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AIDS Care

Psychological and Socio-medical Aspects of AIDS/HIV

ISSN: 0954-0121 (Print) 1360-0451 (Online) Journal homepage: www.tandfonline.com/journals/caic20

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To cite this article: Londiwe D. Hlophe, Peter S. Nyasulu & Constance S. Shumba (2025) "She tells me the HIV is eating my brains": barriers and facilitators to antiretroviral therapy adherence among Eswatini adolescents living with HIV, AIDS Care, 37:2, 310-323, DOI: 10.1080/09540121.2024.2443677

To link to this article: https://doi.org/10.1080/09540121.2024.2443677

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Published online: 30 Dec 2024.

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AIDS CARE
2025, VOL. 37, NO. 2, 310–323
https://doi.org/10.1080/09540121.2024.2443677

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"She tells me the HIV is eating my brains": barriers and facilitators to antiretroviral therapy adherence among Eswatini adolescents living with HIV

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ABSTRACT

Despite the successful rollout of antiretroviral therapy (ART) and positive ART outcomes in the Kingdom of Eswatini, adolescents still present poor ART outcomes including low viral load suppression and suboptimal ART adherence. The aim of the study was to explore the perceptions of adolescents living with HIV (ALHIV) on the barriers and facilitators to ART adherence in Eswatini. We conducted a qualitative study using in-depth interviews among 29 ALHIV and on ART in Eswatini in December 2023. Adolescents aged 10–19 years who were aware of their HIV status were recruited purposively from five Teen Clubs in the Hhohho region. Six barriers to ART were reported by participants namely perceived stigma and discrimination, competing demands between ART schedules and their personal and social lives, medication issues, health facility factors, lack of transport and food, and diminishing support from caregivers. The main facilitators of ART adherence were having a social support system, status disclosure, privacy, HIV and ART knowledge, and motivation to stay alive. Supportive environments are crucial to enhance ART adherence among ALHIV. These can be promoted through multi-component interventions that target status disclosure, increase knowledge of HIV and ART, ensure privacy and address stigma and discrimination.

ARTICLE HISTORY
Received 10 June 2024
Accepted 12 December 2024

KEYWORDS
Adolescents living with HIV; Eswatini; ART adherence; barriers

SUSTAINABLE DEVELOPMENT GOALS
SDG 1: No poverty; SDG 3: Good health and wellbeing; SDG 10: Reduced inequalities; SDG 11: Sustainable cities and communities; SDG 17: Partnerships for goals

Introduction

The Kingdom of Eswatini, a country with the highest prevalence of human immuno-deficiency virus (HIV) globally (24.8%), was the first country in Africa to attain the UNAIDS 95-95-95 target in 2022 (Eswatini Ministry of Health, 2025; WHO, 2023). The UNAIDS 95-95-95 target is a global consensus to aim for 95% of people living with HIV knowing their HIV status, 95% of people who know their HIV status receiving treatment and 95% of people on ART having a suppressed viral load by the year 2025 (UNAIDS, 2023). In Eswatini, by the year 2022, viral load suppression (VLS) was 96.2% among the adult population living with HIV, while it was much lower (77.8%) among adolescents aged 15–19 years (Eswatini Ministry of Health, 2023). Low viral load suppression is associated with suboptimum adherence to ART (Byrd et al., 2019).

The disparity between the adult and adolescent viral load suppression rates is consistent with both global and sub-Saharan Africa (SSA) regional data. The SSA region is the epicentre of the adolescent HIV epidemic, hosting 90% of adolescents living with HIV (ALHIV) globally (UNAIDS, 2023). Despite representing a quarter of the global population, adolescents suffer a disproportionate burden, accounting for 5% of AIDS-related deaths worldwide (UNAIDS, 2023).

Suboptimal adherence to ART among ALHIV is associated with treatment failure, drug resistance, and reduced treatment options, highlighting the critical importance of optimal ART adherence in preventing HIV infections (Bitwale et al., 2021; Desta et al., 2019). Numerous factors influence ART adherence among ALHIV (Ankrah et al., 2016; Chhim et al., 2018; Gitahi-Kamau et al., 2020). These include caregiver-based factors such as caregiver HIV status, age, education level, duration on ART, and caregiver relationship with the child (Evans et al., 2015; Nabunya et al., 2020; Xu et al., 2017). Additionally, ALHIV-based factors such as self-efficacy, dosing frequency, age and gender also impact on the ART

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adherence level (Brathwaite et al., 2021; Chhim et al., 2018; Desta et al., 2019). Further, ALHIV faces barriers including perceived stigma, forgetfulness, financial constraints, and adverse effects of ART (Ammon et al., 2018; Azia et al., 2016; Hudelson & Cluver, 2015; Kim et al., 2018). On the other hand, support from caregivers, peers and healthcare facilities, along with adequate HIV and ART knowledge, self-motivation and simplified treatment regimens, can facilitate ART adherence (Ammon et al., 2018; Kim et al., 2018). However, there is limited data on the barriers and facilitators to ART adherence among ALHIV in Eswatini, despite the reported poor HIV treatment outcomes, such as low viral suppression rates, in this age group compared to the adult population. Therefore, this study was conducted to explore the perceptions of adolescents living with HIV on the barriers and facilitators to ART adherence in Eswatini.

Methods

Study design

We conducted a qualitative descriptive-exploratory study in December 2023 to explore the perceptions of adolescents aged 10–19 years, living with HIV on the barriers and facilitators to ART adherence in Eswatini. This study designed allowed us to explore and provide a dense description of barriers and facilitators to ART adherence among ALHIV from the detailed description of experiences provided by the adolescents. This study sought to explore the perspectives of those who have experienced life with HIV; hence, the study design was suitable for the exploration of the experiences of living with HIV among adolescents (Grove & Gray, 2019).

Study setting

The study was conducted among ALHIV accessing ART care through Teen Clubs in Eswatini. Teen Clubs offer a differentiated ART care model among adolescents through the use of lay healthcare workers also known as expert clients to support ALIHV with HIV counselling and ART adherence support (Ahmed et al., 2022; Eswatini Ministry of Health, 2022). Additionally, Teen Clubs are aimed at developing life skills and assist in facilitating transition from paediatric care to adult care among these adolescents (Eswatini Ministry of Health, 2022). Therefore, Teen Clubs are solely designed for ALHIV with a disclosed status with the aim of peer support (Ahmed et al., 2022). These clubs meet monthly on Saturdays and during the club meetings, ART refills are conducted (Swaziland National AIDS Programme, 2023). Teen Clubs in the Hhohho region were considered in this study based on their membership and vibrancy compared to the other regions. In 2023, there were 99 Teen Clubs with 2308 members in the country of which 31 Clubs with a membership of 1464 ALHIV were from the Hhohho region (63% membership compared to national data) (Swaziland National AIDS Programme, 2023). A total of five Teen Clubs in the Hhohho region with a minimum of two years of being active as of December 2023 were purposively selected with the support of the Ministry of Health, Swaziland national AIDS Program (SNAP); National Paediatrics' HIV Care & Treatment department. Within these clubs, adolescents aged 10–19 years, who had been members for at least six months by the data collection period, were invited to participate to ensure comprehensive ART history.

Participants' recruitment process

The regional Teen Club coordinator facilitated the identification of Teen Clubs that met the study's inclusion criteria. The coordinator also introduced the researcher to the health facility matrons and expert clients (ECs) overseeing these clubs. The researcher explained the study objective to the matrons and ECs, and the ECs assisted in identifying eligible adolescents. The eligibility criteria required adolescents to be aware of their HIV status and to have been Teen Club members for at least six months. Eligible adolescents were introduced to the researcher during Teen Club meetings, where the researcher provided a detailed explanation of the study. Interested participants were given a comprehensive study information sheet in both siSwati and English. Adolescents under 18 years of age received the information sheet along with the researcher's contact information, consent forms and assent forms to share with their guardians. Additionally, the researcher contacted guardians directly to further explain the study.

From the pool of interested adolescents, purposive sampling was employed by the researcher to ensure a broad distribution of adolescents on ART, enabling the study to gather meaningful perspectives and experiences on barriers and facilitators to ART adherence among ALHIV (Gray et al., 2017). The researcher further employed maximum variation sampling to ensure that the sample reflects a diverse group of adolescents to make sure there is variation in the information (Cresswell & Creswell, 2018). This was done by ensuring the capturing of experiences of both

boys and girls, younger and older adolescents and peer educators, also known as Community Adherence to Treatment Support (CATs), who educate and support their peers through door-to-door visits, especially for adolescents living with HIV (ALHIV) who have lost follow-up (Eswatini Ministry of Health, 2016). Interviews were scheduled following the receipt of signed consent and assent forms. Adolescents aged 18 years and above were expected to sign their consent forms without parental consent. A total of 29 adolescents were recruited. The sample size was guided by the richness of data and data saturation, where no new themes emerged (Cresswell & Creswell, 2018).

Data collection and management

An in-depth interview guide was developed and used for data collection, covering topics such as ART access experiences, ART refill experiences, health facility experiences, and medication compliance experiences (ART adherence). The interview guide, along with all consent and assent supporting materials, was translated into siSwati to ensure comprehension by all participants. Consequently, the in-depth interviews (IDIs) were conducted in either siSwati or English, depending on the participants' preferences, and were audio-recorded.

To ensure the validity of the questions, two pilot interviews were conducted: one with an adolescent aged 13 years and the other with an 18-year-old adolescent (Grove & Gray, 2019). Interviews were conducted in private rooms provided by the health facility, although some participants preferred to conduct the interviews at locations of their own choosing. Each interview lasted about 45 minutes.

The audio recordings were transcribed verbatim and those in siSwati translated into English. Personal identifiers of participants were not included in both the transcripts and audio files instead codes were used to identify participants to maintain confidentiality. Both the transcripts and audio recordings were securely stored on a password-protected computer.

Data analysis

Deductive coding approach was used for data analysis (Bingham, 2023). The initial code frames were developed based on the research question being "what are the barriers and facilitators to ART adherence among adolescents living with HIV and on ART in Eswatini?" A code framework was developed and transcripts were coded manually (Cresswell & Creswell, 2018; Grove & Gray, 2019). The code book was reviewed by two independent investigators for comprehensiveness and appropriateness (Cypress, 2017). Major themes were linked with the study aims and objectives and used to summarise data in the process highlighting key agreements and contradictions.

Ethics consideration

Permission to conduct the study was sought from the Eswatini Health and Human Research Review Board (ref. EHHRRB143/2023) and Stellenbosch University University Research Committee (ref. s24/02/037). Furthermore, a letter of support from hospital management teams was obtained from the Ministry of Health, department of health services. Lastly, all participants and guardians in case of participants below the age of 18 were given detailed information on the study. Participants were informed that participation in the study was voluntary and were free to withdraw from the study should they feel so. Only participants who provided signed consent forms and assents forms were included in the study.

Results

Participants' characteristics

A total of 29 participants (14 males and 15 females) were included in the study, of which five (3 females and 2 males) were CATS aged between 15 and 19 years. The mean age of participants was 16.5 years with an average of 10.8 years ART history and 5 years Club membership. Only three (3) participants refilled their medication outside of Club days, and these were two participants who were out of high school and could come any time for refill and one participant who had joined the club just eight months

Table 1. Demographic characteristics of ALHIV.

Characteristics		Frequency	%
Age group	10–14 years	10	34.5%
	15–19	19	65.5%
Sex	Female	15	51.7%
	Male	14	48.3%
Education level	Primary	9	31.0%
	High school	18	62.1%
	Tertiary	2	6.9%
Age at diagnosis	From birth	23	79.3%
	While young	4	13.8%
	Later in life	2	6.9%
Status disclosure	Guardian	19	65.5%
	Health worker or other	6	20.7%
	Self	4	13.8%
Duration on ART	Less than 5 years	2	6.9%
	5–10 years	15	51.7%
	Above 10 years	12	41.4%
Duration in club	Less than 2 years	6	20.7%
	2–5 years	12	41.4%
	Above 5 years	11	37.9%

prior to data collection. Demographic characteristics of the participants are presented in Table 1 together with their ART experience.

Distance to health facility

Among the 10- to 14-year-olds, only two participants walked less than 5 km to the health facility, while the others paid between R20.00 ($1) and R50.00 ($2.60) for a return trip. Among the 15- to 19-year-olds, four participants walked to the health facility, with one residing less than 500 m away and two walking less than 3 km, while the rest paid between R20.00 ($1) and R100.00 ($5.25). One older adolescent walked a 5-hour return journey to the health facility.

ART adherence

Among the 15- to 19-year-olds, only 2 (10.5%) participants reported never missing their medication, while 9 (47.7%) missed it once or twice a week, and 2 (10.5%) missed it for more than a week each month. Among the 10- to 14-year-olds, 4 (40%) reported never missing their medication, while 3 (30%) missed it no more than three days a week. Two participants in this younger group missed their medication by hours, and one missed it once a month.

Themes

A total of six barriers to ART adherence while five facilitators of ART adherence were identified by participants [Table 2].

Barriers to ART adherence

Several reasons were reported as responsible for participants' inability to adhere to scheduled treatment time.

Perceived stigma and discrimination. Stigma and discrimination by their family, peers, and friends were mentioned by participants as main barrier to ART adherence (quotes 1–5). Some of the participants mentioned that they were afraid that once people close to them know of their status, they will start treating them different (quotes 5 and 8). These included relatives visiting them who might then start asking questions or even family members sharing with others their status (quote 7). Participants feared that once people knew their HIV status, they would perceive them as reckless for being infected and discriminate them (quote 6).

On another note, participants believed that people are oblivious of HIV management and still associate HIV with death thus discriminate those living with HIV (quote 2). Due to perceived stigma and discrimination, participants resolved to hide when taking medication in fear of unintended disclosed causing some participants to miss medication (quote 3). Participants described that the fear of disclosure has led into them missing out in life and feeling different from their peers, siblings and partners (quotes 5–9). For instance, some participants mentioned that having and maintaining relationships was hard for them because it increased the chances of unintentional disclosure especially with the monthly Club meetings or refusal to have sex or visiting them (quote 5). This has further led them into self-hate as they feel angry about their HIV status (quotes 9 and 10).

Personal factors. Some personal factors were also reported by participants as barriers to ART adherence. This included forgetfulness caused by waking up late or sleeping early especially when tired, overnight church services, early morning household chores, and playing away from home (quotes 11–13). Forgetfulness resulted in participants missing their medication frequently due to the constant occurrence of some of these activities. For instance, overnight church services were reported by participants to occur twice a month on weekends resulting to participants coming late and tired from the services thus forget taking the medication or wakes up late after the medication time has passed (quote 13). When asked why participants do not take the medication with them during the overnight vigils, participants reported fear of unintended disclosure resulting to stigma as they have religious values to uphold, and HIV is associated with reckless behaviour in church (quote 14).

Also, participants reported status unacceptance as a barrier to ART adherence (quotes 10, 15–17). Failure to accept one's HIV status resulted in participants not taking their medication with a hope that the status will change (quote 16).

Lastly, participants reported getting tired of the medication sometimes and deciding to take a pill break (quote 18). This was mostly evident among the older adolescents. Anger and loss of hope were further associated with pill break among participants (quotes 18 and 19).

The medicine factor. The adverse effects of ART such as tiredness after taking medication, feeling sleepy, insomnia, feeling nauseous or even vomiting and feeling hungry when taking medication resulting to weight gain were mentioned by participants to have had a bearing in adhering to treatment (quotes 20 and 21).

Table 2. Themes, codes and illustrative quotations from participants on the perceptions of barriers and facilitators of ART adherence.

Theme	Sub-themes	Code	Representing quote
Barriers to ART adherence	1. Perceived stigma and discrimination	a. Enacted stigma (family, peers, friends, and community or public)	1. "*Some people don't like people who are on ART … like one of my friends talks bad about people who are on ART. The other time I asked her if she can be a friend with someone who is on ART, and she told me she will never … . I wanted to share with her my status but decided not when she told me she doesn't like people on ART*". Female ALHIV aged 14 years
			2. "*.. It has been fine you know since I have a friend also on ART. But you know when I started it was not easy like it is now. It was not an easy journey thus I took the initiative to be an educator and encourage others to persevere. It's not easy. People assume that you will die, or you are a ghost. Even now it's not easy because when you tell people you are living with HIV, they start to discriminate you and even doubt you that you will achieve your goals. They even ask why waste time since you will die. You also feel like aaah nobody sees me and all doubt me because they feel you will die. Let me end here because you see aunty it's a lot for us living with HIV*". Female ALHIV aged 19 also a peer educator
			3. "*The other time there was a ceremony at home and my aunties and cousins came for some days. I put the medication in a Panadol (painkiller) paper and each time it was time for my medication, like I take my pills at 7 in the morning, my aunt would be like what's that medication for. At first, I lied and said it was for headache until my aunt asked why I have a headache every day. I started to sneak out when it's time for the medication but then sometimes it is not easy, so you just stop taking the medication until they are all gone*". Female ALHIV aged 17
			4. "*My mom supported me because she would even go with me to the teen club meetings and when there was need for parents to come, she would come. But the way she treats me is different compared to how she treats my siblings. The long and short of it is that I feel I am treated like the black sheep of the family. I always feel I am a reminder of what my dad did to her. Like there was a time she told me she wishes I go and don't come back and leave her home, and yet I still stay here at home and cry myself daily*". Male participant aged 19
			5. "*You see aunty don't judge me, my friends have boyfriends but for me before I couldn't have a relationship for more than 3 months because then the person will start asking that I visit them, and I know we will have sex then I can't … . The one boyfriend I told that I am living with HIV ghosted me (stopped talking to her) and I knew it was because of my status … . My current boyfriend doesn't know about my status, but I make sure we use a condom each time we have sex*". Female ALHIV aged 19 also peer educator
		b. Anticipated stigma	6. "*I don't share my status with people because, you see some people once they get to know you will then hear that so and so said that about you like I went fishing for the virus*". Male ALHIV aged 17
			7. "*You see aunty, December is a problem to me like you know the cousins come and stay and when its 7, I need to go by the toilet because they will start asking questions like 'what is the medication for?' and all that stuff you see*". Female ALHIV aged 16
			8. "*Because mommy said people can't know about my status, you see now I can't go for sleepovers and birthday parties at my friends' places or if I go now mommy fetches me early like the other time mommy fetched me just when we were enjoying the party because at 7pm I need to be home*". Female ALHIV aged 10
		c. Internalised stigma	9. "*being on ART is very hard like I always feel like I am the black sheep in the family like when we go for events sometimes I choose to remain behind because I am different, I need to take pills when people are happy enjoying themselves I will be busy checking time to see if it's time for my medication and hiding because I can't be seen drinking HIV pills*". Male ALHIV aged 19
			10. "*I don't know aunty, but you see the moment my mom told me I am positive, everything changed like I didn't like people who are like that and imagine now it's me and I didn't know what to do like I didn't even know what to do like I was angry and hated everything about me*". Male ALHIV aged 17 years
	2. Personal factors	a. Forgetfulness	11. "*I sometimes forget to take the pills like on weekends when I am not going to school because I wake up late and sometimes, I wake up and my mom is gone and find that the time has passed.*" Female ALHIV aged 17.
		b. Being away from home (playing, overnight church services)	12. "*It does happen aunty like when visiting friends or when playing far from home then I come back late*". Male ALHIV aged 17

(*Continued*)

Table 2. Continued.

Theme	Sub-themes	Code	Representing quote
			13. "*It happens aunty like on weekends at church when we go for the overnight services, I come back like sometimes tired or after the time for the pill has passed and all I want is to sleep … the Zion church we have the services twice or three times a month and I can't take the medication with me to church*". Male ALHIV aged 19
			14. "*I can't take my medication to those night vigil lest someone sees them, and you see at church if you have HIV, it means you were sleeping around. Then you see aunty better, I leave them at home but then I forget them when I get home. It's really hard*". Male ALHIV aged 16
		c. Status unacceptance	15. "*So, they tested me and asked if I can accept my status and if they can tell my parents. I was staying with my granny, so they took me to her and came back after a month to check on me and gave me the pills. But when I started them, I was shocked, and would have anxiety attacks and be dizzy so I would sometime skip dozes*". Female ALHIV aged 17
			16. "*There are days I wake up and believe that the results were wrong. Like how come I am the only one among my siblings. Why me and not the others. So sometimes I feel it will change and I stop taking the medication to see if I will really get sick or not. Like I am just like them then why am I taking the pills? Like last year I stopped for 2 weeks then had a flue, so I was like it's just a flue not HIV but then I decided to take them again like my granny saw*". Female ALHIV aged 16
			17. "*You see aunty when I got to know my status, I was angry, I left home and went to stay with a neighbour and stopped taking my pills*". Male ALHIV aged 17
		a. Pill break	18. "*It's not easy taking pills every day. Sometimes I just get tired and give them a break. You see aunty I have to wake up early every day and take same pill and still don't get healed … . The longest was like 5 days and I just wanted to live normal without taking pills every day and feeling like different*". Male ALHIV aged 18
		b. Anger and loss of hope	19. "*There were days I would get angry at my mom like why didn't she protect me. I then feel like I should stop taking the pill and die so they are happy they infected me … I am better now though I understand*". Female ALHIV aged 19 and peer educator
	3. The medicine factor	a. Adverse effects of ART	20. "*When I changed from the syrup to the tablet, things changed aunty. Now I feel tired after drinking my pill like I sleep, and it makes me feel like I am losing my mind a bit … like I have to sleep for 3 hours then I am fine and had to change from morning to 7pm because I used to sleep in class*." Male ALHIV 14
			21. "*What I don't like about the pills is that when I drink them, I feel like throwing out such that at times I vomit and my granny told me to mix it with the food but then it still make me nauseous and makes the food taste bad*". Female ALHIV aged 16
		b. Size and taste of pill	22. "*Eish aunty drinking the pill every day and worse it's big. It's not funny sometimes when it's time for the pill, I feel like dying. It's like it get stuck in my throat like I can't swallow even my saliva*". Female ALHIV aged 16
			23. "*I prefer the syrup to the pill. It used to be better to drink. The pill is very big and bitter, and I am really struggling to drink it. The other time mommy broke it to the food*". Female ALHIV aged 10
		c. Pill container	24. "*The container makes so much noise such that even people can ask what pills you are drinking. It just makes noise and draw attention to you*". Female ALHIV aged 17
	4. Health facility-based factors	a. Huge time demand for the teen club	25. "*The time spent in the Club is sometimes unnecessarily long and I don't like people so now I have to stay there from morning until late. I need to go but when I am refilling, its hard like I sometimes make excuses not to come and come another day when there is no club but then my pills are finished you know … I just don't like being around people*". Male ALHIV aged 16
			26. "*Now that I have to refill mid-week, it's really disturbing because I have to take morning hours off at work and when I reach the health facility, there is a line especially in the mornings where they are till teaching. I am rushing to get back to work and you know I lie saying I am not feeling ok but will come to work only to find a line. Now I have to explain at work, and this happens every second Tuesday of the month. I asked to be changed to three months, but they refused saying for 6 months since I no longer come on Saturdays*". Female ALHIV aged 19 and peer educator
		b. Health workers attitude	27. "*There is this one aunt (expert client) who shouts at you like you are not mentally ok when you come late and its even hard to*

(*Continued*)

Table 2. Continued.

Theme	Sub-themes	Code	Representing quote
			explain why you were late because she starts talking non-stop. The other time, I was late because there was something at home and could not just wake up and come to the club. She didn't ask but started shouting at me … . I went to the toilet and cried and felt like the HIV is a curse". Female ALHIV aged 1.
			28. "*The expert client is our neighbour and you know she knows your status and sometimes you ask yourself who else has she told. At first, I wanted to change the health facility, but my mom counselled me and told me people will always talk*". Female ALHIV aged 18
		c. The location of the ART clinic within the health facility	29. "*When one is coming to the ART clinic it's like everyone can see because it is by the gate here and then people know who comes to this place and now everyone will know that I am HIV positive because they pass to the hospital up*". Male ALHIV aged 16
			30. "*See when you get to the gate, we all do the TB and COVID-19 screening and you see where the ART clinic is (pointing). From the gate you just go down there and if you are just coming to the hospital, you go straight. You see now aunty, it means someone coming to the ART clinic can be seen and this means now people can know your status. It once happened to me when I had not told my boyfriend and that is how he found out and the relationship was over just like that (laughs)*". Female ALHIV aged 19
	5. Economic factors	a. Transport money	31. "*Before I used to board a Kombi (public transport) to the health facility but now there is no money at home, so I walk. Like I leave home at 7 and reach the hospital at 9:30 or 10 O'clock and still need to come back. Sometimes I am tired from school because school is also close to the hospital, so I have been walking whole week then now need to go back. Sometimes I miss the club and like when it's my refill day and the aunt calls and shouts because she doesn't understand*". Male ALHIV aged 17
		b. Lack of food	32. "*There is this one who stopped coming to the Club and when I called her, she told me that she stopped taking the pills because they made her sick because sometimes there was no food at home, and she can't take the pill on an empty stomach*". Male ALHIV aged 19 also a peer educator
	6. Lack of support	Support from guardian/ family members	33. "*When my granny was in hospital I had to go and stay with my stepmom. Each time I forget to say wash the dishes, she will then shout at me and tells me the HIV is eating my brains that's why I even forget simple things. It hurts when she does that because my dad sides with her, and I feel it's better to just die and leave them in peace*". Female ALHIV aged 15
			34. "*Before, my mom will remind me but now that I am old, she doesn't remind me and that is why I sometimes forget my medication*". Female ALHIV aged 18
Facilitators of ART adherence	1. Support system	a. From Guardian/friends/ peers/ partners/teachers	35. "*So, I told my teacher, and she didn't change and I am now a class prefect and I love her and she hugs me and sends me to the office to take things for her*". Female ALHIV aged 10
		b. Reminders	36. "*I told xxx the peer educator that I always miss the pill time and he set for me some alarm in my phone like this one goes on every day same time, and it starts reminding me 15 minutes before the time. It doesn't stop until I close it. Like I can't miss it even if I am in deep sleep even though its irritating when I am tired (laughs)*". Male ALHIV aged 16
	2. Status disclosure	a. By guardian/ health worker to participant	37. "*You see, my mom would say I must drink the pill every day and I didn't know why I was taking that pill. When I asked, she told me it was for asthma but my problem was I have never had any attack, so I stopped drinking the medication. I got sick and was admitted at RFM then the Doctor asked me if I knew why I was taking the pills. I said no then he told me that the pill was for HIV so that I can live longer. I started taking them faithfully when I learnt that I was living with HIV and the pills were for HIV*". Male ALHIV aged 15
		b. By participant or caregiver to friends/ peers/partners or other family members	38. "*I don't have a problem because where I normally visit, they know my status, so I don't have to hide my medication*" Male ALHIV aged 18.
			39. "*When I met my boyfriend, I didn't tell him I was on ART, so I used to hide the medication and avoided talking about HIV. So, one day, I asked him how he would feel if I was HIV positive. He told me that his mom was on ART and then I told him. He was fine with it, and I felt bad I had not told him all this time and now I even ask him to accompany me to the clinic when I go for refill, and he is fine*". Female ALHIV aged 19

(*Continued*)

Table 2. Continued.

Theme	Sub-themes	Code	Representing quote
	3. HIV and ART knowledge	a. HIV Counselling	40. "*When my granny told me that I had HIV, I was angry and stopped taking the pill because for me taking the pill means I am accepting that I am sick. I then came to the club and the aunties talked to me, taught me about living with HIV, what it meant and the fact that I can still live longer and enjoy life. That is when I started the taking my pills faithfully*". Male ALHIV aged 17
		b. ART benefits	41. "*When I started taking the pills, I stopped having the sores on my body and I gained weight (laughs) if you can see my pictures before I took the medication yoo you can be surprised … I actually deleted all of them*". Female ALHIV aged 16
			42. "*My granny told me that one pill adds one month in my life. So, if I don't take a pill, it means I have subtracted a month from my life. Imagine I was supposed to die when I am 70 but then I don't drink my pill like once a month, it meant, I have subtracted a whole year and will now die when I am 69 … (laughs)*". Male ALHIV aged 13
	4. Motivation	a. Role models	43. "*I have this lady I am following on Facebook and Instagram like she is open about her status and shares everything about living with HIV. She is so famous and very beautiful. She makes me believe that I will make it in life, and I just want to be like her and keep pushing. She is married to a HIV negative guy, and they now have a cute son. I just want to be like her … (laughs) … but you see, when you learn of your status, it's like you will die or you won't have a family you see. But when you meet such people my gosh … (laughs)*". Female ALHIV aged 19
			44. "*So there is this Tik Toker I like, she shared how she discovered her status, how she started medication. Yoo she says back then, there used to take like 13 pills (laughs) I wouldn't survive shame (laughs) and to think I complain when its only 1 pill. It's a shame aunty. I just don't have an excuse … (laughs)*". Female ALHIV aged 18
		b. Peers	45. "*Being in the club helps because you meet with others your age and chat and you can see that you are not alone and it makes you feel better, and you want to keep going*". Female ALHIV aged 19
	5. Privacy	a. Status secrecy	46. "*I have kept it a top secret such that no one knows, and I don't use the health facility closer to home I go far so that no one knows me there and I also don't know them. But my mom refills at her workplace as she works in the hospital, but people don't know that I am also on ART. Even when people ask, she tells them it's only her but there is some of her friends who know*". Male ALHIV aged 19 also peer educator
		b. Disguising medication	47. "*You see that container aunty, I hate it. The noise it makes, and the name of the medication is written outside. You see people can google and then know you have HIV (laughs). I just put them in a panadol [painkillers] container while in the hospital and I throw away the container … (laughs) that container doesn't know where I stay. (laughs)*". Female ALHIV aged 16
		c. Choice of health facility	48. "*I use a facility far from home even when I am sick, I don't use the hospital close to home. Imagine you have a headache and now they say they want to test you so they will know your status*". Female ALHIV aged 15

Secondly, some participants reported that the pill's size and bitter taste made it difficult for them to take (quote 22). Younger adolescents preferred the syrup form over the tablet (quote 23). Additionally, some participants complained about the pill container, noting that its noise and distinctive labelling differed from other medication containers (quote 24). These characteristics often exposed participants to unintended disclosure, leading them to hide their medication. This concealment sometimes resulted in missed doses, particularly when they were around people unaware of their HIV status (quote 24).

Health facility factors. Health facility factors such as time spent in the club, attitude of health workers, and location of the health facility were mentioned by participants as a barrier to ART adherence (quotes 25–30). Some participants felt that the time spent in the club was unnecessarily long, especially when they needed to refill their medication (quote 26).

Additionally, the attitude of health workers, particularly the expert clients, was not conducive, as participants reported being shouted at for being late to club meetings without being given a chance to explain (quote 27). Another participant complained about the

discomfort of having someone from their community know their HIV status, fearing that the expert clients might disclose their status to others (quote 28).

Lastly, the location of the health facility and the ART department was another barrier to ART adherence (quotes 29 and 30). Participants mentioned that having the health facility within the community placed them at risk of unintended disclosure of their HIV status, especially since community members knew who attended the Club meetings on weekends (quote 29). Another participant noted that the ART department's location, being separated from the main hospital departments, also led to unintended disclosure of their HIV status (quote 30).

Economic factors. Participants reported that limited finances were a barrier to ART adherence, as it resulted to lack of transport money to attend Club meeting, especially for those living far from health facilities (quote 31). Limited finances also affected the availability of food to be eaten before taking medication, further complicating adherence (quote 32).

Lack of support. Lack of support from guardian was reported as one reason for inability to maintain treatment schedule. Participants demonstrated this lack of support by noting that their guardians or family members would remind them of their status instead of ensuring they took their medication (quote 33). Also, older adolescents mentioned that as they grew older, their guardian stopped reminding them their medication schedule, resulting in missed dozes (quote 34).

Facilitators of ART adherence

Several factors were reported by participants to enable adherence to treatment. These included having a support system, HIV/AIDS and ART knowledge, status disclosure, motivation and privacy.

Support system. Participants reported that disclosure to friends, family members and teachers enhanced adherence to treatment by ensuring support for the participants (quotes 35 and 36). Support was reported to be the main facilitator to ART adherence by majority of the participants aged 10–14 years and some participants aged 15–19 years. This was support from guardians, family members, club peers, the health workers, friends and having a reminder such as an alarm or taking medication same time as guardian (quotes 35 and 36).

Status disclosure. Status disclosure either by guardian or health worker and at times the participant to friends, family members or partners was reported as a facilitator to ART adherence (quote 37–39). For instance, some participants mentioned that before knowing their status, they often skipped their medication because they did not understand its purpose (quote 37). Other participants reported that taking the medication became easier for them after sharing their status with their friends or partners, as they could now openly take their medication without having to hide or lie (quotes 38 and 39).

HIV and ART knowledge. Participants' knowledge about HIV and ART facilitated the status acceptance and desire to take their medication faithfully. Such knowledge also included benefit of ART. For instance, older adolescents reported to have started adhering to treatment after HIV counselling, which led to status acceptance and increased understanding of HIV and ART (quote 40). The perceived benefits of ART, such as living longer (fear of death) and looking healthier or healing from opportunistic infections, were also reported as facilitators to ART adherence (quote 41 and 42).

Motivation. Motivation was identified as another key facilitator to ART adherence among participants. Seeing prominent and beautiful individuals living successfully with HIV provided inspiration (quote 43). Participants reported following "role models" on social media who share their experiences and resilience in dealing with HIV, which motivated them to adhere to their treatment (quotes 43 and 44). Additionally, witnessing peers of the same age group on ART encouraged adherence, as it fostered a sense of shared community and belonging, particularly through the support of Teen Clubs where they could make friends and share their journey (quote 45).

Privacy. Participants reported privacy to be an important facilitator to ART adherence. Privacy included keeping status a secret to avoid stigma and discrimination (quote 46). To prevent status disclosure, participants preferred taking their medication in secret, which allowed them to adhere to their treatment regimen without fear of being gossiped about (quote 46). Additionally, participants developed strategies to prevent unintended status disclosure, such as transferring pills to another container, inserting toilet paper inside the container to reduce noise and choosing a health facility far from their community (quotes 47 and 48).

Discussion

The study found that ART adherence was significantly low among ALHIV, with 40% of younger adolescents and only 10% of older adolescents reporting they never missed their medication. A notable 48% of older adolescents reported missing their medication at least once or twice a week, consistent with findings from a study in Ghana where older adolescent were most likely to miss medication compared to younger adolescents (Ankrah et al., 2016). Poor ART adherence is strongly linked to treatment failure, with a systematic literature review showing a fivefold increase in the risk of treatment failure due to poor adherence (Lailulo et al., 2020). Treatment failure is further associated with unsuppressed viral load, opportunistic infections and AIDS-related deaths (Siraj et al., 2021). Globally, adolescents account for 5% of the AIDS-related death rate (UNAIDS, 2023). Therefore, interventions aimed at supporting ART adherence among ALHIV are crucial to prevent treatment failure and reduce these fatalities (Singh & Mars, 2012).

Multiple barriers were reported to enable poor or suboptimum ART adherence among ALHIV (Ankrah et al., 2016; Azia et al., 2016). In our study, stigma and discrimination was the most reported barrier to ART among ALHIV. Stigma originated from the adolescents themselves, their families and peers. Participants with undisclosed HIV feared stigma and discrimination from those close to them, while those with disclosed status faced stigma through both negative discussions and social isolation. Perceived stigma led to fear of disclosure, forcing adolescents to hide their medication and avoid taking it for fear of being mocked or segregated. These findings align with studies conducted in Kenya and Botswana, where stigma and discrimination were also identified as leading barriers to ART adherence among ALHIV (Apondi et al., 2021; Madiba & Josiah, 2019). Similarly, perceived stigma and fear of disclosure discouraged adolescents from taking their medication outside their homes, as reported in a study conducted in Zambia (Denison et al., 2015).

Additionally, personal factors mainly forgetfulness and being away from home were another barrier to ART adherence among study participants. These findings are consistent with multiple studies that report forgetfulness as a primary barrier to ART adherence (Ammon et al., 2018; Ankrah et al., 2016; Galea et al., 2018; Nabukeera-Barungi et al., 2015; Shubber et al., 2016; Xu et al., 2017). Forgetfulness and being away from home have been linked to competing demands between taking medication and engaging in personal activities such as sports, school and church services, resulting in missed treatment schedules (Ankrah et al., 2016; Madiba & Josiah, 2019). These competing demands highlight the need for realistic medication schedules, which have been shown to facilitate ART adherence (Kim et al., 2018). Moreover, the use of reminders has been associated with increased ART adherence across various studies, and when combined with realistic schedules, it can enhance adherence among ALHIV (Abiodun et al., 2021; MacCarthy et al., 2020; Reif et al., 2020).

Another significant barrier to ART adherence reported by most participants was related to medicine factors, such as adverse effects of the medication, the taste and size of the pills and the pill container. Studies have identified treatment fatigue as a major barrier to ART adherence, especially among older adolescents who were perinatally infected and have been on ART for an extended period (Ammon et al., 2018; Ankrah et al., 2016; Galea et al., 2018; Madiba & Josiah, 2019; Orth & van Wyk, 2021). According to MacCarthy et al. (2018), the pill burden associated with ART often serves as a constant reminder of the adolescents' HIV status, contributing to self-stigma and a desire for a "pill holiday" (Ankrah et al., 2016; MacCarthy et al., 2018). Poor ART adherence, however, is linked to drug resistance, highlighting the need for the development of better pill formulations and regimens to counteract issues related to taste, size and smell (Galea et al., 2018).

Fourthly, health facility-based barriers were reported by adolescent to impact to their adherence to ART. These barriers included the time spent in the club, the attitude of health workers and the location of the ART clinic within the facility. The findings of our study are consistent with other studies, which have shown that the level of satisfaction with health facilities among adolescents is associated with their level of ART adherence (Hudelson & Cluver, 2015; Mesic et al., 2019; Shubber et al., 2016). This underscores the need for adolescent-friendly services that cater to the preferences of adolescents, particularly regarding the location, meeting times, and the choice of health workers at ART clinics (Elashi & Van Wyk, 2022; van Wyk & Davids, 2019). Currently, the Eswatini HIV treatment guidelines stipulate that ALHIV aged 10 years and above should be linked to a Teen Club, which is designed to support ALHIV including those with detectable viral load (Eswatini Ministry of Health, 2024). The Teen Clubs are supported by health workers such as nurses and physicians who provide ART refill and monitoring

(Eswatini Ministry of Health, 2022). The Clubs are facilitated by expert clients (ECs), who take on specific roles traditionally performed by healthcare workers. ECs create a welcoming and supportive environment for adolescents (Ahmed et al., 2023). Additionally, Teen Clubs sessions are run by Teen Leaders also known as CATs. These are older adolescents or youths who have been living with HIV for at least seven years and share their experiences and knowledge with their peers (Eswatini Ministry of Health, 2022). To provide age-appropriate support, Teen Clubs are further divided into subgroups known as "teen cells", such as the 10–14 and 15–19 age groups (Eswatini Ministry of Health, 2022). However, findings from our study indicate a need to strengthen these services to better align with adolescents' preferences and needs.

The fifth barrier to ART adherence among the ALHIV was economic factors as adolescents lacked finances for both transportation to health facility and to buy food to eat before taking their pills. This lack of financial resources resulted in missed refill appointments and difficulties in adhering to medication due to side effects associated with taking pills on an empty stomach (Ankrah et al., 2016; Madiba & Josiah, 2019). A study evaluating the use of financial incentive to improve ART outcomes among adolescents reported a positive association underscoring the need to tailored interventions to address economic needs of ALIHV (Bermudez et al., 2018).

Lastly, lack of support from both caregiver and family members was reported by participant in this study. According studies, support is critical in management of HIV especially among adolescents (Galea et al., 2018; Kim et al., 2018; MacCarthy et al., 2018). However, Ankrah et al. (2016) revealed that the caregiver support diminishes with older adolescents due to assumed pre-adulthood roles assumed by older adolescents resulting to poor ART adherence among older ALHIV (Ankrah et al., 2016).

Five facilitators for ART adherence emerged in this study: support from caregivers and peers, status disclosure by or to the adolescent, HIV and ART knowledge, motivation, and privacy. These findings align with previous research conducted in various settings (Ankrah et al., 2016; Galea et al., 2018; Mesic et al., 2019). Support was identified as the most crucial facilitator, providing adolescents with a sense of acceptance and belonging, ultimately improving ART adherence (Mburu et al., 2019). Studies have consistently shown a positive correlation between support-oriented interventions and ART adherence, with economic incentives at the family level also proving effective (Ammon et al., 2018; Ankrah et al., 2016; Cluver et al., 2015; Mesic et al., 2019; Munyayi et al., 2022). Status disclosure enabled support, as family members, caregivers and peers could offer necessary support such as reminding adolescents of medication schedules, although negative conversations and stigma were reported as potential drawbacks (Ankrah et al., 2016; Madiba & Josiah, 2019; Mburu et al., 2019; Tanyi et al., 2021). Privacy played a complex role, as while it facilitated adherence by preventing stigma and discrimination, it also led to hiding medication out of fear of unintended disclosure (Madiba & Josiah, 2019; Mesic et al., 2019; Tanyi et al., 2021). Nonetheless, in this study, privacy was seen as a facilitator, ensuring protection against stigma and discrimination for the participants.

Additionally, HIV and ART knowledge was reported as a facilitator for ART adherence in our study. This finding is consistent with studies conducted in South Africa, where adolescents began adhering to their medication upon understanding what medication they were on (Cluver et al., 2015). HIV knowledge was also associated with an increase in ART adherence as adolescents got to know that HIV was not a death sentence but rather a manageable condition that allowed them to achieve their life dreams (Galea et al., 2018; Mesic et al., 2019). The benefits of ART knowledge were further highlighted by Lailulo et al. (2020), who noted it as a key motivator of ART adherence, especially among adolescents who had experienced poor health status and adverse treatment effects (Denison et al., 2015; Lailulo et al., 2020). Lastly, motivation has been reported by studies to improve ART adherence (Denison et al., 2015; Orth & van Wyk, 2021). This motivation emanates from adolescents, their peers or significant others (Ankrah et al., 2016; Cluver et al., 2015; Mesic et al., 2019). Motivation is critical in ensuring status acceptance and increasing self-efficacy and confidence among adolescents thereby enhancing increased ART adherence level (Denison et al., 2015; Orth & van Wyk, 2021). A study by Orth and van Wyk (2021) reported that motivation increased adolescents' will to live, thus improving ART adherence (Orth & van Wyk, 2021).

Limitations

The main study limitation is that data were collected from adolescents in only one region of the country who are members of Teen Clubs, with the majority of participants reporting to be perinatally infected. Consequently, there may be a risk of bias, and findings of the study cannot be extrapolated to other ALHIV living in other regions of the country, and not are

members of Teen Clubs. Nevertheless, the study provides a valuable insight into the challenges faced by ALHIV and highlights the importance of interventions aimed at enhancing ART adherence among ALHIV.

Conclusion

The study findings highlight the importance of creating supporting environments for ALHIV to promote ART adherence. Such environments are fostered through status disclosure, comprehensive HIV and ART knowledge, and the protection of ALHIV's privacy. Additionally, the motivation to live and achieve life aspirations is a significant factor in ART adherence among ALHIV. However, there is a critical need for interventions that address the fear of stigma and discrimination, while also preventing enacted stigma from both family and social levels. Realistic medication schedules should be negotiated with ALHIV to balance ART adherence with their personal and social obligations. Lastly, adolescent-friendly health services should be strengthened to ensure these ART services are accessible and usable, with a focus on the needs of adolescents.

Acknowledgments

The authors thank the adolescents who participated in the study and shared their experiences. Secondly, sincere gratitude goes to Ms. Nobuhle Mthethwa (National Paeds HIV Care Treatment Coordinator) and Ms. Nomvuselelo (Hhohho region Teen Club coordinator) for their support in setting meetings with hospital management.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Authors' contribution

LDH: conceptualisation, methodology, data curation, formal analysis and drafting the manuscript. PSN & CS: conceptualisation, methodology and critical review.

Ethical approval

Approval to conduct the study was sought from the Eswatini Health and Human Research Review Board of the Ministry of Health (Protocol Reference Number: EHHRRB143/2023). Secondly, permission to conduct the study at each facility was sought and granted by the Ministry of Health, Director of Health Services office. The management of the health facilities also granted permission to conduct the study. Adolescents 18 years and above signed their own informed consent and caregivers signed the consent for adolescents aged 10–17 years. Those below the age of 18 years also provided written assent in addition to their caregivers' consent.

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