

# EVALUATION OF PERCEPTIONS OF CAREGIVERS AND MOTHERS ON EARLY INFANT DIAGNOSIS AND TREATMENT OF HIV IN SELECTED HEALTH FACILITIES IN KENYA

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## Abstract

**Introduction:** Early infant diagnosis among human immunodeficiency virus (HIV)-exposed infants is a critical component of the prevention of mother-to-child transmission programs. The Kenya Ministry of Health recently revised their early infant diagnosis (EID) guidelines to include HIV DNA PCR testing at birth (pilot only), six weeks, six months, and 12 months postnatal and a final 18-month antibody test, to be in line with World Health guidelines on Management of HIV and treatment for infants. Despite these interventions to address barriers to IED, Kenya faces challenges in the uptake of EID. This study explored perceptions of caregivers and mothers of HIV positive infants in order to make recommendations to strengthen the provision of EID services in Kenya.

**Methods:** We sought to understand the determinants of caregivers and or mothers of HIV positive infants seeking early infant Diagnosis services and treatment in six public health facilities located in six counties of Kenya. We conducted ten focus group discussions with mothers and caretakers of infants seeking Early Infant Diagnosis services and treatment in level four and level five public health facilities in six counties with high, medium, and low prevalence of HIV in Kenya. All Focus Group Discussions were audiotaped, transcribed, translated, and coded for analysis.

**Findings:** Most respondents reported knowledge and awareness of EID services. However, respondents in rural counties reported less knowledge and awareness of EID compared to those from urban counties. Negative provider attitudes complicated respondents' pathway to seeking care in a stigma-free environment. Linkage by Community Health Volunteers to caregivers and mothers of an infant was noted as a critical component to care. While most respondents were satisfied with how they were treated by health providers while seeking services, most respondents complained about delays and long waiting times to receive services. At the community level, intimate partner violence is a key barrier to caretakers and mothers in seeking EID care.

**Conclusion & Recommendations:** Mothers and caregivers of infants had higher levels of awareness (knowledge and understanding) of EID. Interventions to ensure that caregivers and mothers of infants are not stigmatized as well as addressing delays and long waiting times for the provision of services should be implemented while ensuring interventions to assist mothers and caregivers to address and cope with intimate partner violence initiated at facility and community level.

**Key words:** *Early infant Diagnosis, HIV, EID*



## INTRODUCTION

Globally, the annual number of new infections among children (0-14 years) has almost halved since 2010, with a 47% reduction in new HIV cases (HIV/AIDS, 2017). Of the estimated 37.9 million people living with HIV worldwide in 2018, 2.8 million [2.0-3.8 million] were children aged 0-19 (Wilton & Doyal, 2018). Each day in 2018, approximately 980 children became infected with HIV, and approximately 320 children died from AIDS-related causes, mostly because of inadequate access to HIV prevention, care, and treatment services (Adetokunboh & Oluwasanu, 2016). The vast majority of these infections (1.3 million) were averted between 2010 and 2015 (UNAIDS, 2016).

Pediatric HIV infection remains a significant public health issue; 2.6 million children, 2.3 million of whom were in sub-Saharan Africa (SSA), were infected worldwide in 2014 (Manjate Cuco et al., 2015). To reduce HIV mother-to-child transmission (MTCT), different strategies have been recommended by the World Health Organization (WHO) (Baggaley, Doherty, Ball, Ford, & Hirschall, 2015). Although the importance of early detection to signal treatment

initiation for HIV+ infants, EID services in East Africa have received considerably less attention than other aspects of PMTCT care (Samson, Mpembeni, Njau, & Kishimba, 2018). Especially lacking are studies that investigate predictors of “on-time” (infant  $\leq$  six weeks of age) engagement in EID that would help to identify factors that put infants at risk for late engagement and mutable targets for intervention (Opollo et al., 2018).

Kenya’s national guidelines for PMTCT of HIV recommend HIV counseling and testing for all pregnant women, initiating triple highly active antiretroviral therapy (HAART) for all HIV-positive pregnant women regardless of CD4 count (Farid, 2018; Odeny et al., 2018; Pricilla et al., 2018) (WHO Option B from 2010 and WHO Option B plus from 2014 (Izudi, Auma, & Alege, 2017), infant antiretroviral (ARV) prophylaxis for four weeks, counseling to encourage mothers to refrain from breastfeeding with the substitution of formula feeding for 18 months for all HIV-exposed infants and EID with HIV DNA polymerase chain reaction (PCR) at one to two months and four to six months (Nyandwi et al., 2018). For infants with a



positive PCR test result, guidelines recommend that a confirmatory PCR test be performed as soon as possible and that all HIV-exposed children also receive HIV antibody testing at 18 months of age regardless of PCR test results (Ochodo, Kakourou, Mallett, & Deeks, 2018).

As part of a bigger study to an evaluation of early infant diagnosis of HIV among infants attending selected level 4 and level 5 health facilities in Kenya, this study explored the determinants of early Infant diagnosis and treatment among HIV positive infants in regions with high, medium and low HIV prevalence in Kenya.

## METHODS

The study was conducted in six-level four and five hospitals in Baringo, Homa Bay, Nairobi, Trans Nzoia, Kiambu and Machakos counties of Kenya. Using data from NASCOP, the study categorized HIV prevalence across all 47 counties of Kenya into three categories- High prevalence counties, Medium prevalence counties, and low prevalence counties. Using this categorization, the study identified two counties in each region to participate in the study. In Each selected county, the study used a list generated by county health

departments on facilities providing EID services and randomly selected two level 4 or level 5 health facilities per county.

The qualitative comparative study design was employed to explore determinants and barriers of Early Infant Diagnosis and Treatment of HIV positive children in selected health facilities in the five counties. The study population comprised of HIV positive mothers/caretakers of HIV positive infants in sampled facilities enrolled in the study. (To be eligible for the study, one needed to have an HIV positive infant below 18 months and attending MCH clinic offering EID services including treatment for complications, be able and willing to provide consent to participate in the study).

The study was conducted in six counties that were randomly selected from a list of counties from the National Aids Control Program. This comprised two counties with high (above 9%) HIV prevalence two counties with medium (between 5 and 9%) prevalence and two counties with low (below 5%) HIV prevalence. Using this criterion, the study was conducted in Homa Bay County Hospital and Mbagathi Hospital (high HIV prevalence), Machakos general hospital and Kitale County Hospital



(medium HIV prevalence), and Thika General Hospital and Kabarnet County Hospital (low HIV prevalence). All women or guardians with HIV positive children attending comprehensive women treated in selected facilities and were eligible for the study were requested to participate. A saturation point was reached after the second FGDs, where the study team stopped the interviews and moved to the next counties. During the interviews, a total of 3 respondents, however, declined to participate in the study.

A semi-structured interview guide was developed and pilot tested in neighbouring counties. The guide comprised 12 questions seeking information on woman's background; perceptions of how they were treated when they visited the facility; usefulness of information received, duration it took to receive services, types of services received, provided and perceptions of quality of services; if referred for other services; and perceptions of what hinders mothers from seeking EID services;

The data collection team comprised the first author assisted by two nurses from the selected facilities trained on how to obtain informed consent, administer and keep data

from FGDs safe. The data collection team underwent a two-day training to learn how to administer the FGD guide, including obtaining informed consent from study participants. Each data collection team was tasked with ensuring that the FGDs were completed and secured until transcribed. The first author, who was the primary investigator, attended all FGD sessions in order to ensure the overall quality of the data collection efforts, including the quality of the interviews; they also initiated and maintained contacts across their respective regions to insure the study's conduct.

Audio recordings from interviews were transcribed verbatim by using standard transcription technique, and the first author conducted random checks of the transcription to monitor the quality. Transcription of the interviews was performed continuously throughout the data collection process, with the first author communicating regularly with research assistants to discuss the interviews and address any issues or problems that arise. Once all of the interviews are complete, the first, second, and third authors read all transcripts in English to identify an initial set of codes. After reading the transcripts, these



three members of the team created a codebook of codes and their definitions; it included deductive codes from the guides as well as inductive codes emerging from the data (Berg & Lune, 2004). We uploaded transcripts from all of the FGDs into Atlas – ti version 7 software analysis program for further coding and analyzing the data. Data were collected over one month in August of 2019. Each FGD lasted, on average, one and a half hours. All FGDs were conducted in Swahili and recorded using a digital recorder and then transcribed verbatim. These were then translated into English.

To identify an initial set of codes, all transcripts were read in English. After reading the transcripts, a codebook of codes and their definitions was created; it included deductive codes from the guides as well as inductive codes emerging from the data. (Patton, 2005; Richards & Hemphill, 2018) The transcripts from all of the FGDs were then uploaded onto Atlas –ti version 7 software (Friese, 2019) to code the data. FGD data was analysed by first reading the interviews, familiarising with the data, and noting the themes and concepts that emerged. A thematic framework was developed from the identified themes and

sub-themes, which were used to create codes and code the raw data. Once all the data were appropriately coded, a matrix was created in Excel for each identified theme, and the coded data transferred into the matrices. With all the matrices complete, analyses were conducted to assign meaning to emergent themes and concepts and to explore patterns of similarities and differences across interviews and between counties. The unit of analysis was the individual woman.

Approval to conduct this study was granted by the University of Nairobi and Kenyatta National Hospital Ethical Review Committee of Kenya Medical Research Institute. Permission to conduct the study in the selected facilities was granted by the county directors of the health of the five counties. Facilities selected ensure counseling of the mothers/guardians of HIV-exposed children before and after the HIV test was performed in accordance with standard testing and counseling guidelines of MOH. During the data collection, any respondent who required further counseling was referred to the counseling room for further support and counseling. Written consent was obtained from each guardian



before recruitment. No identifier marks or personal information was used in the analysis and subsequent reporting of the study results to keep the identity of the respondents confidential.

## RESULTS

### *Demographics of respondents*

The study comprised a total of 12 FGDs, with each county having two FGDs. Each FGD had a minimum of eight respondents and a maximum of ten respondents. A third of the respondents were aged 21-35 years, followed by those aged 35-46 years and 26-35 years, respectively. Slightly more than a third (39%) of respondents had completed primary school, followed by those who had completed secondary (36%) school and post-secondary school (17%). In terms of marital status, 59% of respondents reported to be in union (married or not married but had a regular partner, while 41% of respondents were not in any union (single or does not have a regular partner).

Regarding the number of children, the number of children ranged from 1 to 7 children. 59% of respondents reported having 3-4 children, followed by 32% of respondents having 1-2 children, whereas 10% of respondents having more than five children as shown in *table 1*.

The study had been designed to target respondents with similar characteristics in each county, and there

were no demographic differences of respondents per county.

### *Knowledge and awareness of EID*

Generally, respondents reported knowledge and awareness of EID services. However, respondents in rural counties reported less knowledge and awareness of EID compared to those from Urban counties. The main source of information was from community Health extension workers.

*My husband got to know about the information from the Community Health worker and has always insisted we visit the facility for the sake of our baby. The CHWs links us with a nurse. Except for the long queues at the clinic, it is easier to get to the facility and get my child to receive treatment (FGD Participant, Machakos County).*

*Given my status, I did not know, since I was scared of attending clinic before I got my baby. I had heard in the village about not breastfeeding baby. The CHW referred me here and I was given more messages (HIV+ mother Baringo County).*

Respondents who were married or had a steady partner reported more awareness and knowledge of EID compared to those who were single or did not have a steady partner. The ability of couples to work together and discuss how to raise the infant plays a critical role in accessing EID services.



Table 1: Demographic characteristics of participants

Study Facilities	Baringo	Homa Bay	Kiambu	Trans Nzoia	Nairobi	Machakos	Total
FGDs	2	2	2	2	2	2	12
<b>Age</b>							
18-20 years	4 (22%)	5 (28%)	4 (24%)	4 (20%)	4 (21%)	4 (21%)	25 (23%)
21-25 years	6 (33%)	6 (33%)	5 (29%)	7 (35%)	8 (42%)	8 (42%)	40 (35%)
26- 35 years	4 (22%)	3 (17%)	4 (24%)	4 (20%)	4 (21%)	4 (21%)	23 (21%)
35-46 years	4 (22%)	4 (22%)	4 (24%)	5 (25%)	3 (16%)	3 (16%)	203(22%)
<b>Attended School</b>							
No School	2 (11%)	4 (22%)	0 (0%)	1 (5%)	0 (0%)	1 (5%)	8 (8%)
Primary	8 (44%)	10 (56%)	4 (24%)	7 (35%)	7 (37%)	7 (35%)	42 (39%)
Secondary	6 (33%)	2 (11%)	8 (47%)	9 (45%)	8 (42%)	9 (45%)	42 (36%)
Post-secondary	2 (11%)	2 (11%)	5 (29%)	3 (15%)	4 (21%)	3 (15%)	19 (17%)
<b>Marital Status</b>							
In Union	10 (56%)	14 (78%)	10 (59%)	11 (55%)	9 (47%)	10 (59%)	64 (59%)
Not in Union	8 (44%)	4 (22%)	7 (41%)	9 (45%)	10 (53%)	7 (41%)	45 (41%)
<b>No. of Children</b>							
1-2 children	6 (33%)	4 (22%)	5 (29%)	8 (40%)	6 (32%)	8 (40%)	37 (32%)
3-4 Children	10 (56%)	12 (67%)	11 (65%)	9 (45%)	12 (63%)	9 (45%)	63 (59%)
5-7 Children	2 (11%)	2 (11%)	1 (6%)	3 (15%)	1 (5%)	3 (15%)	12 (10%)

*While we are struggling financially to raise funds for our day to day use, my husband has been supportive in ensuring we put our heads together and ensure good nutrition for our baby. Coming to this facility, we are able to get assistance on how to raise our baby. Funds we get from casual work assists us to talk and discuss on what we should do. It is the right thing to do, considering our HIV status (**Married, Kiambu County**).*

Unlike respondents who are in a union, respondents who are not in union expressed challenges accessing EID services. The challenges included a lack of support from spouses or families in ensuring infants

are taken to health facilities, and mothers/guardians had to seek support elsewhere to ensure infants accessed the services. The main area of support was reported as funds for transport to a health facility or to purchase basis necessities required for the infant.

*We disagreed with the father of the baby, and i do not get any support. Getting money to go to the hospital is a challenge. I wish he could support, he knows my status and decided to ignore the facility for the sake of our baby (**Nairobi County**).*

*My child looks to be in good health. Since*



*mothers might know that my baby is HIV positive and my relatives might come to know this, and it becomes a problem. I ensure the baby is feeding properly and use herbs to wash the baby and give to drink so that she does not get sick. (Homa Bay County).*

#### ***Perceptions on care received by clients at the Health Facility***

As a result, stigma related to being HIV positive respondents across all FGDs reported fearing of visiting health facilities to receive EID services for their infants. While respondents indicated fear of being known to be HIV positive, negative provider attitudes towards them, support from Community health volunteers to refer and link them to known providers was noted as critical in addressing these fears.

*You know, not many people know my status.... If I go to the facility, they may disclose my condition, and this could leak. It may be helpful if the nurse could maintain (Not in Union, Kiambu County).*

*Since I have been working with the CHV, she was able to talk to the head of the facility, and it is good when you know someone whom you trust is expecting you. I am happy everything went as I had hoped. The line was long, but I am happy I have gotten help (In union, Homa bay County).*

Respondents in all counties reported that several instances of barriers to receiving services.

The main Services, most respondents complained about the waiting times to receive services.

*It took a long time to get to the room. I did not talk to anyone as I suspected everyone in the line was like me. I was happy that the nurse spoke to me very well. She was like a friend and understood my situation and guided me that i should not miss attending the clinic for the sake of my baby. (Not in union, Baringo County). **Partner Violence***

In all FGDs, respondents that reported to be in union and those not in union reported facing one form of violence or another as a key barrier to early infant diagnosis and the continuation of HIV care for mothers and their children. Instances of physical violence that comprised being beaten or assaulted as well as psychological violence that included intimidation from spouse, and family members, denial of resources, and preventing her from working or taking away earnings from her work..

*We disagreed with the father of the baby, and I do not get any support. Getting money to go to the hospital is a challenge. I wish he could support, he knows my status and decided to ignore us (Trans Nzoia County)*





Both respondents that were in union and that not in union reported instances where they disclose their HIV status to their male partners, for fear of being stigmatized. Respondents reported that such husbands were very controlling and often discouraged their spouses from engaging in income generating activities. For respondents whose husbands were also living with HIV, reported support from their husbands in ensuring that their infants received treatment and supported their spouses to take their infants to health facilities. Such support included accompanying the infant's caregiver/mother to the health facility, having open discussions on how to raise their children to ensure their child does not contract HIV.

## DISCUSSION

This study sought to explore the determinants of EID in three regions with high, medium, and low HIV prevalence in Kenya. As noted in previous studies, this study also noted that EID services are widely available in Kenya (Achwoka et al., 2018), however Key findings from this study is that regional difference in HIV prevalence was not significantly differenced; however the location of the region(urban or rural ) presented difference in knowledge levels of EID services where knowledge of EID services was high among respondent

especially those located in urban settings compared to those in more rural settings.

This study also noted that disclosure and stigma were reported as major challenges facing EID by most caregivers. Across all FGDs respondents indicated fear of being known to be positive and negative health care provider attitudes that included verbal insults or unfair treatment such as being made to wait longer; lack of adequate information on services was noted. This finding is similar to the previous finding in similar studies where it was noted that all service providers and caregivers generally perceived EID to be 'good' as infants received care. However, disclosure and stigma were reported as major challenges facing EID by most caregivers (Hassan et al., 2012).

Other studies have noted that community health workers play an important role in health service delivery and are increasingly involved in behavior change interventions, including for hygiene-related behavior change(Aseyo et al., 2018; Aung, Silawan, Rawiworrakul, & Min, 2018), this study noted that while there were negative provider attitudes, it helped where Community Health Volunteers affiliated to a



health facility referred mothers/caregivers to the health facility as the mothers visited health facility while knowing whom to approach and this made the process of navigation for services in the health facility was easy.

The study found out that there is a need for clear signages on where services were being provided was noted as an enabler of infant caregivers in seeking services. Other studies have placed a key focus on a well-designed signage system that can be beneficial for the Hospital users' since it can help reduce the stress of both patients and staff, increase the efficacy of care, improve their safety, and improve health outcomes and overall quality of care(Rodrigues, Tavares, & Coelho, 2017). Furthermore, a good signage system can also help reduce the costs associated with wayfinding issues(Bond et al., 2016), which means more money saved by the Hospitals and by the government. There are some available regulations and standards through which the signage is developed and implemented in these settings; however, the users' experiences and preferences are not captured which results in settings that are not suited for their users(Yoon et al., 2018).

Other studies have noted that shorter waiting times are critical in the acceptability of EID services as well as increasing mothers' satisfaction with services provided at the facility(Brown et al., 2019).

Respondents noted the need to have shorter queues and reduced waiting times are a critical factor in enabling compliance with health facility visits. Other studies have established the close link between intimate partner violence (IPV) and HIV(Carpenter & Stacks, 2009), where IPV can increase risk of HIV by limiting a person's ability to negotiate safer sex and safer drug use and because the short- and long-term effects from IPV may lead people to engage in higher-risk behaviors (Sabri et al., 2019). IPV is common among people living with HIV, in part because IPV and HIV disproportionately affect some of the same populations (Harrigan, n.d). This study noted instances of intimate partner violence that comprised being beaten or assaulted as well as psychological violence that included intimidation from the spouse, and family members, denial of resources, and spouses preventing her from working or taking away earnings from her work which would have



been used to facilitate access to EID services.

## CONCLUSION

This study supports prior research from sub-Saharan Africa, indicating barriers to uptake of Early Infant Diagnosis services. In this study, findings reveal several factors affecting access to IED at individual and facility levels. This includes inadequate knowledge and awareness of EID services, intimate partner violence targeted at mothers of HIV positive women, the cost of accessing EID services, including transport and HIV -related stigma.

At the facility level, provider attitudes to women, long queues, and waiting times to access the services were noted as main challenges. Interventions to ensure that caregivers and mothers of infants are not stigmatized as well as addressing delays and long waiting times for the provision of services should be implemented while ensuring interventions to assist mothers and caregivers to address and cope with intimate partner violence initiated at facility and community level.

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