




Adolescents and Young Adults Knowledge, Adherence and Experiences While on Antiretroviral Therapy in a Tertiary Hospital in Lagos, Nigeria: A Mixed-Method Study

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Abstract

In Nigeria, there is a paucity of data on knowledge and experiences of adolescents and young adults (AYAs) with HIV and ART, as well as their challenges maintaining optimal adherence. A mixed-method study was carried out between August and September 2018 among AYAs attending Lagos University Teaching Hospital, Nigeria. Data collection was via AYAs' hospital records, standardized questionnaires, and in-depth interviews (IDIs). The 4-day ACTG tool was used to measure adherence. Collected data were analyzed descriptively. Assessment of 34 AYAs comprising 18 (52.9%) males with 28 (82.4%) students revealed an overall knowledge score about ART and its effect of 73.6%. Twenty-five (73.5%) had poor knowledge of the development of resistant strains of HIV due to non-adherence recorded. Optimal adherence ($\geq 95\%$) was recorded in 20 (58.8%) AYAs. IDI produced 4 themes: (i) reasons for non-adherence, (ii) ensuring optimal adherence, (iii) Social support systems and disclosure, and (iv) stigmatization. Our study provided formative data and revealed areas for intervention to improve knowledge and adherence to ART.

Keywords

adolescents and young adults, knowledge, experiences, ART, adherence

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Introduction

World health organization (WHO) report shows that worldwide, 410 000(194,000-690,000) young people aged 10 to 24 years old referred to by WHO¹ as adolescents and young adults (AYAs) were newly infected with HIV in 2020.² Globally, HIV is the second leading cause of death among adolescents.³ It is also estimated that over 80% of adolescents living with HIV in the world reside in sub-Saharan Africa.^{3,4} In Africa, this group constitutes a third of the population with Zimbabwe, Nigeria, and South Africa bearing the burden.⁵

In Nigeria, AYAs make up over a third (31.6%) of Nigeria's large and growing population⁶ of over 160,000,000 Nigerians that already make significant social and economic contributions to households and social viability. Adolescents (10-19 years) make up 8% of people living with HIV (PLWH) in Nigeria with an HIV prevalence rate of 1.4%.⁷ HIV infections among

adolescents in Nigeria are attributed mostly to failure in the prevention of mother-to-child transmission (PMTCT).⁷ Kim and colleagues⁸ in their review described features from works of literature that illustrated the vulnerability of AYAs who were not perinatally infected to HIV infection. The vulnerability is that it is a period when a lot of changes in their physical, mental, and emotional development take place. As a result, some engaged in

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alcohol consumption, risky sexual experimentation, and the use of hard drug. The high-risk sexual behavior of AYAs involves their engagement in unprotected sex with multiple partners, transactional sex, being easily coerced into sex, and peer pressure. Though analysis shows that the male AYAs engage in risky behavior than the females;⁵ early sexual debut, marriage, and childbirth also make the African female youths vulnerable to HIV infection.^{5,8} High levels of stigma, gender inequality, punitive laws against repressed vulnerable groups, and poverty are identified structural factors that contribute and increase these vulnerabilities.⁵ In addition to these, AYAs are reported to exhibit weak and limited engagement as well as marginalization from mainstream healthcare services; which has the possibility of affecting their adherence to antiretroviral therapy on detection.^{5,8,9} For the perinatally infected AYAs, their vulnerability lies in their experience of complicated clinical courses, loss of one or both parents with attendant family instability, discrimination, challenges from disclosure, and transition from caregiver to self-care.¹⁰

Available data show a lack of comprehensive knowledge of HIV, AIDS, STIs and reproductive health among AYAs which may negatively impact their adherence to ART. Ahonsi and colleagues⁵ reported less than 60% comprehensive knowledge of HIV and AIDS among African Youths. In Nigeria, data from the National Agency for Control of AIDS (NACA)¹¹ also show that only 22% of adolescents and 27% of young adults have comprehensive knowledge of HIV further adding to their vulnerability.

Antiretroviral therapy (ART) is a combination of three or more antiretroviral drugs to prevent and manage HIV infection by preventing or suppressing viral replication. Due to the effectiveness of ART, more children are surviving to adolescence and adulthood.^{4,10,12} The use of ARTs has led to decreased mortality and morbidity with an increased quality of life as a result of HIV viral suppression and the attendant improvement in the immunological and clinical status of PLWH, including adolescents.^{13,14} However, attaining and sustaining the HIV treatment endpoints, requires not less than 95% continuous adherence to ART.^{3,15,16} Failure of which results in the selection of resistant strains of the virus, which leads to disease progression, reduction of future therapeutic options, and increased risk of HIV transmission due to high viral load (VL). Adolescents have been generally identified as having poor adherence to ART and hence poorer outcomes compared to their adult counterparts.^{7,14,17,18} In a meta-analysis⁸ in which adherence level cut-offs of >85%, 90%, 95% and 100% was used, 62% of AYAs were found to be adherent to ART. A review of adolescents' adherence levels to ART in the United States of America (USA) showed adherence between 28.3% to 69.8%.⁸ Various adherence levels have been recorded in low- and medium-income countries (LMICs). A 2014 systematic review has identified adherence levels of between 16% to 99% in adolescents.³ In Thailand, suboptimal adherence was recorded in 48.4% of the perinatally infected adolescents.¹⁰ Optimal level of adherence was obtained in 84% AYAs (12-24 years) in Africa and Asia from the systematic review

and meta-analysis done by Kim and colleagues.⁸ In the same study,⁸ North America, Europe, and South America recorded the lowest ART adherence. Few published studies in Nigeria assessed ART adherence among AYAs and reported varying percentages of the AYAs with optimal adherence. In two different treatment facilities in Lagos state, optimal adherence level were self-reported by 84%¹⁹ and 26%²⁰ of the AYAs. In a retrospective cross-sectional qualitative study by Tor-Anyiin²¹ in Benue state, Nigeria 89% and 94% AYAs recorded optimal adherence in urban and rural areas respectively. Benue state currently is the second state in Nigeria with the highest prevalence (4.9%) of HIV infection.⁷

Different adherence tools have been used to determine adherence in AYAs. The meta-analysis by Kim and colleagues⁸ revealed that main adherence measures used in assessing AYA's adherence to ART were viral suppression and self-report. These two measures were found to be in agreement as the estimated prevalence of adherence was 62.2% using viral suppression and 59.1% for self-report. Several factors elucidated from the literature have shown that some demographic, psychosocial, HIV disease, treatment regimen, and practitioner factors have been found to significantly affect adherence in AYAs.²² In the study done among perinatally infected AYAs in Thailand;¹⁰ younger age, having extended family member as a caregiver, poor intellectual knowledge of caregiver, being in a relationship, too much engagement with social media, depression, and ease of asking doctors questions were significantly associated with suboptimal adherence.¹⁰

AYAs have diverse needs unique from adults, they may be rebellious, may not have caregivers like younger children and may have challenges associated with puberty and the disease.²² They may vary in their experiences when taking ART, while some may experience adverse effects (AEs), struggle with independency from caregivers, disruption to their lifestyles due to the additional challenge of their HIV status which makes them different from their uninfected peers; others may not. The experiences of AYAs and how they cope with various challenges associated with ART and the possible effect on their adherence in Africa and resource-limited settings are under-reported and need to be examined.⁵ Similar to adults, if AYAs LWH attains undetectable viral load, there is a 94% likelihood of not transmitting HIV, living a longer and better quality of life.¹⁶ Due to the paucity of data for this subset in Nigeria, it justifies the need to generate this much-needed baseline information that will generate information unique to this population in a resource-limited setting (RLS) with a high prevalence of infection. This will provide a better understanding of how to encourage long-term adherence to ART among AYAs. It will also generate indicators for developing target interventions programs that promotes durable adherence to ART among AYAs in RLS. Thus, the study objectives were to assess AYA's knowledge of ART, measure their level of adherence to ART as well as capture their experiences as regards their drug management.

Methods

Study Design

This was a mixed-method pilot evaluation comprising of retrospective chart review, cross-sectional adherence assessment, and in-depth interview conducted among AYAs from August to September 2018.

Setting

The HIV Clinic of Lagos University Teaching Hospital (LUTH) was used for the study. It is one of the clinics set up through funds obtained from the United States Presidential Emergency Plan for AIDS Relief (PEPFAR) program in Nigeria. Lagos University Teaching Hospital is an 800-bed Federal Government-owned Tertiary Healthcare Facility in Lagos, Nigeria. The HIV clinic has pediatric, adolescent, and adult clinic days. The adolescent clinic started on 14th February 2018, holds every Wednesday with an average of 12 adolescents seen weekly. The clinic has a program for disclosure and all the AYAs used in this study have already been disclosed to.

Participants

The study population was adolescents and young adults aged 10 to 24 years on ART. All AYAs who knew their HIV status, consented (≥ 18 years), and assented (10-17 years) after caregiver/parental consent were included in the study. Only AYAs who had their HIV status revealed were chosen for this study because those who have not been disclosed to were still under the care of their parents or caregivers and thus not eligible to attend the adolescent clinic where the study took place. The convenience sampling method was used because this study was largely exploratory. AYAs that met the selection criteria were recruited and assessed when they came for their drug refill or doctor's appointment during the study period. Participants were recruited consecutively for the in-depth interview until a saturation point was reached. Thirty-four (34) AYAs were used for this study which was when saturation in the interview was attained.²³ All the adolescents approached during the study period consented to be part of this study.

Data Sources/Measurement

The tools used were a retrospective review chart, pre-tested semi-structured interview questionnaire based on the study objectives, and AIDS Clinical Trial Group (ACTG) 4-day adherence antiretroviral questionnaire²⁴ used for patient self-report adherence for all prescribed antiretroviral drugs.

A retrospective review chart was used to obtain AYAs baseline information from their hospital records. Information extracted included AYA's demographic and clinic data such as patient's age, gender, marital status, religion, occupation, CD4+ cell count, viral load, the combination of ARVs being

used, baseline opportunistic infections (OIs). This review chart also assisted in screening out ineligible AYAs.

The use of a structured interview questionnaire assessed patients' knowledge of the interplay between HIV, AIDS and ART. The study instrument was developed to address the study objectives and then piloted using a convenient sample of four voluntary AYAs who provided their understanding of the questions asked and how they could be made more understandable. These structured interview questionnaires were sectioned into four (4) parts. Section A addressed the patient's social and clinical data; section B assessed their knowledge of ART, the names of their ARVs, if it can cure HIV, what it does to HIV, and AIDS, possible adverse effects of their combination, what VL represents and the effect of ART on VL. Section C was the qualitative aspect of the study which was an in-depth interview (IDI) conducted by the first and second authors. The first author who trained the second author is a clinical pharmacist who has training in ART adherence counseling which she has practiced for over ten years. The interview guide used sought to get a deeper insight into AYAs' retrospective and current experience with ART. The open-ended questions asked examined AYA's general feelings after initiation of ART (for the behaviorally infected), experiences with ART as AYAs (for those perinatally infected), adverse effects experienced (eg bad dreams, yellow eyes, itching, sadness or worry, diarrhea, unable to sleep, taste problems, stomach ache, shaking hands, change in appearance, etc), symptoms related to IRIS (such as fever, any form of inflammation), actions taken after developing any side effect(s), ability to adhere to instructions given about their medication and incorporating the use of medications into daily routine. Other questions asked in this section were if they were told about adherence. If yes, they should state their understanding of adherence to ART, its effect on their management, what will happen if they do not adhere, their treatment partner, and how they fit the medication into their lifestyle. The structured questionnaire and interviews were conducted the same day on recruitment of the AYA during the weekly clinic days while patients wait to be seen by a doctor or wait to collect their ARVs from the pharmacist. Only one IDI was conducted per participant. Some of the participants preferred to write out their responses on sheets of paper provided, others responded verbally while some used both. Verbal responses were written down by the interviewers. Section D of the study instrument consisted of the ACTG adherence questionnaire which provided self-reported adherence in the study sample. This questionnaire was used because some results from RLS have shown a correlation between the instrument and some objective measures of adherence (MEMS and Pill count).²⁵ The questionnaire assessed the AYAs on the number of missed doses of medication four days before their clinic visit. The ACTG tool also took into consideration the number of different drugs prescribed as well as the doses prescribed.²⁴

Ethical Approval and Informed Consent

Ethical approval was obtained from the Health Research and Ethics Committee of Lagos University Teaching Hospital

(ADM/DCST/HREC/APP/2464). For adolescents aged 10 to 17 years informed assent was obtained with permission of the parent/caregiver while informed consent was obtained from the AYAs ≥ 18 years. Information gathered was treated as confidential and the reporting of findings anonymous. The anonymity of patients was ensured via the use of patient unique identity codes known only to the researchers.

Data Management and Analysis

Data were analyzed using SPSS version 21.0. Categorical data are presented as frequencies and percentages. For the ART knowledge assessment, a score of one was assigned for the correct response to the questionnaire item, while zero was assigned for an incorrect response. The percentage knowledge was computed by expressing the correct responses as a fraction of the total questions. Knowledge scores above 70% were considered high level while those below 30% were considered low level. The responses obtained from the IDI interviewees narrated experiences with taking their medications were later hand-coded based on the interview guide by the primary author using thematic analysis. The four emerging themes from the data are a) reasons for non-adherence, b) methods used to ensure optimal adherence, c) social support & disclosure, and d) coping with stigmatization. The adherence percentage for the four days before clinic attendance was calculated using the formula: $1 - (\text{number of missed dosage units}/\text{number of dosage units prescribed}) \times 100$.²⁵ An AYA was considered adherent if he/she took $\geq 95\%$ of the prescribed doses correctly and non-adherent if $<95\%$ of the prescribed doses were taken.

Table 1. Socio-demographics Characteristics of the Respondents.

Socio-demographic variable	Frequency	Percentage (%)
Gender		
Female	16	47.1
Male	18	52.9
Age		
10 to 14yrs	2	5.9
15 to 24yrs	32	94.1
Mean age with standard deviation: 19.1 ± 1.8		
Marital status		
Married	3	8.8
Single	31	91.2
Religion		
Christianity	27	79.4
Islam	7	20.6
Tribe		
Hausa	1	2.9
Igbo	15	44.1
Yoruba	15	44.1
Others	3	8.8
Occupation		
Student	28	82.4
Employed	3	8.8
Unemployed	3	8.8

Results

A total of 34 AYAs participated in this study. Eighteen (52.9%) were males, 32 (94.1%) fell within the age range of 15 to 24 years old, 31(91.2%) were single and 28 (82.4%) students (Table 1).

Respondents' clinical data showed that 28 (82.4%) were on the first line antiretroviral regimen. Sixteen (47.1%) of them on the first line were on zidovudine + lamivudine + nevirapine combination at the time of data collection. Almost half of the AYAs (48.3%, $n=29$) had ≤ 500 CD4 counts at their last CD4 measurement, 31(91.2%) had VL measurement and 32 (94.1%) recorded the absence of opportunistic infections.

AYAs' ART Knowledge Assessment

Knowledge assessment showed that overall, the average knowledge level of AYAs about ART and its effect was 73.6%. The details are shown in Table 2.

AYAs' Knowledge of Adherence and Adherence Assessment

Most (79.4%) had received preparatory adherence counseling as AYAs. Self-reported adherence to ART of more than 95% was reported by 20 (58.8%).

Assessment of knowledge of adherence showed that 22 (64.7%) knew what adherence means. The knowledge level of all the possible consequences of non-adherence was low (7; 20.6%). Twenty-six (76.5%) correctly knew that not adhering will affect their immune system which could make their health worse. Possible development of resistance mutation which can render their current ART ineffective was known to only 9 (26.5%) of the AYAs. The knowledge that development of resistance strain will require a change of their drugs was known to 12 (35.3%) (Figure 1).

Fifteen (44.2%) of respondents had no treatment partner (TP), 15 (44.2) % still depended on their parents to serve as their TP (Figure 2).

The Narration of AYAs' Experience of Taking HIV Drugs

Based on the narration of AYAs with regards to their experiences, four themes emerged as follows: reasons for non-

Table 2. Assessment of AYA's Knowledge of ART.

Knowledge assessment	Response frequency (%)	
	Correct	Incorrect
Names of ART regimen	26 (76.5)	8 (23.5)
Effect of ART on HIV	26 (76.5)	8 (23.5)
What viral load signify	26 (76.5)	8 (23.5)
Possible ART adverse effects	22 (64.7)	12(32.4)

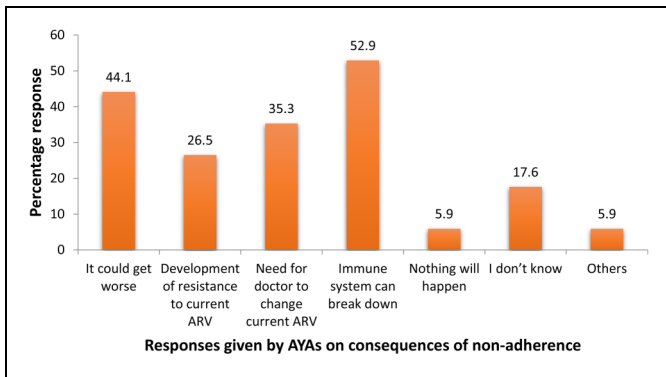


Figure 1. AYAs knowledge of consequences of Non-adherence.

adherence, AYAs strategies for ensuring adherence, social support and disclosure, and coping with stigmatization.

AYAs' Reasons for Non-adherence

Some reasons were proffered for non-adherence. Some of the reasons given were:

- (a) Perceived effect of ART on their physical appearance:

AYA 1: *"I stopped taking my drugs for a while because someone saw me one day and said, 'you use to have good skin, how come you are dark? You might be sick'....."*

- (b) Some found the idea of swallowing the drugs every day for the rest of their life tiring as contained in some statement of reasons for non-adherence:

AYA 3: *"Most times I forget taking my drug because I feel tired in taking it"*

AYA 24: *"I got it from my mother and was told when I was around 10 to 11 years by my parents before then I was taking the drugs without knowing why.... I am now on second line which is not easy as swallowing is tiring and I have other important things to*

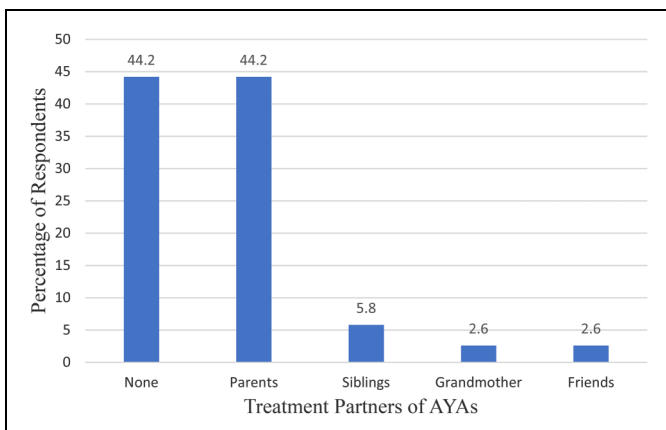


Figure 2. Treatment partner used by respondents.

do and do not want to be thinking about medicine I have to take every day...."

- (c) Lack of father's care, support, and love was a reason given by an AYA who also blamed the father for getting her mother infected and thereby infecting her. This she said was too much to take making her always run away from home and in the process not adhere to her medication.
- (d) Fear of disclosure: The fear of their HIV status being detected by peers, other siblings and relatives was also among the reasons for not adhering. This feeling was described by AYA 15 who said, *"Taking my drugs especially when I'm surrounded by friends. It's very difficult which can, lead to me not taking the drugs to avoid disclosing to people that might end up insulting me"*.

AYA 8 who was perinatally infected said, *"I felt bad because I was the last borne and only one among my siblings infected in my family. I had to stop taking my medicines at a time to avoid disclosure to my siblings and to protect my mum who would have lost them to my aunt who falsely accused her of infecting my father and killing him as a result.... I almost died from not taking my medicines..."*. AYA 32 narrating her own experience said that, *".... After I was disclosed to, I began to have a feeling like everybody is looking at me, that made me not to take it"*.

- (e) In this group, claiming of 'healing' from a church also came to play. One of the AYAs narrated how he was mistakenly disclosed to by a female doctor who assumed he knew his status because he was picking up his drugs himself and adhering. His mum and other caregivers had told him that they were just medicines he must take to keep him strong. The disclosure was so shocking for him. In his bid to get cured, he went for healing in a church. This made him stop taking his medicines which got him very sick after a while and he had to be referred to a counselor on two different occasions to get back on track. Getting him back on track took him three years.
- (f) Intentionally refusing to take the medication also played a role in non-adherence. This reason was expressed in the narration of AYA 2: *".....A week after, I started I wasn't told why I was taking the drugs. I started with tablets and because I don't like taking drugs there are some days, I intentionally didn't take the drug. When I started taking the drugs, I was told to take with plenty water which I did but noticed I throw up when I take too much water. I complained to the doctor, and then my drug was changed to second line"*.
- (g) Among the behaviorally infected adolescents, side effects experienced at the commencement of their medicine decreased adherence. This was narrated by AYA 33 who was switched to the second-line ART comprising of Tenofovir and ritonavir-boosted Atazanavir due to nonadherence. He complained thus, *"...I was*

experiencing very serious stomach ache whenever I take the medicine without eating something, this affected me for long till my girlfriend who also is living with HIV encouraged me to take with or without food- now I have adjusted”.

AYA 4 in her narration said, “...Whenever I take my drugs, I feel sleepy, stressed, and feel tired to do things”

AYA 6 also said, “..... I started with Atripla® (tenofovir + lamivudine and efavirenz) and I started vomiting after taking the drug. I complain to the doctor and a particular drug was recommended to stop it. I think it is “aspirin”. Right now, I am used to the drug because it is like I am taking malaria drug”

- (h) For some AYAs that were perinatally infected, not adhering was a form of rebellion against what fate handed down to them especially when they have more important things to deal with and have been so careful prior to disclosure not to get infected.

AYA's Strategies for Ensuring Adherence

AYAs revealed different strategies they used to ensure adherence. This was captured in the narration by some of the AYAs.

- (a) Quite a number used concealment strategies to adhere:

AYA 3: “.....Whenever I take my drug in school, my friends ask me the name of the drug and I told them it is septrin®. One day some friends saw the pack and googled it but none of them asked me anything, so now I scrap the label off the pack. I never miss my drug, but I noticed if I take it a little bit late than the prescribed time, I purge.”

AYA 18 who was disclosed to at 13 years of age as a result of an argument between her parents said, “.....I tell my friends it is a supplement I take to help me maintain my slim shape...”

- (b) Fear of the negative consequences of non-adherence was a motivator for a number of them. Quite a number revealed that they started becoming serious with adherence after falling ill all the time they stopped taking their medicines. This was explained by AYAs 5 and 23

AYA 5: “I usually feel depressed to be truthful, I feel scared when I miss a dose because I try as much as possible not to miss a dose because I know the implications. I can't remember having any side effect from my drugs”.

AYA 23 said, “.... I do not want cold, cough on the body which is what I have when I miss taking my medicine...”.

- (c) A number narrated that they instinctively know when it is time to use their ARVs:

AYA 7: “all my family are like alarm but now am used to it because it is part of me, my normal routine in the morning make me adhere to my drugs”

This narration was echoed by many of them like AYA 31 and AYA 25 who stated, “..it's part of me -I don't need alarm...” and “ “I am used to it, once it is time, I know”, respectively. AYA 31 further explained that she wakes up about the same time and so taking her medicines has been fitted into her waking-up time.

- (d) Use of Reminder: While some say they just know when it is time to take their medicines, most of the participants use reminders. The use of alarms was a favored reminder, a tactic used by some of them was to set the alarm to ring before the time, at the time and after the time they are to take their medicines.

An AYA who said she was told she got infected via blood transfusion as she was the only person infected in her family revealed she takes her medicines at 7 am and to remind her she set her alarms to ring at 6.30 am, 6.58 am, 7 am and 7.10 am in case she forgets to do so at 7 am.

AYA 28 stated, “...I hardly forget because it (the medicine) is in front of me – my alarm is there”.

The use of close family members and peers of the same status was another form of reminder favored by the AYAs

- (e) Motivation for adherence: Some AYAs revealed they have discovered ways to self-motivate to achieve adherence. AYA 8 and AYA 33 who were perinatally infected AYAs had this to say: AYA 8, ‘I don't want to be a looser, my dream is to be a better person and show the world...using the drugs make me feel fine and I can motivate others too’ while AYA 33 revealed his girlfriend who is also positive motivated him. An AYA who said he got infected from his male partner said he was motivated to take his medicines by this friend who wrongly informed him he will no longer need to take the drugs when he gets virally suppressed. He narrated, “I was initially anxious to achieve viral suppression and made it my goal to achieve that after 6 months but did not till about a year after...”. Another AYA, a female aged 21 said she was detected positive at 9 months and disclosed to at the age of 16 revealed that the disclosure of her status motivated her to take her medication. She further stated, “Since God kept me alive till now, I take my medicines for longer life and to manage myself”.

Social Support & Disclosure. As at the time of this study, there was no support group for AYAs. The only form of support they had was from treatment partners as shown in their response in Figure 2. Almost half 15 (44.2%) of AYAs had no treatment partner, 15 (44.2) had their parents as their treatment partner. It

was noted that AYAs' disclosure of their status was mainly to family members. The disclosure was limited even within the family; this was captured in one of the AYAs narration as follows:

"I have been taking HIV drugs since when I was small. My mum is also HIV positive so I think it is mother-to-child transmission. Apart from my mum and I, nobody knows about our status and it is like a secret between us. Sometimes I feel like telling my sister about it, but I got discouraged because of the way she reacts when HIV issues is brought up.... Right now, I am not in any relationship but eventually, if I have a boyfriend, I don't intend telling him"

Some AYAs admitted to knowing their status before being disclosed to. One of the AYAs narrated as follows: "Before I was disclosed to, I knew already, because I knew through school, I didn't feel anything because I knew already but my concern then was like- this is how I'll be taking drugs every day? How will I tell people close to me, the person am dating?"

In narrating their experiences with how they felt when their HIV status was disclosed to them, some AYAs narrated how they struggled with acceptance. Some remembered feeling bad, surprised, disappointed, giving up on themselves and life, and having suicidal thoughts; while some remembered isolating themselves from people until they could understand their positive HIV status.

All the AYAs expressed their satisfaction with how they are handled by all the healthcare team.

Coping With Stigmatization. Most of the interviewed AYAs said they have not experienced stigmatization, 2 of them admitted to self-stigmatization; as one explained, " ...in the sense that I always ensure that I don't infect my siblings and I keep away from friends"

AYA 4 who experienced stigmatization during the interview shared her experience as follows:

"I stay with my aunt. I don't know how I got HIV but then I am always stigmatized whenever I am at home. Sometimes they isolate me by refusing to share razor blades or safety pins with me. They do not want to sleep with me or even eat food with me. They fear to touch my plate and keep it separate from others (plates)...."

Discussion

In this mixed-method evaluation of ART adherence and associated factors among AYAs, we provided some basic and in-depth experiences of AYAs taking ART which can be exploited for future quantitative research and provide possible guidelines for intervention implementation among this study population.

The percentage of AYAs with good knowledge of the names of their ARV combination as assessed by our study was more than double the 36% recorded by Hosek and colleagues²⁶ in their study done in the USA. The response from our study however shows that there is still room for improvement. It was surprising to find that not all the respondents knew the

names of their ARV combinations. This is because the practice in the facility ensured that before any drug refill at the pharmacy, the dispensing pharmacist ask the patients to state the names of their ARV combinations. The outcome of this study however still shows the need to improve on the AYAs' knowledge in this regard as it is pertinent that they know their drug combination in case they find themselves outside the facility and run out of medication.

About three-quarters of the respondents had correct knowledge of the effect of ART on HIV and what viral load signifies, indicating the need to assess and reinforce these pieces of knowledge from time to time in the course of their routine counseling session and during pharmacy refill. This is important as it has been shown in a study in Malawi¹³ that patients having appropriate health education knowledge was useful in increasing adherence.

The 58.8% of AYAs who achieved $\geq 95\%$ adherence level in our study is twice what was recorded in the cross-sectional study by David and colleagues²⁰ in another large treatment site in Lagos, Nigeria. In that study, the age range, 10 to 19 years used was younger and the clinic setting was different because at 15 years of age they were transferred to an adult clinic whereas in the present study they are attended to at the adolescent clinic. Our result was similar to 56% documented by Hosek and colleagues²⁶ in their IDI study for AYAs in Chicago; but far lower than the 87.2% recorded in Limpopo province of South Africa,²⁷ and 89% and 94% recorded in urban and rural areas of Benue State, Nigeria.²⁰ It was quite interesting to find that the current study recorded a lower self-reported adherence different from the 84% recorded from the same site and study population in 2015.¹⁹ This difference may be as a result of differences in the average age (17.9 ± 2.8 years) in the previous study which was lower than for the AYAs in the current study and all the participants in that study were on a first-line regimen. The 95% adherence level of 58% in our study may not be unrelated to low knowledge of the possible consequences of non-adherence. The low level of adherence in this study gives cause for concern due to the risk of resistance and the limited ART options available in this part of the continent.¹³

While the study in Chicago, USA²⁶ recorded that 60% of the respondents were familiar with the concept of developing drug resistance as a result of non-adherence, with similar high awareness observed in other studies^{10,14} our study recorded only 26.5% knowledge by AYAs. This may be because this study group did not benefit from training as in the Thailand study¹⁰ and effective transfer of knowledge from healthcare providers through their caregivers.¹⁴ Persistent knowledge that resistance evolution may occur as a result of non-adherence and could lead to treatment failure resulting in a switch of ART was weak similar to the 27% previously identified in this facility in 2015.¹⁹ This reinforces the need for intervention packages to address this very poor knowledge regarding all the consequences of non-adherence to ART. This may help to greatly improve adherence in the study population and prevent the spread of the resistant virus and its attendant public health implications.

Previous studies had shown that the main reasons for non-adherence among adolescents were being busy with other things, forgetfulness, sleeping through dose, and change in routine.^{3,25,27} The narration from this study showed that even negative comments on their physical look could lead to non-adherence in this group. For the perinatally infected AYAs, lack of love from a parent especially the one who is perceived to be indirectly the cause of their HIV status led to non-adherence. Discussion around this can form part of the adherence counseling package for this group. Another reason for non-adherence was dislike for tablets, this reason was also given by some of the participants in the qualitative study done in Soweto.¹⁴ Feeling tired of taking their medication every day expressed by some of the AYAs was also the case in the study by Hornschuh and colleagues¹⁴ and the Thailand study.¹⁰ Fear of being discovered as an AYA living with HIV which was voiced as a reason for not adhering was also identified in the review by Reisner and others²²

The main reasons proffered by the participants for ensuring adherence to ART even in the face of possible stigmatization from peers were determined to adhere to treatment and fear of perceived consequences. These reasons can be positively reinforced during adherence counseling to ensure optimal adherence. The habit of scrapping off labels to prevent detection of AYAs' HIV status is also common in the adult population as provided bins overflow at the end of each clinic day with discarded drug packets after drug refill by patients. The use concealment strategy to avoid detection among AYAs in our study though different in form has been reported in the study among AYAs in Soweto, South Africa.¹⁴

The self-stigmatization expressed by some AYAs needs to be addressed as it can result in self-isolation. This situation has been described as being riskier than HIV due to its potential of eroding self-confidence, well-being and negatively impacting relationships with others in AYAs vicinity.²⁸ Lack of social support and isolation has also been identified as contributory to adolescents' disengagement from care in Western Kenya.²⁹ One trend that ran through the narration of the adolescents was the low level of disclosure, this is not surprising as most of them were transferred from the pediatric clinic. It was also interesting to note that disclosure was even restricted within family members as oftentimes HIV uninfected family members were not disclosed to. This reluctance to disclose to other family members and friends was also observed in some other studies among AYAs.^{10,14}

The general expression of satisfaction with their healthcare providers expressed by all the AYAs in our study is also shown in the study by Mabunda and others²⁷ in which 93.2% reported having a good relationship with the healthcare providers. This is good as it means the AYAs feel safe in the facilities and form a good foundation for executing interventions likely to produce positive outcomes.

Study Limitation

Study participants were recruited from only one site hence may be a limitation in the external generalization of the study results. The non-inclusion of AYAs who have not been disclosed to and

those without CD4 count and VL may also have excluded challenges specific to this group. Another limitation is the lack of multivariable or mixed-methods analyses to assess the quantitative and qualitative findings.

Conclusion

This study has shown some areas that may be explored when addressing issues of adherence in AYAs. It has revealed varied knowledge levels with regards to ART, adherence level, causes of non-adherence that did not conform with the norm. The way AYAs cope to achieve optimal adherence in the absence of social support was revealed. These outcomes reveal that AYAs' management can no longer be focused on only how well they adhere to their medication. Building on their good relationship with the healthcare providers provides a springboard for facilities to provide a forum whereby they can freely express themselves, and can be engaged to develop their preferred mode for accessing correct knowledge on HIV, AIDS, ART, and self-care as well as getting psychosocial assistance when needed. The level of non-adherence among the study participants demonstrates also the need for intervention studies designed to reinforce knowledge of ART, improve adherence level by improving knowledge of the implication of non-adherence and develop adherence counseling tools appropriate for AYAs.

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