

# Good Utilization, Low Completion Rates of Early Infant HIV Diagnostic Services at a District Hospital in Rural South Western Uganda

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## Research Article

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# Abstract

**Introduction:** Early Infant Diagnosis (EID) using DNA PCR has been utilized in the diagnosis of HIV worldwide. This study aimed to determine the utilization of EID using DNA PCR.

**Methods:** A mixed methods study involving 164 caregivers and HCWs providing EID services. Quantitative data was analyzed using SPSS software. Qualitative data was analyzed using inductive thematic content analysis. Data was presented in verbatim form as quotes generated from recoded transcripts.

**Results:** 81% (133/164) of the caretakers reported having utilized EID services. There was low level of awareness of the proper frequency and scheduling of tests in the EID program (11%) and poor completion rates with 46.3% of the respondents having completed all the 3 PCR Tests, 12.8 % having done 2 PCR tests and 23.7% had done 1 PCR test. Good knowledge and attitude of health care providers, availability of test kits and follow up of missed appointments were quoted as drivers for good utilization of EID services while long distance from the health facility, delay at the health facility and inconsistencies in turnaround time were reported as barriers to utilization of the service are.

**Conclusion:** There was good utilization of the EID services and low completion rates.

## 1. Background

By the end of 2009, worldwide, about 2.5 million children were living with HIV (WHO, 2010), mostly as a consequence of vertical transmission from mother to child, of whom more than 90% of these children were living in sub-Saharan Africa (Chiduo 2013)

In Uganda 53000 are new born with HIV in 2019 (Avert UK 2020) with delivering women living HIV ranging from 85,000-110,000 (PMTCT Uganda 2015) while about 91,000 HIV-exposed infants (HEIs) aged 0–18 months born to HIV + mothers, were born in 2010, yet only 41,340 (46%) were tested(Kiyaga 2018.).

Out of 78,000 total HIV + children (aged 0–14 years) who were eligible for ART in Uganda in 2010, only 24,031 (31%) were diagnosed and started on ART. With rapid scaling up testing of HEIs, eight years later, the percentage of HEIs receiving a virological test remained low at 44% for the first PCR and 10% for the second PCR (Musoba 2017).

Stock outs of EID test collection kits, long turnaround time of PCR results, long distance from the facility, Knowledge and Understanding of EID by caretakers and mothers are among the factors that affect utilization of EID services (Hassan 2012, Dakum et al 2019, Ankrah and Dako-Gyeke 2021 and Thiha et al 2017)

At Rushere Community Hospital, routine EID data of the past two years (April 2018 – April 2020) indicated that 96% of the HEIs enrolled in the EID system had done the first PCR test and 81% of these babies had early testing by the age of 6 weeks. However, only 44% had done the second PCR test and 21% did the third PCR test.

Timely receipt of EID remains a challenge and previous studies have shown that mothers with HEIs do not normally take their children for testing. Therefore, study aims to determine the gaps in the utilization of EID service testing using DNA PCR scheduled times.

## **2. Methods**

### **Study Design**

A mixed study employing both quantitative that is the number and percentage of clients utilizing the service and qualitative method involving focus group discussion (FGD) with caretakers and health workers conducted from July to August 2020.

### **Study Setting**

The study was conducted at Rushere Hospital in Kiruhura District in South Western Uganda at the HAART & maternity clinic. The health facility is a Private, Not for Profit Community Hospital located about 67km by road Northeast of Mbarara Regional Referral Hospital (MRRH) and approximately 265km by road Southeast of Kampala. It serves an estimated rural population of 361300 people. The HAART clinic operates on Tuesday and Friday with a client population of approximately 30 participants per clinic day, while the maternity clinic receives HIV positive pregnant, lactating and breastfeeding mothers every first and last Wednesday of the month.

### **Study Population**

The study unit was HIV positive caregivers (both men and women) of child-bearing age between 15–45 years who had been attending the EID or HAART clinic for a period of more than one month at the time of our study after getting informed consent.

Health workers who provide health services at either the EID or HAART clinic who worked at the facility for not less than 6 months at the time of the study. The District Health Officer (DHO) of Kiruhura District.

### **Sample Size Estimation**

The sample size was estimated using Kish Leslie formula with a proportion of 94% (Violari et al., 2012) at a power of 80 and a significance of 95%, giving a sample size of 179 caregivers.

### **Sampling and Data Collection**

The respondents were conveniently selected at the time of utilization of service until the sample size was reached due to the facility being private meaning few clients can obtain a service with little pay.

From the above sample size, two FGD involving caretakers who came with their children on a clinic day were approached and briefed on the study after which consent was obtained. Questionnaires were issued and these were coded.

In depth interviews with the DHO, counselors, laboratory technician, and nurses were also conducted during our period of study at their earliest convenience in their private offices to determine health workers awareness and limiting factors affecting the service. The interviews consisted of open-ended questions that explored perceived barriers and drivers to the utilization of EID services.

## **Data Collection Tools**

Questionnaires, an interview guide, and a focused group discussion guide were used to collect the data.

The questionnaire method used a set of questions to which the respondents answered verbatim and responses were recorded by the research investigators i.e. interviewer-administered questionnaire.

Two focused group discussions comprised of 8–12 participants selected by purposive non-random sampling based on the age and attendance of the EID /ART clinic; using a peer counselor to recruit them. Informed written consent, which was also translated in the local language, was obtained. Focused group discussion guides bearing open-ended questions and audio digital recorders were used for the sessions. The first focused group discussion comprised of young care givers from 15–30 years, 8 females, 2 male, and lasted one hour. The second consisted of 8 care givers above 30 years of age and lasted for 45 minutes. Information collected included individual factors, interpersonal relations, family, and social support that affected the utilization of EID services.

In depth interviews with the District Health Officer (DHO), counselor, laboratory technician, and nurses providing heading the HAART clinic and EID were conducted during our period of study. The interviews consisted of open-ended questions that explored perceived barriers and drivers to the utilization of EID services and an audio digital recorder was used to capture the responses. The interviews were five in number and lasted between 15 minutes to 45 minutes each. Pilot interviews were held with three local physicians and questions were adapted when necessary.

## **Data Management and Analysis**

Data was collected, cleaned, and entered into Excel. Checking for fully printed pages of the questionnaires was done prior to issuing them to the participants. They were reviewed in real time for completion of all fields and the completed questionnaires were entered. Mode of entry was double data entry.

The entry screen was prepared and it entailed the addition of checks for each response to ensure that incorrect responses or entries weren't allowed. This data was then exported to the software that was used for analysis.

## **Quantitative data:**

Data analysis was carried out using SPSS Version 20.0 software. We generated proportions and frequencies for the demographics and other individual characteristics of the participants.

## **Qualitative data:**

The audio recordings were double checked, copied, and backed up daily. Data was analyzed manually using inductive thematic content analysis as described by Lundman to generate themes of barriers and facilitators of utilization of EID HIV diagnostic services in phases starting with familiarization with the data. The investigators, were divided into two teams, read the transcripts several times until they made sense of them and took note of the commonly occurring statements. The two teams generated codes with their code definitions by reviewing the data iteratively which were agreed on by the study team, inter coder agreement was reached, and the data condensed to have themes and sub-themes. Data was presented in verbatim form as quotes generated from recoded transcripts

## **Ethical considerations**

Approval from the Research and Ethics Committee of MUST (MUREC 1/7) and from the DHO of Kiruhura District before conducting the research. Informed written consent was obtained from our participants before carrying out the research. For children informed consent from a parent and/or legal guardian for study participation. We ensured confidentiality through the use of serial numbers instead of respondents' names and codes. Ensured privacy through the use of password protected computers and hard copies were kept in cabinets that were lockable. All methods were performed in accordance with the relevant guidelines and regulations

## **Data Availability**

The datasets used and/or analyzed during the current study available from the corresponding author on reasonable request

## **3. Results**

As shown in Table 1, the study recruited 164 caretakers. Majority of these participants were females aged below 30 years, were married, and had studied up to primary level.

Table 1  
Demographic Characteristics of the Participants.

VARIABLE	CATEGORY	FREQUENCY	PERCENTAGE
1.GENDER	Female	125	76.2
	Male	39	23.8
		164	100
2.AGE	18–25	26	15.9
	26–30	47	28.7
	31–35	24	14.6
	36–40	33	20.1
	41–45	34	20.7
			100
3.MARITAL STATUS	Single	14	8.5
	Married	128	78.0
	Separated	13	8.0
	Widow/ widower	9	5.5
4.EDUCATION LEVEL	None	46	28
	Primary	96	58.5
	Secondary	20	12.2
	Tertiary	2	1.3
		164	100
5. HEARD ABOUT EID	No	33	20.1
	Yes	131	79.9

Only 11% (15 of the 164 participants) were fully aware of the frequency and proper scheduling of the EID services. They all received information from the hospital with 4 having received information from both hospital and radio talk shows by health workers.

Eighty one percent (133/164) of the caretakers reported having utilized EID services at Rushere Hospital. 83.5% (111/133) wanted to know the status of the baby, 6.8%( 9/133) were following Doctors orders, 5.2%( 7/133) knew their HIV/AIDS positive status and thus decided to also take their babies for testing and 4.5%( 6/133) took their babies for testing to prevent them from contracting the virus .

31 out of 164 did not take their babies for EID service and the reasons are mentioned below in table with their frequency. (Table 2)

Table 2  
Shows reasons why babies did not receive EID with their frequencies and percentages

Reasons for not testing the children	Frequency	percentage
Wife's role to take child for testing	8	25.8
Busy	6	19.3
Unaware	6	19.3
Baby died before first PCR	5	16.1
Pending/ under age	2	6.5
Age at testing was overdue	2	6.5
Its father's role to take child for testing	2	6.5

Table 3  
Number of PCR Tests Done

	No PCR	1 PCR	2 PCR tests	3 PCR Tests
Frequency	28	38	21	77
Percentage	17%	23.2%	12.8%	47%

Caretakers who completed all 3 tests wanted to know the status of the child (48/77) and (29/77) were following health workers' orders. Reasons for not completing the tests included 34.8% lack of knowledge (of the need to complete all tests), 13% inconsistencies in results (either loss or delay in return), 13% distance from the facility and 8.7% being busy. 30.4% baby positive at the first test or second test. (Table 3)

Two themes were generated: Barriers and Drivers (to the utilization of EID services)

The theme of Drivers was generated from.

- ✓ Good knowledge and attitude of health care providers
- ✓ Availability of test kits
- ✓ Follow up of missed appointments

## Good knowledge and attitude of health care providers

The health workers were well aware of the age when the different PCR tests were supposed to be performed and records showed that all the three tests were being performed at the facility.

The health workers registered mothers according to their EDD cohorts. When HIV positive mothers delivered at this hospital, they recorded the infant immediately in the register and followed them. When the time reached for the first PCR, the health workers tested the HEIs.

*'During antenatal when a mother tests positive, she is counseled on HIV and how to live with HIV and when she has been on ART, we should collect the viral load on the first visit. When she turns positive on first visit, we should initiate her on ART and give her appointment date and advise her to deliver at the facility and the baby should take Nevirapine syrup within 24-72hours then we guide the mother on when to take the first PCR.*

*She should take the first PCR at 6 weeks on the first contact of the baby within an average of 4–8 weeks, we should remove the 1st PCR then we give her the return date to pick the results because we don't do the testing on this facility so they take the samples to a different facility then do the second PCR on 9 months and when the baby reaches 1year they wean off the baby, 6 weeks after cessation of breastfeeding we do the 3rd PCR.*

*Then when the 3rd PCR results turn negative, we stop the CTX and we advise the mother to bring the baby at 18months, then at 18 months we do rapid test and when it turns negative we discharge the baby and the mother continues with the care. If the baby turns positive, we refer her to ART. We do 3PCRs and one rapid test.'* (D4 female health worker)

## Availability of test kits

Health workers reported that EID test kits are consistently available. This is an important driver of the utilization of EID;

*"The test kits are always there. We have never run short of them. Before they get finished, we look at how many kits are remaining in the store and then we make an order. The good thing is that the driver normally comes twice in a week, so if I see that we are running short of them, I tell the driver to come with them."* D5 lab technician

## Follow up of missed appointments

Through phone calls and outreaches



*'I came for testing and also tested my child. When I went back home, the nurse kept calling to inform me about the next visit when I should bring my baby for testing again.'* FGD1 female member

*"When this baby was born, I brought it to the hospital for testing. The results were out negative but the doctors advised me to keep bringing it to the dates they allocated for further testing. The baby went through the whole process of testing and I used to bring it myself. The services are good .When I come here, I find the services and they work on me."*FGD 1 male member

*"Right now we are having a lot of outreach because of my approach, because of my population. We need to have a task delivery model, which can suite them. Here, when you deliver services which are only facility-based, you are leaving out a lot of population because you will find that some of these facilities are 10 to 15 kilometers from where the population lives. However, then we have been having what we call outreach. Like now we have outreaches for immunization supported by what, then we can have out reaches for what. Therefore the other approach was make sure we integrate, so that when we are going to immunize children in parish X, can you also be able to follow E.I.D mothers?"*D3

*'there is what we call implementation and there is what we call understanding the gymnastics of your population where you are working. If you pass a policy and it is going to work, it may be effective in Bushenyi, if you understand the population dynamics of Bushenyi; if go to Bushenyi Municipality and you find they the population they are squeezed and they are next to each other. Therefore that means it if you want to improve your E.I.D services in a method that was done in Bushenyi, clearly the population set up in my district may not be a favorable way of doing it because as you have seen the population is sparsely populated and as you have been talking about Karamoja. However, then what does it mean? It means we need what we call District Specific Interventions supported for E.I.D, and the way you are supporting Bushenyi and the way you support Kiruhura, things cannot work. Now for those two interventions I had to lead the struggle myself with my intervention probably at some cost or no cost, to see that things improved basing on how my population is spread out, basing on the characteristics of my population.'*D3

The theme of barriers to the utilization of EID emerged from the sub-themes of;

## **Distance from the health facility**

Respondents mentioned the lack of transport money to a health facility as a barrier to utilization of EID services.

*"Distance between the hospital and the places where we stay is very far. Sometimes you don't have transport to come to the hospital or even some mothers deliver along the way because they couldn't reach here in time. If they could extend government hospitals to every sub county, it would be easy for us to access those services. For example, I pay twenty thousand for a motorcycle to and from the hospital. That's a lot of money for me as a peasant."* FGD2 female member

# Delay at the health facility

*".....we delay so much at the facility that we get hungry and uncomfortable in one place for a very long time."*FGD2 female member

## Inconsistencies in turnaround time (TAT); Results delay or fail to come back.

*".....delay in receiving results since the test is not carried out at the facility. In the past few months, they could call when a child turns positive before the results reach the facility, but they no longer call us which affects us."* (FGD1 member)

### 4. Discussion

Only 11% (15 / 164 participants) were fully aware of the frequency and proper scheduling of the EID services. All 15 tested their children according to the testing algorithm and had completed the necessary tests at the right age. Lack of knowledge was a leading cause for participants who did not complete the tests

These findings were similar to a study where inadequacies in knowledge were associated with maternal none reporting for EID services in South Africa.(Izudi 2017) in Uganda (Nsubuga et al 2019) and in Tanzania (Bwana et al 2016 Samson et al 2018 and Bwana et al 2018).

There was good utilization of the EID services with 81% (133/164) of the caretakers reported having utilized EID services at Rushere Hospital above recommended by WHO (WHO, 2007). This is above the national average of 40.2%as per CPHL and narrowing it down to specific districts, EID utilization was 76% in Kabale, 30% in Kaboong, 29% Kamuli, 40% Tororo and 51% Kiruhura.(Musoba 2017). Health education from the health workers also contributed to good utilization of the service, a substantial number of caretakers reported that health workers reminded the care givers to return for subsequent visits.

The health workers were well aware of the age when the different PCR tests were supposed to be performed and records showed that all three tests were being performed at the facility which is different from studies by (Hassan et al 2012) in Kenya and in South Africa (Ngandu et al 2019).

Furthermore, outreaches for the EID program ensured that in at least every community HEIs were tested and identified. Integration with the use of media so that information reaches individuals who cannot access the hospital facility enables continuous community sensitization so that information reaches every guardian to know about EID services. EID utilization of 81% among HEIs using DNA-PCR tests was above the national average.

Completion Rate; 46.3% of the respondents had completed the 3 PCR Tests, 12.8% had done 2 PCR tests, and 23.7% had done 1 PCR test. These are all below the global target of 75%, signifying poor completion rate (Chatterjee et al 2011) Low completion rates were majorly due to lack of proper knowledge on the frequency, schedule of tests, and the importance of EID. Despite the large number of HEIs enrolled in the EID system, we have a low number of HEIs completing all tests, thus target interventions will not be achieved.

Transport expenses to and from the facility, delays at the facility during appointments, and inconsistencies in results also contributed to low completion rates. Availability of test kits as a driver was contrary to the findings of a study conducted in seven health centers in Uganda. (Kiyaga et al., 2018)

A complex interplay between facility level and client- level barriers was revealed by our data as also shown in study by (Ankunda et al 2020).

Long distance to the facility maybe compounded by delays at the facility hindering the utilization of EID services (Makau et al 2015 and Kiilu et al 2019).

At the administrative level, the lack of funding for the EID program was a barrier to utilization (Peter et al 2017).

## **5. Study Limitations**

Short period of the study. However, this did not affect the findings as the study strength of the mixed methodology with concurrent triangulation of results enabled assessing of both caregiver and health service factors affecting the uptake of EID.

## **6. Conclusion**

There was good utilization of the EID services but with low completion rates.

## **7. Recommendation**

To increase proper utilization of EID services, improvement of caregiver knowledge of EID is needed, particularly on the importance of EID, frequency and schedule of visits in order to achieve the intended outcome of zero new HIV infections and improved quality of life for HEIs.

District specific interventions for EID service delivery should be implemented.

Integration of both facility and community-based interventions should be employed to increase awareness of availability and utilization of EID services.

## **Declarations**

## **Data Access**

The data shall not be shared to protect the identity of respondents.

## **Ethical Approval**

This study was approved by the Research and Ethics Committee of MUST (MUREC 1/7), the District Health Officer of Kiruhura District, and the Uganda National Council of Science and Technology (RESCLEAR/01).

## **Consent**

All respondents gave informed consent.

## **Conflicts of Interest**

The authors promulgate that they have no conflicts of interest pertaining the publication of this article.

## **Authors' contributions**

Dr. Patrick Orikiriza conceptualized the study. Ruth Nakawungu and Memory Ayebarirwe designed the methodology. Davis Nduhuura and Mark Kyambadde collected and curated data. Dr. Joel Bazira supervised the data collection. Kevin Apio and Dr. Joel Bazira did formal data analysis and wrote the original drafts of the manuscript. Dr. Elias Kumbakumba validated and reviewed the manuscript including mentorship. Kevin Apio and Dr. Joel Bazira wrote the final manuscript.

All authors read and approved the final version of the manuscript.

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