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Return to care of children and adolescents living with HIV who missed their clinic visits or were lost to follow-up: a continuous quality improvement study in Uganda

Ssentongo Mugerwa Saadick ,[1] Jonathan Izudi ,[2,3,4] Boniface Oryokot,[1] Ronald Opito,[5] Baker Bakashaba,[1] Abel Munina,[1] kokas Opolot,[6] Daniel Ogwal,[6] Julius Ssendiwala,[7] Kenneth Mugisha[1]

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For numbered affiliations see end of article.

Correspondence to
Ssentongo Mugerwa Saadick; ssentongomugerwasaadick@gmail.com

ABSTRACT

Background While the UNAIDS 95-95-95 targets have been met among adults, those for children and adolescents remain suboptimal. This study aimed to improve the return-to-care rates among children and adolescents living with HIV (CALHIV) who missed clinic appointments at a county-level rural health facility in eastern Uganda.

Methods Between January 2023 and January 2024, we conducted a continuous quality improvement (CQI) study. A CQI committee was established through entry meetings and training, and quality of care gaps were identified through data reviews. We prioritised one gap for CQI through ranking, performed a root-cause analysis using a fishbone diagram, and developed and ranked improvement changes using the impact-effort matrix. The improvement changes were implemented using Plan-Do-Study-Act cycles. The changes included (1) line listing CALHIV with missed appointments and following up via phone calls; (2) weekly data reviews to harmonise missed appointments and (3) assigning community health workers (CHWs) to trace and return CALHIV to care. We tracked and plotted the proportion of CALHIV returning to care over time to assess improvements.

Results Before the implementation of CQI initiatives (August 2022–January 2023), the average return-to-care rate was 35% (baseline). Following the initiation of CQI in February 2023, the average return-to-care rate increased to 59% from February to May 2023 with the introduction of line listing (phase 1), to 69% from June to September 2023 with the implementation of weekly data reviews (phase 2), and to 88% from October 2023 to January 2024 with the involvement of CHWs (phase 3), ultimately reaching a peak of 100% in January 2024.

Conclusion The CQI approach improved the return to care of CALHIV who missed clinic appointments, allowing access to optimal care and better health outcomes. These findings should serve as preliminary data for larger randomised studies.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Many HIV programmes are struggling with the return to care of children and adolescents living with HIV (CALHIV) following missed clinic appointments. No return to care is a barrier to optimal adherence to antiretroviral therapy (ART) and leads to suboptimal viral load suppression, including increased morbidity and mortality among CALHIV.

WHAT THIS STUDY ADDS

⇒ Using a continuous quality improvement study, we show that the return to care of CALHIV can be optimised using simple, cost-effective and context-relevant measures. Such improvements would optimise adherence to ART, reduce morbidity and mortality and lead to a better quality of life among CALHIV.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ We provide preliminary data that might inform the design of a large-scale stepped-wedge cluster randomised trial. Some of the measures used to improve return to care might be added to existing HIV treatment guidelines as additional tools to improve retention of CALHIV.

INTRODUCTION

Tremendous progress has been registered in achieving the United Nations Programme on HIV/AIDS (UNAIDS) 95-95-95 targets among adults living with HIV, but the progress among children and adolescents living with HIV (CALHIV) has been relatively slow. The 95-95-95 targets aim to improve HIV diagnosis, treatment and viral suppression, ultimately reducing transmission and enhancing the quality of life for people living with HIV (PLHIV). The first 95% ensures that 95% of PLHIV know their HIV status, the second 95% ensures that 95% of those diagnosed with HIV initiate antiretroviral therapy (ART) and the third 95% ensures that 95% of those on ART achieve viral suppression.

Following the 95-95-95 targets, data from 2023 show that among children living with HIV, 66% knew their HIV status, 86% of those who knew their status were on ART and 84% of those on ART had a suppressed viral load.[1] Studies conducted in several African countries, including Rwanda, Kenya and Ghana, suggest that treatment interruptions are a significant risk factor for unsuppressed viral load.[2–7] Missed clinic appointments and treatment interruption are influenced by factors at the individual, interpersonal, health system and structural levels. These include transportation barriers, unplanned mobility, stigma, mental health problems, long waiting times and a lack of perceived benefits of ART among other factors.[8] Approximately 50%–80% of individuals on ART in sub-Saharan Africa (SSA) experience treatment interruptions, which is exacerbated by loss to follow-up (LTFU).[9]

A previous study conducted in Uganda reported a 9%–20% incidence of LTFU among PLHIV,[10] and another study reported an incidence rate of 21 per 1000 person-months.[11] The negative effects of treatment interruption include progression to advanced HIV disease, increased mortality due to opportunistic infections such as tuberculosis (TB) and cryptococcal meningitis, higher rates of HIV transmission due to unsuppressed viral load and the development of HIV drug resistance.[12] Serere Health Center IV, located in Serere District, provides care for 125 CALHIV aged 0–19 years. Between August 2022 and January 2023, we conducted a retrospective review of medical records on treatment interruption among CALHIV at the health facility. The review identified 54 CALHIV who had interrupted treatment due to missed clinic appointments, of whom only 22 (40%) were followed up by health workers and successfully returned to care.

To improve return-to-care rates among CALHIV who experience treatment interruption due to missed clinic appointments, we initiated a continuous quality improvement (CQI) study. The CQI study aimed to increase the proportion of CALHIV returned to care from 40% in January 2023 to 80% in January 2023 at the health facility using simple, effective and context-relevant measures.

METHODS

Context and design

We conducted a CQI study at Serere Health Center IV in rural eastern Uganda. We adhered to the Standards for Quality Improvement Reporting Excellence guidelines in reporting these findings.[13] Serere Health Center IV is a rural, county-level health facility, providing HIV care to nearly 2000 PLHIV. It is located in Serere district, about 205 km by road, northeast of Kampala, the capital city of Uganda and serves a population of 285 903 persons.[14] The district-level HIV prevalence is 2%.[15] The health facility offers HIV prevention, care, treatment and support services to PLHIV, including those at risk for HIV infection. The health facility has an HIV clinic established in 2008 to offer comprehensive HIV care. By March 2023, a total of 1553 PLHIV had been enrolled in care, including 125 CALHIV.[16]

The HIV clinic is accessible throughout the week. The clinic is staffed by eight healthcare providers, including one medical doctor, two clinical officers, one nursing officer, one psychosocial counsellor and three data entrants. Additionally, the clinic has a team of community health workers (CHWs) comprising two HIV expert clients (individuals living with HIV who serve as role models due to their suppressed viral load and improved quality of life), four village health team members, two mentor mothers, two group antenatal care peers and two young people and adolescent peers.

CQI is a systematic approach to addressing quality of care gaps and improving health service delivery and health outcomes.[17] CQI uses routine data to identify gaps and context-relevant measures to improve the process and health systems. Serere Health Center IV has a health facility CQI committee supported by the AIDS Information Center with funding from the Centers for Disease Control and Prevention (CDC) under the US President's Emergency Plan for AIDS Relief (PEPFAR). The role of the CQI team is to identify gaps in HIV care, including addressing them using CQI interventions.

Identification of quality gaps, root causes and improvement changes

The health facility CQI committee included representatives from each departmental Work Improvement Team (WIT). Within the HIV clinic, there is a WIT to address performance gaps. We trained the HIV clinic WIT on the CQI toolkit through a 3 hour Continuous Medical Education session focused on the basic concepts of CQI. The CQI training was followed up by the district CQI team with mentorship sessions in January 2023, and they were supported to start a CQI project. To identify the quality-of-care gaps, the WIT conducted a retrospective data review from August 2022 to January 2023 (baseline). Among CALHIV, we found suboptimal viral load coverage (90%) and low return-to-care rates (40%). In contrast, among the adults, the return to care after missed appointments was 82% (table 1). Additional quality of care gaps among children, adolescents and adults included missed clinic appointments and low screening for TB. Using a theme matrix selection, the CQI team prioritised return to care among CALHIV based on its impact on the quality of life and urgency. The CQI team did not prioritise addressing missed clinic appointments and low screening for TB among children, adolescents, and adults.

MEASUREMENTS

CQI intervention and implementation process

The CQI was conducted in a stepwise manner. Step 1 focused on problem identification. Based on the baseline data (table 1), a prioritisation matrix was used to focus on the gap of most urgency that negatively impacted the HIV programme using ranked scores of 1–5. The WIT

Table 1 Thematic matrix selection for prioritising return to care gaps

QI themes	Beneficiary	A	B	AxB	Selected?
82% return to care after missed appointments among PLHIV 20 years and above	Patients	5	4	20	No
40% return to care after missed appointments among CALHIV aged ≤19 years	Patients	5	5	25	Yes
90% viral load coverage	Patients	4	3	12	No

A denotes the impact score on quality of life; B denotes the score on the urgency to improve; AB denotes the product of A and B.
CALHIV, children and adolescents living with HIV; PLHIV, people living with HIV ; QI, quality improvement.

assigned the gap that had a high public health impact the highest rank score of 5, while that with a lower public health impact received the lowest ranked score of 1. The overall ranked score was a product of the urgency and impact scores. Return to care after missed clinic appointments among CALHIV had the highest ranked score of 25, so the CQI team selected it for improvement.

In step 2 (figure 1), a root cause analysis was conducted using the fishbone diagram.[18] This approach identified several contributing factors: health service delivery-related causes included the lack of a simplified tracking system for missed appointments among CALHIV, such as using stickers to flag active patients, outdated contacts and address information and a lack of timely follow-ups for

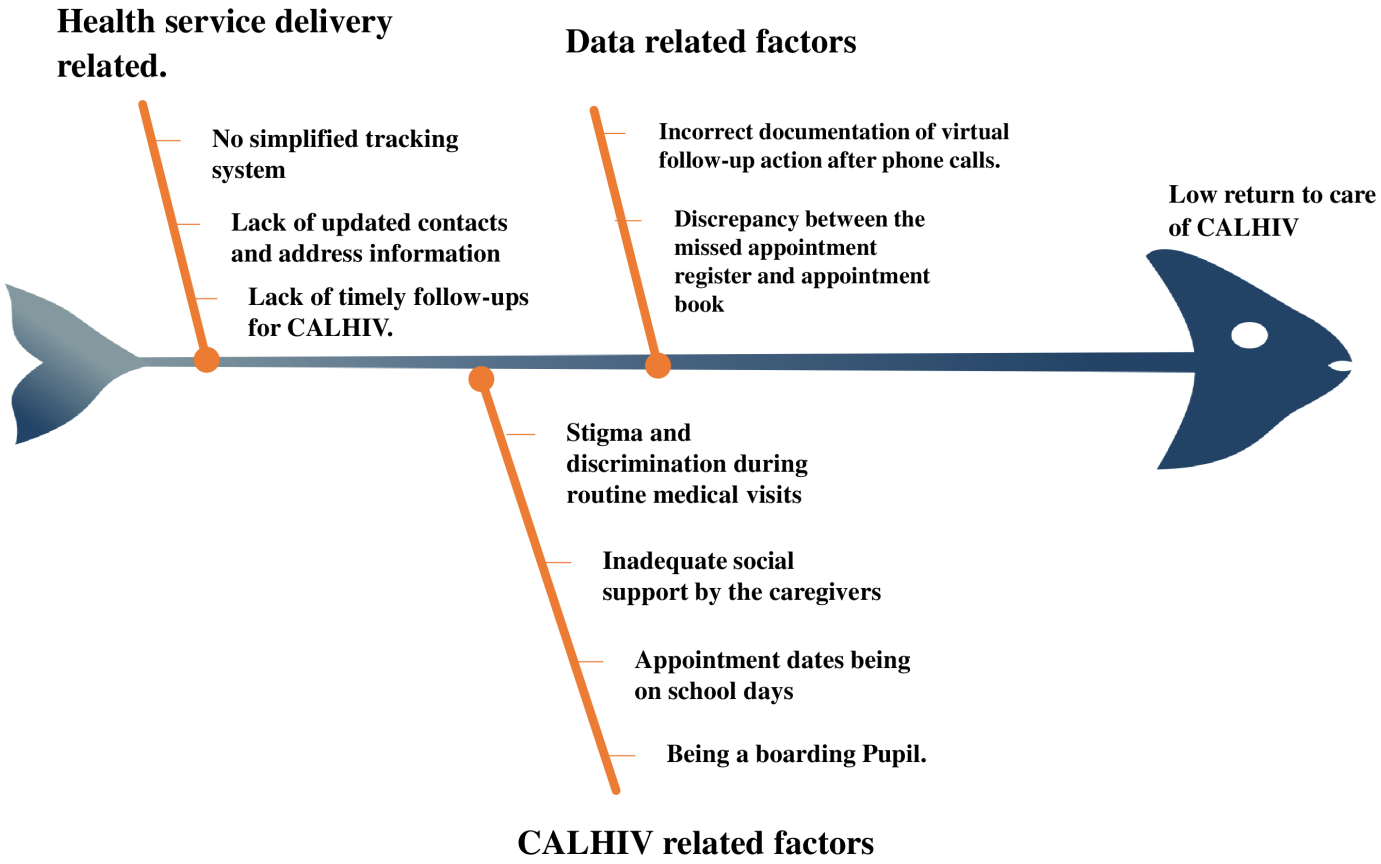


Figure 1 A root cause analysis of low return to care among CALHIV, conducted using a fishbone diagram. The analysis identified key causes, categorised into three main areas: (1) health service delivery-related factors, including the lack of a simplified tracking system, lack of timely follow-ups for CALHIV and outdated contact/address information; (2) CALHIV-related factors, such as clinic appointments coinciding with school days, being a boarding pupil and experiences of stigma and discrimination and (3) data-related factors, including incorrect documentation of virtual follow-up action after phone calls and discrepancy between the missed appointment register and appointment book. CALHIV, children and adolescents living with HIV.

CALHIV who had missed their appointments. CALHIV-related factors included clinic appointments coinciding with school days, being a boarding pupil, stigma and discrimination during routine clinic visits, and inadequate social support by caregivers and parents to enable positive living. Data-related causes included incorrect documentation of missed clinic visits and LTFU status after phone calls. For example, some follow-up actions were inaccurately documented following virtual phone calls, and discrepancies were observed between the missed appointment register and the appointment book. Specifically, certain CALHIV who initially missed scheduled appointments and were recorded in the missed appointment register were not updated on returning to care. Consequently, their records continued to reflect a missed appointment status despite re-engagement.

Guided by identified root causes, in step 3, we developed improvement changes using the impact-effort matrix. We created a list of all the proposed improvement changes on a flipchart. We clarified their meanings to the CQI team, which included members from the department of laboratory, the data unit, clinicians, peers and CHWs.

We then eliminated duplicates, revised the list, recorded it on a new flipchart and assigned alphabetical letters to each change for easy recognition. The CQI team members independently ranked each improvement change while assessing its potential impact as being high or low, including the effort (resources) required to implement each change.

The improvement changes with high impact and low effort or resource requirements were prioritised for implementation to enhance care and retention among CALHIV (figure 2). The initial steps included the line listing of CALHIV, followed by follow-up through phone calls and physical visits. Then, we clustered CALHIV by parish, with a CHW assigned to facilitate follow-up. Weekly data review meetings were established to monitor and track the return-to-care status of CALHIV. Additionally, family clinics were introduced for both caregivers and CALHIV to improve understanding of the importance of appointment adherence and the retention of CALHIV in care.

In step 4, the Plan-Do-Study-Act (PDSA) cycles were used to implement the prioritised improvement changes. The first PDSA cycle involved creating a line list of CALHIV who missed scheduled clinic appointments, and this triggered immediate follow-up through phone calls and physical visits. The HIV Clinic Head compiled and maintained the list at the end of each clinic day and shared it with all clinic staff. Phone and physical follow-ups were initiated simultaneously in February 2023. The second PDSA cycle involved weekly data reviews, typically conducted every Monday at 2 pm, to review the missed appointments register and identify CALHIV who had missed their clinic visits. The cycle also involved data harmonisation across the appointment register, client cards and missed appointment register; and the establishment of a same-day family clinic for CALHIV and their caregivers. The third PDSA cycle involved clustering of CALHIV who had missed their clinic appointment per their place of residence and assigning a CHW to follow-up and facilitate their return to care. Additionally, a counterbook was established to document all follow-up actions conducted by CHWs.

Study outcomes

The primary outcome was the percentage of CALHIV who returned to care among those who had missed their

	Low effort	High effort
High impact	• Follow-up using phone calls. • Clustering CALHIV according to parishes. • Weekly data review meetings to track the status of return to care. • Family clinics for both the caregivers and CALHIV.	• Using GIS to map clients' locations. • Establishing a message platform for health education on retention in care.
Low impact	• Identify the focal person to carry out supervision of follow-up action done.	• Use Excel tool to track client's status using color codes • Use of motivators for chronic treatment interrupters.

Figure 2 The impact-effort matrix showing the change package to improve return to care among CALHIV. The change package was promised due to its low impact and low resources needed to implement it and was decided on by the Work Improvement Team (WIT). The final changes as per the impact-effort matrix were implemented, including a line listing of CALHIV, immediate follow-up through phone calls and physical visits, clustering CALHIV by parish and assigning a CHW, weekly data review meetings and introducing family clinics for both caregivers and CALHIV. CALHIV, children and adolescents living with HIV; CHW, community health workers; GIS, geographic information system.

clinic appointments during the reporting month. The numerator was the number of CALHIV who returned to care, while the denominator included the total number of CALHIV listed as having missed an appointment during the same period.

Monitoring of CQI implementation

To ensure the successful implementation of CQI packages (interventions), we appointed a facility CQI focal person to routinely abstract data on missed appointments, including implementing follow-up actions. All follow-up actions were documented in a national CQI documentation journal provided by the Uganda Ministry of Health. Data were abstracted on the number of CALHIV due for an appointment but missed them, the start and end dates of follow-up action, the CQI study objective, indicator and problem statement. The CQI focal person plotted the percentage of CALHIV who had returned to care over time (months) in the CQI documentation journal, along with annotations of the improvement changes. Key lessons learnt during the CQI implementation were also documented. We conducted monthly CQI meetings to track the CQI implementation status, explored implementation challenges and redesigned or developed newer implementation approaches or modified existing ones.

Statistical analysis

We summarised the proportion of CALHIV returned to care using frequencies and percentages and plotted the percentages against time in months to demonstrate improvement over time. The period was divided into a baseline phase and three phases based on the activities conducted at that time: (1) August 2022–January 2023, the baseline period, during which no CQI intervention was implemented; (2) February 2023–May 2023, phase 1, which involved the implementation of the first CQI package, including timely phone calls and physical follow-ups, informed by line-listing of CALHIV who had missed their clinic appointment; (3) June–September 2023, phase 2, during which weekly data review meetings were held to review the missed appointments register and harmonise data between the appointment register, client cards and missed appointment register

and (4) October 2023—January 2024, phase 3, during which CALHIV were grouped/clustered by village and assigned to CHWs for tracing and return to care. Each phase of the CQI initiatives was annotated on a line graph (figure 3).

RESULTS

Before the implementation of CQI initiatives (figure 3), return-to-care rates for CALHIV in 2022 were 31% (n=5) in August, 33% (n=6) in September, 27% (n=3) in October, 40% (n=10) in November and 44% (n=8) in December. In January 2023, the rate was 36% (n=4). Following the introduction of CQI interventions in February 2023, which included line listing of CALHIV who missed clinic visits, followed by timely phone calls and physical follow-ups, return-to-care rates improved from 36% (n=4) in January to 80% (n=8) by May 2023. Despite additional measures such as weekly data reviews and family clinics, return-to-care rates fluctuated between 69% (n=9) in June 2023 and 80% (n=12) in July 2023. In response to a drop to 55% (n=12) in August 2023, CHWs were engaged to follow-up with CALHIV who had missed their clinic appointments. This intervention led to a steady increase in return-to-care rates, reaching 74% (n=17) in September, 78% (n=7) in October, 82% (n=14) in November, 92% (n=11) in December, and achieving 100% (n=5) in January 2024.

Lessons learnt

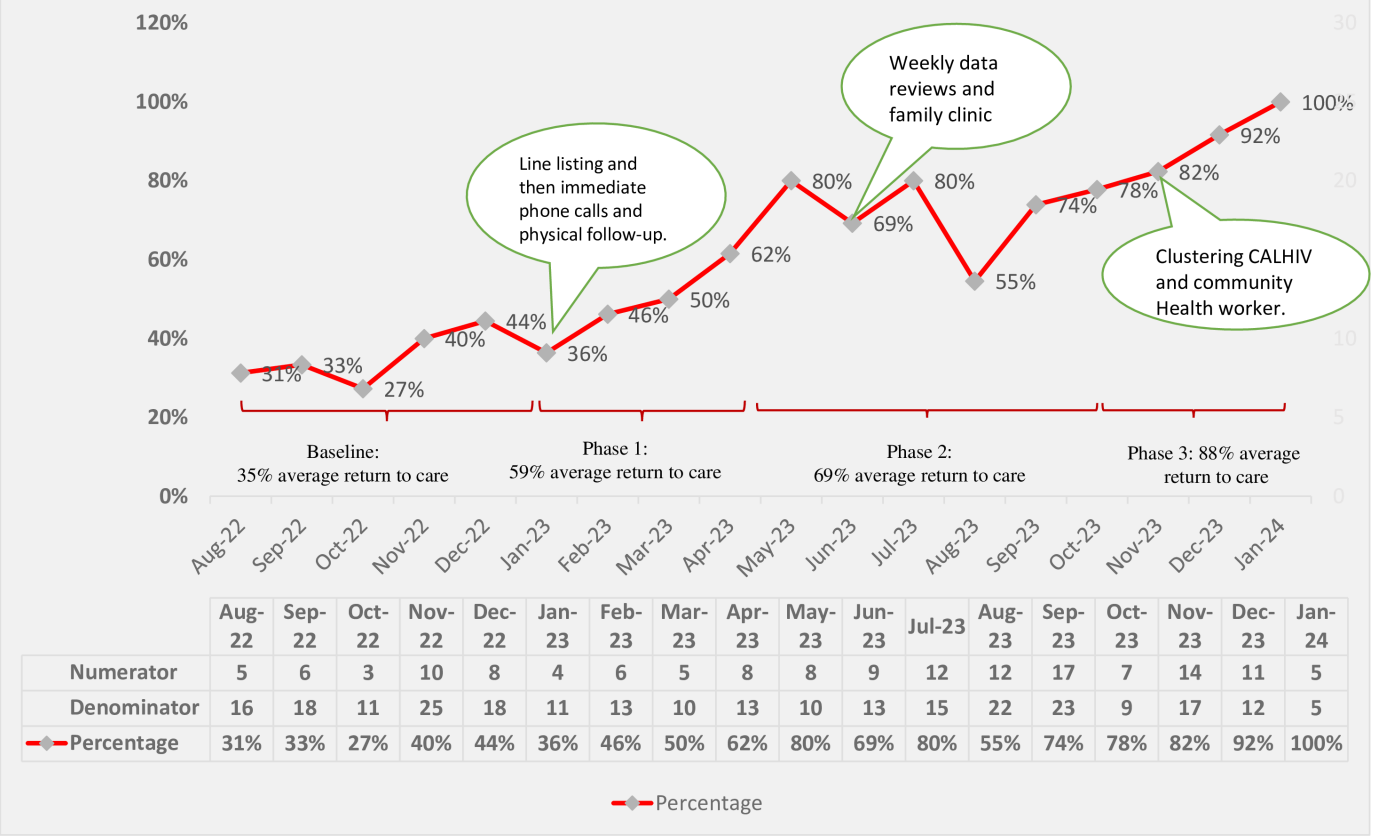
We aimed to increase the return to care of CALHIV who missed clinic appointments at a rural health facility in eastern Uganda using a CQI approach. A combination of context-relevant strategies was employed, including line listing of CALHIV, weekly data reviews to identify those needing follow-up, family clinics and clustering by place of residence, followed by assigning CHWs to track CALHIV in the community.

We found that line listing improved the early identification of CALHIV who missed their clinic appointments. This intervention has also been used in a previous CQI study in mid-western Uganda by Izudi and colleagues to improve retention among CALHIV.[19]

Another study in Northeastern Uganda also showed that the use of line listing for people with bacteriologically confirmed pulmonary TB improves sputum smear microscopy monitoring.[20] Similarly, in the USA, line listing has been used to identify children and adults who had missed their clinic appointments and facilitate their return to care.[21] Consistent with our findings, a study conducted at six clinics in the USA showed that phone calls or text messages effectively facilitated the return to care of most CALHIV who missed appointments at a primary healthcare level.[22]

A meta-analysis also found that mobile phone call reminders improved return to care among PLHIV who missed clinic appointments, consistent with our findings.[23] Furthermore, data harmonisation through weekly data review meetings reduced the misclassification of PLHIV as having missed clinic appointments. This allowed healthcare providers to focus efforts on accurately identifying and tracing CALHIV who had truly missed their appointments. This finding aligns with other studies that reveal weekly data review meetings enhance data accuracy and documentation, leading to timely follow-up actions and increased return-to-care rates.[19 24 25]

Establishing family clinics creates a supportive environment for health workers, caregivers and CALHIV, facilitating improved adherence to treatment. This approach also reduces missed clinic appointments and treatment interruptions, ultimately enhancing retention in care.[24 26–28] During family clinics at Serere Health Center IV, both caregivers and CALHIV received joint health



	Aug-22	Sep-22	Oct-22	Nov-22	Dec-22	Jan-23	Feb-23	Mar-23	Apr-23	May-23	Jun-23	Jul-23	Aug-23	Sep-23	Oct-23	Nov-23	Dec-23	Jan-24
Numerator	5	6	3	10	8	4	6	5	8	8	9	12	12	17	7	14	11	5
Denominator	16	18	11	25	18	11	13	10	13	10	13	15	22	23	9	17	12	5
Percentage	31%	33%	27%	40%	44%	36%	46%	50%	62%	80%	69%	80%	55%	74%	78%	82%	92%	100%

Figure 3 A line graph showing the proportion of CALHIV who returned to care, plotted as percentages over time (in months). The timeline is divided into distinct phases: (1) baseline period (August 2022–January 2023), with no CQI intervention; (2) phase 1 (February–May 2023), which involved the implementation of timely phone calls and physical follow-ups informed by line-listing of CALHIV; (3) phase 2 (June–September 2023), which introduced weekly data review meetings and (4) phase 3 (October 2023–January 2024), which involved clustering CALHIV by village and assigning them to CHWs. Each phase of the CQI initiative is annotated on the line graph. CALHIV, children and adolescents living with HIV; CHWs, community health workers; CQI, continuous quality improvement.

education on the importance of appointment-keeping and ART adherence. This led to improved return-to-care rates among CALHIV and this is consistent with a previous study.[29]

Our study found that clustering CALHIV by their place of residence (village) and assigning a CHW for home-based follow-ups improved return to care and this aligns with a past study.[30] This finding is also consistent with studies conducted in the USA that employed navigators to enhance retention and facilitate return-to-care for PLHIV and mother–child pairs of HIV-exposed children.[31 32] In the ZENITH trial conducted in Zimbabwe, CHWs were used to support clinic visits and facilitate return for CALHIV, resulting in a significant reduction in the odds of virologic failure.[33] Overall, scaling up return-to-care strategies for CALHIV may improve retention, reduce virologic failure and enhance treatment adherence, leading to better health outcomes and lower transmission rates.

Ultimately, this approach would contribute to sustainable HIV care, support the UNAIDS target of ending the HIV epidemic by 2030 and reduce the HIV burden among children and adolescents.

Strengths and limitations

This CQI study has strengths and limitations. This is one of the few CQI studies conducted in rural eastern Uganda to improve the return to care among CALHIV who missed clinic appointments. We used feasible, low-cost, context-relevant strategies to improve the return to care of CALHIV, potentially increasing the adoption and scalability of such measures in similar settings. However, a limitation of the study is the small number of CALHIV included, although all available data were considered. The lack of qualitative data to correlate the findings was another limitation. The CQI initiatives improved return to care, but this conclusion is based on data up to January 2024. We do not yet know whether the improvements have been sustained beyond that period. Given these limitations, the findings should be considered preliminary data to inform a prospective, multicentre, stepped-wedge cluster randomised controlled trial. This would enable the use of a larger sample size and extended follow-up period to evaluate the effectiveness of the interventions.

CONCLUSION

This CQI study showed that the return to care of CALHIV improved when simple and context-relevant measures were implemented. The measures included a line listing of CALHIV who missed clinic appointments, leading to follow-up via phone calls and physical follow-ups. Additionally, the use of CHWs to trace CALHIV in the community and routine data reviews helped accurately identify those needing follow-up. Involving family members through family clinics also played a key role in enhancing return to care.

Author affiliations
[1]Directorate of Program Management and Capacity Development, AIDS Information Center, Kampala, Uganda, Kampala, Uganda
[2]Department of Community Health, Faculty of Medicine, Mbarara University of Science and Technology, Mbarara, Uganda
[3]African Population and Health Research Center, Nairobi, Kenya
[4]Directorate of Graduate Training, Research and Innovation, Muni University, Arua, Uganda
[5]Directorate of Program Management and Capacity Development, AIDS Information Center, Kampala, Uganda, Kampala, Soroti, Uganda
[6]Department of Health, Serere District Local Government, Serere, Uganda
[7]Makerere University School of Public Health, Kampala, Kampala, Uganda

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Ethics approval This study involves human participants. Ethical approval was obtained from the Makerere University School of Public Health Research Ethics Committee with Reference number of 815. Participants gave informed consent to participate in the study before taking part.

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ORCID iDs
Ssentongo Mugerwa Saadick http://orcid.org/0009-0006-6270-4953
Jonathan Izudi http://orcid.org/0000-0001-9065-0389

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