

Caregiver factors influencing seeking of Early Infant Diagnosis (EID) of HIV services in selected hospitals in Nairobi County, Kenya: A qualitative Study

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Abstract – Early Infant Diagnosis (EID) is the practice of testing babies for the HIV virus within the first 4–6 weeks of life or at the earliest opportunity thereafter. In order to correctly inform caregivers the HIV status of their infants, and link HIV-infected infants to care and treatment, a 'cascade' of events must successfully occur. This cascade of events involves early detection, and retention into care and treatment protocols.

The current study aimed at assessing maternal factors influencing seeking of EID of HIV services in selected hospitals in Nairobi County. More specifically, caregiver-level factors were assessed to establish maternal perceptions towards EID service delivery, knowledge, attitudes and practices. The study was conducted at Mathare North Health Center, Mbagathi District Hospital and Kibera South Health Center in Nairobi County, which serve the catchment area of Kibera, Kawangware and Mathare slums. Qualitative data was collected using Focused Group Discussions (FGDs) guide.

Six FGDs were conducted with women of different age-groups, two FGDs in each of the 3 selected facilities. Trained local facilitators were used to conduct the FGDs in Swahili. All FGDs were audio-taped, transcribed, translated and stored safely in a computer. FGDs were discussed and interpreted using the Health Belief Model (Tarkang & Zotor, 2015) and presented according to the emerging themes. The findings of the study were used to inform ways of improving infant health outcomes as they go through the EID program.

Some of the key findings of the study were that: mothers appreciated having the EID program as it ensured that their infants got ART prophylaxis. Additionally, the mothers got counselling services from the providers on how to reduce MTCT. Some of the challenges the mothers cited included; stigma and discrimination from their partners, family members and neighbors, long waiting times while seeking EID services,

difficulty in disclosure of status to their significant others and lack of funds to cater for transport costs to the healthcare facilities to attend their scheduled clinics. Gaps in knowledge were also identified from the focus groups such as lack of adequate knowledge in prophylaxis dosing for their infants and feeding methods.

Recommendations given by the mothers during the focus groups included; improved counselling for partners to reduce stigma and discrimination, provider assisted disclosure and provision of funds to cater for transport costs. We recommend that maternal education to be heightened during PMTCT and EID through rigorous educational packages for HIV positive mothers and their partners to reduce stigma and discrimination. Additionally, telephone reminders and home visits would enhance adherence improving infant health outcomes

Use of qualitative methods are a critical component to better understand why ART eligible mothers choose not to initiate their infants into the EID program on time or continue with treatment to achieve desirable infant health outcomes.

Index terms: Early Infant Diagnosis, Caregiver factors, HIV, health outcomes, qualitative.

Introduction

HIV infection continues to be a global public health concern with an estimated global prevalence of 36.7 million people living with the HIV virus at the end of 2015 (UNAIDS, 2016). In spite of being a preventable disease if effective prevention interventions are not put in place, it will continue to cause morbidity and mortality amongst populations.

In Kenya the prevalence of HIV is estimated at 6% with 1.6 million People Living With HIV/AIDS (PLWHA), of whom

179,894 are children aged 0-14 years. MTCT rates remain high in Kenya with estimates of 14% and 10,390 HIV infant deaths in 2013 (Government of Kenya, 2014). In the absence of timely HIV testing and timely ART initiation, one third of infants living with HIV die before their first birthday, and more than half die before the age of 2 years. Thus, EID is a key driver for the implementation of early initiation of infant ART and is associated with lower mortality and morbidity of HIV infected/exposed infants (Tejiokem, et al., 2011).

Prevention strategies that are effective in reducing disease burden among infants include PMTCT (Prevention of Mother to Child Transmission) and EID (Early Infant Diagnosis). An estimated 430,000 new HIV infections occurred in children of which 90% were as a result of Mother To Child Transmission (MTCT) of HIV and 90% of these children were found in Africa (WHO, 2013).

The EID cascade includes the offer and acceptance of EID testing among HIV-exposed infants, including those for whom HIV exposure was unknown, accurate specimen collection, transport, and laboratory processing, relay of results to both healthcare providers and infants' families/caregivers and linkage to care, cotrimoxazole prophylaxis, and ART for infants identified as HIV infected (NASCO, 2014).

Without any interventions, between 15 % and 45 % of infants born to these women will acquire HIV with 5–10 % during pregnancy, 10–20 % during labor and delivery, and 5–20 % through breastfeeding of their infants (De Cock, et al., 2000). Encouraging progress has been made in scaling up and improving the quality of programs. In 2012, approximately 900,000 pregnant women living with HIV in low and middle income countries received ARVs to prevent MTCT. ART primarily for their own health or the most efficacious antiretroviral prophylaxis (UNAIDS, 2013). This represents one third more than the number who received it in 2009.

Care-givers are at the center of the EID program since the infants are totally dependent on the care-giver for the attendance and completion of the EID cascade. HIV positive women face a number of challenges that affect their health and ultimately the health of their infants. Health systems need to respond well to the needs of women to ensure comprehensive service delivery that caters for their different requirements (Vancouver/Richmond Health Board, 2001). Some of the barriers that were identified that led to poor uptake and retention of infants in the EID program as reported by the care-givers included; stigma and discrimination i.e. In a study conducted by Boender, et al (2012), a care-giver reported that she had not disclosed to her mother about her HIV status since she feared that her mother would disclose her status to everyone and she would end up being stigmatized and discriminated;

“I never got married and feared to tell my mother. She is harsh and will tell everybody to stigmatize me. Nobody knows about

my and my daughter's HIV status. They discriminate you, even at work”.

Onono et al, (2015) also demonstrated that stigma and discrimination played a big role in determining whether the caregivers would bring their infants to the EID program. Most mothers in this study experienced at least an episode of stigma or discrimination due to their HIV status and they hence reported that it was a great barrier to seeking services.

Partner disclosure was also reported as a barrier to the completion of EID cascade of care i.e. Males in the African community are still visualized to be the key decision makers in the households and therefore male involvement has been seen to improve ANC (Antenatal Clinic) which increases PMTCT uptake and is associated with reduced MTCT and infant mortality (Boender, et al, 2012). Other caregiver level barriers that were identified and deemed to undermine the EID program included; knowledge of PMTCT, maternal adherence to ART, food insecurity, cultural factors, lack of accurate health information and social support and overcrowded health systems that caused long waiting times (Murrey et al., 2009).

Methods

A qualitative study was conducted in three facilities: Mbagathi District Hospital, Mathare North Health Center and Kibera South Health Center in October 2018. The study was undertaken using a semi-structured Focused Group Discussion (FGD) Guide. For analysis, the authors were interested in HIV positive women who had infants less than one year old enrolled into the EID program, so as to get a description of the women's perceived susceptibility, severity, benefits, barriers and cues to action towards the EID program of HIV. Hence, the data included in this paper were only from Focus Group Discussions that were conducted in the three selected facilities. The findings of this study will be used to inform policy on the key things that affect caregivers as they seek EID services and increase women's knowledge on how to reduce HIV transmission to their infants, this will also encourage increased access to EID services.

The first author trained three women in FGD facilitation, so that they could assist in conducting the FGDs, which were conducted by the first author and the trained women. The three women were selected because of their roles as facility mentor mothers and their influence in the community of the selected study areas. During the training, we reviewed written informed consent in both Swahili and English, went through the research ethics and practiced note taking. We also practiced facilitation of the FGD with the use of a tape-recorder to ensure that the three women were well prepared to assist in undertaking the FGD.

We conducted a pre-test of the FGD in Kibera Health center for practice of facilitation with the trained women. The focus groups in the three facilities were divided into two sessions, session one was for women below 18 years to 24 years and mothers between 25 years to 49 years. The inclusion criteria for the younger women was that they were able to give consent, and those less than 18 years had next of kin to give consent after the consent was

obtained from the mother. The other inclusion criteria that applied across to all the women was that they all attended their CCC clinic in the selected hospitals.

The exclusion criteria was mothers who were “on transit” in the selected hospitals and mothers who were not caregivers to the infants. Other demographic data were not collected for the purpose of the FGD.

The participants were selected by the facility mentor mothers within the selected hospitals. All the participants were read an informed consent in both English and Swahili, depending on their preference, and written informed consent was obtained from all the participants. If a participant could not read or write, the consent form was read to her and an X on her form marked her consent, along with a signature of a witness. All focus groups had 4-6 participants each. Participants were given a snack after their participation and reimbursed transport costs as well. Ethical approval was sought from Kenya Medical Research Institute (KEMRI) Scientific Ethics Review Unit (SERU). Clearance to carry out the study was given by Board of Postgraduate Studies (BPS) of Jomo Kenyatta University of Agriculture, Science and technology (JKUAT). Permission also sought from Nairobi City

Council and the Medical Superintendent of the facilities where the study was undertaken.

The FGD guides covered the following areas: Exploring maternal knowledge and understanding of; services that will be offered to her and her infant during the EID program, feeding practices, Infant ART and prophylaxis, reduction of MTCT, Attitudes towards the EID program, Perceived benefits of the EID program, Perceived Challenges of the EID program and finally, ways to improve EID services offered to the mother infant pair so as to meet their various needs and expectations. The focus groups were translated to Swahili and focus group participants were given a choice of whether to participate in English or Swahili. All focus groups were recorded and transcribed, note taking was also done concurrently. The first author listened to all the recordings and read all focus group transcripts and transcribed them according to the emerging themes.

The Health Belief Model by Tarkang & Zotor (2015) was used to cluster the mothers’ responses thematically. The model is outlined in the table shown below;

Table 1: Health Belief Model by Tarkang & Zotor (2015)

Concept	Definition	Application
Perceived susceptibility	Mothers’ opinion on chances of getting a condition or passing on the condition to the infant	Perceived heightened risk or low perceived risk of HIV transmission to the infant, based on personal traits or behaviors
Perceived severity	Mothers’ opinion of how serious a condition and its consequences are	Perceived consequences to the infant by virtue of the mother being HIV positive
Perceived benefits	Mothers’ belief in the efficacy of the advised action to reduce risk or seriousness of impact	Perceived positive effects or benefits to be expected following the EID program initiation and completion
Perceived barriers	The mothers’ opinion of the tangible and psychological implications and costs of attending the EID program	Identify and reduce barriers through reassurance, incentives and assistance
Cues to Action	Strategies to activate readiness	Perceived solutions to the challenges that the mothers felt were affecting them and possible ways that could improve their experience as the mother-infant pair go through the EID program
Self-Efficacy	Confidence in one's ability to take action	Provide training, guidance in performing action.

The other authors read the transcribed content and gave their input. All focus group participants were asked the same questions, and emerging themes noted. The quotes are

representative of what was said about the particular theme, unless otherwise noted.

The unit of analysis was the focus group. The frequencies of the emerging themes were entered and noted in an excel spreadsheet.

Results

Perceived susceptibility

All mothers were aware that their infants were at a risk of HIV infection due to the HIV positive status. Some of the respondents reported as follows;

P1: "If I have cracked nipples I will not breastfeed my child because the baby might get infected if he suckles from my cracked nipple"

P2: "Taking my ARVs well is important so that I can keep the amount of virus in my body low, so as to not pass the HIV virus to my infant".

(FGD1)

The mothers were all very determined to ensure that they do not pass the virus to their infants and were willing to do what it takes to ensure that they have healthy HIV free infants, P4: "I will do wherever the healthcare providers tell me to do so that I do not pass on the virus to my infant".

(FGD5)

Perceived severity

All the mothers were aware of the severity of their illness the consequence of the disease to themselves, their infants and their partners as well. None of the mothers wanted their infants or HIV negative partner to acquire the disease due to the burden associate with living with HIV. Some of their sentiments were as follows;

P1: "HIV is not an easy disease to live with because you have to take ARVs every day to keep you alive"

P2: "If I don't take my ARVs well, my viral load will become high and I risk passing on the virus to my infant when he is breastfeeding"

(FGD2)

P1: "My partner and is HIV negative, so we have to use condoms so that I don't pass on the virus to him. Sometimes he however refuses to wear a condom, I become very worried when this happen because I don't want him to become sick too, if we both die, who will take care of our children?"

(FGD3)

Perceived benefits

Benefits to the mother

Some of mothers indicated that some of the many benefits that they got from attending the EID program was that they able to easily and quickly access ART and prophylaxis for their infants,

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and that they were encouraged by the healthcare providers to stick to the EID program even though they did not want to keep the pregnancies

P3: "I had lost all hope as I did not even want this pregnancy in the first place, but the providers gave me a lot of hope and encouraged me, I was able to continue with the EID program well thereafter".

P4: "I had even stopped taking my ARVs but when I started this program, the health workers gave me courage and hope to restart my ARVS, now am well with my infant".

The mothers were also walked through the EID journey by the health workers through constant encouragement and follow up to ensure that they adhered to the treatment program.

(FGD6)

Mothers also reported on benefitting from education about appropriate feeding practices to avoid passing the HIV infection to their infants.

P2: "We are given education on giving prophylaxis, appropriate feeding practices and PMTCT infections".

Another mother reported that meeting other HIV infected women during the EID process in the clinic gave her an opportunity to share her experience with the other mothers and in so doing, encourage each other.

P3: "When we come to the clinic we meet other HIV positive mothers and we encourage each other, we give each other hope and the mentor mothers also encourage us"

(FGD3)

All mothers reported that at the very least, they were able to get their ART and education about PMTCT.

Benefits to the infant

The mothers reported to have gained knowledge on appropriate feeding practices for their infants to avoid spreading of the virus especially during the breastfeeding period. One of the mothers reported that she had actually seen a great difference between the other children that she had given birth to and not enrolled into the EID program, and the current baby that is enrolled into the EID program.

P1: "My other babies were always sick with either diarrhea or influenza, but this baby has never been sick since we started this clinic because we are given good education on raising the baby well, and close baby monitoring has also helped".

P2: "We are taught on good infant feeding practices by the healthcare providers" reported another mother.

(FGD4)

P3: "I did not have a lot of milk and I almost wanted to do mixed feeding a few weeks after delivery, this is because my baby was crying a lot and my relatives and friends were pressurizing me to give the baby food but I refused. The healthcare providers encouraged me to keep breastfeeding to increase milk supply".

(FGD1)

Pressure to mix feed infants from relatives is usually a big barrier towards the achievement of exclusive breastfeeding for 6 months, more so for out HIV exposed infants who stand a risk of getting infected with HIV if appropriate feeding practices are not enforced.

Perceived barriers

The mothers had a number of challenges that were affecting them and their infants. The researcher identified the key emerging challenges as reported by the mothers. One of the greatest challenges that the mothers were facing was cost of transport to attend their scheduled infant and mother clinics.

P3: "Sometimes getting bus fare is a big challenge, I am forced to borrow 100 Ksh from friends so as to be able to attend my scheduled clinics"

(FGD2)

On average the mothers reported that 200 Ksh is what they would need to cater for transport associated costs. The mothers reported that they would keep borrowing since they cannot ask the healthcare facility to provide for them transport. This is because they would only be advised to transfer to the nearest healthcare facility, which was not an option for them due to fear of stigma and discrimination.

The facilitator probed the mothers further and asked them if there was a healthcare facility that offered EID services near where they lived so that they do not have to incur transport charges. Majority of the mothers reported there were nearby healthcare facilities that offered EID services but that was not an option for them due to fear of stigma and discrimination from the community.

P3: "Transport money to the facility is a big challenge and when we discuss this with the healthcare providers they advise us to go to the nearest facility to reduce transport costs. This is not an option for me because in the nearby facility my neighbors might see me going to CCC and the services are better here anyway"

(FGD3)

Stigma and discrimination was also cited as a great concern by most of the mothers in the FGD. Stigma was originating from various sources such as the mothers partners, neighbors and other relatives. It was seen as a major barrier to adherence and accessing EID services, since it hindered some mothers from attending their scheduled clinics. All the mothers reported to have at least one or more incidents of stigma and discrimination

P4: "My partner is HIV negative and is aware of my positive HIV status, he agreed to marry me despite him knowing my status. He sometimes stigmatizes me by blaming me for my HIV status which really hurts me. He accuses me of being unfaithful to him especially when I am coming for my CCC appointments."

In response to this statement one of the mothers advised the other mothers that the only way to earn respect from their spouses and reduce stigma and discrimination is to be economically empowered.

P5: "I want to encourage women to look for ways to generate income and be self-sustaining this way your husband will respect you and you will not have to keep borrowing money every time you want to attend your clinic" (FGD4)

Some partners did not support the mothers financially especially to come for their appointments.

P3: "My husband will not give me a coin to come for my appointments despite the fact that I am unemployed. I am forced to save from the little money he leaves for food. Sometimes I call the healthcare providers in EID in advance and tell them that they will have to give me transport back home since I only have money for one way trip. They usually help but you cannot borrow each time"

P2: "Some neighbors know my HIV status so whenever I leave the house they start gossiping me, one neighbor even insulted me pertaining my status and I felt very bad because I did not ask for this disease".

(FGD5)

Another mother also had fear of stigma and discrimination from the neighbors due to the close proximity of the houses which were semi-permanent and had very little privacy.

P1: "Our houses are connected wall to wall so whenever I want to swallow my drugs, I cover myself with blankets to reduce the noise the medicines make in the tins so that they don't know that I am taking medicine"

On the same breath, another mother conveyed the same concerns;

P2: "Those ARV containers make a lot of noise, so whenever I come to pick the medicine I must roll them in a sweater to reduce the noise made by the tablets in the plastic containers and put the medicine in at least 3 bags to reduce the noise they make so that when I am walking people will not hear that I am carrying ARVs in my bag"

(FGD4)

Another mother reported how stigma and discrimination had affected her life and adherence to ART

P4: "I was really discriminated and stigmatized by my nuclear family when I disclosed my HIV status to them. I defaulted on

my treatment for a long time and this caused treatment failure on first line, am now on second line treatment and very keen to take my drugs not to have treatment failure again”

(FGD1)

Another challenge reported by the mothers was that sometimes getting food or at least one meal that is balanced was a problem. Adequate nutrition is a key factor in the management of HIV clients. It is important for the mothers to have an adequate and balance diet so that this can boost their immune system, as well as ensure sufficient nourishment for their children from breast milk.

P1: “My husband ensures that the baby food is available but doesn’t bother to ensure that I get a balanced meal. Sometimes the money left behind is too little so I buy food for my infant and sacrifice myself.”

Another mother reported that she doesn’t care much about her own food as long as her baby gets food. She went further to explain that lack of adequate food sometimes made her not adhere to her drugs due to the effects of taking the ARVs on an empty stomach.

P2: “My husband gives me very little money for food so I mostly buy for my baby food and eat whatever else is available”. “I sometimes don’t get enough food for myself and my child. I can sometimes only take porridge only the whole day. This is usually very bad because the night ARVs give you a lot of dizziness if you take them on an empty stomach”

(FGD2)

Disclosure of HIV status was another big challenge to majority of the mothers. Mothers feared the consequences of disclosing their status to their spouses or other close relatives and friends. Disclosure is a great barrier to drug and clinic adherence both to the mother and the infant. Provider assisted disclosure improves adherence

P2: “I am married as a second wife, my husband’s other wife and I have never met. I have not disclosed my status to my husband, and he does not know my status either. I find it difficult to disclose to him my status, with time I will. He gives me very little financial support and at times I go hungry with my other children”

P3: “I do not visit my rural home because I have not disclosed my status to anyone and I will not be able to explain why I am taking medicine every night and why child is also taking medicine every day. I don’t want them to stigmatize me”.

P4: “Long ago when I used to visit my rural home, since I have not disclosed my status to anyone, I used to remove my tablets from the medicine bottle and put in a paper and hide under my mattress, my viral load went very high and I had to disclose to the healthcare workers that I was removing my medicine from the dispensing bottle. I was discouraged from doing this, now I don’t go to my rural home anymore”

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(FGD4)

P1: “I have not disclosed my status to anyone else other than my husband, I would like help in disclosing to my sister as well, she is very sensitive and might get blood pressure and we are very close”

P2: “I disclosed my status to my nuclear family members and they were very supportive, they even remind me to take my medicine”

P3: “I am a student in college and I sometimes delay to take my medicine because I get delayed in school. I have not disclosed my status to any person in school so I cannot carry my medicine to school”

(FGD2)

Partner support was yet another challenge that affected majority of the mothers which ultimately undermined care and treatment efforts for both mother and child.

P1: “My partner is HIV positive and he says that he was infected by someone and has vowed to keep spreading the disease. I am aware he has multiple partners and he refuses to use a condom. I have to pick for him his ARVS and remind him to take the medicine otherwise he will not take the medicine.”

P2: “My husband had refused to take medicine and attend his CCC clinics, I had to come to pick the medicine for him and even then, sometimes he would refuse to take the medicine. One day he just changed and stated taking his medicine and attending clinics.”

P3: “My husband knew his HIV status after I disclosed to him my HIV status. He refused to go for testing until he was very sick and admitted to hospital and tested positive then and started on ARVs. He defaulted on his medication for a while and would only take medicine if I went and picked them for him. He also refused to use condoms. My problem is that my husband has turned me into his drug mule, he can never come for his medication or come for clinics, if I don’t pick his medication for him, he will not take his medicine. I have talked to the healthcare providers and they advised me to bring his card and telephone number then they will talk to him”

P4: “My husband will only take medicine if I bring them myself, he refuses to come for his own medicine, I have no problem picking the drugs for him as long as he swallows them”

(FGD4)

Of great concern was that some partners had behaviors that could increase the mother’s viral load and put her infant at risk as well. For instance one mother reported that;

P3: “Since I told my husband my HIV status he has been very supportive, he even calls from work to remind me to take medicine, he also gives me money to come to hospitals for my appointments. The only challenge is that my partner has refused

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to come for testing, the mentor mothers who support us in the treatment program have attempted to call him on several occasions to come to the hospital, but he has never agreed to come. I don't know his HIV status and he doesn't take ARVs".

P4: "My husband's medicine was changed to the new type of ARVs, since then my husband has refused to take these medicines and instead takes mine which are the same as the ones he used to take"

(FGD2)

Another partner behavior that increased the risk to the mother and infant as reported by some of the mothers was refusal to use condoms during coitus.

P5: "My partner has completely refused to use condoms, every time I pick them they expire in the house. He says he will not use condoms with his wife since he is not having sex with any other person outside their union. If I insist that we will not have sex, he says that he will go and seek sex elsewhere"

P6: "I knew my HIV status with this current pregnancy, with the other pregnancies I was HIV negative. When I disclosed my status to my husband he was very cross with me and he said not to bring up the topic again. We do not use condoms because he refuses, I am aware that he is adding me his virus but there is nothing I can do about it, he gets very angry when I speak about my HIV status"

(FGD4)

Long waiting times as the mother-infant pair sought for services was yet another challenge reported by the mothers. Long waiting times reduce adherence to scheduled CCC and EID clinics.

P1: "The healthcare workers take very long health breaks delaying our treatment and increase waiting times. So I don't come early, I finish my work first in the house then come at noon so that I don't stay for too long in the hospital"

P2: "Often the consultation room services begin very late, some doctors come in late in the morning which makes us stay in the hospital for very long. I wish the services would start on time so that we can be attended to quickly and so that we can go back to our other issues at home"

(FGD6)

P4: "The delays in the general CCC could be a contributory factor to our men refusing to come for their own drugs. My husband initially used to come to pick his own drugs, but the long waiting time in the general CCC made him to stop coming for the drugs because he said that he is wasting too much time in the CCC and this could make him get fired from his workplace. I don't mind getting him the drugs, because at least he is agreeing to swallow the drugs"

(FGD3)

Most of the mothers also reported that they experienced some side effects due to swallowing the ARVs such as dizziness, abdominal discomfort, diarrhea, nausea and vomiting when they were first put on ARVs. However they also reported that the symptoms disappeared after some time. These side effects did not stop them from continuing their treatment all the same

P1: "Initially the ARV drugs gave me a lot of dizziness and with time the effects disappeared"

(FGD5)

All the mothers reported that that they had not experienced ARVs stock outs but had to buy medication for co-morbidities and other opportunistic infections as these drugs were often out of stock.

P2: "There has never been a stock out of ART, however if you have co-morbidities you will not get any medication, you have to purchase in the chemist"

(FGD6)

None of the mothers reported challenges in prophylaxis administration to their infants.

Cues to Action

Cues to action were the perceived solutions to the challenges that the mothers felt were affecting them and possible ways that could improve their experience as the mother-infant pair go through the EID program. The cues to action were reported as perceived by the mothers as follows.

1. Reduction of waiting times in the consultation rooms and in the laboratory;

"Patients should be seen in the order they have come and not skipping other patients."

"Start clinics on time so that mothers can leave on time as well"

"There are too many processes before one is seen and you can enter up to 5 rooms a day before you are done with the final process the services should all be offered under the same room"

"Separating drug dispensing points for HIV patients and the general population to reduce waiting times"

2. To ease the cost of transport;

"If we can be given a little money to come for clinic appointments, this would go a long way in ensuring that we do not miss our scheduled appointments due to lack of bus fare"

"Giving long appointment dates such as three months or six months can reduce the cost of coming to the hospital by reducing the number of hospital visits"

3. To improve partner support;

“Invite our partners to come for counselling in order to understand more so our negative partners, this will reduce stigma and discrimination”

4. To improve adherence;

Economic empowerment so that the mothers can be independent and not rely so much on their spouses, relatives and friends “If you hear of any casual work kindly let me know so that I can generate my own money”

“Telephone reminders two or three days before the appointment days would go a long way in ensuring we keep our scheduled appointments”

Self-Efficacy

All mothers were aware of how to take their ARVs and were confident that they would not pass on the virus to their infants if they adhered to the education and instructions given to them by the healthcare providers. Some mothers however felt that in addition to the routine hospital education they received, additional take away materials to read at home would increase their awareness on PMTCT.

In addition to use of the Health Belief Model by Tarkang & Zotor (2015) maternal Knowledge, knowledge gaps, Attitudes and Practices (KAPs) were also explored. The findings were as indicated below:

1) Exploring knowledge on how to reduce Mother To Child Transmission (MTCT)

All mothers knew at least one way of preventing MTC infections during the antenatal, delivery and breastfeeding periods

Prevention during pregnancy/antenatal clinic

Mothers reported the following ways of reducing chances of infection to their unborn infants: maternal ART adherence, infant prophylaxis, condom use, starting ANC early enough by 3 months. One of the mothers reported that:

P1: “In early pregnancy I was vomiting a lot and by the time my pregnancy was 7 months, I had a very high viral load. The doctors told me that it was because I was vomiting my ARVs, something that could have been prevented. I however was put on good medicine and my viral load went down”

(FGD3)

All mothers reported that they were given prophylaxis drugs for infant before birth and given instructions on how to take the drugs. Some mothers however reported that they did not know why they were giving the prophylaxis especially the septrin:

P3: “I was given 3 types of drugs which I cannot recall the names while I was pregnant, and instructed on how to give the

baby, I however was not told why I was giving my baby these drugs.”

P4: Another mother reported that “septrin is given to my baby to prevent HIV infection just like Nevirapine and another ARV drug that I cannot recall the name”

(FGD2)

From the above sentiments it was clear that some mothers did not know the use of the medication given to them during pregnancy. They all however reported to administer the medicines given to them to their infants immediately after birth.

Prevention during delivery

All mothers’ reported to have been given prophylaxis for their infants immediately after birth, and all were hospital deliveries. The mothers reported as follows;

P1: “I was given prophylaxis for my infant during pregnancy, after delivery I not sure of how to give the medicine so my husband explained to me that I should give the baby the medicine first before breastfeeding”

(FGD1)

P4: “When I was admitted in labor, I called the nurse and told her that I was HIV positive and that I had carried my infant prophylaxis drugs with me. The nurse was very happy and assured me that immediately after birth my baby would be weighed and given the drugs”.

(FGD2)

P5: “I need to ensure I deliver in the hospital for safe delivery of my infant”

(FGD5)

“I ensure that I take my ARVs very well to reduce chances of infection to my baby and also give my baby prophylaxis on time every day”

(FGD4)

From the above sentiments, mothers were well knowledgeable on how to ensure they do not transmit the virus to their infants during the delivery period. They all reported to have gained this knowledge primarily from the healthcare facilities during the antenatal care clinic visits.

Prevention after delivery and during breastfeeding period

Some of the ways that mothers thought could reduce transmission of HIV during the breastfeeding period included;

P5: “One should avoid rubbing children gums with traditional medicine to relieve teething pain as this could pass on the virus if the baby has bleeding gums”

P6: "To prevent infection to my baby during breastfeeding, I check to ensure I have no wounds in my breast, and seek medical attention if I see breast wounds"

(FGD4)

All mothers also knew the various ways of reducing HIV transmission to their infants during the breast feeding period. On further probing by the facilitator, all the mothers also knew that maternal ART adherence reduced their viral load reducing transmission during the breast feeding period.

2) Exploring Knowledge on infant prophylaxis, (drug type, dosing, side effects and benefits)

Most of the mothers knew the infant prophylaxis types and benefits of the drugs however there was a knowledge gap on drug dosing and drug side effects as reported by some mothers:

P1: "I only know that I give my baby septrin, I don't know the names of the ARV Prophylaxis I am giving my infant"

P2: "I can't remember the names of the drugs that I give to my infant, but I know the dosing since I am given instructions for use in the hospital"

(FGD2)

One thing of great concern was that Majority of the mothers did not know the correct dosing for the infant prophylaxis and were not aware of when they should stop the drugs

P4: "I do not know when I should stop the drugs for my infant but I will continue to give my baby prophylaxis drugs until the healthcare worker tells me to stop"

(FGD5)

It is imperative for the mothers to be able to recognize drug side effects and dosing to avoid adverse drug reactions to the infant.

3) Knowledge on maternal ART (drug type, dosing, side effects and benefits)

Only one mother knew the ARV types she was taking. All the other mothers did not know the names or the potential side effects of the ARVs they were taking. They however were aware of the dosing schedule. All mothers were aware of septrin and dosage of the same.

"I don't know the type of drugs I take nor the side effects but I am aware of my dosing schedule which is one tab in the morning and one tab in the evening"

"I can't remember the names of my ARVs, I only remember septrin as one of the drugs that I take"

(FGD3)

4) Knowledge on feeding practices

All mothers practiced exclusive breast feeding up to six months and introduced other foods at 6 months. A few mothers however had no knowledge on when they should stop breastfeeding.

"I practiced exclusive breastfeeding for 6 months and introduced other feeds at 6 months, I however don't know for how long I should continue breast feeding my infant perhaps you could tell me"

(FGD6)

5) Exploring maternal attitude towards the EID Service delivery

All mothers were willing to bring their infants for the 18 months period EID program irrespective of the infant HIV status. There were no reported cultural barriers hindering the mothers from bringing their infants for care.

The mothers reported that the services offered to them were generally good other than long waiting hours to see the clinicians. They also reported good interpersonal relationships with the healthcare providers:

P1: "I am happy with the services and attitudes of the health workers in the EID program. I wish we could be retained here and not discharged back to the main CCC clinic after the 18 months"

(FGD3)

All the mothers expressed dissatisfaction with services offered in the general CCC because of long waiting times: P3: "In the general CCC you have to wake up at 5am so that at least by 12 pm you have been discharged"

(FGD1)

However the mothers expressed dissatisfaction with lab services offered to them. They reported that they had to queue for long periods of time to get their blood drawn for viral load counts and PCR testing for their infants. This made their infants to become distressed and delayed them from going back to their duties back at home. They also reported delays in the receipt of their infants PCR results as well as their viral load counts. The mothers' reports were as follows:

P5: "You have to wait in the queue like any other patient and it takes a very long time"

(FGD3)

The mothers requested to have alternative lab/testing area for their infants and themselves as well as their infants. P4: "We request to have our own lab/bleeding area specifically for HIV exposed infants, this would reduce on waiting times"

(FGD3)

Long Turn-around time from collection of the sample to receipt of the same to the caregiver was also reported as a challenge by the mothers. Most mothers reported an average waiting time of two to three months:

P1: "I received my 6 weeks PCR results when my baby was four and a half months. They say that the results take some time these days"

P3: "I waited for about two months and decided to enquire about my baby's results during one of my normal hospital visits."

(FGD6)

There were also reports that the lab results would get misplaced and you would be required to repeat the test:

"Sometimes the results get misplaced and you are force to repeat the test"

(FGD4)

However, mothers in one of the facilities reported that they were removed lab samples in the service delivery rooms and did not have to go and queue in the lab for sample removal. In the same facility, mothers got their infants PCR results in the next visit which was scheduled between one or two months.

All the mothers were very satisfied with the counselling services offered to them as reported below:

P4: "Counselling is done very well such that even if you had decided not to take medicine, you will be counselled to start"

P5: "I had defaulted on my PMTCT visit and the mentor mothers looked for me in my house and restarted me on ART. My husband and I had separated and the counsellors looked for him and reconciled us."

(FGD3).

Discussion

The success of the EID program is pegged on ensuring that the caregivers understand the benefits of timely initiation of their infants into care. High maternal knowledge was attributed to improved EID attendance, in a study conducted by Makau, Okwara, & Oyore (2015), this also lead to improved health seeking behavior in the mothers and good infant health outcomes. A study by Adeniyi et al., (2015) demonstrated that nearly all the study participants were not aware of how soon or the right time for ARVs to be initiated to their infant with HIV infection. This could lead to delay in initiation into care with consequent poor infant outcomes.

Stigma and discrimination also undermine the efforts of PMTCT strategies, Adeniyi et al., (2015) point out that Stigma resulting from their own disclosure to others reduced their likelihood of recommending other members of their community into the EID program. Similarly, a study by Hassan et al., (2011) cited that

lack of appropriate social support structures to facilitate disclosure and handle possible stigma and discrimination. One of the caregivers stated the following concerning disclosure: "...you might tell one who ends up taking you to the chief... you might be jailed and asked to pay a lot of money; you cannot tell anyone about this illness, people are taken to court... you cannot tell anyone, it is your secret". Inappropriate social support structures for disclosure were seen to be a contributing factor to general drop-out of caregivers from the EID program.

A study with similar findings by Hlarlathie, et al., (2014) demonstrated that non-disclosure to partners and other persons in the caregivers lives had many different complex dimensions where the fear of disclosure was very real and put the mother and infants life at great risk especially due to poor adherence.

Makau, Okwara, & Oyore (2015), study demonstrated that mothers stated the following factors that negatively influenced EID uptake; inaccessibility of health services due to long distances to the hospitals, long waiting times at the service delivery points and lack of transport to attend their scheduled clinic.

Although no direct costs were incurred by the caregivers while seeking EID services, indirect costs were mentioned by the caregivers in our study such as cost of transport as they come for EID services and cost of buying non-ART drugs for opportunistic infections.

These findings were similar to those of Hassan et al., (2011) where the authors stated that caregivers complained of cost implications of travel to the healthcare facilities and long waiting times to get services. The caregivers recommended longer appointment schedules to reduce the number of hospital visits. Transport costs was also cited as a perceived barrier by Hlarlathie et al., (2014), where caregivers pointed out that it was a great barrier to accessing services to them. These authors also found out that stigma and discrimination, lack of or inadequate male partner support and the influence of men and other women living in the household of the caregiver influence her ability to seek EID healthcare services or not. These factors therefore needed to be explored further to assess the impact they had on maternal health seeking behavior as they go through EID.

Our study had limitations found in most qualitative studies where findings of the research were not tested to discover whether the findings were statistically significant or due to chance. Further, no attempt was made to assign frequencies to the linguistic features which were identified in the data. Despite these limitations, the study was able to learn from the participants the EID process the way the mothers experience it, their perceptions and interpretation of EID concepts in real time. Central themes were able to be identified and emerging issues documented for future action and recommendations.

Conclusion

Despite the good knowledge of mothers about infant HIV infection and the availability of treatment, inadequate knowledge

on appropriate feeding practices, ART therapy and prophylaxis for both mother and child undermine PMTCT efforts. Additionally, stigma and discrimination as well as fear of disclosure reduce adherence to care and treatment. These challenges need to be addressed through urgently through community education, partner counselling and assisted disclosure as part of the PMTCT package in our country so as to improve adherence and ultimately improve infant health outcomes.

Competing interests

The authors declare no competing interests.

Authors' contributions

Elizabeth Mueke Kiilu development of the concept and manuscript, Simon Karanja and Gideon Kikuvi critically reviewing of the document from its conception, up to manuscript submission and the final approval. All authors read and agreed to the final version of this manuscript and equally contributed to its contents and to the management of the case.

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