

# Understanding and Improving **Viral Load Suppression** in Children with HIV in Eastern and Southern Africa



**Cover photo**

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# Executive Summary

Nearly seven out of every ten children with HIV globally lives in Eastern and Southern Africa<sup>1</sup>. Despite progress in reducing new HIV infections in children, the region is far behind in reaching the 95-95-95 fast-track global targets for ending AIDS among children by 2030. Viral load suppression (VLS) is critical to treatment success and reducing child morbidity and mortality. In order to accelerate progress towards ending AIDS, there is an urgent need to better understand the challenges to and facilitators of VLS among children (aged 0-14 years) who are on antiretroviral therapy (ART). This study explored trends and factors associated with paediatric VLS in Uganda, Malawi and Zimbabwe with the aim of informing paediatric HIV programmes in the region and improving health outcomes for children.

The study used cross-sectional mixed-methods, including: (1) a comprehensive literature review, (2) secondary analysis of Laboratory Information Management System (LIMS) data from Malawi, Uganda and Zimbabwe for the period 2016, 2017 and 2018, (3) a review of 275 patient records for selected facilities in Malawi, and (4) qualitative in-depth interviews with 16 health workers and 36 caregivers at selected health facilities in Malawi. After data cleaning, 66,158, 71,941 and 121,370 LIMS records were eligible for analysis for 2016, 2017 and 2018, respectively. A substantial amount of data missing in the LIMS and extracted data limited the level and extent of analysis.

The study found that one out of every three children who had a viral load test had not achieved viral load suppression. VLS among children with HIV remained low across the three years, ranging from 69% in 2016, 64% in 2017 and 65% in 2018.

Children aged 1-4 years had the lowest rates of VLS, with 62% in 2016, 58% in 2017 and 54% in 2018. Being on ART for a longer duration and adhering to ART appointments were associated with VLS. Complexities in administering antiretrovirals (ARVs), bitter taste, high numbers of pills, increased burden of taking other drugs, malnutrition and lack of food negatively affected children's drug adherence. A supportive home and community environment for caregiver and child increased the likelihood of both optimal adherence and VLS.

Health facility-related factors influenced the overall management of paediatric ART, including failure to follow-up children with unsuppressed viral load, long-waiting times, distances to health facilities, and child unfriendly services. In addition, non-recording of essential data such as viral load test results, CD4 count, adherence, ARV formulation, exposure to ARVs for prevention of mother-to-child transmission of HIV, and nutritional status impeded clinical and programmatic decision-making.

**Several policy, programme, and research actions are recommended to improve VLS and health outcomes for children with HIV:**

## **Provide essential support to caregivers and children**

Paediatric ART success depends heavily on caregivers who, in turn, require psychosocial and material support. From the time of ART initiation until the child becomes an adult, caregivers need psychosocial support services, with linkages to health facilities, that focus on eliminating stigma, identifying support networks, and mobilizing community resources. Given shortages of health workers, expanding the role of different cadres is warranted. Trained community workers and peers, linked to health facilities, can provide consistent support to caregivers and children.

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1 UNAIDS 2020 Estimates. <https://aidsinfo.unaids.org/>

## **Promote paediatric viral load testing and child-friendly drug regimens**

The low rate of paediatric VLS indicates the need to scale-up viral load monitoring. In addition, given the low rates of VLS among children on first line Nevirapine, there is an urgent need to transition children to more efficacious Lopinavir and Ritonavir-based or Dolutegravir-based regimens in line with current WHO guidelines.

## **Strengthen paediatric HIV service delivery accessibility, coverage and quality**

Health workers play an important role in supporting caregivers and children, including managing the disclosure process to the child, explaining the complexities of administering paediatric formulations, and providing on-going support for treatment adherence.

Decentralization to primary health care centres, alongside investments in strengthening health worker capacity to manage paediatric ART, is essential to reaching children who either do not know their viral load or are not virally suppressed. Also, reduced waiting times, expanded clinic hours and multiple month prescriptions may help compliance with ART appointments and improve VLS. Home visits and community-based refills of ARVs for stable children on ART may address some of the challenges faced by caregivers in assuring regular clinical assessments and drug refills.

## **Improve case management with multi-sectoral linkages and referrals**

Nutrition, food security and co-morbidities must be addressed to achieve treatment success. Protocols on nutrition screening and support for children on ART must be followed and linkages made to social protection programmes for food insecure households.

## **Strengthen paediatric HIV data collection, analysis and use**

Shortcomings in documentation, data entry, storage, utilization of data and interfaces between different data sources call for country-specific investment of resources in both laboratory information management systems and patient records, particularly information that will help health workers and programme managers make informed clinical and programmatic decisions.

## **Enhance understanding of paediatric VLS**

Country-specific studies that explore gaps in knowledge on paediatric HIV and VLS will assist policy makers, service providers and programme implementors in ensuring that children receive the support and services they need for their health and wellbeing. Proposed research includes implementation research on family-centered approaches to care and treatment, including the relationship between caregiver's and children's adherence; scaling up support to caregivers; tailoring support for children in different age groups; and exploring the potential impact of social protection initiatives.

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# Acronyms

ART	Antiretroviral therapy
ARVs	Antiretroviral drugs
ATV/r	Atazanavir/ritonavir
AZT	Zidovudine
ESA	Eastern and Southern Africa
EFV	Efavirenz
HIVDR	HIV drug resistance
LIMS	Laboratory Information Management System
LPV/r	Lopinavir-ritonavir
NNRTI	Non-Nucleoside Transcriptase Inhibitor
NVP	Nevirapine
PMTCT	Prevention of Mother to Child Transmission of HIV
RAL	Raltegravir
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
VLS	Viral Load Suppression
WHO	World Health Organization





An estimated

**1.2 million**

children (aged 0-14) are  
living with HIV in Eastern  
and Southern Africa



# 1.0 Introduction

Global efforts to prevent new HIV infections, increase treatment coverage and end AIDS-related deaths are focused on the fast-track 95-95-95 targets. At least:

- diagnose 95% of all people living with HIV.
- provide antiretroviral therapy (ART) to 95% of those diagnosed.
- achieve viral load suppression for 95% of those on treatment by 2030.<sup>2</sup>

While remarkable progress has been made, children lag behind in achieving each of these targets. An estimated 1.2 million children (aged 0-14 years) are living with HIV in Eastern and Southern Africa (ESA). In 2019, only 58% of these children were receiving lifesaving treatment, an estimated 74,000 new paediatric HIV infections occurred, and 46,000 children died from AIDS related causes.<sup>3</sup>

Viral load suppression (VLS) is essential to reducing child morbidity and mortality yet several ESA countries have shown alarmingly low rates of VLS among children, especially as compared to adults.<sup>4</sup>

## Children are lagging behind adults in viral load suppression<sup>4</sup>

**Malawi:** Children at 42% vs adults at 67%

**Uganda:** Children at 39% vs adults at 84%

**Zimbabwe:** Children at 47% vs adults at 86%



National data confirms the need to better understand how to achieve paediatric HIV treatment success. UNICEF commissioned this study to generate evidence on trends and factors associated with paediatric VLS in three ESA countries with high HIV prevalence, Malawi, Uganda and Zimbabwe. The evidence and recommendations shared in this report are intended to help inform paediatric HIV policies and programmes in the ESA region, accelerate progress towards the 95-95-95 goals and, ultimately, to improve health outcomes for children with HIV.

2 UNAIDS, Understanding Fast Track: Accelerating Action to End the AIDS Epidemic by 2030. [https://www.unaids.org/sites/default/files/media\\_asset/201506\\_JC2743\\_Understanding\\_FastTrack\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/201506_JC2743_Understanding_FastTrack_en.pdf)

3 UNAIDS 2020 Estimates. <https://aidsinfo.unaids.org/>

4 [https://phia.icap.columbia.edu/resource\\_categories/summary-sheets/](https://phia.icap.columbia.edu/resource_categories/summary-sheets/)

**“ Viral load suppression is essential to reducing illness and death yet several ESA countries have shown alarming low rates of VLS among children, especially as compared to adults. ”**



# 2.0 Methodology

This was a cross-sectional mixed-methods study that entailed (1) a comprehensive literature review, (2) secondary analysis of laboratory information management systems (LIMS) data from Malawi, Uganda and Zimbabwe, (3) patient records review from selected facilities in Malawi, and (4) in-depth interviews with health workers and caregivers at selected health facilities in Malawi.

**Table 1. Data collection, targeted study population, source of data**

<b>Data Collection Method</b>	<b>Population</b>	<b>Source of Data</b>
Literature review	Children with HIV aged <15 years	Relevant publications about medical, socio-demographic, economic and structural factors were considered. An internet search and review of country ART guidelines and reports was undertaken. A systematic review of country ART guidelines, reports and peer-reviewed published papers between 2014 and 2019 was done using Google scholar, Pubmed, Scopus, Ovid, ProQuest, EBSCO, and HINARI. The following key search words were used in different combinations; antiretroviral therapy; HIV; viral load; viral suppression; children; optimal therapies; new formulations, paediatric, ART guidelines, ART adherence and VLS in children; caregivers of children on ART; ARV formulations and VLS in children; barriers and facilitators to ART adherence in children; barriers and facilitators to VLS in children; virological failure in children on ART; optimizing ART in children; virological response for children on ART; factors related to ART adherence in children, factors related to VLS in children.
Quantitative analysis of LIMS data	Children aged <15years in LIMS in the period 2016-2018	National level LIMS data from Malawi, Uganda and Zimbabwe.
Client records review	Children aged <15 years with records for period 2016-2018	Eight health facilities in Malawi (Kamuzu Central Hospital, Queen Elizabeth Central Hospital, Bwaila Hospital, Thyolo District Hospital, Machinga District Hospital, Zomba Central Hospital, Mangochi District Hospital, Lilongwe Area 25 Health Center).

Data Collection Method	Population	Source of Data
Health care worker in-depth interview	Health care workers who provide direct paediatric HIV care	Seven health facilities in Malawi (Kamuzu Central Hospital, Queen Elizabeth Central Hospital, Bwaila Hospital, Thyolo District Hospital, Machinga District Hospital, Zomba Central Hospital, Lilongwe Area 25 Health Center).
Caregiver in-depth interview	Caregivers aged >18 years of children with HIV	Eight health facilities in Malawi (Kamuzu Central Hospital, Queen Elizabeth Central Hospital, Bwaila Hospital, Thyolo District Hospital, Machinga District Hospital, Zomba Central Hospital, Mangochi District Hospital, Lilongwe Area 25 Health Center).

The Ministries of Health in Malawi, Uganda and Zimbabwe provided access to raw LIMS data for the period 2016 – 2018. A data cleaning process was undertaken that included discarding records that did not have viral load (VL) results, did not indicate age, or the indicated age was above 14 years. It is important to note the incompleteness of data on reason for viral load test, duration on ART and ART regimen (see Table 2).

**Table 2. LIMS records completeness in Malawi, Uganda and Zimbabwe**

Characteristic	2016	2017	2018
Raw LIMS data received (before cleaning)	338,289	450,211	744,672
Data on children <15 years received	100% (69,977)	100% (72,756)	100% (122,716)
Eligible children <15 years with viral load result (Used for analysis)	95% (66,158)	99% (71,941)	99% (121,370)
Reason for viral load test	93% (65,361)	81% (58,621)	82% (100,497)
Duration on ART	75% (52,409)	66% (48,337)	71% (86,602)
ART Regimen	68% (47,678)	59% (42,673)	57% (70,229)

The following sampling procedures were followed for each data source:

- a. LIMS data (Malawi, Uganda, Zimbabwe):** The study used all available LIMS data after cleaning.
- b. Client records review (Malawi):** A two-stage random sampling method was used in sampling client records. First, a list of all facilities with a high volume/number of children on ART who had a viral load test was drawn for sampling. Using data from the sampled high-volume facilities, the second stage of sampling was undertaken of children with results indicating VLS (<1000 copies per ml after being on ART for six months) and those indicating unsuppressed viral load (> 1000 copies per ml after being on ART for six months). Probability proportionate to the number of children on ART who had a viral load test and expected VLS were used to determine the sample size for each selected facility. A total of 275 records were reviewed. Among these, 137 children were suppressed and 138 were not suppressed.

**c. Health workers (Malawi):** 16 health workers who provided paediatric ART services at the selected health facilities were interviewed to provide a qualitative view on virally suppressed and non-suppressed cases. These included 6 clinical officers, 6 nurses, and 4 expert clients<sup>5</sup>. Health workers were interviewed at the health facilities at which they work. Theoretical saturation determined sample size.

**d. Caregivers (Malawi):** Non-probability sampling methods were used in sampling caregivers of children with HIV who had a viral load test and results categorized as virally suppressed or non-suppressed. Only caregivers who were available on the day of the paediatric clinic day were selected. Theoretical saturation determined sample size. A total of 36 interviews with primary caregivers were conducted. These included 26 mothers, 6 aunts, 2 grandmothers, 1 father, and 1 sister. Their ages ranged from 17 to 57 years.

All qualitative and quantitative data gathered during the study were kept in locked cabinets to ensure confidentiality. LIMS data was stored in excel and STATA files. Clinical files with reviewed data were entered directly onto a password protected web-based app (KoboCollect). An encrypted back-up copy of the electronic databases and files was made and stored under lock and key in a secure room.

The study commenced after receiving ethical approval from research regulatory authorities, the National Health Sciences Research Committee of Malawi, the Uganda National Council for Science and Technology, Uganda National Health Laboratory Services, and the Medical Research Council of Zimbabwe.

Incomplete data for key study variables (such as ART regimen, duration on ART, reason for viral load tests) in both LIMS and reviewed client records limited the extent of analysis in this study.

The primary outcome was virologic suppression, defined as having <1000 copies of viral RNA/ml of blood plasma. Data sets were combined by year. Data was analysed using STATA version 16.0. First, descriptive analysis of continuous variables was undertaken. To determine the association between VLS and the categorical variables, cross-tabulations were conducted providing the frequency in each category and proportion of children with/without VLS. To determine the factors associated with VLS and direction of association, the 2018 data set was used by conducting logistic regression univariate analysis for each category independent variable against the outcome (VLS). Crude odds ratios (OR) and 95% confidence interval (CI) were calculated at p-value of 0.05. The following sub-categories were used as the reference: Female for Sex, <1 year for age group, <1 year for period on ART, First-line nevirapine (NVP) for the ART regimen, and Routine for Reason for viral load test. The significant variables were then entered together in the multinomial logistic regression model with 95% CI and p-value at 0.05 to determine the independent predictors of VLS. Adjusted odds ratios and 95% confidence intervals were calculated. The missing and “other” were dropped in the logistic regression as it was not clear which categories of clients were categorized as “other”. Similar analyses were conducted for the records review data from the eight health facilities in Malawi. Using ATLAS, thematic content analysis was used in analysing qualitative data. Particular attention was paid to themes on factors influencing suppression and/or failure to suppress.

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5 An Expert Client is someone living with HIV who provides support on HIV testing, treatment and adherence to other people living with HIV.







# 3.0 Findings

## 3.1 Treatment history and VL testing of children with HIV

Routine and targeted viral load testing throughout treatment is fundamental to making clinical decisions that will achieve VLS and reduce child morbidity and mortality<sup>6</sup> and detecting HIV drug resistance (HIVDR). HIVDR influences failure to suppress on ART and subsequently virologic failure.<sup>7</sup> Children with a high viral load at ART initiation need more time to achieve VLS and are predisposed to developing HIVDR and increased mortality.<sup>8,9</sup>

The majority of children in this study were on first-line Nevirapine (NVP) (see Tables 3 and 4). The reviewed records in Malawi indicated that about one-third (33.8%) of children maintained the regimen given at ART initiation while slightly above one-third (39.0%) had switched due to treatment failure.

Routine testing was the main reason for a viral load test. In the LIMS data, there was a noticeable increase in the proportion of children who had a viral load test after post-intensive adherence counselling<sup>10</sup>, ranging from 1.2% in 2016 to 4.2% in 2018. There was no noticeable increase in viral load testing for suspected treatment failure. The review of records in Malawi indicated suspected treatment failure as the main reason for a second viral load test.



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6 Bain L, Nkoke C, Noubiap J. UNAIDS 90-90-90 targets to end the AIDS epidemic by 2020 are not realistic. *Comments, BMJ Global Health*, 2017, Vol. 2. E000227.

7 Salou M., et al., High rates of virological failure and drug resistance in perinatally HIV-1 infected children and adolescents receiving lifelong antiretroviral therapy in routine clinics in Togo. *JIAS*, 2016, Vol.19. 20683.

8 Bińczak A., et al., Determinants of virological outcome and adverse events in African children treated with pediatric nevirapine fixed dose combination tables. *AIDS*, 2017, Vol. 31, pp.905-915.1376.

9 Anigilaje E., Adenbighe S. Mortality in a cohort of HIV infected children: A 12-month outcome of antiretroviral therapy in Mauidi, Nigeria. *Hindawi Advances in Medicine*, 2018. 6409134.

10 A viral load test performed after three months of monthly intensive adherence counselling following an unsuppressed routine viral load.

**Table 3. Treatment history and viral load tests of children with HIV (Malawi, Uganda, Zimbabwe)**

Characteristics		2016 % (n)	2017 % (n)	2018 % (n)
<b>ART regimen</b>	1st Line – NVP	42.9 (28,358)	32.3 (23,257)	25.7 (31,246)
	1st line – EFV	22.5 (14,894)	20.1 (14,428)	19.9 (24,132)
	1st Line – AZT			0 (5)
	1st Line – DTG			0 (20)
	2nd line – LPV/r	5.6 (3,685)	5.8 (4,187)	6.2 (7,471)
	2nd line – ATV/r	0.8 (542)	0.8 (605)	1.6 (1,956)
	2nd Line – RAL			0 (3)
	Other Regimen	0.3 (199)	0.3 (196)	4.8 (5,801)
	Missing	27.9 (18,480)	40.7 (29,268)	41.8 (50,736)
<b>Reason for test</b>	Routine	97.2 (64,334)	77.4 (55,676)	78.3 (94,966)
	Post IAC	1.2 (775)	3.9 (2,774)	4.2 (5,141)
	Suspected Treatment Failure	0.3 (207)	0.2 (147)	0.5 (632)
	Other	0.1 (45)	0 (24)	0.1 (166)
	Missing	1.2 (797)	18.5 (13,320)	16.9 (20,465)
<b>Duration on ART (years)</b>	0-<1	3.5 (2,342)	4.5 (3,203)	2.4 (2,884)
	1-4	51.1 (33,816)	38.5 (27,728)	40.1 (48,726)
	5-9	21.8 (14,410)	21.1 (15,210)	24.9 (30,185)
	10-14	2.8 (1,841)	3.1 (2,196)	4.0 (4,807)
	Missing	20.8 (13,749)	32.8 (23,604)	28.6 (34,768)
<b>Viral load</b>	Suppressed	69.0 (45,615)	64.2 (46,196)	65.3 (79,211)
	Non-suppressed	31.0 (20,543)	35.8 (25,745)	34.7 (42,159)

“

The study found that one out of every three children who had a viral load test had not achieved viral load suppression.

”

**Table 4. Treatment history and viral load tests of children with HIV (Malawi)**

Characteristic	% (n)		Characteristic	% (n)	
<b>Age at ART initiation (years)</b>	<1	14.9 (41/275)	<b>Initial ARV Regimen</b>	First Line EFV	2.65(7/275)
	1-4	51.3 (141/275)		First Line NVP	92.4 (254/275)
	5-9	24.7 (68/275)		Second Line LPV/r	5.1 (14/275)
	10-14	9.1 (25/275)	<b>Initial ARV Regimen Formulation</b>	Tablet	76.4 (210/275)
<b>Duration on ART (years)</b>	<1	0.4 (1/275)		Pellets	2.9 (8/275)
	1-4	49.1 (135/275)		Not Indicated	20.7 (57/275)
	5-9	30.9 (85/275)	<b>Regimen I still current</b>	Yes	33.8 (93/275)
	10-14	19.6 (54/275)		No	66.2 (182/275)
<b>PMTCT Exposure</b>	Yes	13.5 (37/275)	<b>Reason for Regimen I change</b>	Program Changes	12.6 (23/182)
	No	20.0 (55/275)		Substitution	33.0 (60/182)
	Unknown	66.6 (183/275)		Switching	39.0 (71/182)
<b>CD4 count at Baseline</b>	Yes	13.0 (28/216)		Weight or Age Changes	15.4 (28/182)
	No	87.0 (188/216)	<b>Adherence to appointments</b>	Optimal (≥95%)	72.0 (198/275)
<b>CD4 count status at Baseline</b>	<500 cells/μL	60.7 (17/28)		Poor (<95%)	12.4 (34/275)
	≥500 cells/μL	39.3 (11/28)		Missing	15.6 (43/275)

“ Lack of documentation, storage and utilization of data in both the LIMS and patient records was common in all three countries. ”

Characteristic	% (n)		Characteristic	% (n)	
<b>Ever stopped ART</b>	Yes	1.8 (5/275)	<b>Adherence by missed doses (1st Year of ART)</b>	Optimal (≥95%)	28.7 (79/275)
	No	98.2 (270/275)		Poor (<95%)	28.0 (77/275)
<b>WHO Clinical Stage at ART Initiation</b>	I	29.1 (80/275)		Missing	43.3 (119/275)
	II	0.7 (2/275)	<b>Adherence by missed doses (Latest)</b>	Optimal (≥95%)	32.0 (88/275)
	III	29.1 (80/275)		Poor (<95%)	24.4 (67/275)
	IV	25.1 (69/275)		Missing	43.6 (120/275)
	Unknown	16.0 (44/275)	<b>First Viral Load Suppressed</b>	Yes (<1000copies/ml)	54.2 (149/275)
<b>Nutritional Status at ART Initiation</b>	Normal	8.4 (23/275)		No (≥1000copies/ml)	45.8 (126/275)
	Moderate Malnutrition	2.9 (8/275)	<b>Second Viral Load Suppressed (Only 110 had a second VL)</b>	Yes (<1000copies/ml)	47.3% (52/110)
	Severe Malnutrition	12.7 (35/275)		No (≥1000copies/ml)	52.7% (58/110)
	Unknown	76.0 (209/275)		No second viral load	60.0 (165/275)
<b>Ever had TB</b>	Yes	4.4 (12/275)	<b>Reason for second Viral Load</b>	Routine	36.4 (40/110)
	No	95.6 (263/275)		Suspected Treatment Failure	29.1 (32/110)
<b>Ever had ARV Side effects</b>	Yes	1.8 (5/275)		Post-IAC	5.5 (6/110)
	No	98.2 (270/275)		Not Indicated	29.1 (32/110)
<b>Ever had opportunistic Infections</b>	Yes	0	<b>Current Viral Load suppression</b>	Yes (<1000copies/ml)	64.7 (178/275)
	No	100 (275/275)		No (≥1000copies/ml)	35.3 (97/275)

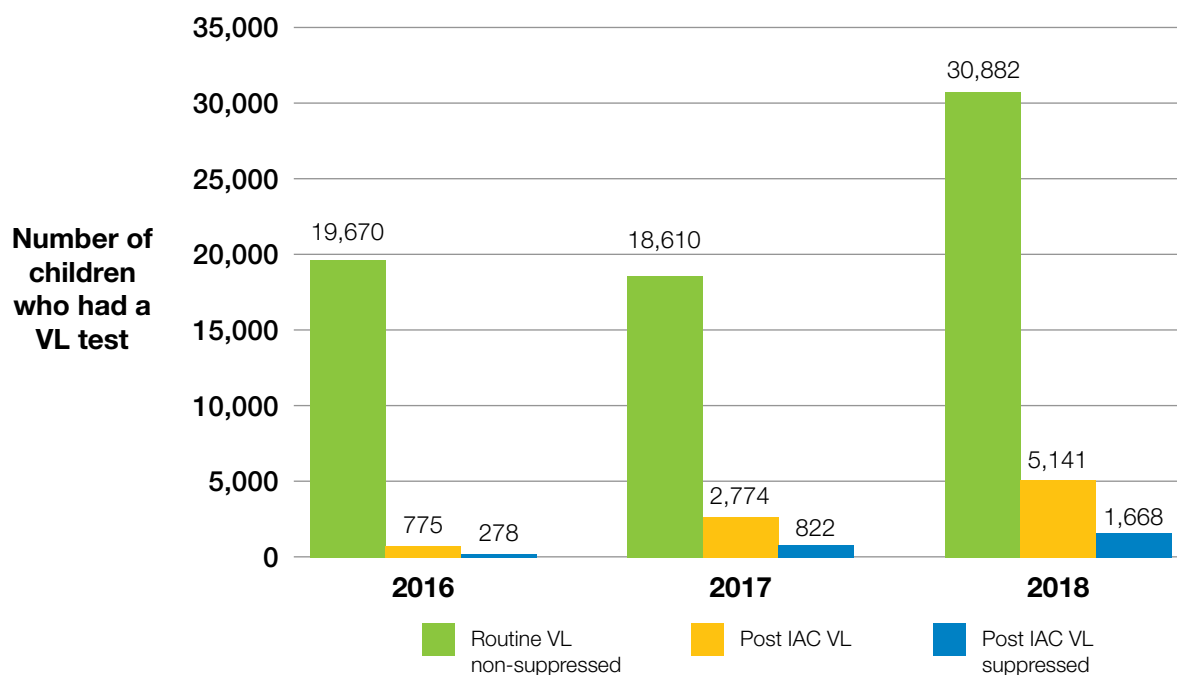


## 3.2 Viral load suppression trends and associated factors

### 3.2.1 Paediatric viral load suppression trends

From 2016 to 2018, VLS in children remained relatively static in Uganda, while declining in Malawi and Zimbabwe (see Figure 1.) Consistently, one-third or more of children were not virally suppressed.

**Figure 1. Viral load suppression trends by country and by year**



### 3.3.2 Sex

Across the three countries, being female increased the odds of viral suppression (see Table 5). However, sex did not come out as an independent predictor for VLS from the Malawi records (see Table 6).

### 3.3.3 Age

LIMS data from the three countries indicated that children aged younger than one year were more likely to have VLS than older children while both multi-country LIMS data and the Malawi records showed children aged 1-4 years were the least likely to have VLS.

### 3.3.4 Treatment regimen

Children on first-line NVP regimen had the lowest proportion of VLS, with 63.6% in 2016, 59.1% in 2017 and 63.7% in 2018 (see Table 5).

In Malawi, VLS was higher among children who were initiated on ART with first-line Efavirenz (EFV) (85.7%) than among those who were initiated on first-line NVP (65.8%) and second-line Lopinavir (LPV/r) (35.7%) (see Table 7). Children still on their initial regimen had higher VLS (74.2%) than those who had been switched to a different regimen (59.9%). VLS was highest among children who switched regimens due to programme changes (78.3%), substitution (71.7%) or weight/age changes (75.0%), compared to those who switched regimen due to treatment failure (38.0%) (see Table 7).

The influence of acceptability of regimens by caregivers and children on ART adherence has been well-documented.<sup>11, 12</sup> Interviews with caregivers and health workers were categorical on “pellets being a challenge in administering” and/or “formulations that are bitter for children” as underlying factors in most cases of non-adherence. A comment from one of the caregivers sums up the overall impression:

“Administering pellets is laborious. They have to be taken twice a day, I have to give [them] with food for my child. At one time the hospital gave us a certain type that was very bitter for my child. I had to spend more than five minutes trying to give her a morning dose. I have two other children going to primary school and I also need to prepare going to work. Imagine what my mornings are like...”

**[Caregiver, Malawi]**

A health worker responsible for the LPV/r pellet programme reported that many children remain with high viral load despite patient and caregiver counselling. He narrated a case of a 3-year old girl who has been on pellets since the age of 18 months. Her routine and targeted viral loads had been very high since ART initiation. Discussions with the caregiver revealed that the mother did not know how to administer pellets, despite demonstrations to her during clinic visits, so she had stopped giving the child the pellets. The girl was switched to AZT/3TC/NVP, the first-line regimen for children, and suppressed within 3 months.

Cases of children failing to adhere or suppress because they were taking “too many pills” were reported across the eight facilities in Malawi. The current recommended regimen for children is taken twice daily. In addition, children are expected to take other medications such as co-trimoxazole to prevent opportunistic infections and isoniazid preventive therapy to prevent tuberculosis (TB). Caregivers with children who were failing to suppress described their everyday experiences:

“We are both on ART, why am I supposed to take so many pills mum? Why can't I be given the one tablet like yours? They are big these tablets and I won't swallow them.”

**[Caregiver in Malawi narrating what her child says about taking ARVs (ABC/3TC + LPV/r).]**

“This medication is too much for a child. He has to take his pills twice daily plus CPT [co-trimoxazole]. I really feel for him when he refuses to take it. Three years is too young to be going through this experience. How do you convince such a young child that this medicine is good for your health?”

**[Caregiver, Malawi]**

### 3.3.5 Duration on ART

Children who have been on ART for more than four years have an increased likelihood of VLS (see Tables 5 and 6). In the multivariate analysis, duration on ART was an independent predictor with children on ART for 10-14 years having twice the likelihood of VLS than those on ART for less than five years.

11 Pasipanodya B., et al. Assessing the adoption of lopinavir/ritonavir oral pellets for HIV-positive children in Zimbabwe, JIAS, 2018, Vol.21. e25214.

12 Kektinwa A., et al., Acceptability of lopinavir/r pellets, tablets and syrups in HIV-infected children. Antiretroviral Therapy, 2016, Vol.21, pp.579-585.

### 3.3.6 Adherence

ART adherence has been well documented as a key contributor to treatment and virologic success.<sup>13, 14</sup> In Malawi, VLS was higher (64.1%) among children with optimal adherence ( $\geq 95\%$ ) to clinic appointments compared to the VLS (58.8%) of children with poor appointments adherence (see Table 7). Also, in Malawi, VLS was 68.8% among children with adherence by missed drug/pill count, although health workers noted that measuring adherence by pill count is unreliable as some caregivers attempt to manipulate the pill count by calculating the number of pills to be brought back to the clinic.

**Table 5. Factors associated with viral load suppression (Malawi, Uganda, Zimbabwe)**

Characteristics		Viral load suppressed % (n)	ORcrude (95%CI)	P-value	ORadjusted (95%CI)	P-value
<b>Sex</b>	Female	67.3 (42,369/62,936)	Ref		Ref	
	Male	63.0 (36,233/57,502)	0.83 (0.81; 0.85)	<0.001	0.85 (0.82; 0.88)	<0.001
<b>Age groups (years)</b>	0-<1	78.1 (975/1,248)	Ref		Ref	
	1-4	53.5 (9,418/17,616)	0.32 (0.28; 0.37)	<0.001	0.71 (0.45; 1.15)	0.167
	5-9	66.1 (32,551/49,275)	0.54 (0.48; 0.63)	<0.001	1.27 (0.78; 2.07)	0.330
	10-14	68.1 (36,267/53,231)	0.60 (0.52; 0.69)	<0.001	1.26 (0.78; 2.06)	0.343
<b>ART Regimen</b>	1st Line –NVP	63.7 (19,889/31,246)	Ref		Ref	
	1st line –EFV	75.0 (18,109/24,132)	1.72 (1.65; 1.78)	<0.001	1.70 (1.63; 1.77)	<0.001
	1st Line-AZT	60.0 (3/5)	0.86 (0.14; 5.12)	0.865		
	1st Line-DTG	100 (20/20)				
	2nd line – LPV/r	75.4 (5,636/7,471)	1.75 (1.66; 1.86)	<0.001	1.85 (1.74; 1.97)	<0.001
	2nd line - ATV/r	74.3 (1,453/1,956)	1.65 (1.49; 1.83)	<0.001	1.67 (1.49; 1.86)	<0.001

13 Smith C., et al. Assessing adherence to antiretroviral therapy in a rural paediatric cohort in KwaZulu-Natal, South Africa. *AIDS Behaviour*. 2016, 20(11):2729-2738.

14 Ssebunya R., et al., Antiretroviral therapy initiation within seven days of enrolment: outcomes and time to detectable viral load among children at an urban HIV clinic in Uganda. *BMC Infectious Diseases*, 2017, Vol.17. S12879-017-2550-2.

Characteristics		Viral load suppressed % (n)	ORcrude (95%CI)	P-value	ORadjusted (95%CI)	P-value
Reason for test	Routine	67.5 (64,084/94,966)	Ref		Ref	
	Post IAC	32.5 (1,668/5,141)	0.24 (0.20; 0.28)	<0.001	0.19 (0.14; 0.26)	<0.001
	Suspected Treatment Failure	32.9 (208/632)	0.23 (0.25; 0.22)	<0.001	0.19 (0.17; 0.20)	<0.001
Duration on ART (years)	0-<1	65.4 (1,886/2,884)	Ref		Ref	
	1-4	64.6 (31,476/48,726)	0.96 (0.90; 1.04)	0.384		
	5-9	69.7 (21,042/30,185)	1.22 (1.12; 1.32)	<0.001	1.43 (1.29; 1.58)	<0.001
	10-14	77.7 (3,737/4,807)	1.85 (1.67; 2.05)	<0.001	2.15 (1.88; 2.44)	<0.001

**Table 6. Viral load suppression among children disaggregated by age, duration on ART, PMTCT exposure etc. (Malawi)**

Characteristic	N	Suppressed % (n)	Non suppressed % (n)	
Overall	275	64.7 (178)	35.3 (97)	
Sex	Female	137	65.7 (90)	34.3 (47)
	Male	138	63.8 (88)	36.2 (50)
Age in Years (2018)	<1	1	0	100 (1)
	1-4	61	52.5 (32)	47.5 (29)
	5-9	101	64.3 (65)	35.6 (36)
	10-14	112	72.3 (81)	27.7 (31)
Age at ART initiation (years)	<1	41	43.9 (18)	56.1 (23)
	1-4	141	63.8 (90)	36.2 (51)
	5-9	68	79.4 (54)	20.6 (14)
	10-14	25	64.0 (16)	36.0 (9)
Duration on ART (years)	<1	1	0	100 (1)
	1-4	135	62.2 (84)	37.8 (51)
	5-9	85	70.6 (60)	29.4 (25)
	10-14	54	63.0 (34)	37.0 (20)
PMTCT Exposure	Yes	37	56.8 (21)	43.2 (16)
	No	55	69.1 (38)	30.9 (17)
	Unknown	183	65.0 (119)	35.0 (64)

Characteristic		N	Suppressed % (n)	Non suppressed % (n)
CD4 count at Baseline	<500 cells/μL	17	70.6 (12)	20.4 (5)
	≥500 cells/μL	11	90.9 (10)	9.1 (1)
	Missing	247	63.2 (156)	36.8 (91)
WHO Clinical Stage at ART Initiation	I & II	82	76.8 (63)	23.2 (19)
	III & IV	149	63.1 (94)	36.9 (55)
	Unknown	44	47.7 (21)	52.3 (23)
Nutritional Status at ART Initiation	Normal	23	87.0 (20)	13.0 (3)
	Moderate Malnutrition	8	50.0 (4)	50.0 (4)
	Severe Malnutrition	35	77.1 (27)	22.9 (8)
	Unknown	209	60.8 (127)	39.2 (82)
Guardian Relationship	Biological Parent	194	61.3 (119)	38.7 (75)
	Non-Biological Parent	46	73.9 (34)	26.1 (12)
	Not stated	35	71.4 (25)	28.6 (10)
Ever had TB	Yes	12	50.0 (6)	50.0 (6)
	No	263	65.4 (172)	34.6 (172)
Ever had ARV Side effects	Yes	5	60.0 (3)	40.0 (2)
	No	270	64.8 (175)	35.2 (95)
Initial ARV Regimen	First Line EFV	7	85.7 (6)	14.3 (1)
	First Line NVP	254	65.8 (167)	34.2 (87)
	Second Line LPV/r	14	35.7 (5)	9 (64.3)

**Table 7. Viral load suppression among children disaggregated by ART regimen and adherence (Malawi)**

Characteristic		N	Suppressed % (n)	Non suppressed % (n)
Initial ARV Regimen Formulation	Tablets	210	68.1 (143)	31.9 (67)
	Pellets	8	50.0 (4)	50.0 (4)
	Not Indicated	57	54.4 (31)	45.6 (26)
Regimen I still current	Yes	93	74.2 (69)	25.8 (24)
	No	182	59.9 (109)	40.1 (73)
Reason for Regimen I change	Programme Changes	23	78.3 (18)	21.7 (5)
	Substitution	60	71.7 (43)	28.3 (17)
	Switching	71	38.0 (27)	62.0 (44)
	Weight or Age Changes	28	75.0 (21)	25.0 (7)
	No Change	93	74.2 (69)	25.8 (24)



Characteristic		N	Suppressed % (n)	Non suppressed % (n)
Adherence to appointments	Optimal (≥95%)	198	64.1 (127)	25.9 (71)
	Poor (<95%)	34	58.8 (20)	41.2 (14)
	Missing	43	72.1 (31)	27.9 (12)
Adherence by missed doses (1st Year of ART)	Optimal (≥95%)	79	62.0 (49)	38.0 (30)
	Poor (<95%)	77	63.6 (49)	36.4 (28)
	Missing	119	67.2 (80)	32.8 (39)
Adherence by missed doses (Latest)	Optimal (≥95%)	88	62.5 (55)	37.5 (33)
	Poor (<95%)	67	64.2 (43)	35.8 (24)
	Missing	120	66.7 (80)	33.3 (40)
First Viral Load Suppression	Yes (<1000 copies/ml)	149	96.0 (143)	4.0 (6)
	No (≥1000 copies/ml)	126	27.8 (35)	72.2 (91)

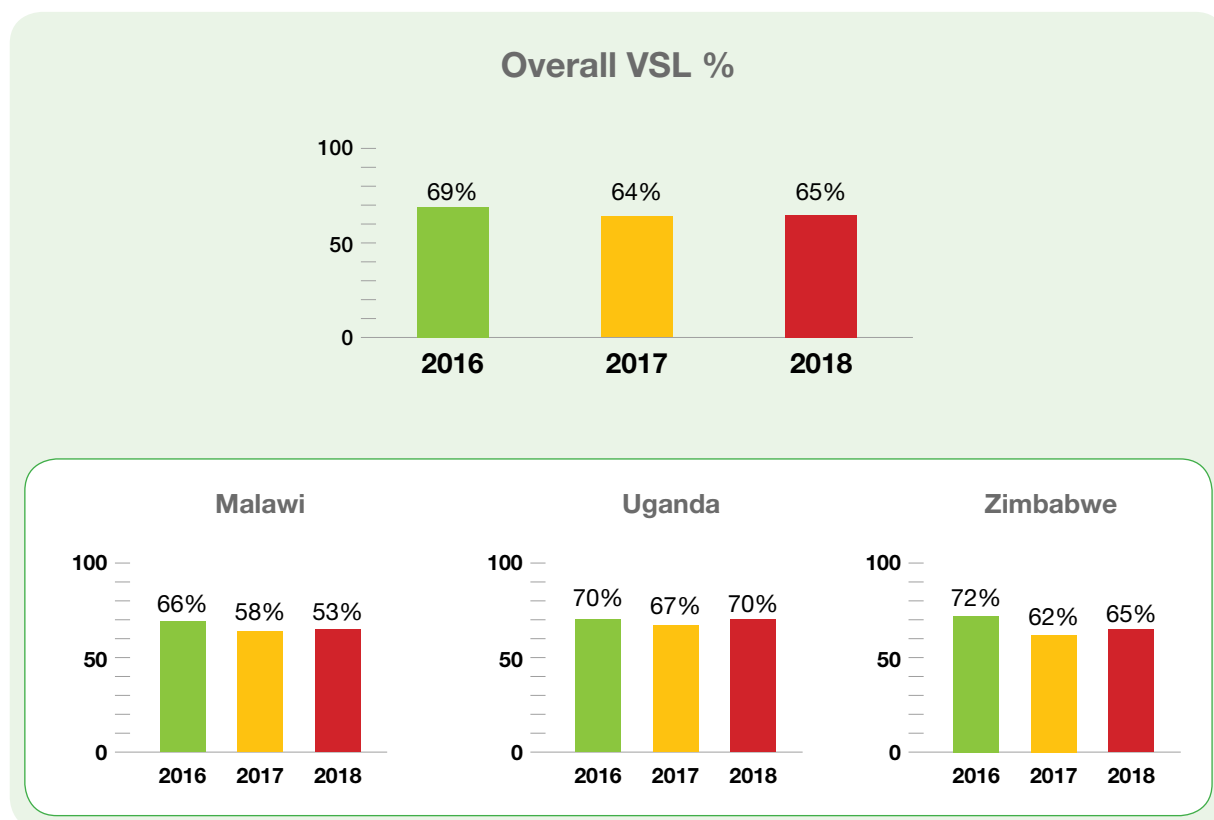
**Table 8. Factors associated with viral load suppression (Malawi)**

Characteristic		Viral load Suppressed % (n)	OR (95% CI)	p-value	OR (95% CI)	p-value
Sex	Female	65.7 (90/197)	Ref			
	Male	63.8 (88/138)	0.92 (0.56; 1.51)	0.738		
Age in Years	<5	52.5 (32/62)	Ref		Ref	
	5-9	64.3 (65/101)	1.70 (0.89; 3.22)	0.109		
	10-14	72.3 (81/112)	2.46 (1.28; 4.66)	0.007	2.80 (0.80; 9.78)	0.105
Age at ART initiation (years)	<1	43.9 (18/41)	Ref		Ref	
	1-4	63.8 (90/141)	2.24 (1.12; 4.57)	0.024	1.82 (0.62; 5.37)	0.276
	5-9	79.4 (54/68)	4.95 (2.10; 11.59)	<0.001	1.44 (0.38; 5.47)	0.588
	10-14	64.0 (16/25)	2.27 (0.82; 6.30)	0.116		
Duration on ART (years)	<5	62.2 (84/136)	Ref			
	5-9	70.6 (60/85)	1.46 (0.84; 2.56)	0.187		

### 3.3.7 Intensive Adherence Counselling (IAC)

The standard of care for patients with unsuppressed viral load is three months of IAC followed by a viral load test. As Figure 2 illustrates, a small but growing proportion of children with unsuppressed viral load had a post-IAC viral load test: 4% in 2016, 15% in 2017 and 17% in 2018. Nonetheless, VLS following IAC remained low across the three countries, at 36% in 2016, 30% in 2017 and 32% in 2018.

**Figure 2. Non-suppressed viral load cascade (Malawi, Uganda, Zimbabwe)**



### 3.3.8 Poverty and food insecurity

Economic factors play a key role in ART adherence and VLS. Competing demand for food, school fees, and transport to health facilities are barriers to children receiving the care they need.<sup>15, 16</sup>

Most of the records reviewed in Malawi did not include nutrition status despite Ministry of Health guidelines. Where data was available, 12.7% (35/275) had severe malnutrition at ART initiation and 77.1% (27/35) of these children achieved VLS. Of the 2.9% of children (8/275) with moderate malnutrition at ART initiation, only half (4/8) achieved VLS. Given the small numbers and without further study it is difficult to ascertain why children with moderate malnutrition did not achieve better rates of VLS. One possible explanation proffered by caregivers in the qualitative interviews was that nutrition services at health facilities target severely malnourished children, while those with moderate malnutrition are not provided with specialized support.

Availability of food also played a major role in promoting adherence. A number of caregivers reported that they could not consistently provide adequate food for their children and that it is challenging to convince children to take ARVs in the absence of food.

15 Busza J., et al., "I don't want financial support but verbal support." How do caregivers manage children's access and retention in HIV care in urban Zimbabwe? *JIAS*, 2014, Vol.17. 18839.

16 Wadunde I., et al., Factors associated with adherence to antiretroviral therapy among HIV infected children in Kabale district, Uganda: a cross-sectional study. *BMC Research Notes*, Vol.11, p.466. S13104-018-3575-3.

### 3.3.9 Psycho-social support

Social support systems at family and community level affect adherence and VLS.<sup>17</sup> Caregivers' knowledge, attitudes and behaviour have a direct impact on adherence.<sup>18</sup> VLS is higher among children whose caregivers receive support from both within and outside the household, and whose caregivers express high hopes for their children's health and future.<sup>19</sup> In addition, children's adherence and VLS benefit from child-friendly counselling, age-appropriate understanding of their HIV status, and supportive home and school environments.<sup>20,21</sup>

The review of records and qualitative interviews in Malawi confirmed that social support systems have a strong bearing on ART adherence and subsequent VLS. Children with a supportive system at household, community and/or health facility level had a higher chance of VLS than those without.

John (*not his real name*) is a 5-year old boy living with HIV. He started taking ARVs when he was around 3 years old. His parents divorced after John had already been diagnosed with HIV and initiated on ART. After the divorce, John lived with his father. There was no one supervising whether John was taking or being given ART twice daily as prescribed and, as a result, he had poor adherence for 2 years. John's health deteriorated and he had an unsuppressed VL. His aunt took him from his father after realizing how he was deteriorating. Once in the care of his aunt, John's ART adherence has improved and is between 95-100% as she does direct observation.

**(Based on caregiver interview, Malawi)**

Cases of immediate or extended family members reminding children on ART to take medication or providing it when the caregiver was away (particularly where the child was still young) were reported among children that were virally suppressed. In cases where there was no support from the immediate or extended family, chances of the children failing to take ART and thus failing to suppress were high. Stigmatization, disclosure of HIV status and being on ART were common concerns in most non-supportive households. Some caregivers reported that their children "... *often missed ARVs whenever they visited relatives who did not know the mother and child HIV status.*" The importance of support systems was also noted for children at boarding schools.

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17 Ferrand R., et al., The effects of community-based support for caregivers on the risk of virological failure in children and adolescents with HIV in Harare, Zimbabwe. *Lancet Child Adolescent Health*, 2017, Vol.1. S2353.

18 Nyogea D. Determinants of antiretroviral adherence among HIV-positive children and teenagers in rural Tanzania: a mixed methods study. *BMC Infectious Diseases*, 2015, Vol.15, p.28.

19 Olds P., et al. Explaining antiretroviral therapy adherence success among HIV-infected children in rural Uganda: A qualitative study. *AIDS Behaviour*, 2015, Vol.19. S10461-014-0924-7.

20 Akahara C., et al. Assessment of antiretroviral therapy adherence among children attending care at a tertiary hospital in southeastern Nigeria. *Hindawi Journal of Tropical Medicine*, 2017. 3605850.

21 Pilgrim N., et al., Challenges to and opportunities for adoption and use of early warning indicators to monitor pediatric HIV drug resistance in Kenya. *BMC Pediatrics*, 2018, 243, Vol.18. S12887-018-5.

Sam (*not his real name*) is a 13-year-old boy with HIV. He lives with his parents in a small town in Malawi. While staying at home, Sam took his ARVs as prescribed. He had the support of his parents and siblings and a suppressed VL. While living at boarding school, Sam did not disclose his HIV status to anyone. Concerned about stigma, he did not take his treatment as regularly as prescribed and did not go to the nearby clinic for ARV refills. By the end of the year Sam was wasted, developed opportunistic infections and admitted to a district hospital. A routine viral load test was undertaken and it was >40,000. IAC was conducted that involved his parents and the head teacher. It was resolved that Sam should take his ARVs at the head teacher's house. After 3 months, Sam had a suppressed VL.

Children's health also improves when they understand their HIV status and are active agents in their own health care.<sup>22</sup> Health workers and caregivers appreciated the contribution of peer support groups to children having better HIV knowledge and improved adherence. As one caregiver noted, *"Clubs provide a forum where young children get to realize they are not alone, they are not any different from others and they can live a happy fruitful life."*

### 3.3.10 Health facilities

The quality, efficiency, and accessibility of health services have a direct impact on adherence, retention and VLS, including factors such as distance to facilities, waiting times and visit frequency.<sup>23,24</sup> Studies have also shown the success of decentralization and task shifting in delivering quality care for children on ART, improving adherence, lowering hospitalization rates, and achieving VLS.<sup>25,26</sup> Similarly, caregivers and health workers in this study noted a number of key health facility-related issues with direct or indirect influence on adherence and the subsequent effect on VLS.

ART service provision schedules proved challenging for working caregivers or those travelling long distances. Congested health facilities resulted in some caregivers leaving the health facility without completing appointments or collecting medicines.

Health workers and caregivers also noted staff shortages as a problem. One caregiver summed up that *"... services are often rushed as health workers try to clear queues as quickly as they can before a day ends."* Adherence counselling, for example, is often provided in a group rather than on an individual basis and, as a result, client-specific issues may not be addressed. One-on-one adherence counselling was reportedly undertaken only for serious and unique cases that could not be handled in groups.

Most health facilities did not have a child friendly infrastructure and many lacked the space for confidential appointments. One caregiver noted, *"My child does not like coming to the hospital."*

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22 Beima-Sofie K., et al. Pediatric HIV disclosure intervention improves knowledge and clinical outcomes in HIV-infected children in Namibia. JAIDS, 2017, 1, Vol.75.

23 Vreeman R., et al. Adherence to antiretroviral therapy in a clinical cohort of HIV-infected children in East Africa. PLoS ONE, 2018, Vol.13. 0191848.

24 Busza J. et al.

25 McHugh G., et al. Clinical outcomes in children and adolescents initiating antiretroviral therapy in decentralized healthcare settings in Zimbabwe. JIAS, 2017, Vol.20. IAS.20.1.21843.

26 Kim M., et al. Multimonth prescription of antiretroviral therapy among children and adolescents: Experience from the Baylor International Pediatric AIDS Initiative in 6 African countries. JAIDS, 2018, Supp 2, Vol.78. 1730.



*There is no place for her to play freely. I have even seen mothers going back home before getting medication after their children started crying.”*

Health worker’s skills were cited as another concern. One paediatric ART manager reported cases of children being prescribed the wrong dosage, particularly as their age and weight change. In one case a 4-year old had a persistently high viral load, despite optimal adherence. Further examinations showed that the child had been underdosed for his age, leading to the failure to suppress. His dose was adjusted accordingly.

**...shortages, under-dosing, quality, efficiency, and accessibility of health services have a direct impact on adherence, retention and VLS.**





# 4.0 Conclusion

Findings from this study highlight that, during 2016-2018, one out of 3 children who had a viral load test were not virally suppressed in Malawi, Uganda and Zimbabwe. A number of factors contributed to whether children achieved viral suppression.

## **Children are more likely to achieve VLS when they and their caregivers have support from families, communities and health workers**

Supportive networks for caregivers and children positively influenced paediatric VLS. Concerns over stigma were likely to restrain disclosing that a child is on ART, a situation that often impacted adherence and, subsequently, VLS.

Although some caregivers opt not to disclose children's HIV status for fear of stigma, disclosure facilitates adherence which leads to children's improved health status. Disclosure of HIV status also has the potential to open up social support systems for the child and caregiver and address some of the barriers to adherence and VLS. Indeed, health workers and support networks were important in building caregivers' confidence to share information about the child's HIV status and request support.

Overall, children aged 1-4 years were disproportionately affected by poor VLS than older children, suggesting this age group requires specific attention. Being on ART for a longer period of time, especially for 10 or more years, was associated with VLS. As children became more treatment experienced, were disclosed to and disclosed their HIV status to others, they were more like to understand the importance of adherence which, in turn, contributed to VLS.

## **Drug regimens and formulation continue to challenge paediatric VLS**

Several drug-related issues were associated with unsuppressed viral load. Some issues were related to the drug itself, as children on first-line EFV had higher VLS than those on first-line NVP. Other issues included high pill burdens, frequent daily intake of drugs, and complexities in administering LPV/r pellets and their bitter taste.

## **The quality, efficiency, and accessibility of health services has a direct impact on adherence and VLS**

Viral load testing at the time of ART initiation provided critical information for predicting VLS and the subsequent clinical management of children with HIV. Importantly, children with high viral loads were not receiving post-IAC, a key component of managing VLS. When children did receive post-IAC, VLS did not always follow, suggesting that further attention should have been given to the quality of counselling and to suspected treatment failure due to drug resistance.

Clinic schedules, staff shortages, waiting times, inadequate space for confidential counselling, and unfriendly attitudes by service providers contributed to whether children received timely, comprehensive and supportive care.



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### **Multi-sectoral challenges affect treatment success**

Malnutrition was associated with morbidity and unsuppressed VL. However, nutrition screening was not routinely performed, despite national guidelines. Availability of food was linked to ART adherence and willingness by children to take ARVs, resulting in VLS. Other poverty-related factors, such as the ability to pay for transport to health facilities, also influenced adherence to clinic appointments.

### **Data management systems play a critical role in clinical care and understanding challenges to VLS**

Lack of documentation, storage and utilization of data in both the LIMS and patient records was common in all three countries. For example, in Malawi records were missing data for key variables at ART initiation, such as CD4 count, mid and upper-arm circumference, body mass index, and exposure to ARVs for prevention of mother-to-child transmission of HIV. Follow up indicated that data was missing either because recording was not done, data entry was incomplete/had errors, or data was lost during migration from one system to another (such as the migration from a paper-based system to electronic medical records system in Malawi).

# 5.0 Recommendations

Children living with HIV face life-long treatment. Viral load suppression is critical to sustaining quality of life, preventing treatment failure, achieving optimal ART outcomes, and preventing the transmission of multi-drug resistant virus later in life. The following recommendations aim to inform policy, programmes and research to improve VLS and health outcomes for children with HIV:

## **Provide essential multi-year support to caregivers and children**

Paediatric ART success heavily depends on caregivers who, in turn, require emotional and material support. From the time of ART initiation until the child becomes an adult, caregivers need psychosocial support services, with linkages to health facilities, that focus on eliminating stigma, identifying support networks, and mobilizing community resources. Similarly, learning from the success of peer support groups, children should have access to age-appropriate psychosocial support, linked to both health facilities and the community environment, including residential schools. Existing support platforms, such as those for PMTCT, should be extended to include multi-year support for the mother and child(ren).

## **Promote paediatric viral load testing and child-friendly drug regimens**

Clear guidelines exist for routine and targeted viral load testing for children with HIV.<sup>27</sup> Although this study did not look at the prevalence of paediatric viral load testing, the low rate of paediatric VLS indicates the need to scale-up viral load monitoring. In addition, given the low rates of VLS among children on first line NVP, there is also an urgent need to transition children to more efficacious Lopinavir and ritonavir (LPV-r)-based regimens.

## **Strengthen paediatric HIV service delivery accessibility, coverage and quality**

Health workers play an important role in supporting caregivers and children on ART. Health workers need to assist caregivers in managing the disclosure process to the child, understanding the complexities of administering paediatric formulations, and managing care and treatment over many years, including on-going support for treatment adherence.

Given shortages of health workers, expanding the role of different cadres is warranted. Trained community health workers who understand the child's environment can provide on-going support to caregivers and children, especially on disclosure of HIV status and adherence. This might include separate age-appropriate counselling sessions for children, without the presence of a caregiver, to allow them to freely express their concerns.

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27 <https://clinicalinfo.hiv.gov/en/guidelines/pediatric-arv/clinical-and-laboratory-monitoring-pediatric-hiv-infection>

Decentralization to primary health care centres, alongside investments in strengthening health worker capacity in managing paediatric ART, is essential to reaching children who are not achieving treatment success. Also, reduced waiting times, expanded clinic hours and multiple month prescriptions may help adherence to ART appointments and improve VLS. Home visits and community-based refills of ARVs for stable children on ART, especially children with elderly guardians, may address some of the challenges faced by caregivers in assuring regular clinical assessments and drug refills.

### **Improve case management with multi-sectoral linkages and referrals**

Nutrition, food security and HIV must be addressed to improve health outcomes for children, including VLS. Health records suggest that there is little support to nutrition programming except when dealing with cases of severe malnutrition. Protocols on nutrition screening and support for children on ART must be followed and linkages made to social protection programmes for food insecure households. Similarly, screening for other co-morbidities, such as TB, must be conducted to ensure children are receiving optimal treatment.

### **Strengthen paediatric HIV data collection, analysis and use**

Serious shortcomings in documentation, data entry, storage and utilization of data call for country-specific investment of resources in data systems. For example, countries need to strengthen and build capacity in data entry. Reviewed data and records did not have complete data, such as viral load results, CD4 count, nutritional status, adherence, guardian relationship, ARV formulation, etc., and yet this information is important for health workers and programme managers to make informed clinical and programmatic decisions.

Linkages/interfaces between different data sources will facilitate the prompt use of viral load testing for patient management. In Malawi, for example, viral load data is collected and stored within the LIMS system but there is no linkage to the electronic medical records. Furthermore, electronic medical record systems should be upgraded to prompt health workers to collect data with restrictions on proceeding or exiting the system unless all essential data is collected.

### **Include paediatric VLS in evidence generation and use**

Although evidence is growing on paediatric HIV, there are still notable gaps in knowledge about adherence, VLS and associated health outcomes. Country-specific studies will assist policy makers, service providers and programme implementors in ensuring that children receive the support and services they need for their health and wellbeing. Proposed research includes implementation research on what works to increase VLS at scale; family-centered approaches to care and treatment, including the relationship between caregiver's and children's adherence; scaling up support to caregivers; tailoring support for children in different age groups; and exploring the potential impact of social protection initiatives.



**Children with a supportive system at household, community and/or health facility level had a higher chance of VLS than those without.**



