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Long-term retention and positive deviant practices in Uganda's community client-led antiretroviral distribution groups (CCLADs): a mixed-methods study

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ABSTRACT

Background HIV testing and starting antiretroviral therapy (ART) are pivotal in treating people living with HIV (PLHIV) but sustaining PLHIV on treatment remains challenging. We assessed retention and attrition in community client-led antiretroviral distribution groups (CCLADs) in Uganda and identified positive deviant practices that foster long-term retention.

Methods Using explanatory mixed methods, we collected longitudinal medical data from 65 health facilities across 12 districts in East Central Uganda. Quantitative phase, from 18 April 2021 to 30 May 2021, employed survival analysis and Cox regression to assess retention and identify attrition risk factors. Qualitative inquiry focused on four districts with high attrition from 11 August 2021 to 20 September 2021, where we identified nine health facilities exhibiting high retention in CCLADs. We purposively selected 50 clients for in-depth interviews (n=22) or focus group discussions (n=28). Using thematic analysis, we identified positive deviant practices. We integrated quantitative and qualitative findings into joint displays.

Results Involving 3055 PLHIV, the study showed retention rates of 97.5% at 6 months, declining to 89.7% at 96 months. Attrition risk factors were lower levels of care (health centre three (adjusted HR (aHR) 2.80, 95% CI 2.00 to 3.65) and health centre four (aHR 3.61, 95% CI 2.35 to 5.54)); being unemployed (aHR 2.21, 95% CI 1.00 to 4.84); enrolment year into CCLAD (aHR 23.93, 95% CI 4.66 to 123.05) and virological failure (aHR 3.41, 95% CI 2.51 to 4.63). Of 22 clients interviewed, 8 were positive deviants. Positive deviants were characterised by prolonged retention in CCLADs, improved clinical outcomes and practised uncommon behaviours that enabled them to find better solutions than their peers. Positive deviant practices included fostering family-like settings, offering financial or self-development advice, and promoting healthy lifestyles.

Conclusions Findings underscore the importance of addressing factors contributing to attrition and leveraging positive deviant practices to optimise retention and long-term engagement in HIV care.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Despite strides in identifying and starting people living with HIV (PLHIV) on treatment, sustaining their long-term engagement in care remains challenging requiring additional innovative approaches.

WHAT THIS STUDY ADDS

⇒ Retention of PLHIV on antiretroviral therapy (ART) in community client-led antiretroviral distribution groups (CCLADs) surpassed the UNAIDS target of 95% during the first 12 months. However, retention rates fell below the target in subsequent years.

⇒ Identifying positive deviant practices provides cost-effective, culturally sensitive approaches to enhance long-term retention in community ART groups.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Empowering PLHIV pre-CCLAD enrolment and providing tailored professional support for those facing virological failures or adherence issues, without requiring them to leave CCLADs, enhances social cohesion within groups.

⇒ Future research should explore positive deviant practices at health facility level and across contexts to inform region-specific strategies.

BACKGROUND

Interruptions in HIV treatment can inadvertently increase a person's risk of poor health outcomes, such as uncontrolled viral load and drug resistance.[1 2] Maintaining HIV care, continuity and preventing attrition are crucial to reducing HIV transmission risk, treatment failure and supporting viral load suppression in people living with HIV (PLHIV).[3 4] According to the UNAIDS 95-95-95 strategy, by 2025, 95% of all PLHIV should know their HIV status, 95% of people diagnosed with HIV should receive sustained antiretroviral therapy (ART) and 95% of those receiving

ART should achieve viral suppression.[5] Retention of PLHIV in care remains challenging across age groups and geographical locations despite progress in identifying and starting them on ART.[1 6 7]

In community ART delivery models, ART is delivered to individuals or groups of PLHIV in the community. They are a novel approach that encourages PLHIV to participate more heavily in their own care while reducing the logistical barriers to treatment access.[1] Despite their benefits, participation in community ART delivery models remains low compared with facility ART delivery models,[8 9] and some studies report higher levels of disengagement in sub-Saharan Africa (SSA).[10] Notable though, group models were implemented and expanded during the COVID-19 peak pandemic period, supporting treatment continuity and viral load suppression at that time.[11 12]

In Uganda, the community client-led antiretroviral delivery (CCLAD) model was implemented by the Ministry of Health (MOH) in 2017. The CCLAD model consists of several client-led psychosocial groups (CCLADs).[13] Each CCLAD group is composed of 3–12 members who choose their counterparts and represent each other at a health facility to pick up ART refills. Compared with traditional facility models, CCLADs are led and managed by PLHIV themselves, with ownership vested within the community. In contrast, traditional facility models are supervised by healthcare professionals within healthcare facilities.[13] By September 2020, CCLADs had enrolled only 5.7% of PLHIV—requiring more than double this number to meet the 15% target projected for 2021–2022 by the MOH.[13–15] Studies in Uganda have focused on determining the enablers and barriers to community-based models,[16–18] with reports of preference for facility models.[17 19] Nevertheless, quantitative evidence on long-term retention of PLHIV in CCLADs is scarce, and further research is required on strategies to enhance participation and meet the 95% retention target recommended by UNAIDS.[20]

To ensure sustained retention in CCLADs, treatment programmes require adaptable, locally acceptable strategies that encourage behaviour change. The positive deviance approach has effectively addressed persistent challenges in HIV prevention programmes,[21–24] but few studies have used this approach to improve retention.[20] The approach identifies behaviours and strategies that enable individuals and groups to solve problems more effectively than their peers while making use of the same resources and facing similar or worse challenges.[25 26] Thus, by understanding the practices of PLHIV who have stayed in CCLADs longest, strategies can be developed to improve long-term retention. This study was conducted to (1) assess long-term retention in CCLADs, (2) identify risk factors for attrition and (3) identify positive deviant practices promoting long-term retention in CCLADs.

METHODS

Study design and settings

An explanatory mixed-methods design was used. Quantitative data were collected and analysed, and findings guided qualitative data sampling, collection and analysis.[27 28] Quantitative data were extracted from client medical records while qualitative data used the positive deviance approach to identify unique practices of PLHIV (individuals or groups) who were enrolled in CCLADs. Through joint displays, quantitative and qualitative data were integrated to gain new insights.

The study was conducted in Uganda's East Central region, which comprises 12 districts (5 urban and 7 rural). 'Urban' was defined as districts in Uganda that have city, municipality, town council or town board status.[29 30] In 2017, the region reported a viral suppression rate of 48%, which was the lowest in the country. Additionally, it exhibited relatively high HIV prevalence rates among adults aged 15–64, reaching 4.7%.[31] All 12 districts were included in the study. Up to 134 accredited public and private-not-for-profit facilities provided ART services to approximately 85 000 PLHIV in the region in 2019.[32] Decentralised HIV services are primarily delivered by these health facilities for free.[33] CCLADs were first introduced by private-not-for-profit facilities as a pilot programme in 2013. In 2017, Uganda's Ministry of Health (MOH) adopted guidelines for differentiated care, which allowed for implementation of CCLADs in all health facilities.[13]

Quantitative part

An analytical cross-sectional study design was used.

Target population and selection criteria

The target population consisted of PLHIV receiving ART refills from CCLADs in the region. The study population included PLHIV aged 18 years or older, who were enrolled in CCLADs between 1 January 2013 and 31 December 2020. Newly enrolled clients in CCLADs (less than 2 months) and those who had not received their first ART refill in the group were excluded.

Sample size

Since the CCLAD model was relatively new, we collected medical records of all eligible PLHIV in CCLADs within the region who met our criteria to ensure maximum precision.

Variables

A data extraction tool was created using three health facility source documents: the electronic medical records system,[34 35–37] the client's ART card[13] and the CCLAD monitoring form. Using the tool, these variables were extracted for each individual: client initials and unique number, age, sex, occupation, village/district, health facility, CCLAD group code, adherence status, viral load, clinical stage, regimen change, the status of PLHIV in CCLADs, date of enrolment/attrition from CCLADs and reasons for entry or attrition, and CCLAD group code.

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Treatment outcomes and definitions

The primary outcome was retention in CCLADs—defined as the period from joining the CCLAD to leaving it or censoring (end of follow-up or death). Individuals in CCLADs were followed up from the date they joined the CCLADs (between 1 January 2013 and 31 December, 2020). They were required to have been part of the CCLAD for a minimum of 2 months and to have received at least one ART refill within CCLADs. A secondary outcome was attrition—was defined as the act of a PLHIV leaving their initial CCLAD temporarily or permanently. In this study, attrition was classified into two categories—switching or withdrawing. Switching occurred when a PLHIV temporarily returned to facility-based care for monitoring or joined a new CCLAD group. In the withdrawing group, there were PLHIV who moved to alternative ART models, stopped receiving ART or were lost to follow-up. PLHIV who were lost to follow-up were defined as those who missed ART pick-up for at least 90 days but had not died or transferred out.[38]

Other treatment outcomes included were the latest recorded clinical stage, viral load and adherence. Viral load results and adherence status data were collected for each year from 2017 to 2020. Virological suppression was defined as less than 1000 copies/mL.[13] In our study, viral load results ranging between 1 and 1000 copies/mL were categorised as 'suppressed with detectable viral load'. PLHIV with zero copies/mL were assigned a 'suppressed with an undetectable viral load' status. Annual viral load analyses aimed to identify PLHIV who experienced virological failure throughout the study period. Adherence assessed and recorded at each ART refill visit using pill counts was adopted. Adherence was defined as 'good' if ≥95%, 'fair' if 85%–94% and 'poor' if <84%.[38] See online supplemental file 1 for more variable definitions.

Data collection

Data were collected at 65 health facilities using clients' files and the routine electronic monitoring system between 18 April 2021 and 30 May 2021. An electronic version of the data extraction tool (designed in the KoBo toolbox) was created, accessible offline on a mobile phone or laptop. Six experienced research assistants (four men and two women) were identified and trained (half-day) on the questionnaire content and the ethical procedures. A hard copy and electronic version of the data extraction tool were pretested against eight client files from one health facility. Pretest feedback was used to revise the tool.

Data analyses

Clients' sociodemographic, clinical and group characteristics were summarised by descriptive statistics. Retention was assessed as an open cohort, where individuals entered the cohort throughout the follow-up period. Prior to assessing CCLAD retention and attrition, missing data (WHO clinical stage, group size, patient occupation, regimen change in CCLADs, history of virological failure) were imputed by multiple imputation using chained equations (MICE).[39 40] MICE approach imputed missing values using observed values for a given individual and the relations observed in the data for other participants. Using 'mi impute' command, we set the number of imputations to 50 ensuring this number slightly exceeded the percentage of missing data for the variable with the highest proportion of missing data (43%). Retention proportions were estimated using the Kaplan-Meier method.[41] We also analysed retention by cohort (pre-2018 cohort, 2018 cohort, 2019 cohort and 2020 cohort) to identify retention differences over time.

For attrition, the univariable and multivariable Cox proportional hazards regressions were run. The multivariable model aimed to provide a comprehensive understanding of the relationship between risk factors and attrition from CCLADs. Potential confounders such as age, sex, WHO clinical stage and level of care were identified from the literature[42–44] and included in the model alongside other predictors. Multicollinearity was assessed using the variance inflation factor (VIF), with a threshold of <5 considered acceptable. The WHO clinical stage exhibited a higher VIF and was excluded from the final set of variables lowering the mean VIF to 1.88 from 7.97.

Proportional hazards assumption was assessed using Schoenfeld residuals before model fitting while Cox-Snell residuals (online supplemental file 2) evaluated the goodness-of-fit.[45] Backward elimination method was then employed, initially fitting the model with all variables except WHO stage. Non-significant variables ($p>0.05$) were sequentially removed, starting with those with the highest p values. We compared this model with one including only significant variables at the univariable level and there were no differences in the final variables significant at $p<0.05$. Time-varying effects for virological failure were incorporated, and an interaction term for gender and CCLAD composition was included (interaction term was non-significant). Clustering in the variables was accounted for by including a cluster-robust SE in the multivariable model to estimate the coefficient's SE, thus addressing potential residual correlation within clusters. All statistical analyses were performed with Stata/IC V.13.1. Strengthening the Reporting of Observational Studies in Epidemiology checklist for reporting quantitative data was followed (online supplemental file 7).

Qualitative part

Individual in-depth interviews (IDIs) and focus group discussions (FGDs) were used.

Study participants and recruitment

Four districts with high attrition of PLHIV from initial CCLADs were identified using historical data collected in the quantitative part. Within the four districts, nine health facilities were selected where attritions were highest. Participants for IDIs and FGDs were recruited from the nine health facilities based on these criteria: (1) those who were enrolled or had previously belonged in

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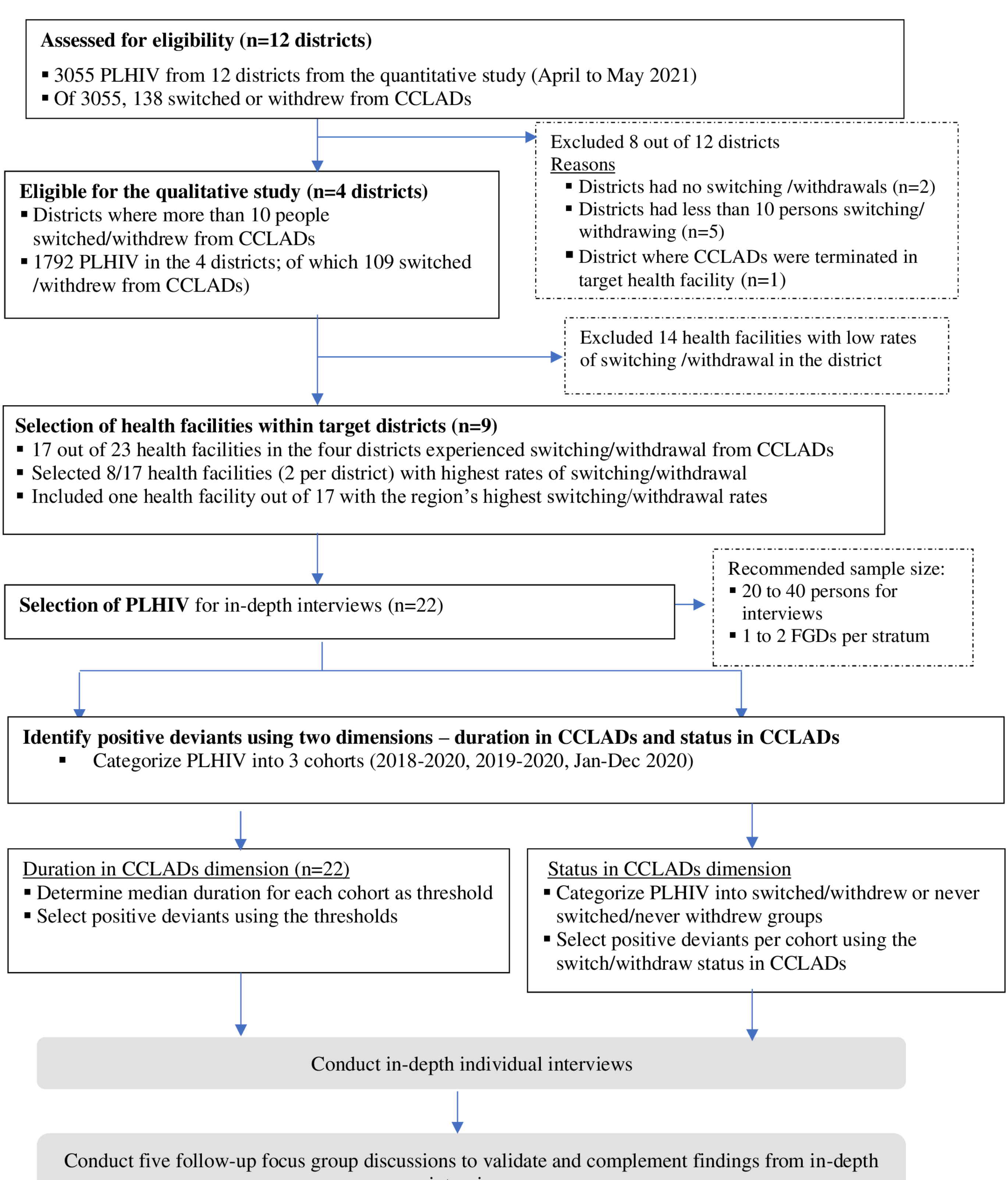

Figure 1 Selection criteria for target sites and positive deviants in the study. CCLADs, community client-led antiretroviral distribution; FGDs, focus group discussions; PLHIV, people living with HIV.

CCLADs in districts experiencing high attrition and (2) those who were alive and receiving ART in CCLADs or returned to the facility model within the high-attrition districts. PLHIV attending IDIs included those attending CCLAD activities or who had returned to the facility model. For the FGDs, only clients attending CCLAD activities were selected. The FGDs were used to validate findings from IDIs. Figure 1 shows detailed criteria for

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Table 1 Summary of integration level and implementation strategy

Level of integration	Implementation strategy	Details
Study design	Explanatory sequential design	A two-phase design involving the collection and analysis of quantitative data of 3055 PLHIV, followed by the collection and analysis of qualitative responses from 22 semi-structured interviews and 5 focus group discussions
Methods	Connecting	Quantitative data collected from the first phase served as the sampling frame for the qualitative phase
Interpretation and reporting	Joint display table	Contrasted the quantitative results and qualitative findings in a single table to allow side-by-side comparison

PLHIV, people living with HIV.

selecting participants for IDIs and FGDs, including positive deviants.

Sample size

As part of the purposeful sampling method, the positive deviance comparison strategy was used. The strategy involves comparing persons and groups that have discovered solutions with peers where the problem persists.[46 47] In the study, 50 of 1702 PLHIV enrolled in CCLADs in the 4 high attrition districts were selected (figure 1). In total, 22 PLHIV participated in IDIs and 28 in the FGDs. The total number selected for IDIs and FGDs matched the recommended sample to reach saturation in qualitative research.[48 49]

Data collection and qualitative aspects assessed

A semistructured questionnaire, topic guide and observation checklist were created using information from various studies.[17 47] Information was collected on age, sex, group size and composition, meeting frequency, duration and activities, as well as individual responsibilities. Other variables assessed were respect, confidentiality, consensus and cooperation, and communication channels. A bilingual translator translated the tools into Lusoga, the local language. An expert committee of bilingual professionals reviewed the translated tools to evaluate linguistic and cultural appropriateness. These tools were then tested with representative participants for comprehension, clarity and cultural relevance. Translated tools were back-translated into English, ensuring alignment with the cultural context and linguistic preferences of the target population. Four qualitative interviewers pretested the tools at two health facilities with four PLHIV and two CCLAD groups and incorporated feedback. To recruit participants for IDIs, research assistants worked with health providers within ART clinics to identify PLHIV in CCLADs and made telephone calls to explain the objectives of the study. FGD participants were invited through their group leaders. Each research assistant interviewed clients individually during IDIs at the health facility (45–60 min). In FGDs, one research assistant observed non-verbal behaviours and summarised key discussion points while the other facilitated the discussion. FGDs took place at the health facility and lasted up to 90 min. Some FGDs included PLHIV from the same CCLAD group to observe their non-verbal behaviours and interactions. Data saturation was achieved in both IDIs and FGDs.

All IDIs and FGDs were audio recorded, and field notes were taken. Occasionally, research assistants used translators where people spoke a different language. PLHIV who participated in the study received monetary compensation for their time and travel expenses.

Data analyses

Audio recordings were transcribed into English by native speakers and transcripts were double-checked for accuracy. A list of notes taken during the interviews was also compiled and compared with responses from the interviews. Three authors performed a thematic analysis of the qualitative responses. Open coding was used to identify common and uncommon practices.[50] A common practice was defined as a behaviour or practice that supported long-term HIV retention and was commonly practised by both positive deviants and the comparison group. Uncommon practices were defined as positive, unique and demonstrably successful behaviours or practices common among positive deviants, rather than the comparison group. The final list of codes was generated after comparing and harmonising terms used by the three coders. A checklist of Consolidated Criteria for Reporting Qualitative Studies was followed (online supplemental file 8).[51]

Data integration

This study approached integration from the three levels proposed by Fetters *et al*.[27] Integration refers to a conscious effort to combine quantitative and qualitative research approaches to achieve a better understanding of the topic.[52] Table 1 summarises the levels of integration used in the study.

Patient and public involvement

We engaged various stakeholders including representatives from projects supporting HIV services, and health authorities in refining our research question and methods. Health facility focal persons, CCLAD leaders and members contributed insights to refine our study

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Table 2 Sociodemographic and treatment characteristics of PLHIV in CCLADs (N=3055)

Variable	n (%)
Women	1985 (64.9)
Age, median (IQR)	48 years (40–54)
Age category	
18–24 years	32 (1.1)
25–49 years	1559 (51.0)
50+ years	1464 (47.9)
Living area	
Rural	2402 (78.8)
Urban	653 (21.4)
Occupation	
Employed in agricultural sector	1112 (36.4)
Employed in other sectors	559 (18.3)
Student	7 (0.2)
Unemployed	55 (1.8)
Missing	1322 (43.3)
Level of care	
Health centre III	1419 (46.5)
Health centre IV	364 (11.9)
General hospital	365 (11.9)
Private not- for profit	907 (29.7)
Retention on ART at joining CCLADs, median (IQR)	7 years (4–10)
Retention on ART at joining CCLADs	
0–5 years	1005 (32.9)
6–10 years	1438 (47.1)
11 years	612 (20.0)
Good/excellent adherence (95% and above)	2993 (99.0)
Viral load outcomes (latest recorded status)	
Suppressed, Un detectable (0 copies/ml)	2239 (73.3)
Suppressed, detectable (1–1000 copies/mL)	474 (15.5)
Unsuppressed viral load (>1000 copies/mL)	70 (2.3)
Missing	272 (8.9)
ART regimen change (before and during CCLAD membership)	
No	141 (4.6)
Yes	2914 (95.4)
WHO clinical stages (latest recorded status)	
Stage 1	1810 (59.3)
Stage 2	1224 (40.0)
Stages 3 and 4	15 (0.5)
Missing	6 (0.2)

ART, antiretroviral therapy; CCLADs, community client-led antiretroviral distribution groups; PLHIV, people living with HIV.

tools, including the questionnaire and discussion guides. CCLAD leaders facilitated site selection and patient recruitment for FGDs. All CCLAD members including leaders contributed to data interpretation, particularly identifying positive deviant practices. Our dissemination targets CCLAD leaders, facility focal persons and key stakeholders, including hospitals, at facility and district levels, and the wider research community.

Table 3 Group-level characteristics of PLHIV in CCLADs (N=3055)

CCLAD group characteristics	Number, %
Total no. of CCLAD groups	619 (100)
Duration in CCLADs (months)	Median (IQR)
All	7 months (4–19)
Status in CCLADs	
Active in CCLADs	2907 (95.2)
Switched/withdrew	138 (4.5)
Died	10 (0.3)
Median group size (IQR)	5 members (3–38)
CCLAD group size	
Below 3 members	258 (8.5)
3–12 members	1907 (62.4)
13 and above	890 (29.1)
CCLAD gender composition	
Majority male	515 (16.8)
Majority female	2522 (82.5)
Unknown	18 (0.6)
Year of enrolment into CCLADs	
2017 and before	670 (21.9)
2018	358 (11.7)
2019	585 (19.2)
2020	1442 (47.2)
ART regimen change after joining CCLADs	
Yes	1659 (54.0)
No	1255 (41.1)
Missing	141 (4.6)

ART, antiretroviral therapy; CCLADs, community client-led antiretroviral distribution groups; PLHIV, people living with HIV.

RESULTS

Quantitative part

Table 2 summarises the sociodemographic and treatment-related characteristics of PLHIV enrolled in CCLADs between 1 January 2018 and 31 December 2020. Data were collected from 3055 PLHIV enrolled at 65 healthcare facilities. Of the total, 51.0% were adults aged 25–49. 65% of the population were women while 78.0% were rural dwellers. Within the study period, 2914 (95.4%) clients changed their ART regimens. A suppressed viral load outcome status was achieved by 88.0%. Of the PLHIV with unsuppressed viral loads, 2.3% continued to receive ART in CCLADs until the end of the study. The majority (99%) of PLHIV belonged to WHO stages 1 and 2.

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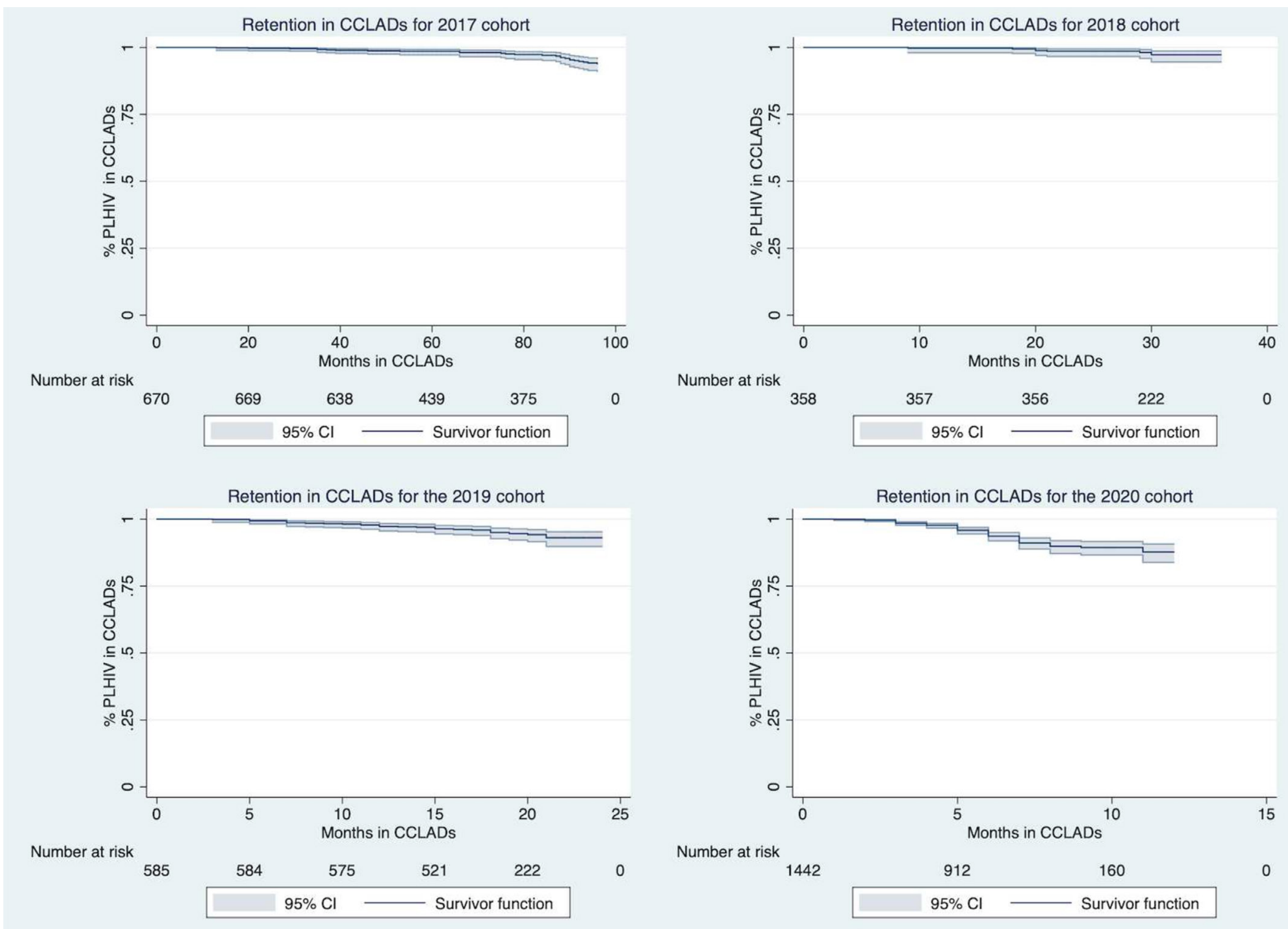

Figure 2 Retention of PLHIV in CCLADs by year of enrolment from 2017 to 2020. CCLADs, community client-led antiretroviral distribution; PLHIV, people living with HIV.

Table 3 presents the group-level characteristics of PLHIV enrolled in CCLADs. The region had 619 CCLADs serving PLHIV. The median CCLAD duration was 7 months. The most common CCLAD group size was 3–12 members (62.4%) with a median of five members. Enrolment in CCLADs peaked in 2020 (47.2%), and 71.5% of CCLADs had mostly female members. By the end of the study period, 4.5% of PLHIV had switched or withdrawn from their initial CCLADs.

Retention in CCLADs for PLHIV

Of the 3055 PLHIV, 95.2% were alive and on ART in CCLADs at the end of the study period. However, at 6, 12, 24, 36 and 96 months, retention rates in CCLADs were 97.5%, 95.9%, 94.7%, 93.0% and 89.7%, respectively. Online supplemental file 5 shows the proportion of PLHIV retained in CCLADs across months stratified by age, gender and retention on ART, living area and patient occupation. PLHIV aged 50 years and above, women, and those on ART for 11 years or more exhibited higher retention rates. Similarly, individuals living in urban areas or employed in sectors other than agriculture demonstrated better retention rates. Figure 2 shows retention across the four cohorts—organised by year of enrolment in CCLADs. Retention in CCLADs was high and relatively stable in the 2017 and 2018 cohorts. In the subsequent years, PLHIV remained in CCLADs for a shorter time than previous years.

Attrition from CCLADs

Table 4 summarises the status/outcomes of 138 PLHIV who switched or withdrew from initial CCLADs during the study period. Rather than switching (39.9%), attrition through withdrawing (60.1%) affected retention in CCLADs.

Table 5 shows the univariable and multivariable results for factors associated with attrition (switching/withdrawing). In both models, individuals who died were censored. In the multivariable model, regimen change was the most confounded independent variable. Attrition risk factors in the multivariable model were; being enrolled at lower levels of care (health centre three (adjusted HR (aHR) 2.80 CI, 95% CI 2.00 to 3.65), health centre four (aHR 3.61, 95% CI 2.35 to 5.54)); being unemployed (aHR 2.21, 95% CI 1.00 to 4.84); year of enrolment into CCLAD (aHR 23.93, 95% CI 4.66 to 123.05) and virological failure (aHR 3.41, 95% CI 2.51 to 4.63).

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Table 4 Outcomes of PLHIV who switched/ withdrew from the CCLADs (N=138)

Outcomes/reasons	Frequency (%)
Withdrew from CCLADs	
Lost to-follow-up	8 (5.8)
Self-transfer/transferred-out*	30 (21.7)
Joined other community-based models†	30 (21.7)
Returned to facility-based models	15 (10.9)
Switched from CCLADs	
Returned to facility-based models‡ (temporary)	47 (34.1)
Joined other CCLAD groups§	8 (5.8)
Total	138 (100)

*n=18 transferred-out, n=5 self-transfer, n=7 changed residence/relocated.
†n=30 joined CDDPs.
‡n=1 developed TB, n=4 pregnancy, n=30 virological failure, n=12 intensive adherence counseling.
§n=5 conflicts in the former group, n=3 splitting a big group.
CCLADs, community client-led antiretroviral distribution groups; CDDPs, community drug distribution points; TB, tuberculosis.

Qualitative part

22 PLHIV (8 positive deviants, 14 others) attended the IDIs. 28 PLHIV (all positive deviants)—20 women and 8 men—participated in five FGDs. Three out of five FGDs consisted of PLHIV selected from the same CCLAD group. The remaining two FGDs consisted of PLHIV from different CCLADs. The individual and group characteristics of PLHIV who participated in IDIs and FGDs are included in online supplemental files 6,7. Figure 3 presents IDI participants' responses on social cohesion and group interactions within CCLADs while figure 4 summarises the themes, subthemes and uncommon practices.

We identified common practices in both positive deviant and comparison groups using interview data from IDIs and FGDs. Common practices were narrated in the same way and practised by both groups.

Common practices among positive deviants and the comparison groups/individuals

Common practices were selected based on the practices with the highest number of mentions and similarity between the positive deviant and comparison groups. Online supplemental file 8 shows the list of identified common practices.

Uncommon but successful practices among positive deviants in CCLADs at group level

To identify uncommon practices, we considered practices that were more common and widely practised among deviant groups and less in the comparison groups. Three key themes were identified among uncommon practices as explained below.

Theme 1: creating a family environment in the CCLADs

Positive deviants mentioned they adopted strategies that promoted normalcy as opposed to serostatus. For example, they engaged in group bonding activities such as tea parties and saved for significant days like Christmas to share good times as a family.

> *We are united and interact with each other as family. We also help one another when there's a problem because we are now related* (Male 49 years—FGD 2)

When asked how they managed to keep group members actively engaged in CCLAD activities, positive deviants reported that establishing management structures and group rules, allocating periodic assignments to members who did not hold positions in the CCLADs—served as enablers for active engagement and bonding.

Theme 2: caring for group members' financial and economic development

The majority of the CCLADs started with a single goal—convenience for PLHIV in accessing ART refills. However, the scope slowly expanded beyond treatment to accommodate income-generating activities to boost individual finances and promote self-development. Positive deviants also used such projects to create jobs for the unemployed or support agricultural production.

> *Some group members have land which they ask members to use freely by planting vegetables 'eikubi' and sell them later and get some money. So, whoever has free land will give it out and we plant our crops there and we sell them like sweet potatoes, cassava* (Female 45 years—FGD 3)

> *We have a savings account; this is what we do as a group. Each one of us has our personal business. It's from this savings account that we can borrow money which we use to start or sustain our personal business* (Female 61 years—IDI 20)

Theme 3: prioritising a healthy and productive lifestyle for group members

Group members equated having a suppressed viral load or good adherence to good self-care and vice versa. In turn, they supported each other to maintain a suppressed viral load status by emphasising treatment adherence and good nutrition.

> *We have developed the culture of supporting one another to take drugs at the correct time. If you miss, you might get other complications that will make your condition worse. Even when you have a trip, we make sure you travel with the medication to avoid skipping treatment. We do this because we don't want a member to get high viral load which would mean that he/she doesn't take good care of him/herself* (Male, 46 years, FGD—3)

> *We collectively offer to dig each other's gardens in turns. If we have planted crops for one member, we plant for another member the next day until all members are covered. This is how we help*

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Table 5 Cox proportional hazards univariable and multivariable model for attrition (N=3055)

	Univariable model			Multivariable model		
	HR	P value	(95% CI)	Adjusted HR	P value	(95% CI)
Age at joining CCLADs						
Below 50	1.16	0.355	0.84 to 1.62			
50+ years	1.00 (ref)					
Sex						
Men	1.19	0.300	0.85 to 1.68			
Women	1.00 (ref)					
Living area						
Rural	1.93	0.002	1.27 to 2.93	1.18	0.538	0.70 to 1.97
Urban	1.00 (ref)			1.00		
Level of care						
Health centre III	3.49	<0.001	1.80 to 6.80	2.80	<0.001	2.00 to 3.65
Health centre IV	4.55	<0.001	2.21 to 9.38	3.61	<0.001	2.35 to 5.54
General Hospital	1.00 (ref)			1.00		
Private not-for-profit	0.05	<0.001	0.02 to 0.18	0.04	<0.001	0.01 to 0.12
Occupation						
Agricultural sector	1.75	0.020	1.09 to 2.79	1.39	0.266	0.77 to 2.52
Other sectors	1.00 (ref)			1.00		
Unemployed	3.52	0.008	1.39 to 8.91	2.21	0.049	1.00 to 4.84
CCLAD group size						
12 members or less	7.27	<0.001	4.46 to 11.85	0.53	0.458	0.10 to 2.81
13 members and above	1.00 (ref)					
CCLAD group composition						
Majority male	1.11	0.682	0.68 to 1.81			
Majority female	1.00 (ref)					
Year of enrolment into CCLADs						
2020	52.09	<0.001	18.81 to 144.28	23.93	<0.001	4.66 to 123.05
Before 2020	1.00 (ref)					
Retention on ART at joining CCLADs						
0–5 years	5.01	<0.001	2.89 to 8.69	1.14	0.599	0.70 to 1.85
6–10 years	3.08	<0.001	1.85 to 5.14	1.15	0.660	0.63 to 2.09
11+ years	1.00 (ref)					
WHO clinical stage						
Stage 1	0.61	0.487	0.15 to 2.47			
Stage 2	0.18	0.016	0.04 to 0.73			
Stage 3 and 4	1.00 (ref)					
ART regimen change in CCLADs						
No	3.46	<0.001	2.33 to 5.14	1.03	0.878	0. 75 to 1.41
Yes	1.00 (ref)			1.00		
History of virological failure						
Yes	4.45	<0.001	2.86 to 6.93	3.41	<0.001	2.51 to 4.63
No	1.00 (ref)			1.00		

ART, antiretroviral therapy; CCLADs, community client-led antiretroviral distribution groups.

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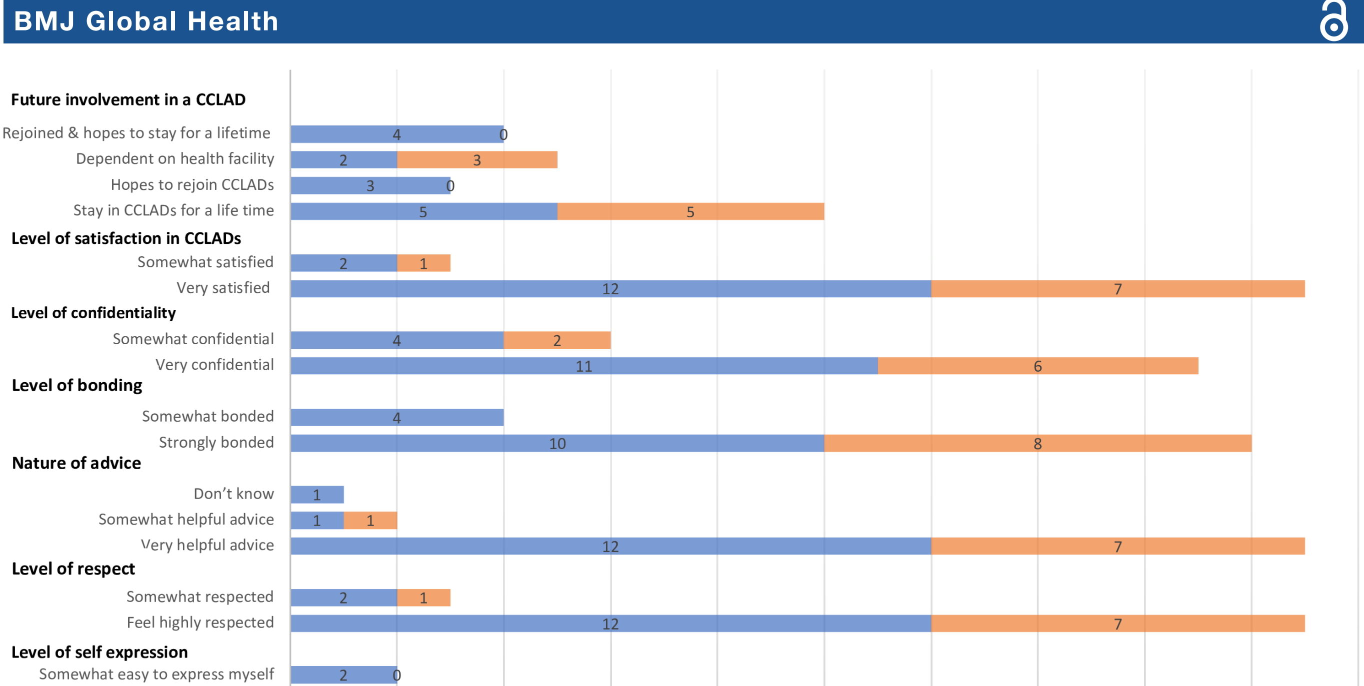

Figure 3 Responses on social cohesion and interactions within CCLADs among PLHIV attending in-depth interviews (n=22). CCLADs, community client-led antiretroviral distribution; PLHIV, people living with HIV.

one another to get food and earn extra money (Male 56 years, IDI—16)

DATA INTEGRATION

Tables 6 and 7 show the joint displays combining both quantitative and qualitative data. Meta inferences were shown at the end of both tables.

DISCUSSION

The study had three major findings. First, retention of PLHIV on ART in CCLADs was higher than UNAIDS' recommended target of 95% during the 12-month follow-up (95.9%) but gradually decreased to 89.7% at 96 months. Second, the following factors were associated with attrition: being enrolled at lower level of care (health centres 3 and 4), being unemployed, year of enrolment into CCLAD and virological failure. Qualitative reasons for the attrition were conflicts between group members, lack of self-development activities and chronic illnesses like hypertension. Third, positive deviant behaviours were identified and classified under three themes: fostering a family-like environment, providing financial and economic guidance, and prioritising health and productivity.

This study demonstrated that early retention rate (at 6 and 12 months) met UNAIDS' target of 95% but declined below this threshold after 12 months. Analysis by age and retention on ART before joining CCLADs revealed that individuals aged 50 and above, as well as those who had been on ART for 11 years or more prior to joining CCLADs, had retention rates exceeding 95% within the first 36 months. This can be attributed to enrolment of stable clients (those with consistent adherence to ART and who have achieved and maintained viral suppression) into CCLADs. Qualitative data highlighted factors influencing retention, such as achieving a deep sense of belonging, creating social goals, availability of 3–6 months' ART refills and proximity to ART pick-up locations. Findings on initial high retention align with similar studies in SSA,[53–55] and those indicating that community group activities enhance connectedness[8] and belonging.[56] However, results contrast with a Ugandan study reporting increasing retention in CCLADs from 97% at 12 months to 98% at 24 months.[52]

The year of enrolment into CCLAD also influenced retention rates in CCLADs. Almost half (47.2%) of PLHIV in the study were enrolled in CCLADs in 2020. Of these, 87.7% were remaining at the end of 12-month period. Retention rates across cohorts enrolled before 2020 demonstrated that over 95% remained in CCLADs during the initial 12 months. Higher attrition rates in the 2020 cohort may be linked to insufficient awareness about CCLADs. Health facilities aimed to reduce congestion in ART clinics at the onset of the pandemic, allowing less time to prepare clients before the transition. Qualitative data showed that some individuals relocated during the COVID-19 pandemic, hindering their participation in CCLAD group activities. Social distancing restrictions further suspended CCLAD group meetings, potentially affecting bonding among members. Other studies have documented similar effects of the COVID-19 pandemic on retention in HIV care.[57 58]

The median survival time in CCLADs was 7 months and risk factors for CCLAD attrition were having a history of virological failure, and enrolment at lower levels of care and being unemployed. Analyses show that some people who were temporarily switched to the facility model

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Figure 4 A mind map summarising the themes, subthemes and uncommon practices promoting retention of PLHIV in CCLAD groups in Uganda. CCLADs, community client-led antiretroviral distribution; PLHIV, people living with HIV.

following virological failure had been out of their CCLADs for over a year. This pattern disrupts group bonding, and relations and individuals may find it difficult to reintegrate leading to attrition. Also, data showed that 89% of PLHIV enrolled at lower health centres and 87% of those in smaller CCLADs lived in rural areas, suggesting unique retention challenges among rural dwellers. Qualitative reasons for attrition included personal preferences, fear of stigma, conflicts within former CCLADs, relocation and having other chronic conditions such as hypertension. Moreover, in small CCLADs, the cost of collecting ART refills increased where 1–2 months' refills were prescribed. For CCLADs where members favoured venues outside their villages or were unemployed, logistical obstacles appeared to hinder regular attendance. Several studies have reported high turnover of PLHIV after virological failure,[59–61] those initiating ART in smaller health facilities[44] and conflicts in CCLADs.[17] Another study found that household economic strengthening improved health outcomes and kept clients in care longer.[62] This approach may be suitable for rural residents, where 87% of the unemployed individuals who exited CCLADs lived.

The study identified effective practices that enabled positive deviants to overcome challenges and stay in CCLADs. In contrast to quantitative findings which show

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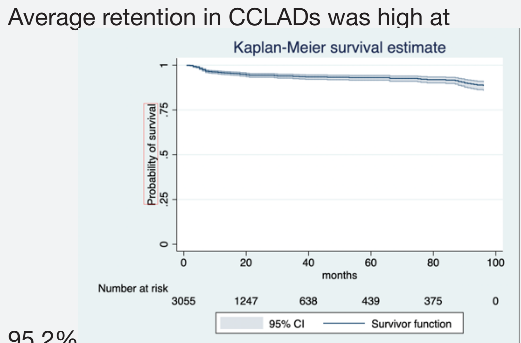
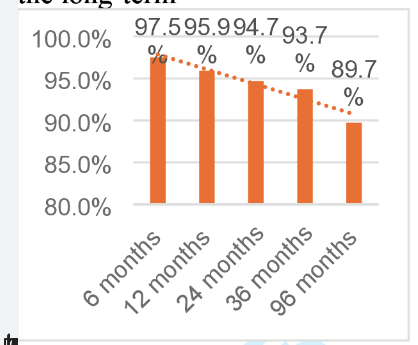
Table 6 Long-term retention and strategies to improve retention

Quantitative constructs	Qualitative constructs
Average retention in CCLADs was high at  95.2%	Theme: Creating a family environment in the CCLADs 'We are like family because we are very close to one another. Whatever we discuss, we agree on it as a group. We also do activities together like farming, growing vegetables, selling charcoal.' (Female, 40 years) 'When I reach here for a meeting, my friends encourage me. Most times I come when I have a lot of thoughts on mind.' (Female, 33 years) 'I am very satisfied with the choice of the venue. I am the one who lives closest to the meeting venue; other members stay in a nearby village. Nevertheless, we are all close to the venue.' (Male, 56 years)
Meta inferences—Complementarity and expansion. Findings from the qualitative phase highlight additional factors that contribute to high retention of PLHIV in CCLADs such as forming strong bonds, receiving helpful advice and convenience. Up to 86% of those who participated in IDIs reported high satisfaction levels in their CCLAD groups.	

CCLADs, community client-led antiretroviral distribution groups; IDIs, in-depth interviews; PLHIV, people living with HIV.

small CCLADs as a risk factor at univariable level, seven out of the eight positive deviants identified in the qualitative study belonged to smaller CCLADs (<7 members). This can be attributed to practising positive deviant practices, such as actively supporting struggling members in their treatment, setting health-related goals like maintaining suppressed viral loads, fostering family-like environments and resolving conflicts. Positive deviants are

Table 7 Risk factors for attrition and strategies employed by positive deviants

	Qualitative constructs	
Quantitative constructs	**Quotes from comparison groups/individuals**	**Quotes from positive deviants**
Declining retention in CCLADs in the long-term Retention rates fell from 95.9% at 12 months, to 89.7% at 96 months. Some of the reasons for attrition documented in client records include conflicts in the former group, experienced virological failure, required intensive adherence counselling, pregnancy and contracted 	'We cut off rumor mongers in our groups most especially those whom we know talk too much and never keep secrets in the community' (Male, 68 years) 'I left the group because I suffer from high blood pressure and at the time, I wasn't feeling well. The health workers decided that I return to the center where I can receive drugs for both HIV and hypertension at once.' (Female 51 years) 'We have not discussed on how to develop ourselves; imagine we have children but still live-in rented homes. We have not yet planned out how and where we will leave our children in case we die. We need a savings scheme, children's insurance but we don't discuss such things' (Female, 45 years)	Theme: providing financial or self-development advice 'We talk about agriculture since majority of us are farmers, we sometimes share various seeds of different agricultural crops when we meet so that everyone can have a variety of plants' (Female, 65 years) Theme: Creating a family environment 'In my group, some members had started revealing secrets of the group. We decided to talk to them. It's not that whoever makes a mistake must be expelled from the group. We held meetings, each one of us confessed, and everyone got to know their faults. So, all misunderstandings were solved there and then' (Male, 46 years) 'We don't talk about irrelevant topics and gossip. We always meet for a purpose. We avoid topics that develop into conflicts' (Female, 47 years)
Meta inferences: Confirmation (reasons for leaving CCLADs) and expansion (highlighting gaps that may become risk factors and possible solutions) Declining retention rates may be attributed to conflicts among members and lack of self-development activities, presence of other chronic illness, among others. Qualitative findings provide more details on the nature of conflicts (social, financial), additional possible risk factors, and identify successful practices that may provide solutions to address such issues to reduce attrition and improve long-term retention in CCLADs.		

CCLADs, community client-led antiretroviral distribution groups.

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distinguished by their ability to succeed where others have failed, despite having similar resources/settings. As a self-development initiative, positive deviant CCLADs assigned responsibilities (rotational) to their members encouraging involvement and confidence. Like this, social relationships play an important role in facilitating retention in HIV programmes.[63] Community-based models continue to experience barriers to uptake and long-term engagement due to stigma, lack of commitment and disputes among members.[8 18] As demonstrated in this study, positive deviant practices and behaviours can address such problems and retain PLHIV in care.

However, we noted the predominance of male group leaders in sampled CCLADs. This could be linked to cultural and gender-related beliefs, where men are viewed as natural leaders, are respected, and highly energetic. Cultural barriers and unequal power relations among community groups or members due to age, sex and other differences influence decision-making, and active participation in social groups.[64] Offering empowerment sessions to PLHIV before joining CCLADs can enhance participation and self-expression of minority groups, thereby improving self-management, social cohesion and treatment outcomes.

This study has several limitations. First, incomplete data were observed in five variables, which were addressed through imputation to mitigate uncertainty. Second, certain individuals, such as those below 18 years old or newly enrolled clients yet to receive their first ART refill in CCLADs, were excluded based on study criteria, further impacting group sizes. Third, COVID-19 restrictions hindered the observation of non-verbal behaviours at CCLAD group meetings, although FGDs were used, they were not conducted in their natural settings. Additionally, since most interviewees resided in rural areas, findings may not be generalisable to urban settings due to potential space constraints for meetings in homes. Moreover, logistical challenges prevented data collection from people who transferred out, opted for the community individual model and those who were lost to follow-up. Notwithstanding its limitations, this study also had strengths. Mixed methods were used—combining quantitative and qualitative results which provided deeper insight into retention and attrition risks. The qualitative study identified uncommon, but effective strategies used by positive deviants to stay longer in CCLADs. This is the first study to use the positive deviance approach to improve the retention of PLHIV in CCLADs. Results can be generalised at the regional level.

CONCLUSION

This study significantly advances understanding long-term retention trends among PLHIV in CCLADs, identifying attrition factors and successful practices employed by positive deviants. The positive deviance approach offers promise for cost-effective, culturally sensitive interventions to enhance long-term retention. Recommendations include providing empowerment sessions for PLHIV before joining CCLADs and offering tailored professional support for those experiencing virological failures or adherence challenges without requiring them to leave CCLADs to enhance social cohesion within groups. Future research should explore positive deviant practices at health facility level and across contexts to inform region-specific strategies.

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Patient consent for publication Not applicable.

Ethics approval This study involves human participants and institutional ethics approvals were obtained from the following: (1) Graduate School of Medicine, University of Tokyo, Japan (2020386NI); (2) Makerere University Health Sciences' Research Committee, (MAKSHSREC-2020-77) and (3) Uganda National Council for Science and Technology (UNCST), (SS895ES). Participants gave informed consent to participate in the study before taking part.

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