

**"I could miss lessons," Facilitators and Barriers to ART and Clinic Adherence in School Going Kenyan Adolescents**

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**Abstract**

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Adolescents living with HIV (ALHIV) face unique barriers to adherence to antiretroviral therapy and clinical care that require unique health interventions. Adolescents spend the majority of their time in school, making it critical to understand the barriers to optimal health for ALHIV within the school environment. We conducted in-depth interviews and focus group discussions with adolescents, caregivers, and healthcare workers from 9 different facilities in Kenya. Analysis focused on identifying the barriers and facilitators to antiretroviral therapy and clinic adherence while attending school, using Anderson's Model of Health Services Utilization to organize them into contextual and individual categories that either led to adherence or non-adherence. In the school context, the largest barrier adolescents faced in treatment adherence was inadvertent disclosure, due to school policies on drug storage and missed lessons, and lack of privacy. In both the school and clinic contexts, scheduling conflicts forced adolescent to choose between school or clinic adherence. Support at the individual level from caregivers was important in managing challenges faced in school and clinic adherence. Support from both the clinic and school also helped adolescents adhere to treatment and clinic visits. School policies around medication storage and inflexible clinic schedules negatively affected ALHIV adherence while in school. Participatory research is needed to engage school staff and collect positive experiences and strategies for developing interventions for schools aimed at reducing stigma and loss to follow-up.

## INTRODUCTION

In 2018, there were an estimated 1.6 million adolescents living with HIV (ALHIV), 190,000 new HIV infections, and 33,000 deaths from AIDS-related causes among adolescents ages 10-19 [1]. The majority of ALHIV (89%) live in sub-Saharan Africa [1]. ALHIV have suboptimal HIV testing, linkage to care and antiretroviral therapy (ART), and lower rates of viral suppression compared to other groups [2,3]. In Kenya, almost 40% of ALHIV are not virally suppressed [4], and the population of ALHIV is continuing to grow through a combination of incident infections among adolescents, as well as perinatally-infected children aging into adolescence [5]. There is an expected lag of two decades before the number of perinatally-infected adolescents decreases, highlighting the need for interventions addressing the challenges adolescents face [6].

Adolescence is a time of transition, including physical, psychosocial, emotional, and cognitive changes as they work towards independence [7]. For ALHIV, these changes are compounded with the challenges of living with a chronic illness. ALHIV can experience poor growth, delayed pubertal development, chronic skin manifestations caused by HIV, and physical changes associated with medication use, all of which may result in low self-esteem, depression, and substance abuse [6,8]. Additionally, ALHIV typically transition from pediatric to adult HIV care and transition from primary to secondary school during this time period. Both of these changes can lead to loss of follow up in adolescents. However, interventions to facilitate continued engagement in care and adherence have not fully addressed these unique challenges [9,10].

Attending secondary school is an important milestone in adolescent development but may pose substantial barriers for adherence to ART and clinic appointments. Fifty-eight percent of adolescents were enrolled in boarding or day secondary schools in Kenya in 2014 [11]. ALHIV may miss school to attend clinic and many experience rigid class schedules that do not facilitate ART adherence. In a systematic review, many studies identified the school environment as challenging for ALHIV [12]. In addition to the challenges to ART adherence posed by attending school, ALHIV face challenges excelling in school due to the effects of attending clinic and adhering to ART. Challenges with adherence and school have been associated with poor mental health outcomes [8]. Interventions tailored for adolescents attending school have been identified as necessary in addressing adolescent challenges to adherence [10,12–14].

Andersen's Model of Health Services Utilization seeks to understand health service utilization based on the interactions of four levels of factors: contextual characteristics, individual characteristics (including predisposing, enabling, and need), health behaviors, and health outcomes [15] and can be used to identify barriers affecting health outcomes. Characterizing how the school environment affects adherence among adolescents can help to identify key areas for intervention development.

## METHODS

This study analyzed data collected from two studies focusing on adolescents in Kenya to elucidate barriers to adherence to ART and clinic attendance associated with school.

The Adolescent Transition To Adult Care for HIV-infected adolescents in Kenya (ATTACH, NCT03574129) study is a clinical trial designed to evaluate, design, and implement an intervention to facilitate transition to adult care for ALHIV in Kenya. Through surveys with 102 large HIV treatment facilities, the study identified 5 large clinics with different availability of transition tools and processes for facilitating transition. Adolescents, their parents or primary caregivers, and health care workers (HCW) were recruited from these 5 clinics to participate focus group discussions (FGDs) and individual interviews (IDIs). This analysis focuses on data from 16 FGDs that were conducted with ALHIV ages 14-24 years. All ALHIV who participated knew their HIV status, and had been on ART at least a year. Adolescents were purposively sampled to fill strata related to whether they had transitioned to adult care or remained within pediatric or adolescent care systems.

The Public Health Adolescent Services Evaluation (PHASE) study is a national evaluation of adolescent HIV services in Kenya. The primary objective of the PHASE study is to assess uptake and acceptability of

a nationally implemented Adolescent Package of Care (APOC) and determine baseline rates and correlates of key adolescent health indicators. In addition to surveys, the study conducted IDIs with adolescents and primary caregivers as well as FGDs with HCWs at four facilities in Western Kenya. Data for this analysis includes 40 IDIs that were conducted with ALHIV ages 14-19 years (10 per facility), 40 IDIs with caregivers of ALHIV ages 10-19 years (10 per facility) and 4 FGDs with HCWs who offer care to ALHIV (1 per facility).

#### *Data collection*

IDIs and FGDs in both studies used pilot-tested, semi-structured question guides that focused on understanding experiences with HIV care and treatment for ALHIV in Kenya. Question guides explored experiences with HIV disclosure, barriers and facilitators to seeking and receiving HIV treatment services, and the role of relationships in caring for ALHIV. FGDs and IDIs were facilitated by trained Kenyan social scientists and conducted in the language(s) preferred by study participants (English, Luo, Kiswahili, or a combination of those languages). FGDs also included a note taker. Because groups were not stratified by gender, when possible, facilitators for ALHIV FGDs included both a male and female facilitator. ATTACH FGDs took approximately 100 minutes, PHASE FGDs took approximately 2 hours, and PHASE IDIs took approximately 60 minutes to complete. All FGDs and IDIs were audio recorded, translated when necessary, and transcribed verbatim.

#### *Ethical approval*

The ATTACH study was approved by the University of Washington Institutional Review Board (IRB) and by the Kenyatta National Hospital/University of Nairobi Ethics and Research Committee (ERC). The PHASE study was approved by the University of Washington IRB and the Kenya Medical Research Institute (KEMRI) ERC. All study participants provided written informed consent if 18 or older. Participants who were 14-17 years of age provided written assent and their parent or guardian provided written consent.

#### *Data Analysis*

Transcripts were analyzed using directed content analysis [16] techniques, based on Andersen's Model. Andersen's Model was used to create broad categories of codes related to contextual and individual characteristics of ALHIV influencing adherence to medication and clinic visits. Inductive methods were used to identify specific factor codes falling within broader contextual and individual categories that are derived directly from the transcripts (Figure 1).

The codebook was tested and refined through an iterative process of reviewing transcripts against the developing codebook and making revisions to ensure all emerging concepts and themes were captured. Once the codebook had been finalized, transcripts were evenly divided between three coders and independently coded using ATLAS.ti. Coders exchanged and reviewed one another's coded transcripts and noted discrepancies in code application and interpretation. Differences in code application and interpretation were reviewed and revised as a group. Queries were generated from coded transcripts to compare coded segments of transcripts and identify divergent and convergent themes. Thematic network analysis was used to group and visualize barriers and facilitators within and between the tiers of Andersen's model [17].

## **RESULTS**

#### *Participant Characteristics*

A total of 88 ALHIV participated in 16 FGDs in the ATTACH study and 40 ALHIV participated in IDIs in the PHASE study. In both studies, the majority of participants were attending school, 43% were in secondary school in ATTACH and 15% in PHASE. The average age of adolescents in ATTACH was 19, compared to 16 in PHASE. For caregivers interviewed in the PHASE study, 82.5% were females and 60% of interviewees were the parent of the adolescent. HCWs that participated in FGDs had a median age of 33, and 72% were female. HCWs had been at their current clinic an average of two years and had experience providing HIV care for an average of four years (Table 1).

ALHIV, caregivers, and HCWs all identified the school environment as a critical barrier to engagement in HIV care and medication adherence for ALHIV. Andersen's Model facilitated characterization of the barriers

and facilitators that ALHIV, caregivers, and HCWs identified into the domains of school context, clinic context, and individual characteristics.

### **School Context**

Participants described how school policies around medication use negatively influenced ART adherence, leading to inadvertent or forced disclosure of HIV status. This was especially true for adolescents attending boarding school, where dorm and locker searches, as well as lack of privacy in dorm rooms, made it challenging to keep medication use private. Often, school policies required that adolescents store medications with school nurses, forcing disclosure of HIV status even if adolescents were not ready or did not feel comfortable disclosing. Adolescents feared that school nurses would not keep their information private and might not be aware of how certain actions could lead to inadvertent disclosure of their status to others.

*"...sometimes the school nurse leaves keys to her drawers with other students then sometimes when you go to take your medication you get it is the prefect. Now you will be afraid to take because now you have to disclose to the prefect that you are looking for your medication." -17 yr. old male*

Adolescents attending boarding schools who felt uncomfortable storing medications with school nurses described the challenges of trying to keep medications with them in their dorm rooms. Dorm and locker searches were described as common practice and made it challenging for adolescents to keep their ART use private. When medications were found during searches, school staff sometimes asked questions about what the drugs were for and why they were hidden in front of others, leading to fear and anxiety about forced disclosure.

*"There is a time she [his friend] had gone to school, and you find that those who go to school there is always the searching at the gate, so a certain teacher found the drugs and lifted them up and begun to ask what the drugs were for, so you find the girl feel guilty, so something like that may also contribute in that even when she gets to the school, maybe she will end up throwing all of them to the toilet" -18 yr. old male*

Adolescents feared inadvertent disclosure through other students noticing the frequency with which they took pills or other students searching their belongings. Many adolescents noted fears of other students finding out about their medication use as a reason that they would discard medication or not take medication while attending school.

*"You want to take the medication, but you find that when others are around, you feel that it is an embarrassment being able to take them in front of them or maybe they can mock you. So, you find that just because of your friends you can delay taking the drugs or even you can leave them at all" -16 yr. old male*

Adolescents even described hiding in bathroom stalls to take medications. A few participants experienced rumors being spread about them throughout the school and noted how this negatively influenced their life.

Determining which school staff to trust and choosing to whom to disclose was an ongoing challenge for ALHIV. Many adolescents feared that if they shared their positive status with staff, the staff would spread rumors or tell other students. Deciding who to tell was often based on necessity, to avoid repercussions if the drugs were found, and the individual's position in the school. The headmaster or matron was identified by many participants as someone commonly disclosed to because of his/her position of authority and ability to avoid problems during dorm searches.

*"Maybe, let's say you have gone somewhere like for camp, or you have joined high school, I had to tell the matron because she is the one coordinating the dormitory. She searches, so if she comes and finds them [ARVs], it will be difficult to explain but if you tell her in advance it will be easier." -16 yr. old female*

Other adolescents chose to disclose to someone they were more comfortable with, or they felt had a role at the school that would make it easier for them to understand their situation and keep their information private.

*“For me in school I have only told my class teacher and I thank God he is a biology teacher he understands that HIV is just a virus ... so, he understands when I tell him that I am going to do and so place so he writes for me” -18 yr. old male*

Confronted with rigid class schedules and long commuting times, adolescents described a lack of control over maintaining their medication schedule consistently.

*“You may find sometimes in boarding school, ... a teacher is in class attending to a lesson until your pill time passes, so it forces you to take your medication late and yet you had chosen your pill time.” -17yr. old female*

Participants also struggled with being forced to take pills on empty stomachs due to school mealtimes. Side effects of some ART medications, including drowsiness, made it challenging to identify the ideal time to take medications, and medication side effects negatively influenced attending classes.

*“I do feel very dizzy when I take this pill. I take my pills at 10pm, [and] it needs that I rest a lot but in school we wake up at around 4am. I still do feel dizzy, thus sometimes [it] makes me to miss going for my dawn classes.” -17 yr. old female*

## **Clinic Context**

Clinic schedules and services that were not organized around school schedules, such as adolescent clinic days scheduled during the week, negatively influenced adolescent adherence to clinic visits. Respondents from one facility mentioned how they had been helped by clinic being moved to a weekend, but this was not always helpful since some adolescents still attended school activities on weekends. Clinic attendance during exam times was reported as being especially challenging, with many adolescents and caregivers having to choose between taking the exams or missing clinic.

*“The common reason why I may miss coming [to clinic] is that sometimes I could be sitting for my exams and I have a clinic appointment and probably at that time I was not aware that we were going to have exams. So, you know I can't miss sitting for my exams because I should be coming for my clinic visit; so sometimes I may postpone coming for my clinic visit with even two days until Saturday” -16 yr. old male*

Support groups hosted by clinics allowed adolescents to meet others who attended the same school. Knowing that they were not the only one struggling at their school was comforting to many. The support groups also gave adolescents the opportunity to discuss challenges and get advice from others who shared their experiences.

*“When you are in school, you are worried about where to keep your drugs, if you take them to the nurse, at the sanatorium, your friends keep asking, ‘you never get well? Every morning you are going to the nurse, I used to go to the nurse but ...’ You know if you meet a friend, they will encourage you, ‘I was in a similar situation and this is what I told them.’ They will give you a shortcut on what to tell them. so, you will learn from her.” -19 yr. old female*

Having clinic staff provide holistic, multi-level support for adolescents improved clinic attendance. HCWs described taking time to contact caregivers when adolescents did not come to clinic and providing adolescents with adherence support to strategize medicine taking and manage drug side-effects to minimize non-adherence.

*“You know when I was introduced to them [ART] they told us that they have some side effects so they encouraged us to be taking them when going to bed. Like when you are in school you should*

*be going on with your lessons. So for not interfering with your lessons because you are [being] affected, you take them after your preps then you sleep.” -17 yr. old female*

Adolescents and HCWs described the need for school staff to be informed about HIV care practices and the need for confidentiality and flexibility for adolescents living with HIV attending school.

*“School principals and the teachers should be empowered on how to handle the HIV positive adolescents in the school so that if at all they happen to have a child like that, they can help in monitoring maybe how the child is coming to the clinic and how the child is taking drugs and such.” -female HCW*

### **Individual characteristics**

At the individual level, adolescents relied heavily on support from caregivers to navigate barriers to adherence. Caregivers played a strong role in supporting both day and boarding students in the challenges they faced in school by disclosing the adolescent’s status to teachers for them.

*“Because I go to school early, I take [my ART medicines] at 6. Then where I school is near our home. On the first day my grandfather talked to the head teacher and asked for my permission to leave school 10-15 minutes earlier even if the teacher is in class.” -14 yr. old female*

Even caregivers who did not disclose for their adolescents from the start, realized that it was in the adolescent’s best interest over time.

*“Yeah it was a challenge so taking it was such a big challenge now it just forced me to go to school and disclose and they told me that they have a lot of girls who are on care, so it was not an issue” -46 yr. old female caregiver*

Personal relationships and the emotional support adolescents got from caregivers were important in adolescents gaining confidence in accepting and managing their HIV.

*“The last topic that I remember us talking about is that I should now learn to take care of myself. So from that talk I got encouraged and I started having that positive... attitude. So when I went back to school I said to myself that there was nothing to worry about it was all about my life and I have to live it as it is.” -19 yr. old female*

### **Discussion**

As Andersen’s Model hypothesizes, different categories of barriers to health service utilization influenced health outcomes individually but also interacted and influenced one another. In this study, interactions between individual characteristics and clinic and school contexts either facilitated or hindered adherence. Caregivers demonstrated support in disclosing the adolescent’s status to school staff and making arrangements that helped adolescents to adhere to both medications and clinic visits. HCWs communicated with caregivers when an adolescent missed a clinic appointment. Adolescents gained advice about how to take medication to avoid disclosure or side-effects from HCWs, and received encouragement around status acceptance from caregivers. However, clashes in scheduling between school and clinic schedules forced adolescents into choosing between clinic attendance and exams. Lack of disclosure due to fear of stigma prevented adherence, while policies on medication storage led to inadvertent or forced disclosure.

Our results showed that adolescents and their caregivers experience disclosure as a double-edged sword. On the one hand, disclosure to school staff was recognized as key to garnering necessary support for medication and treatment adherence. On the other hand, disclosure to the “wrong” staff member could lead to stigmatizing reactions, including discrimination and judgement from friends and peers. While our data

demonstrated that caregivers played a large part in disclosing for their adolescents, a systematic review focusing on quality of life for ALHIV did not note this theme in any of the included studies[12].

While studies have not used Andersen's Model to examine school and clinic contexts concurrently, they have identified characteristics which affect adolescent adherence in school. The school context has been shown to affect adolescent loss to follow-up, quality of life, and adherence through lack of privacy in boarding schools leading to inadvertent disclosure, stigma and discrimination in schools leading to loss to follow-up, and side effects from medications such as dizziness and nausea leading to missed classes and non-adherence [8,10,12–14]. Inaccurate HIV knowledge among teachers and lack of appropriate training to prepare them to educate adolescents about HIV has contributed to stigma within schools, and even policies intended to help ALHIV in boarding schools, such as school staff holding medications or a student's status being shared with teachers who are expected to provide support, can have negative effects [12,13,18].

Class schedules can be a barrier to clinic attendance, particularly for adolescents in boarding schools due to strict absenteeism rules and distance to clinics [10,12,13]. Only one study has noted interaction in between contexts and similar to our study, it found that school and clinic schedules clashed causing nonadherence [13]. Studies have explored the community or household context, but have not compared barriers between these contexts and school [10,12,13]. Students attending boarding school struggle more than those living at home to adhere to ART, due to the absence of the same social support they receive when home [14]. HCWs helping to facilitate connections between adolescents attending similar schools during support group meetings, as noted by ALHIV participants, might help improve feelings of peer support within boarding school settings.

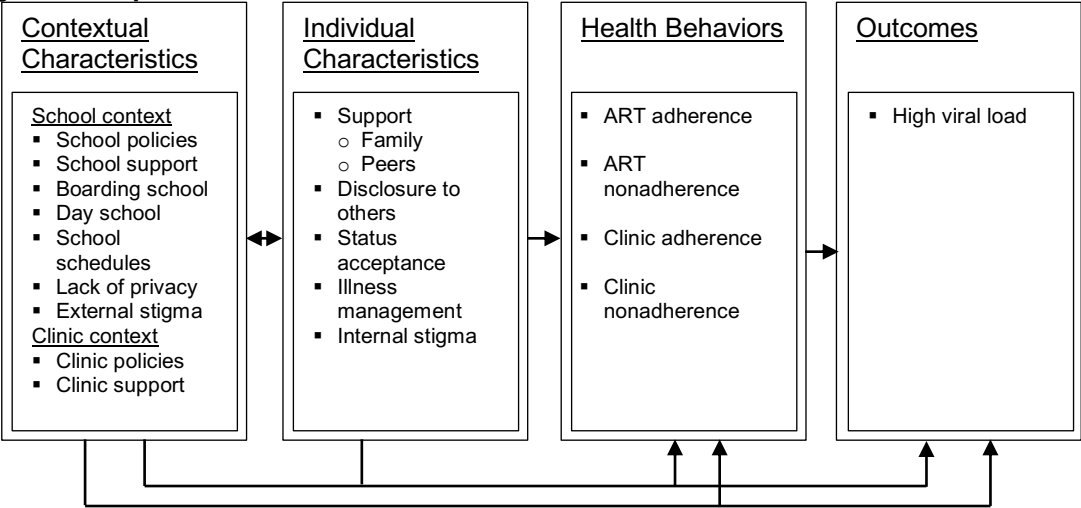
### **Limitations**

The two studies included in this analysis do not show a complete picture of barriers for adolescents in schools. Due to the recruitment process, all of the adolescents in these two studies had the support of a caregiver excluding the perspectives of adolescents who have not disclosed to their caregivers and adolescents who have not been disclosed to. While neither study explicitly focused on the impact of the school environment on adolescent adherence in their question guides, adolescents, caregivers, and HCWs all brought up school themselves, demonstrating the strong impact of school on adolescent adherence.

### **Conclusion**

School and clinic environments, along with interpersonal interactions between ALHIV and their caregivers, strongly impact an adolescent's ability to adhere to both medication and clinic visits while they are attending school. This demonstrates the need to involve schools in developing interventions aimed at ALHIV adherence. The negative experiences described on this study illustrate the barriers in schools that need to be addressed, such as stigma and the lack of control ALHIV have during their time in school. The positive experiences that some ALHIV describe of gaining the necessary support in schools provides an opportunity to replicate these positive factors in the future through training school and clinic staff. With an understanding of barriers faced by ALHIV a next step would be engaging with school staff to gain another necessary perspective. Through participatory research an understanding of the challenges and solutions school staff may have in supporting ALHIV would be gained and serve as a starting point for developing interventions for ALHIV attending school.

**Figure 1 Adopted Andersen's Model**



**Table 1: Sociodemographic characteristics of FGD and IDI participants**

Characteristic	Population			
	ATTACH Adolescents N=88	PHASE Adolescents N=40	Caregivers N=40	HCWs N=39
	Median (IQR) or n (%)			
Female	52 (59.0)	27 (67.5)	33 (82.5)	29 (74.4)
Age (years)	19 (16-22)	16 (15-17)	45.5 (37-53.5)	33 (28-42)
Education*				
Primary	16 (18.1)	20 (50.0)	20 (50.0)	2 (5.1)
Secondary	43 (48.8)	15 (37.5)	13 (32.5)	8 (20.5)
College/polytechnic	7 (7.9)	1 (2.5)	4 (10.0)	29 (74.4)
Not currently enrolled	21 (23.8)	4 (10.0)	–	–
None	1 (1.1)	–	3 (7.5)	–
Attends boarding school	18 (20.4)	–	–	–
Relationship status				
Single	74 (84.0)	25 (62.5)	–	–
Steady boyfriend/girlfriend	3 (3.4)	14 (35.0)	–	–
Married	11 (12.5)	1 (2.5)	–	–
Employed	5 (5.6)	–	16 (40.0)	–
Relationship to adolescent				
Parent	–	–	24 (60.0)	–
Aunt/Uncle	–	–	4 (10.0)	–
Sibling	–	–	3 (7.5)	–
Grandparent	–	–	5 (12.5)	–
Other relative	–	–	4 (10.0)	–
HCW Cadre				
Nurse	–	–	–	7 (17.9)
Counselor	–	–	–	15 (38.5)
Clinical Officer	–	–	–	6 (15.4)
Lab Technician	–	–	–	4 (10.3)
Other***	–	–	–	7 (17.9)
Years employed at current clinic	–	–	–	2 (2-5)
Years providing HIV care	–	–	–	4 (2-9)
Years working with adolescents	–	–	–	3 (1-6)

\*Education: For adolescents, current class; for caregivers and HCWs, highest education completed.

\*\*Some caregivers and ALHIV participants were dyads (n=16).

\*\*\*HCWs also included cough monitor (1), data clerk (1), nutritionist (1), peer educator (1), pharmacy technician (2), and triage officer (1).

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