



The Open AIDS Journal

Content list available at: <https://openaidsjournal.com>



RESEARCH ARTICLE

School-level Barriers of Antiretroviral Therapy Adherence and Interventions to Overcome them Among Adolescents Living with HIV in Western Kenya: A Qualitative Study

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Abstract:

Background:

Adolescents in Kenya spend the majority of their time in a school environment. However, research to understand Antiretroviral Therapy (ART) adherence among adolescents living with HIV (ALWHIV) in school settings is sparse.

Objective:

To improve the design of appropriate interventions to better support this vulnerable population, the study aimed to explore school-related barriers to ART adherence experienced by ALWHIV.

Methods:

Qualitative data were utilized from a larger mixed-methods study on ALWHIV conducted at a major teaching and referral hospital in Kisumu, Kenya. Participants encompassed ALWHIV, their caregivers, teachers, and health care providers. Transcripts from a total of 24 in-depth interviews and five focus group discussions were analyzed in NVivo using a thematic approach.

Results:

Four themes emerged as key barriers in a school setting: negative experiences following HIV status self-disclosure, a strong desire for secrecy, restrictive school policies, and health education focused on sexual transmission of HIV. Participants suggested a range of potential interventions to better support ART adherence for ALWHIV, including coaching ALWHIV on disclosure strategies, promoting empathy among teachers and students, transition-preparing for ALWHIV, changing the narrative about HIV transmission in schools, providing water in schools, and introducing adherence support programs in schools, including the use of mobile technology.

Conclusion:

ALWHIV in Kenya experience numerous important challenges while trying to maintain optimal ART adherence in the school environment. Interventions that create supportive school settings are critical for better health outcomes among ALWHIV.

Keywords: Adolescents, Barriers, Adherence, Antiretroviral therapy, Schools, Interventions.

Article History

Received: July 26, 2021

Revised: September 02, 2021

Accepted: October 12, 2021

1. INTRODUCTION

Although significant advances have been achieved in HIV prevention, treatment, and care, progress for adolescents living

with HIV (ALWHIV) is far from optimal [1]. Young people represent an increasing proportion of the population living with HIV globally. In 2019, 460,000 individuals between the ages of 10 to 24 were newly infected with HIV, 37% of whom were between the ages of 10 and 19 [2]. Of the 2.1 million ALWHIV worldwide, 1.5 million reside in East and Southern Africa, 83% of whom are adolescent girls [3]. In 2017, Kenya was among the four countries with the highest number of ALWHIV after

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South Africa, Mozambique, and Nigeria [4]. Similar to other parts of the world, the incidence of HIV in Kenya is declining in all age groups except in people 15-24 years of age. Approximately 110,000 adolescents aged 10-19 years are living with HIV in Kenya [5] and according to the Kenyan Ministry of Health 2018 AIDS Response Progress Report, one-third of all new HIV infections were young women aged 15-24 years [6, 7]. Different factors contribute to these gender disparities, including barriers to accessing sexual and reproductive health and HIV services, early sexual experiences that may be nonconsensual, age-disparate sex, unequal power dynamics, gender inequality, and poverty [7, 8].

Globally, ALWHIV have comparatively poor antiretroviral therapy (ART) outcomes [9, 10]. ART adherence and retention in care among adolescents decline with increasing age [10, 11], leading to high mortality [11 - 13]. Optimal ART adherence refers to a series of behaviors, including taking prescribed medication daily and following strict dosage instructions, timing intervals, and dietary guidelines [9, 14 - 16].

ALWHIV face individual, social, and structural challenges that create substantial barriers to retention in care and adherence to ART [9, 17, 18]. The unique developmental transitions that occur during adolescence can pose both challenges and opportunities for adherence. Studies that have investigated the progression of ALWHIV through the HIV care pathway have generally found their outcomes to be poor and worse than for adults or young children. Once ART has been initiated, retention in care [19] and adherence to treatment are also poor, with a recent systematic review showing that an average of only 62% of 12 to 24-year olds achieved 95% or greater adherence [20]. Despite having worse HIV care outcomes than other age groups, the current evidence on how to support adolescents' linkage, retention, and adherence to ART is limited [21].

Risk factors for adolescent non-adherence include poverty, high-risk sexual behaviors, substance abuse, social exclusion, disorganized families, lack of social support, mental health problems, stigma, delays in disclosure, unfriendly clinics, and unsupportive school environments [22 - 26]. Other barriers to adherence include self-esteem, body image, peer pressure, the severity of illness and difficult medication routine, lack of knowledge and accurate information about ART medications, and forgetfulness [27 - 34].

Although Kenya has made investments in the HIV response to reduce HIV prevalence by 50%, HIV-related morbidity remains the leading cause of death among adolescents. A study reviewing 10,096 ALWHIV on ART for more than six months found that only 27% had achieved viral suppression (HIV viral load <1000 copies/ml) [35]. Another study found that those who were 15 to 29-year old were much less likely to adhere to ART compared to those who were 30 to 64-year old [36]. Moreover, one study conducted at 109 clinics across Kenya revealed that older ALWHIV (aged 15-19 years) were more likely to be lost to follow-up than their younger peers (10-14 years) [37].

School-going adolescents in Kenya spend the majority of their time in a school environment. Studies have reported on

HIV prevention interventions in school settings [38 - 40]. Other studies have investigated discontinuation of care or low adherence among adolescents, and some of these in the school setting [41, 42]. For example, a study in Kisumu, Kenya, focused on retention in care, and findings suggested that stigma was the leading factor in the loss to follow-up in ALWHIV care [41]. Another study conducted in Muranga, in central Kenya, found that students in a day school had a 90% lower risk of being non-adherent to ART compared to students in boarding schools [42]. However, research on ART adherence interventions in the school setting is still lacking. It is critical that the design of adherence-support interventions reflects an understanding of the barriers to ART adherence that ALWHIV face while they are at school.

To improve such understanding, we performed an in-depth analysis of school-related issues among ALWHIV using data collected for a larger study conducted by our team. The parent study employed mixed methods to study ALWHIV and ART adherence in Western Kenya. The study encompassed 1) a quantitative assessment of ART adherence among ALWHIV in Kenya using electronic drug monitors (EDM), a method that research team members had used successfully in other contexts to study adherence among post-natal women and ALWHIV [43 - 45] and 2) a subsequent qualitative exploration of the perspectives of ALWHIV and a range of key informants regarding ART adherence challenges experienced by adolescents, the facilitators that help them overcome challenges, and views of potential interventions. We applied a socio-ecological approach, one that recognizes individual, interpersonal, community, and structural barriers and facilitators, to acknowledge the intertwining relationship between individuals and their environment in our data collection and analysis. Such approaches have been used in other studies to explore barriers to HIV care [46] and predict HIV treatment adherence among youth [47].

The parent study found that adherence barriers experienced in school environments were among the most intransigent challenges experienced by ALWHIV in Kenya. This motivated the present sub-study, which was an in-depth qualitative exploration of school-based ART adherence issues and potential solutions among ALWHIV. This topic has been explored in Uganda [48], but, to our knowledge, this is the first study to center on ALWHIV and their adherence challenges within the school environment in Kenya.

2. METHODS

2.1. Study Setting

The study was conducted at the Comprehensive Care Center (CCC) at Jaramogi Oginga Odinga Teaching and Referral Hospital (JOTRH) in Kisumu, the third-largest city in Kenya after Mombasa (second largest) and Nairobi (Capital city). JOTRH is a referral and teaching hospital serving more than five million people in 10 counties of the Western Kenya Region. The hospital provides specialized clinical services, research activities as well as curative, preventive, promotive, and rehabilitative health services [49].

2.2. Study Participants and the Parent Study

Participants in the present study were those who participated in the qualitative component of the parent study, including ALWHIV and several groups of key informants: the caregivers of ALWHIV participants, teachers, and health providers who provide care and treatment for ALWHIV. The participants in the parent study included adolescents who were 15-19 years of age, HIV-infected, received ART at the comprehensive care center, and provided consent or assent (depending on age). For those less than 18 years of age, their guardian/caregivers signed written informed consent. They also agreed to use eCAP for three months to monitor adherence. They were selected using a convenience approach among ALWHIV who were present at the CCC on days when data collection occurred.

Caregivers were parents/guardians of an ALWHIV on ART at the study clinic aged 15-19 years; they provided consent for their child who was less than 18 years of age, knew the HIV status of their child, and gave their consent for their own participation in the study. ALWHIV were requested to inform their caregivers/guardians about the study. Those who agreed to participate were contacted via phone by the study supervisor, and an interview appointment was made. Health care provider participants included physicians, nurses, pharmacists, social workers, and counselors at the study clinic, cared for adolescent patients between 15-19 years and provided informed consent. They were identified to participate in the study if they were on duty on the days of data collection at the CCC. Teachers all worked in schools around Kisumu City, interacted with HIV-positive adolescents on ART, willing to provide consent to participate in the study, and collaborated with the CCC in the care of ALWHIV at their schools. They were recruited on a convenience basis. The research supervisor first identified teachers known to the HIV clinical staff and then relied on snowball sampling to expand the number of participants until the planned sample size was reached.

Prior to data collection, experienced research assistants were trained by the principal investigator (MAO) for three days. Training activities included detailed discussions about research objectives, use of the data collection instruments, protection of human subjects, and research ethics. The research assistants practiced implementing both quantitative and qualitative data collection activities using role-play techniques.

Data collection for the parent study occurred from August-November 2018 in two steps. First, the 33 enrolled ALWHIV participated in ART adherence monitoring using EDM for a period of three months. Specifically, participants used eCap pill bottles made by Information Mediation Corp [50], which collected data on the timing of openings as a proxy for adherence. Participants used the bottle for one of their medications, returning to the clinic monthly for refills and data scanning. The data were formatted to provide reports with a calendar view of the time and date of all doses taken in the prior month. Following adherence monitoring, the adherence status of each ALWHIV participant was assessed, using a threshold of $\geq 95\%$ to define "optimal adherence." Adherence was defined as taking ART as prescribed, every day and on time, defined by a two-hour window around the prescribed

dose time. Qualitative data collection, which provided data for the present study, took place after adherence assessments were completed.

2.3. Qualitative Component of the Parent Study

Data sources for the parent study encompassed both in-depth interviews (IDIs) and focus group discussions (FGDs). IDIs with ALWHIV participants, as well as with each group of KIs (caregivers, teachers, and health care providers), were designed to foster in-depth probing of the personal experiences of the main study population. Five KI interviews were conducted with members of each KI group (15 total). To supplement the more personal and in-depth data of the IDIs, a total of five FGDs were conducted to gain additional insights from group engagement into collective experiences and opinions, particularly related to potential interventions for ALWHIV. Two FGDs (one with males and one with females) were conducted with a sub-group of ALWHIV. From the IDIs, a group of eight to ten adolescents was conveniently selected to participate in the FGDs. One FGD was also conducted with each group of KIs, with eight to ten individuals participating in each FGD. Each FGD included KI participants who agreed to take part, along with an additional three to five individuals, as explained above.

2.4. In-Depth Interviews (IDIs)

A total of 24 IDIs were completed with ALWHIV. The nine who did not take part had either moved from a previous location, were busy, or simply declined to participate in the qualitative study. Semi-structured interview guides in English were used to conduct the IDIs. As Kenya is a multi-lingual country, the research assistants spoke English, Kiswahili, and a local language. Each interview took place using the language preferred by the participant. Where needed, research assistants conducted simultaneous translation. The IDIs explored the in-depth perceptions and experiences of participants regarding the barriers to and facilitators of ART adherence at the individual, interpersonal, community, and societal/policy levels. Questions also probed possible ways to overcome adherence challenges for adolescents. Typical questions included: "thinking about you, not anybody else or circumstances, what things about you as a person may have prevented you from taking your medication in the past and on time?", "think about people whom you relate with, in what ways do their actions, reactions, comments, attitudes may have prevented you from taking your HIV medicines in the past or now," and "think about the environment, the community that you interact with, your culture, the school environment, in what ways do they prevent you from taking your HIV medicines?" The face-to-face qualitative interviews were audiotaped and took place for a duration of 31 to 91 minutes. Field notes were made during IDIs. All interviews were conducted at a private space provided by the hospital leadership.

2.5. Focus Group Discussions (FGDs)

The FGDs were conducted following the completion of the IDIs. Two research assistants led each FGD, with one posing questions and the other taking notes. As with the IDIs, the study guide was semi-structured. Names of participants were

avoided to the degree possible during each FGD to protect the privacy of participants. The focus of each discussion was on generating a frank exchange among participants of viewpoints on adherence barriers and facilitators from the IDIs, and their opinions on potential interventions for ALWHIV. Simultaneous translation was used when needed to ensure that all participants were able to engage fully in the conversation. Each FGD was audio-recorded and took 60-90 minutes to complete. Field notes were made during FGDs. All FGDs were conducted at a private space provided by the hospital leadership.

2.6. Data Management and Initial Analysis

All audio-recorded IDIs and FGDs were transcribed locally, and those that were in the local language were translated into English by bilingual research assistants. Transcripts were then shared via a secure system with the team based in Boston. Two researchers read the typed interview transcripts separately for accuracy and completeness. They developed the initial codes individually and then compared the codes to reach a consensus, with input and reflections from two other research assistants. Transcripts were imported into NVivo 12 qualitative data analysis software for in-depth coding and analysis by the Boston-based team. The analysis utilized a thematic approach and sought to identify emerging patterns related to barriers and facilitators to ART adherence among ALWHIV. The analysis from the parent study identified a number of key themes on barriers to ART adherence, including school environment, medicine and medicine containers, stigma, and religion. The present study focused on findings related to the school environment.

2.7. Supplemental Analysis for the Present Study

The analysis of the sub-study made use of the rich set of IDI and FGD transcripts created for the parent study. Utilizing NVivo, the Boston-based team collaborated with the local researchers to pursue an in-depth exploration of key themes related to the school environment for ALWHIV. We started with the original theme of the school environment as unsupportive, which was identified in the main analysis, and then created sub-themes for further investigation and analysis. Additional sub-themes were developed as the analysis continued. For instance, one theme that emerged from the data on adherence barriers was related to restrictive school policies and structures. As we explored more deeply, we found a number of more focused sub-themes, including policies related to medicine storage, movement of students within schools, and lack of private spaces. We pursued the same approach with regard to the data related to potential interventions. We also identified illustrative direct statements by participants.

3. RESULTS

The background characteristics of the 24 ALWHIV study participants are shown in Table 1. The age range was 15-19 years, with the highest number at 17 years of age (seven, 29%). Fourteen (58%) were male, and 10 (42%) were female. Half (12, 50%) were attending high school at the time of the interview; nearly the same number (10, 42%) were in middle school. Nearly half (11, 46%) had a mother as the primary caregiver. Other caregivers included father, mother and father,

aunt, grandmother, and grandfather. At the time of the IDI, 13 (54%) stated that they had known about their HIV status for 10-14 years. Half were on one dose regimens; average adherence among all ALWHIV was 62.75% (range: 2.44%-95.35%). Only one had achieved $\geq 95\%$ adherence over the three-month monitoring period. Six had achieved adherence levels above 80% (mean: 88.88%), while 18 had below 80% (mean: 54.04%).

Table 1. Demographic information.

Characteristics	N =24	Percent
Age		
15	3	13%
16	6	25%
17	7	29%
18	2	8%
19	4	17%
Not available	2	8%
TOTAL	24	100%
Gender		
Male	14	58%
Female	10	42%
TOTAL	24	100%
Occupation		
Student	21	87.5%
Not a student/not employed	3	12.5%
TOTAL	24	100.0%
Education		
Primary	10	42%
Secondary	12	50%
Post-secondary	2	8%
TOTAL	24	100%
Knowledge of HIV Diagnosis		
2-4 yrs	5	21%
5-9 yrs	5	21%
10-14 yrs	13	54%
Not available	1	4%
TOTAL	24	100%
Primary Caregiver		
Mother	11	46%
Father	2	8%
Mother + Father	1	4%
Aunt	4	17%
Grandmother	3	13%
Grandfather	1	4%
Other-	2	8%
Total	24	100%

3.1. Qualitative Results

We identified four key themes related to barriers to ART adherence among ALWHIV within the school environment: 1) negative experiences following HIV status self-disclosure, 2) desire for secrecy, 3) restrictive school policies not supportive for students' ART adherence, and 4) health education focused on HIV as a sexually transmitted disease. We also identified suggestions on potential interventions to help adolescents overcome these challenges. These are described in more detail

below, with direct statements from IDIs and FGDs to illustrate themes.

3.1.1. Theme 1: Negative Experiences Following HIV Status Self-disclosure in School

Study participants stated that ALWHIV generally had negative experiences when they disclosed their HIV status. The sub-themes discussed under this theme are: violation of confidentiality, bullying from teachers and peers, ridicule and isolation, and friendships ending after HIV disclosure.

Violation of confidentiality

Many ALWHIV admitted that they did not trust their teachers enough to disclose their status to them, either due to a personal negative experience or due to stories they heard from their peers. Many of the ALWHIV expressed frustration that their teachers or school staff, such as guidance counselors, would disclose a student's HIV status without permission. ALWHIV described not trusting their teachers due to these indiscretions. They expressed that they did not expect that their teachers could help them with their ART regimens at school. Some ALWHIV described missing doses because of an abrupt HIV status disclosure. As one participant elaborated:

“It was an issue with the teacher. I was new in that school (last year), but one day in 2017, I went to disclose to the so-called, ‘guidance and counseling teacher’, and that story went public,I became an introvert, or I disassociated from others and all that. So, I wasn't comfortable taking the drugs in the presence of others—besides, that story was already spreading. I was trying as much as possible to avoid anything that could make it known to others that I was taking the drugs (Adol_017).”

Other participants provided similar statements. One caregiver described how an ALWHIV recounted their reluctance to confide in their teachers:

“...it's only their principal that knows her case, only that, but the rest of the teachers I have not told them because you know some teachers and their mouths; some teachers may take your condition as a joke, and at times you ask for permission, and they tell you, why do you always ask for permission, are you the only one who is ever sick? (CT_001).”

A teacher in an FGD also confirmed that ALWHIV do not trust all teachers to keep their status a secret:

“Students tend to be very sensitive; they would want to know if you have the capacity to keep confidentiality (FGD_TEACHERS).”

A health care provider agreed with these sentiments:

“So it becomes very difficult for them. The same goes for schools; we even have teachers who are not very supportive of girls and boys who are taking medication in schools. They want to take those drugs, they want to harass these children, they want to make it known to the whole staff that so and so is taking medication, and that is in itself a stigma (HC_004_3).”

Bullying from teachers and peers at school

Several ALWHIV explained that they experienced some form of violence and bullying at school. One described a peer slapping the medicine from his hands:

“So, when the alarm went off, they asked me...why is it that when it is 6 sharp, the alarm goes off, and then you go out?” someone followed me. He followed me and saw me taking medication. After he saw me, I told him that it was Panadol, he said, he didn't believe me...he beat me, he slapped me so that the drugs came out and he said that, “Are these not ARVs?” (Adol_006).

This participant did not report the incident to the teacher due to fear that the teacher would disclose his status to other students or use his name as an example in class when discussing HIV. The ALWHIV participant did not trust their teacher or other school staff enough to disclose to them. The following quote further demonstrates the predicament following the abuse in school:

“The reason why I did not tell him... I've realized how he teaches... so he might use me as an example so that people know I'm on medication like he had said that, “let's say in the class 4 book, there are some pictures like for HIV” (Adol_006).”

Ridicule and isolation

Another sub-theme that emerged was the constant ridicule that ALWHIV experienced, including other students avoiding physical contact and not wanting to drink out of the same cups as an ALWHIV. They explained that some individuals exhibited obvious discomfort with students who took HIV medication. A participant described his fear of disclosing:

“Some of them will abuse you the moment you disclose to them this information (Adol_018).”

Another ALWHIV explained that once some of the fellow students discovered that she was HIV positive, she stopped taking her medicines:

“Yes, when it comes to stigmatization there are some students that, after finding out that I was infected, they go spreading to all the people that girl is infected with HIV. And that’s the way you stop taking your drugs completely (Adol_002).”

Yet another participant recounted his experience with a teacher to whom he had disclosed and suspected that he had told other teachers.

“I don’t know how that teacher influenced other teachers so that I started having problems with other teachers, like three teachers who were his close friends, I find that they were isolating me from everyone else (Adol_017).”

One ALWHIV recounted the isolation that his cousin went through after disclosing his status as a reason for not disclosing his own status:

“People started to laugh at them. People did not want to play with them (Adol_026).”

Friendships ending after HIV disclosure

ALWHIV described the challenge of keeping friends in school after their HIV status was disclosed. They also noted the subsequent effect on their mental health, and as a consequence, this led to poor ART adherence. One participant gave an example of losing friends after the teacher disclosed his status:

“Like for my case, that time when my status was revealed to the school, there were so many friends I had, suddenly all of them evaporated, and I remained with only 3, so that is how it was. So when you are with them, people would be saying, “That is the boy who has HIV,” so you feel like you’re with them; you’re in that world but also outside. You’re not with them (Adol_017).”

Some ALWHIV described being pressured into stopping their medicine due to the attitudes and behaviors of their peers. A few mentioned that peer pressure influenced them into negative behaviors leading to poor adherence:

“On taking drugs, most of the time, they’re the ones who would influence you into the negative things that they are doing. And you

will also find yourself doing the same things that they are doing. If they tell you to stop taking medication, you will stop (Adol_032).”

Additionally, they feared that disclosure of their status could affect their personal relationships, as explained by one ALWHIV:

“When someone knows your status, it can be a very bad thing. So it is also a big challenge because let us pretend that maybe you wanted a certain girlfriend, and it happens that she already knew your HIV status. That can be a challenge (Adol_012).”

3.1.2. Theme 2: Desire for Secrecy

A majority of ALWHIV desired to keep their status a secret. This was characterized by two sub-themes: fear of being seen at the school dispensary and fear of suspicions by other students.

Fear of being seen at the school dispensary

ALWHIV participants complained that at some boarding schools, students were not allowed to keep medicine in the dormitories and that they could only be kept at the school dispensary with the nurse. They explained that they preferred to skip their doses due to fear of disclosing their HIV status to the school nurse or being seen at the dispensary. One teacher described a student’s experience:

“When they are in a boarding school, they keep their drugs at the school dispensary with the school nurse. You are not to have your drug within your reach in the dormitory, so they keep them there...So they were saying it was so difficult for them to take their medicines...from home to the dispensary because it will force them to explain to this nurse that “these are my ARVs, I take them at this time so I will be coming and taking them here.” They found they were not ready to disclose... people will know that they are HIV positive... So they felt that they would rather carry their drugs and throw them on the way when their parents forced them to carry them. They don’t want people in school to know that they are HIV positive (T_005).”

Fear of suspicion by other students

ALWHIV emphasized that the need to excuse themselves from class could draw suspicion among peers in school and lead to stigmatization. For example, acts like carrying water bottles, leaving class at the same time even during exams, or asking for permission to be away on specific days of the week, all became suspicious to other students. The quotes below demonstrate one participant’s experiences on two different

occasions:

“When I went back for the exams, people were asking me, “Why is the invigilator, all these days during the exams, every day he tells you to just go out,” I told them that I have some problem and that is why they’re calling me (Adol_006).”

“My classmates that I sat next to, when the alarm went off, they said that he is taking medication. I was pained that these people had already known after I kept it a secret from them when I was in class 8, so it is in 3rd term that they discovered that these people are going to leave here knowing that I’m on medication and even if we meet in secondary, they’ll tell others that I’m on medication and so I was scared. So, I disposed of the medication, and I did not swallow it that day (Adol_006).”

One caregiver explained that her child was afraid that carrying a water bottle to school would draw suspicion because water bottles were generally forbidden at school for all students:

“I had asked that she should be allowed to have enough water, that she should go with her own water bottle. So they have been asking why she carries water...when she is in school, adherence becomes a problem because of maybe stigma or how her colleagues talk to her. You can find her colleagues asking her, “What have you been suffering from?” because you find that she carries water all the time. So that stigma affects her (CT_002).”

The same caregiver remarked that on some occasions, her daughter thought that others were talking about her, and this made her more guarded:

“She will think that maybe they are talking about her. So she will become shy and isolate herself. And it is that isolation that can affect her adherence (CT_002).”

Stigma was also mentioned as a major barrier to HIV disclosure at school. As this healthcare provider explained:

“What I am seeing as a personal barrier is a stigma...our ALWHIV are not ready to disclose their HIV status in public. Those who are in high school and they are having colleagues...around, it reached the time that they are supposed to take their drugs they take their drugs late, or sometimes they miss, and

they miss taking their drugs (HC_001).”

3.1.3. Theme 3: Restrictive School Policies and Structures

Study participants overwhelmingly reported that the school culture was one of the biggest barriers to adherence. Some of the school policies were very restrictive and affected ART adherence. These were explained in the following sub-themes: optimal ART adherence is difficult to achieve in school, students are not allowed to keep medication in dormitories, students must always ask for permission to leave class, and lack of private spaces to take their medicine.

Optimal ART adherence is difficult to achieve at school

A majority of study participants described some of the policies at school (day and boarding) as barriers to optimal ART adherence for ALWHIV. They lamented that the majority of teachers were generally not trained on how to interact with ALWHIV. Additionally, they believed that some of the school policies made it difficult for ALWHIV to privately take their medication. For example, some stated that they had been searched when they entered school grounds and that any medicine found in their bags was thrown away because guards mistook them as potentially ‘recreational’ drugs, as one adolescent described:

“I was going to school, I was carrying medicines in my bag, and the security officer came and frisked me and found the medicines, and then he told me that “you have started using drugs,” he called the principal and the principal sent me home for 1 week. I stayed at home and never went to boarding, so I’m in day school currently (Adol_006).”

Once inside the school, ALWHIV stated that there was a lack of drinking water and that at certain schools, students were not allowed to carry water bottles, which, if they did, would be confiscated by guards. In the absence of drinking water, the ALWHIV said that they were either forced to swallow their pills dry, which could be uncomfortable, delayed taking their medicine, or just did not take them at all. One participant stated:

“We’re not allowed to carry water, and so we just use school water and sometimes there is no water...Yeah, so when you enter from the gate, your bag is checked. If you have water, they confiscate it plus the bottle (Adol_032).”

Students are not allowed to keep medicine in dormitories

At boarding schools, medicine could only be kept at the nurse’s dispensary. If ALWHIV wanted to keep their medicine with them in their dormitories, they would be punished. One teacher explained what happened to a student:

“She was having her drugs with her in the dormitory because she wanted to take them but as she was taking people started speculating, why does she at this time run to the dormitory..., she was also once punished for sneaking and going back to the dormitory (T_005).”

In certain situations, medicines kept with the school nurse were not always accessible to ALWHIV. One healthcare provider explained this challenge as follows:

“So one of the challenges that we have had with our ALWHIV... who are in boarding school that whoever has keys to that place probably during the weekends is not there and the drugs are locked. Sono matter how much they want to take their medication, they can't access them (HC_001).”

Students must always ask for permission to leave class

Participants described the inconvenience encountered when, due to a desire to avoid taking their medicine in front of other students, they had to ask for permission to leave the class in order to take their medicine. One ALWHIV described a time that they were denied permission to leave class to take their medicine:

“It is in secondary school that I started going to the deputy because of my class teacher, I just don't understand my class teacher, even if I go to ask him for permission, I once asked him for permission, and he refused (Adol_032).”

Participants also lamented that if they were in school and needed to attend medical appointments, it would be difficult for them to get to the clinic. As explained by an FGD male ALWHIV and a caregiver:

“I don't know if I can say this, but I wish they could do something to the HIV-infected student so that they don't miss appointment dates. There are cases where you have an appointment date, but you have to skip and take exams (FGD male ALWHIV).”

“So there was only one teacher when she was in class seven, she told the teacher that she wanted to go to the clinic and he shouted at her why she always goes to the clinic every time. She really felt bad when the teacher told her that. She came and told me that she will never tell the teacher about her visit to the clinic again. This is because she shouted at her...She told me that there were other children who also went to request permission from the

teacher, and they got the same treatment. The teacher shouted at them (CT_004).”

Lack of private spaces to take medicine

Study participants also complained that there were no spaces at school where students could take their medication safely and privately. Because of this lack of privacy, some ALWHIV chose not to take their medicine at all while in school. As a teacher explained:

“...Okay maybe just the lack of privacy because the moment you are having your lunch there, for you to take them, the rest will ask why are you taking the drugs and why do you keep on taking the drugs (T_003).”

Some ALWHIV mentioned that they were far away from their medicine when the reminder alarm went off, and when this happened, they often decided to take their medication at a later time. As one adolescent recounted:

“Sometimes, the alarm goes off, and I'm still far away, sometimes the alarm goes off and I'm in class...but the teacher is teaching, so I'm afraid of taking the medication, so I end up extending the time (Adol_006).”

Some ALWHIV described having to report to school at 6:30 am, coinciding with when they were supposed to take their medication. In this situation, the students stated that they took their medicines early before going to school. An ALWHIV explained:

“Another challenge, in the morning, when you are going to school, like when they had instructed me to be taking medication at 6:30. That time finds me in school. So, if it finds me in school, I have to take the medication with me (Adol_012).”

3.1.4. Theme 4: Health Education is Focused on HIV as a Sexually Transmitted Disease

Some caregivers and ALWHIV stated that the teaching on HIV in school focused largely on HIV as a sexually transmitted infection and the use of condoms as a preventive measure. Participants believed this focus led to misconceptions and stigma among students and teachers because some ALWHIV are infected in utero and have not yet had sexual experiences. Study participants stated that this misunderstanding caused more distress and prevented ALWHIV from disclosing to others their HIV status. In the words of a caregiver:

“What I want to say is that the current textbooks in primary school are too harsh

towards HIV. Most of these books indicate that HIV is a result of sex, but a child may have gotten it from birth (FGD-Care Taker).”

Teachers also mentioned about lack of resources with which they can engage and/or create HIV/AIDS awareness among students. These sentiments were supported by health care providers:

“Yes, in schools, if we can involve teachers and give them health information on how to support our children in adolescence who are taking medication within their set up (HC_004_3).”

In addition to the teachers and schools not being well equipped, ALWHIV also mentioned that there was a general lack of education about HIV in schools. One healthcare provider mentioned that some school nurses were not well prepared to discuss HIV and ARTs, and hence were not able to provide proper support to students:

“School nurses and school matrons...what is their perception of HIV? For you to be a school nurse, I think it should be a requirement you are supposed to go through HIV education and training on ART, adherence, and psychosocial support for ALWHIV and children with HIV...what we have seen in most schools we have noticed that the school nurses don't know what ARVs are, and the schedule for taking them (HC_001).”

One ALWHIV explained that the content of their lessons on HIV at school was stigmatizing, and other students began to compare it to Ebola:

“And it is at that period we are being HIV and AIDS in school, and then people were giving their opinion how HIV is, and they were naming it as some sort of Ebola (Adol_029).”

Although ALWHIV participants sometimes explained that some teachers were supportive, there was a general consensus among all study participants that the majority of teachers did not know how to help students living with HIV. Some key informants stated that even when teachers were aware of challenges, they did not know how to address them, especially when neither students nor their parents disclosed the HIV status of the student to the school leadership. A healthcare provider explained that teachers were often not able to take adequate and appropriate action when students were sick and needed support at school:

“We find that most of the barriers come from parents, especially if a parent now tells the daughter or the son that “this is your secret, don't even tell the matron,” especially those in boarding. So you find that when they're sick, to help them is very difficult because now it is private between him/her and the parents. So sometimes parents are also a barrier due to stigmatization (FGD_HW).”

3.1.5. Suggested Recommendations to Improve ART Adherence

During FGDs, ALWHIV and all the three groups of KIs (caregivers, teachers, and health care providers) were asked to suggest actions that might be taken to improve adherence among ALWHIV in Kisumu County. The suggestions that were relevant to the school environment included: teach ALWHIV how to disclose their status, promote empathy among teachers and students, prepare ALWHIV to manage transitions, change the narrative about HIV transmission, provide water in all schools, and introduce adherence programs in schools and use of mobile technology. Below we briefly discuss each subtheme.

Teach ALWHIV how to disclose their status

Participants recommended that parents should have conversations with ALWHIV about how to approach teachers and their peers. With appropriate education and support, ALWHIV may gain a better understanding and appreciation for their illness and can build trust and better relationships at school.

“We find that most of the barriers come from parents, especially if a parent now tells the daughter or the son that “this is your secret, don't even tell the nurse especially those in boarding schools. So you find that when they're sick, to help them is very difficult because now it is private between him/her and the parents. So sometimes parents are also a barrier due to stigmatization (FGD_HW_HW11).”

ALWHIV in the FGD also suggested that when going to enroll in school, the hospital should collaborate with the respective schools to facilitate disclosure. If the status is being disclosed, it should be done by a specific teacher who is charged with handling these cases. In some cases, ALWHIV stated relief when others knew their status; they even found that it helped them to stay on track with their medication regimen, as this adolescent described:

“If you are free with people, I don't think if you can be late. If you are free with people, they even remind you about time (Adol014).”

Promote empathy among teachers and students

ALWHIV proposed that more empathy and understanding among students and teachers should be promoted. One teacher suggested that both teachers and students should learn to express empathy in a sensitive manner, showing understanding of the issues that may be distressing ALWHIV. This way, attitudes and behaviors towards HIV can start to change slowly in school.

“... the others who are not infected should not look at these people as if they are like people with a very bad disease. It is just like malaria which needs to be taken as a regular disease (FGD_TEACHERS).”

“I’m of the opinion that teachers should be sensitized on confidentiality together with the guards and caregivers within the school (FGD_CT_2).”

Prepare ALWHIV to manage transitions

Preparing ALWHIV for transitions was mentioned by health care providers in FGDs as an important aspect of preparation towards self-advocacy. Participants mentioned that transitions include changing schools from primary (middle) to high school and from high school to college. They explained that greater challenges existed among those transitioning from day to boarding schools. An example was given that when ALWHIV are in day school and live at home, they have a family as a support system to help them adhere to medications. In boarding schools, they are on their own and are expected to take care of themselves. The ALWHIV need preparation for this transition so that they can better adhere to their medications. Health care providers discussed this in the FGDs, as follows:

“...you find that if transition for example, you have an adolescent who is in class 8 that is transitioning from primary school to high school. In class 8, this child was in day school, the parents/guardians were the ones who were reminding this adolescent to take medication. So they were not prepared for boarding school....in boarding school, the environment is different, you have to remind yourself to take your drugs; you have to take care of yourself; you have to remember your clinic days... If they are not prepared for that transition, adherence becomes an issue. And the same goes for transitioning from high school to college. So you find the environment in high school is different from the environment in college. If it is not taken care of properly by us the healthcare workers and involving even the caregivers and the parents, adherence becomes a major issue (FGD_HW).”

Provide water in all schools

All study participants expressed concerns that students did not have access to water at school. They suggested that teachers should ensure that students can easily access portable water whenever they need to.

“What I want to add is that in most schools water is not clean. Some schools lack

water until students go for the unsafe water at the river. So, there should be a way that the school organizes clean and safe drinking water (FGD_CAREGIVERS).”

Adherence programs in schools

Some caregivers suggested the creation of various behavioral interventions at school, for example, providing students with specific strategies to manage their regimen, educational interventions providing basic information to students about the patient’s illness, triggers, signs, and symptoms of which they should be aware, and emergency phone numbers.

Participants suggested that using rewards might be a strategy that may help increase compliance in youth and can be easily implemented. Some ALWHIV also lamented that some of them walk long distances for hospital appointments. They suggested that hospitals should be built close to a school:

“Maybe they establish a hospital in the boarding schools that can help instead of going a distance. Yes, it can be of help. You can find an individual coming far distance and then again another distance to collect drugs (Adol_014).”

“Yeah. To the day scholars, I would request that, you can contact the administration, if they can even get a pharmacy just next to the school so that there is no need of coming to, very far, maybe she can just come to the hospital when she is not feeling well but if it is only taking of drugs, let them have a pharmacy in the school compound (CT_002).”

“I think there should be a place where the children can get drugs within the school in case their drugs are over or they have forgotten at home (FGD_CAREGIVER).”

It was also recommended that the guidance counselors in schools should not be a teacher because of the need to protect confidentiality.

“And in the school setting, we found that...the guiding and counseling master should not be a teacher. This guy should be a guiding and counseling professional. So, even if you

disclose it to him, it will not blow out to the school (FGD_CAREGIVER).”

Use mobile technology

Teachers stated that they have seen how students are very excited to use technology and mobile apps, so they think using technology in this population may be a good approach to improve their adherence. One participant suggested that frequent contact of patients with providers has the potential to improve their adherence to ART treatment and will likely change behavior over time. Provider partnerships with these teenagers to encourage self-management behaviors may be one of the ways to reduce the poor consequences due to lack of adherence.

“I think of another enabler being effective to follow up for these adolescents...however, we should do follow up by phone calls and maybe when you call, you will find that this adolescent was almost going into treatment fatigue and you can encourage before we get problems is when we start home visits and phone follow-ups when we’ve just realized that the viral load is high. But if we make it that these are the adolescents who are coming this particular month, all of them are done follow-ups. I think that one will help us (FGD_HCW).”

4. DISCUSSION

This study aimed to explore the key school-related ART adherence barriers, as well as perspectives on interventions to address them, from ALWHIV and several groups of KIs in western Kenya. It contributes to a growing body of work on challenges faced by ALWHIV, who are moving towards full adulthood. By taking advantage of an existing rich qualitative dataset collected as part of a larger mixed-methods study, one whose quantitative component found very poor adherence levels among adolescent participants; this analysis was able to probe the challenges experienced by a struggling, highly-vulnerable population living with HIV. One of its strengths was its use of multiple qualitative methods, both IDIs and FGDs, as well as multiple study populations. Collecting and analyzing data from the most important groups of adults surrounding adolescents (caregivers, teachers, and health care providers) allowed for the triangulation of data across key thematic findings. It also facilitated recommendations for interventions to address the challenges faced by ALWHIV from those groups of individuals closest to adolescents and suggested remedies. Below we discuss in more detail several of our key findings.

One important finding related to the strong reluctance of ALWHIV to disclose their HIV status in school is because of present and past negative experiences. ALWHIV complained of constant violation of confidentiality by teachers, peers, and even the school nurses. They mentioned being subjected to physical and verbal abuse when an individual’s HIV status was

revealed. Keeping friendships was challenging after their HIV status was disclosed. The disclosures could be by adolescents themselves, teachers, peers, or the school nurse. Due to these challenges at school, ALWHIV explained that they tried to keep their HIV-positive status a secret as much as possible and performed all sorts of maneuvers to hide their status. Some of the ways in which they kept their status secret were by avoiding taking their medicine in front of their peers, teachers, or school nurses, avoiding being seen at the dispensary, and not carrying medicine around. ALWHIV did whatever it took to avoid anything that might raise suspicion of their HIV-positive status, which discouraged adherence to their ART medications. This finding has been echoed in other studies [51, 52], highlighting the urgency of developing appropriate interventions to create a more supportive school environment.

Although many standards and codes of practice refer to the importance of confidentiality and empathy in Kenyan schools, it is often overlooked in practice by teachers [41]. Previous studies also found that students generally do not disclose their status to school staff and teachers. Much of this has to do with the desire for secrecy and fears about disclosure [42]. A study from Uganda described ALWHIV feeling stigmatized and discriminated against by their teachers [53]. ALWHIV in our study also described being ridiculed, isolated, and losing friends following disclosure of their HIV status. The desire for confidentiality and fear is an added stressor for these ALWHIV and may lead to depression [41]. Teenagers may experience emotional unpreparedness, lack of knowledge and skills, and general comfort in discussing HIV with their teachers.

Overall, the school environment in Kenya seemed to be a larger source of stress rather than support for ALWHIV [48, 53]. Some study participants described school policies as very restrictive, stressing that they do not provide an optimal environment for adherence to ART. For instance, they were not allowed to carry drinking water in the school compound, creating a serious challenge to ART adherence [54]. Other restrictions included prohibiting students from carrying medicine of any kind. When they enter the school gates, their luggage may be searched, and any medicine found confiscated by school authorities. They were expected to leave any medication with the school nurse. Besides the discomfort with lack of confidentiality, the school nurses were not present all the time, affecting the timing for taking their medicine. School rules that do not allow students to take their medication have been observed discretely in previous studies [42]. Students in this study also faced stringent rules; for example, they needed permission to excuse themselves from the classroom or during exams. Another study conducted in Kisumu city concluded that students’ ability to remain in HIV care was dependent on the school environment [41]. A study conducted in Muranga in central Kenya found that students in a day school were more likely to be adherent than students in boarding schools. Additionally, those in boarding school often lack privacy, which causes them to avoid taking their medicine [42].

Participants described the current content of HIV education as problematic. The content focuses mainly on the sexual transmission of the virus. Although our study was not designed to look for a mode of transmission, anecdotal evidence from

clinic nurses suggested that the majority of ALWHIV in our study may have contracted HIV in utero. Nonetheless, the discourse around HIV transmission in schools led to feelings of embarrassment and being stigmatized, which resulted in poor adherence to ART. Other studies have found that HIV misinformation perpetuates stereotypes about HIV [55] and that teachers may put particular emphasis on sex and/or name-call HIV-positive students, breaking confidentiality [41].

This study identified a number of potential school-located interventions, including preparing teachers and students to better support ALWHIV and coaching ALWHIV to manage both transitions and HIV status disclosure effectively. Study participants suggested that parents need preparation to be able to support ALWHIV on how to manage the various transitions in their lives.

In view of the reported challenges in maintaining optimum ART adherence by adolescents in Kenyan schools, health policymakers and their technical advisors should consider simplifying the ART regimen by reducing dosing frequency and providing single-pill regimens (where feasible) to be taken once daily, either before the beginning of classes in the morning or after class in the evening. These actions have the potential to reduce the need to take ART medications multiple times during the day and unnecessary suspicions and stigmatization from their peers, teachers, and school staff. Studies have demonstrated better adherence with once-daily ARV regimens than with twice-daily regimens and better adherence with single-tablet formulations than with multiple-tablet regimens [56, 57]. Additionally, using current guidelines for supporting learners living with HIV in Kenya [58], teachers, school principals, security guards, support staff, and school nurses should be educated about the critical role of ART adherence in therapy outcomes and how they can support ALWHIV. Creating empathy among these individuals towards ALWHIV will address some of the school-related barriers that limit ART adherence, including lack of drinking water, not allowing students to carry medications, confiscating of students' medications by security guards, and lack of private spaces to take medications.

Some participants suggested teaching adolescents self-advocacy and self-disclosure. Studies have shown that self-disclosure among ALWHIV increases condom negotiation and use, and improves ART adherence [59 - 61]. It was found to be positively associated with increased access to support systems, mental health improvements, decreased feelings of isolation [61, 62], delayed disease progression compared to those who have not disclosed, and was found to reduce the likelihood of transmitting HIV to sexual partners [61]. Findings from a study in Uganda in the school setting suggested that partial disclosure to a few trusted people was vital for psychosocial support, reminders to take medicine, and for permission to leave class to go to their medical appointments [48]. However, these findings were not tested in the school setting, and more research is needed to examine this recommended strategy. A study from the UK stated that it is more important to understand the forces that keep ALWHIV from disclosing (such as stigma) first in order to design interventions that support them best. The same study suggested improving discussion and communication

about HIV within households and the healthcare setting first with safety planning for when disclosures do not go as planned as a way of beginning this process [62]. Participants also suggested creating adherence support programs in schools, making drinking water available, and using mobile technology to maintain contact with ALWHIV. The use of mobile technologies is of particular interest because they are popular among youth, and other health initiatives have capitalized on such interest to engage with vulnerable youth [63].

5. STUDY LIMITATIONS AND STRENGTHS

This study had certain limitations. The generalizability of the findings cannot be done due to qualitative methodology and the small samples for IDIs and FGDs, with a lack of geographical variation. However, the mixed methods nature of the data can provide a clearer picture of why some ALWHIV may have higher adherence than others, and similarly, why others struggle with adherence. Participants were selected by convenience sampling among ALWHIV who were present at the CCC on days when data collection occurred. This could have introduced a selection bias as we might have selected only adolescents who actually go to the clinic for care. Finally, although we interviewed some teachers, they did not represent all the teachers and all schools. The perspectives of school administrators and HIV-negative students in a future larger-scale study would add more insight.

CONCLUSION

Our study findings highlight the challenges that ALWHIV in Kenya experienced trying to maintain optimal ART adherence in the school environment. The majority of ALWHIV complained of having negative experiences following disclosure of HIV-positive status, leading them to do anything necessary to keep their status a secret. The restrictive school policies further made it difficult for the ALWHIV to adhere to ARTs. The discourse around HIV being a sexually transmitted disease stigmatized the ALWHIV. The development and testing of interventions to create more empathetic school environments for ALWHIV will be critical in efforts to achieve better health outcomes for this population.

AUTHOR'S CONTRIBUTIONS

All authors have made significant contributions to the manuscript. The first author (MAO) led the study concept and design, coordinated data collection in the field, conducted an initial literature review, assisted with data analysis, and wrote and reviewed the final manuscript. The second author (HC) assisted with data analysis, literature review and wrote and reviewed drafts and final manuscript. The third author (LLS) assisted with study concept and design, literature reviews and drafts, and the final manuscript. The fourth author (LJM) assisted with the study concept and design and read drafts and the final manuscript. The fifth author (NS) assisted with quantitative data analysis and read drafts and the final manuscript. The sixth author (JO) assisted with study concept and design, field supervision, data collection, and reviewed drafts and the final manuscript. The seventh author (PA) collected data and read drafts and the final manuscript. The eighth author (DOK) assisted with the study concept and

design and reviewed drafts and the final manuscript. The ninth author (JO) assisted with study concept, design, data collection and reviewed drafts and the final manuscript. All authors approved this version for submission and agreed to be accountable for all aspects of the work represented in the manuscript.

RESEARCH TEAM

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ETHICAL APPROVAL AND CONSENT TO PARTICIPATE

The study was approved by the institutional review board at the Boston University Medical Center (H-37384) and the Ethics Committee at the Jaramogi Oginga Odinga Teaching and Referral Hospital (reference #: ERC/IB/VOL 1/444).

HUMAN AND ANIMAL RIGHTS

No animals were used in this research. All human research procedures were followed in accordance with the ethical standards for research.

CONSENT FOR PUBLICATION

All informed consent forms were read by or to participants. Verbal consent was obtained for all participants at the start of the study. Assent forms were read by adolescents (or to adolescents) who were less than 18 years of age.

AVAILABILITY OF DATA AND MATERIALS

This sub-analysis utilized transcripts from a larger qualitative mixed-methods study. The analysis of these data is still ongoing for other planned manuscripts and is not available publicly at the moment. Once we complete all our analyses, we will place the transcripts in a repository where they will be available upon request.

FUNDING

The study was supported by the Boston University School of Public Health through an Early Career Catalyst Award (# 9090012102).

STANDARDS OF REPORTING

COREQ Guideline has been followed in this study.

CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

ACKNOWLEDGEMENTS

We would like to thank Lawrence Okungu and Ken Omolo, who helped with the recruitment of study participants

and managed the adherence monitoring systems and follow-up of study participants. We also acknowledge the research assistants who worked tirelessly within a short time to conduct interviews and data collection. We appreciate the study participants, ALWHIV, parents/guardians, and teachers who gave their time to be in the study. We also thank the hospital and clinic leadership at JOOTRH for allowing us to conduct the research. Finally, we are grateful to the Boston University School of Public Health (BUSPH) for the funding.

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