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Retention in care of HIV-exposed infants and associated infant and maternal factors in Teso Sub Region, Eastern Uganda

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Abstract

Introduction Globally, about 2.1 million children less than 15 years old get infected, and 110,000 die due to HIV/AIDS-related causes. Approximately 50% of HIV-exposed infants (HEI) are retained in Early Infants Diagnosis (EID) services for follow-up testing within the recommended timeframe of 18 months after birth. However, the retention of exposed infants who depend on the adults along their 18-month care cascade remains unknown. This study aimed to assess the retention in care of HEIs at the critical monitoring points of their care cascade and to establish factors associated with infant and maternal factors in order to improve the retention rates.

Methods A retrospective cohort study utilizing quantitative methods of data collection was employed. The study examined 366 records of HIV-exposed infants born in 2021 in the Teso Sub-region. Retention rate was determined for 1st, 2nd, and 3rd PCR and rapid tests at 1.5, 9, 13.5, and 18 months, respectively. The Kaplan-Meier curve was used to estimate the retention rates at different time points of follow-up. The Cox proportional regression model was used to establish the factors associated with retention of HIV exposed infants in care.

Results The study included 366 HIV-exposed infants (HEIs). The rate of retention was highest at 1.5 months (91.3%) but declined to (89.5%) at 9 months and 13 months (82%) before stabilizing back at 85.8% by 18 months. At multivariate analysis, factors that were significantly associated with retention in care of HIV-exposed infants included district of residence, with retention being higher in Kumi (aHR:1.50 :95%CI: 1.09–2.06) and Serere district compared to Bukedea district (aHR:1.54 :95%CI: 1.14–2.09). Timely EID registration (aHR:0.33 :95%CI: 0.12–0.71) and Timely initiation of Nevirapine prophylaxis (aHR:0.86:95%CI: 0.59–0.97) significantly reduced retention in care of HEIs.

Conclusion Retention in care showed an early peak, followed by a gradual decline during mid-follow-up, and later stabilized toward the end of the observation period. The retention in care of HIV-exposed infants was significantly higher among infants residing in Kumi and Serere districts compared to Bukedea. Timely EID registration and timely initiation of Nevirapine prophylaxis significantly reduced retention in care. These findings underscore the importance

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of strengthening early infant diagnosis while addressing contextual barriers to enhance continuity of care with targeted support to lower-performing districts like Bukedea.

Keywords Retention in care, HIV-Exposed infants, Loss to follow-up

Introduction

Globally, 50% of HIV-exposed infants (HEI) are retained in Early Infants Diagnosis (EID) services within the recommended time frame [1, 2]. Approximately 2.1 million children less than 15 years old get infected, and 110,000 die due to HIV/AIDS-related causes [3]. Factors such as long distances to health facilities, young maternal age, delay in registration of infants into care, poor or no partner support, and low socioeconomic status contribute to the poor retention rates of HIV-exposed infants in EID services [4]. Studies have continued to reveal that maintaining HIV Positive women and their exposed infants in care can reduce the 15 to 45% risk of HIV transmission during pregnancy, childbirth, and breastfeeding [5, 6].

Sub-Saharan Africa bears over 90% of the burden of mother-to-child transmission of HIV, with a 48% reduction of new HIV infections in 2019, but this is still unacceptably high and is mainly contributed to by infants who get lost or miss care appointments [7]. Studies in Africa have revealed that, without HIV treatment, almost half of vertically infected children will die by their second birthday [8–11]. Therefore, they need to be monitored closely in a health care system for the first 18 months of their lives [12]. Another study in Africa added that 34% of HIV-exposed infants are lost to follow-up within the first three months, and an additional 45% are lost after their initial HIV test, before undergoing the definitive test at 18 months [13], therefore a key component of PMTCT programs, needs to be designed to identify HIV-infected newborns before clinical disease manifests, thereby enhancing their care and follow-up [14]. This means that all the HIV-Exposed Infants (HEI) need comprehensive follow-up to prevent them from acquiring HIV with the aim of reducing HIV related infant morbidity/ mortality [15, 16].

In Uganda, vertical transmission of HIV contributes to up to 18% of all new infections and 90% of infections among children. Uganda has generally not made rapid progress to meet the 2030 targets outlined in the Global Alliance Target to End AIDS in Children [1]. This is largely due to suboptimal retention of HIV HIV-exposed infants (HEIs) in care, leading to increased new pediatric infections [5, 17]. A study in Arua found that 30.5% and 37.3% of exposed infants dropped out of care by the time they reached 18 months [5]. Another study in Uganda found retention at 18 months to be 69.5%; non-retention was higher among infants whose mothers had given birth at home, were young, and those who were virally non-suppressed [18]. Whereas the Ministry of Health (MOH)

has noted a decrease in MTCT rates to 5.8% over the last five years, it remains above the national target of less than 5%. (eMTCT) and retention of infants along the care cascade is critical to achieving this target [19].

In Teso Sub Region, the retention of Adult HIV patients in care was at 78% in 2022, far below the 95% set target [1], however, the retention of exposed infants who depend on the adults along their 18-month care cascade remains unknown. The MOH recommends that HIV-exposed infants receive care at the mother-baby care point alongside their mothers until they reach 18 months of age [20]. Many infants who start care do not complete the 18-month cascade, and this lapse in continuity of care compromises their health outcomes, making them vulnerable to seroconversion, opportunistic infections, delayed developmental milestones, and increased mortality. Therefore, the present study is intended to determine retention rates of HEIs at the critical monitoring points of their care cascade and to establish its associated infant and maternal factors in order to improve retention in care of HEIs.

Methodology

Study setting

The study was conducted in three districts, i.e., Kumi, Bukedea, and Serere district in Teso Sub Region, Eastern Uganda. Kumi, Serere, and Bukedea are districts located in the Teso Sub-region of Eastern Uganda. All three districts are remotely located, hard-to-reach, with the majority of the population still living below poverty levels [21]. Data was collected from 17 health facilities, with 3 facilities from Bukedea, 7 from Kumi, and 7 from Serere. The area is characterized by relatively low HIV prevalence compared to other parts of Uganda, but retention of HIV-exposed infants in care remains unknown. Kumi, Bukedea, and Serere face challenges in healthcare delivery, partly due to their geographic features, such as surrounding water bodies, making accessibility to HIV care and treatment increasingly hard.

Study population

The study population comprised of HIV Exposed infants (0–18 months) and their mothers who registered in the 2021 birth cohort and received at least one clinical review at the Mother Baby Care Point.

Study design

The study adopted a retrospective cohort design employing quantitative methods of data collection. The study

design measured both the cause and effect [22]. It was considered suitable because the study was focusing on a cohort of HIV-exposed infants born in 2021 who were supposed to receive an 18-month package of care. This design allowed us to retrospectively track the points at which these HIV-exposed infants were dropping out of care and to determine the associated infant and maternal factors. The outcome variable for this study was retention in EID care services, measured over time from birth up to 18 months.

Sample size estimation

According to Hao Liu et al. [23], the total sample size required in a cohort design to achieve 80% power at a significance level of 0.05 would be at least 240 assuming log hazard ratio $\theta = 0$ and null hazard rate $\lambda_0 = 0.6$, while keeping all other design parameters constant, and assuming that all participants are recruited at time 0 and fixed follow-up time τ . Then the total sample size has the following explicit formulae;

$$= \left\{ \frac{z_{\alpha/2} + z_{\beta}}{\theta} \right\}^2 \left\{ \frac{1}{\gamma(2 - e^{-\lambda_0\tau})(1 - e^{-\lambda_0\tau})} + \frac{1}{(1 - \gamma)(2 - e^{-\lambda_1\tau})(1 - e^{-\lambda_1\tau})} \right\}$$

Based on Hao Liu's assumption [23], a sample size of 366 of HEIs was considered for review in the 2021 birth cohort.

The total study population consisted of 1,212 HIV-exposed infants (HEIs) identified from EID health chart records across three districts in the Teso sub-region: Bukedea, Kumi, and Serere. Of these, 287 HEIs were from Bukedea, 416 from Kumi, and 509 from Serere.

The total calculated sample size was 366 participants. To ensure equal representation from each district, we applied probability proportional to size (PPS) sampling, thus we calculated 87 participants from Bukedea, 126 from Kumi and 153 from Serere to participant in the final study.

Sampling procedure

The study employed a multi-stage sampling approach. In the first stage, simple random sampling was used to select three districts Bukedea, Kumi, and Serere from the eight districts in the Teso sub-region. These districts formed the primary sampling units.

In the second stage, cluster sampling was used to select government health facilities that provide HIV-exposed infant (HEI) care services within each selected district. A total of three facilities in Bukedea, seven in Kumi, and seven in Serere were selected based on their provision of EID services.

The researcher then reviewed EID health chart records from these selected facilities to identify all eligible HEIs.

Eligibility criteria included the availability of complete demographic information and caregiver contact details to allow for proper follow-up and record verification. Through this process, a total of 1,212 HIV-exposed infants (HEIs) were identified across the three districts: 287 from Bukedea, 416 from Kumi, and 509 from Serere.

In the third stage, probability proportional to size (PPS) sampling was applied to determine the number of participants to be selected from each district. Using the total calculated sample size of 366 participants, PPS yielded 87 participants from Bukedea, 126 from Kumi, and 153 from Serere. This ensured that each district contributed participants proportionate to its HEI population, thereby improving representativeness and minimizing sampling bias.

In the final stage, systematic random sampling was used to select the actual study participants from each district's HEI list. A skip interval of three (3) was calculated by dividing the total number of HEIs in each district by the number of participants required from that district. Every third HEI record was systematically selected until the required sample for each district was achieved.

Data collection methods and tools

Data was collected using a structured quantitative data abstraction tool that was uploaded onto the Kobo Toolbox electronic data collection platform. Infant information was extracted from the HIV-exposed infant registers and exposed infant follow-up cards, while maternal data was obtained from HIV care cards and the Uganda Electronic Medical Records (EMR) system, where these records are maintained.

Data collectors used mobile phones to enter information directly into Kobo Toolbox in real time. The submitted data were synchronized to the secure Kobo server and subsequently downloaded into Microsoft Excel for daily review and quality checks. The use of Kobo Toolbox was preferred because it ensures real-time data capture, enhances data integrity, minimizes transcription errors, and is more cost-effective than traditional paper-based abstraction followed by manual data entry.

Kobo Toolbox is an open-source platform specifically designed for mobile and offline data collection in resource-constrained settings. All study variables and questions were programmed into the system, enabling seamless and accurate data entry directly into an electronic database.

Study variables

Dependent variable

The dependent variable was the retention in care of HIV-exposed infants (HEIs). Retention in EID care cascade was measured as duration in months from registration until the point of last clinic attendance, death,

or censoring. This was a continuous variable (time-to-event data). Event Occurred: 1 (retained in care until the study end or a significant time point e.g. 1.5, 9, 13.5, or 18 months), these points were selected because they were critical monitoring points for HIV-exposed infants, and clinic attendance was a must because blood samples must be drawn from the infants to diagnose HIV. First PCR at 4–6 weeks or 1.5 months, 2nd PCR at 9 months, 3rd PCR at 6 weeks after cessation of breastfeeding, and last test at 18 months. Censored: 0 (e.g., lost to follow-up, turned positive, or study ended without an event, or death).

Independent variable

The independent variables of the study were as follows: Maternal and infant factors. The maternal factors included; maternal age at enrolment into EID care. This is a numerical variable; it was captured in absolute years but later categorized as below 20 years, 20–24 years, and greater than 25 years. Baseline, and viral load at the time of the event was measured in copies/ml (VL < 400 ml and > 400 copies/ml was non-suppressed), ART use during ANC which is a categorical variable will be measured as Yes/ No for use or nonuse, ANC use during recent pregnancy (never used, or ever used), Marital status was categorized as married, single or divorced, residence was categorized as urban or rural. Infant variables include; Age which is a numerical variable measured in months, (1.5 months, 9 months, 13.5 months, and 18 months), body weight which is a numerical variable was measured in Kgs, it was then categorized as below or above 5 kg, current feeding practice (Exclusive breastfeeding, complimentary feeding or replacement feeding), mode of delivery (spontaneous vaginal delivery, or cesarean section), place of delivery (health facility or home), and time of NVP (Nevirapine) prophylaxis initiation (At birth, At 6 weeks or after 6-weeks).

Quality control measures

Pre-testing was done with 37 exposed infants and their corresponding mothers' records, which constituted 10% of the sample size. Kumi HCIV was chosen because this facility presents similar characteristics both in the population characteristics and services. This helped in identifying areas for modification and corrections before the actual data collection. Pretesting familiarized the research assistants with the data abstraction tool.

Training of research assistants was done for three days. This training covered the review of the content of the data abstraction tool, but also the utilization of the electronic kobo toolbox. Two research assistants were recruited and trained on how to conduct the data abstraction.

Data editing and corrections; data editing was done at the point of data entry into the kobo toolbox, the excel sheet was downloaded daily for editing and final editing

of the excel sheet was done after final data collection. The purpose was to ensure all required fields were accurately completely filled as requested.

Data management and analysis

Quantitative data analysis

The Excel sheet was downloaded from the Kobo toolbox, data was checked for consistency, repetitions, and completeness. Incomplete data was imputed and repeated data were left out. The cleaned data was imported into stata Version 16 software for analysis and measurements of retention in care. Censoring was done during the initial stages of data preparation and subsequent follow up visits. Participants were censored if they had not experienced the event of interest by the end of the study period, were lost to follow-up, transferred out, or had incomplete follow-up information. These censoring statuses were recorded systematically to ensure accurate estimation of retention outcomes.

Data was then factored into all subsequent analyses, including descriptive statistics, univariate and bivariate, and multivariate modeling. Proper handling of censoring ensured accurate estimation of survival probabilities, hazard ratios, and other metrics essential for understanding the retention and survival of HIV-exposed infants.

An event Indicator was created by forming a binary variable indicating retention as (1) or loss to follow-up/death/positivity as (0), and the Time Variable was defined as the time until the event or censoring. Exploratory Data Analysis was done to understand the distribution of data and preliminary insights. Summary statistics were computed for maternal and infant factors; missing values or outliers were identified. Overall retention was then visualized using a Kaplan-Meier curve and a histogram.

Univariate Analysis frequencies and percentages were obtained to describe socio-demographic and other categorical variables. Overall retention was computed, and the retention at the different points of monitoring (1.5 months, 9 months, 13.5 months, and 18 months) across districts and in health facilities was also computed. The mean and standard deviations were computed for numerical variables, and the causes of attrition were also analyzed in percentages and presented in a figure.

Bivariate Analysis cross-tabulation with the outcome variable was done to establish possible associations between the retention of exposed infants in care and the maternal and infant factors using Cox proportional regression model. P-values were computed, and the independent variables with $p\text{-value} \leq 0.2$ at the bivariate analysis, and those that were not statistically significant but with strong evidence from literature to influence retention were entered into a multivariable Cox proportional regression model to adjust for confounding. Statistical

significance of variables in the final model was assessed based on a p-value threshold of ≤ 0.05 .

Multivariate Analysis was conducted using the Cox proportional Regression model for all predictor variables with $p\text{-value} \leq 0.2$ at the bivariate analysis, considering a 95% Confidence interval. At this level, all known and unknown confounders were controlled.

Results

Characteristics of participants

Of the 366 participants, 126 (34.4%) received care from the district of Kumi, 153 (41.8%) from Serere district, and 87 (23.8%) from Bukedea district. Of all the participants, more than half, 197 (53.8%) received their care from a health facility of level III, while only 41 (11.2%)

received it from a hospital. Nearly half 190 (51.9%) of the participants studied were male, and the majority ($n = 326$ or 89.1%) of the mothers had delivered in a health facility, and 325 (88.8%) had a spontaneous vaginal delivery. The overall mean age of the mothers was 29.1 years (standard deviation or SD 6.6), with most of them ($n = 191$ or 52.2%) aged between 25 and 34 years. 261 (71.3%) participants were married, 305 (83.3%) lived in rural areas, 318 (86.9%) were peasants, and only 26 (7.1%) had unsuppressed viral load (VL) at infant registration (Table 1).

The trend in adherence to EID clinic appointments over time

Figure 1 shows the trend in adherence to EID clinic appointments over time. The highest EID clinic attendance was at 1.5 months (91.3%), and the lowest was at month 13 (82%). EID attendance dropped between months 9 (89.1%) to 85% at month 18.

Retention of HIV-exposed infants (HEIs) in care

Of the 366 participants, 314 (85%) were retained in care at month 18, and the total time at risk of Loss, death or seroconversion was 175.94 days (Fig. 1). The incidence rate of retention in care was 1.78 per 1000 person-years (95% CI 1.59–1.99), and the median time to retention was 54.7 days (95% CI 5.46–5.47) (Fig. 2).

Final outcome of infants at the end of 18 months

Of the 366 HEIs at month 18, 314 (85.8%) had a negative HIV test result, 25 (6.8%) had died, 21 (5.7%) were lost, and 6 (1.6%) tested positive for HIV (Fig. 3).

Kaplan-Meier curve showing differences in retention with timely EID registration

Figure 4 shows the probability of retention by timely EID registration. The figure shows that infants who were timely registered in EID experienced less retention compared to those who were registered late. This impression was confirmed using a formal hypothesis employing the log-rank test, and the difference was statistically significant. ($p < 0.001$).

Bivariate and multivariate analysis of the factors associated with retention in care of HIV-exposed infants

At bivariate analysis, factors that were significantly associated with retention of HIV-exposed infants included: District, Age at registration, Timely EID registration, Timely initiation of Nevirapine prophylaxis, Mothers' duration on ART, and Weight at registration (kgs). At Multivariate analysis, after controlling for other factors, variables that were significantly associated with retention of HIV-exposed infants included: District of residence, Timely EID registration, and Timely initiation of Nevirapine prophylaxis. The retention of HIV-exposed infants

Table 1: Characteristics of study participants

Variables	Frequency (n = 366)	Percentage %
District		
Bukedea	87	23.8
Kumi	126	34.4
Serere	153	41.8
Level of health facility		
Hospital	41	11.2
HCIV	128	35.0
HCIII	197	53.8
Sex of infant		
Male	190	51.9
Female	176	48.1
Place of delivery		
Home	40	10.9
Health facility	326	89.1
Mode of delivery		
Spontaneous vaginal delivery	325	88.8
Cesarean section	41	11.2
Mother's age (years)		
15 to 24	98	26.8
25 to 34	191	52.2
35 and over	77	21.0
Mean (SD) = 29.1 (6.6)		
Marital status		
Single	85	23.2
Married	261	71.3
Divorced/separated	20	5.5
Residence		
Urban	61	16.7
Rural	305	83.3
Employment status		
Employed	16	4.4
Unemployed	32	8.7
Peasant	318	86.9
Mothers VL at infant registration		
Suppressed	312	85.2
Unsuppressed	26	7.1
Not due for VL testing	28	7.7

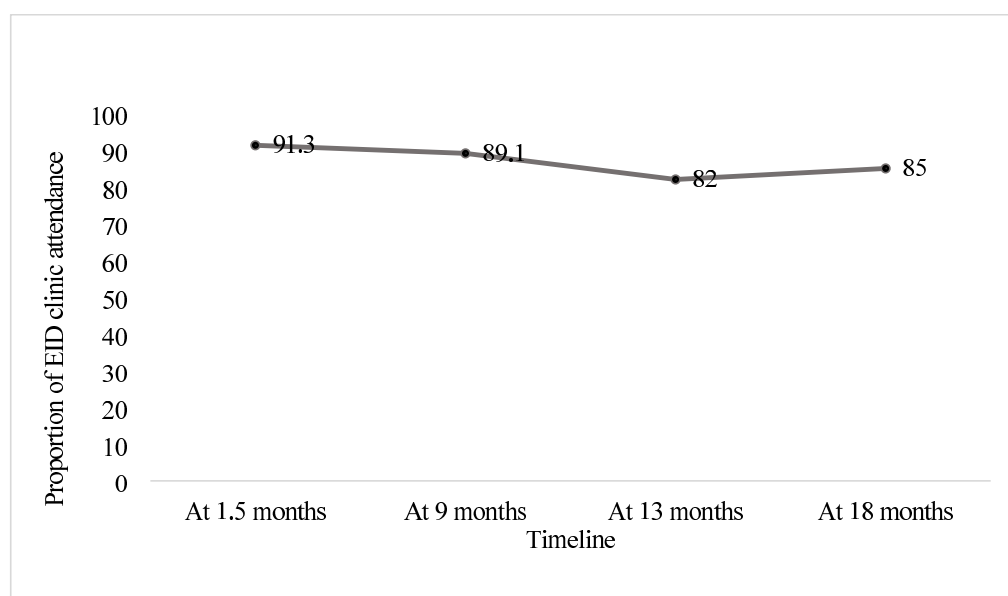


Fig. 1 The trend in adherence to EID clinic appointments over time

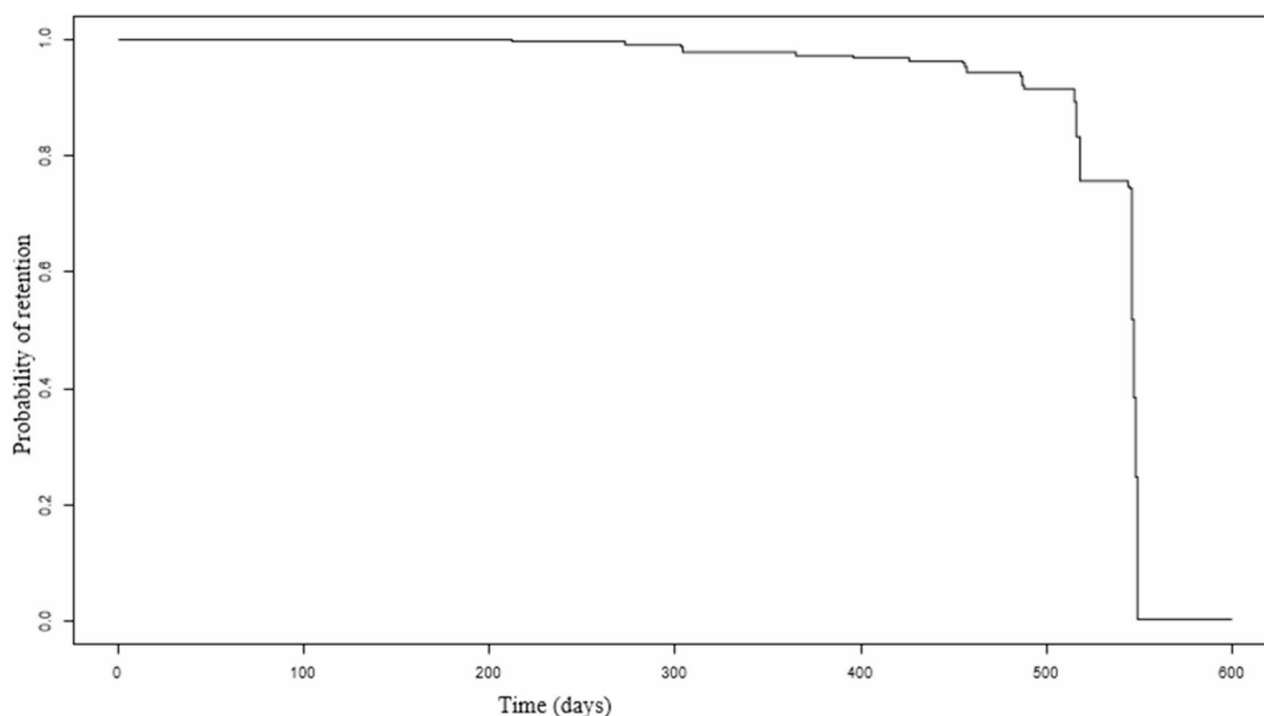


Fig. 2 Kaplan Meier Analysis of HIV-exposed infants (HEIs) along the cascade

was higher in Kumi district compared to Bukedea district (aHR:1.50 :95%CI: 1.09–2.06). In addition, the retention of HIV-exposed infants was higher in Serere district compared to infants in Bukedea district (aHR:1.54 :95%CI: 1.14–2.09). The retention in care was lower among infants who were diagnosed with HIV early compared to those diagnosed late (aHR:0.33 :95%CI: 0.12–0.71). Retention in care was also lower among HIV-exposed

infants who initiated Nevirapine prophylaxis early compared to those who initiated it late (aHR:0.86:95%CI: 0.59–0.97) (Table 2).

Discussion

The study observed a U-shaped trend in retention at the EID clinic. Retention was initially high, gradually declined during the mid-follow-up period, and later

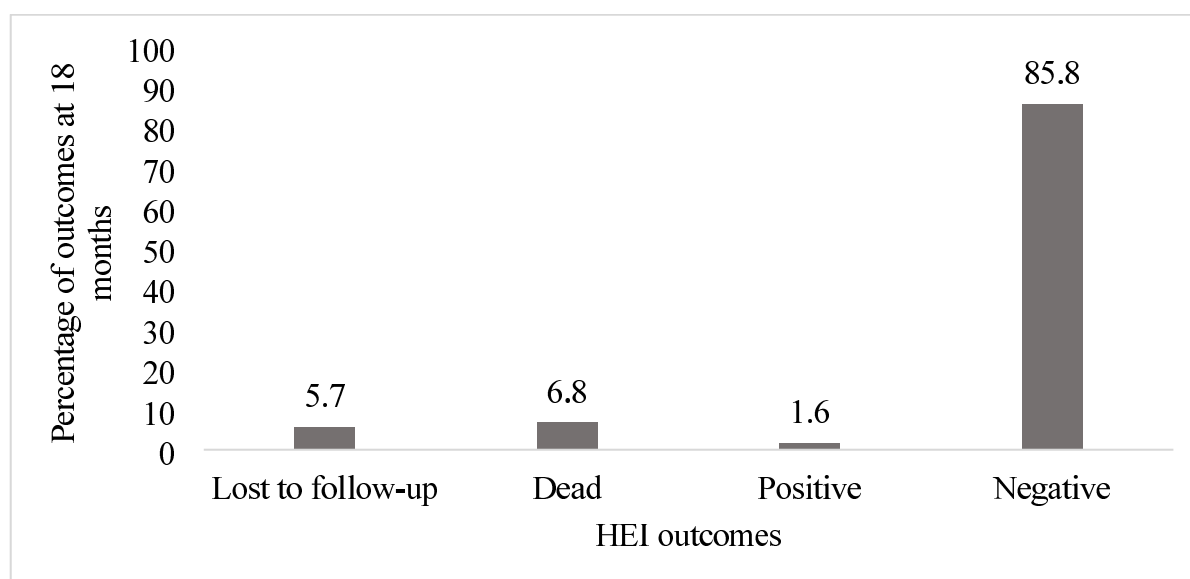


Fig. 3 Outcomes of infants in the 2021 birth cohort at 18 months

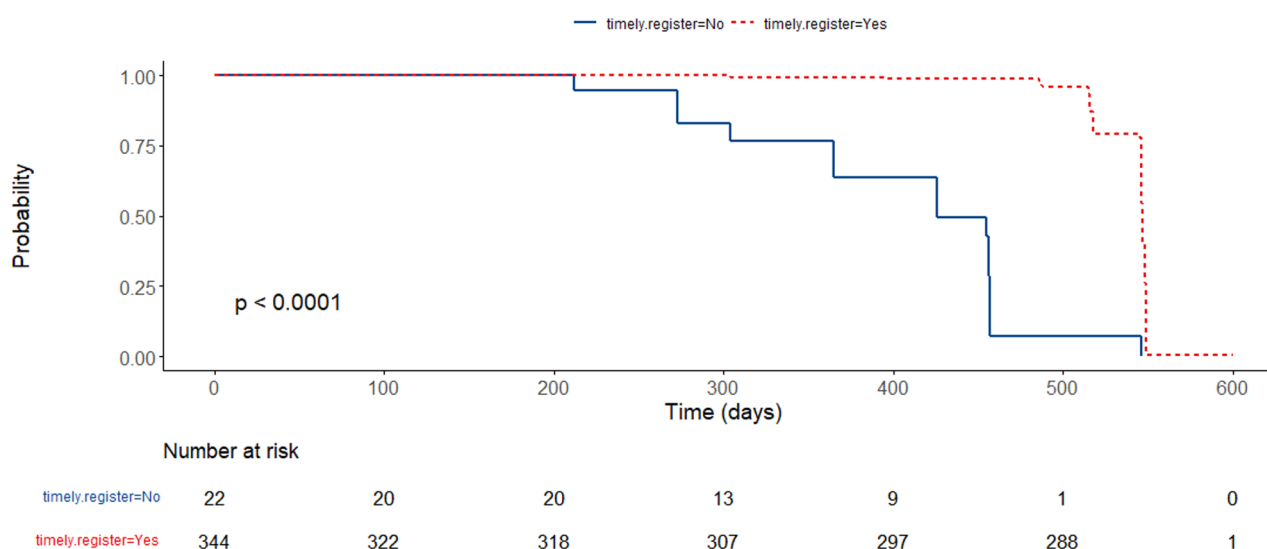


Fig. 4 Kaplan-Meier Curve showing differences in retention with timely EID registration

stabilized toward the end of care. The high attendance at 1.5 months may indicate strong initial engagement with healthcare services. This could be attributed to early counselling, the perceived importance of initial visits, and the close monitoring of newborns during the early stages. The steady decline in retention from 9 to 18 months might reflect several factors, including decreased perceived risk as infants grow older, challenges in accessing healthcare services, or caregiver fatigue over time. It could also suggest gaps in follow-up support or a reduction in the emphasis on the importance of continued attendance as infants get older.

When compared with a similar study done in Zimbabwe, which reported retention rates of 91% at 6 months,

59% at 12 months, and 52% at 18 months [24], our study shows a less steep decline. This suggests that while both settings experience significant drop-offs, the present study maintains relatively higher retention over time. A similar study found loss to follow-up rates as high as 48% by 18 months in Uganda, which is more pronounced in the present study [25]. This difference could be due to regional variations in healthcare delivery, the strength of community support systems, or other socio-economic factors. The declining trend observed in our study aligns with broader trends in Uganda and many African countries, as reported by [5], where retention rates dropped from 79.4% at 3–6 months to 69.3% at 12–18 months. Our findings are slightly higher, indicating better

Table 2 Bivariate and multivariate analysis of the factors associated with retention in care of HIV-exposed infants

Variables	Levels	Unadjusted HR (95% CI)	P value	Adjusted (95% CI)	P value
District	Bukedea	1		1	
	Kumi	1.30 (0.96–1.74)	0.001	1.50 (1.09–2.06)	0.012
	Serere	1.31 (0.98–1.73)	0.001	1.54 (1.14–2.09)	0.034
Age at registration (months)	Mean (SD)	1.77 (1.62–1.94)	0.021		
Timely EID registration	No	1		1	
	Yes	0.55 (0.31–0.82)	0.001	0.33 (0.12–0.71)	< 0.001
Weight at registration (kgs)	Mean (SD)	1.07 (1.96–1.18)	0.049		
Place of delivery	Home	1			
	Health facility	1.08 (0.69–1.70)	0.984		
Mode of delivery	Spontaneous vaginal delivery	1			
	Cesarean section	1.82 (0.26–1.67)	0.521		
Feeding option at last visit	Exclusive breastfeeding	1			
	Complementary feeding	0.59 (0.32–1.08)	0.123		
	Replacement feeding	0.77 (0.52–1.12)	0.132		
Timely initiation of Nevirapine prophylaxis	No	1		1	
	Yes	0.62 (0.45–0.86)	0.001	0.86 (0.59–0.97)	0.021
Mother's age (years)	15 to 24	1			
	25 to 34	1.17 (0.87–1.58)	0.672		
	35 and over	1.17 (0.82–1.65)	0.456		
Residence	Urban	1			
	Rural	1.00 (0.72–1.40)	0.261		
Employment status	Employed	1			
	Unemployed	0.55 (0.26–1.15)	0.441		
	Peasant	0.91 (0.55–1.50)	0.671		
Mothers VL at infant registration	Suppressed	1			
	Unsuppressed	1.11 (0.65–1.91)	0.316		
	Not due for VL testing	1.27 (0.69–2.32)	0.278		
Mothers' duration on ART (months)	Less than 5	1			
	5 to 9	0.98 (0.63–1.52)	0.814		
	10 and over	1.16 (1.32–1.86)	0.051		
ANC use during this pregnancy	No	1			
	Yes	1.98 (0.54–2.79)	0.731		
ART use during ANC	No ART	1			
	Life-long ART	0.96 (0.59–1.57)	0.712		

Statistically significant results at a 5% significance level

retention, but the downward trend is consistent with these broader patterns.

Similarly, the MOH Annual Report 2014/2015 revealed that only 64% of HIV-exposed infants were retained by two months of age, and just 28% by 18 months [26]. This retention is significantly lower than what we observed in our study, where 91.3% attended the EID clinic at 1.5 months, and 82% remained in care by 18 months. The difference could be attributed to improvements in health-care delivery, better access to mother-baby care clinics, and enhanced community engagement efforts over time. The findings indicate that while retention rates are relatively high, there is still a need to address the slightly elevated loss to follow-up and mortality rates. Strengthening follow-up mechanisms, especially for at-risk infants, and enhancing community-based support could further

improve outcomes. Policymakers should consider revising guidelines to ensure that interventions are tailored to reduce loss to follow-up and mortality rates to meet WHO recommendations and national targets.

Of the 366 HIV-exposed infants (HEIs), retention at 18 months was 85.8%. The attrition was accounted for by, 25 infants (6.8%) who died, 21 (5.7%) were lost to follow-up, and 6 (1.6%) tested positive for HIV. The 85.8% retention rate at 18 months is relatively high compared to other studies conducted in Uganda [5, 27, 28], indicating strong community engagement with the healthcare system throughout the cascade. However, it still falls short of the WHO recommendation of 95% retention. The 6.8% mortality rate is notably higher than the national infant mortality rate of 3.3% [29]. This disparity suggests that HIV-exposed infants are at greater risk, underscoring the

need for enhanced care and monitoring. The 5.7% loss to follow-up is slightly above the WHO recommendation, which suggests that loss to follow-up should be less than 5%. This highlights a critical area for intervention to improve retention and reduce the risk of infants dropping out of care. The 1.6% transmission rate among infants is concerning but remains within the expected range for a breastfeeding population like Uganda, where the eMTCT target is to keep transmission below 5%. This indicates that while the overall transmission rate is low, there is still room for improvement.

The retention rate at 18 months (85.8%) according to this study is significantly higher than the 52% reported in Zambia's rural Mansa district, where attrition was primarily due to loss to follow-up and infant mortality [30]. This difference may be attributed to stronger healthcare systems and follow-up mechanisms in our setting. Similarly, another study found a retention rate of only 51% at 18 months in Mbarara, Uganda, with 10% of infants alive but not in care [25]. Our findings demonstrate better retention, possibly due to more effective community outreach and follow-up strategies in our region. Retention rates in Uganda, remained at only 62.7%–69.5% by 18 months, with most infants alive but not in care [4]. Our higher retention rate suggests that interventions in our study area may be more effective in keeping infants engaged in care.

The findings indicate that while retention rates are relatively high, there is still a need to address the slightly elevated loss to follow-up and mortality rates. Strengthening follow-up mechanisms, especially for at-risk infants, and enhancing community-based support could further improve outcomes. Policymakers should consider revising guidelines to ensure that interventions are tailored to reduce loss to follow-up and mortality rates to meet WHO recommendations and national targets.

Despite similar district-specific profiles, the better retention of HIV-exposed infants in Kumi and Serere districts may be due to better healthcare infrastructure with well-equipped health centers, trained personnel, adequate HIV care and treatment, improved health system performance, and community awareness compared to Bukedea. The relatively lower retention rate in Bukedea may suggest the need for more targeted interventions to address the factors contributing to this disparity. These interventions should focus on strengthening healthcare infrastructure, increasing the availability of HIV care and treatment, and increasing community awareness programs to encourage caregivers to adhere to follow-up schedules.

Early diagnosis of HIV exposed infants was associated with lower retention in care. The study finding may be explained by the fact that infants who were diagnosed early may appear healthy initially, leading caregivers to

neglect follow-ups. Conversely, caregivers of infants diagnosed late may be more motivated to seek care because the child is symptomatic or severely ill. The study finding is consistent with two similar studies conducted in Zimbabwe and Malawi which found that early diagnosis of HIV in infants did not necessarily correlate with higher retention in care [31, 32]. However, the study finding is inconsistent with two previous studies conducted in South Africa which showed that timely HIV diagnosis in infants was associated with improved retention in care [32, 33]. The difference in the two study settings may be attributed to the fact that South Africa may have a more robust healthcare system and community-based support programs that might provide better support for HIV exposed infants following early diagnosis, leading to higher retention in care following early diagnosis.

The retention in care also was lower among HIV exposed Infants who had initiated Nevirapine prophylaxis on time. The lower retention in care among HIV-exposed infants who initiated Nevirapine prophylaxis on time highlights critical gaps in follow-up and continuous engagement in HIV care programs. While early initiation of prophylaxis is crucial in preventing HIV transmission, factors such as caregiver perceptions, health system barriers, stigma, and poor integration of services contribute to disengagement from care. Strengthening caregiver education, integrating follow-up services with routine child healthcare, and addressing logistical and social barriers can improve retention rates and ensure optimal health outcomes for HIV-exposed infants. In contrast to the present study, most previous studies have shown increased retention with timely initiation of NVP prophylaxis [5, 34–36].

Study strength and limitation

The major strengths of this study included utilizing data from different health facilities in three districts across Teso sub region, ensuring a representative sample size for robust analysis. This wide geographic coverage enhanced the external validity of the findings. In addition, the study used high statistical power at 80%, reducing the chances of a Type II error. The main limitation was the reliance on routine data not initially collected for research purposes. This constrained the analysis of certain exposure variables. However, we used data from reliable and reputable sources with clear documentation of how the data was collected. We also recommend another study using primary data collection methods like interviews for certain exposure variables.

Conclusions

This study highlighted important gaps in the continuum of care for HIV-exposed infants, particularly in sustaining engagement beyond the early months. Retention in

care was higher in Kumi and Serere districts compared to Bukedea. In addition, Timely EID registration and early initiation of Nevirapine prophylaxis were significantly reduced retention in care, highlighting gaps in early engagement and continuity of care.

Recommendations

- With retention lower in Bukedea compared to Kumi and Serere, targeted interventions should be implemented in the Bukedea district to improve the retention of HIV-exposed infants.
- Improve counseling and follow-up mechanisms to ensure that timely EID registration and Nevirapine initiation are achieved while addressing possible factors contributing to early dropout from care.
- Strengthening caregivers' education, integrating follow-up services with routine child healthcare, and addressing logistical and social barriers can help to improve retention rates and ensure optimal health outcomes for HIV-exposed infants.
- Implement community-based interventions such as transportation support, mobile health services, and community health worker involvement to mitigate barriers that hinder regular healthcare visits.
- Conducting a qualitative study to explore the experiences, and challenges of caregivers and healthcare providers regarding retention of HIV-exposed infants in care. Such a study would provide deeper contextual insights and help explain the underlying reasons for observed patterns, thereby informing more targeted and effective interventions.

Abbreviations

AIDS	Acquired immune deficiency syndrome
ARVs	Anti-retroviral drugs
ART	Antiretroviral therapy
DBS	Dried blood spot
DNADeoxyribonucleic acid	
EMTCT	Elimination of mother-to-child transmission
HEI	HIV exposed infant
HIV	Human immune deficiency virus
MOH	Ministry of Health
PCR	Polymerase chain reaction
PMTCT	Prevention of mother-to-child transmission of HIV
UNICEF	United Nations Children's Fund
WHO	World Health Organization

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Author contributions

B.S.L, N.R., S.Z., and H.M.K. conceptualized the research idea. B.S.L and S.Z. was responsible for data collection and analysis. H.M.K., S.Z., and A.A. drafted the manuscript. A.W., A.A.B., Z.N, and K.M.M., critically reviewed the manuscript draft. All authors read and approved the final manuscript for publication.

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Data availability

Data is available upon request from the corresponding author at [ssziwas@gmail.com].

Declarations

Ethics approval and consent to participate

Approval to conduct the study was sought from the Research Ethics Committee of Uganda Christian University. Administrative approval was obtained from Bukedea, Kumi and Serere district health offices and the respective health facilities to access patient data. Confidentiality was assured by ensuring that identification features, such as names, are not recorded on the research tools. The collected data was kept under key and lock to ensure the privacy of information.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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Corresponding author's research interests Swaibu Zziwa is a public health researcher from Uganda with research interests in HIV care and retention, maternal and child health, injuries and disabilities, and health services research in low-income settings.