV viral suppression compared to 66- 83% of individuals >25 years old,[19] falling short of the target set out by UNAIDS.

To achieve viral suppression goals for ALHIV, a multitude of factors, including patient, provider, and health system factors, need to be considered. At the health systems level, timely viral load sample processing and return to the clinic is needed. At the provider level, timely actions on the viral load results, especially initiation of enhanced adherence counseling for ALHIV with non-suppressed viral load results and a repeat of viral load to confirm treatment failure, is necessary. At the individual level, ALHIV should be knowledgeable about their illness and

possess self-management and efficacy skills to manage their health condition, including ART adherence.

ART adherence is defined as the degree to which an individual adheres to taking the prescribed antiretroviral drug regimen and is critical in maintaining HIV viral suppression and improving health outcomes for people living with HIV.[7,8] Low ART adherence can lead to increased viral replication and disease progression, leading to reduced quality of life and early mortality.[9] An ART adherence rate of around 80-95% is ideal for achieving viral suppression goals.[10,11] However, ART adherence among ALHIV is significantly lower than this recommended range, with studies reporting a global adherence rate of 62.3%, which increases the risk of viral non-suppression and opportunistic infections. [12–15]

Guidelines in Kenya recommend HIV viral load testing every six months for ALHIV, and if the viral load is not suppressed, healthcare providers initiate HIV adherence counseling and repeat the viral load after 3 months of "excellent adherence" to rule out treatment failure.[16] However, a recent analysis found that only 29% of the adolescents with non-suppressed viral load received recommended viral load testing within 6 months.[20] The reasons for delays in repeat testing are not well described in the literature and could be driven by factors related to patients, providers, and health systems.[21]

Achieving viral suppression goals for ALHIV requires individual adherence to ART as well as efficient and effective health systems to routinely monitor viral load and coach adolescents when adherence falters. At the health systems level, we need to identify where the breakdown occurs in the viral load information chain, leading to the development of strategies that enhance viral load monitoring and clinical decision-making practices. At the individual level, we need to understand self-efficacy skills among ALHIV so targeted interventions can be developed to enhance their self-management skills.

In doing so, the first study (Chapter 2) of this dissertation seeks to understand if HIV viral load results are available at facilities' electronic medical record (EMR) systems in comparison to

a National Database system and if ALHIV are aware of their latest HIV viral load results and subsequent treatment plans. The second study (Chapter 3) identifies health system factors that impact the return of HIV viral load information to clinics and ALHIV clients and how healthcare providers make decisions around when to repeat confirmatory viral load testing for ALHIV who are enrolled in Enhanced Adherence Counseling (EAC) following non-suppressed result. The third study (Chapter 4) seeks to measure adherence self-efficacy to ART at an individual (ALHIV) level and evaluate the relationship between ART adherence self-efficacy, viral suppression, and its predictors.

The overarching framework for this study is guided by Anderson's Behavioral Model (ABM) for health service use. ABM provides a theoretical framework for understanding how environmental (such as health system and provider action) and personal characteristics (such as adherence self-efficacy) combine to influence health behavior (adherence to ARTs) and, ultimately, health status outcome (viral suppression).[22] ABM has been used to examine healthcare and treatment utilization among people living with HIV.[22,23] Given that ABM considers both patient and environmental-related factors associated with health behavior, this framework can be utilized to assess ART adherence-related factors leading to viral suppression at both personal and environmental among ALHIV. Figure 1 is an adapted version of the ABM displaying the constructs that will be assessed in this study.

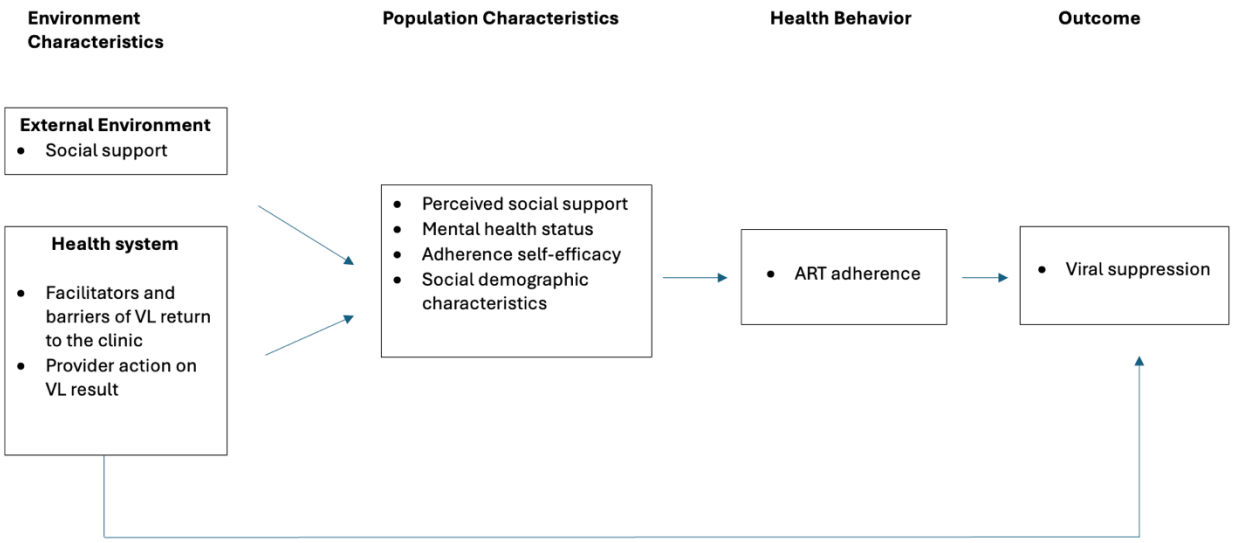

Figure 1: Adapted Anderson Behavior Model

Thus, in summary, at an individual level, this study aims to fill gaps in the literature around (1) ALHIV's knowledge of their viral load results and treatment plans and (2) ALHIV's HIV adherence self-efficacy skills and cofactors (such as perceived social support and depression symptoms) and their association with viral suppression. At the health system level, this paper seeks to (1) understand where the breakdown occurs in return of and action on viral load results and (2) how healthcare providers make decisions around when to repeat confirmatory viral load testing following non-suppressed viral load results and ALHIV's subsequent enrollment in EAC. In determining these gaps, targeted interventions can be developed at individual and system levels to increase adherence to ART and achieve and maintain viral load suppression among ALHIV.

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Chapter 2

Do Adolescents Living with HIV in Kenya Know Their Viral Load Results? Record Audit and Adolescent Exit Surveys in Kiambu and Nakuru Counties

Abstract

Background: Timely and accurate return of viral load (VL) results to adolescents living with HIV (ALHIV) is essential for early detection of adherence challenges and treatment failure, as well as provision of counseling.

Methods: This cross-sectional study evaluated VL data of ALHIV aged 15-19 years enrolled in 6 HIV care facilities in Kiambu and Nakuru Counties in Kenya. In these clinics, HIV VL results are downloaded from the National Database and reentered to participant medical files by a facility staff. We randomly selected and abstracted 20% of VL results available in the National Database from the selected clinics of ALHIV seen from January 2020 to December 2021 and compared them with VL data in clinic-based electronic medical records (EMR). ALHIV attending care participated in exit surveys at the same six facilities. We summarized the proportion of results available in both the EMR and the national database. Modified Poisson regression model with robust standard errors assessed the relationship between adolescents' characteristics and knowledge of VL results.

Results: Overall, 207 charts were randomly selected, of whom 86% (n=179) matched National Database source records; however, 7% (n=14) of VL results were missing from the clinical-based EMR, and 8% (n=17) were incongruent between the National Database and EMR. Only half (52%) of the n=132 surveyed ALHIV reported receiving their last VL result. Older adolescents (18-19 years) were more likely to receive their test results than younger (15-17 years) (65% vs. 44% respectively) (Prevalence ratio [PR]: 1.46, 95% Confidence interval [CI: 1.06 – 2.02], p=0.02).

Conclusion: Most VL data in facilities matched data in the VL data in the National Database. However, >10% of missing or incorrect data records suggest gaps need to be addressed in the transfer of VL data. Only half of the ALHIV knew about their last VL results. Future research and interventions that address data systems consistency and accuracy in addition to VL communication and literacy are key to meeting viral suppression goals.

Keywords: ALHIV, viral load literacy, data accuracy

Background

The World Health Organization (WHO) recommends that countries with a high HIV prevalence adopt routine HIV viral load (VL) testing to monitor antiretroviral therapies (ART) response.[1] National guidelines in Kenya recommend a HIV VL every six months for adolescents living with HIV (ALHIV), and if the VL is not suppressed at this time, healthcare providers initiate HIV adherence counseling and repeat the viral load after 3 months of "excellent adherence" to rule out treatment failure.[2]

Timely and accurate return of viral load (VL) results to adolescents living with HIV (ALHIV) is essential for early detection of adherence challenges and treatment failure, as well as the provision of counseling. In a previous study of audited routine electronic medical record (EMR) data, we found that only 8% of ALHIV with non-suppressed VL received recommended repeat VL testing within three months and only 29% within six months.[3] This finding suggests gaps in the diagnosis of treatment failure that may be driven by the availability of laboratory information, provider behavior, or ALHIV engagement in care.

Both health systems and individual-level factors may play a role in the routine uptake of VL testing and provider adherence to treatment guidelines.[4] Within the Kenyan health system, laboratory constraints, including accurate and timely return of test results from the National lab, have been documented.[5] At the time of this study, the VL sample was collected at the facility's designated lab and taken to the Kenya Medical Research Institute laboratory for processing. VL results became available through the National AIDS and STI Control Programme (NASCOP) Database from where the facility staff obtained the VL results and uploaded them to ALHIV's EMR. Thus, VL information may be available in the National Database but not in the facility-based electronic medical record (EMR) system. Or, if results are in the EMR, it is possible that the necessary information is not being returned by the provider to adolescent clients and their caregivers.

Many ALHIV in Kenya attend care independently after the age of 15, without a caregiver, to prompt service engagement or service needs.[6] As a transitional life stage, adolescence poses an opportunity to encourage self-management of HIV, including adherence to medication and discussing test results and treatment plans with health providers. However, provision and understanding of VL information to help adolescents and young adults gain independence in care is necessary. VL literacy is defined as the ability of people living with HIV to understand the meaning of VL and its broader implications on their health and well-being.[7] Among those living with HIV, VL literacy is known to have a positive effect on stigma reduction and overall well-being.[7,8] However, literature around assessment of VL literacy among ALHIV is sparse.[7–9]

Identifying whether VL results are accurately returned to ALHIV and their caregivers is important to ensure early detection of and intervention with adherence challenges, and timely regimen switch if necessary.[10] This study sought to understand whether VL information was available at the facility-based EMR and if ALHIV 15-19 years were aware of their VL results and treatment plan in six HIV care facilities in Kiambu and Nakuru Counties, Kenya.

Methods

Study Design

This cross-sectional study aimed to understand the flow of VL results for ALHIV in Kenya. Routine medical records were audited to determine a correlation between results available in the NASCOP Database and the health facility EMR. We also conducted anonymous exit surveys of ALHIV attending care at health facilities to determine whether they were aware of their VL status.

Participants and Setting

The study was conducted across six healthcare facilities that offer HIV care and treatment services to ALHIV in Kiambu and Nakuru Counties, Kenya. These two counties were purposefully selected based on their approximation to Nairobi. Kiambu and Nakuru Counties are located in

central Kenya with a mid-level (1-3%) HIV prevalence rate and have a mix of urban and rural populations.[11] Kiambu County facilities consisted of two county hospitals and one sub-county hospital, and Nakuru County facilities consisted of three sub-county hospitals. Kiambu health facilities used EMR consistently and had comparatively fewer reported power outages and staff shortages compared to Nakuru facilities. Selected facilities provided HIV care and treatment services, were operated by the government, and had a moderate to high volume of adolescent clients (>150). These facilities also utilized a well-functioning EMR system supported by implementing partners and offered VL testing to ALHIV clients, even if conducted through off-site laboratory services as discussed above. In these facilities, the VL sample is taken to the National laboratory for processing, from where the facility staff obtains the VL results and uploads them to ALHIV's EMR. ALHIV aged 15-19 were eligible to participate in the exit survey if they had sought HIV care services at the six selected sites and were aware of their HIV diagnosis.

Data Collection

We extracted VL data of ALHIV between January 1, 2020, and December 31, 2021 (a 24-month period) from the NASCOP Database. A simple random sampling technique was used to select 20% of NASCOP VL records. This selected VL was then compared with the VL data in EMRs at the six facilities using unique patient identification numbers. Facility adolescent champions assisted in identifying ALHIV attending care for recruitment to the exit survey. Eligible ALHIV were asked to complete a brief anonymous survey. This survey was collected on paper and later entered into a REDCAP database by the study team member.[12] The adolescent exit survey questions assessed whether ALHIV is taking antiretroviral therapy (ART), when their last VL testing was, whether they received their VL results, and if they did, what was their VL status and subsequent treatment plans.

Statistical Analysis

We performed descriptive statistics of VL data that was abstracted from the NASCOP database and EMR from the six facilities. Mean and frequencies of suppressed and non-suppressed VL, along with the percentage of matching, non-matching, and missing VL, were calculated. From the exit survey data, descriptive statistics (median and frequencies) of the social demographic characteristics, awareness of ART and viral load status, and subsequent treatment plans were assessed among ALHIV. Further, a bivariate Poisson regression model assessed the association between ALHIV characteristics and knowledge of VL results.

Ethical Considerations

We obtained approvals from both the Kenyatta National Hospital Ethics and Regulation Committee (P501/06/2021) and the University of Washington Institutional Review Board (STUDY000013432). Waivers of parental and written consent were obtained. Following ethical approvals, we obtained permission from the participating counties, followed by letters of approval from the participating facilities to access their records. Sensitization meetings were conducted at all sites to ensure that the facility teams were aware of the study and its expectations. Verbal informed consent was obtained from all ALHIV participants.

Results

Records audit

Overall, 1,031 viral load records were abstracted from the national database from 745 adolescents (Table 1). The mean age of adolescents whose VL samples were examined was 17 (standard deviation [SD:1.4]); 56% (n=416) were female. Most VL samples were from Kiambu County Health facilities (68%, n=698), while 32% (n=333) were from Nakuru County Health facilities. Overall, 71% (n=733) of records from the National Database indicated a suppressed result, 28% (n=291) were non-suppressed, and 0.1% (n=2) had a missing result. Approximately

0.5% of the results were inconclusive or could not be obtained; therefore, a new sample collection was advised. VL suppression varied by facility from 66-78%.

Table 1: Description of viral load records (N=1031) from 745 Adolescents attending six Nakuru and Kiambu County facilities

Adolescent characteristics (n=745)	N (%) or mean (SD)
Age	17 (1.4)
Sex	
Male	329 (44)
Female	416 (56)
Viral load records extracted (n=1031)	
County	
Nakuru	698 (68)
Kiambu	333 (32)
Viral load result	
Suppressed	733 (71)
Non-suppressed	291 (28)
Missing	2 (0.1)
New sample advised	5 (0.5)
Viral suppression by facility	
Facility 1 (n=420)	281 (67)
Facility 2 (n=189)	132 (70)
Facility 3 (n=99)	77 (78)
Facility 4 (n=74)	55 (74)
Facility 5 (n=204)	151 (74)
Facility 6 (n=56)	37 (66)

Table 2 lists the number of audited records in each of the facilities. Among 207 facility records sampled for auditing (n=12-80 per facility), 86% (n=179) of the VL results matched with the National Database record. Approximately 7% (n=14) of VL in the facility EMR did not match with the NASCOP Database as the VL was recorded incorrectly in the EMR. Additionally, 8% (n=17) of VL was missing in the EMR but was recorded in the National Database. By facility, the range of matching results ranged from 50%-94%, though some sites had smaller numbers of adolescent records audited.

Table 2: Audited viral load records in six participating facilities

Facility Name	Number of charts audited	Number (%) of VL data matching w/National Database	Number (%) of VL that did not match w/ National Database	Number (%) of VL missing
Facility 1	80	75 (94)	3 (4)	2 (3)
Facility 2	39	36 (92)	1 (3)	2 (5)
Facility 3	21	16 (76)	2 (10)	3 (14)
Facility 4	15	14 (93)	1 (6)	0 (0)
Facility 5	40	32 (80)	3 (8)	5 (13)
Facility 6	12	6 (50)	4 (33)	2 (17)
Total	**207**	**179 (86)**	**14 (7)**	**17 (8)**

ALHIV characteristics: adolescent exit surveys

A total of 132 ALHIV were surveyed in six facilities. The number of ALHIV surveyed per facility ranged from 18 to 33. Approximately 55% (n=72) of ALHIV surveyed identified as female (Table 3). The median age was 17 years (IQR:15,19), and approximately 64% (n=84) were currently attending secondary school. Most (97%, n=128) of the ALHIV who participated in the survey reported currently taking ARTs, and of these, nearly 88% (n=112) reported taking ARTs for more than two years.

Table 3: Adolescent exit surveys from the six facilities in Kiambu and Nakuru Counties

Adolescent characteristics (n= 132)	Median (IQR), N (%)
Age (overall)	17 (15,19)
15 -17 years	82 (62)
18 -19 years	49 (37)
Missing	1 (1)
Sex	
Male	59 (45)
Female	72 (55)
Did not identify	1 (1)
Current school level	
Primary	20 (15)
Secondary	84 (64)
Not currently enrolled	16 (12)
Other (Polytechnic, University)	12 (9)
Taking ART	128 (97)
Duration of ART use among those taking ART (n=128)	
Less than 6 months	13 (9)
6-12 months	2 (2)
1-2 years	1 (1)
More than 2 years	112 (88)
Last Viral Load testing	
Less than 1 month ago	22 (17)
Between 1-6 months ago	69 (52)
More than 6 months ago	41 (31)
Received the result of the last viral load testing	68 (52)
VL result among those who received their VL results (n= 68)	
Reported viral suppression	56 (82)
Reported non suppression	10 (15)
Did not know viral load status	2 (3)
Next planned VL test among those suppressed (n=56)	
Less than 3 months	6 (11)
3 months	12 (21)
6 months	22 (39)
Don’t know	16 (29)
Next planned ART refill among those suppressed (n=56)	
1 month	1 (2)
3 months	48 (86)
6 months	7 (13)
Treatment plan among those non-suppressed (n= 10)	
Be seen more frequently	3 (30)
Attend adherence counseling	1 (10)
Attend support groups	6 (60)

Knowledge of VL testing, results, and treatment plans

ALHIV were asked about the timing of their last VL test; 31% (n=41) indicated their last test more than 6 months ago, while 69% (n=91) reported that the last VL testing was within 6 months. Over half (52%, n=68) of the adolescents reported receiving their last VL result, whereas 38% (n=51) reported that they did not receive their last VL results, and 9% (n=12) were unsure if they received their VL results. Sensitivity analysis restricted to ALHIV who had viral load testing more than 1 month prior to surveys, assuming it may take >14 days for the VL result to return to the facility, similarly found 53% (n=58) reporting they received their last VL result.

Among ALHIV who stated they received their VL result, most (82%, n=56) reported that they were virally suppressed, while 14% (n=10) reported that they were not virally suppressed and 3% (n=2) did not know the status or remember the results. Among adolescents who reported viral suppression, 39% (n=22) reported that they were to be tested again in 6 months, and 28% (n=16) adolescents did not know when their next VL testing would take place. The majority of those who were virally suppressed (86%, n=48) reported 3-month medication refill cycles. Adolescents who reported being not virally suppressed reported treatment plans, including attending support groups (60%, n=6), being seen more frequently (30%, n=3), and attending adherence counseling (10%, n=1).

Sociodemographic characteristics and knowledge of viral load results

Older ALHIV between age 18 and 19 years of age more frequently reported receiving their test result compared to younger 15-17 year olds (65% vs. 44% respectively) (Prevalence ratio [PR]:1.46, 95% Confidence interval [CI]: 1.06-2.02, p=0.02). No statistically significant differences in knowledge of results and education level (primary: 30%, secondary: 56% p= 0.14) sex (female: 54%; male: 52%, p=0.84) were observed.

Discussion

This study abstracted VL data available in the national database and compared it with the VL data available in facilities' EMR, in addition to assessing adolescent awareness of their VL results. Overall, most (86%) VL data in the facilities matched with the National Database source records, with 8% missing and 7% incongruent, suggesting some room for improvement in completion and accuracy, but generally complete information. Surprisingly, only half of the young people surveyed were aware of receiving their last viral load result, and even when restricted to those with a test more than 1 month ago, similar proportions (53%) reported receiving results.

Our evidence suggests that test results were generally flowing from the laboratory where sample collection occurred to the processing laboratory and back to HIV care facilities. However, >10% of the VL data were missing from the facilities or did not match with the corresponding National Database records. Similar issues of missing and inconsistent data have been reported in other settings in Kenya,[13] including one study where VL tests not being returned from the National lab was the most frequently observed data quality issue.[5] While some data discrepancies may not impact treatment decisions and outcomes, mismatched and unreturned VL data has the potential to initiate a change in the HIV treatment course. Training on proper data entry, reporting, and monitoring for consistency may be valuable to prevent VL inconsistencies and to prevent misdiagnosis.

We found relatively low levels of awareness of the last VL results among ALHIV. This finding is similar to a qualitative study in Zimbabwe which observed limited understanding of what VL testing and undetectable VL meant among ALHIV.[7] In Kenya, gaps in HIV knowledge, including routes of transmission, impact, and risk of infection with other STIs, navigating a romantic relationships, and misconceptions and fears of ARTs among ALHIV have been reported.[14] In the age group of age 15 and older, where many attend HIV care alone,[6] knowledge and understanding of HIV VL results, status, and subsequent treatment plans, in addition to routes of transmission and STI awareness, is crucial to enable them to manage HIV with increasing independence.

Given more than half of Kenyan youths currently have access to phones, smartphones, and the internet and this access likely will increase over time,[15] web-based or mobile health-based education is one potential avenue to explore to increase VL literacy and self-management in this population. Computer-supported web-based education programs have been found to reduce hospital admission and morbidity among adult asthma patients in Scotland[16] and increase self-efficacy for adolescents with Type I diabetes mellitus in Turkey.[17] A systematic review found that electronic health and web-based interventions were successful methods of improving physical activity in adolescents and young adults. [18] Thus, VL and HIV-related education for adolescents and self-management skills could draw on experiences from other chronic conditions and be optimized through technology such as web-based health or mobile devices.[19,20]

While this study provides valuable insights into the VL data completeness and accuracy and ALHIV awareness of their HIV viral load results, there are some limitations of the study. This study had limited funding, with a small sample size in both data audits and exit surveys, and possible selection bias in choosing six care facilities. Importantly, supply chain shortages following the COVID-19 pandemic may have also influenced test availability in these facilities, which would not have been detected since we used the National Database as source data. However, even with these limitations, our study provides new data regarding VL data systems in Kenya and the VL literacy and communication gap between HIV care providers and older ALHIV. Further research into VL communication dynamics between the National Database and the clinics could provide insights on how to address challenges with VL data returning to clinics and to ALHIV.

Conclusion

Most of the VL data in the National Database matched with the facilities' EMR, suggesting that a large number of VL results were being returned to the health facilities. However, missing or incorrect data records suggest a need for streamlined processes to ensure correct and timely entry for clinical management, and there are gaps in awareness of VL results among adolescent

clients. Future research and interventions that address data systems consistency and accuracy, as well as VL literacy and health communication, are essential to empower ALHIV to meet viral suppression goals.

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Chapter 3

Navigating viral load information flow and provider decision-making for adolescent clients at HIV clinics in Kenya

Abstract

Background: Achieving viral suppression goals for adolescents and young adults living with HIV (ALHIV) requires multifaceted strategies, including efficient and effective health systems to routinely monitor HIV viral load (VL) and support adolescents when adherence falters. This study aims to identify where weaknesses in the VL information flow occur in return of VL results to clinics and ALHIV clients and how health providers determine a “good adherence” to repeat confirmatory VL testing for ALHIV with non-suppressed VL enrolled in enhanced adherence counseling.

Methods: In this cross-sectional study, 4 focus group discussions were conducted with purposively selected 29 healthcare providers from various phases of VL information flow. Additionally,10 in-depth interviews were conducted with healthcare providers who were in the direct care of providing ART, VL testing, or counseling. Thematic analysis identified 9 themes in different phases of the VL information flow and enhanced adherence counseling sessions.

Results: Themes in the sample collection phase consisted of (1) individual and family level challenges, ALHIV not presenting to the laboratory, (2) facility-level challenges: a shortage of personnel and long queues at the laboratory, and (3) facility-developed strategies to improve sample collection. In the sample processing and turnaround to the clinic phase, one theme was identified: (1) supply chain constraints affecting laboratory-related delays. In the client notification and management phase, three themes were identified: (1) lack of VL information affected treatment decisions, (2) client-specific factors impacting dissemination of VL results, and (3) the first healthcare providers to address non-suppressed VL were adherence counselors. In the enhanced adherence counseling sessions, two themes were identified, (1) reluctance to repeat VL until adherence challenges are resolved and (2) measuring adherence through subjective means.

Conclusion: The identified themes highlighted that individual, social, and health systems factors were perceived as contributing to success or delay in the ability to obtain timely VL results and repeat confirmatory VL testing for ALHIV with non-suppressed VL. To meet viral suppression goals, interventions that support ALHIV motivation, combined with health systems processes, as well as mobile tools responsive to the social context of ALHIV lives are necessary.

Keywords: ALHIV, Enhanced adherence counseling, VL information flow

Background

Of 39 million people living with HIV, roughly 1.6 million are adolescents ages 10-19 years of age.[1,2] Over the past two decades, antiretroviral therapy (ART) has led to significant improvement in HIV survival; however, mortality reductions among adolescents and young adults living with HIV (ALHIV) have stagnated.[3] HIV viral suppression among adolescents is lower than in adult populations, ranging from 27% to 89% one year after ART initiation, contributing to increased risk of HIV transmission and disease progression, morbidity, and mortality.[4] HIV is one of the leading causes of mortality among adolescents in sub-Saharan Africa and globally;[5] an estimated 27,000 ALHIV died of AIDS-related causes in 2022 globally.[6]

While numerous individual and family-level barriers to non-suppression have been identified,[7–9] achieving viral suppression goals for adolescents requires multifaceted strategies, including efficient and effective health systems to routinely monitor HIV viral load (VL) and support adolescents when adherence falters. VL testing is one of the most effective ways to monitor the efficacy of ART and allows assessment of adherence treatment response and early detection of treatment failure.[10] In 2013, WHO recommended that all countries with a high prevalence of HIV adopt routine HIV VL testing practices for monitoring ART response.[11]

HIV guidelines in Kenya recommend testing for HIV VL every six months for adolescents. If VL is not suppressed, healthcare providers initiate enhanced adherence counseling (EAC) and repeat VL after 3 months of excellent adherence to rule out treatment failure.[12,13] EAC is a targeted counseling strategy designed to help clients identify individual barriers to adherence and develop strategies to improve viral suppression.[14] EAC in Kenya is typically conducted in three sessions, with the first session occurring immediately after a non-suppressed VL result, where understanding of VL (non-suppressed, suppressed) and common ART adherence challenges are identified. ALHIV Clients and counselors then develop a plan to address identified adherence challenges.[13] The second and third EAC sessions center around reviewing and modifying adherence plans from the previous sessions. During the third session, if the adherence is deemed

"good," then the guideline recommends repeating VL testing.[13] However, even with this guidance, an analysis of routine medical records in Kenya found only 29% of the ALHIV with non-suppressed VL received recommended repeat VL testing within six months.[15] Delays in VL return trends have similarly been noted in other African countries.[16] Further, the recommendation to establish "good adherence" for three months prior to repeating confirmatory VL testing has posed challenges in Kenya, as there is no suggested timing for re-testing if adherence is not resolved, and the counseling may take time or be hindered by school and clinic schedules.[15]

The reasons for delays in repeat VL testing have not yet been well described in the literature and could be driven by provider judgment or ALHIV care-seeking behaviors. Further, limited studies have explored how healthcare providers assess and determine when adolescent clients reach a good adherence once they start on EAC. In this analysis, we aimed to identify where weaknesses in the VL information flow occur by exploring health systems factors that impact the return of HIV VL information to clinics and ALHIV clients. Further, among a subset of healthcare providers we sought to explore how they determine when adolescents who are enrolled in EAC meet "good adherence" to confirm treatment failure through repeat VL testing.

Methods

Study Design

Focus group discussions (FGDs) and in-depth interviews (IDIs) were conducted with healthcare workers at Kenyan HIV care facilities between July and September 2022. Each focus group consisted of 4-10 participants selected using stratified purposive sampling with assistance from HIV care facility managers. Ten in-depth interviews were subsequently conducted with health providers involved in direct ART or counseling care to better understand how providers assess ART adherence before repeating a confirmatory VL testing for treatment failure.

Population and Setting

The study site included six health facilities providing HIV care to adolescents in Kiambu and Nakuru counties. Kiambu and Nakuru counties are located in central Kenya with mid-level (1-3%) HIV prevalence and have a mix of urban and rural populations.[17] FGD participants were health providers from multiple cadres and along various phases of information flow from the facility laboratory, where the VL sample was collected, to the HIV clinic, where VL results are disseminated and managed. Health providers for the FGDs included clinical officers, nurses, peer counselors, adherence counselors/ psychologists, laboratory technologists, community health workers, link desk officers, adolescent youth champions, and health record officers, who had been working in their respective clinical site jobs for at least 6 months. IDI participants were health providers who provided adherence counseling, made decisions about when to repeat VL testing, or actively collected viral loads for adolescents who had a non-suppressed viral load. Health providers for the FGDs included clinical officers, nurses, counselors, and technicians who had been working in their clinical site for more than 6 months.

Data Collection

FGDs and IDIs were conducted in the health facilities or in a virtual setting by a Kenyan study team member using semi-structured guides (see appendix) that were developed by the multi-disciplinary study team. Only participants and the interviewer were present in the room during FGD and IDI. The FGD guide explored VL testing processes such as frequency of VL testing, average turnaround time for the VL results, reasons for shorter or longer turnaround time, factors that affected VL turnaround time to the facility and the adolescents, strategies in place to ensure prompt turnaround, and provider readiness to discuss VL results with the adolescents. Focus group discussions lasted up to 55 minutes. The IDI guide explored how providers determine ART adherence in adolescents who are enrolled in EAC and when they repeat VL testing. IDIs lasted up to 35 minutes. Each FGD and IDI interview was recorded and transcribed by a study team member.

Ethical Approval

We obtained approvals from the Ethics and Regulation Committee (ERC) (P501/06/2021) at the University of Nairobi and Kenyatta National Hospital and the University of Washington Institutional Review Board (UWIRB) (STUDY000013432). Sensitization meetings were conducted at all sites to ensure that the facility teams were aware of the study and its expectations. Written informed consent was obtained from all the participants in both the focus group discussion and in-depth interviews.

Analysis

We utilized deductive thematic analysis[18] to code and identify FGD themes related to VL testing, return, and management. The thematic analysis process included several phases; familiarization with the data, generating initial codes based on the questions, searching for themes, reviewing themes, and producing the report. A preliminary codebook was developed prior to the start of the analysis using focus group discussion guide questions. After initial code development, two coders coded the same transcript for consensus coding using ATLAS.ti software.[19] During consensus coding, disagreements in codes were discussed until a consensus was reached, if unable to reach a consensus a third member of the team was available to resolve the discrepancies. After the completion of consensus coding, the remaining transcripts were divided between two coders who independently coded the remaining transcript. During the coding process, any new codes that captured additional information related to research questions or topics were discussed by both coders and added to the master codebook. New codes that were added included adherence counseling sessions, support groups, VL management challenges, and consequences of delay in viral load results. Codes were then organized and examined to search for themes. The themes were reviewed and defined in a reiterative manner with the study team and were categorized in various phases of the VL flow chain from the point of sample collection to the dissemination of results.

Reflexive thematic analysis (RTA) was used to code and identify IDI themes related to determining ART adherence in the context of EAC, repeat VL testing after starting EAC, embracing the primary researcher's reflexivity and subjectivity. We used RTA because we wanted to capture providers' experiences and perceptions beyond the questions that we asked. The RTA included several phases. In the first phase, the data corpus was read and reread to become more familiarized with the data. In phase two, the primary coder systematically went through the dataset and identified segments that were interesting, relevant, and meaningful and coded them. In this phase, the primary coder received assistance from their supervisor, who jointly coded the first two transcripts, and compared notes and codes to allow for the exploration of multiple assumptions and alignment in the interpretation of data.[18,20] The remaining transcripts were coded by the primary coder. In phase three, after all the relevant data were coded, codes were analyzed to generate initial themes. In phase four, themes were reviewed and assessed to see if they fit the dataset as well as the coded extracts. Phase five involved refining and naming themes and in phase six, we wrote an analytic narrative with vivid data extracts. Each of these six steps of the focus group and in-depth interviews analysis were performed in a recursive and reiterative manner and the final report was also written in a reiterative process with the entire study team.

Rigor/ trustworthiness

The first author is a PhD student who has been trained in the US healthcare system. Self-reflection was done by the first author while analyzing and writing this paper through reflexive journaling, examining her position and influence in the interpretation of the result. A secondary coder for the focus group discussion is a Kenyan research assistant who is familiar with the Kenyan healthcare system and qualitative research. The trustworthiness of the focus group analysis was achieved through two coders developing a codebook together and conducting a consensus coding, before moving on to code the rest of the transcripts. The rest of the FGD transcripts were individually coded by one coder and reviewed by another. Each difference in the

application of the code was discussed by both coders until a consensus was reached. Further, the supervisors of the first author and the rest of the study team reviewed the themes.

While coding in-depth interviews, to ensure the validity of the inductive coding process and sense check ideas, exploration of multiple assumptions, and alignment in the interpretation of data first two transcripts were coded together with the first author's supervisor. Each of the codes in these two transcripts was compared and discussed. Braun and Clarke's 15-point checklist for good thematic analysis was utilized as a guide to ensure systematic and reflexive analysis.[18] Further, the supervisors of the first author and the rest of the study team reviewed the themes and the manuscript of the study.

Results

Participant Characteristics

The characteristics of the participants of the focus group discussions and in-depth interviews are shown in the table below (Table 1). The median age of the participants in focus groups was 34 years (IQR: 32,42) and the majority (82.8%, n=24) of participants identified as female. In focus groups, approximately 38% (n=11) of participants were from Kiambu County, and 62% (n=18) were from Nakuru County. The participant cadres of the study are summarized in Table 1. The average length of employment at the present healthcare facility among the participants was 36 months (3 years) for participants in focus groups.

The median age of the in-depth interview participants was 32 (IQR:30,52), and the majority identified themselves as females (80%, n=8) (Table 1). Out of 10 participants, more than half of the participants (60%, n=6) were from Kiambu County health facilities. The majority were nurses (40%, n=4) and clinical officers (30%, n=3). Average employment at the present health facility was approximately 32 months (IQR 24- 48).

Table 1: Focus group (n=29) and in-depth interview (n=10) study participants

Characteristic	Focus Group Discussions N (%) or median (IQR)	In-depth Interviews N (%) or median (IQR)
Age (years)	34 (32,42)	32 (30,52)*
Sex		
Female	24 (82.8)	8 (80.0)
Male	4 (13.8)	1 (10.0)
Not Identified	1 (3.4)	1 (10.0)
County		
Kiambu	11 (37.9)	6 (60.0)
Nakuru	18 (62.1)	4 (40.0)
Cadre		
Clinical officer	7 (24.1)	3 (30.0)
Nurse	6 (20.7)	4 (40.0)
Adherence counselor	5 (17.2)	1 (10.0)
Peer counselors	4 (13.8)	1 (10.0)
Lab Technicians	2 (6.9)	1(10%)
Psychologist	1 (3.4)	
Adolescent champion	1 (3.4)	
Health record officer	1 (3.4)	
Community health worker	1 (3.4)	
Link desk officer	1 (3.4)	
Months employment at present site	36 (24,60)	32 (24,40) *

* 1 IDI participant (nurse) missing demographic information

Identified Themes

Each of the identified themes related to barriers and facilitators of VL information flow was categorized into different phases of the VL information flow, which are 1) VL sample collection phase, 2) VL processing and turnaround time to the clinic phase, 3) client notification and management phase from the focus group discussion and 4) enhanced adherence counseling of non-suppressed clients from the in-depth interviews. The themes identified in the focus groups and interviews are listed in Table 2.

Table 2: Themes according to phases of the VL information flow

Phase of VL information flow	Themes and subthemes
Focus Group Discussions	

Sample collection	• *Individual and family level challenges: ALHIV not presenting to the laboratory*
	• *Facility-level barriers: Shortage of personnel and long queues at the laboratory*
	• *Facility-developed strategies to improve sample collection*
	  ○ *Ensuring sample collection before ALHIV leave*
	  ○ *Provider-client communication*
	  ○ *Process improvement*

Processing and turnaround to the clinic	• *Supply chain constraints*
Client notification and management	• *Lack of VL information affected treatment decisions* • *Client-specific factors impacting dissemination of VL results* • *First healthcare providers to address non-suppressed VL were adherence counselors*
In-depth Interviews	
Enhanced adherence counseling	• *Reluctance to repeat VL until adherence challenges are resolved* • *Measuring adherence through subjective means*

Sample collection phase

In the VL sample collection phase, three themes emerged, which were I) individual and family level challenges: ALHIV not presenting to the laboratory for VL testing, II) facility-level barriers: a shortage of personnel and long queues at the laboratory, and III) facility-developed strategies to improve VL sample collection. Subthemes within facility-developed strategies included ensuring sample collection before ALHIV leave, improving provider-client communication, and process improvement.

<u>Individual- and family-level challenges: ALHIV not presenting to the laboratory for VL testing</u>

Participants in three focus groups noted that ALHIV scheduled for sample collection sometimes missed their laboratory visit.

> *You could send a client* (to the lab), *but they don't go.* - Participant A2

In many cases, they attributed this loss to adolescent fear of venipuncture.

> *Recently we had an adolescent meeting, and some were to give the samples for viral load, but they ran away. They are afraid of getting the injections. That one is also a challenge because they disappear*.
> - Participant D1

Participants also suggested that caregiver barriers impacted the VL sample collection. They described how caregivers may pick up medications for ALHIV who were unable to attend visits at scheduled times, largely because of conflicting school schedules, or when they accompanied ALHIV, they did not have time to wait with ALHIV for sample collection.

> *Even the caregiver themselves, sometimes the problem is not even the adolescent, it is the caregiver. When they come to collect drugs, they just leave claiming that their time is being wasted, and you find that the adolescent is even still in school uniform. And the next thing you hear them say that they already have the drugs, so it is just the blood. Some of the caregivers are very intolerant, so you just give them their way. Sometimes they say that they have been called back to work, and you see them leave with the adolescent. So, that is a big challenge.* - Participant D4

<u>Facility-level barriers: shortage of personnel and long queues at the laboratory</u>

Participants additionally identified facility-level factors, including understaffed laboratories and long queues at the laboratories, interfered with obtaining VL samples. In two focus groups, participants mentioned long wait times led ALHIV to leave the clinic before sample collection.

> *There are those who get tired of waiting. Not that they won't be drawn from, they feel that they can leave and come back the next day, because of the queue. They look at the queue and decide to leave and come back some other time*. - Participant D7.

When ALHIV had their clinic visits scheduled on weekends, participants also noted that laboratory staff were not always available to collect samples.

> *Another challenge which mostly happens during weekends maybe Saturdays. You will find that the lab technician who is coming in was not meant to work on that day and they come from far. The technician is*

> *requested but you find a challenge because of lack of facilitation and this person was not supposed to be on duty. It's a challenge*. - Participant C4

Facility-developed strategies to improve viral load sample collection

Healthcare providers reported that health facilities had developed their own strategies to improve VL sample collection. These strategies included ensuring a sample collection before leaving the facilities as well as focusing on provider-client communication and process improvement.

Ensuring sample collection before ALHIV leave: Several groups discussed strategies to ensure the opportunity for drawing the VL sample is not lost, by generating systems-level interventions to ensure sample collection before the adolescent leaves clinic. For example, some sites changed clinic flow so that samples were collected before picking up medication at the pharmacy.

> *We also started encouraging clients to have the samples taken first before they take their drugs. And for those whose results are missing on several occasions, they are escorted to the lab because for us there is a distance and the path to going back home is closer than to the lab. So, there are those who are escorted to the lab*. - Participant B3

Others looked to confirm the client completed the sample collection, either by having the pharmacy confirm the laboratory visit, or escorting ALHIV to the laboratory for a lab draw.

> *… nowadays we write something when we send them to the lab, then the lab people will sign it after drawing the blood. Then the client will return that small paper to the clinician to go to the pharmacy. So, you will know that client has drawn blood. Before that you could send the client, but they failed to go*. - Participant A2

Provider-client communication: Participants in several focus groups identified aspects of provider-client communication that supported an understanding of the importance of VL testing. This included education about why VL testing is done,

> *I think …, through the adolescent records, we get their names and when their date comes, we get prepared even so that we can escort them, talk to them about the importance of having their viral load done, we try and create a close relationship with them*. - Participant D4

Process improvement: Other process improvements included motivating clinic attendance by providing incentives, scheduling visits outside school hours, and navigating ALHIV through the laboratory visit to increase uptake of viral load testing.

> *Maybe they are in boarding school so you know it can be very hard to get that child to come. So, you wait* (to schedule appointments) *until schools close. - Participant B8*

> *We escort them and be there as it is done, and then we release them so that they don't waste time with queuing; we give them first priority.- Participant D4*

VL processing and turnaround time to the clinic phase

Supply chain constraints

In the VL processing and turnaround time to the clinic phase, one theme emerged: a supply chain constraint. Participants in all focus groups highlighted persistent laboratory delays in returning VL results to clinic, largely thought to be related to the shortage of reagents and testing kit commodities.

> *Most of the time we are told there are stockouts of reagents, that is why they delay. So that's the major reason.* - Participant B1

> *There is a time there was an issue with reagents….so the turnaround was getting a bit delayed.* - Participant A2

> *For the last almost 2 years we have not been doing viral loads due to the commodities.* - Participant C7

Poor communication between the laboratory and the clinic on the status of results or reasons for delay during times of supply shortage was further raised as a challenge.

> *We also had a situation where no one could explain what happened because the samples were sent in February, and we got the results in July. That was after following up for so long, every time we questioned, we were told we shall be updated on the progress. So, no one actually told us what happened, we finally got the results but we didn't get the answers to how they delayed*. - Participant B3

Client notification and management phase

Finally, in a client notification and management phase, three themes emerged, which were lack of VL information affected treatment decisions, client-specific factors impacting dissemination of VL results, and adherence counselors are the first healthcare workers to address viremic/non-suppressed VL.

Lack of VL information affected treatment decisions

Participants in the focus groups reported the delays in VL result receipt affected their treatment decisions. In some cases, providers reported they had to assume suppression with the absence of VL data and client reports of adherence.

> *When a client tells you they take medication every day at a specific time and they have never missed, you treat like any other suppressed client*.- Participant C3

Others expressed concern that they were unable to monitor treatment response or make appropriate regimen switches if needed.

> *We also have a situation whereby maybe the sample you have sent was a confirmation of the prior viral load status and it delays for so long but this person keeps insisting they are taking their drugs well. We cannot really be able to tell if it's true unless you see the viral load is suppressed or not. So sometimes you can't even make decisions if this was someone who was supposed to be on a second line regimen. You can't do anything because this person assures you they are taking their drugs well and you should wait for the results and when the results take more than 3 months, you are stuck there*. – Participant B3

Client-specific factors impacting dissemination of VL results:

Participants reported the timing of VL notification to adolescent clients depended on the VL result. ALHIV with elevated VL results were contacted immediately for adherence counseling, while those who had suppressed VL received their VL results at their next scheduled visit.

> *As soon as we get the results, we give the results to the concerned persons. The one who are okay (virally suppressed), we give them results as they come for their clinics. The ones that are having issues (unsuppressed), as soon as we get the results, we call them*. - Participant C7

> *It depends. For example, if the viral load is high, it's our initiative to ensure that immediately we get the results, the client receives their results and begins the adherence counseling sessions. This can be through phone or maybe we invite them to the facility. So, if it's high, we are able to contact them through phone but if the results are undetectable, they get the results upon coming back to the facility for their appointments.* - Participant A4

However, participants noted that non-working phone numbers, client not picking up calls, and failure to attend follow-up appointments resulted in delays in the response to elevated VL.

> *Sometimes we have challenges with contacting the clients once we've got the viral load results. So, sometimes their lines are not going through, or they are going through and they are not picking, or they promise that they will come on a particular day and they don't come. So, that also contributes to them getting their results late.* - Participant C2

> *Some of them miss their appointments and you will find some don't have working contacts, there is no one you can contact.* - Participant B3

Additionally, for ALHIV in boarding school, results could not be acted on until ALHIV were on school break, especially if they had not disclosed their HIV status to the school.

> *With this new curriculum, you may find that you need to see the adolescent, but the teachers won't release the patient from school. So, it is a challenge. And when you talk to the parent, they will not go and talk to the patients as you have told them*. - Participant D4

> *Some of the adolescents in boarding school and have not disclosed their status either to a teacher or maybe the matron, and they are forced to keep their drugs themselves. So, upon receiving viral load results for such an adolescent who is in boarding school, measures to address the issues affecting their adherence takes too long because you have to wait for this adolescent to close school before passing the message to the adolescent.* - Participant A2

<u>The first healthcare workers to address non-suppressed VL were adherence counselors</u>

Participants in all four focus groups stated adherence counselors are the first healthcare workers to meet with ALHIV after elevated VL results. It is through adherence counselors that ALHIV with non-suppressed VL receive their results and immediately begin EAC.

> *If the viral load is high, it's our initiative to ensure that immediately we get the results, the client receives their results and begins the adherence counseling sessions*. - Participant A4

> *As an adherence counselor. Those viral loads are always on my table and when every client comes, they must see me before they see the clinician. When I see that client first and I have the viral load results with me, when doing the adherence counseling, I also give the results. For those with high viral load, that's when I find the barriers before sending the clients to the clinician. That makes it easy and the result cannot be forgotten. It will be on the table and I have to see them before they proceed to the clinician.* - Participant C3

Enhanced Adherence Counseling

In-depth interviews with healthcare providers yielded two major themes around determining "good adherence" among non-suppressed ALHIV during enhanced adherence counseling: reluctance to repeat testing and subjective determination of adherence.

<u>Reluctance to repeat VL until adherence challenges are resolved:</u>

Healthcare providers discussed that for ALHIV enrolled in EAC sessions as recommended by treatment guidelines, they prioritize making sure causes of medication adherence are resolved prior to completing EAC and repeating the next confirmatory VL test. They emphasized the guideline recommendation of switching ART regimen with elevated VL, however expressed concern that if adherence is not met, then they will have switched ARTs unnecessarily. Thus, providers reported that they want to make sure that they repeat VL only after optimization of adherence to ART.

> *We delay the VL, we prepare the child enough, and upon getting satisfactory results of adherence that's when we do [repeal VL testing]… you know when we do VL just because the guidelines say that you should do it after three months of adherence sessions and then you just do it and then it comes back high…There are so many issues when it comes to these children. So, you'll find that regimen would fail. So, we usually avoid the drug resistance in cases of adolescents. We usually switch where it is just necessary*. - Participant I3

Further, there was a consensus among all providers that completion of three EAC sessions was required before repeating VL testing as recommended. However, depending on how adolescents are doing with adherence, sometimes more than three EAC sessions might be

needed prior to repeating VL to confirm treatment failure. Thus, prior to repeating confirmatory VL testing, providers prioritize ensuring that medication adherence issues are resolved, regardless of the number of EAC sessions adolescents have undergone or the time lapsed since last elevated VL test.

> *At least three sessions, after the third one then we can do the viral load. But there are others who even after the third one, they still say maybe they are still forgetting or they have issues. There are days they are missing so we give them a little more time before we get them to do the viral load.* - Participant I6

Measuring adherence through subjective means:

Almost all providers interviewed stated that a decision about when an adolescent reaches good adherence is determined by adherence counselors through a shared decision-making process with adolescent and their caregivers if involved in the adolescent's care.

> *There are those questions that you will have to ask. Some of the things and decisions that you make together [with adolescents]... And if this adolescent has a guardian you will also have to confirm with the guardian if the adherence has improved.* - Participant I9

Specifically, adherence counselors reported assessing differences in how adolescents respond to questions about HIV, how they feel about taking medications, and what would happen if they were to repeat VL testing. They report noticing differences in how adolescent clients answer these important questions around HIV and management as they progress through each of the EAC sessions.

> *From the counseling sessions, we will always notice a difference on how the client the client responds, on how they feel about HIV, on how they feel about the drugs. So, it's basically the clients themselves saying they feel they are ready.* - Participant I6

Further, if caregivers are involved in adolescents' care, then counselors also inquire with caregivers if medication adherence has improved.

> *We even interact with the guardians, we ask them how they're doing because at times, like when they're in school their guardians come to pick drugs for them.* - Participant I8

Finally, though reported less frequently, in addition to a shared decision-making process, providers also reported performing pill counts, to assess if the medication is being taken.

> *We do pill counts, we get the client's report, we get the caregiver's report, and even with the interaction of the client you will know. Maybe the issue was self-stigma. You would just know that this child has worked on this side, this child is still weak on this side and then you help her out.*- Participant I3

Discussion

This study aimed to explore VL information flow and clinical decision-making around meeting good adherence and repeating confirmatory VL testing once enrolled in EAC at adolescent HIV care facilities in Nakuru and Kiambu Counties from the perspective of health system stakeholders. Individual, social, and health systems factors were perceived as contributing to success or delay in the ability to obtain timely VL results and provide them to ALHIV and their caregivers across all phases, including VL sample collection, processing and turnaround, client notification, and adherence counseling. Without timely and accurate VL information, healthcare providers in these adolescent HIV care facilities felt their treatment decisions were limited. These delays could have detrimental consequences, particularly to heavily treatment-experienced adolescents requiring regimen changes for resistant viral mutations.[21]

One of the individual factors driving the lack of VL information identified was ALHIV not presenting to the lab as expected. Fear, anxiety, and distress over needle phobia among adolescents have been cited in the literature globally,[22,23] and our findings suggest this may lead to avoidance behavior in ALHIV who require regular blood draws. In other HIV studies in Kenya, adolescents older than fifteen often present to care alone,[24] thus providers may want to consider either stress management techniques with ALHIV[25] or, as happened at participating facilities, systems-level strategies to remove opportunities to leave before care is completed.

At the health system level, our study revealed that a shortage of VL testing supplies and staffing in the laboratories impeded the smooth flow of VL samples for ALHIV. Other research

studies and newspaper outlets have similarly cited significant gaps in both the HIV testing supply and staff shortages in Kenya and other low and middle-income countries, particularly during the COVID-19 pandemic.[26–29] A 2022 survey in 47 African countries found that there were only 1.55 health workers per 1,000 people, significantly lower than the World Health Organization threshold of 4.45 health workers per 1,000 people needed to deliver essential health services and achieve universal health coverage.[30] If the UNAIDS 95- 95-95 goal is to be achieved by 2030, then strengthening VL monitoring programs by making sure that there are sufficient testing supplies, reagents, and staffing in low and middle-income countries is essential.

In the social context, boarding school is a common academic setting for many children and youth in Kenya.[31] Providers reported that, for ALHIV who are in boarding schools, the VL results notification, discussion, adherence counseling, and repeat confirmatory VL testing process is slower than expected, as they often wait until school is closed to attend the clinic. This delay results in delays in result notification and timely onset of adherence sessions. Utilization of technology such as mobile health has had a positive impact on retention and engagement in care among people living with HIV may provide opportunities to deliver tailored outreach and communication to youth outside of the traditional physical clinical setting.[32–35]

Once results were received, adherence counselors communicated non-suppressed VL results to ALHIV, who were then enrolled in EAC. In concordance with the national guideline, ALHIV with non-suppressed VL results were required to complete three EAC sessions at minimum, however, depending on how ALHIV are doing with adherence issues, sometimes more than three sessions may be necessary. The national guideline states that “adherence must be thoroughly addressed, before switching the patient to next line of ART”,[13] thus in alignment with this recommendation, healthcare providers in our study reported waiting to repeat VL testing until a good adherence was achieved.

Confirmation of good adherence was primarily through subjective measures. The sole use of these measures raises concerns about social desirability and memory recall biases, which lead

to the overestimation of adherence.[36] A combination of subjective measures with objective measurement of pill counts however has been shown to have the highest diagnostic accuracy for first-line ART failure in South Africa.[37] Further, approaches like unannounced telephone pill counting have been found to be a feasible and valid measure of ART adherence in young adults[33,38,39], and could be a useful approach for ALHIV residing in boarding schools.

This study has strengths and limitations. Our findings are strengthened by the fact that we reached data saturation during coding process and the themes discussed above are representative of the participant's experiences. While the different representations of cadres and clinics provided robust insight into VL processes, the generalizability of this study is limited by the small sample size, and participants representing only two counties in Kenya and may not translate well to other counties. Further, we purposely selected participants and thus may have not included the perspectives of healthcare providers who did participate in this study. Our focus groups included senior staff, which may have impacted the ability of other staff members to speak freely.

Conclusion

Efficient and effective health systems to routinely monitor HIV VL and support adolescents when adherence falters are essential to achieving viral suppression goals for ALHIV. Interventions that support ALHIV motivation, combined with health systems processes, as well as mobile tools that are responsive to the social context of ALHIV lives are necessary.

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Chapter 4

Psychosocial Correlates of Adherence Self-Efficacy and HIV Viral Suppression among Adolescents and Young Adults in Western Kenya

Abstract

Background: Among people living with HIV (PLHIV), adherence self-efficacy is a strong predictor of initiation and maintenance of HIV medications.

Methods: Enrollment data from a longitudinal cohort of Kenyan ALHIV enrolled in the Data-informed Stepped Care (DiSC) were used to assess correlates of ART adherence self-efficacy and HIV viral suppression. ALHIV completed behavioral surveys at enrollment, and viral load data was abstracted from a National Database. Linear mixed effects regression models and general linear mixed effects regression models were used to determine associations between HIV adherence self-efficacy scale (HIV-ASES) scores, viral suppression, and predictors of interest.

Results: Among 1,033 ALHIV enrolled in the parent study, 68% were female, 45% were ages 15-19, and 44% currently attended or had completed at least secondary school. ALHIV who had moderate-to-severe depression had a total HIV-ASES score that was 13.7 points lower (95% CI: - 20.13 – -7.17) than those with none-or-mild depressive symptoms (p <0.001). In the bivariate analysis, ALHIV in the 20-24 years age group trended towards having 2.32 points higher total HIV-ASES score compared to 10-14-year-olds (95% CI: -0.44- 5.11 p=0.10), but this was not statistically significant in multivariate analysis (p=0.15). No significant difference in HIV-ASES score was noted among sex, education level and perceived social support. Further, ALHIV with high perceived social support scores had 1.55-fold higher odds of suppressed viral loads (95% Confidence interval [CI]: 1.11 – 2.15) than those with low social support. Although not statistically significant, ALHIV with high adherence self-efficacy scores more frequently had suppressed viral loads compared to those with low levels of adherence self-efficacy scores (68% vs. 74%, p=0.14),

Conclusions: To increase self-efficacy for ART pill-taking and reach viral suppression goals among ALHIV, interventions targeting mental health, especially among younger ALHIV, are imperative.

Keywords: HIV, adolescence, Kenya, adherence, self-efficacy

Background

Adherence to antiretroviral treatment (ART) is critical in maintaining HIV viral suppression and improving health outcomes for adolescents and young adults living with HIV (ALHIV). Low ART adherence leads to increased viral replication and disease progression, reduced quality of life, and early mortality among individuals living with HIV.[1] While a 95% adherence rate is considered a benchmark for good adherence, recent studies have noted that an ART adherence rate of 80-95% is acceptable for achieving viral suppression goals.[2,3] However, even with this broader adherence rate range, multiple studies have reported ART adherence among ALHIV is significantly lower than among adults. [4–6] Common barriers to ART adherence among ALHIV range from personal and caregiver factors to treatment and health system-related factors, some of which are stigma, forgetfulness, secrecy, ART side effects, inconvenience, and lack of support.[7] Targeting self-efficacy could be a focal point in addressing some of these ART adherence barriers while enabling ALHIV to self-manage their HIV.

Self-efficacy is defined as an individual's belief in their ability to implement a specific behavior or a set of behaviors.[8] Among adolescents and young adults, self-efficacy is related to positive outcomes such as improved academic performance, emotional health, and quality of life.[9] Self-efficacy score measures have been used to predict outcomes of various chronic conditions such as asthma, type 2 diabetes, hypertension, and other chronic health conditions. [10–13]

Within the broader construct of self-efficacy, specific concepts of adherence self-efficacy relating to treatment plans have also been studied. Adherence self-efficacy is defined as "confidence in one's ability to adhere to treatment plans" and has been known to be an important predictor of medication adherence for HIV as well as other chronic conditions.[14,15] Among adults living with HIV, adherence self-efficacy is a strong predictor of initiation and maintenance of ART,[16,17] however, there have been few studies of adherence self–efficacy among adolescents on ART in Kenya or sub-Saharan Africa (SSA). In determining these gaps, interventions can be

developed to target adherence self-efficacy, which could be a potential avenue to increase the self-management of HIV for adolescents and youths. Thus, in this paper, we measured adherence self-efficacy to ART and evaluated the relationship between ART adherence self-efficacy, depression, perceived social support, and HIV viral suppression among ALHIV in Kenya.

Methods

Study Population and Design

This study utilized baseline data from a longitudinal cohort of Kenyan ALHIV enrolled in the Data-informed Stepped Care (DiSC) to Improve Adolescent HIV Outcomes study.[18] ALHIV ages 10-24 years were recruited from nine HIV care and treatment facilities located in Kisumu, Homabay, and Migori counties.

Conceptual Framework

This analysis is guided by CK Ewart's Social Action Theory (SAT), which emphasizes a model of behavior change and the social context and support that assist in achieving and maintaining that behavior change.[19–21] According to SAT, health behaviors result from the interaction of three domains: *contextual influences*, the *process of self-change,* and *self-regulation.*[21] The *contextual influences* encompass the context in which the health behavior occurs, such as individuals' background and demographics, life stressors, and mental health state. The *process of self-change* includes self-change processes such as self-efficacy and social support. *Self-regulation* is an action state, which includes actions such as adherence to ART to reduce HIV viral load. Thus, intended health behaviors are shaped by the social-environmental system and interpersonal factors of the individual, which can both hinder or facilitate a behavior change.[19] SAT has been utilized in various studies to promote healthy behaviors such as ART adherence.[22,23] Figure 1 represents measures assessed in this study based on Social Action Theory.

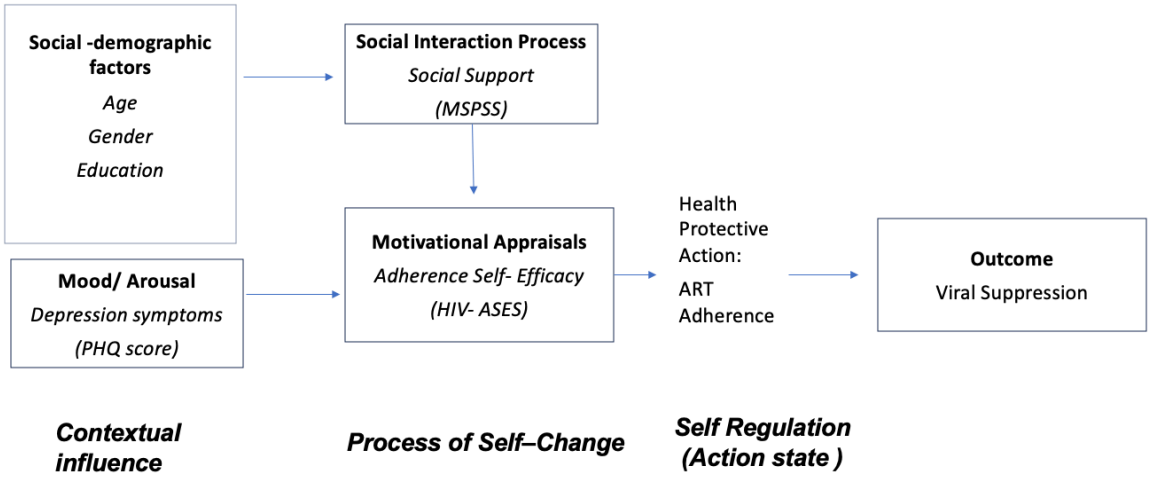

Figure 1. *Organization of study constructs and measures based on the adaptation of Social Action Theory.*

Data Collection

Demographic and behavioral surveys were administered by trained study staff via tablets at enrollment. Additionally, viral load (VL) data of all patients in the participating facilities were downloaded from the National AIDS and STI Control Programme database. We matched the VL result within three months of baseline surveys to study participants using a unique patient identifier number. If there were two VLs collected within the three-month window, the VL collected closest to the survey date was used.

Measures

Survey variables analyzed in this study are the socio-demographic characteristics (age, gender, and highest education level), the Multidimensional Scale of Perceived Social Support (MSPSS),[24] the Patient Health Questionnaire-9 (PHQ-9),[25] and the HIV adherence self-efficacy scale (HIV-ASES).[26] VL suppression classification is based on Kenya's HIV Treatment Guideline

definition and cut-off values for suppressed status as < 200 copies of HIV RNA / ml of blood.[27] In alignment with clinical guidelines, a PHQ-9 score of 9 or below was considered as having none to mild depressive symptoms, and a score of 10 or higher was considered as moderate to severe depressive symptoms.[25] The MSPSS is a brief questionnaire designed to measure perceptions of social support from three sources: family, friends, and significant others. In this study, high social support is categorized as those with a higher than median MSPSS score. HIV-ASES is a psychometric scale that assesses people living with HIV's confidence to carry out important treatment-related behaviors around adherence to treatment plans, including medication adherence and ability to follow plans for nutrition, exercise, etc. We categorized participants as having high HIV-ASES if the total score was above the median HIV-ASES score.

Statistical Analysis

We analyzed surveys of ALHIV with complete responses to any of the variables of interest Descriptive statistics included counts and proportions or medians with interquartile ranges (IQR). HIV-ASES mean scores and proportions with viral suppression were compared across categorical age groups, sex, education, depression status, and perceived social support scores using linear mixed-effects regression models accounting for facility cluster as a random effect for linear outcome (HIV-ASES) and generalized linear mixed effects regression models accounting facility cluster as a random effect for binary (viral suppression) outcome. Variables with p-values <0.10 in the bivariate analysis were included in a multivariable general linear mixed model. All analyses were conducted using R.[28]

Ethical Approval

We obtained approvals from the University of Washington Institutional Review Board (STUDY00005767) and Maseno University Ethics Review Committee (ERC) (MSU/DRPI/MUERC/00799/19). Caregivers and adolescents provided informed consent and

assent until August 2019. On August 22, 2019, we received approval from Maseno ERC to waive parental consent of adolescents ages 15-17 who come to the clinic with no caregiver.

Results

Participant Characteristics

Of 1393 ALHIV enrolled in the parent trial, we excluded 360 ALHIV who had incomplete responses to any of the variables of interest and analyzed complete survey responses from 1,033 ALHIV. Among 1,033 ALHIV included in the analyses, the median age was 17 (IQR:15, 20) (Table 1). Most participants were female (68%). About 44% currently attended or had completed secondary school. Nearly all participants (98%) reported no or mild depressive symptoms over the past two weeks. HIV adherence self-efficacy (HIV-ASES) cumulative scores were relatively high among the participants, with a median HIV-ASES score of 99 out of 110 (IQR: 90,105). The median perceived social support score was 42 out of 60 (IQR: 37,47).

Table 1: Characteristics of ALHIV participants (n=1,033)

Characteristic	Median (IQR) or N (%)
Age (overall)	17 (15, 20)
10- 14 years	209 (20)
15-19 years	467 (45)
20- 24 years	357 (35)
Sex	
Male	328 (32)
Female	705 (68)
Education level	
Primary school	576 (56)
Secondary level or higher	457 (44)
Cumulative PHQ-9 score	2 (0,4)
Depressive Symptoms	
None to mild depressive symptoms (PHQ score of ≤9)	1009 (98)
Moderate to severe depressive symptoms (Total PHQ score ≥10)	24 (2)
HIV adherence self-efficacy scale (HIV-ASES) score	99 (90,105)
Multidimensional Scale of Perceived Social Support (MSPSS) score	42 (37,47)
Viral suppression*	
Suppressed VL (<200 copies/ml)	535 (71)
Non- suppressed VL (≥200 copies/ ml)	217 (29)

*among 752 participants with matching VL records

Itemization of HIV adherence self-efficacy scale

When we evaluated each of the HIV-ASES questions in an itemized manner, we found that for all questions except question three, the median score was 10. Question three assessed incorporating treatment in daily routine, including in front of people who don't know HIV status. The median score for this item was 5 (IQR:0,10) (Table 2).

Table 2: Itemized HIV adherence self-efficacy scale

ASES Question	Median score (IQR)
1. Keep to your treatment plan even when side effects begin to interfere with daily activities	10 (8,10)
2. Include your treatment into your daily routine	10 (9,10)
3. Include your treatment into your daily routine even if it means taking medication or doing other things in front of people who don't know you are HIV-infected	5 (0,10)
4. Keep to your treatment schedule even when your daily routine is disrupted	10 (9,10)
5. Keep to your treatment schedule when you aren't feeling well	10 (9,10)
6. Keep to your treatment schedule when it means changing your eating habits	10 (9,10)
7. Keep with your treatment even if doing so interferes with your daily activities	10 (9,10)
8. Keep with the treatment plan your physician prescribed even if your T-cells drop significantly in the next three months	10 (10,10)
9. Keep with your treatment even when you are feeling discouraged about your health	10 (9,10)
10. Keep with your treatment even when getting to your clinic appointments is a major hassle	10 10,10)
11. Keep with your treatment even when people close to you tell you that they don't think that it is doing any good	10 (10,10)

Correlates of HIV adherence self–efficacy

We assessed the overall adherence self-efficacy score among different age groups, sex, and education levels, as well as depressive symptoms and perceived social support (Table 3). ALHIV who had moderate-to-severe depression had a total HIV-ASES score that was 13.7 points lower (95% CI: - 20.13 – -7.17) than those with none-or-mild depressive symptoms ($p < 0.001$). In the bivariate analysis, ALHIV in the 20-24 years age group trended towards having 2.32 points higher total HIV-ASES score compared to 10-14-year-olds (95% CI: -0.44- 5.11 p=0.10), but this was not statistically significant in multivariate analysis (p=0.15). There were no statistically significant differences in total HIV-ASES scores by sex, education, and those with high and low levels of perceived social support

Table 3. Correlates of HIV adherence self-efficacy (n=1033)

	HIV-ASES score[1] Mean (SD)	**Bivariate Analysis**[2] Coefficient estimate (95% CI)	**Unadjusted p-value**	**Multivariate Analysis**[3] Coefficient estimate (95% CI)	**Adjusted p-value**
Age group					
10-14 years	93.8 (12.9)	Ref		Ref	
15-19 years	93.3 (17.5)	-0.43 (-3.06 – 2.20)	0.75	-0.25 (-2.85 – 2.36)	0.85
20-24 years	96.2 (16.1)	2.31 (-0.44 – 5.11)	0.10	2.08 (-0.72 – 4.91)	0.15
Sex					
Male	93.0 (17.8)	Ref		Ref	
Female	95.1 (15.4)	1.96 (-0.17 – 4.09)	0.07	1.48 (-0.69 – 3.66)	0.18
Education level					
Primary school	94.1 (16.5)	Ref			
Secondary school	94.8 (15.9)	0.52 (-1.47 – 2.52)	0.61		
Perceived social support[4]					
Low social support	95.0 (15.7)	Ref			
High social support	93.9 (16.7)	-1.13 (-3.10 – 0.86)	0.27		
Depression symptoms[5]					
None-mild depression	94.7 (15.6)	Ref		Ref	
Moderate-severe depression	81.8 (29.9)	-13.65 (-20.10 – -7.10)	<0.001	-13.70 (-20.13 – -7.17)	< 0.001

[1] Total mean HIV adherence self-efficacy scale (HIV-ASES) score. Total cumulative score possible was 110. Mean score among all participants was 94.38 and median was 99.

[2] Bivariate linear mixed effects model clustered by facility to account for random effect,

[3] Multivariable liner mixed effects model clustered by facility to account for random effect. Only variables with p≤0.10 in bivariate analysis were used in the multivariate model.

[4]Multidimensional Scale of Perceived Social Support (MSPSS) measured perceived social support. High social support was defined as score greater than median MSPSS score. Median MSPSS score was 42. total cumulative score possible was 60.

[5] Patient Health Questionnaire-9 (PHQ-9) assessed depression symptoms. PHQ-9 score of ≤9 or below was considered as having none to mild depressive symptoms and a score of ≥10 was considered as moderate to severe depressive symptoms.

Correlates of viral suppression

A total of 752 ALHIV had a complete survey and matching viral load data within 3 months of baseline surveys. Most 71% (n=535) of the participants had a suppressed viral load. ALHIV with high social support had higher odds of viral suppression compared to those with low social support (75% vs. 67% respectively, adjusted OR: 1.55, CI:1.11–2.15) (Table 4). Additionally, although not statistically significant, there was a trend for higher odds of viral suppression among females (74%) compared to males (67%) (adjOR:1.37, CI: 0.98 – 1.93). ALHIV with high adherence self-efficacy scores more frequently had suppressed viral loads compared to those with low levels of adherence self-efficacy scores (68% vs. 74%, p= 0.14), but this was not statistically significant. Age groups, education levels, and severity of depression symptoms were also not associated with viral suppression in univariate analyses.

Table 4: Correlates of HIV viral suppression (VL < 200)

	Viral suppression[6] (N, %)	Bivariate Analysis[7] Odds Ratio (95% CI)	Unadjusted p-Value	Multivariate Analysis[8] Odds Ratio (95% CI)	Adjusted p-value
Age groups					
10-14 years (n= 169)	116 (69)	Ref			
15-19 years (n= 355)	248 (70)	1.1 (0.74 – 1.65)	0.64		
20-24 years (n= 228)	171 (75)	1.35 (0.86 – 2.14}	0.19		
Sex					
Male (n= 257)	171 (67)	Ref		Ref	
Female (n= 495)	364 (74)	1.39 (0.99 – 1.94)	0.058	1.37 (0.98 – 1.93)	0.07
Education level					
Primary school (n=434)	304 (70)	Ref			
Secondary school (n=318)	231 (73)	1.06(0.76 – 1.48)	0.73		
Perceived social support [9]					
Low social support (n= 363)	242 (67)	Ref		Ref	
High social support (n= 389)	293 (75)	1.56 (1.12 – 2.16)	0.008	1.55 (1.11 – 2.15)	0.009
Depression symptoms[10]					
None-mild depression (n=734)	520 (71)	Ref			
Moderate- severe depression (n=18)	15 (83)	2.19 (0.62 – 7.77)	0.23		
HIV adherence self-efficacy[11]					
Low adherence self-efficacy (n=372)	253 (68)	Ref			
High adherence self-efficacy (n= 380)	282 (74)	1.28 (0.92 – 1.76)	0.14		

[6] Viral suppression classification is based on Kenya's HIV Treatment Guideline definition and cut-off values for suppressed status as < 200 copies of HIV RNA / ml of blood

[7] Bivariate generalized linear mixed effects regression model accounting facility cluster as a random effect.

[8]Multivariate generalized linear mixed effects regression models accounting facility cluster as a random effect. Only variables with p≤0.10 in bivariate analysis were used in the multivariate model.

[9] Multidimensional Scale of Perceived Social Support (MSPSS) measured perceived social support. High social support was defined score greater than median MSPSS score. Median MSPSS score was 41 among 752 ALHIV with matching VL. Total cumulative score possible was 60.

[10]Patient Health Questionnaire-9 (PHQ-9) assessed depression symptoms. PHQ-9 score of ≤9 or below was considered as having none to mild depressive symptoms and a score of ≥10 was considered as moderate to severe depressive symptoms.

[11] HIV adherence self-efficacy scale (HIV-ASES) measured adherence self-efficacy. High adherence self -efficacy was defined as score above the median HIV-ASES score. Median ASES score was 99 among 752 ALHIV with matching VL. Total cumulative score possible was 110.

Discussion

This study of a large cohort of ALHIV found a positive correlation between adherence self-efficacy and mental health and a link between social support and viral suppression. Our findings indicate relatively high levels of adherence self-efficacy to ART among ALHIV, with a single item driving self-perception of HIV-ASES: incorporating treatment into a daily routine even if it meant taking medication in front of others who were unaware of their HIV status. Similar findings of difficulty taking medication in public spaces, using the HIV-ASES psychometric tool, have been reported among ALHIV in Nairobi.[29,30] Perceived stigma and fear of unintended disclosure associated with taking ART in public have been noted among ALHIV globally as contributors to ART adherence.[31–33] Well-designed interventions that target internal stigma reduction and enable adolescents to take their ART in whatever spaces they choose are imperative to improve HIV outcomes among ALHIV.

In our study, we found that adherence self-efficacy scores were inversely associated with depression. ALHIV who had moderate-to-severe depression had significantly lower adherence self-efficacy score compared to those with no-or-mild depression. Self-efficacy has been found to mediate the association between depression and treatment adherence in chronic illnesses such as heart failure and hypertension.[15,34] Further, among those living with HIV, depression is associated with a low level of ART adherence. [35–37] Identifying and treating mental health illnesses such as depression potentially impact self-efficacy skills, which leads to improved medication adherence and ultimately overall HIV outcomes among ALHIV. Thus, at the health systems level, structural interventions, such as prioritization of treatment for mental health conditions, which targets emotional and physiological states, could be utilized to enhance self-efficacy for HIV management.

Social support has similarly been noted to have a robust effect on health, with its role as a protective factor against morbidity and all-cause mortality.[38,39] Social action theory and social cognitive theory both indicate that social support likely influences self-efficacy beliefs.[21,40,41]

However, we did not find that the perceived social support score was associated with the adherence self-efficacy score, though other studies have found that social support had a positive relationship with treatment self-efficacy.[41,42] We found that ALHIV with high perceived social support scores had higher odds of having suppressed viral loads. Similar findings have been reported in other studies among ALHIV.[43,44]

Although not statistically significant, ALHIV with higher adherence self-efficacy scores were more frequently virally suppressed. Higher ART adherence self-efficacy has been associated with increased self-reported adherence and VL suppression among ALHIV in Kenya and among adults in the United States.[45,46] Studies of adolescents and youth in Thailand report that adherence self-efficacy is associated with increases in overall quality of life and physical health.[29] Given self-efficacy's mediating factor in Social Action Theory and based on literature findings as discussed above, it can be a potential area to target to increase self-management of HIV for adolescents and youth.

This study has strengths and limitations. We analyzed data from a large cohort of adolescents using expanded enrollment criteria to include a representative sample of ALHIV under the age of majority. Some limitations should be acknowledged to contextualize the reported findings. This analysis was cross-sectional, thus temporal changes in variables were not assessed. Participants of our study were adolescents and youth in western Kenya and may not be generalizable to the broader population. Further, participants filled out a lengthy survey that consisted of multiple measures and could have been impacted by social desirability and recall biases. ALHIV were also not required to fill all of the survey questions; thus, we did have a large number of ALHIV with missing data. Those with missing data may have different experiences or opinions. There may have been possible confounding variables that we did measure which has the potential to impact the findings.

Conclusion

Emotional well-being and social support are essential to improve adherence self-efficacy and viral suppression among ALHIV. To meet viral suppression goals in ALHIV, interventions targeting perceived stigma reduction and increasing self-efficacy, which empower and enable adolescents and youths to take their HIV medication in any space they desire, are imperative.

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Chapter 5

Conclusion

Achieving viral suppression goals for adolescents and young adults living with HIV (ALHIV) requires individual adherence to antiretrovirals and efficient and effective health systems to routinely monitor viral load and coach ALHIV when adherence falters. At the health system level, this dissertation assessed whether viral load information was available at the facility-based electronic medical record system and the factors that impacted the return of viral load information to clinics from the lab processing center and, ultimately, to ALHIV clients. Additionally, at the provider level, we aimed to understand how healthcare providers determine when a good adherence is reached prior to repeating confirmatory testing for treatment failure for ALHIV with non-suppressed viral load who are enrolled in enhanced adherence counseling. At the individual level, we explored if ALHIV are aware of their viral load results, measured their adherence self-efficacy to ART regimen, and evaluated the relationship between ART adherence self-efficacy, depression, perceived social support, and HIV viral suppression.

Chapter 2 of this dissertation was a cross-sectional study that explored the availability of viral load at the facility-based EMR and if ALHIV were aware of their viral load results and treatment plan in six HIV care facilities in Kiambu and Nakuru Counties, Kenya. Our findings showed that out of 207 charts that were randomly audited for viral load at the facilities, a large majority (86%, n=179) matched with the national database records. However, we did find that ≥ 10% of results were missing or were incongruent between the national database and facility EMR, which suggests a need to streamline processes to ensure correct and timely entry for clinical management. Further, our exit surveys with ALHIV revealed that only slightly more than half (52% of the n=132) reported receiving their last viral load result. Older ALHIV (18-19 years) were more likely to receive their test results than younger ALHIV (15-17 years) (65% vs. 44% respectively) even though ALHIV 15 years and older are attending the clinic by themselves (without their caregivers).[1] This finding highlights that viral load literacy, the ability to understand the meaning of viral load and its broader implications,[2] is critical for this age group so ALHIV can be empowered to request their test results and take charge of their HIV care.

Chapter 3 was a cross-sectional study consisting of four focus group discussions with 29 healthcare providers across various phases of the viral load information flow and ten in-depth interviews with healthcare providers who were in the direct care of providing ART, repeating viral load testing, or involved in enhanced counseling. Thematic analysis yielded nine themes in different phases of the viral load information flow and enhanced adherence counseling sessions. A few themes that interfered with viral load flow ranged from individual and family-level challenges to facility-level challenges in obtaining viral load samples, supply chain constraints affecting laboratory-related processing delays, client-specific factors impacting dissemination of viral load results to ALHIV, and healthcare providers' reluctance to repeat viral load until adherence challenges are resolved. The identified themes highlighted individual, social, and health systems factors that were perceived as contributing to success or delay in the ability to obtain timely viral results and repeat confirmatory viral load testing for treatment failure for ALHIV with non-suppressed viral loads.

Finally, Chapter 4 of this dissertation encompassed examining enrollment data from a longitudinal cohort of Kenyan ALHIV enrolled in the Data-informed Stepped Care. Among 1,033 ALHIV with complete responses, we assessed the correlates of HIV adherence self-efficacy to ART and viral suppression. We noted that a single item on the HIV-adherence self-efficacy scale was driving the self-perception adherence self-efficacy, which was incorporating treatment into a daily routine, even if it meant taking medication in front of others who were unaware of their HIV status. Adherence self-efficacy scores were higher in ALHIV 20-24 years than in 15-19-year-olds and 10–14-year-olds. Depression symptoms affected self-efficacy scores, as ALHIV with no or mild depressive symptoms had higher adherence self-efficacy scores than those with moderate-to-severe depressive symptoms. ALHIV with high perceived social support scores had higher odds of suppressed viral loads than those with low social support, and although not statistically significant, ALHIV with high adherence self-efficacy scores more frequently had suppressed viral loads compared to those with low levels of adherence self-efficacy scores. These findings

suggest that emotional well-being and social support are essential to improve adherence, self-efficacy, and viral suppression among ALHIV.

Implications for future research

We found in our study that for ALHIV who are in boarding schools, viral load results notification, discussion, adherence counseling, and repeat confirmatory viral load testing process are slower than expected; thus, future research could assess different stakeholders' perspectives about delivering care while ALHIV are in school through web and mobile-based technologies. Further, while our research did assess if ALHIV knew their last viral load results and subsequent treatment plan, we did not capture what viral load results mean. In other sub-Saharan countries, studies have reported limited comprehension of what undetectable viral load means, and in Kenya, gaps in HIV knowledge, including routes of transmission, impact, and risk of infection with other STIs, navigating a romantic relationship with HIV-negative persons have been documented.[2,3] Thus, future research around the comprehension of viral loads among ALHIV in Kenya may provide a greater in-depth understanding of VL literacy to develop targeted interventions.

Implication for clinical practice

This dissertation study has several implications for clinical practice. There is a need to streamline viral load return processes to ensure correct and timely entry for clinical management, including a system that directly feeds viral loads into the electronic medical record system in clinical facilities. Education around viral loads and what undetectable viral loads could mean for ALHIV in terms of not just well-being but also navigating future relationships could help improve viral load testing practices and self-management of HIV. Delivering HIV care outside of the traditional facility setting could improve delays around results notification, adherence counseling, and repeat confirmatory viral load testing for treatment failure for ALHIV who are in boarding

school. The combination of objective measures in addition to subjective measures for determining good adherence could have higher diagnostic accuracy. Lastly, a multifaceted approach, including education, advocacy, and community engagement, to reduce the stigma associated with taking ART is imperative in enabling ALHIV to take their medication outside of their homes.

Conclusion

Taken together, this dissertation provides a new understanding of the current state of HIV viral load return and action processes, along with baseline ALHIV knowledge of viral loads and self-efficacy skills. Further, it provides insights into where and how health systems in Kenya better act on HIV VL results and key considerations to take into account when developing interventions targeted at an individual (ALHIV) level to enhance self-management skills to increase ART adherence and achieve viral suppression goals.

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Appendix A: FGD Guide

ROAR- Return of HIV viral load results to adolescents and young adults living with HIV in Kenya

Health care worker
Focus Group Discussion Guide
Information Gathering

Interviewer Instructions: Copies of the informed consent form should be provided to the participant and read aloud for the benefit of those who cannot read. Participants should be provided an opportunity to ask any questions. Verbal agreement to participate should be taped.

The following set of questions is a guide. Try to ask all the questions below in the order given, but it is more important to maintain the flow of discussion.

Welcome and Introductions

Before turning on the recorder, start with the following introductory script:

Hi, my name is _____. Thank you for agreeing to talk to me today. As mentioned earlier, I am a researcher and I am trying to learn more about how viral load results are relayed to adolescents where you work. Your answers will be used to improve viral load dissemination at this clinic and other clinics in Kenya.

How many of you have participated in a focus group discussion before? [show of hands]

Before we get started today, here are a few important things to know:

- We are here to learn from you. There are no right or wrong answers to anything we will be asking. We are interested in your opinions; we are not testing your knowledge in any way.
- If there is any question you would rather not answer, for any reason, please just say "Pass," and we will move on to the next question. You can stop participating at any time.
- Also, the purpose of our discussion today is not for everyone to agree. We are interested in hearing all of your opinions, even if you are unsure about something or if you disagree with something someone said. If you have a different idea from what others have said, please feel free to share your point of view.
- Please stop me from moving on to a new subject if you still have something you would like to say, and feel free to come back to a topic if you think of additional thoughts as we go on.
- We also ask that everyone please keep confidential what others share in this discussion. We, as researchers on the study, will also keep your information confidential.
- The research team may take short sections of what you say and share them with non-study members. The research team will keep your identity confidential.
- To make sure we have heard what you say correctly, I will be using this audio recorder. This will also make it easier for me to listen to what you have to say in today's discussion. When we start the

discussion, we will turn on a recorder and record the rest of the discussion. This recording will be transformed into a written document but the transcript will not have your names on it.

- Each of you have been assigned to a study number. This will help us keep information about who you are private from others. If you want to respond to something someone else in the group said, please refer to them by their study number.

[Logistics: please turn off cell phones; location of restrooms; food and beverages, etc.]

We'll talk for about one and a half hours.

Does anyone have any questions before we get started?

Is it okay if I tape our discussion? [Wait for the participants to give verbal consent to taping]

I am turning on the recorder now.

Before beginning interview questions, please read the following script for the recording:

Today is [day of week], [month, day, year] and it is now [time of day]. This is focus group [facility name} conducted at [discussion location]. We have [number of participants] in our discussion today.

You are now ready to begin asking the questions outlined below.

Semi-Structured FGD Questions

The following questions will ask you about the processes by which you obtain viral loads results and provide them to adolescent clients.

ROAR FGD GUIDE FOR HEALTH WORKERS

1. How frequently is viral load laboratory testing done at your facility?
    a. Is this different for adolescents vs. other age groups?

2. What is the average turnaround time of the viral load?
    a. Are the tests sent to an outside laboratory?
    b. How long before results are seen in the database?
    c. Are results transmitted and recorded in the adolescent EMR file? On paper?
    d. On average, how long is it from blood draw to the clinic receiving the result?
    e. How long between blood draw and the adolescent receiving the results?

3. What are some reasons it might take longer (or shorter) to receive results?
    a. What facilitates prompt viral load results dissemination to adolescents?
    b. What makes it harder?
    c. Do you manage suppressed vs. unsuppressed results differently? If so, how?

4. What other factors do you think affect viral load return to both the facility and the adolescents?
   - Facility factors
   - Socio-economic factors
   - Family factors
   - Implementing partner's factors
   - Education factors
   - Social factors

5. Are there actions or programs in place to ensure prompt relaying of viral load to the adolescents?
   - Actions by the facility
   - Actions by the county health government
   - Actions by the implementing partners.
   - Actions by NASCOP (National Aids and STI control Program)

6. Are there ways that return of viral load information to adolescents could be improved? How?

7. When an adolescent comes for a clinic visit, how do you determine if there is a viral load result available for them?

8. How well do you think you've been prepared to explain viral load results to your adolescents?
   a. What is the most difficult part of this?

9. Does your facility have guidelines and policies on how to relay viral loads results to the adolescents?

10. Are there challenges to getting viral load testing done? Has it affected your practice on how you manage HIV?

11. If there have been difficulties obtaining viral load testing, how are you managing those who are suspected to have treatment failure given no VL results?

Anything else you a want to talk about regarding viral load and dissemination of results to adolescent clients

Appendix B: IDI Guide

ROAR STUDY- Return of HIV viral load results to adolescents and young adults living with HIV in Kenya

Key informants IDI guides
Interview Guide

Interviewer Instructions: The following set of questions is a guide. Try to ask all the questions below in the order given, but it is more important to maintain the flow of discussion. Suggested probes have been included.

Welcome and Introductions

Before turning on the recorder, start with the following introductory script:

Hi, my name is _____. Thank you for agreeing to talk to me today. As mentioned earlier, I am a researcher and I am trying to learn more about how viral load results are relayed to adolescents in HIV care. We also want to learn how providers assess adherence to ART and manage adolescents who are not virally suppressed.

During this conversation, I am interested in understanding all of your thoughts, experiences, and opinions. I will ask you questions that you are free to answer in any way you wish. Your opinion is very important to us. You do not have to answer all the questions. If you want to stop the interview at any time, just tell me and we can stop.

There is no right or wrong answer to anything that I ask. If a question is unclear to you, please feel free to ask me to explain it.

The research team may take short sections of what you say and share them with non-study members. I would like to record the interview so I don't miss anything that you say. I will not include your name on any documents or in the recording. Your identity will be kept confidential.

Is it okay if I record our discussion? [Wait for the participant to give verbal consent to recording]

Thank you. We are now ready to begin our longer discussion.
I am turning on the recorder now.

Before beginning interview questions, please read the following script for the recording:

Today is [day of week], [month, day, year] and it is now [time of day]. I am speaking with participant [participant ID].
Can you confirm for me again, by stating yes or no, that you are willing to participate in the conversation today?

You are now ready to begin asking the questions on the following page

Semi-Structured Interview Questions

The following questions will ask you about your experiences caring for adolescents living with HIV.

ROAR IDI guide for key informants

1. How frequently do you do viral load testing for adolescent clients?
    a) Does this vary based on health status?
    b) In which situations would you test more or less frequently?

2. How does your clinic receive viral load results?
    a) How is this information provided to adolescent clients?
    b) Are there any challenges in getting results back to clients?
    c) What systems are in place (or should be in place) to make returning results easier?

3. If an adolescent is not virally suppressed, what action do you take?
    a) How frequently do they return to clinic?
    b) Do you involve their parents? Why or why not?
    c) Are there extra services? What are these?

4. How do you conduct enhanced adherence counseling?
    a) How many sessions? What situations might require more or less?
    b) How do you determine if an adolescent has good adherence?
    c) How long do you continue counseling before you recheck a viral load?

5. What are some of the common reasons adolescents have adherence challenges?

6. The national guidelines recommend repeat VL testing in 3 months - what do you do if adherence is not optimized in 3 months?

7. How do you track adherence sessions?

8. What else *you would like to add?*

Do you have any questions for me before we end our conversation today?

Thank you for taking the time to talk to us!