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"Swallowing these drugs every day, you get tired": a mixed-methods study to identify barriers and facilitators to retention and HIV viral load suppression among the adolescents living with HIV in TASO Mbale and TASO Soroti centers of excellence

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Abstract

Background Adolescents aged 10–19 years, living with HIV (ALHIV) lag in attaining optimal viral load suppression (VLS) rates and retention in care. This study aimed to identify barriers and facilitators to both treatment outcomes in TASO Mbale and TASO Soroti centers of excellence.

Methods We used a mixed methods approach, extracting secondary data on ALHIV who were active in care during April-June 2022 quarter to determine one year retention and VLS (HIV RNA copies < 1000/ml). Analysis was done in STATA Corp, 15.0. We used logistic regression to determine predictors and adjusted odds ratio (aOR) to report levels of predictability, using 95% confidence interval (CI) and $P < 0.05$ for statistical significance. For qualitative component, purposive sampling of 59 respondents was done. Focused group discussions, key informant interviews, and in-depth interviews were used to collect data. Thematic content analysis was done using Atlas ti.

Results There were 533 ALHIV, median age of 15 years, interquartile range of 11–18 and 54.2% females. 12-month retention rate was 95.9% and VLS of 84.0%. Poor and fair adherence [aOR = 0.044, 95% CI 0.010–0.196, $P < 0.001$)], [aOR = 0.010, 95% CI (0.002–0.039) $P < 0.001$] respectively had decreased odds for VLS while multi-month dispensing of drugs (aOR = 3.403, 95% CI 1.449–7.991, $P = 0.005$) had increased odds of VLS. For retention, being with a non-biological caregiver (aOR = 0.325, 95% CI 0.111–0.9482 $P = 0.04$) decreased the odds. Meanwhile key barriers included: individual ones such as internal stigma and treatment/drug fatigue; facility-level such as prolonged waiting time and lack of social activities; community level include stigma and discrimination, inadequate social support and food shortage. In terms of facilitators, individual level ones included good adherence and knowledge of one's HIV status;

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facility-level such as provision of adolescent friendly services and community-level like social support and decent nutrition.

Conclusions VLS rate was sub-optimal mainly due to poor adherence. HIV programs could utilize the barriers and facilitators identified to improve VLS. Conversely, retention rate at one year was good, likely due to provision of adolescent friendly health services. ALHIV and their caregivers need to be empowered to sustain retention and improve VLS.

Keywords Adolescents, Viral load suppression, Retention, Barriers and facilitators, TASO

Introduction

One of the global aspirations to ending HIV/AIDS as a public health problem is ensuring that 95% of people living with HIV (PLHIV) across all populations and age groups attain and sustain HIV viral load suppression (VLS) [1]. This requires that PLHIV are identified, initiated on antiretroviral therapy (ART), retained in care and remain adherent. To this, there is notable progress with five countries: Eswatini, Botswana, Tanzania, Zimbabwe and Rwanda already achieving the milestone in the general population [2]. However, the adolescents (aged 10–19 years) living with HIV (ALHIV) remain disproportionately behind [3].

In 2022, 27,000 (about 4% of global AIDS-related mortality) AIDS-related deaths occurred among the 1.65 million ALHIV, majorly residents in sub-Saharan Africa [4]. Furthermore, The Joint United Nations Program on HIV/AIDS (UNAIDS) estimates, indicated that the global VLS in the sub-population was at 46% during the same year. A recent systematic review in SSA, reported a 55% VLS among the ALHIV and 65% adherence [5]. Similarly, in Uganda, routine programmatic data indicate that by the end of June 2022, retention rate at one year stood at 65% and VLS rate at 71%, both far below the 95% global targets.

Barriers to optimal VLS identified include; difficulties finding transport money, unfriendly health care settings, drug stock outs, prolonged waiting time, unfavorable school timetable, non-disclosure of HIV status and drug side effects [5–11]. Conversely, identified enablers include reliable stock-levels of drugs in the facilities, good attitude of health-workers, availability of transport money, social/family support, and positive peer influence [5, 8, 9]. To counteract the barriers while enhancing the enablers, interventions implemented in different settings across Uganda include; treatment optimization with dolutegravir (DTG)-based regimens, peer-driven approaches such as the Youth and Adolescent Peer supporters (YAPS), and differentiated service delivery models including multi-month dispensing [12–14].

Whereas many barriers and facilitators to retention and VLS are known, both retention and VLS remain sub-optimal across several settings in Uganda, including The AIDS Support Organization (TASO) Uganda. Additionally, the factors tend to vary from one setting to another, possibly justifying the persistent sub-optimal levels of the two treatment outcomes despite the interventions so far implemented. Thus, we propose to adapt the implementation of operation triple zero (OTZ) [15] model in the TASO setting to close these gaps. As part of the implementation strategy, we identified barriers and facilitators to both retention and VLS to facilitate adaptation of OTZ in the setting.

Methodology

Study design

A mixed-methods study (explanatory sequential) was preferred to comprehensively elicit barriers and facilitators to retention and VLS, from the key stakeholders including caregivers, health workers and the adolescents themselves.

Study setting

We conducted the study in TASO Mbale and TASO Soroti centers of excellence (COEs). Both COEs provide comprehensive HIV services such as prevention, care, treatment and support to more than 13,300 PLHIV including 583 ALHIV as at the end of September 2023. In terms of adolescent services, both facilities implement the YAPS model, an adaptation of the community adolescent treatment supporter (CATS) of the Zvandiri intervention in Zimbabwe [16, 17]. The YAPS are typically young people living with HIV, have overcome internal stigma, can constructively write and speak in English language [14]. Further, viral load tests are the standard measure of treatment response and plasma samples are shipped to the central public health laboratory for analysis. Plasma HIV RNA viral load copies of < 1000/mL were considered suppressed in line with the Uganda national guidelines [14].

Study population

We considered ALHIV who were active in care in the April-June 2022 quarter. In addition, caregivers and health workers including peers, were also engaged to provide qualitative insights.

Inclusion criteria

All ALHIV active in the April-June 2022 quarter, and aged 10–17 years, to allow for complete follow-up of the cohort for at least one year.

Exclusion criteria

ALHIV aged 18 years and above were excluded as these would have transitioned within 12 months of implementation. In addition, those with incomplete information on key variables such as ART status and VL were excluded.

Sample size and sampling procedure

For quantitative component

We used a census sampling technique, enrolling all the eligible ALHIV into the study.

Qualitative component

A purposive sampling approach was preferred.

Study outcomes

HIV viral load suppression We adopted a standard ministry of health definition of VLS, already defined earlier. We considered any VL test done within the previous 12 months.

Retention ALHIV active in care basing on most recent clinic encounter being within the next scheduled clinic appointment or expected visit missed but still inside 28 days of the reporting period, using the United States' President's emergency plan for AIDS Relief (PEPFAR) definition [18]. We measured retention among the ALHIV at one year, categorizing outcomes as active (if ALHIV was within their most recent appointment), dead (those confirmed to have died), lost to follow-up (untraceable individuals after at least four attempts) and transfer out for those who shifted to other facilities.

Adherence The measurement was based on self-reports by the clients and adherence levels categorized as poor, for below 84%, fair for 85–94% and good if more than 95% as per national standards. This approach could lead to an over-estimation of optimal adherence levels.

Data management

Data collection

For quantitative data

We used a questionnaire to abstract secondary data from patient files, registers and Uganda electronic medical records, entered into an online database hosted on KoBo toolbox [19]. The tool was tested in TASO Gulu and TASO Masindi centers of excellence, making necessary adjustments before final deployment. Teams of three individuals, including YAPS, counsellors and Monitoring and Evaluation officers were trained to conduct data abstraction. Data was downloaded and exported to Microsoft Excel, version 2019 for basic cleaning and preparation for final analysis in STATA Corp, version 15.0.

Qualitative data

The outer and inner settings of the consolidated framework for implementation research (CFIR) was used to design the data collection tools [20, 21]. We trained a team of experienced research assistants from Makerere University School of public health for one day, to collect qualitative data using interview guides. Key informant interviews (KIIs), in-depth interviews (IDIs) and focus group discussions (FGDs) were used to gather data from respondents. Health workers including clinicians, counsellors, medical doctor, nurses and the YAPS who worked closely with the ALHIV offered their expert perspectives through KIIs, while caregivers and ALHIV responded to the IDIs and FGDs. For FGDs, groups of 6 ALHIV with non-suppressed VL, six ALHIV with suppressed VL, six caregivers of ALHIV with suppressed VL and six caregivers of non-suppressed VL. Each FGD took an average of 45 min, IDIs and KIIs took 1 h. In total, we conducted 35 interviews. All interviews were conducted face-to-face within the clinic setting, in comfortable rooms without the presence of non-participants to ensure confidentiality. Interviewers used semi-structured interview guides with translations from English to Luganda, Ateso and Lumasaba languages. Data was collected as audio-tape recording and complemented with field notes.

Data analysis

Quantitative data Univariates were summarized as frequencies, and percentages. Pearson's chi-square was used to determine association among the various categorical variables, at a confidence interval of 95%. Variables with P-value less than 0.2 were considered for multivariable analysis. To determine factors associated with retention and VLS, logistic regression was used, with adjusted odds ratios (aOR) preferred for reporting magnitude of association using 95% confidence interval, at $P < 0.05$ level of significance.

Qualitative component Audio recorded data was transcribed into texts, translated to English and entered into Atlas ti. for the analysis. Four research assistants conducted the initial coding. Working with BO, AIO, AK and DK, the team developed codebooks that were used to complete the thematic analysis using content deductive approach. The four research team members then met

virtually to refine the codes to ensure they made sense. Major themes and sub-themes were developed in line with the study objective. Key statements were transcribed verbatim and reported as appropriate.

Results

From Tables 1, 2, 533 records were considered for analysis, 54.2% being females with median age of 16 years, interquartile range of 11–18. Importantly, all the adolescents were on optimal ART regimens, 38.0% were living with non-biological parents, and 69.0% were in school.

Table 1 Basic demographic characteristics of the ALHIV at TASO Mbale and Soroti COEs included in the study

Variables	Frequency (N = 533)	Proportion (percentage)
Study centres		
TASO Mbale CoE	304	57
TASO Soroti CoE	229	43
Current age		
11–14 years	199	37.3
15–18 years	334	62.7
Age at diagnosis		
0–2 years	232	43.5
3–5 years	156	29.3
6–10 years	118	22.1
11–15 years	24	4.5
> 15 years	3	0.6
Sex		
Female	289	54.2
Male	244	45.8
Pregnancy status (N = 289)		
Yes	2	0.7
No	287	99.3
School going status		
Not at school	165	31
At school	368	69
Caregiver present		
No	8	1.5
Yes	525	98.5
Caregiver relationship (N = 525)		
Biological parent	324	61.7
Guardian	201	38.3
Caregiver HIV status (N = 525)		
HIV Negative	153	29.1
HIV Positive	230	43.8
Unknown	142	27
Distance to facility		
< 5 km	207	38.8
> = 5 km	326	61.2

Table 2 Clinical characteristics of ALHIV at TASO Mbale and Soroti COEs, included in the study

Variables	Frequency (N = 533)	Proportion (percentage)
Current retention at 12 months		
Active	511	95.9
Died	4	0.8
Transferred out	8	1.5
Lost > 28 days	10	1.9
Current viral load suppression		
Non-suppressed	134	25.1
Suppressed	399	74.9
Adherence scores		
Good	494	92.7
Fair	27	5.1
Poor	12	2.3
Baseline WHO clinical stage		
Clinical stage I	50	9.4
Clinical stage II	438	82.2
Clinical stage III	32	6.0
Clinical stage IV	13	2.4
Baseline CD4 count		
< 200 copies	66	12.4
> = 200 copies	209	39.2
Not done	258	48.4
Current ART regimen		
ABC-3TC-DTG	88	16.5
AZT-3TC-DTG	29	5.4
TDF-3TC-DTG	406	76.2
TDF-3TC-LPV/r	1	0.2
Other	9	1.7
Current ART line		
First line	449	84.2
Second line	71	13.3
Third line	13	2.4
Current DSDM approach		
CCLAD (community client-led ART Delivery)	25	4.7
CDDP (Community drug delivery points)	106	19.9
FBG (facility-based groups)	354	66.4
FBIM (facility-based individual management)	40	7.5
FTDR (Fast-track drug refills)	8	1.5
MUAC (Mid-upper arm circumference)		
Green	498	93.4
Yellow	23	4.3
Red	12	2.3
TB status		
No signs and symptoms	498	93.4
Presumptive	28	5.3
TB diagnosed	7	1.3
OVC (orphaned and vulnerable children) status		

Table 2 (continued)

Variables	Frequency (N = 533)	Proportion (percentage)
Ever enrolled	323	60.6
Never enrolled	210	39.4
Benefited from OVC services (N = 323)		
No	62	19.2
Yes	261	80.8
MMD (multi-month dispensing)		
< 3_months	59	11.1
3 to 5 months	273	51.2
More than 5 months	201	37.7
Disclosure status		
Yes	522	97.9
No	11	2.1

Regarding viral load, all the adolescents had at least a VL test done within the previous 12 months with an average VLS rate of 84.0%. As for retention at one year, it was impressively high at 95.9%, attributed to the implementation of differentiated service delivery including multi-month dispensing and community-based ART delivery approaches. In addition, the high rate of HIV status disclosure (97.9%) could also have played a role as well as treatment optimization. Further, adherence was generally good, at 92%. However, it is important to remember the subjective nature of the measurement used on this occasion.

Meanwhile, several factors were associated with retention and VLS as detailed in Table 3. For retention, disclosure of HIV status (P < 0.001), multi-month dispensing (P = 0.002), OVC status (P = 0.01), caregiver relationship (P = 0.03), school going status (P = 0.023) and age at diagnosis (P < 0.001). Conversely, multi-month dispensing (P < 0.001), current differentiated service delivery model (DSDM) (P < 0.001), current ART line (P = 0.008), current regimen (P = 0.008), and adherence (P < 0.001) were associated with VLS.

In Table 4, certain key predictors emerged as significant determinants of the 12-month retention on Antiretroviral Therapy (ART). Adolescents with non-biological caregivers, had less odds of remaining in care (aOR = 0.325, 95% CI 0.111–0.948, P = 0.04). These findings emphasize the critical role of biological parental support in sustaining adolescent retention in care. Also, adolescents on ABC-3TC-DTG had decreased odds of remaining in care compared to those on TDF-3TC-DTG (aOR = 0.288, 95% CI 0.101–0.823, P = 0.02). This is possibly linked to non-fixed dose combination of ABC/3TC/DTG.

Viral load suppression (VLS)

As indicated in Table 5, adherence to ART significantly influenced viral load suppression. Adolescents with fair adherence had significantly lower odds of suppression compared to those with good adherence [adjusted OR = 0.010, 95% CI 0.002–0.039, P < 0.001). Similarly, poor adherence was associated with significantly reduced odds of suppression (adjusted OR = 0.044, 95% CI 0.010–0.196, P < 0.001). The DSDM approach significantly influenced suppression outcomes. Adolescents in the Community Client-Led ART Delivery (CCLAD) and Community Drug Distribution Point (CDDP) approaches showed higher odds of suppression compared to the Facility-Based Group (FBG) model, but this was significant only for CDDP (adjusted OR = 0.4634, 95% CI 0.216–0.996, P = 0.049). Adolescents in the Facility-Based Individual Model (FBIM) had markedly lower odds of suppression (adjusted OR = 0.070, 95% CI 0.028–0.174, P < 0.001). Longer dispensing intervals were strongly associated with better viral suppression. Adolescents with 3–5 months of dispensing had significantly higher odds of suppression (adjusted OR = 3.403, 95% CI 1.449–7.991, P = 0.005). Those with more than 5 months of dispensing showed even higher odds of suppression (adjusted OR = 5.553, 95% CI 2.078–14.842, P = 0.001).

Qualitative findings

As presented in Table 6, a total of 59 respondents participated in the study, majority of whom being peasants, those with post-primary education, and aged at least thirty years.

We classified barriers and facilitators into three main themes: individual level, facility-level and community-level factors. Key barriers identified include:

Individual level barriers

Internal stigma, was a commonly cited barrier to both retention and viral load suppression. ALHIV feel uncomfortable in environments where they have not disclosed their HIV status, culminating into viral non-suppression. This includes schools, unfamiliar hospital settings and those in sexual relationships where the spouse is ignorant of the adolescent's HIV status. One adolescent commented:

> *"First of all, we like bragging a lot, for example when you are dating a girl and when she comes home, for example she has finished a full week, you will not show her that you are on treatment, you will not swallow the drugs."-male non-suppressed adolescent.*

The adolescents need to be supported to overcome their own internal stigma and helped to disclose HIV

Table 3 Bivariate analysis of association between various categorical variables and retention and viral load suppression among the study participants

	Retention					Viral load suppression		
	Active (N = 511) (%)	**Died (N = 4) (%)**	**Transferred Out (N = 8) (%)**	**Lost > 28 days (N = 10) (%)**	**P-value**	**Suppressed (N = 430) (%)**	**Non-suppressed (N = 81) (%)**	**P-value**
Age group								
11—14 Years	187 (94.0)	2 (1.0)	4 (2.0)	6 (3.0)	0.4	166 (88.8)	21 (11.2)	**0.03***
15—18 Years	324 (97.0)	2 (0.6)	4 (1.2)	4 (1.2)		264 (81.5)	60 (18.5)	
Age at diagnosis								
0–2 Years	219 (94.4)	3 (1.3)	4 (1.7)	6 (2.6)	**< 0.001***	183 (83.6)	36 (16.4)	0.64
3–5 Years	152 (97.4)	0 (0.0)	0 (0.0)	4 (2.6)		128 (84.2)	24 (15.8)	
6–10 Years	117 (99.2)	0 (0.0)	1 (0.9)	0 (0.0)		97 (82.9)	20 (17.1)	
11–15 Years	21 (87.5)	1 (4.2)	2 (8.3)	0 (0.0)		20 (95.2)	1 (4.8)	
16–19 Years	2 (66.7)	0 (0.0)	1 (33.3)	0 (0.0)		2 (100.0)	0 (0.0)	
Sex								
Female	279 (96.5)	3 (1.0)	4 (1.5)	3 (1.0)	0.37	242 (86.7)	37 (13.3)	0.08
Male	232 (95.9)	1 (0.8)	4 (1.5)	7 (1.8)		188 (86.7)	13.26 (13.3)	
Adherence scores								
Good	474 (96.0)	3 (0.6)	8 (1.6)	9 (1.8)	0.3	424 (89.5)	50 (10.5)	**< 0.001***
Fair	26 (96.3)	1 (3.7)	0 (0.0)	0 (0.0)		3 (11.5)	23 (88.5)	
Poor	11 (91.7)	0 (0.0)	0 (0.0)	1 (8.3)		3 (27.3)	8 (72.7)	
Caregiver relationship (N = 525)								
Biological parent	317 (97.8)	1 (0.3)	3 (0.9)	3 (0.9)	**0.03***	265 (83.6)	52 (13.4)	0.81
Guardian	186 (92.5)	3 (1.5)	5 (2.5)	7 (3.5)		157 (84.4)	29 (13.6)	
Baseline WHO clinical stage								
Clinical stage I	48 (96.0)	0 (0.0)	1 (2.0)	1 (2.0)	0.98	45 (93.8)	3 (6.2)	**0.02***
Clinical stage II	418 (95.4)	4 (0.9)	7 (1.6)	9 (2.1)		353 (84.4)	65 (15.6)	
Clinical stage III	32 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)		22 (68.8)	10 (31.2)	
Clinical stage IV	13 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)		10 (76.9)	3 (23.1)	
Current ART regimen								
ABC-3TC-DTG	80 (90.9)	1 (1.1)	3 (3.4)	4 (4.5)	0.776	9 (11.3)	71 (88.7)	**0.008***
AZT-3TC-DTG	29 (33.0)	0 (0.0)	0 (0.0)	0 (0.0)		9 (31.0)	20 (69.0)	
TDF-3TC-DTG	392 (445.5)	3 (3.4)	5 (5.7)	6 (6.8)		59 (15.1)	333 (84.9)	
TDF-3TC-LPV/r	1 (1.1)	0 (0.0)	0 (0.0)	0 (0.0)		1 (100.0)	0 (0.0)	
Other regimens	9 (10.2)	0 (0.0)	0 (0.0)	0 (0.0)		3 (33.3)	6 (66.7)	
Current ART line								
First line	431 (96.0)	3 (0.7)	5 (1.1)	10 (2.2)	0.36	372 (86.3)	59 (13.7)	**0.008***
Second line	67 (94.4)	1 (1.4)	3 (4.2)	0 (0.0)		49 (73.1)	18 (26.9)	
Third line	13 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)		9 (69.2)	4 (30.8)	
Current DSDM approach								
CCLAD	25 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)	0.56	23 (92.0)	2 (8.0)	**< 0.001***
CDDP	101 (404)	1 (4.0)	0 (0.0)	4 (16.0)		79 (78.2)	22 (21.8)	
FBG	339 (1356)	3 (12.0)	7 (28.0)	5 (20.0)		305 (90.0)	34 (10.0)	
FBIM	39 (156)	0 (0.0)	0 (0.0)	1 (4.0)		16 (41.0)	23 (59.0)	
FTDR	7 (28)	0 (0.0)	1 (4.0)	0 (0.0)		7 (100.0)	0 (0.0)	
OVC status								
Ever enrolled	316 (97.8)	0 (0.0)	2 (0.6)	5 (1.6)	**0.01***	269 (85.1)	47 (14.9)	0.441
Never enrolled	195 (92.9)	4 (1.9)	6 (2.86)	5 (2.38)		161 (82.6)	34 (17.4)	

Table 3 (continued)

	Retention					Viral load suppression		
	Active (N = 511) (%)	Died (N = 4) (%)	Transferred Out (N = 8) (%)	Lost > 28 days (N = 10) (%)	P-value	Suppressed (N = 430) (%)	Non-suppressed (N = 81) (%)	P-value
MMD								
< 3 months	51 (86.4)	1 (1.7)	4 (6.8)	3 (5.1)	**0.002***	218 (83.5)	43 (16.5)	**< 0.001***
3 to 5 months	261 (95.6)	3 (1.1)	4 (1.5)	5 (1.8)		30 (58.8)	21 (41.2)	
More than 5 months	199 (99.0)	0 (0.0)	0 (0.0)	2 (1.0)		182 (91.5)	17 (8.5)	
Disclosure status								
Yes	502 (96.2)	2 (0.4)	8 (1.5)	10 (1.9)	**< 0.001***	9 (100.0)	0 (0.0)	0.189
No	9 (81.8)	2 (18.2)	0 (0.0)	0 (0.0)		421 (83.9)	81 (15.1)	

* **p < 0.05**

Table 4 Logistic regression for predictors of retention among the ALHIV at TASO Soroti and Mbale COEs who were included in the study

Variables	N = 533	Unadjusted		Adjusted	
		P-value	OR[CI]	P-value	OR[CI]
Caregiver relationship (N = 525)					
Biological parent	324			ref	
Non-biological (Guardian)	201	**0.01***	0.274 [0.110 0.684]	**0.04***	0.325 [0.111 0.948]
Current ART regimen					
TDF-3TC-DTG	88			ref	
ABC-3TC-DTG	29	**0.03***	0.357 [0.145 0.880]	**0.02***	0.288 [0.1009 0.823]
AZT-3TC-DTG	406		1		1
Other	10		1		1
Current DSDM approach					
FBG	25	ref		ref	
CCLAD	106		1		1
CDDP	354	0.83	0.894 [0.3171 2.519]	0.929	1.055 [0.320 3.476]
FBIM	40	0.60	1.726 [0.2219 13.421]	0.875	1.199 [0.124 11.590]
FTDR	8	0.29	0.310 [0.0358 2.681]	0.05	0.072 [0.005 0.998]

* **p < 0.05**

status to significant others. Another barrier highlighted was poor adherence. Good adherence was found to be associated with VLS, and a respondent said:

> *"I realized, she just picks from the container, then she used to go and hide them under her bed, then you ask her have you swallowed? then she says yes"- caregiver of a non-Suppressed ALHIV.*

This was a common experience reported by caregivers and even health workers. It thus calls for empowerment of the adolescents to appreciate the need to adhere well and also treatment support from caregivers or peers. In addition, it is worth noting that some adolescents become non-adherent merely to explore its potential effect on their health as one health worker observed:

> *"As they come here, they will discuss that do you know for me I have taken now one week. They told me to come on such a day, I did not. I have come but I am okay, next time you are doing viral load, the very child is suppressed and then they will say you see they tell us if you miss your drugs, you will get non-suppressed but for me I have not. So, they try some of these things. Some of them intentionally refuse to come for appointments because they want to first stop taking drugs and see what will happen actually"-counsellor, TASO Mbale CoE*

Table 5 Logistic regression for predictors of viral load suppression among the ALHIV at TASO Soroti and Mbale COEs who were included in the study

Variables	N = 533	Unadjusted		Adjusted	
		P-value	OR[CI]	P-value	OR[CI]
Adherence scores					
Good	494		ref		
Fair	27	**< 0.001***	0.015 [0.005 0.053]	**< 0.001***	0.010 [0.002 0.039]
Poor	12	**< 0.001***	0.044 [0.011 0.172]	**< 0.001***	0.044 [0.010 0.196]
Current ART line					
First line	449		ref		
Second line	71	**0.007***	0.432 [0.236 0.791]	0.31	0.619 [0.243 1.573]
Third line	13	0.095	0.357 [0.107 1.196]	0.23	5.771 [0.338 98.487]
Current DSDM approach					
FBG	25		ref		
CCLAD	106	0.743	1.282 [0.290 5.675]	0.88	0.874 [0.145 5.291]
CDDP	354	**0.002***	0.400 [0.222 0.723]	**0.049***	0.464 [0.216 0.996]
FBIM	40	**< 0.001***	0.078 [0.037 0.161]	**< 0.001***	0.070 [0.028 0.174]
FTDR	8				
MMD					
< 3 months	59		ref		
3 to 5 months	273	**< 0.001***	3.549 [1.859 6.774]	**0.005***	3.403 [1.449 7.991]
More than 5 months	201	**< 0.001***	7.494 [3.551 15.818]	**0.001***	5.553 [2.078 14.842]

* **p < 0.05**

Table 6 Basic demographics of qualitative respondents

Variables		
Age-group	10–14	6
	15–19	18
	20–24	8
	25–29	0
	30 +	27
Sex	Female	31
	Male	28
Education level	Primary	15
	Post-primary	24
	None	20
Occupation	Peasant	22
	Health worker	10
	Business person	09
	Student	16
	Mechanic	1
	Disc Jockey	1

Sometimes, this is due to negative peer influence. For example, in one session, it was reported that ALHIV can by consensus, agree to abandon ART for some time as noted in the quotation below

> *"Now, mine swallows the medicine very well but sometimes when they are in a group and they sit with their fellow positive friends, so they say let us just leave this because now we are grown up and they miss like one day and then the following morning"-caregiver for a suppressed adolescent.*

Treatment fatigue is another barrier. Considering that 43.5% of the ALHIV were diagnosed by the age of two years and overall, 95% by 10 years, means that majority have been on ART for a long time. Thus, some of the ALHIV may become fatigued from having to swallow drugs daily. Here, one adolescent notes;

> *"Swallowing this drug every day, you can get tired, you dodge, you go and keep the medicine, they ask "have you swallowed? you say yes, I have swallowed, yet you have kept. Because now, like today you have swallowed, tomorrow again and the next day the same medicine, you keep asking yourself am now tired"-non-suppressed male adolescent.*

It is thus, vital for health workers including peers to empower the adolescents in order to have a positive outlook to life.

Facility-level barriers

Firstly, lack of social activities within the facilities. It is worth noting that the opportunities for the adolescents to meet and interact periodically is important for creating a

strong social fabric that glues together peers. This bond normally goes a long way in enhancing individual's self-esteem, treatment literacy and overall positive outlook to life. Unfortunately, the adolescents observed that these were missing, denying them the great opportunities to meet, share experiences, learn from and encourage one another to improve well-being and health outcomes.

"I think some of our colleagues why they are not suppressing is because there is no motivation that used to exist, like food, the things that they used to give, the games that were here now when you come here you stay hungry the whole day...." Suppressed adolescent, FGD.

Prolonged waiting time was another important barrier observed. PEPFAR [22] recommends that PLHIV need to take less than one hour accessing services in a facility to motivate clinic attendance and stimulate retention in care. However, it was noted that sometimes the clinics are heavy, leading to prolonged waiting time. This potentially demotivated some ALHIV from attending scheduled clinic appointments as one adolescent observed as follows:

"Sometimes people are many, that when you reach here as in the line like at 11am there, you may leave here at around 4pm. By the time you reach where I stay, like for me am from Ngora, it will be at around 8pm there." Female non-suppressed adolescent.

Community-based barriers

The study also identified important community-based barriers to retention and VLS. One commonly cited barrier was external stigma and discrimination. The respondents noted this, occurring from the wider community but also in schools, as demonstrated in the quote below:

"My mother disclosed to that teacher, that teacher had no secret. He went on telling, people, telling people. Children did not want to sit with me on the same desk. Then it reached time when I hated myself and I told my mother to get for me another school, which she did."-male non-suppressed adolescent

Stigma and discrimination are selfish vices that deprive victims of the opportunity to peacefully live and exploit their full potential. It can lead to reduced self-esteem, a feeling of self-unworthiness and full-scale mental ill-health if unaddressed. There is thus, need to continuously sensitize the communities including teachers to elevate awareness to this vice that can lead to catastrophic outcomes. It can also stimulate adverse behavior including rejecting drugs among the adolescents who are affected, as noted in the quote below;

"Mine decided to throw the drugs away, you hear that? because the colleagues were laughing at him, he didn't know why he was taking the drug, so when he saw the drug, the colleague said "eeeh, this drug we saw our grandmother also used to take the same drug. So, you are taking drugs for HIV, then he became shy, then he throws the drugs in the dust bin."-caregiver, non-suppressed adolescent.

Further, respondents revealed lack of food as a credible barrier to retention and VLS. As one respondent observed,

"Some of us life is very difficult. Even to get what to eat sometimes it's very difficult. you know staying with grandparents, they only think that digging is the only important thing in their life...."- female non-suppressed adolescent.

The lack of food frustrates optimal adherence, leading to non-viral suppression. Food and nutrition generally are important in improving absorption and also tolerability of drugs.

On the other hand, inadequate social support was yet another major barrier cited. Social support is critical in chronic care and without it, the disease condition can overwhelm the system. One respondent said:

"The biological father doesn't want to see the child and does not want to know that he has a child. He said that "those are HIV affected children; I don't want them. Let them die so that I can get condolence and I eat. And even when the child goes to the father, he doesn't give him anything, not even a single coin." Caregiver of a non-suppressed adolescent."

In this study, eight (8) ALHIV were without caregivers, exacerbating this barrier even further. Moreover, some of the ALHIV had unstable caregivers, moving from one to another. This inconsistency affects optimal social and economic support. The instability deprives the adolescents of good nurturing as most times, nobody is there to take full responsibility. It also frustrates the efforts of health workers who attempt to provide treatment literacy and empower the caregivers due to the frequent changes in caregivers. To this, health-workers need to periodically engage the caregivers including teachers to continuously sensitize them on their basic responsibilities, as suggested by a respondent indicated in the quotes below:

"The counsellors should regularly invite parents or caregivers of those adolescents for counselling sessions on how to support these adolescents because

when caregivers take time without having such sessions, they tend to forget everything and relax. So, there should be continuous sessions for caregivers. Adolescent should be invited for the sessions such that he/she also knows what to do when it comes to adherence and how to live with their peers at school"-caregiver, suppressed adolescent.

In terms of facilitators to both retention and VLS, we also categorized them as individual, facility and community-levels.

Individual level facilitators

Knowing one's HIV status was a good motivation for optimal retention and VLS. As noted earlier, 11 ALHIV had not yet been disclosed to and yet disclosure was associated with good retention in care. Disclosing HIV status can attract better social support with good retention in care and VLS as highlighted in the quotation below:

"He advises me to take my medicine at the right time and before taking drugs you must first eat something. I always take in the morning and he tells me that, make sure that there is tea in the morning to take before you swallow your drugs. Yes, I told him that I am positive so we use condoms and he told me that if you stop taking medicine, I will also leave you." female virally suppressed adolescent.

Good adherence is another important facilitator. Respondents observed that those who swallow their drugs properly had suppressed their viral loads as well. Considering that all the adolescents were on optimal regimens (DTG-based or protease inhibitor-anchored), means that with good adherence, the ALHIV should ideally suppress their viral load. One caregiver observed the effect of good adherence in the following quote:

"He swallows the medicine very well because we came here and they told him the time that he should take the medicine and when that time reaches, we have to tell him or even when he doesn't remember we try to remind him and tell him to swallow the medicine but he has never missed ever since he started swallowing medicine." -caregiver of a suppressed adolescent

Facility level facilitators

Respondents identified provision of adolescent friendly services as a facilitator. The facilities provided differentiated services including community ART delivery approaches, multi-month dispensing, appointment reminders, presence of the YAPS, clinical and psychosocial services. These services inspire adolescents and their caregivers to adhere to their scheduled appointments. Moreover, the ALHIV also noted the good attitude of health-workers in the two COEs as stated below:

"I have found it good in that when we reach the health workers attend to us very well. They don't ask for many things, they ask if the patient is swallowing the medicine very well and we tell them that yes, the medicine was well swallowed so that is the good thing here. Another thing why the clinic is okay is that I might forget of my appointment they call me and remind me of the appointment and immediately I also say it is fine I am coming and I organize myself and come so they remind me"-caregiver of a suppressed adolescent.

Another respondent stated that:

"Sometimes I fear to disclose to someone who is not of my age everything but I can disclose to someone of my age everything."- virally suppressed adolescent. This statement underscores the importance of implementing the YAPS program to enhance quality of HIV services among the ALHIV.

"They want a young person maybe who is a doctor to attend to them. Someone who understands them better because you may find that maybe someone of 60 years or 40, or 50 years. So, at times they don't feel comfortable sharing issues with them and you find someone has a problem and they come to see the doctor and goes back with it so when you interact with them so why didn't you see the doctor that means there is fear to share with those elderly people so they want their age range."- YAPS, TASO Mbale

Community-level facilitators

Social support. As already noted, social support is fundamental in achieving good health, especially with chronic care. This support includes reminding the adolescents of their scheduled clinic visits, caregiver supervision of adherence and provision of transport money for clinic visits as well as decent food. We illustrate these with the following quotations.

"On the side of nutrition much as the situation is not so good, but at least we endeavor to see that after taking his drugs, he has to have something to take like porridge or tea even if we don't have escort and also lunch, he has to eat in time as well as supper."- caregiver of a non-suppressed adolescent

"For me whenever I get medicine, I take it home but it is my father who gives me to take because sometimes I forget"-suppressed adolescent

It is thus important for health workers to empower the adolescents and their caregivers to disclose HIV status of those in schools to the administrators.

Discussion

Overall, in this study, retention rate at 12-months was high at 95.9%. To the contrary, VLS rates among the ALHIV in the setting was sub-optimal, at 84%. To this, we identified several barriers and facilitators. The findings will also act as a baseline for the adaptation and implementation of Operation Triple Zero (OTZ) model to the TASO setting.

The retention rate surpassed most previous studies. For example, Muwanguzi et al., reported 65% among the adolescents and young people aged 15–24 years [6], 29% by Izudi et al., [23], 69.5% by Cluver et al., [8], Zanooni et al., 89% [24] and 35.7%, Nimwesigwa et al., [12]. As for VLS, it was higher than reported by Hlophe et al., [5] at 55%, 65% by Simms et al., [10], 62% in Kenya [25] and 81% by Tugume et al., [7]. This is attributable to factors such as provision of adolescent health friendly services as enshrined in the WHO guidelines [26]. These include differentiated service delivery approaches, good attitude of health workers toward the ALHIV, proper appointment management systems, multi-month dispensing of ART and the presence of YAPS.

Peer driven models such as the CATS and Teen Clubs, demonstrated positive impact on improving retention among the adolescents in Zimbabwe [17, 27]. The YAPS model is designed to enhance peer-to-peer support including adherence counselling, building on socio-cognitive theory which contends that individuals are more likely to be influenced by their peers [28]. Indeed, this finding underscores the contribution of the YAPS program in improving treatment experience among the ALHIV. Uganda started its implementation in 2019 to enhance peer-driven quality of HIV services using age-appropriate messages and techniques [12]. Interestingly, these factors were associated with low retention in one study conducted in western Uganda [12], which found that ALHIV in facilities implementing the YAPS model and enrolled into the FBGs were more likely to be lost to follow-up. This likely reflects the complexity or uniqueness of ALHIV needs and implementation fidelity (or lack there-of) of the interventions, in the different settings. Nevertheless, both community-based DSDM and MMD counteract the challenge of lack of transport money, ensuring consistent availability of drugs and good adherence.

Without doubt, adolescent friendly services are critical in improving retention and VLS. As Ritchwood et al., noted, health-worker-client relationship plays a central role in optimizing retention and VLS among the ALHIV [29]. They observed that the ALHIV referred to their service providers as 'family' and facilities as 'home'. It is therefore unsurprising that friendly health workers were identified in this study as motivators for adolescents and their caregivers to remain in care, a similar finding by Cluver et al., in a South African study [8]. Thus, these interventions need to be up-held in-order to sustain the good retention rate. However, facility-based ALHIV under individual management need to be supported so as to attain the required level of VLS.

Further, effective social support system is another important enabler. In their study, Lypen et al., [30] identified four different types of social support; emotional (expressions of love, trust and care), informational (advice, information and suggestions), appraisal (useful information for self-evaluation) and instrumental (tangible support). They also demonstrated a wide range of sources of social support such as family members, friends including spouses, health workers, teachers and religious leaders. Social support provides the necessary oil for lubricating the engine that runs the chronic care machine. As Damulira et al., [31] reported in their study, caregiver/family social support was associated with self-reported adherence among the ALHIV in Uganda. Indeed, Okonji et al. [32] report that family-centered interventions were critical in improving adherence and retention among the adolescents and young people living with HIV in their study. Indeed, our study found a strong influence of good adherence on VLS. Also, in this study, adolescents on non-fixed ART combinations such as ABC/3TC/DTG likely struggle to adhere, thus affecting their retention in care. Indeed, this complex could explain why ALHIV who lived with non-biological caregivers had decreased odds for retention in care. Thus, strong cohesive families remain the bed-rock of achieving optimal adherence, and treatment outcomes among the ALHIV and programs need to prioritize family centered approaches in line with the Uganda national focus of integrated community service delivery model (ICSDM) [14].

We recognize important study strengths and include: The mixed methods design ensured robustness, with qualitative and quantitative approaches complementing each other. Secondly, the design and deliberate approach employed to collect and analyze qualitative data provided rigor and ensured reliable findings. Finally, the use of routine programmatic data for the quantitative component provided credible and reliable information since it likely reflects the true situation on the ground.

Further, we also acknowledge some key weaknesses of this study: firstly, it only considered two TASO sites without involving any public health site. This can potentially diminish its wide applicability in other settings, given the obvious differences in the capacities of TASO sites and

public health facilities. Nonetheless, the findings can still be useful in a wide range of settings as adolescent challenges may cut across. Secondly, the use of secondary data for the quantitative analysis led to exclusion of some ALHIV due to incompleteness of crucial information. The missed individuals could have added value to the findings. Nonetheless, the use of a census approach ensured that the sample size was large enough to counteract the potential effect of exclusions.

Conclusion

Our findings indicate that the short-term retention among the adolescents living with HIV in TASO Soroti and Mbale COE was high, attributed to provision of adolescent friendly services, and sub-optimal VLS due to several barriers identified. There is thus, need to actively involve adolescents and their caregivers in the design and provision of health interventions to ensure they meet the needs of the ALHIV.

Recommendation

We recommend the implementation of OTZ in the setting to ensure health-workers, adolescents themselves and the caregivers are all actively involved in the provision of health services.

Abbreviations

ALHIV	Adolescents living with HIV
ART	Anti-retroviral therapy
CCLAD	Community client-led ART Delivery
CDDP	Community drug delivery points
DTG	Dolutegravir
DSDM	Differentiated service delivery model
FBIM	Facility-based individual management
FGD	Facility-based group
FTDR	Fast-track drug refill
ICSDM	Integrated Community Service Delivery Model
MMD	Multi-month dispensing of drugs
MUAC	Mid-upper arm circumference
OTZ	Operation Triple Zero
OVC	Orphaned and vulnerable children
YAPS	Youth and adolescent treatment supporter
VLS	Viral load suppression

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12981-025-00719-7.

Additional file 1.

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Author contributions

BO: Conceptualization, overall scientifical direction of the study, resource mobilization, draft manuscript writing, reviewing the final manuscript and coordination of the research team. AK, DK, YM, SMS, KM, TM, CO, AK, BB: Writing draft manuscript and reviewing final work. AIO: Methodology design, data analysis and draft manuscript writing. BME and ENM: Conceptualization, resource mobilization, reviewing final manuscript and providing important intellectual input. All authors read the final manuscript and consented to publishing the work.

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Data availability

The dataset used in the analysis is attached as a supplementary material.

Declarations

Ethics approval and consent to participate

This study received approval from the TASO research ethics committee (REC), (TASO-REC-2022–176) and Uganda National Council of Science and Technology (UNCST). TASO REC is a local institutional review board, founded in 2011, under the stewardship of the Uganda National Council of Science and Technology. We received a consent waiver for the quantitative data collection since there was no direct contact with participants. However, for qualitative data, informed assent and consent were obtained.

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