Exploring the Disparities between Health Knowledge and Adherence among Adolescents living with HIV on Second-line Antiretroviral Therapy in Rural Western Kenya

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ABSTRACT

Background and Objectives: Adolescents living with HIV on medication have an additional duty to ensure adherence to antiretroviral therapy. There have been documented challenges in retaining adolescents in care and treatment programs, loss to follow-up, and poor adherence that have led to continued deaths. Adolescents on second-line antiretroviral therapy have reduced therapeutic options as they have resisted first-line drugs, and the third-line is not available in this resource-poor setting. Ensuring and upscaling adherence support is crucial. This study sought to find out the level of basic health literacy in terms of knowledge of one's drugs, HIV re-infection, and HIV drug resistance and how this knowledge influenced adherence.

Materials and Methods: This was a longitudinal ethnographic research coupled with a mixed methods approach. Semi-structured questionnaires were administered to 37 participants. The study conducted ten in-depth and 13 key informant interviews, participant observation, and three focus group discussions. Quantitative data was analyzed using SPSS, and cross-tabulations were done to identify appropriate relationships. Qualitative data was analyzed thematically and presented using descriptive reports and verbatim quotations.

Results: Participants who had basic knowledge of the ARVs they were taking exhibited good adherence compared to those who did not know their ARVs. Among the participants, 72% knew what HIV re-infection was, yet 43% still had poor adherence. This was similar to basic knowledge of HIV Drug Resistance.

Conclusion: There was sufficient health knowledge. However, the study observed a lack of ability to translate knowledge into practice. Other factors alongside health knowledge in determining health-promotive behaviour could be explored.

Paper Type: Research Article
Keywords: Adolescents, Adherence, Kenya, Knowledge, Medical Anthropology.

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Introduction

Adolescents (10-19 years) are disproportionately affected by HIV and AIDS as they transition into adulthood (1). Adolescence is characterized by less parental support and supervision, increased risk-taking, and immature judgment (2). Adolescents living with HIV (ALHIV) are responsible for a chronic disease that requires life-long daily antiretroviral therapy (ART). Research shows that challenges faced in retaining adolescents in care and treatment programs, loss to follow-up, and poor adherence among those on ART have contributed to deaths among ALHIV (3). Adherence support for adolescents must thus be scaled up to sustain treatment, reduce instances of HIV drug resistance (HIVDR), and promote the achievement of global targets of 90-90-90 for treatment by 2020 and eliminate AIDS as a public health threat by 2030 (4). Thus, understanding the reasons for non-adherence to ART among ALHIV is essential as countries move to provision of ART to all persons living with HIV irrespective of CD4 levels in line with WHO guidelines on ART (1) and also in conformity with the WHO alert issued regarding the rising levels of HIV Drug Resistance (HIVDR) in highly endemic zones. In addition, because poor adherence can lead to virological failure and subsequent HIVDR, it is crucial to elucidate factors necessitating persistent sub-optimal adherence for ALHIV to avoid reduced therapeutic options for this age group.

In Sub-Saharan Africa (SSA), for instance, only 26% of adolescent girls aged 15-19 years and 36% of adolescent boys of the same age have a comprehensive health knowledge of HIV against the WHO recommended level of 85% (3). The Kenya Demographic and Health Survey (KDHS) of 2022 reported a comprehensive and correct HIV knowledge level of 52% among adolescents. However, no survey has been done specifically among ALHIV on ART about accurate HIV knowledge. Furthermore, these surveys were conducted among adolescents generally and, therefore, may not accurately show the levels of HIV knowledge among ALHIV on ART. Similarly, ART knowledge is yet to form part of these surveys; neither has been explicitly conducted among ALHIV to ascertain the level and accuracy of ART knowledge to address the gaps in knowledge and thus promote adherence to ART.

Even though massive intervention strategies have been implemented since HIV was discovered, the numbers of ALHIV have continued to rise, accompanied by a rise in the deaths of ALHIV even after initiating ART. These HIV–related deaths have been orchestrated by poor ART adherence. ALHIV in second-line ART are at a higher risk of failing their treatment again and also have reduced therapeutic options as third-line ART is not widely available in resource-limited settings. ALHIV who struggle to adhere to their ART regimen may be experiencing low health knowledge levels regarding adherence. Active participation in healthcare is crucial for patients to benefit from ART fully. This article, as part of a more extensive doctoral study, endeavors to answer the following two research questions among 15-19-year-old ALHIV on second-line ART:1) What is the health knowledge level among ALHIV in terms of [1] general ARV knowledge [2] HIV re-infection [3] HIV drug resistance. 2)

To what extent do the exhibited levels of health knowledge influence adherence?

Materials and Method

Design

Our research involved a focused ethnographic study combined with a mixed methods approach. I administered semi-structured questionnaires to all respondents and conducted in-depth and key informant interviews and focused group discussions. The interviews and discussions lasted between 45 minutes to 2 hours. The tools were piloted, and triangulation was done to promote validity and reliability and translated into the local language to ensure respondents understood the questions.

Study Area

The study was conducted in Gem sub-county, Siaya County. Siaya County has been categorized as one of the highly endemic zones in the country (5). It is part of the KEMRI/CDC Health and Demographic Surveillance Area (HDSA), which provides comprehensive population-based data on various health indicators and population knowledge and beliefs at the individual and household level (6).

Study Population

The study targeted male and female ALHIV on second-line ART aged 15-19 years enrolled in the 29 public patient support centers (PSCs) in Gem sub-county and are residents of the sub-county. The study also engaged their caregivers as well as key informants.

Sample Size and Sampling Technique

There were 29 PSCs in the study area. The study randomly selected a patient support center from the six administrative wards comprising the sub-county. Six PSCs were obtained and utilized for identifying study participants. Considering the small number of ALHIV on second-line ART enrolled in the sampled PSCs, the study recruited all 37 ALHIV on second-line ART as respondents. The unit of analysis was ALHIV on second-line ART. The study used the PSCs as points of initial contact with the respondent whenever they came for clinical appointments.

Data Collection

Once contact was established, the ALHIV and their caregiver provided informed consent and permission to participate in the study. As part of this, the respondents also gave directions to their homes for subsequent fieldwork engagements. I proceeded to locate the homes and build rapport. Afterward, a semi-structured questionnaire was administered to all 37 participants involved in the study. In the process, I identified 10 (3 female and 7 male) respondents and engaged in-depth for nine months. I conducted 13 key informant interviews with six adherence counselors, six peer educators, and the adherence and retention officer from the Centre for Health Solutions, which plays a supervisory role in all the PSCs within the sub-county. The study also conducted three focus group discussions with eight male, eight female ALHIV, and eight caregivers towards the end of the research process that began in July 2017 and ended in October 2018.

Data Analysis and Presentation

Data interpretation began while the fieldwork was in progress. I reflected on the information I had gathered after every research phase and noted emerging themes and how these shaped the course of research. Once the fieldwork was completed, I coded the data from the semi-structured

questionnaires administered and subjected it to the Statistical Package for Social Science (SPSS) to establish frequencies and percentages. I then did cross-tabulations, which helped pinpoint relevant connections between the qualitative data sets. Transcription, translation, and coding of voice-recorded data from in-depth interviews and FGDs followed. The process led to emerging themes and patterns that I used to establish explanations and deductions. The presentation of quantitative data utilized tables containing frequencies, percentages, and correlations between various variables and adherence to ART. Qualitative data was presented by using descriptive reports and direct quotations.

Results

Socio-demographic characteristics of the respondents

Good adherence (G) in this study referred to ALHIV who had suppressed Viral Loads (VL) of less than 400 copies, with the lowest reported being 37 copies, and whereas poor adherence (P) referred to unsuppressed VL of more than 1000 copies with the highest reported being 112,000 copies. The study had 37 respondents consisting of 19 males (G9/P10) and 18 females (G12/P6). The ages of respondents were as follows: 15 years (G8/P11); 16 years (G2/P1); 17 years (G7); 18 years (G1/P2) and 19 years (G3/P2). The study also looked at the orphanhood status of the respondents, with results showing double orphans: 20 (G11/P9); maternal orphans: 5 (G2/P3); paternal orphans: 4(G3/P1) and non-orphans: 8(G6/P2). The study also found out the educational level of the respondents. The educational institution represented this the respondents were part of. Different aspects of HIV health knowledge are part of the academic curriculum in Kenyan schools. Among the respondents, those in primary schools were 18 (G10/P8); day secondary schools: 7(G5/P2); boarding secondary schools: 7(G4/P3); tertiary institutions: 2(P2) and 3(G3) were not in any formal institution of learning. Finally, I looked at the mode of infection among the respondents and found that 13 (G10/P3) had been infected behaviorally/sexually, whereas 24 (G12/P12) had been infected perinatal.

Theme 1: Basic Antiretroviral Therapy Knowledge and its Influence on Adherence to ART

It was essential to establish whether ALHIV could identify and name their ARVs because it has been reported previously that ALHIV who understand what antiretroviral drugs they are on, how the drugs work, and common side effects are in a better position to take care of their health and by extension, this would promote adherence to ART. This study sought to establish whether ALHIV knew and could identify, either by name or appearance, the specific ARVs they were taking.

Evidence presented in Table 1 shows that respondents who had basic knowledge of the ARVs they were taking, that is, they could identify their ARVs by appearance, had good adherence as opposed to those who did not know their ARVs and thus exhibited poor adherence. In addition, older ages of 17, 18, and 19 years were more knowledgeable about the ARVs they were taking than younger ages of 15 and 16 years. Among respondents aged 17-19 who knew their ARVs, a majority could identify them from a shelf consisting of other ARVs they were not taking. However, only 3 (2 male and 1 female)

respondents knew their ARVs by name. However, despite knowing the ARVs, four male respondents (two 18-year-olds and two 19-year-olds) still had poor adherence.

Table 1. Relationship between Knowledge of ARVs and Adherence to ART

Gender of ALHIV	Female		Male		Total
Knowledge of ARVs	NO	YES	NO	YES	
Good Adherence		12		9	21
15		4		4	8
16		1		1	2
17		3		4	7
18		1			1
19		3			3
Poor Adherence	5	1	5	5	16
15	5	1	4	1	11
16			1		1
18				2	2
19				2	2
Total	5	13	5	14	37

Relationship between Knowledge of ARVs and Adherence to ART

The lack of the ability to identify and name their ARVs among respondents aged 15 and 16 was a cause of concern as they constituted 60.5% of the study sample. Most of this age group (44.7%) were in primary schools, which contributed to their inability to identify and name their ARVs. A female caregiver reported during an IDI that knowing the ARVs her son was taking saved the situation. She narrated that:

There was a time I traveled, and he went for pill refill while I was away. After a short time, he started complaining of persistent headaches that were not stopping even after I gave him panadol. You know, we have been taught that when something like this happens, we check if the drugs are being taken, as the doctor said. So I told him to bring them so I could give them to him. But when he brought it, I immediately saw that one bottle was smaller than the other one. Usually, his bottles are of the same size. I was not able to read the names of the drugs; they are challenging, but I knew that the small bottle was not his, so we went to the doctor, who was sorry for the mistake but was also very happy that we saw the mistake before it took long.

Such instances could be rare, but whenever they occur, knowledge of one's ARVs can help correct the mistake before a lot of damage happens to one's health. During caregiver interviews and FGD with caregivers, I observed that caregivers on ART could identify their ARVs and those of respondents under their care compared to their counterparts who were not on ART. One female caregiver of a male ALHIV during an IDI reiterated that:

I know them; we started early when he was eight. It is like my food; it is in my mind, so I know them. I also know mine, and I have told him why he is taking ARVs so he is comfortable (IDI with female caregiver).

However, the social worker in one orphanage did not know, nor could she identify, the ARVs that one female respondent was taking. When I inquired why this was so, she responded that it was the mother-care employee who was in charge of her drugs and not herself, so she had never bothered. The mother-care employee, an older woman, and a retired community health volunteer could identify the ARVs taken by this female respondent.

Coupled with the ability to identify and name one's ARVs, it was necessary to

establish whether respondents knew how (referring to biological rationale) the ARVs worked in their bodies; as an adage goes, 'knowledge is power.' Knowledge of the way ARV worked was vital as it helped to emphasize why the drugs were to be taken as prescribed without missed doses or delays in timing. Study findings showed that almost half, 18 respondents, knew what the ARVs were doing in the body but not how the ARVs worked. The respondents said that ARVs 'duoko rateke mag kute chien' (ARVs reduce viral load), and others said ARVs 'mero kute' (ARVs make the virus sleep). In essence, respondents were aware that the primary role of ARVs in the body was to reduce one's HIV VL but had no knowledge of how the ARVs accomplished this role. The remaining 19 respondents could not relate ARVs and reduced VL. They were taking drugs as instructed. However, compared with adherence levels, respondents who exhibited good adherence were 21. In contrast, those with poor adherence were 16, implying that three had good adherence, even among 19 who could not relate ARVs to reduced VL. When asked why they needed to take their medication as prescribed, all the respondents answered in the affirmative. Study findings show that 32.5% of respondents understood why they should take their medication as prescribed to prevent the viral load from increasing, a frequently used clinical indicator to determine adherence. Another closer response was avoiding opportunistic infections/sickness (21.6%). Yet other respondents could also relate to taking their medication as prescribed and good health (24.3%) that would ensure long life (16.2%). Generally, therefore, all the respondents demonstrated knowledge of why they were required to take their medication as prescribed despite 16 presenting with poor adherence. However, as much as respondents in the study were aware of valid reasons why they should take their ARVs as prescribed, in practice, 16 of them did not. All confirmed this (6) adherence counselors who were key informants as they reported that ALHIV on first-line had better adherence than those on second-line despite those on second-line being at more risk due to reduced therapeutic options. Reasons given for this scenario were that most ALHIV on the first–line were non-orphans and thus were getting social support from their parents. In contrast, those on the second line were mainly double and partial orphans living with caregivers and were not getting adequate social support. Some caregivers were giving respondents second-line ART drugs without disclosing to them what those drugs were for and the need to take them as prescribed. Similarly, one key informant during KII reported that:

The second-line clients have challenges back at home, and most of them do not stay with their parents; they are orphans. This leads to non-disclosure and virological failure. By the time we address these barriers and empower the client to be resilient and take responsibility for their lives, mutation has occurred and must be switched to second-line. Once we do this, most of them respond well to the second line (KII with adherence counselor).

Similarly, all the respondents interviewed while administering the semi-structured questionnaire were aware of one thing or the other that could happen to them if they did

not take their drugs as prescribed by the doctor.

The findings in Table 2 showed that all the respondents knew the dire consequences that would occur if they did not take their ARVs as prescribed. A majority (40.5%) reported that they would die, and one would assume that the fear of death would be a solid motivation to adhere to medication and thus exhibit undetectable VLs, but this was not the case going by the reports obtained from key informants and also poor adherence shown by 16 respondents. Secondly, other respondents expressed consequences relating directly to their health, that is, different types of sickness now and again (37.8%) that may affect their weight. During an IDI, a female caregiver of a male respondent narrated that:

Before failing first-line, he used to forget, but after the ordeal, he saw how his skin was affected by rashes and the embarrassment he got from his peers, and also how he lost a lot of weight until his trousers were falling off. Now, he takes it without being reminded. He is scared of experiencing the same thing if this line fails again (IDI with a female caregiver).

I had met this particular male respondent on initial contact, looking 'very bad'; he had skin rashes all over his body that were peeling and oozing blood as he scratched himself. He was pretty thin for his age and had evidently lost some weight. On making inquiries from the key informant in the PSC where he was enrolled, he had failed first-line, and it was just two weeks since he had been shifted to second-line ART. I remembered having watched videos that portrayed HIV-positive people as very thin, sickly, and full of opportunistic infections. Having such an image and listening to respondents report about sickness and weight loss as resultant consequences of not adhering to ARVs, one would expect nothing short of good adherence reports from healthcare providers concerning these study participants. However, the knowledge and resultant behavior of some respondents did not concur. While all the respondents reported knowing what would happen, for instance, if they delayed the time or missed doses entirely, they still went ahead and missed doses. At the same time, some had poor timing, as had been reported by healthcare providers during key informant interviews. When the researcher asked during FGDs for both male and female respondents why they knew the consequences but were not adhering to prescriptions on ART, they answered that:

One could go mad if all the time they are thinking of drugs; we just live like anybody else and not thinking of drugs all the time. Then you realize time has passed, sio maksudi (it is not intentional for most of us).

Table 2. Consequences of not taking ARVs as Prescribed by the Health Care Provider

Consequences	Frequency	Percent
I can get different diseases like cough, diarrhea, headache	5	13.5
I may die	15	40.5
I will lose weight	2	5.4
My health will deteriorate and I will start being sick now and then	8	21.7
VL will increase	7	18.9
Total	37	100.0

Consequences of not taking ARVs as Prescribed by the Health Care Provider

Theme 2: Knowledge of HIV Re-Infection and its Influence on Adherence to ART

The onset of adolescence as a developmental stage heralds the beginning of boy/girl relationships that may end up in sexual debut. The study sought to determine whether respondents knew what HIV re-infection was, how it came about, and its consequences in instances where it occurred. Evidence presented in Table 3 showed that out of 37 respondents, 27 (G21/P6) knew what HIV re-infection was, while 10 (P10) did not know what it was. Among those who knew what HIV re-infection was, 16 reported that if one had sex without using a condom/unprotected sex, then they would be exposing themselves to HIV re-infection. During an FGD with female respondents, few among them were aware that unprotected sex with an infected person would bring about HIV re-infection but could not mention its consequences. However, during an FGD, their male counterparts had more positive responses that pointed to a higher level of awareness. In addition, results from caregiver IDIs and FGDs indicated caregiver knowledge of HIV re-infection but none of its consequences. One female caregiver (also on ART and a widow) of a male respondent reported during an FGD that:

I have told him that nywando kute (HIV re-infection) is real and he should avoid it. I have even explained that since I realized my status, chunya nokalo wach tuk tuk (I stopped bringing men to my house) (Female caregiver: FGD discussant).

While conducting KIIs, it was reported that most respondents had unsuppressed VLs because they had become sexually active and changed sexual partners casually. Yet, they did not use condoms due to either unavailability or peer pressure. During an FGD with male respondents, discussants reiterated that sex was part and parcel of youth culture:

Ka idhi gi nyako e thum, ok inyal duoke dalagi maok inindo kode, mano sheria mar ojande (if you go with a girl to night dances, you do not just escort her back to her home without having sex with her, that is the law among us youths). Most of the time, we meet the girl while at night dances (popular disco matanga), and because you did not plan it and you are in a hurry and also did not carry a condom, you just have sex (Male ALHIV: FGD discussant).

In addition, during IDIs, one female respondent in a mixed day secondary school reported having input a method of family planning, levonorgestrel implants (generic name: Jadelle), locally referred to as 'Omuogo,' that prevented her from getting pregnant. This respondent reported that she had sexual encounters with her boyfriend, who was also in her class, and was not worried about condom use since she had the family planning method in place. It is evident here that the fear of an unwanted pregnancy supersedes that of HIV re-infection. Another female respondent also said she lived with her grandmother and slept in her kitchen. This is where her boyfriend visited her at night, and it is him who always came with a condom. I asked what would transpire in instances where the boyfriend showed up without a condom. She responded that it had never happened, but she would not turn him down all the same if he did not carry a

condom. This is a worrying trend since most respondents who were discussants in an FGD reiterated that they would not consider disclosing their status to anyone, not even their sexual partners, for fear of rejection and would, in turn, not ask to know the status of their sexual partners as well. Yet again, respondents' knowledge and behavior did not concur; 27 demonstrated knowledge of HIV re-infection and reported unprotected sexual intercourse with an infected person as the primary cause of HIV re-infection but still proceeded to engage in unprotected sexual intercourse with partners they did not know their HIV status no wonder there were 6 exhibiting poor adherence among them. Furthermore, the remaining ten respondents who did not know about HIV re-infection and showed poor adherence were not safe either because of the influences of peer pressure that they were bound to encounter.

Table 3. Relationship between Knowledge of HIV-Reinfection and Adherence to ART

Knowledge of HIV-Reinfection	NO		NO Total	YES		YES Total	Total
Gender	Female	Male		Female	Male		
Good Adherence				12	9	21	21
15				4	4	8	8
16				1	1	2	2
17				3	4	7	7
18				1		1	1
19				3		3	3
Poor Adherence	5	5	10	1	5	6	16
15	5	4	9	1	1	2	11
16		1	1				1
18					2	2	2
19					2	2	2
Total	5	5	10	13	14	27	37

Relationship between Knowledge of HIV-Reinfection and Adherence to ART

Theme 3: Knowledge of HIV Drug Resistance and its Influence on Adherence to ART

Results from semi-structured questionnaire interviews with ALHIV showed that 27 (G21/P6) had basic knowledge of HIVDR. Despite having translated the instrument into the local dialect, 10 (P10) respondents were not able to demonstrate awareness of the existence of HIVDR. This high level of knowledge of HIVDR was because before being shifted to second-line ART, in-depth counseling was done, part of which entailed drug resistance information (Table4).

The researcher went ahead to inquire whether respondents knew whatever led to HIV Drug Resistance. Most (54.1%) of ALHIV mentioned that poor timing or delay in taking drugs, as well as missing drugs, would create an environment where HIV would become resistant to drugs and HIVDR would occur. Only 5.4% of ALHIV associated HIVDR with HIV re-infection, whereas only 5.4% knew that prolonged use of ARVs may expose

someone to HIVDR. One of the key informants during KII reported that unlike first-line ART, where there are many drugs, there is only one drug in second-line ART. Finally, the study established whether ALHIV knew the consequences of experiencing HIVDR. The most mentioned consequence was death. Among respondents who knew HIVDR, twenty reported that they would die quickly; three said other opportunistic infections such as cough and diarrhea would attack them and make them thin, while four reported that they would go to the doctor for help, probably to change their drugs.

One male respondent narrated during an IDI that:

He told me (the doctor) that the second-line drug is the best, and it is the one if you mess with, then there is no way I will be able to help you. He told me there is a third line, but it is costly and not readily available. He gave me an example of someone they had put on third-line, but to date, his drugs had not come. So you know I do not want to be like that man (IDI with Male ALHIV).

During KII, it was indicated that only two of the ALHIV on ART in that PSC (irrespective of ART line) had achieved zero VL in the year. In the same year, this particular PSC lost three ALHIV on ART. Subsequently, this key informant was worried that if that trend continued, primarily as the ALHIV on ART were proceeding on long holidays and Christmas celebrations, which in most instances are marked by a lot of sexual recklessness among the youth, their VLs would not be good.

Table 4. Relationship between Knowledge of HIVDR and Adherence to ART

Knowledge of HIVDR	NO		NO Total	YES		YES Total	Total
Gender	Female	Male		Female	Male		
Good Adherence				12	9	21	21
15				4	4	8	8
16				1	1	2	2
17				3	4	7	7
18				1		1	1
19				3		3	3
Poor Adherence	5	4	9	1	6	7	16
15	5	4	9	1	1	2	11
16		1	1		1	1	1
18					2	2	2
19					2	2	2
Total	5	5	10	13	15	27	37

Relationship between Knowledge of HIVDR and Adherence to ART

Discussion

The study results have shown that older respondents aged 17-19 years had higher levels of general health literacy about the basic knowledge about the ARVs they were taking. Younger respondents aged 15 and 16 years (60.5%) had low levels of general health knowledge concerning the ability to identify the ARVs they were ingesting. This finding is consistent with those of studies that reported

that many ALHIVs on ART in the Asian Pacific lacked critical knowledge about ARVs and ART regimens and did not know the name of their treatment regimen (7, 8). Knowledge of one's ARVs was essential because, in instances where ALHIV moved to other PSCs without official transfer letters or where a healthcare provider mistakably dispensed the wrong ARVs, ALHIV could remedy the situation before the harm occurred. Various strategies geared towards sensitization and awareness creation have targeted people living with HIV who are parents/guardians of perinatally infected adolescents (PIAs) with an expectation that this knowledge would trickle down to their children, who eventually become adolescents (9). This study has shown that this expectation has not been met and that some PIAs do not even know they are taking ARVs. Such strategies also ignore behaviorally infected adolescents (BIAs) whose parents may not be infected. This study has shown good adherence among most BIAs compared to PIAs, thus higher health knowledge levels. However, this was influenced by age and level of education, where most BIAs were older adolescents in secondary schools.

This study has also shown that health knowledge does not necessarily have to be precise and scientific. However, respondents can understand specific health-related information and still benefit from the same in health promotion. Respondents could not scientifically explain how the ARVs worked but expressed a lay understanding that still had a promotive impact on their health behavior. Similarly, among respondents who did not know about HIV re-infection and HIVDR, some exhibited good adherence. This finding aligns with a study conducted in South Africa (10), which observed that although participants had difficulties explaining the biological rationale of why ARVs had to be taken as prescribed, they were aware of what ARVs did in the body, mainly reducing viral load.

This study has shown that health knowledge alone is not a sufficient predictor of behavior. This was evident from the fact that despite respondents knowing their ARVs and reasons why they should take them as prescribed by the healthcare provider, they still exhibited poor adherence. Factors such as caregiver knowledge, HIV and ART status, and orphanhood status were crucial in promoting adherence to ART among respondents. This study concurs with other studies that reported that parents of adherent children could identify their children's drugs and had higher perceptions of their ability to administer the prescribed ARV dose (11-13). It was also evident from key informant reports that knowledge alone was not enough in ensuring adherence, but rather the interaction between this knowledge, the social setting, HIV status disclosure, and individual resilience towards life. According to the social-ecological perspective (SEP), the healthfulness of a situation and the well-being of its participants is assumed to be influenced by multiple facets of both the physical and the social environment (14). Promoting individual adherence enabling factors, such as positive attitudes and good adaptive skills, would thus improve adherence (15, 16). Respondents reiterated that poor timing or missing doses was not intentional or rather pre-meditated but resulted from them living their lives as

anybody else, not on lifelong medication. This apparent disconnection between knowledge of risk and actual behavior has also been reported by Adebola (17), who stated that lack of risk perception is more challenging when the adverse outcomes are not immediately apparent and in cases where there is insufficient information. However, this study has established that ALHIV have sufficient information concerning why they must adhere to ARVs and that adverse outcomes were visible since all had failed first-line and had experienced ill-health. Could this disconnect imply a lack of capacity to act on knowledge due to socio-cultural constraints, such as peer influence and the quest for normalcy? According to SEP, the way individuals construe adherence does not only include 'how to adhere' as guided by the prescriptions from the health care provider and 'why to adhere' based on individual aspects but also on the opinions of significant others, which influence the willingness and ability to adhere (18). These, coupled with interrelationships within the mesosystem, adherence to ART shifts from an individual activity to a relational one influenced by positive relationships and supportive environments. Consequently, it may not be sufficient to argue that because the ALHIV knows the consequences of not taking ARVs as prescribed, they will adhere to medication prescriptions. Adherence is thus a complex phenomenon that knowledge cannot achieve alone.

This study's finding points to low or no use of condoms among ALHIV who were sexually active, yet they were aware of the existence of condoms and knew about HIV re-infection. This concurs with other studies done in different socio-cultural contexts; for example, despite 88% of 15-19-year-old girls knowing about condoms in Vietnam, only about 45% knew where a condom could be obtained (19). Even in settings where HIV knowledge was relatively high, knowledge of a source of condoms remained low, particularly among girls. According to Idele (3), in population-based surveys conducted across East and Southern Africa, between 2000 to 2008 and 2009 to 2015, just 37% of young women had comprehensive and correct knowledge about HIV. In West and Central Africa, it stands at a mere 24%. Adolescent girls tend to have worse levels than boys. NASCOP (20) reported that 52% of adolescents exhibited comprehensive health literacy against the WHO recommended level of 85%. Although this is a reasonable quantitative picture of health knowledge, it speaks generally of adolescents. In this regard, therefore, the statistic could be lower among ALHIV on ART and even worse among those on second-line ART. However, as it has been reported earlier in this study, it is essential to reiterate that knowledge and probably availability and accessibility of condoms is not a sufficient indicator for non-use as factors that either promote or hinder specific behavior, according to SEP originate from an interplay of the microsystem, mesosystem and the exosystem. Just as Idele et al. (3) observed, a basic understanding of HIV and how it spreads is necessary for prevention. However, it is not sufficient to change HIV behavior and reduce risk.

According to Onywera (21), transmitted drug resistance levels in western Kenya were relatively higher than for most regions, including urban centers. Health knowledge

among respondents about HIV drug resistance was relatively high, with a majority able to ascertain what it was, how it came about, and its influence on their lives as patients on ART. The viral load monitoring done by the patient support centers, as much as it acted as an indicator of good or poor adherence, also promoted positive health behavior when those with high viral load succumbed. This served as evidence of the importance of adhering to ART among respondents. Accompanied by the fact that respondents had already resisted the first-line regimen, there was a realization that resistance was real and could limit therapeutic options in the future. This agrees with a study that explains that VL monitoring avoids the accumulation of resistance mutations that significantly reduce the activity of next-line options (21). This study thought it was necessary to establish the level of knowledge about HIVDR among ALHIV on second-line ART because, as has been reported previously, patients may experience baseline viral resistance or could develop resistance due to poor adherence among other clinical factors such as drug-drug interaction, malabsorption of medication, which can cause prolonged low serum blood levels of ART (22). Similarly, the emergence and transmission of viral drug resistance represent a challenge to the efficacy of ART. Consequently, basic HIVDR knowledge among ALHIV on second-line ART is essential to assist clinical efforts to preserve ART for as long as possible, especially now that they already have reduced therapeutic options.

Study Limitations and Strengths: The study was limited in two ways; firstly, as a focused ethnographic study geared towards an in-depth understanding of matters related to ART adherence, it had a relatively small sample size of 37. Its findings may thus not be generalizable to bigger populations. Secondly, it only focused on ALHIV on second-line ART because they are at a higher risk of failing their treatment regimen again, yet they already have reduced therapeutic options, thus excluding those on first-line ART. However, results could still apply to ALHIV on the first line to act as pointers of areas that would lead to poor adherence, hence necessitating a shift to the second line.

Conclusions

Given the HIV drug resistance alert issued by WHO in July 2017 in highly endemic zones, the test and treat strategy, and the guideline to shift patients to second-line ART at the slightest sign of failure of first-line ART, the study concludes that there was sufficient health knowledge in terms of basic knowledge on ART related issues among respondents. However, the study observed a need for more ability to translate knowledge into practice as some respondents had knowledge yet exhibited poor adherence and vice versa.

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Ethical approval and consent to participate: This study was carried out in accordance with the Helsinki Declaration. The Maseno University Ethics and Review Committee approved the study. Permissions were granted by the Centre for Health Solutions (CHS) as it has a supervisory role over all the public PSCs in Gem Sub-County and the PSC in charge of the six sampled PSCs. The study used adherence counselors and peer educators within the PSCs as points of initial contact with respondents and their caregivers. I got written informed consent from caregivers who accompanied the respondents to the PSC and assent from respondents. The study did not harm the respondents physically, psychologically, or otherwise. The study, however, ensured the data collection methods' comfort, confidentiality, and privacy. The study participants were assured that their responses would be kept confidential and not shared in a manner that could potentially jeopardize their privacy.

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