



# HIV-Related Knowledge, Attitudes, Behaviors and Experiences of Kenyan Adolescents Living with HIV Revealed in WhatsApp Group Chats

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## Abstract

**Introduction:** Mobile technologies represent a scalable platform for delivering knowledge and interventions targeting adolescents living with HIV (ALWH) in low and middle income countries. Data from mobile interventions can be used to assess the contextual understanding and experiences of ALWH. **Methods:** We examined HIV-related knowledge, attitudes, beliefs, behaviors, and experiences of Kenyan ALWH revealed in the contextual data from enrollment in a WhatsApp<sup>®</sup> group chat intervention. **Results:** Thirty ALWH (17 female, mean age 15.4) on ART, engaged in HIV care and aware of their status, were enrolled. Qualitative analysis of WhatsApp<sup>®</sup> chat discussions identified a gap in HIV knowledge, high medication-taking literacy, need for mental health support and significant barriers to adherence. Participants discussed challenges with HIV stigma and medication-taking in the school setting. **Conclusion:** These discussions demonstrate a need for education on HIV topics, mental health support for ALWH, and interventions for stigma mitigation in the school setting.

## Keywords

HIV, adolescents, mHealth, WhatsApp, Kenya

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## Introduction

The advent of combined antiretroviral therapy (ART) transformed HIV from a terminal illness to a manageable chronic disease, yet HIV/AIDS remains a leading cause of death for adolescents ages 10 to 19 years globally, especially in sub-Saharan Africa (SSA).<sup>1,2</sup> Adolescents living with HIV (ALWH) face myriad inter-related clinical, social, behavioral, and mental health challenges to HIV treatment. ALWH often have high rates of loss to follow-up in clinical programs and low rates of adherence to treatment compared to adults and younger children.<sup>3-14</sup>

For adolescents with perinatally acquired HIV, HIV care in the adolescent years often includes learning about their own HIV status (disclosure) and the challenges that come with accepting their diagnosis and managing their own treatment.<sup>15,16</sup> In comparison to adolescents with behaviorally

acquired HIV, adolescents with perinatally acquired HIV demonstrate lower levels of HIV knowledge, which may be influenced by age at disclosure and level of autonomy in their

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### ***What Do We Already Know About This Topic?***

High rates of mobile phone usage in Kenya provide important opportunities for health interventions targeting adolescents. Data from mobile interventions can be used to assess the contextual understanding and experiences of adolescents living with HIV and thus shed critical light on the unique needs of the population.

### ***How Does Your Research Contribute to The Field?***

We identified a critical gap in HIV knowledge among perinatally infected adolescents living with HIV and a need for increased opportunities for mental health services and peer support.

### ***What Are Your Research's Implications Toward Theory, Practice, or Policy?***

Interventions in the school setting are needed to mitigate the effects of HIV stigma, and to support ART adherence and improved mental health for adolescents living with HIV.

care.<sup>17</sup> HIV-related stigma and discrimination may negatively impact the development of peer networks and social support, which in turn affects all aspects of HIV care and treatment,<sup>18,19</sup> including both physical and mental health outcomes. There are few adolescent-specific clinical programs for HIV care,<sup>20</sup> particularly in low-and-middle-income countries (LMIC), despite ALWH facing unique challenges—including transitions in care from pediatric to adult settings and increasing autonomy and control over their own health and behavior. Interventions targeting ALWH and their unique educational, social and behavioral needs are needed to improve outcomes among this vulnerable population.

Mobile-based technologies represent a scalable platform for delivering knowledge and interventions targeting ALWH in LMIC. Mobile phone ownership in sub-Saharan Africa (SSA) has rapidly increased over the past decade, and greater than 80% of Kenyans own a cellphone, with 15% owning a smartphone.<sup>21,22</sup> Mobile phones have been used successfully among adolescents in resource-rich settings for HIV education and adherence support through SMS reminders,<sup>23-28</sup> as well as to provide peer support for ALWH, which may further promote social and behavioral health as well as adherence to treatment.<sup>29</sup> Support groups delivered via common social media platforms like Facebook, have been found to be an acceptable method for individuals to share their disease-related experiences and seek information and support.<sup>30</sup> Additionally, adolescents experiencing homelessness who communicated with peers on online platforms were found to have higher HIV knowledge and to engage in more preventative health behaviors.<sup>31</sup>

Importantly, data from mobile interventions can be used to assess the contextual understanding and experiences of

ALWH, and thus shed critical light on the unique needs of the population. Studies have investigated the nature and actual content of messages exchanged in mobile or internet based interventions for peer support that have targeted a range of health conditions and experiences, including people living with physical disabilities, diabetes and cancer, among others.<sup>32-36</sup> Analysis of these group discussions revealed that the most common types of interaction among participants was to provide disease-related information and interpersonal support.<sup>30-33</sup>

There are few data on the content of mobile support groups for adolescents or other people living with HIV (PLWH) in LMIC. Previous studies in the United States have analyzed the content and types of interactions among adult PLWH enrolled in mobile based interventions for peer support.<sup>37,38</sup> In a study analyzing the content of web-based support groups for adult PLWH, information sharing and emotional support were the most common types of interactions.<sup>37</sup> Analysis of participant discussions revealed a critical gap in HIV knowledge, noting that participation in web-based support groups may have the ability to improve self-efficacy and coping among PLWH through the provision of knowledge and support.<sup>37</sup> Little research has focused on the nature and content of actual messages exchanged by adolescents living with HIV engaged in mobile-based interventions in LMIC.

We conducted a pilot intervention trial of a mobile-based mental health, peer support intervention in which Kenyan ALWH were provided with smartphones and encouraged to participate in group chats using the WhatsApp<sup>®</sup> platform. The results of this feasibility and acceptability pilot intervention trial, including adherence outcomes, are described elsewhere.<sup>39</sup> Here, we sought to examine and characterize the HIV-related knowledge, attitudes and beliefs, behaviors, and experiences of Kenyan ALWH revealed in the contextual data from their WhatsApp group chats.

## **Methods**

### ***Study Design***

We conducted a prospective, qualitative inquiry included in a broader mixed method pilot study to evaluate the feasibility and acceptability of a mobile-based mental health and peer support intervention using the WhatsApp<sup>®</sup> platform with ALWH in the AMPATH program in western Kenya. AMPATH,<sup>40,41</sup> the Academic Model Providing Access to Healthcare, is a long-standing partnership between a consortium of North American and Kenyan academic medical centers in partnership with the Kenyan Ministry of Health that provides comprehensive care for over 160,000 people living with HIV, including over 6,000 children and adolescents, across western Kenya.<sup>42</sup> The AMPATH-Turbo comprehensive care clinic is located in rural Turbo sub-county and provides HIV care and testing as well as care for chronic diseases including oncology, hypertension, diabetes, among others. Feasibility and acceptability of the intervention using pre- and post-test interviews and questionnaire are published elsewhere.<sup>39</sup> Content and

qualitative analysis of the WhatsApp® chat transcripts as described here provide an organic assessment of adolescent knowledge, attitudes and beliefs about HIV, as well as self-reports of their HIV-related behaviors and experiences, in a group context led by the ALWH themselves.

Thirty ALWH aged 10 to 19 years who were on ART, engaged in HIV care, and aware of their HIV status, were identified by clinic staff and recruited by the study team at the AMPATH-Turbo comprehensive care clinic in western Kenya. Participants were provided with a smartphone with the WhatsApp® application preinstalled, a SIM card, and phone credit (~ 7 USD per month). ALWH enrolled in the study were placed in 1 of 2 WhatsApp® groups based on their age, either a group for 9 to 14-year-olds or for 15 to 19 year-olds. Each group had 15 study participants at baseline. A trained pediatric HIV adherence and disclosure counselor facilitated the WhatsApp® groups according to a structured curriculum to encourage positive support between members, to introduce weekly group discussion topics, and to answer participants' questions. Weekly group discussion topics were informed by formative qualitative work with this cohort, as well as a multimedia curriculum developed previously by this research team that has modules on stress management, drug and alcohol abuse prevention, intimate relationships, and issues related to HIV adherence, disclosure, and stigma.<sup>43</sup> Additionally, the WhatsApp chat platform remained open outside of the structured modules to allow for natural communication among participants, and these conversations were monitored by the study counselor. In addition, the counselor contacted individual participants via direct WhatsApp® messaging every other week throughout the duration of the study period. Participants could contact the study counselor individually on an unscheduled, as-needed basis in the same manner. Group members participated in the mobile mental health support intervention for 6 months.

### **Data Collection and Analysis**

All WhatsApp® chats from the 6-month pilot intervention were downloaded, translated into English (from Kiswahili), and transcribed for analysis. A system of manual, progressive coding of the transcripts using Dedoose software (Sociocultural Research Consultants, LLC) was utilized to identify emerging concepts. Thematic analysis was done through open coding by 2 researchers (AC and RM), involving line-by-line review of transcripts to identify meanings and processes. These researchers independently extracted and compared themes. Along with an additional analyst (JA), the research team reviewed transcripts several additional times to revise the coding structure as needed and compared and collapsed results based on consensus across the 3 analysts (AC, RM, JA). Axial coding, the process of relating categories to their subcategories and linking them together at the level of properties and dimensions, was used to organize the themes into their causal relationships. Hypotheses and concepts were developed inductively from the data. Quotes as presented here are excerpted directly from the English translations of the transcripts.

### **Ethical Approval and Informed Consent**

This study was approved by the Indiana University School of Medicine's Institutional Review Board, Indianapolis, Indiana, USA, and the Moi University / Moi Teaching and Referral Hospital's Institutional Research and Ethics Committee in Eldoret, Kenya (approval number 0001887). All participants gave informed consent prior to enrollment in the study. All caregivers of participants under the age of 18 years old consented to their participation in the mobile-based support group. Caregivers were aware of the purpose of the support group and that the adolescents would be given a mobile phone. Minors provided assent and adolescents 18 years or older provided informed consent.

Study participants were assigned a pseudonym to use during the WhatsApp® discussions to protect their privacy. The study counselor who facilitated the groups was trained in mental health counseling by the AMPATH program and had specific training in referral mechanisms available for participants in this setting. If the counselor suspected any participant was suffering from a serious mental or behavioral disorder or episode, the counselor referred the patient for additional counseling at AMPATH that is provided for free to all patients.

## **Results**

### **Participant Demographics**

Twenty-nine out of the 30 participants initially recruited completed the intervention pilot and follow up and were included for analysis (one participant did not complete the study due to barriers experienced at boarding school that made it difficult to fully participate in the intervention). The mean age of participants was 15.4 years and the majority (56.7%, N = 17) were female.

### **Participant Engagement**

Participants engaged in the WhatsApp group chats for 6 months with weekly educational modules led by the counselor. Aside from the counselor-designated discussions, which were once a week for 1 to 2 hours, most interactions were among participants, with the counselor joining in only to clarify misconceptions as needed. Often times, the participants continued conversations that were introduced by the counselor beyond the designated time or would start new topics. The participants interacted, on average for 3-5 days per week for 6 months and the analysis is based on 650 pages of transcripts. Participation varied widely by group and session; the younger group (ages 10-14) had less engagement at 22 pages of transcripts, than the older group (ages 15-19) at 628 pages of transcripts. Participant 1, 2, 3 as indicated in the data tables indicates a conversation between adolescents in the group chats.

### **HIV Literacy**

Participants engaged in extensive conversations around HIV literacy topics, including the differences between HIV and

**Table 1.** HIV Literacy.

| Subtheme                               | Illustrative Quote                                                                                                                                                                                                                                                                                                                                                                                                                       |
|----------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| HIV vs. AIDS                           | <p>“HIV is the virus, AIDS is the disease.”—Female, 15 years</p> <p>Participant 1: “Does AIDS really respond to treatment?”—Female, 18 years</p> <p>Counselor: “Yes it does respond to treatment but having so many infections in your body will weaken your body before you can completely treat all of them. You will be very weak and you will lose a lot—like schooling and also getting your healthy body back will take time.”</p> |
| Viral Strains                          | <p>“How many types of HIV do we have?—Do we all have the same type of HIV?”—Male, 14 years</p> <p>Counselor: “It’s true when you get different strains it becomes a problem to treat, there are some strains that are resistant to treatment, so it’s good to take care and suppress the one in your blood to undetectable levels.”</p>                                                                                                  |
| Viral Load                             | <p>“Viral load number is the enemy in the body. Then CD4 is a bodyguard/soldier.”—Male, 17 years“</p> <p>If you stop using medicine your viral load will not remain low.”—Female, 18 years“</p> <p>Is it possible for the virus to die once it gets to undetectable levels?”—Male, 16 years</p>                                                                                                                                          |
| HIV Transmission                       | <p>“If a mother knows that she has AIDS, is there a way they protect their children from getting infected?”—Male, 14 years“</p> <p>Can HIV be spread through sharing a toothbrush?”—Female, 17 years</p>                                                                                                                                                                                                                                 |
| STIs                                   | <p>“If, for example, you find yourself infected with HIV and gonorrhea, can you get treated?”—Female, 18 years“</p> <p>Now what if you have syphilis, do you continue with these [HIV] medicines?”—Female, 18 years</p>                                                                                                                                                                                                                  |
| PREP                                   | <p>Participant 1: “Is PREP for preventing infection?”—Female, 17 years</p> <p>Participant 2: “You use PREP before being exposed.”—Counselor</p>                                                                                                                                                                                                                                                                                          |
| Side Effects                           | <p>“If you take drugs late, then in the morning you get a hangover like you didn’t sleep the whole night.”—Male, 18 years</p>                                                                                                                                                                                                                                                                                                            |
| Perception of Severity: HIV vs. Cancer | <p>“Because HIV can be prevented and you can live a normal life if you are positive, but with cancer you go for treatment almost daily.”—Female, 14 years“</p> <p>We are lucky because someone with cancer is sometimes not allowed to eat some foods, but those with HIV can eat anything.”—Male, 17 years</p>                                                                                                                          |

AIDS, strains of the virus, the significance and meaning of viral load tests, and encouraged each other to be engaged and knowledgeable about their results (Table 1). The adolescents had a strong understanding of these topics, and were taught the use of metaphors to describe biological and viral properties, such as CD4 cells as “body guards” or “soldiers” during the sessions. The role of the HIV counselor was particularly important in discussions around HIV literacy, as the counselor was able to interject to provide accurate responses to questions and identify and clarify common misconceptions.

Clarifying the routes of HIV transmission was of interest, as was the impact and risk of infection with other STIs and the use of PREP with HIV negative partners. Among these participants who all had acquired HIV perinatally, there was a particular interest in learning more about HIV transmission from mother-to-child, as some participants questioned how and from whom they became infected and did not understand the concept of maternal transmission. The majority of participants did not have strong STI literacy, and asked many questions about the possibility of co-infection with other STIs. Participants discussed the common side effects that they experienced because of ART treatment and shared strategies for managing them.

The perceived severity of HIV was initiated by the participants and discussed at length. In comparison to other health conditions, the majority of adolescents’ viewed HIV as “better” and that they were “lucky” to have HIV compared to other illnesses, like cancer. The participants perceived HIV as both preventable and treatable, which they did not believe to be the

case for cancer. Accessibility and ease of treatment for HIV was also noted as a perceived benefit of having HIV over other health conditions in this setting. Participants identified a need for a safe place to ask questions about their health and to better understand HIV-related specifics.

### *Medication Taking Literacy*

The adolescents discussed HIV drug adherence extensively (Table 2). The majority of participants had high medication-taking literacy, and generally understood that they needed to maintain adherence in order to stay healthy. The participants understood the consequences of missing doses and encouraged each other to take their medicines according to their clinical schedule. The participants acknowledged and discussed barriers to ART adherence, such as general forgetfulness and perceived stigma that led to hiding their medication from others. The most common suggestion for overcoming medication-taking barriers was identifying places to hide their medications so that others would not find it. The participants also identified fear and stress related to medication-taking. There were many questions regarding common misconceptions of HIV medication taking, including the ability to borrow someone else’s medicines and eventually being able to stop taking medicines all together. Two participants were not sure if they would eventually be able to stop taking their HIV medications. Several participants had questions about the availability of a cure for HIV, for which the counselor provided clarity on the current need for long-term medication-taking in light of cure.

**Table 2.** Medication-Taking Literacy.

| Subtheme                      | Illustrative Quote                                                                                                                                                                                                                                                 |
|-------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Definition                    | “It’s the way you relate your medicine with time, like punctuality in terms of taking medicine.”—Male, 15 years<br>Drug adherence is taking drugs the right way.”                                                                                                  |
| Reminders                     | “Ok guys night, see each other on Wednesday at the meeting and come with the bottles of drugs, remind each other.”—Male, 17 years                                                                                                                                  |
| Borrow Medication             | “You mean I can’t borrow? If I may ask, what if your ARVs are finished and your neighbor has who can help you—do you mean I should not borrow?”—Male, 15 years                                                                                                     |
| Consequences of Non-Adherence | “If you have not been taking your medicine for a long time, your viral load will be very high and it is very easy to get TB—that’s why you are given medicine.”—Counselor<br>I was told if I don’t take ARVs, I will not be as strong in the body.”—Male, 16 years |
| Adherence Education           | “What if I get late to reach home do I still take the medicine or I just stop?”—Male, 16 years<br>What happens when you are not taking food and are using drugs; some fear they might die if they take medicine without food”—Female, 15 years                     |
| Barriers to adherence         | “What makes most people fail to take the medicine as required?”—Counselor<br>Participant 2: “Fear of being seen.” Female, 17 years<br>Participant 3: “Feeling like you are not loved at home, being oppressed, stress or something like that.”—Male, 16 years      |

**Table 3.** HIV Infection in the School Setting.

| Sub-Theme                        | Illustrative Quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
|----------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Secrecy                          | “In boarding [school] you can easily stop taking the medicine for fear of being seen.”—Male, 16 years<br>Participant 1: “What would happen if they knew that you are taking medicine?”—Female, 18 years<br>Participant 2: “I will stop going to that school.”—Female, 18 years<br>Participant 1: “What if your parent is not willing to get you out of that school?”—Female, 18 years<br>Participant 2: “I would lie that the medicine is for the chest.”—Female, 15 years |
| Disclosure                       | “I can’t disclose because people will talk about you for a whole year.”—Female, 18 years                                                                                                                                                                                                                                                                                                                                                                                   |
| Strategies for medication taking | “Someone had shared that they put a paper in the bottle to minimize the noise—but never remove from the bottle.”—Male, 18 years<br>“I had a tactic, I would wait in the evening before prep time, I go remove, and then when I go to sleep, I swallow.”—Male, 18 years                                                                                                                                                                                                     |
| Stigma                           | “Students will hate you because of your HIV status.”—Female, 18 years<br>“In fact, what I experienced was the fear of asking for permission to go pick medicine.”—Male, 18 years                                                                                                                                                                                                                                                                                           |
| Treatment by Teacher             | “I saw I was treated badly, I said then I’m discovered.”—Male, 16 years<br>“By the way there was a time they found out, but the principal was very helpful because he used to keep them [ARVs] in his office.”—Male, 16 years                                                                                                                                                                                                                                              |
| Response to HIV Discussions      | “But at school the teacher discourages me because he says if you are HIV positive you can’t live long.”—Female, 18 years<br>“But for me, when the teacher is teaching about HIV I feel like crying in my heart—but I persevere.”—Male, 17 years                                                                                                                                                                                                                            |

### HIV Infection in the School Setting

A major theme that arose from the WhatsApp® chat transcripts was the challenges and experiences that ALWH have in the school setting (Table 3). Boarding schools are common for secondary education in Kenya,<sup>44</sup> which presents its own unique challenges for ALWH. The adolescents were knowledgeable about the importance of ART adherence, but they also described the importance of keeping their HIV status a secret from their classmates and teachers because of the risk of stigma or discrimination. Nearly all adolescents reported skipping or delaying taking medication during school hours in order to keep their status a secret. The majority of adolescents had previously established tactics for taking their medicines during school, including removing the pills from the bottle so as not to draw attention to themselves, and sneaking

away when nobody was looking. The participants identified the critical need for a space to find solutions to common medication taking problems and discuss tactics for maintaining adherence in secret. The majority of participants acknowledged the presence of stigmatizing behavior in the school setting, and the impact that it has on their behaviors and feelings.

Participants discussed the role and behavior of teachers in the school setting. Participants identified how their teacher’s knowledge of their HIV status affected how the teacher treated them, both favorably and unfavorably. Discussions on HIV in the classroom were especially challenging for many of the adolescents, citing that discussing HIV made them feel like the teacher found out about their status and was talking about them. The adolescents acknowledged their own emotional responses to the way that HIV discussions were

**Table 4.** Relationships.

| Subtheme                        | Illustrative Quote                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
|---------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Confidentiality                 | "It's telling someone about something personal and it is supposed to be a secret between you two."—Female, 17 years                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| Child-Parent Relationship       | Counselor: "What do you really enjoy in your parent?"<br>Participant 1: "Allowing me to go to school."—Male, 14 years<br>Participant 2: "Providing food."—Female, 17 years<br>Participant 3: "They guide us to the right side."—Male, 15 years<br>Participant 4: "When he focuses on my studies with my sister and my brother."—Female, 18 years<br>Participant 5: "The way she brought us up."—Female, 19 years<br><br>Participant 1: "How can one deal with a harsh parent?"—Female, 14 years<br>Participant 2: "In case a parent is harsh seek help from a counselor."—Female, 14 years<br>Participant 3: "All is by respect."—Male, 14 years<br>Participant 4: "Yes if you do not respect them you cannot go far."—Female, 18 years                      |
| Home Stigma                     | "True and whenever you make a mistake they [relatives] keep reminding you that you are HIV positive."—Female, 18 years                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
| Friendship                      | "I want to know how to find a friend who shares with you personal stuff."—Male, 15 years<br><br>Counselor: "Friend is a person with you when you are in the state of trouble and time, he cares about you and does not hurt you. Even if others disagree with him he stands with you to the end—finding such friends is not easy."                                                                                                                                                                                                                                                                                                                                                                                                                           |
| Disclosure to Friends           | "There is no good friend in my world, it's better to keep it a secret."—Male, 17 years<br><br>Counselor: "Having a friend does not necessarily mean that you should tell him your secret. There are those who do good to you but are not true friends."                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| Romantic Relationships          | "If you know your status, you need to keep away from dating, think about other things first."—Female, 14 years<br>"What if you get married to someone who is not HIV positive, will you really have a good life?"—Female, 18 years                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| Disclosure to romantic partners | "It's possible to have an HIV negative partner but make sure you tell him about your status so that you prevent infecting them."—Male, 17 years<br><br>Participant 1: "I don't think having a girlfriend is wrong and also think it's good to tell her about your status. If they are not comfortable it's fine because there are those who will love you despite your HIV positive status."—Male, 17 years<br>Participant 2: "Look at it this way bro, if you tell her you are positive she will go telling everyone, even your friends."—Male, 17 years<br>Participant 3: "It depends if I tell her and she tells others—I will tell her I was just joking"—Male, 17 years<br>Participant 4: "You will first make an agreement with her."—Female, 18 years |
| Sex                             | "Guys what is the right time of doing sex? Assume you've been asked that what would you answer?"—Male, 17 years<br><br>Counselor: "I say the ones who have not begun do not be in a hurry and for those already having sex use protection—although it still has its risks, it's not 100%."                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| Group relationship              | Participant 1: "Hey our bro, Robert* sorry for losing your Dad."—Male, 17 years<br>Participant 2: "But all pray and give hope to live because we are all travelers in the world."—Female, 14 years<br>Participant 3: "Very sorry, bro Robert,* don't lose hope."—Female, 14 years<br><br>"Guys I have a problem where I am now, mum is not in, and I've had visitors at home, my confusion is the time to take drugs, I've some fear when I want to take the medicine, meaning I don't want them to know my secret, can you help me please."—Male, 17 years                                                                                                                                                                                                  |

\*Participant name has been changed.

facilitated in the classroom and identified stigmatizing behavior on the part of the teacher. Adolescents shared feelings of stress, fear, and loneliness. The adolescents heavily relied on one another during conversations about the school setting, the majority of which shared their personal experiences and feelings in the group chats.

### Relationships

The adolescents discussed and asked questions about varying types of relationships that they experience and observe (Table 4). They discussed confidentiality in relationships and sought advice on disclosure and how to know if one could trust someone with sensitive information.

Within their family dynamics, participants discussed relationships with their caregivers and sought advice on how to navigate “harsh treatment.” Several participants shared their own experiences dealing with challenging caregivers. The counselor did not make referrals related to trauma, neglect, or abuse based on participant discussion. In the home setting, many adolescents described experiences of discrimination from relatives and sought advice on how to navigate medication-taking when visitors are present. Friendship was an important topic for the adolescents, who articulated the importance and value of friendship, but expressed challenges with finding friends with whom they could be honest about their HIV status and other personal matters. Many of the adolescents felt strongly about not disclosing their HIV status to friends for fear of betrayal in maintaining their secret. Finding and maintaining open and supportive friendships was a real challenge for this group.

Discussions around navigating romantic relationships as an ALWH was of particular importance to the participants. They posed questions around the possibility of loving and marrying an HIV negative person, how to date as an ALWH, and how to know when to disclose their HIV status to their partner. Sexual initiation was discussed, and the adolescents identified maturity and stability as important characteristics in choosing a romantic partner.

The relationships that participants were developing with one another through this intervention were also on display. The adolescents encouraged each other to stay positive, to take medicine properly, complete homework assignments, and participate in discussions, and they offered support during challenging times, such as illness or a loss of a family member. Importantly, this intervention facilitated an environment in which the adolescents could be open and honest about their HIV status with their peers, something that they indicated as a significant challenge in their day-to-day lives. The adolescents acknowledged and discussed challenges with creating and maintaining peer relationships related to non-disclosure and fear of stigmatization, highlighting the value of a peer support intervention for participants.

### Other Topics of Interest

The adolescents brought up other topics in which they had questions or thoughts, including what it means to be healthy, experiences and concerns around waterborne illnesses and general hygiene practices. Participants were particularly interested in learning more about drug and alcohol use, and its impact on their HIV medications. Notably, religion played a large role in the lives of these participants, who generally viewed God as someone who provided strength, protection for them, and a possible cure for HIV. The adolescents encouraged one another to attend church weekly and to lead prayer in the WhatsApp® group chats before signing off for the evening.

### Discussion

#### *Critical Gap in HIV Education Among Adolescents with Perinatally Acquired HIV*

Our results demonstrate gaps in critical areas of HIV knowledge, including routes of transmission, STI prevention, medication-taking skills and chronic disease management among ALWH in western Kenya. In a study assessing HIV knowledge among adolescents with perinatally and behaviorally acquire HIV, Barnes *et al* found that adolescents with behaviorally acquired HIV had significantly better understanding of HIV-related topics than their perinatally infected counterparts.<sup>17</sup> These results may be influenced by increased autonomy in care engagement and management among behaviorally infected adolescents,<sup>17</sup> highlighting a need for continued education and progression to autonomy among adolescents with perinatally acquired HIV. Our data supports this need for ongoing education and support for adolescents with perinatally acquired HIV, as they demonstrated inconsistent knowledge regarding HIV topics. Provider discussions with adolescents with perinatally acquired HIV and their caregivers are important in increasing HIV-related health literacy, but opportunities for education within environments established for peer engagement are also critical. Here, we see evidence that the mobile platform intervention and use of pseudonyms allowed participants to speak freely and share experiences without fear of retribution, allowing participants to discuss difficult topics with their peers. Future use of mobile interventions with this population should incorporate HIV education.

#### *Need for Increased Opportunities for Mental Health Services and Peer Support*

While there are few data on mental and behavioral health disorders among ALWH in Kenya and other LMIC,<sup>45,46</sup> the literature shows that psychiatric disorders, general psychological distress, and behavioral problems are leading causes of health-related disability among children and adolescents worldwide—affecting 10-20% of the population.<sup>47-49</sup> Moreover, evidence demonstrates that only 1% of schools in LMIC

have mental health professionals on staff,<sup>50</sup> with only an estimated one psychiatrist for every 4 million children in LMIC.<sup>51</sup> This is concerning as participants identified a need for a place to ask questions, find solutions to problems, and foster feelings of support. Fear of stigmatization is a major reason for non-disclosure of status among ALWH,<sup>52</sup> which may subsequently lead to isolation and mental health problems. The adolescents discussed challenges with their mental health and peer relationships, reinforcing the critical need for opportunities for peer support for ALWH.

Given the lack of mental health services available for ALWH and the stigma surrounding it, opportunities to extend mental health services through alternative modes of delivery—such as teleconsultations and tele-psychiatry—may offer particular benefits for adolescents in LMIC.<sup>51</sup> A recent systematic review of randomized control trials assessing phone-based and computerized interventions for PLWH concluded that the delivery of mental health and social support through these modalities was generally acceptable to patients and effective at improving outcomes<sup>53</sup>; however, the review did not find studies that evaluated comparable interventions to this one, which focused on creating a virtual space for peer counseling and education among ALWH in East Africa. Adolescents need a safe space to discuss challenges, feel supported and empowered to make good choices. Our data demonstrates this need, as participants asked questions like, “When is the right time to have sex?” and “How do you know you can trust a friend?” Participants acknowledged the emotional and mental health responses they experience because of HIV discrimination, as well as the lack of peer relationships and support. Creating more spaces for adolescents to seek guidance and support for their day-to-day challenges and experiences is important and may play a role in improving mental health and in crisis prevention. The open dialogue in these WhatsApp<sup>®</sup> chat groups further points to the potential for using virtual platforms for mental health support options in this setting.

### *Interventions in the School Setting Are Necessary*

Participants discussed significant challenges related to HIV stigma and medication-taking in the school setting, pointing to another key space for intervention. In several studies in SSA, HIV-related taunting, gossiping or bullying by peers at school are critical experiences for HIV infected adolescents<sup>54-57</sup> and may lead to problems in school attendance or accessing peer support networks.<sup>58,59</sup> In Kenya, both adolescents and their caregivers report that HIV stigma in schools hurts their retention in care, adherence to medications, mental health, and beliefs about themselves.<sup>60,61</sup> Our data describe the connection between HIV stigma in the school setting and the perceived barrier to medication-taking. The adolescents’ suggestions for maintaining good adherence all preserve secrecy of their HIV status, highlighting how they consider the environment unsafe for disclosure. Participants acknowledged fear of HIV stigma and its impact on their medication-taking, which outweighed the perceived benefits of ARV adherence.

Adolescents in this study, as well as in published literature, also report experiencing HIV stigma from their teachers,<sup>15,61</sup> as well as stigmatizing aspects of the current curricular content related to HIV.<sup>15,61</sup> In Kenya, little is known about HIV perception and stigmatizing behaviors of teachers, as many primary and secondary school teachers rely on Ministry of Education approved syllabi to disseminate HIV information in the classroom. The context in which this information is relayed in the classroom is dependent entirely on the attitude of the teacher. Not only do school-based experiences of HIV stigma directly impact infected adolescents, but stigmatizing content and negative teacher attitudes shape the beliefs of their peers regarding HIV and its treatment.<sup>62</sup> The adolescents detailed their experiences listening to stigmatizing lessons and opinions from teachers in the classroom, which led to significant emotional responses and fear in requesting critical and necessary support, perpetuating a cycle of secrecy. The adolescents in this study acknowledge and describe feeling scared, embarrassed and stressed routinely during school, emotional responses that not only impact ART adherence, but also self-stigma, that may ultimately lead to significant mental illness. The stigmatizing behavior by teachers may also impact the beliefs and behaviors of the adolescents’ peers, for whom the participants did not support HIV disclosure. The adolescents in this study detail significant challenges with making and maintaining friendships in which they feel safe and empowered to disclose their HIV status, which could be influenced by the stigmatizing behavior modeled for their peers in the classroom. The adolescents spend most of their waking hours in school, making this a critical setting for intervention.

### **Limitations**

There are several limitations to this study. First, this was a small pilot study of 29 participants, which may limit generalizability. Second, the perspectives gathered in this study are from a specific population in western Kenya and may not be generalizable to other regions in SSA or resource-limited countries. Lastly, despite high user engagement, we did not assess the number of participants that contributed to each theme. Future studies should consider the volume of engagement within each topic and resulting theme to prioritize areas of future intervention.

### **Conclusion**

ALWH in Kenya meaningfully engaged in an HIV education and peer support intervention via WhatsApp chat application. We found this platform to be useful in facilitating critical conversations for this population, in which adolescents could seek information and support as well as help in navigating challenging situations. The content of these conversations demonstrate a good understanding on medication and importance of adherence but elucidate the need for further education to support HIV literacy and mental health support for adolescents with



perinatally acquired HIV, as well as intervention opportunities for stigma mitigation in the school setting.

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