Exploring Utilization of Early Infant Human Immunodeficiency Virus-Diagnostic Services at a District Hospital in Rural South Western Uganda. (; Patients' and Health Workers' Experiences)

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Authors' contributions

This work was carried out in collaboration among all authors. Author PO conceptualized the study. Authors RN and MA designed the methodology. Authors DN and MK collected and curated data. Author JB supervised the data collection. Authors KA and JB did formal data analysis and wrote the original drafts of the manuscript. Author EK validated and reviewed the manuscript including mentorship. Authors KA and JB wrote the final manuscript. All authors read and approved the final version of the manuscript.

Original Research Article

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ABSTRACT

Introduction: Early Infant Diagnosis (EID) among HIV Exposed Infants (HEIs) is tailored to improve the management of these infants. The use of Deoxyribonucleic Acid Polymerase Chain Reaction (DNA PCR) has been utilized in the diagnosis of these infants worldwide with the aim of reducing morbidity and mortality to improve the quality of life of these infants. This study aimed to determine the utilization of Early Infant Diagnosis using Deoxyribonucleic Acid Polymerase Chain Reaction tests (DNA PCR).

Methods: This was a mixed-method study employing both qualitative and quantitative methods that involved 164 purposively selected caregivers of HIV Exposed Infants enrolled in the Early Infant Diagnosis program 18-45 years and health workers (HWs). Quantitative data was exported and analyzed using Statistical Package for the Social Sciences (SPSS) software for descriptive statistics. Qualitative data was analyzed using inductive thematic content analysis to generate themes of barriers and facilitators of utilization of Early Infant HIV diagnostic services. Data was presented in verbatim form as quotes generated from recoded transcripts.

Results: Eighty one percent (133/164) of the caretakers reported having utilized Early Infant Diagnostic services at Rushere Hospital. This was due to health education by the health workers and follow-up of missed appointments. Awareness of the proper frequency and scheduling of tests in the Early Infant Diagnosis program was quite low with 15/164 participants (9.1%) knowing correct testing schedule intervals. There were poor completion rates with 46.3% of the respondents having completed all the 3 Polymerase Chain Reaction Tests, 12.8 % had done 2 Polymerase Chain Reaction tests and 23.7% had done 1 out of the 3 required Polymerase Chain Reaction tests.

The drivers to the utilization of Early Infant Diagnosis obtained from focus group discussions were good knowledge and attitude of health care providers, availability of test kits and follow up of missed appointments while the barriers to the service are distance from the health facility, delay at the health facility

Conclusion: There was good utilization of the Early Infant Diagnosis services and low completion rates which calls for increased awareness to achieve the intended outcome of zero new HIV infections and improved quality of life for HIV Exposed Infants. Both facility and community based interventions should be employed to increase awareness of availability and utilization of Early Infant Diagnosis services.

1. INTRODUCTION

By the end of 2021, world health organization (WHO) estimates 38.4 million people worldwide to be infected by HIV [1], 4.5 % of these are children younger 15years [2] 88 % of the children hail from sub-Saharan Africa, the epicenter of HIV and AIDS. Each day in 2020, approximately 850 children became infected with HIV and approximately 330 children died from AIDS related causes, mostly because of inadequate access to HIV prevention, care and treatment services .A systematic review done in 2020 revealed overall pooled prevalence of vertical HIV infection in East Africa to be 7.86 % which is way more than the WHO-desired (less than 5%) [3].

In Uganda, mother to child transmission of HIV accounts for 14% of all cases and recent studies suggest that half of these cases occur among HIV exposed infants (HEI) especially of mothers who stopped HIV treatment during pregnancy and breastfeeding [4]. New HIV childhood infections increased from 5300 in 2019 to 5500 in 2021 [5]. The number of women living HIV ranges from 85,000-110,000 (6). About 91,000 HIV-exposed infants (HEIs) aged 0–18 months were born to HIV+ mothers in 2010, yet only 41,340 (46%) were tested [6,7].

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 [8–11].

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.

While the progress of early infant diagnosis of HEIs is promising, children have continued to be affected by the pandemic .Without diagnosis and treatment, babies with HIV die before their second birthday, United Nations Children's Fund (UNICEF) advocates for early infant diagnosis and immediate treatment for HEIs [12].

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.

1.1 Objectives of the Study

1. To find the degree of awareness in HIV positive women of child bearing age about the availability and importance of early infant diagnosis services
2. To determine caregiver factors that affect uptake of the early infant diagnosis services
3. To establish the health service factors that determine the uptake of early infant diagnosis services

2. METHODOLOGY

2.1 Study Design

A mixed method 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.

2.2 Study Setting

The study was conducted at Rushere Community Hospital in Kiruhura District in South Western Uganda at the Highly Active Anti -Retroviral Therapy (HAART) & maternity clinic. The health facility is a Private Not For Profit (PNFP) 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. It is a focal center and provides free, excellent EID and HIV services. 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. The study setting was purposely selected because of the high number of clients enrolled in the EID program and the facility being the hub that receives all EID results for the different health facilities in Kiruhura district.

2.3 Study Population

The study unit was HEIs of 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 and the District Health Officer (DHO) of Kiruhura district.

2.4 Sample Size Calculation

The sample size was estimated using Kish Leslie formula [13]:

$$n = \frac{Z^2 \, \mathrm{p} \, (1 - \mathrm{p})}{d^2}$$

n being the sample size of study, **Z** the statistic corresponding to the level of confidence, **p** is expected prevalence (that can be obtained from same studies or a pilot study conducted by the researchers) and **d** is the precision (corresponding to effect size) or a level of 95% confidence interval. The z value was 1.96 with a prevalence of 94%, d was the precision which was 0.05 at a power of 80 and a significance of 95%, giving a sample size of 179 caregivers.

2.5 Sampling and data Collection

The respondents were conveniently selected at the time of utilization of service until the sample size was reached.

Inclusion criteria:

HEIs who attended EID clinic between the periods of April 2018- April 2020.
Care givers of HEIs above.

The health workers who provided services at the EID clinic.

Exclusion criteria:

Care givers of HEIs above who didn't give informed consent.

Health workers who had worked at the facility for a period of less than 6 months due to limited time of involvement in the EID system.

2.6 Data Collection

Questionnaires, an interview guide, and a focused group discussion (FGD) guide were used to collect the data. A mixed-method study was used to ensure study findings grounded study participant and health worker experiences.

Interviewer-administered questionnaire was used which included a set of questions to which the respondents answered verbatim and responses were recorded by the research investigators. Each lasted for about 40 minutes.

Two focused group discussions (FGD) comprised of 8-12 participants sampled purposively 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 males, 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. Validity was maximized by use of a uniform study guide for all discussions

Key-Informant interviews with the District Health Officer (DHO), counselor, laboratory technician, and nurses heading the HAART clinic and EID were conducted during our period of study. They were purposively selected for involvement of all key stakeholders and because of their deeper and comprehensive understanding of the EID program. Pilot interviews were held with three local physicians and questions were adapted when necessary.

The in-depth 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.

2.7 Data Management and Analysis

Data were collected, cleaned, and entered into Microsoft 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.

2.8 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.

2.9 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 [14] to generate themes of barriers and facilitators of the 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 recorded transcripts.

2.10 Data Availability

The datasets used and/or analyzed during the current study are available from the corresponding author upon a reasonable request.

3. RESULTS

3.1 Quantitative Data

3.1.1 Socio-demographics and patient characteristics

The study recruited 164 caretakers. The majority of these participants were females aged below 30 years, were married, and had studied up to the primary level.

3.1.2 The level of awareness on availability and importance of Early Infant HIV Diagnostic services (objective one)

Only 9.1% (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 f or testing and 4.5% (6/133) took their babies for testing to prevent them from contracting the virus.

3.1.3 Reasons for not taking HEI for EID

31 out of 164 did not take their babies for EID services and the reasons are mentioned in Table 2 with their frequencies.

Table 1. Demographic Characteristics of the Participants

Variable	Category	Frequency	Percentage
1. Gender	Female	125	76.2
	Male	39	23.8
	Total	164	100.0
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
	Total	164	100.0
3. Marital Status	Single	14	8.5
	Married	128	78.0
	Separated	13	8.0
	Widow/ widower	9	5.5
	Total	164	100.0
4. Education Level	None	46	28.0
	Primary	96	58.5
	Secondary	20	12.2
	Tertiary	2	1.3
	Total	164	100.0
5. Heard About EID	No	33	20.1
	Yes	131	79.9
	Total	164	100.0

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 the 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 the child for testing	2	6.5
Total	31	100.0

Table 3. Number of PCR Tests Done

	No PCR	1 PCR	2 PCR tests	3PCR Tests	Total
Frequency	28	38	21	77	164
Percentage	17.0%	23.2%	12.8 %	47.0%	100.0%

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.

3.2 Qualitative Data

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

3.3 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 Expected Date of Delivery (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 counselled on HIV and how to live with HIV and when she has been on Anti-retroviral Therapy, 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 with 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 18 months, then at 18 months we do the 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)

3.4 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." ID5 lab technician.

3.5 Follow Up on 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.' 1st FGD 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 suit them. Here, when you deliver services which are only facility-based, you are leaving out a lot of the population because you will find that some of these facilities are 10 to 15 kilometres 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 outreaches for what. Therefore the other approach was making 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 them 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 upon my district may not be a favourable 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 based on how my population is spread out, based on the characteristics of my population.'D3

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

3.6 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

3.7 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

3.8 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 9.1 % (15 / 164) of our study 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 are similar to a studies where inadequacies in knowledge were associated with maternal non-reporting for EID services for instance in Uganda [15] Kenya [16], Tanzania, Ghana [10], South Africa [16] and in Tanzania [17,18].

There was good utilization of the EID services with 81% (133/164) of the caretakers reporting having utilized EID services at Rushere Hospital above recommended by WHO [12]. This is above the national average of 40.2%as per Central Public Health Laboratories (CPHL) and narrowing it down to specific districts, EID utilization was 76% in Kabale, 30% in Kaboong, 29% Kamuli, 40% Tororo and 51%Kiruhura. 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 caregivers 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 [8] and in South Africa [16].

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 2PCR tests, and 23.7% had done 1 PCR test. These are all below the global target of 75%, signifying a poor completion rate [19]. Low completion rates were majorly due to a 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. The availability of test kits as a driver was contrary to the findings of a study conducted in seven health centres in Uganda [7].

A complex interplay between facility-level and client- level barriers was revealed by our data as also shown in a study by Ankunda et al. [20]. Long distances to the facility may be compounded by delays at the facility hindering the utilization of EID services found by the Nkhonjera et al. [21], [10,22–24]. At the administrative level, the lack of funding for the EID program was a barrier to utilization as it found in recent studies [25].

5. CONCLUSION

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

6. STUDY LIMITATIONS

The study period was shorter. 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.

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 the availability and utilization of EID services.

FUNDING SOURCE

DISCLAIMER

This paper is an extended version of a preprint document of the same author.

The preprint document is available in this link: https://www.researchsquare.com/article/rs-1342532/v1

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CONSENT

As per international standard or university standard, respondents' written consent has been collected and preserved by the author(s).

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).

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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