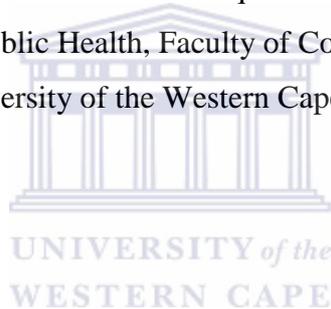


**FACILITATORS AND BARRIERS TO HIV TESTING FOR INFANTS OF  
CAREGIVERS WHO DELIVERED AT ENTEBBE HOSPITAL, WAKISO DISTRICT,  
UGANDA.**

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A Mini-thesis submitted in partial fulfilment of the requirements for the degree of Masters in  
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**Key words:** HIV, HIV testing, Early HIV testing, Uptake, Caregiver, Infant, Facilitators, Barriers

## Abbreviations

ART	Antiretroviral treatment
DBS	Dried Blood Spot
EID	Early Infant Diagnosis
HIV	Human Immuno Deficiency Virus
PCR	Polymerase Chain Reaction
PMTCT	Prevention of Mother-to-Child Transmission
WHO	World Health Organization
MOH	Ministry of Health
MTCT	Mother-to-Child Transmission



## **Definition of Key Terms**

**Caregiver:** A biological parent or any other adult that is the key carer for a child.

**Uptake:** refers to the number of children who are tested for HIV

**HIV counselling and testing (HCT):** Provision of pre-test counselling, HIV test results and post-test counselling for the caregiver of the child at risk of HIV.

**Exposed Children:** Children born to HIV-positive mothers and therefore at risk of being HIV-positive.

**Infant:** Child less than 12 months of age (WHO, 2010).

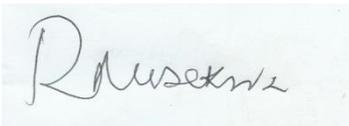
**HIV PCR test:** A test used to detect the presence of HIV among infants. It is used in children below 18 months of age since they are still carrying the mother's HIV.

**Peer Mothers:** HIV-positive mothers who support mothers living with HIV to adhere to their medication.



## **DECLARATION**

I declare that this mini thesis research titled: **Barriers and facilitators to early HIV testing for caregivers who delivered at Entebbe hospital**, Kampala is my own work. None of this work has been submitted for any degree of any other award in this or any other university. All sources of information used in the research have been acknowledged and referenced.



Ruth Musekura

Date: 8/11/2016.



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## **Abstract**

### **Introduction**

Despite overwhelming evidence about benefits of early initiation of antiretroviral treatment (ART) for HIV-exposed children in terms of reducing their morbidity and mortality, there are children in Uganda and globally who still do not access treatment. Early infant diagnosis (EID) of HIV infection offers an opportunity for identifying, follow up and testing for HIV-exposed infants. In Uganda, despite the availability of EID of HIV infection for infants, many are left undiagnosed or diagnosed when it is too late, resulting in high HIV-related child mortality. The aim of this research therefore was to explore the facilitators and barriers to EID of HIV for infants of mothers who delivered at Entebbe hospital in Uganda and from this propose lessons for increasing EID uptake.

### **Methodology**

The study utilised a qualitative exploratory approach using in-depth interviews with mothers who brought back their children for early HIV testing and those who never returned their children for testing. Key informant interviews were conducted with health care providers and peer mothers. Interviews were recorded and transcribed verbatim. Data were analysed using the thematic content analysis approach to identify themes and patterns in the data.

### **Results**

Individual, health facility, community and economic factors were found to affect EID uptake. Individual factors include limited knowledge about: the timing for EID, the efficacy of PMTCT interventions and HIV treatment and the fact that asymptomatic children can be HIV-positive. Other caregiver factors include fear of finding out their children are HIV-positive, denial of HIV status, fear of disclosure and the resulting stigma and discrimination, caregiver religious and cultural beliefs. The negative attitudes of the health care workers, fear of breach of confidentiality, inadequate EID information from the health care workers, caregiver place of delivery and long waiting times were the health facility factors affecting EID.

### **Conclusion**

Early infant diagnosis is a critical gateway to prevention and care services for paediatric HIV. The results of this study suggest that factors at caregiver level are critical drivers that influence uptake of EID at Entebbe hospital, Uganda. Providing information to caregivers and promoting awareness about the benefits of testing infants early are the recommended strategies for increasing uptake.

**Key words:** HIV, HIV testing, Early infant HIV testing, Uptake, Caregiver, Infant, Facilitators, Barriers



## **CHAPTER 1: INTRODUCTION**

### **1.1 Background**

HIV remains one of the world's most serious public health problems with an estimated 36.9 million people living with HIV globally at the end of 2014. Of these, 70% were from sub-Saharan Africa (UNAIDS, 2015). HIV continues to be a key cause of mortality with 1.2 million people dying of AIDS related illnesses in 2014 (UNAIDS, 2015).

Among children, HIV is also a challenge with nearly 2.1 million children living with HIV worldwide in 2014 most of who were from sub-Saharan Africa (UNAIDS, 2015). Globally about 220,000 new HIV infections occurred among children in 2014. Though this was a reduction of 48% from 2009, it is still unacceptably high with the advent of prevention of mother-to-child transmission (PMTCT) interventions (UNAIDS, 2015).

There exists growing evidence from resource limited settings on favourable health outcomes among those HIV-infected children who initiate Anti-Retroviral Treatment (ART) early and remain in follow-up (Janssen et al., 2010; Ndirangu et al., 2010; O'Brien et al., 2006; Sauvageot et al., 2010).

If children who are HIV-positive are not detected early and started on treatment they progress faster to illness and are more likely to die compared to adults or older children (Newell et al., 2006). Without HIV treatment, almost half of vertically infected children will die by their second birthday (Bland, 2011; Newell et al., 2004, Marston et al., 2011; Becquet et al., 2012). HIV significantly contributes to child mortality and morbidity in sub-Saharan Africa (Liu Li et al., 2012). Despite the proven benefits of ART, treatment coverage for HIV-positive children continues to lag behind that of adults with only 31% of the 2.1 million children living with HIV under 15 years of age accessing ART globally in 2014 compared to 27% in 2013 and 10% in 2009 (UNAIDS, 2015). This leaves a number of eligible HIV-positive children vulnerable to morbidity and the possibility of mortality within one year (Marston et al., 2011, UNAIDS, 2012).

Low treatment coverage is attributed to delays in getting results and losses along the testing – treatment cascade (UNAIDS, 2015). As a result, most HIV- infected children are tested and started on treatment when they are already exhibiting HIV signs and symptoms and as a result they do not reap the benefits of early treatment. In fact studies conducted in sub-Saharan Africa (SSA) show that the median age for ART initiation is 4.9 and 9 years and in

all these cases children were brought to the health facility when they are already very sick with severe immune deficiency (Bolton - Moore et al., 2007; Kiboneka et al., 2008).

The World Health Organisation (WHO) therefore recommends virological testing by DNA Polymerase Chain Reaction (PCR) at 4–6 weeks of age for all HIV-exposed children and early initiation of ART for infected children (WHO, 2010). Despite this recommendation for testing, out of the estimated 1.2 million HIV-exposed infants among the 21 priority countries only 49% received a virologic test to establish their HIV status within the first two months of life (UNAIDS, 2015).

About 20,600 children were newly infected with HIV in 2011, a reduction of 25% from 2009 (UNAIDS, 2012) and the proportion of infants accessing testing in the first two months increased from 9% in 2009 to 28% in 2011 (WHO, 2011). Even with these gains made in Early infant Diagnosis (EID), paediatric ART coverage in Uganda in 2013 remained low with only 44% of eligible children accessing treatment (Elyanu et al., 2013). A Ministry of Health survey also showed that only 42% of HIV-positive mothers aged 15 – 49 years who gave birth in the last two years before the survey said that their baby had ever been tested for HIV as part of PMTCT services (MOH, 2011). This calls for an investigation of the reasons why caregivers do not take their babies for HIV testing at 6 weeks even when benefits of early HIV testing and treatment are documented. Few studies have evaluated the reasons for failures to return children after delivery for EID of HIV (Cook et al., 2011).

## **1.2 Problem Statement**

An estimated 20,600 infants in Uganda got infected with HIV through mother-to-child-transmission (MTCT) in 2012 (UNAIDS, 2012). If infants are not tested and started on ART, 50% will die before they turn two years of age (Newell et al., 2004). Paediatric ART coverage in Uganda in 2013 remained low with only 44% of eligible infants accessing treatment (Elyanu et al., 2013). Though early HIV testing provides an entry point for starting children on treatment (Woldesenbet et al., 2015), in Uganda only 41.9% of exposed infants were tested for HIV in their first 2 months of birth in 2013 (UAC, 2014). Although this has increased from 9% in 2009 it is still relatively low and a cause for concern (WHO, 2011). These numbers suggest that many at risk infants are not being tested for HIV. Most infants are started on treatment once they are already sick. This has implications for the development of children and their long-term morbidity and mortality (Newell et al., 2006). HIV infected infants are 12 times more likely to die during their early stages of life compared to uninfected

infants. Yet evidence shows that early initiation of ART reduces infant mortality among infants within the first 3 months of life (Violari et al., 2008). However for the infants to be initiated onto ART they first need to be tested for HIV. In fact, the majority of HIV- positive children who die are those who have never been diagnosed or who come to the health facility too late (Naidoo, 2007). It is not clear why these exposed children are not being tested. In Uganda, like in most other sub-Saharan African countries there are a limited number of studies that explore facilitators and barriers to HIV testing for infants from a caregiver's perspective. Most studies focus on the supply rather than demand side of what facilitates or bars caregivers from accessing HIV testing (Kiragu et al., 2008; Schenk et al, 2014).

This study therefore investigated the factors that may act as facilitators or barriers to early HIV testing for infants exposed to HIV in Uganda.

### **1.3 Purpose**

The experiences and perceptions of caregivers of HIV-exposed children, health care workers and peer mothers will be used to inform programming on early HIV testing for children. The findings will provide recommendations for practical interventions that could increase uptake of early HIV testing for infants in Wakiso district, Uganda. The findings will also be shared with and of use to the Health Promotion Division of Uganda's Ministry of Health for the design of appropriate behavioural change communication messages to increase the uptake of HIV testing for exposed infants.

Results from the study will contribute towards addressing gaps in HIV prevention, care and treatment programs by contributing to improvements in HIV treatment outcomes for infants thus increasing chances of survival for those infected and exposed.

The Global Plan towards Elimination of New HIV infections Among Children and Keeping their Mothers Alive proposes 100% treatment coverage for eligible children by 2015 so as to contribute towards achievement of Millennium Development Goal No. 4 (MDG 4). This strategy has now been complemented with the 2030 Sustainable Development Goals (SDGs) that emphasizes a reduction in HIV-related deaths among infants and adults through universal access to various interventions that include HIV testing and treatment (WHO, 2015, UNAIDS, 2015). This research is a modest contribution towards the achievement of these targets.

From a public health perspective and clinical implications by highlighting challenges of universal coverage of EID, the study provides valuable input into designing effective

strategies towards universal coverage of EID. Findings from the study will also guide infant testing and diagnosis counselling and support services of PMTCT programmes. The findings will help in the design of culturally appropriate responses to support caregivers and mother's uptake of EID.

#### **1.4 Outline of the thesis**

This thesis is comprised of six chapters. This chapter has introduced the study, its aim and objectives and outlined the problem statement as well as the purpose of the research. The second chapter presents a review of the literature related to facilitators and barriers to HIV testing for infants. Chapter three describes the research design and methodology used to study facilitators and barriers to HIV testing for infants of HIV-positive mothers. The fourth chapter presents the findings of the study. Chapter five discusses and interprets the findings of the study while highlighting the limitations encountered. The sixth and final chapter presents the conclusion and recommendations drawn from the study.



## **CHAPTER 2: LITERATURE REVIEW**

### **2.1 Introduction**

This chapter provides an overview of previous research, and summarizes the state of knowledge about the facilitators and barriers to HIV testing for children exposed to HIV. The intention of reviewing existing literature is to identify what is already known about the research question and to build upon existing knowledge (Galvan, 2009; Mouton, 2001). The review starts off with an examination of literature on vertical transmission. It then delves into the importance of early infant diagnosis (EID) and early HIV treatment for infants in order to place the study into context. This is followed by a review of the literature about the facilitators and barriers to HIV testing for infants at different levels that include the individual or caregiver, community or interpersonal and institutional or health facility levels.

### **2.2 Vertical transmission of HIV**

Paediatric HIV infections are normally a result of vertical transmission of the virus. Without any preventive interventions, infection can occur *in utero*, during labour and delivery or postpartum during breast feeding. Without medical prevention, 20% to 45% of HIV-exposed infants could become infected (WHO and UNICEF, 2007).

Mother-to-child-transmission (MTCT) of HIV remains one of the major challenges of the HIV epidemic, especially in sub-Saharan Africa (SSA) (Sperling et al., 1996; De Cock et al., 2000). Nearly 400,000 infants are infected with HIV as a result of mother-to-child transmission of HIV (MTCT) (WHO, 2010). According to the Ugandan Demographic and Health Survey (2011) about 21% of HIV transmission in Uganda is due to MTCT of HIV (UBOS, 2011).

In 2003, the United Nations adopted a comprehensive strategic approach to prevent HIV in infants and young children. This strategy comprises of four approaches, namely: primary prevention among women of reproductive age; prevention of unintended pregnancies among women infected with HIV; preventing HIV transmission from a mother to her infant; and providing treatment, care and support to mothers living with HIV (WHO & UNICEF, 2007). Despite the major strides made in tackling MTCT of HIV worldwide, with variations in different countries (WHO, 2010), children still accounted for 220,000 of new HIV infections in 2014, the majority of these new infections in SSA (UNAIDS, 2015).

### **2.3 Early infant Diagnosis of HIV**

According to the WHO, early infant diagnosis (EID) involves testing of infants born to HIV-positive women within the first 2 months of life to establish their HIV status and eligibility for antiretroviral treatment (ART) (WHO, 2015). The recommendation is that HIV testing for infants is done using a virological test with dried blood spots (DBS) for Polymerase Chain Reaction (PCR) at six weeks to establish if a child has been infected through MTCT (WHO, 2010). Testing is repeated throughout the breastfeeding period when the risk of transmission is still high. Antibody tests can only be accurate if used to exclude HIV infection after 12 months or to confirm infant infection after 15–18 months (WHO, 2010). Infants found to be HIV-positive undergo a viral load test before being referred for early initiation of ART (Creek et al., 2008; Khamadi et al., 2008).

EID has benefits at the individual, family and policy levels. At the individual level, EID helps in, first, identifying HIV-positive infants so that they can get clinical evaluation and be put on ART early or be treated for opportunistic infections (OIs) and, secondly, identifying HIV-negative infants so that their HIV-positive mothers are counselled on how to prevent HIV transmission (Creek et al., 2007, WHO, 2013).

EID also has psychosocial benefits to families of uninfected infants. Families who do not know that not all infants delivered by HIV-positive mothers are infected usually assume that all such infants are infected with HIV (Creek et al., 2007). Research evidence shows that, due to such pessimism, a family may be reluctant to care for an infant born to an HIV-positive mother especially if the mother is very ill or dies. In contrast, families tend to be more attached to HIV-negative infants (Creek et al., 2007). As a result, EID may provide reassurance to families of those uninfected infants and lead to better quality of care for the infants (Creek et al., 2007).

At policy level, EID programs enable prevention of mother-to-child transmission (PMTCT) programs to monitor their efficacy and influence policy decisions. Routine EID has been found to improve attitudes towards PMTCT programs and morale among health care providers who realize that PMTCT can help infants stay HIV-negative (Creek et al., 2007).

### **2.4 Paediatric HIV treatment**

Early initiation of ART among children has been proved to have immunological, virological and clinical benefits for HIV-exposed infants (Puthanakit et al., 2005; Chiappini et al., 2006; Song et al., 2007; Wamalwa et al., 2007; Violari et al., 2008; Hassan et al., 2011; Cotton et

al., 2013, Bitnum et al., 2014). An HIV treatment trial in South Africa revealed that introducing ART before 3 months of age and before clinical signs and symptoms of HIV emerge resulted into a 76% reduction in morbidity and a 75% reduction in mortality in infants (Violari et al., 2008).

As a result of this evidence the 2010 WHO guidelines were revised to propose providing treatment to all HIV-infected infants less than 2 years irrespective of their immune status or clinical staging (WHO, 2010). Due to the decentralization of paediatric care and treatment guidelines and the availability of easier ART initiation guidelines and child-friendly paediatric formulations, the number of children on ART has increased by five times globally since 2006 when less than 100,000 children were on ART (UNAIDS, 2012). Even the 2013 WHO ART guidelines have been revised further and now propose that ART is initiated in all HIV-positive children under-5 years (WHO, 2013).

Despite all the efforts made to simplify drug regimens and improve access to ART, improve antenatal testing and maternal enrolment in PMTCT programmes, several challenges still inhibit the identification of HIV-exposed infants and infected children in many developing countries consequently delaying or inhibiting their initiation on HIV treatment (Cook et al., 2011; Chatterjee et al., 2011; Ahmed et al., 2013). This partly explains the low coverage of paediatric treatment in most HIV high burden countries compared to the proportion of adults on treatment. For instance, whereas 38% of adults living with HIV got enrolled on ART programmes in 2013, only 24% of children aged 0–14 years living with HIV received HIV treatment (UNAIDS, 2012).

As a result of the failure to appropriately address paediatric HIV treatment needs, including the need to identify, as early as possible, infants who are HIV-positive, the rate of decline in AIDS-related deaths among children is very small compared to the drop in new infections among children. It is estimated that children, who comprise 9% of all people living with HIV, contributed to 13% of AIDS-related deaths in 2013 (UNAIDS, 2014). EID strategies have to be strengthened so that infants benefit from early ART otherwise if they remain undiagnosed, many will die from AIDS-related complications. However, to be able to scale-up HIV testing for children, the barriers to early HIV testing for infants need to be understood better. Research literature about these barriers is examined in the subsequent sections of this chapter.

## **2.5 Barriers and Facilitators to HIV Testing for Infants**

The review in this section examines the existing evidence regarding the factors that facilitate and inhibit EID uptake. The factors are examined here at three levels: the individual or caregiver level; community-level and the health facility level.

### **2.5.1 Individual Caregiver Level Factors**

Individual caregiver factors that affect uptake of testing identified within previous research include maternal receipt and consumption of ART, independent maternal source of income, maternal level of education, various aspects relating to maternal knowledge of importance of EID and the efficacy of PMTCT interventions, fear of an HIV-positive result for the infant, denial of their own and child's HIV status, male involvement in EID, fear of unintended disclosure of HIV status and the resulting stigma and discrimination from the community. Caregiver religious and traditional beliefs were also found to be factors influencing EID uptake.

#### **2.5.1.1 Maternal receipt of ART**

A retrospective cohort study conducted in rural Mozambique revealed that maternal receipt of ART improved health outcomes for the mother and chances of EID uptake. This, the authors argue was because access to ART improved their understanding of HIV and increased the regularity of their interactions with health care workers, to identify their exposed infants (Cook et al., 2011). Maternal receipt of ART was also a predictor of EID in an observational study of initiation of paediatric ART in Uganda (Boender et al., 2012) and in a cross-sectional study of determinants of EID and treatment in informal settlements in Nairobi, Kenya (Makau et al., 2015) and in a study in Malawi where testing of index clients was found to be an effective means to identifying HIV exposed and infected children (Cohen et al., 2010). The significance of mothers on ART to uptake of EID was demonstrated in a study in Kenya where 2/3 of infants who were lost to follow up had mothers who were also lost to follow up with HIV care (Hassan et al., 2011).

These studies suggest that maternal receipt of ART has the potential to positively influence maternal health which in turn may impact upon EID uptake (Cook et al., 2011). Caregivers who are not taking ART were found to have limited awareness about the availability of paediatric ART and the importance of early HIV testing for infants (Donahue et al., 2012). It will be important to know whether the same views are advanced by caregivers in the current study.

### **2.5.1.2 Influence of Maternal economic status**

In the aforementioned study in Mozambique, an independent source of income for the mother increased the chances of follow-up for EID (Cook et al., 2011). The study conducted in Nairobi also revealed that a mother's monthly household income was significantly associated with EID uptake (Makau et al., 2015). Health workers in a mixed methods study in Uganda which focused on barriers to initiation of paediatric ART revealed that caregiver's lack of employment is a key barrier to accessing EID (Boender et al., 2012). It must be noted that the studies by Cook et al. (2011) and Makau et al. (2015) were both quantitative, so the reasons for the findings were not explored. Moreover the evaluation by Cook et al. (2011) was done in the first year of the EID program. It is therefore difficult to generalize the findings over settings with established EID programs where there could be interventions that offer financial assistance to cash-strapped caregivers to enable them access services.

Although in most countries EID is provided free of charge, and in a study in Kenya (Dye, Apondi & Luganda, 2011) and another in Zimbabwe (Schacht et al., 2014), provision of free HIV testing services was found to encourage HIV testing. There are however possible indirect costs that affect access to EID. The opportunity cost of time spent seeking care and transport costs incurred were cited by caregivers in a study in Kenya as a barrier to seeking EID (Kiragu et al., 2008; Hassan et al., 2011). Lack of transport fare to travel the long distances to testing centres was also mentioned as a barrier to EID in several other SSA studies (Makau et al., 2015; Ahmed et al., 2013; Peltzer & Mlambo, 2010; ICWLHIV & GNP, 2015. Schacht et al., 2014; Boender et al., 2012). In Kenya, caregivers also complained of costs for treating opportunistic infections (OI) (Kiragu et al., 2008).

Post-natal economic migration of the caregiver influenced the enrolment of the infant on EID in a study conducted in Namibia, Nigeria and Kenya. Migration made follow-up by the health facility difficult (OPHID, 2014). In a related study, service providers in Kenya mentioned that economic migration of caregivers affected their ability to seek EID services (Hassan et al., 2012). Some caregivers who had a source of income were constrained from seeking EID by their busy schedules (Braitstein et al., 2011).

### **2.5.1.3 Maternal level of education**

A trial to understand the predictors of loss to follow-up of infants in a large urban cohort of Malawi (Ioannidis et al., 1999) and a case control study to determine factors affecting loss to follow-up in a Nigerian PMTCT program (Oladokun, Brown & Osinusi, 2006) concluded

that more educated mothers were more likely take up EID. A study by Thior et al. (2007), among postpartum women in Botswana, revealed the contrary: women who were more educated were less likely to accept Voluntary Counselling and Testing (VCT) for themselves and their infants, since they were able to weigh the pros and cons of a positive HIV result. In fact, a study by Makau et al. (2015) found that low levels of formal education or no formal education at all did not significantly influence the uptake of EID. These studies were different from the current study in context and method, so it is hard to draw conclusions from the cited research to this context.

#### **2.5.1.4 Caregiver's fear of an HIV-positive result for the infant**

Some studies in SSA suggest that caregivers may develop feelings of fear, embarrassment and stigma as a result of the possibility of their infants being tested positive. This, coupled with being emotionally unprepared for a sick child (Yeap et al., 2010; Peltzer et al., 2010; Donahue et al., 2012; Buzdugan et al., 2012; ICWLHIV, 2013; Adeniyi et al., 2015) and the association of HIV to death since it has no cure (Schacht et al., 2014) may discourage them from EID . In one study mothers however admitted that HIV was treatable if children are tested early and started on treatment though this did not reduce their feelings of fear (Chhagan et al., 2011). Observing the health status of other HIV positive children improve while on ART motivated some mothers to take their children for HIV testing (Schacht et al., 2014).

#### **2.5.1.5 Maternal lack of adequate EID information**

Several studies reveal that maternal knowledge about EID had a positive effect on EID (Adeniyi et al., 2015). In Kenyan studies a significant association exists between maternal knowledge of the importance and right timing of EID and its uptake (Kiragu et al., 2008; Makau et al., 2015; Hassan et al., 2011). Similarly, in cross-sectional surveys in South Africa, limited knowledge about EID and vertical transmission prevented uptake of EID (Yeap et al., 2009; Peltzer et al., 2010; Woldesenbet et al., 2015). This poor knowledge has been partly attributed to the health care providers, who, according to Hassan et al. (2011) and OPHID (2014), were not conversant with accurate EID information.

#### **2.5.1.6 Caregiver's belief in the efficacy of PMTCT interventions**

Caregiver misperceptions about the efficacy of PMTCT interventions have also been cited as one of the barriers to accessing EID in South Africa. Some mothers felt it was not important to test a child for HIV if she had adhered to PMTCT requirements (Peltzer et al., 2010).

Many caregivers in another South African study believed that strict adherence to PMTCT guidelines resulted in no risk of HIV transmission to the infant. They were not aware that PMTCT interventions were not completely protective (Yeap et al., 2010). In a Ugandan study, 12% of women interviewed did not think it was possible for a mother to pass on the virus to an unborn baby (Bajunirwe & Muzoora, 2005).

#### **2.5.1.7 Caregiver's perception of the health status of infants**

In a retrospective study about EID in Kenya, Vreeman et al. (2010) found that some caregivers did not understand or see the benefit of testing their children because they looked healthy. Similar findings were made in Uganda (Boender et al., 2012), Mozambique (Schacht et al., 2014) and South Africa (Peltzer et al., 2010; Adeniyi et al., 2015). This may explain why a majority of the infants brought for EID are very ill (Hassan et al., 2011; Kiragu et al., 2008; Boender et al., 2012).

#### **2.5.1.8 Denial of own and child's HIV status**

In a study in Uganda, health workers shared that denial of HIV status for the child was one of the factors that delayed health-seeking behaviour among caregivers (Boender et al., 2012). In another multi-country study among women living with HIV in Namibia, Nigeria and Kenya, denial of HIV status was cited as a barrier to seeking EID for HIV-exposed children (ICWLHIV & GNP, 2015). This challenge extends to caregiver's denial of their own HIV status (Nuwaha et al., 2002). This denial delays early diagnosis of HIV for both infants and their adult caregivers, compounding the problem of low enrolment on ART.

#### **2.5.1.9 Frequent change of caregivers**

Frequent change of caregivers was found to be a challenge in diagnosing HIV-exposed infants and linking those that test positive to treatment and care in a study in Kenya (Hassan et al., 2011). In a descriptive implementation study in Zimbabwe, HIV-exposed infants who were orphans and/or vulnerable or those whose mothers had moved away or died also failed to access EID on time or at all (OPHID, 2014).

#### **2.5.1.10 Lack of male involvement in EID**

The literature demonstrates the critical role of male involvement in EID. In a study in Zimbabwe, male involvement was perceived to be important for access to EID services for infants. Respondents noted that it becomes difficult to access EID because male partners, not in support of women seeking services for themselves and their children, would abuse them if

their infants were tested for HIV without their knowledge (OPHID, 2014). In a study in South Africa (Peltzer et al., 2010), respondents also mentioned that male partners would be violent if they had their infants tested for HIV. Resource dependence on men makes it difficult for women to seek health services on their own or explain matters pertaining to seeking postnatal services

Motivation from a partner, on the other hand, is a facilitator for caregivers seeking HIV testing for children, while lack of support structures to facilitate disclosure and deal with stigma were said to inhibit HIV testing for infants, as was revealed in a study in Kenya (Hassan et al., 2011). In another study in Kenya lack of support from male spouses was a hindrance to HIV testing for children and husbands only gave consent to mothers to test a child when the child was visibly sick (Kiragu et al., 2008).

#### **2.5.1.11 Caregiver beliefs**

The value attached to traditional versus modern medicine was found to be a barrier to EID access. In a Mozambican study caregivers revealed that they preferred alternative care because they believed some diseases have spiritual causes which required traditional rituals first before modern medicine, as a result, HIV-exposed children missed out on early HIV testing (Schacht et al., 2014). In the same study it was mentioned that traditional healers in some instances act as motivators for EID by referring patients to health facilities. In a study in Kenya, respondents mentioned that caregivers of HIV-exposed children opted to visit traditional healers first before seeking bio-medical attention. Services from traditional healers were considered affordable, accessible and free of stigma (Kiragu et al., 2008). Similarly, about 9% of respondents in a study in Western Kenya admitted that their HIV-exposed children were not returned for follow-up care because they believed that they were healed by faith or traditional medicine (Braitstein et al., 2011) while in a study in Malawi caregivers preferred traditional doctors because they thought their children were bewitched (Donahue et al., 2012).

Traditional cultural practices associated with child delivery also impact uptake of EID. A study conducted in Kenya, Namibia and Nigeria, found that HIV-positive mothers were not comfortable taking their infants out of home before the elapse of a socially acceptable number of days (ICWLHIV & GNP, 2015). Similarly, Village Health Workers (VHWs) in a study in Zimbabwe found that Shona customs demand women deliver at their parents' home thus affecting her ability to take the child for testing (OPHID, 2014). A retrospective study in

Botswana revealed that the tradition of mothers leaving their marital homes after delivery to stay with parents made it difficult to identify and locate HIV-exposed infants. Due to fear of disclosure and stigmatization, the mothers were reluctant to seek EID services in their new places of abode (Motswere-Chirwa et al., 2014). In Nigeria, too, HIV-positive women mentioned that tradition inhibits them from moving babies around a lot (ICWLHIV & GNP, 2015). This customary limitation of movement does not support the frequent visits to health facilities associated with EID.

The religious beliefs of caregivers have been found to have adverse effects on their uptake of EID. In Zimbabwe HIV-positive mothers belonging to the Apostolic faith resisted seeking EID services after delivery (OPHID, 2014). In a study from Western Kenya there was a general belief in the power of God to heal their children, some mentioned that they could not seek divine intervention and also continue taking HIV medication (Wachira et al., 2012).

Fatalistic beliefs about HIV were another potential barrier to HIV testing for infants. In a study in Gauteng province of South Africa, both caregivers and health workers believed that knowing a child's status would make the disease advance faster and that taking HIV treatment is futile (Yeap et al., 2010). Fatalistic beliefs about early and certain death for infected children were also one of the barriers to EID cited in studies in Kenya (Kiragu et al., 2008) and Malawi (Chi konde, 2009; Donahue et al., 2012). In India, caregivers shunned EID because ART only prolonged life (Chaturvedi et al., 2009).

It is important to note that some fatalistic beliefs have their roots in real experiences (Schacht et al., 2014). It would therefore be critical to explore these in a period when ART is widely available.

#### **2.5.1.12 Infants tested for HIV to comply with tenets of a responsible mother**

The social experience has possibly begun to change some traditional norms. Mumtaz et al. (2013) notes that social values may now include HIV testing for infants and adults as a sign of a good mother. The authors note that the urge to protect their infants prevailed over caregiver's fear of stigma, a key barrier to the uptake of HIV testing.

#### **2.5 .2 COMMUNITY OR INTERPERSONAL FACTORS**

Community and interpersonal factors that were found to affect HIV testing in the literature review include fear of unintended disclosure and the resulting stigma and discrimination from the community and social support (or lack of it) from the social network.

### **2.5 .2.1 Fear of unintended disclosure and the resulting stigma and discrimination**

Stigma and the potential risk of disclosure prevent people from seeking counselling and testing (UBOS, 2011; Berendes & Rimal, 2010). Donahue et al., (2012) posit that high levels of stigma in a community can affect the willingness to disclose and the lack of disclosure can perpetuate internal and externalized forms of stigma. Kiragu et al., (2008) found that stigma is believed to affect access to EID because HIV testing for infants gives a clue to parental HIV status and may attract undue attention and critique. People fear not only discrimination against their children but also against themselves (Braitstein et al., 2011; Berendes et al., 2011), this may result in seeking HIV testing for children in far off districts, as a study in India revealed (Chaturvedi et al., 2009).

Similarly a cross-sectional study in Zimbabwe found that the decision to test children was linked to their parent's status and their perceived risk. Almost half of those interviewed (42%) found it difficult to test their children because they fear that the children will be discriminated against (Buzdugan 2012). A prospective observational study in Kenya found similar results; 30% of HIV-exposed children were not returned to the clinic due to fear of community or family discrimination (Braitstein et al., 2011).

An explorative study from South Africa found that mother's experiences of stigma led to fear of EID (Adeniyi et al., 2015). Similar fears were cited by caregivers in research in Namibia, Kenya and Nigeria (ICWLHIV & GNP, 2015). HIV-positive mothers feared the repercussions of disclosure of child's status on their ability to breastfeed which is strongly positive normatively. Fear of disclosure as a barrier to EID was also cited in other studies in South Africa (Peltzer et al., 2010), Botswana (Motswere-Chirwa et al., 2014) and Uganda (Boender et al., 2012; Byakika-Tusime et al., 2009). These findings show the critical role stigma plays as a barrier to HIV testing in different contexts. In the context of Uganda, the level of stigma and discrimination associated with HIV is very high and the positive accepting attitudes towards PLWH are as low as 20% among women and 31% for men (UBOS, 2011).

### **2.5.2.2 Influence of social support networks on EID uptake**

In a study in Kenya social support groups were found to be facilitators for caregivers seeking EID, while lack of support structures to facilitate disclosure and deal with stigma was found to inhibit HIV testing (Hassan et al., 2011). Oladokun, Brown and Osinusi (2006) found that

being a member of a support group was associated with better follow-up as a result of social support and education from the group. Groups provide mothers with emotional support and information on EID (Peltzer et al., 2010; Makau et al., 2015). Caregivers were also found to be more ready to seek HIV care if they felt supported by their family (Schacht et al., 2014).

However in a study by Wachira et al. (2012), community systems and structures were found to play a less important role in supporting caregivers than expressed in other studies. Due to changes in economic times, the study concluded that HIV was increasingly being seen as an individual issue. Additionally, due to stigma and discrimination, HIV-positive mothers opted to keep matters pertaining to their HIV status and that of their children a secret. Lack of psychosocial support leads to further isolation and may impact negatively on HIV- positive mothers' and their infants' health (Donahue et al., 2012).

### **2.5.3 Institutional or health facility related factors**

The review found client-counsellor dynamics related to confidentiality, attitudes of the health care provider, quality of counselling, mode of service delivery and place of delivery were possible institutional or health facility factors affecting uptake of EID.

#### **2.5.3.1 Quality of counselling**

The review revealed that the quality of counselling provided by health care providers might have an impact on access to EID services. In a study in Kenya, health care providers did not sufficiently cover EID during their antenatal and PMTCT training so they could not provide sufficient information to caregivers during antenatal care visits thus impacting on caregiver's motivation to access EID services (Hassan et al., 2012). Horwood et al. (2010) reveal that due to lack of knowledge and training in paediatric HIV care and treatment, health workers do not recommend EID to caregivers. Similarly, Phelps et al. (2013) and Yeap et al. (2010) report that lack of knowledge regarding the importance of EID for HIV and treatment initiation for children or fear that ART administration for children is complex possibly made health workers uncomfortable recommending EID. The results of research in Namibia, Kenya and Nigeria found that the failure of health workers to provide sufficient information on the importance of EID reduced uptake of EID (ICWLHIV & GNP, 2015).

#### **2.5.3.2 Negative attitudes of health workers**

Besides the potentially poor quality of counselling by health workers, their attitudes and perceptions regarding EID may also be a barrier to EID. Zimbabwean research suggests that some health care workers were reluctant to offer testing to children for fear that the child

would be seen as a burden within their household if testing positive, resulting in mistreatment, stigmatization or neglect (Kranzer et al., 2014). Others were concerned about increased workload if they became involved in performing pre- and post-test counselling (Ntuli et al., 2011).

Negative and discriminatory attitudes from health workers characterized by mistreatment during antenatal visits and during delivery made women living with HIV reluctant to return their children for HIV testing, a study in Nigeria, Kenya and Namibia revealed (ICWLHIV & GNP, 2015). Poor health worker's attitudes were also found to be a barrier in a study in Kenya (Kiragu et al 2008) and another in South Africa (Varga et al., 2008).

#### **2.5.3.3 Caregiver's fear of breach of confidentiality by health workers**

Instances of health worker's breach of the patient's confidentiality as a hindrance to EID were cited in a study conducted among HIV-positive mothers in Namibia, Kenya and Nigeria (ICWLHIV & GNP, 2015).

#### **2.5.3.4 Long waiting times at the health facilities**

Long lines and overcrowding were mentioned as barriers to EID in a South African study (Yeap et al., 2010) and a study in Mozambique (Schacht et al., 2014). Women living with HIV in a study in Namibia, Kenya and Nigeria also cited long waiting times as a barrier to EID. Participants in this study revealed that after waiting for long hours they were told the clinic is closed for the day forcing mothers to delay testing till a later date or not seek services at all (ICWLHIV & GNP, 2015). In another similar study in Nairobi, Kenya (Makau et al., 2015) and one in Uganda (Boender et al., 2012), long waiting times were also cited as barriers to EID and early treatment initiation among HIV-exposed children.

#### **2.5.3.5 Caregiver's place of delivery**

The place of delivery has been suggested as a barrier to EID. A study in Zimbabwe revealed that mothers who delivered at home and those who knew their HIV status were less likely to take their children for EID (OPHID, 2014).

HIV-positive women in a study in Kenya confided that some women may opt to deliver at home, they did so with the hope that by the time they return to their health facilities, nobody will know they are HIV-positive. As a result their infants missed out on EID (ICWLHIV & GNP, 2015). In another study in Kenya, delivery in public health facilities was associated

with improved EID uptake since mothers were able to interact with staff that are familiar with ARV guidelines who ably and appropriately guided mothers (Makau et al., 2015).

#### **2.5.3.6 Effect of integrating EID services into maternal and child health services**

Provision of HIV services at the same location as maternal and child health clinics has been found to increase chances of having HIV-exposed children tested (Ndiritu et al., 2006; Rollins et al., 2009; Goodson et al., 2013; ICWLHIV & GNP, 2015). Several studies show that integrating antenatal, PMTCT, EID and paediatric HIV care services improves outcomes for HIV-infected infants in developing countries (Cook et al., 2011; Spensley et al., 2009). A study in Mozambique revealed that there was increased retention in early infant diagnosis through linkages between maternity and EID (Ciampa et al., 2011). Lack of coordination of maternal health services, on the other hand, leads to lower uptake of EID, as revealed by Braun et al., (2011).

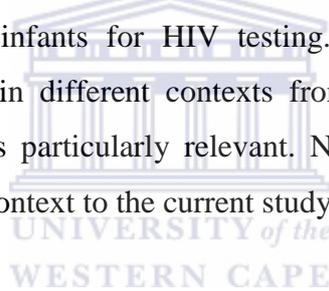
It is surprising that, although several sub-Saharan African countries have high coverage of six-week immunization (WHO & UNICEF, 2013), implying that families are still within reach of the health system within those weeks, most women and newborns are said to be lost from the health system after delivery without accessing EID (Peltzer et al., 2010). The high six-week immunization coverage does not translate into high EID rates (Chatterjee et al., 2011).

Some studies show that lack of space and privacy inhibits EID at immunization clinics even in better resourced countries (Rollins et al., 2009). Studies in rural areas of sub-Saharan Africa reveal that lack of privacy and fear of stigma are barriers to maternal disclosure at immunization clinics. Without disclosure infants miss out on EID during immunisation (Michaels et al., 2013; Bwirire et al., 2008). Moreover, approaches such as Provider Initiated Testing and Counselling (PITC) which is said to contribute to uptake of HIV testing is sometimes regarded as non-voluntary and coercive in certain research (Musheke et al., 2013). If PITC has not been routinely implemented or if health care workers are not informed or sensitized about identifying signs and symptoms of HIV, they might continue treating opportunistic infections for children several times without taking an HIV test for the infant (Musheke et al., 2013).

## **2.6 Conclusion**

This review has identified several factors affecting EID at an individual, community or interpersonal, institutional or health facility levels and economic factors. Some of these factors include maternal education, maternal income, knowledge about EID and PMTCT, attitudes of the health worker, quality of counselling, fear of breach of confidentiality, fear of disclosure, care giver religious and traditional beliefs, fatalistic beliefs about HIV, health status of the child, fear of disclosure due to stigma and discrimination at individual and community level among others.

However, because most of the studies that have examined the factors affecting HIV testing for infants have used the quantitative approach, they did not explain the underlying reasons and meaning to some of the factors discussed. The qualitative approach adopted in this study will therefore help the researcher delve further to understand the reasons behind what inhibits or facilitates caregivers taking infants for HIV testing. Moreover, most of the studies reviewed have been conducted in different contexts from the planned setting where the understanding of these factors is particularly relevant. Nevertheless, the studies reviewed provide a good background and context to the current study.



## **CHAPTER 3: METHODOLOGY**

### **3.0 Overview**

This chapter describes the methodology that was used to conduct the study. It covers the aims and objectives of the study, the study design, the study population and sampling. The sample size and sampling approach used are also presented in this section. Data collection methods, mode of analysing the data and ethical considerations are described in this chapter. Methods for ensuring trustworthiness have also been described in detail.

### **3.1 Aims and Objectives**

#### **Aim**

The aim of the study was to explore the factors facilitating and inhibiting HIV testing for infants at risk of HIV in Wakiso district, Uganda.

#### **Objectives of the study were as follows**

- To explore caregiver factors that facilitate or inhibit HIV testing for infants.
- To explore health facility related factors that facilitate or prevent HIV testing for infants.
- To explore community level factors that influence HIV testing for infants

### **3.2 Study design**

Burns and Grove (2003) define the research design as an overall plan for carrying out research or a blue print that guides the planning and implementation of a study so as to fulfil the intended objectives. The research design utilized in this study was a qualitative descriptive research approach, in order to facilitate an in-depth understanding of the facilitators and barriers to uptake of early infant Diagnosis (EID) for infants at Entebbe Hospital, Wakiso district.

For this study the researcher utilised a qualitative approach to understand the research question from the perspective of caregivers who are the actual people who experience facilitators and barriers to EID (Chopra & Coveney, 2008). The qualitative research approach was considered to be an appropriate way to study the subjective nature of humans so as to understand study phenomena using non statistical methods of analysis (Langford, 2001). The researcher's questions pertaining to what facilitates or bars caregivers from taking children for EID were answered by the respondents using the descriptive qualitative design.

The qualitative research approach was selected because of its ability to help study in-depth a

small number of cases in this instance the experiences of caregivers, service providers and the community about HIV testing for infants. It also helps describe complex phenomena (Baum, 1995). The researcher in turn translated the experiences into a manner that facilitated understanding of the study subject (Burns & Grove, 2003).

The approach also enabled the researcher to gather data that reflects the reality as constructed by the respondents (Green & Thorogood, 2004). However due to the small sample size involved in the qualitative approach, research findings will not be generalised to the whole population (Joubert & Ehrlich, 2012).

### **3.3 Study population and Sampling**

The study population is the entire set of individuals or elements who meet the sampling criteria (Burns & Grove, 2003). The study population included all HIV-positive women or the caregivers of babies of HIV-positive women who delivered at Entebbe hospital. These caregivers were believed to be appropriate respondents to share experiences regarding facilitators and barriers to EID since they are the people responsible for returning the infants to the facility for screening (Rice & Ezzy, 1999). Key informants who comprised of health care workers and peer mothers were part of the study population. The health workers were those working at the maternal and child health clinic. Peer mothers were supporting the health workers at the same clinic.

Burns and Grove (2003) describe the sampling technique as the process that entails selecting a group of people or behaviours or other elements with which to conduct the study in a situation where the population cannot be managed due to its size. Since in Qualitative research the focus is on describing a range of experiences rather than statistics or numbers a large random sample is not necessary (Basset, 2001). Purposive sampling was therefore used to select information-rich cases for in-depth study to examine a range of experiences and perspectives on what facilitates or inhibits caregivers from taking their infants for EID (Rice & Izzy, 1999). Purposive sampling entailed identifying study participants according to predetermined criteria that are pertinent to a particular research question (Mays & Pope, 2000).

Caregivers were selected from the records of mothers who delivered at the health facility. With the assistance of the supervisor for the Maternal and child Health wing a sample consisting of two sets of caregivers; those who brought back their children for the recommended HIV testing at 6 weeks and those who did not bring their children for HIV

testing, was purposively selected. The two groups presented different perspectives and would provide evidence for both challenges and facilitators. Caregivers were either biological parents of HIV-exposed infants or caregivers with primary responsibility for an HIV-exposed or infected child. Caregivers were selected for the interview if they had stayed with the child for at least six months prior to the interview date and spent most of the time with the child.

Eight caregivers whose children were brought for HIV testing and another 8 whose children were not brought back were purposively selected from records at the maternal and child health clinic at Entebbe hospital with assistance from clinic staff and peer mothers. Purposive sampling was used to select those caregivers who delivered from Entebbe hospital, those with live births and those who were comfortable sharing their experiences.

Those caregivers who failed to bring children for testing were traced with the assistance of peer mothers who work closely with the hospital and counsellors within the clinic. Due to unreliable contact information and relocations only 6 out of the targeted 8 caregivers who defaulted participated in the interview. The 6 were from a pool of over 15 caregivers initially identified. The researcher sampled a bigger number of caregivers who did not bring their infants back for testing in anticipation that some might be reluctant to participate. Indeed some changed their minds after confirming availability while others switched off their phones.

The exclusion criteria were those caregivers who relocated from the locality of Entebbe Hospital, those whose children died, those who had had a miscarriage and caregivers who were too sick to participate in the study.

Caregivers who expressed interest were asked for convenient times and places to meet for interviews. Contacts of those who agreed to participate were given to the study team. All participants were given more details about the study, and then an informed consent process was implemented for those who showed interest to participate.

Key informants who were conversant with the study subject by virtue of their daily interactions with caregivers of HIV-exposed infants within the maternal and child health clinic were purposively selected. In order to ensure participating health workers were experienced, the researcher checked with the supervisor of the maternal and child health section to select only those who had worked at the hospital providing paediatric and/or general HIV and AIDS services for 12 months preceding the research. Health care workers who are not permanently employed at the hospital and those who are on leave were excluded.

Two peer mothers who were supporting health workers within the maternal and child health wing were also purposively selected to explore their perceptions of health facility related factors. Peer mothers were interviewed to introduce a community perspective to the study by sharing their experiences while interacting with caregivers of children at risk of HIV. By 12 months the researcher assumes that the health worker is likely to have interfaced with majority of caregivers with HIV-exposed or HIV infected children who attend the clinic and therefore has enough experience and an appreciation of the facilitators and barriers to EID.

Four key informants who include two health care workers who are permanently employed at Entebbe hospital were selected to participate in the interview.

### **3.4 Piloting of the interview guides**

According to Polit and Beck (2008) pilot testing helps the researcher identify possible weaknesses regarding the questions and responses provided by participants. The interview guide was piloted on two caregivers attending the maternal and child health clinic and a counsellor within the same clinic. Pilot testing the interview guide provided the opportunity to become familiar with the interview process and the questions therein. The pilot testing also ensured that the questions were well phrased and easy to understand as well as culturally sensitive. It also ensured that the guides captured the objectives of the study. Following the pretest some probing questions on the facilitators and barriers to EID were added to the interview guide. After making the necessary changes based on the pilot test the interview guides were translated into Luganda. The Luganda version of the interview guide was pretested thereafter. Some of the wording in the Luganda interview guide was changed to make it more culturally acceptable and meaningful. A few words which had not been appropriately translated were corrected. Since the purpose of the pre-test was to improve the interview guide results of the pilot interviews have not been included in this research report.

### **3.5 Data collection and data collection tools**

Data collection is a formal procedure of gathering data necessary to address the research problem or research objectives (Langford, 2001). This study utilised semi-structured interviews guides collect data on the research subject. These in-depth semi-structured interviews were used with caregivers to explore their experiences, their value system and the factors that influence their health seeking behaviours on behalf of the children they are caring for. According to Boyce & Neale (2006), in-depth interviews are suitable for collecting detailed information about a respondent's thoughts and behaviours. Mack et al. (2005) noted

that one-on-one interviews are suitable when studying sensitive subjects such as HIV/ AIDS since participant's responses would not be influenced by the presence of peers. In-depth interviews were selected because the subject of HIV testing children has been studied before in other settings. Since the study topic is sensitive one-on-one semi-structured interviews offered a sense of trust and privacy especially for caregivers of HIV-exposed children (Liamputtong & Ezzy, 2005).

Data was collected from May to July 2015. Study participants were encouraged to express themselves freely regarding the questions posed by the researcher. The researcher first developed rapport with the caregivers before delving into the research questions. The researcher expressed a non-judgmental attitude towards the thoughts and words of the participants. The participants were informed that there was no right or wrong answers and they were continuously encouraged to speak out their minds. The researcher was more of a learner in the course of the interview while the respondents were the educators (Spradley, 1980). The researcher also informed the participants that nothing they mentioned would be revealed to the health care providers. This allowed them to speak freely without fear of losing credibility with the nurses (Shenton, 2003).

The researcher listened keenly to the respondents and through non-verbal expressions showed interest in their opinions and kept eye contact. This approach made the respondents comfortable and they opened up providing rich data. At the beginning of the interviews the respondents were given the opportunity to express their opinions uninterrupted following the introductory questions and this was followed by probing questions so as to obtain additional information and clarifications.

Interviews were audio-recorded after seeking permission from the respondents. Recording the interviews enabled the researcher to concentrate on what the participants were saying so as not to miss any information. The audio recordings were also helpful during the data analysis process.

All interviews in English were conducted by the Principal Investigator (PI) while those in Luganda were by a research assistant who was trained by the PI. All key informant interviews were in English. The PI held regular debriefing sessions with the research assistant to clarify any issues that cropped up during the interviews.

While confirming appointments, respondents were given the option of choosing places for the interviews. Interviews with caregivers who brought children back for HIV testing were

conducted in a private place within the premises of the health facility. Some of the interviews of caregivers who did not bring their infants back for HIV testing were conducted at places away from the health facility. These caregivers were afraid of being reprimanded by health workers for not returning their children. Most had not disclosed their status and were therefore afraid of being stigmatised. Some of the interviews were conducted at trading centres away from places where these caregivers reside while others were at places of work for the caregivers, as long as the work places were private enough with no interruptions from other people. Conducting the interviews away from the health facilities and homes of the caregivers who defaulted enabled the respondents to express themselves freely without fear that someone was listening to the interview. Caregivers who defaulted requested that the interviewer did not come to the interviews with any branding that associated the interviewee with HIV/AIDS issues. Comfort and privacy of the respondents was deemed critical for building rapport and trust during the interviews.

Since the key informants were working in a very busy hospital the researcher had to conduct interviews during times and days when they were available. The PI conducted some of the interviews with key informants at the clinic late in the afternoon, when the number of patients at the clinic had reduced. Most interviews with key informants were held on Fridays which was a less busy day. This enabled the key informants to respond to the interviews without interruptions.

During the interviews the PI kept field notes. Langford (2001) defines field notes as written accounts of what the researcher hears, sees and experiences while collecting data and during the analysis process. The notes were used to augment the audio-recorded data. The audio data were helpful to the researcher in that she could listen to this as often as was found necessary so as to gain an understanding of the meaning derived from the information gathered from the interviews and while analysing the findings.

### **3.6 Data management**

Prior to data analysis the PI transcribed the English audio recorded interviews verbatim. A research assistant with experience conducting and transcribing interviews transcribed the Luganda audio recordings which she later translated into English. The vernacular versions were later back-translated into the local language to ensure that the correct meaning was captured. An additional research assistant conversant with Luganda read through the translations to ensure that the right meaning has been captured. The transcripts were typed and assigned file names to facilitate easy retrieval. Field notes were included on the relevant

transcripts.

Each of the transcripts was assigned an identifier that indicates the place, date and time of the interview including an identifier for each respondent (Kielmann et al., 2011). A checklist of all the interviews was developed so as to make it easy to access the information easily.

### **3.7 Data analysis**

According to Kielmann et al. (2011: 64) data analysis involves “making sense of the data – interpreting or assigning meaning to what is seen or heard by placing it within a given context”. This research utilized thematic analysis that involved scanning all the data to spot the common aspects that recur, and identify the main themes that summarize all the views that were gathered (Patton & Cochran 2002).

The researcher utilized Patton & Cochran’s stages of thematic analysis. Analysis started with familiarisation with the data while in the field. This allowed for adaptation of the interview schedule according to participant responses (Strauss & Corbin, 1994, Pope, Ziebland & Mays, 2007). The initial phase of data analysis entailed familiarization with the transcribed data to attach meaning. The researcher repeatedly read the data transcripts and played back the audio-recordings to familiarize herself with what the participants were communicating. This was followed by coding of data into emerging themes, sub-themes, categories and sub-categories. The next phase involved identifying main themes, which were placed into categories of meaning as they emerged, and combined into groups of ideas. This was followed by the process of refining these themes through collapsing similar themes into one, and separating other themes into two. The final phase involved integrating and interpreting themes, giving meaning that other readers would be able to discern.

The patterns and relationships found under the different themes were then utilized to write the results chapter. The literature was then reviewed to support the interpretation of the findings so as gain meaning and interpretation from the data gathered from participants. This information formed the discussion section of this report.

While analyzing data the researcher who was working with a health Non governmental organization was conscious of the possible influence of her experiences and thoughts on the analysis and results of the study. This required ensuring reflexivity (Creswell & Miller, 2000; Rice & Ezzy, 1999) by continuously reflecting on her thoughts, views and experiences. Some of her thoughts partly underly the ideas presented in the discussion of findings in which an interpretive perspective was utilised.

### **3.8 Rigour**

Within qualitative research rigor is gauged by its trustworthiness or the extent to which study findings are true to the data collected and analysed (Babbie & Mouton, 2001). Credibility, transferability, dependability and confirm ability are the four criteria by which trustworthiness is evaluated (Lincoln & Guba, 1985).

To ensure credibility, the researcher utilised triangulation of different data sources which included health care workers and peer mothers. Triangulation helps check for relationship between information from different sources (Creswell & Miller, 2000). Triangulation of sources increased the credibility of the research (Marshall & Rossman, 1985). Some of the questions used in the caregiver interviews were also used in the health worker and peer mother interviews in order to get diverse views about the particular issue.

According to Lincoln and Guba (1985) member checking is a key method for validating the credibility of qualitative data. It provides the participants with a chance to determine whether the initial findings and interpretations are consistent with their views and experiences shared during the research. Member checking can be done informally during data collection or formally after data is collected and analysed (Polit & Beck, 2008). In this study member checking was done during data collection. The researcher summarised key points at the end of interviews with the caregivers and key informants to ensure that her understanding of the information shared is correct.

Confirmability refers to the degree to which the findings are the products of the focus of the inquiry and not the biases of the researcher (Babbie and Mouton, 2001). An audit trail was kept to determine if the interpretations and conclusions are traceable back to the sources and supported by the inquiry. Transcripts of the interviews were checked against the recordings. Information gathered from interviews was checked against literature to establish if similar findings were revealed by other studies elsewhere.

### **3.9 Ethical considerations**

Ethical approval for this study was sought from the Senate Research Committee of the University of Western Cape (Appendix 9) and the administration of Entebbe hospital before data collection (Appendix 10). The proposal was shared with the hospital administration for review and scrutiny.

The three fundamental principles of human research ethics: autonomy, beneficence and

justice were adhered to during the research process (Polit & Hungler, 2003; Orb, Eisenhauer & Wynaden, 2000).

To ensure the participants' autonomy, participation in the study was on a voluntary basis and participants who agreed to participate were requested to sign a consent form (Appendix 1). Before signing the consent form, participants were given an explanation of the benefits and possible risks of participating in the study. Participants were informed that they are free to stop participating in the study at any time without providing reasons for their action. They were informed that by withdrawing they will not face any repercussions (Appendix 3). The consent form also had a second signatory line for participants to sign if they agreed to have the interview recorded. The interview was not audio taped if a participant did not agree to be recorded. In observance of the principle of beneficence, which involves doing good to others and preventing harm, study participants were informed that discussing HIV/AIDS issues affecting the children they take care of can be emotionally sensitive. During the interviews respondents were protected from psychological, emotional and physical discomfort. Prior arrangements were made for a counsellor to support caregivers affected by participation in the study free of charge. The researcher had the counsellor's telephone contact in case there was need to contact her in instances where interviews were conducted away from the hospital vicinity. If in the course of the interview any emotional discomfort was felt by the respondents, appropriate referrals were made. In one instance a caregiver who did not bring her infant back for testing was supported to access counselling services and the child was tested and started on treatment. In order to adhere to the principle of justice the researcher made sure that the participant information sheet (Appendix 3) and Consent form.

(Appendix 1) were both translated into the local language, Luganda, in order to ensure that participants clearly understood the research before consenting to participate (Orb, Eisenhauer & Wynaden, 2000).

Even though the caregivers who participated in this study did not benefit directly from the study, they were informed that their participation will help health care workers to better support other HIV-positive mothers access EID services for their infants. They were informed that the information that they provide will inform programming on the scale up of HIV testing for infants.

Respondents were selected according to the research proposal. The researcher fulfilled the appointments made with the caregivers. The right to privacy for the respondents was duly respected. For instance the researcher was sensitive about the choice of venues for the interviews with caregivers who did not bring back their infants for HIV testing. The researcher respected their choice of venue for the interviews. Interviews were conducted away from people's homes to ensure privacy and confidentiality. Some of the interviews were at work places especially if these were free of other parties. Other interviews were conducted in restaurants that were not frequented by customers.

Contacting HIV-positive women in their homes was considered sensitive. No physical visits were made to caregiver's homes to avoid unintended disclosure of the respondent's status. Appointments and reconfirmations were all made on phone.

Caregiver participants were given a small amount of money as a contribution towards their transport fare.

### **3.10 Summary**

This chapter described the research design and methodology. The Qualitative research approach has been described in this chapter with justification as to why it was selected for use in this study. Under the research methodology procedures for determining the study population, Sample and sampling technique, data collection, data analysis, establishing rigor and ethical considerations have been described.

Data collection instruments which are in- depth interview guides ( Health care workers – Appendix 5) and data collection methods which include in-depth interviews (caregivers - appendix 6) and field notes have been presented in this chapter. Methods of ensuring rigor were shared in this chapter

## **CHAPTER 4: RESULTS**

### **4.1 Introduction**

The previous chapter described the research methodology. This chapter details the study findings. The first section provides a description of the socio – demographic characteristics of the study participants. The second section provides the barriers and facilitators to HIV testing for infants based on the responses of the caregivers who took children for testing, caregivers who did not seek early infant diagnosis for HIV (EID) and key informants who include health care workers and peer mothers.

### **4.2 Characteristics of study participants**

#### **4.2.1. Caregiver study participants**

The analysis consisted of responses from 14 caregivers with a split of eight caregivers who returned their children for HIV testing and six who did not take their children back for HIV testing at the recommended time. In terms of the respondent's relationship to the child, all the fourteen caregivers interviewed were biological mothers of the children. The ages of the respondents ranged from 20 to 38 years. Two caregivers had no education, seven finished primary level education, three had secondary education and two tertiary education.

Twelve respondents were married and either living in the same house with the husband or the husband was working away from home. Two were separated from their husbands while none of the respondents were divorced or single.

In terms of employment, some of the study participants were engaged in some form of income generating activity. While two of the respondents were in formal employment; two were in small scale businesses; five were casual labourers while five were stay at home mothers who were not involved in any form of income generating activity.

#### **4.2.2 Characteristics of key informants**

Four key informants comprising of two health care workers and two peer mothers participated in the study. The key informants included different cadres of health workers, all female, one nurse, one counsellor and two peer mothers. The key informants were working at the Maternal and Child Health wing of Entebbe hospital holding responsibilities that involve HIV testing for infants and mothers and provision of maternal and child health services. All the key informants had been working with the hospital for over 12 months at the time of the interview.

### **4. 3 Facilitators and barriers to HIV testing for infants**

For the purpose of this study, facilitators and barriers to HIV testing for infants have been grouped into individual, community, economic and health facility or institutional related factors as detailed in subsequent sections.

#### **4.3.1 Individual caregiver factors**

Individual factors relating to the caregiver that came up during this study include maternal knowledge of EID, belief that asymptomatic infants are HIV-negative, fear of an HIV-positive outcome and denial of own and child's HIV status. Other factors identified were; fear of unintended disclosure and the resulting stigma and discrimination, mother on Anti-retroviral treatment (ART), fulfilling roles of a responsible and caring mother, and religious and cultural beliefs as explained in subsequent paragraphs.

##### **4. 3.1.1 Maternal Knowledge of EID and PMTCT**

A number of respondents demonstrated good knowledge of how infants get HIV and how they can prevent them from HIV infection. Knowledge of EID for HIV and its benefits contributed towards caregivers' decisions to test children for HIV. Whereas most mothers had some understanding of EID and prevention of mother-to-child transmission of HIV (PMTCT), the level of knowledge differed between those who tested their children and those who did not.

Some caregivers mentioned that HIV infection can occur during delivery if appropriate precautions are not taken to prevent transmission of the HIV virus.

*They told me that it is not good to deliver my baby away from the hospital. They said if I deliver in the hospital the nurses will help me avoid giving the HIV virus to my baby. (Caregiver whose child was not tested for HIV)*

Caregivers were aware of other precautions that are taken to protect their babies from HIV infection such as breast feeding.

*They said that if I deliver in the hospital when I am HIV-positive, they will give the newborn baby a tablet. They even stop you from breastfeeding the baby to avoid giving her HIV. (Caregiver who tested child for HIV)*

Some caregivers understood the importance of utilizing ART for themselves and the baby as a preventive measure for mother-to-child-transmission of HIV.

*If a mother is HIV-positive and she does not take her HIV medicines according to what the health workers says her baby can be born with HIV. (Caregiver who tested child for HIV)*

Most of the participants were also aware of the importance of EID for HIV. Knowledge of the devastating impact of HIV on children made caregivers test them for HIV so that they can start treatment. They understood that EID for HIV is an entry point for life saving ART.

*I was told that if my child is tested for HIV early and found positive they can start him on HIV treatment which makes the child live a longer life if started early. I have seen how HIV affects children and I do not want my child to be like that. (Caregiver who tested child for HIV)*

Most of them were aware that HIV testing for infants is available. They knew places where they can obtain an HIV test for their children. They said they got this information from the health workers during antenatal visits. There are some who received information from other HIV-positive mothers. Those caregivers who took their children for an HIV test mentioned that they did so due to the information they obtained from the health worker.

*The health workers told me that if I want to know the HIV status of my baby I have to take him to the hospital for testing. She said they will take blood from the foot of the baby in order to carry out the test. What the health worker told me helped me decide to test my child. But I also talked to other mothers who have the same problem as me (Caregiver who tested child for HIV).*

Despite the high levels of awareness about prevention of mother-to-child transmission (PMTCT) and aspects pertaining to EID there was a lack of understanding of the timing for the first HIV test for the infants. Some caregivers especially those who defaulted on EID for HIV were not sure of the exact time when an HIV-exposed child should be tested. Their knowledge differed in terms of the first time infants should be tested for HIV. Very few of the caregivers knew that an HIV-exposed child should be tested at 6 weeks.

*The time to test a child, is not exact, you can take a child at any time. It depends on when the mother is ready to take the child. (Caregiver whose child was not tested for HIV)*

Some caregivers mentioned that HIV testing for children can wait until the mother is strong enough to take the child to the clinic.

*Some times after giving birth you are still tired. If they cut you (caesarean) you are still not strong. You need to first be strong before you can think about other things.*  
(Caregiver who tested child for HIV)

There are some caregivers who mentioned that an HIV-exposed child should be tested while still young but could not qualify how young. On the contrary, some caregivers were aware that children should be tested at 6 weeks though they felt that testing an infant for HIV at 6 weeks was too early since the child would be too young and they could not bear the pain of a prick from a needle. Others felt their children could be tested anytime the mother was ready to do so.

*I am not sure of the right time for the child to be tested. All I remember being told by the health worker is that the child should be tested when it is still young.* (Caregiver who tested child for HIV)

*Even if the health worker told me to bring the child six weeks I thought that was too early. I wanted to wait until my child was older. My baby was too young to be pierced .*  
(Caregiver whose child was not tested for HIV)

Other caregivers were worried that a lot of blood would be taken from their young children while carrying out the HIV test.

*My child seemed to be very small at that time. I hear they take a lot of blood in order to do the HIV test on the baby.* (Caregiver whose child was not tested for HIV)

There is a possibility that some misinterpret the information provided by the health workers as illustrated by the quote below.

*The health workers told us to wait before bringing the infant for an HIV test. They said the child could not be tested immediately after birth.* (Caregiver whose child was not tested for HIV)

#### **4.3.1.2 Belief that HIV-exposed infants without HIV symptoms are HIV-negative**

Some caregivers were not aware that HIV infection could be asymptomatic. In the absence of any illness or symptoms of HIV in the caregiver, some caregivers mentioned that they did not find it necessary to take their children for HIV testing. When children were in good health and not in need of immediate clinical care, caregivers assumed they were HIV-negative. In the absence of physical symptoms or deterioration of health some caregivers perceived their children as not being infected.

*My child was growing well and she was not falling sick often. I did not see the need to take her for HIV testing even if I know I am HIV-positive. If the child was also HIV-positive she would be falling sick all the time. She would lose weight or have a skin rash. (Caregiver whose child was not tested for HIV)*

*My child looks healthy she does not get sick all the time so there is no need to take her for HIV testing. She eats well and drinks well. When she falls sick that is when I will take her to the clinic. She gets the cough and flu which all other kids also get. (Caregiver whose child was not tested for HIV)*

What the caregivers mentioned was confirmed by the health care workers who said that some HIV-positive mothers associate being asymptomatic with being HIV-negative. The health workers attributed this to misinterpretation of information by the caregivers.

*Some caregivers are reluctant to take their infants to the hospital unless the child is very sick. When the child falls very sick they have no choice but to bring them to the hospital for check-up. They do not think preventing sicknesses is important. It is when such children are brought that we encourage the mothers to test them for HIV. Some of these children are usually too sick. (Key informant 3)*

One key informant however seemed to think that some caregivers were careless and that's why they did not bring their children for testing.

*Some mothers are careless and do not care about the health of the child and that is why they either do not bring their children for testing early or they bring them when they are already very sick. (Key informant 2)*

Though the above assertion was from one health worker, it was re-echoed by a few caregivers who suggested that some caregivers they know failed to take their children for HIV testing even when they had transport and the support.

*I do not know how to explain this but may be some people don't mind. They keep saying they will go but they never go. Even when they have the money and people who help them they don't. May be they don't care about their children. (Caregiver who tested child for HIV)*

#### **4.3.1.3 Perceived low risk of HIV infection in infants due to mother's adherence to PMTCT requirements**

Some caregivers were not aware that PMTCT interventions are not fully protective. Findings reveal that a few of the caregivers do not consider their children to be HIV-positive because they have adhered to most of the requirements for PMTCT as per the advice provided by the health care workers during antenatal care visits.

*Though the health care workers told me to take back my baby at one and ½ months I did not do so since I was sure that my child was not HIV-positive, since I did what the health workers asked to me to do to protect my child from HIV. (Caregiver whose child was not tested for HIV)*

Some of the PMTCT practices they cited include delivering in the hospital under the care of a professional medical worker and taking ART throughout their pregnancy. Others felt that by not breast feeding, their babies were safe from HIV.

*I delivered with the help of the health care workers at the hospital and I was taking my medicine as the health care workers told me so my child should be okay. There was no need of going back with the kid for HIV testing maybe I will do so in future.(Caregiver whose child was not tested for HIV)*

The belief that PMTCT was fully effective was more prevalent among caregivers who did not seek EID for HIV. On the contrary, caregivers whose children were tested for HIV mentioned that they were advised to return their children for HIV testing to confirm the HIV status even if they had adhered to all the PMTCT practices.

*The health worker said we should take children for HIV testing even after putting in place all the PMTCT measures they asked us to do. They said the only way to be sure that the child is okay is to test our children for HIV. (Caregiver who tested child for HIV)*

#### 4.3.1.4 Maternal awareness of availability and efficacy of HIV treatment

There are some caregivers who revealed that knowing that HIV treatment for children exists gave them a sense of hope and the motivation to take their children for testing.

*Now it is not like before when HIV medicines for children were not there. To know that when the child is sick ( HIV-positive) we have medicine that makes them feel better gives us hope.*(Caregiver who tested child for HIV)

Others mentioned that seeing the health and quality of life of children of other HIV-positive mothers improve due to HIV treatment was a facilitator for taking children for HIV testing

*If you test a child and it is positive they give them medicine which gives them life. If you do not test you cannot be able to know what to do. Your child can even die.*  
(Caregiver who tested child for HIV)

Key informants interviewed agreed that availability of life prolonging antiretroviral therapy motivates some caregivers to bring their children for testing. They mentioned that HIV is no longer a death sentence. Testing and getting to know one's own status and that of the child was no longer associated with death but it was seen as a gateway to starting and obtaining treatment so as to prolong one's life.

*We encourage the mothers to bring their children for testing after delivery. We tell them that if the child is found to be HIV-positive there are medicines that help them stay healthy and live longer. It's not like before when we did not know what to do.*  
(Key informant 4).

There are however some caregivers who were sceptical about HIV medicine for infants. These caregivers mentioned that they had heard that there were challenges with medication for infants in terms of the taste, the dose and side effects and they feared that they would not manage to have their children on medicines if they test positive. Some caregivers were concerned about side effects of HIV treatment among children considering that their own experiences with ART were not good as adults.

*Some mothers see how difficult the medicine is for adults and they think the young child cannot manage. You have to eat well. Some get problems with the medicine (side effects). Some prefer to delay that stress of medicine by not taking their children for HIV testing.* (Caregiver who tested child for HIV)

#### 4.3.1.5 Fear of an HIV-positive test result for the baby

Fear of a positive HIV result was found to be a demotivator to HIV testing for infants. Some of the caregivers interviewed said they had not tested their children due to fear of learning that their child is HIV-positive. Others reported that they were not emotionally ready to find out about their children's status.

*I do not know how to explain this to you. Can you imagine being told that your child has HIV and you know you also have? (she sighs). Okay I had problems with money for transport but also every time I tried to take my child for HIV testing I felt so scared. I am still scared of the whole thing even now. It is not easy for me. May be let me stay without knowing. (Caregiver who tested child for HIV)*

Another caregiver also cited fear as a barrier to HIV testing for her infant noting that whereas HIV is manageable among adults it is difficult to manage among infants.

*It is a difficult thing (long silence and thoughtful) like us who are sick (meaning HIV-positive) and you are again told that your baby is also sick? (long pause) It makes me scared. If you a big person you can try to manage but a child. It is better I do not know that my child is sick. (Caregiver whose child was not tested for HIV)*

Some of the fears regarding an HIV-positive status seemed to stem from the beliefs caregivers have about HIV. They felt HIV in children was a death sentence. Whereas some caregivers were aware of the availability and efficacy of paediatric HIV treatment which they found as a source of hope for their children, there are some who harboured fatalistic beliefs about HIV. These caregivers revealed that getting to know the status of the child would make the child sick since the caregivers would be worried often. They mentioned that this would make their child's illness progress faster.

*If you take the child for testing and you are told the child is HIV-positive you will keep getting worried and the child might die. For me I can live with my problem but for my baby (silence) it cannot be easy. I prefer not to know my child's problem. (Caregiver whose child was not tested for HIV)*

Some key informants confirmed that indeed fear of knowing that a child has a positive HIV result is one of the challenges caregivers face regarding decisions to take their infants for HIV testing.

*Some can be strong but there are some parents who cannot handle that information so they decide not to bring their children. Those caregivers decided to stay away from the hospital. (Key informant 1)*

Caregivers expressed fear of the child falling sick often, fear that the child might eventually die and fear of how they would manage to live with an HIV-positive child. Positive results would make them feel anxious thus affecting their day to day way of life and the health of the child.

*For us who have HIV we are all the time worried about our lives. We do not know if we can live for long. Now if you take your child for HIV testing and they tell you that they are also sick you will worry more. You start worrying about two people. You will start thinking that your child is going to die. You make the life of your child shorter because you worry a lot. (Caregiver whose child was not tested for HIV)*

Other caregivers harboured feelings of guilt. They were worried about having infected their children.

*At least let me keep thinking that my child is okay. I was feeling bad all the time I was pregnant. I thought I had made my baby sick. If I test her and they tell me that she is sick I will die of guilt for having made her sick. Let me not know. (Caregiver whose child was not tested for HIV)*

#### **4.3.1.6 Denial of own and child's HIV status.**

Some caregivers revealed that it is difficult and it takes long to accept one's HIV status. When it comes to their children they are still in denial. Caregivers revealed that some mothers avoid taking their medicine because it reminds them that they are sick and yet they want to forget. Some believe that their children cannot be HIV-positive and as a result they do not take them for HIV testing.

Denial of HIV status makes some caregivers move to different health facilities to confirm that they are not HIV-positive.

*When I was first told that I am HIV-positive it was not easy for me to agree. I moved from one clinic to another taking other tests to confirm that I am not HIV-positive. Now with my child it is difficult to think she is also positive and that is why I have not taken her for an HIV test. (Caregiver whose child was not tested for HIV)*

Another caregiver shared an experience that depicts the debates that dominate the minds of some caregivers who are in denial of their HIV status. Such protracted debates result into failure to seek EID for HIV.

*When you are pregnant and on medicine you keep thinking – may be the baby will be born normal may be it will not. This goes on in your mind until the baby is born. When the baby is born you start fighting with thoughts about taking them for HIV testing. However to take the step to take the baby for testing is a hard thing to do. You sometimes think that may be it is better not to know so that you keep hoping that the baby is okay. I have been like that for some time. (Caregiver whose child was not tested for HIV)*

Some key informants who are peer mothers agreed with the above assertion. They confessed that similar debates characterised their minds prior to testing their children for HIV. The peer mothers cited sharing of experiences among mothers as a means to counteracting such doubts about EID for HIV.

#### **4.3.1.7 Fulfilling the role of a responsible and caring mother**

Some caregivers mentioned that taking their infants for HIV testing was part of fulfilling their role as mothers. They mentioned that good mothers take responsibility and care for the health of their children. Mothers who did not test their children for HIV were seen as negligent regarding matters pertaining to the health of their children.

*I think any caring and good mother has to take their child for HIV testing. A good mother takes care of her child's health. (Caregiver who tested child for HIV)*

Other caregivers mentioned that they took their children for HIV testing because they were eager to know their children's state of health. They viewed HIV testing as an opportunity for them to ascertain the true HIV status of their children.

*I took my child for testing because as a good mother I was anxious to know her status. I wanted to stop feeling bad that I made my baby sick. (Caregiver who tested child for HIV)*

They mentioned that they had put a lot of effort into trying to ensure that they protect their children from infection by adopting PMTCT interventions. HIV testing for their infants was a means of putting to an end caregiver's feelings of guilt harboured throughout their pregnancy.

*I was feeling guilty thinking I gave my baby the disease (HIV). I could not rest enough. I made sure I do whatever the health worker (PMTCT interventions) advised me so that I protect my baby from getting HIV. (Caregiver who tested child for HIV)*

The caregivers were anxious to know the status of their children since an HIV-negative child would give them reason to continue living.

*I kept waiting for the day when I would know how my baby is. If my baby was HIV-negative I would feel happy as a mother for protecting him. Having a child who is HIV-negative would give me something to look forward to. (Caregiver who tested child for HIV)*

Key informants interviewed confirmed that anxiety about the status of HIV-exposed infants makes some caregivers return their children for HIV testing.

*For a mother to hear that her baby is having HIV (pause) it really hurts them so much. I have seen mothers when they come back for the results. You tell them your baby is not HIV-positive and she will be so happy she will hug you she will almost lift you up as if you are the one who made it possible so this is a real motivator for them (pause) to hear that their baby is free from HIV - she will say 'Let me be sick but not my baby. They will take their children for testing because they are anxious to know their wellbeing after a long wait. Any good mother would act like that. (Key informant 3)*

#### **4.3.1.8 Mother on ART**

Being on ART was found to be one of the facilitators for taking infants for HIV testing. All the caregivers in this study were also biological mothers to the children. Those on ART had their own clinic appointments that necessitated that they visit the clinic often for prescription refills exposing the woman to more intensive support which increases understanding of the importance of EID and PMTCT.

*When I went back to the hospital to pick my medicine after giving birth the health workers kept asking me about my baby. I had met some of them when I was giving birth so maybe they knew I had a small child. I decided to do something about it. I accepted to test the child for HIV. (Caregiver who tested child for HIV)*

One key informant confirmed that constant follow up compelled some of the caregivers to return their children for HIV testing. The key informant mentioned that Provider initiated

HIV testing and counselling with health workers recommending that children of HIV-positive mothers undergo voluntary testing at points of contact at health facilities helps in identifying HIV-exposed infants. Places where caregivers obtain refills for their antiretroviral medicines are one of the points of contact.

*When some caregivers come for their HIV medicine we ask: how about the baby? We then find out whether they have tested their children or not. If they have not, we encourage them to have their child tested. (Key informant 2)*

#### **4.3.1.9 Lack of Financial and decision making autonomy**

Most caregivers mentioned that their husbands were the key decision makers regarding health seeking practices for themselves and their children even in situations where the spouses were not living under the same roof. Lack of autonomy in decision making regarding health care seeking seemed to affect EID. This was especially true with those women who had no independent source of income and relied on their spouses for finances necessary for them to seek health care

*The father of the child decides on things to do with the child's health since he is the one who brings money to the house. Mothers also add to the decision since they tell him that the baby is sick. He however decides whether the child should or should not be taken to the clinic. Some don't want to give the money so the children suffer. (Caregiver who tested child for HIV)*

For some caregivers support from their spouses facilitated access to EID for HIV.

*I managed to take my child for HIV testing because my husband supported me to take her. We talked about it and decided to do so. (Caregiver who tested child for HIV)*

Limited decision making and financial autonomy seems to affect caregiver's ability to take children for HIV testing. Whereas men were said to be the key decision makers health workers mentioned that in some instances men were reluctant to get involved in EID for HIV.

*Some mothers have problems with their husbands. Some of these men just say it is up to you if you are sick of HIV. Some will not provide transport to the health facility, he will not care, and he will not be involved. I think sometimes lack of male involvement makes it difficult for the caregivers. (Key informant 3).*

The situation was however different for caregivers who had a source of income and those who were not living with their spouses either because they are not married or they are

separated. These caregivers mentioned that they were the sole decision makers regarding matters to do with seeking health care for themselves and their children.

*He works and I work. When the child is sick and my husband is at home I tell him. If he is not around I take the child to the hospital since I have some money. When it was time to take the child for HIV testing I did not inform him since I had the money for transport, I knew he would start blaming me in case the child turned out HIV-positive.*  
(Caregiver who tested child for HIV)

#### **4.3.1.10 Disclosure**

##### **Voluntary disclosure of status**

A few of the caregivers revealed that disclosure of their HIV status was one of the facilitators for uptake of HIV testing for their infants. Disclosure of status eliminated the idea of secrecy making it possible for them to test their children at the recommended time. However caregivers revealed that they had mainly disclosed to their spouses and a few close family members. These caregivers admitted that disclosure to their spouses helps them get support and avoid questions from their spouses whenever they have to go to the hospital for services. Partner's support was also critical in terms of providing financial means to help caregivers meet transport costs to and from the hospital while taking their children for HIV testing

*When I was told the results of my test when I was pregnant I was very scared and I wanted someone to talk to so that the burden can be small. Since me and my husband we talk I told him. It was not easy the first time but after wards he supported me. Since he knew about my status early it was not very difficult to tell him that I was taking my child for testing.* (Caregiver who tested child for HIV)

Majority of the caregivers interviewed however confessed that they had not disclosed their status to their spouses. Failure to disclose made it difficult for HIV-positive mothers to fulfil their appointments at the hospital and as a result this had an impact on their ability to obtain health care for themselves and that of the infants. Fear of emotional and physical abuse as well as blame made most caregivers fail to disclose to their partners.

*When you test and your child is positive your husband will start saying that the child is sick because of you. He will start blaming you for bringing the disease (HIV) to the family. I feared that we would start fighting about this and we can separate even. He will start saying that I sleep around and as a result I brought the sickness.* (Caregiver whose child was not tested for HIV)

## **Fear of unintended disclosure of status**

For some caregivers fear to disclose the status of the child to the father was a barrier to seeking EID. For some caregivers, if the children tested HIV-positive and are placed on ARV medication the fathers would become suspicious. Taking ART would result into involuntary disclosure of status.

*If I take the child for testing and he is positive. How will I tell the father? The child will have to take medicine, I will have to hide so that he has his medicine which is difficult. (Caregiver whose child was not tested for HIV)*

Most of the caregivers interviewed revealed that they feared visiting the hospital to seek HIV testing for their children because they were concerned that it would result into involuntary disclosure. The caregivers were afraid of disclosure of the child's status /and or the mother to other family members (including the father) or disclosing the child and the mother's status to the community. Disclosing the child's HIV status implies disclosing the mother's status and this was seen as a threat to the entire family due to fear of discrimination from the community.

*These things about our sickness are not easy. When someone finds you at the clinic with your child they will tell someone else who will also tell another person and in a short time the whole village will know about your problem. It's better you avoid going to places like the hospital where people can easily find you and start talking. I do not want everyone to know about my condition and that of my child. (Caregiver whose child was not tested for HIV)*

Some caregivers who had not disclosed to their spouses were worried their spouses would demand to know where they are going.

*I was not sure of what to tell my husband when going away from home. He will ask (pause) where are you are going with the child and you do not have an answer and it is difficult to keep telling them lies. (Caregiver whose child was not tested for HIV)*

One of the key informants confirmed that fear of disclosure was a barrier to EID for HIV.

*Some mothers fear to bring their children for testing because this might make their husbands suspicious. If a baby is tested and found positive it means they start on HIV medicine and the husband will want to know why the child is taking the syrup. (Key informant 1)*

As a result of fear to disclose to partners some caregivers were forced to take their children for HIV testing in secrecy. These caregivers mentioned that they were worried about their husband's reaction if they mentioned where they were going.

*I lied to him when I first brought the baby for the first HIV test after birth. He was not at home today and since he does not know about my status I always tell him that am going to my sister's place when am coming to the hospital. But I can tell you it is difficult when your partner does not know. (Caregiver who tested child for HIV).*

Some of the caregivers who took an HIV test for themselves without spousal involvement were worried of people finding them at the hospital and they inform their husbands. Some were worried this would result into violence from their spouses.

*Some caregivers fear that people who know their husbands can see me at the hospital and they start talking. They can say to him we saw your wife and child at the hospital and yet I have never told him that I tested HIV-positive. They are afraid that if he got to know he would be violent and even leave them. (Caregiver who tested child for HIV)*

Some caregivers were worried that if their children are tested and found HIV-positive they would be stopped from breastfeeding. Stopping to breast feed would be a sign that they and their children are HIV-positive.

*When you test your child and she is HIV-positive they sometimes ask you to stop breast feeding. Some people know that if you stop breastfeeding when the baby is six months, it means you are HIV-positive. That scares me. I am scared of people knowing about my status at that time. (Caregiver who tested child for HIV)*

Some of the health workers confirmed that caregiver's fear of involuntary disclosure affected their ability to seek EID for their children.

*Though HIV is not a taboo these days people still fear to come to the clinic. They fear meeting someone that they know. They fear people talking about their condition. They find it difficult to fulfil their appointment at the health facility. In the process, the HIV-exposed children suffer. (Key informant 2)*

Caregiver's concern about involuntary disclosure seemed to be due to fear of stigma and discrimination from the community and family members. Caregivers revealed that

involuntary disclosure was bound to lead to stigma and discrimination from some family and community members.

*If you test the child and it is positive and the people where you live get to know they will start treating the child badly, some will not want the child to play with other children. Others will start talking and pointing fingers at the child. (Caregiver whose child was not tested for HIV).*

#### **4.3.1.11 Influence of care - giver beliefs**

##### **Belief in faith healing**

Some respondents mentioned that their belief and trust in God inhibited them from taking children for testing. They mentioned that due to God's intervention their children do not have HIV.

*I trust that God protected me and my child from HIV. The bible says God heals all our sicknesses and all our sins. I also know God has powers over HIV. When the pastor prays for someone they get a healing. The pastor prayed for me and I got healed. If am okay then my child is also fine. I decided not to take the child for HIV testing. (Caregiver whose child was not tested for HIV)*

As a result of their belief in faith healing some caregivers revealed that they abandoned their HIV medication thus affecting EID for their infants.

*I am sure prayers works. I prayed for divine healing from my HIV sickness and protection for my unborn baby. Because I was healed I stopped taking my HIV medicine and going to the hospital to get more. You cannot take medication and still go to church. Since I was not picking medicine the time for testing my child passed without me noticing. (Caregiver whose child was not tested for HIV)*

Some of the key informants mentioned that the religious factor is increasingly becoming a barrier to uptake of HIV care services including EID.

*Some believe that Jesus heals and therefore there is no need to seek HIV testing services. I am talking about those who are born again or let us say saved. They pray for God's healing. (Key informant 3)*

Another key informant had similar views as evidenced in the quote below.

*They tell us that if they have a problem they have people who pray for them and they get healed. Even when some of the caregivers test HIV-positive and they do not take their medicine. Some think they are okay and so are their children. (Key informant 2)*

### **Cultural beliefs**

One factor that was not prevalent since it was mentioned by few caregivers is the cultural beliefs that inhibit mothers from leaving their homes before their babies are of a certain age. Caregivers who tested their children mentioned that some mothers they know feared leaving their homes with babies especially if after delivery they were being looked after by their mothers in law.

*I know about mothers who after giving birth fear to leave home before their babies are old. Some fear what their mothers in law will say if they (mothers) don't respect culture. They say new mothers have to stay home for some time. (Caregiver who tested child for HIV)*

### **Section summary**

This section has outlined the facilitators and barriers to EID for HIV at an individual level. Some of the key facilitators presented are the mothers' constant exposure to the health system due to being on ART, maternal knowledge of EID and PMTCT, voluntary disclosure of status and the caregivers' urge to fulfil the responsibilities of a mother.

Though maternal knowledge of the importance of EID comes out as a facilitator, limited knowledge about the timing for EID inhibits some caregivers from testing their infants. Lack of maternal understanding, that PMTCT is not 100% protective and those children who are not asymptomatic may not be HIV-negative, came out as barriers to EID for HIV. Other individual barriers presented in this section include fear of unintended disclosure of status and the resulting stigma and discrimination from the family and community, faith and cultural beliefs and limited decision and financial autonomy of caregivers especially those who are solely dependent on financial sustenance from their spouses. Health facility factors are described in the next section.

#### **4.4. Institutional or health facility factors**

Institutional or health facility factors that were mentioned during this study include health care workers attitudes, lack of confidentiality and long waiting times at the hospital.

#### 4.4.1. Health care worker attitudes

HIV-positive mothers require adequate information in order to make the correct decisions about their health and that of their infants. Caregivers revealed that this information can among others be obtained from the health workers before delivery and after delivery or during postnatal visits.

Some of the caregivers interviewed revealed that the health workers they met during antenatal care motivated them to return their babies for testing. The caregivers gave credit to the support, counselling and information the health workers provided. This was especially true among caregivers who returned children for HIV testing.

*The health workers were nice to me and they treated me well. When they got to know that I was HIV-positive they told me many things about how I should protect my baby from getting HIV. They told me to give birth in the hospital. They said I should take my medicine every time. They said after giving I should take my baby for HIV testing for HIV testing. Every time I came back to the hospital they would keep giving me helpful information. (Caregiver who tested child for HIV)*

There are however some caregivers who reported that health care workers were often rude and this affected their ability to seek care and return their children for HIV testing.

*Some of the nurses look at you badly. They talk to you badly. It is as if it was our choice to be HIV-positive. (Caregiver whose child was not tested for HIV)*

There are some caregivers who mentioned that health workers displayed negative attitudes during the period when they were seeking antenatal care making them not return their infants for testing after delivery.

*Some of them don't have time for us. Some say how can you be HIV-positive and you become pregnant. You find few who are good but most of the time some don't care much because they have many people to see. Some want to have you out of the line as quickly as possible. (Caregiver whose child was not tested for HIV)*

Caregivers whose children were tested for HIV mentioned that some HIV-positive mothers they know were reluctant to return to the health facility if they had missed their EID appointments at one and a half months because of fear of reproach by staff. As a result some caregivers continuously postponed taking their child for HIV testing.

*Some mothers say that if they don't go back at the time they are asked to some health workers can be rough on them. Some mothers could be ill and that's why they fail to come back. They fear that if they come back later and try to explain the health workers will shout at them and every person present at the facility will know they have HIV. (Caregiver who tested child for HIV)*

Some caregivers mentioned that mothers they know feared being scolded by health workers for failing to fulfil their appointments

*The mothers I know say health workers quarrel instead of listening to them and trying to understand the problems they face. (Caregiver who tested child for HIV)*

Some claimed that lack of sufficient information on EID inhibited them from taking their infants for testing. Their efforts to ask questions were sometimes frustrated by the health workers due to their heavy workload.

*Some caregivers say that when you ask too much the health workers say you are bothering them and yet you want to get information about how to protect your child. Some counsellors talk to themselves. They think mothers understand what they are saying. Some do not let mothers ask questions maybe because they want to see many other patients. (Caregiver who tested child for HIV)*

Some key informant health worker seemed to recognize treating caregivers well was an important motivator for them to return their children for HIV testing

*As long as you give her the best care you can. You make her your friend. We have made them some our friends. You continue counselling them telling and telling them the importance of coming back to test their children. Many of them (caregivers) come back. (Key informant 1)*

#### **4.4.1.2 Fear of lack of confidentiality**

There are some few caregivers who cited breach of confidence by some health workers as a barrier to HIV testing for children. Perceptions about confidentiality were related to characteristics of the hospital environment and the health workers providing HIV services.

Some respondents were of the view that having health workers who reside in the same community as themselves resulted in a breach of confidentiality

*This place is a small area some of the people who treat us also live where we live. Sometimes when you go to the hospital and they see you they talk. If you have a*

*problem and you tell them they talk. I am waiting to take my child far where they do not know me. (Caregiver whose child was not tested for HIV)*

Other caregivers were of the view that the counselling environment was not appropriate making it difficult for them to return for assistance regarding EID for HIV.

*Some mothers say there is little space for counselling. Sometimes you are in the counsellor's room and you feel people in the corridor are listening to what you are talking. (Caregiver who tested child for HIV)*

#### **4.4.1.3 Long waiting times at the facility**

One of the other deterrents from seeking HIV testing services for infants early were the long waiting times at the hospital. Whereas some caregivers found the long waiting times not to be a problem and were ready to wait for a substantial amount of time there are those who associated long waiting times with an increased risk of compromising confidentiality.

Some caregivers fear that someone who knows them might come to the hospital while they are waiting to have their children tested and as a result find out that they are HIV-positive.

*When I was pregnant and attending antenatal care I would sometimes stay at the hospital for the whole day waiting to be attended to. If you stay at the hospital long after leaving home very early in the morning other people start wondering why and they start talking I think because the services are free at the hospital everyone goes there. After giving birth I could not manage to go through the same thing because I had another child to take care of and I had to work. I therefore kept postponing taking my baby for testing. (Caregiver whose child was not tested for HIV)*

#### **Section summary**

Factors that affect EID for HIV at the health facility level have been described in the preceeding section. Whereas some caregivers view health workers as a source of information that facilitate access to EID there are some caregivers who mentioned that they inhibit access to EID by displaying negative attitudes, contravening confidentiality and failing to provide adequate information in an interactive manner that facilitates understanding. Some caregivers perceived long waiting times as one of the factors bound to compromise confidentiality of their HIV status thus making them opt not to test their infants for HIV.

## 4.5. Community factors

Social support from the community and family structures was the key community factor identified as affecting EID for HIV as outlined below.

### 4.5.1 Social support

Social network influence and social support were found to be factors affecting decision making regarding testing for infants. A few of the caregivers mentioned that their decision to take children for HIV testing was a result of influence and advice from some members of their social network. They mentioned that the social support from people in their family/community was a source of psychological and emotional support.

Some of the caregivers cited support from church related groups as a motivator for seeking EID for HIV.

*When I spoke to members of my church social support group they encouraged me to take back my child for HIV testing. Some of them told me about their experiences with testing their children. Others promised to support me. (Caregiver who tested child for HIV)*

Some of the caregivers revealed that social support groups facilitate EID for HIV especially if they comprise of people who are also HIV-positive.

*If you are part of groups of people who also have HIV problems like yourself it can be helpful. They understand the problems you are going through. Some of them have also taken their children for HIV testing. They are not like some people who you tell about your problem and they give you the wrong advice. They tell you that if you are HIV-positive then it is a must your baby is also sick and you should not waste time by taking them for testing. (Caregiver who tested child for HIV)*

Other caregivers sought the views and support of their peers and selected family members when making decisions regarding seeking HIV testing for their infants. This was due to the fact that such networks were important sources of psychosocial support and for family members a source of economic support.

*At first I was scared of taking my baby for testing I asked a friend of mine who is also HIV-positive and she said I should take my child. She told me all the good reasons. My husband also convinced me to go. (Caregiver who tested child for HIV)*

However some caregivers especially those who did not take their children back for HIV testing were not comfortable confiding in other people. They cited fear of stigma and discrimination as one of the major reasons for shunning support groups. When asked who they speak to regarding matters pertaining to health seeking for their children they confessed that they are not comfortable speaking to anyone.

*We keep the information to ourselves because we fear people talking about us. You cannot trust some people. They belong to such groups to talk about other people's problems. (Caregiver whose child was not tested for HIV)*

Some preferred to keep matters pertaining to their status to themselves claiming that support groups comprise of strangers who do not understand their situation as HIV-positive mothers.

*I like to keep the knowledge of my child's situation a secret instead of getting help from strangers who do not understand my problems. (Caregiver whose child was not tested for HIV)*

## **4.6. Economic factors**

### **4.6.1. Lack of transport**

Some caregivers of HIV-exposed infants may be concerned about the status of their children, but lacked the motivation or self-efficacy to take their children to the clinic to be tested due to challenges with transport. Though EID services are provided free of charge, some caregivers reported that there were other indirect costs like transport that inhibited them from bringing back children for HIV testing. This finding was more common among those caregivers that stayed a distance away from the hospital and those who were not employed or solely depended on their husband's financial support for survival. Some came from a distance as far as 10km and they had to pay over UG shs 3,000 to and from the hospital. For some caregivers especially those who never returned children for HIV testing meeting the family's basic needs was a priority over taking their children for HIV testing.

*There are also some women who do not work. Sometimes they do not have transport to take them from where they stay to the place from where the child can be tested. They say I will go when I get money. When the money comes there are other problems. (Caregiver who tested child for HIV)*

Financial challenges forced some caregivers to forego EID for HIV as evidenced in the quote below.

*I have two other children to feed in addition to the small one. If I use the money for transport to take one child to the hospital how will I look after the others? I decided to wait until there was reason to take all of them.*(Caregiver whose child was not tested for HIV)

Some caregivers depend on their husbands for funds to cater for all their expenses since they do not work. Some fear to ask for funds for transport, fear that their spouses will demand to know the reason why they need the money.

*I ask for all the money I need from my husband and I every time I ask I have to explain to him why I need the money. When I was pregnant it was easy because he could see. Now am not sure of the reason to tell him since he does not know that I am positive and therefore I need transport to take the child for testing also. (PCR test) I want peace at home so I cannot say at all.* (Caregiver whose child was not tested for HIV)

On the other hand there are some caregivers who said that they stayed within the hospital vicinity and therefore transport was not a problem. For those caregivers staying near the hospital, it was easy for them to walk to and from the hospital.

A key informant confirmed that lack of transport is a challenge for caregivers especially those who have to depend on their spouses.

*Some say they stay very far, far away from here and they do not have money for transport. There are others who have no money to come and yet they have the time since they are not working. They have to get all the money from their husbands.*(Key informant 4)

For some caregivers availability of free HIV testing services for infants was a motivating factor for uptake of EID. Caregivers reported that they did not have to travel all the way to Kampala (city of Uganda) to seek services for their infants. They mentioned that though they had to pay for transport to and from the hospital, at least the services were provided free of charge. This was especially mentioned by caregivers who either did not have meaningful employment and or those who had to rely on their husbands to provide for their needs.

#### **4.6.1.2 Migration in search of employment**

Some caregivers were forced to migrate in search of employment resulting in self-transfer to other health facilities. Migration created challenges with change of service providers leading to failure to access EID services for HIV.

*I could not bring my child for testing because I had to move to the village. I could not afford to pay rent for the house I was renting since I was not working. I sold what I had and I went back to the village to look for work. While there I went to another clinic and I told them that I had been on ARVs and I wanted my child tested for HIV. I was told to go back to the clinic I was visiting so that I get a transfer form and then I get started on ARVs in the new clinic in the village. I did not have enough transport to come back to the clinic at Entebbe hospital to get a transfer form which allows me to join another clinic. I said to myself that if I get transport I will go back to Entebbe hospital and get the transfer form but because I was not working that was not possible. (Caregiver whose child was not tested for HIV)*

#### **4.6.1.3 Caregiver busy schedule and forgetfulness**

A few of the respondents reported that their busy schedule and work engagements and the need to earn money to survive were barriers to seeking HIV testing for their children. A clinic appointment required them to dedicate a whole day and yet caregivers needed to work so as not to lose customers. This was common among self-employed women. As a result of this busy schedule some of the caregivers admitted finding it difficult to get time to take back their children for testing

*Others (mothers) work and they do not have time to go to the government hospital because you have to line up some times for a whole day. By the time you reach the doctor you find you still have to wait. You find that you have failed to do any of your work which gives you money to take care of your family. They prefer to treat whatever sicknesses their child gets instead of taking them to the hospital. (Caregiver who tested child for HIV)*

Caregiver's busy schedules impacted on their ability to remember to fulfil appointments for their infants.

*They (health worker) told me the time when to take the child back for an HIV test but I do not remember exactly when and I got busy with many other things like looking*

*after my two other children who are also young. (Caregiver whose child was not tested for HIV)*

Others have their minds preoccupied with many issues including fears about giving birth to an HIV-positive child that they do not concentrate on the information provided by the health workers and as a result they end up picking the wrong information and forgetting what they are advised to do.

*HIV-positive mothers have a lot on their minds. You have problems with taking your HIV medicine. You are worried about giving birth to an HIV-positive child and you are scared of what your husband will think if the child is HIV-positive. Some mothers end up end up forgetting some of the information the health worker says or sometimes you do not get things right. Sometimes there is a lot of information to think about. (Caregiver who tested child for HIV)*

A concern about the caregiver's forgetfulness was also raised by some key informants who mentioned that it is important to continuously repeat information about EID of HIV to caregivers whenever there is an opportunity. Some suggested use of community meetings and market days to remind mothers to take their children for HIV testing.

*If we want HIV-positive mothers to return their infants for testing we need to keep repeating information about EID for HIV every time we interact with them. This should happen during their antenatal and post natal visits. Maybe we can work with leaders in the community. (Key informant 1).*

Other key informants mentioned that follow up calls using village health teams would help remind and sensitise mothers to bring children for HIV testing.

*Sensitization should reach every one. As health workers we are trying to do our work but if the caregivers are not sensitized they could remain there in the villages without bringing their children for testing. Village health workers can help. (Key informant 2).*

### **Section summary**

Economic factors that affect EID for HIV have been outlined in the above section. Though EID for HIV services are provided free of charge, caregivers fail to take children for HIV testing due to lack of transport. Migration in search of employment and busy schedules are the other economic barriers identified.

#### **4.7 Summary of results**

This chapter has outlined the main findings of the study in regards to facilitators and barriers to HIV testing for infants. Factors affecting EID for HIV have been cited at the individual level, health facility, community and economic levels.

At the individual level, maternal knowledge of EID and PMTCT was mentioned as one of the motivating factors with caregivers commending health workers as a critical source of such information. Limited knowledge about timing for EID however comes out as a barrier to accessing EID for some caregivers. This chapter reveals other knowledge related barriers identified at the caregiver level which include the belief that asymptomatic children are HIV-negative since caregivers adhered to the PMTCT advice from the health worker.

Though knowledge about availability of HIV treatment and its efficacy motivates some caregivers to access services there are some caregivers whose fear of a positive outcome for their infants coupled with denial of own and child's positive status bars them from accessing EID. Being on ART is mentioned as a facilitating factor since such mothers constantly interact with the health system and interface with the health workers who provide information and reminders to the mothers.

Voluntary disclosure of status is mentioned as a facilitator to EID while involuntary disclosure partly due to the hospital environment and infant feeding practices is said to be a barrier to EID since it creates stigma and discrimination. From the results it is clear that stigma and discrimination continue to play a key role in the lives of HIV infected mothers and their health seeking behaviours with particular challenges faced by those who have not disclosed their status.

Faith and cultural beliefs and forgetfulness of the caregiver are the other barriers to EID for HIV identified at the personal level while at the health facility level, health worker negative attitudes, fear of lack of confidentiality and long waiting times were identified as barriers to EID.

Economic barriers to EID have been identified to include lack of transport especially for those caregivers who depend on their spouses for financial support and yet they were faced with limited male involvement in health care seeking for their children. To make ends meet some caregivers migrate in search of employment leading to challenges with accessing EID services. Caregiver's busy schedule is the other economic barrier to accessing EID services.

In the next chapter the results presented in this chapter will be discussed in relation to the literature reviewed under Chapter 2.



## **CHAPTER 5: DISCUSSION**

### **5.1 Introduction**

This chapter is a discussion of the key findings of the study which mainly focused on the barriers and facilitators to HIV testing for infants. This chapter discusses these findings with relation to the literature reviewed in Chapter 2. The findings are derived from interviews with caregivers whose children sought early infant diagnosis (EID) for HIV, caregivers who did not seek EID and key informants.

In this chapter individual factors discussed include influence of maternal knowledge and awareness about uptake of EID, fatalistic beliefs about HIV, knowledge about the protective nature of Prevention of Mother-to-Child-Transmission (PMTCT) practices, perception about the health status of HIV-exposed child and influence of society's expectations of a responsible mother. Other individual factors include influence of disclosure and the resulting stigma and discrimination. The discussion on socio-cultural factors covers the negative influence of religion, post-delivery cultural practices and social support from the community and individuals. Socio-economic factors cover lack of transport due to the financial status of caregivers and the long distances involved when travelling to the health facilities as well as lack of decision making autonomy due to lack of an independent source of income. Health facility factors include the attitudes of the health workers, fear of lack of confidentiality, long waiting times at the health facilities and lack of adequate information on EID.

It is anticipated that understanding the factors that motivate and inhibit caregivers from seeking EID services will contribute information helpful in improving the uptake of HIV testing for infants at both facility and national levels.

### **5.2 Individual facilitators and barriers to EID**

#### ***5.2.1 The Influence of maternal knowledge and awareness on uptake of EID***

Findings from this study show that maternal knowledge and awareness of the importance of EID and PMTCT had an influence on caregiver's ability to seek HIV testing services for their infants. The study found that maternal knowledge about EID was limited and the caregivers lacked understanding about the right timing for EID. The finding here is consistent with that of similar studies in Kenya (Hassan et al., 2011) and South Africa (Adeniyi et al., 2015; Peltzer et al., 2010) which explored the dynamics and constraints to EID and found that EID uptake was influenced by the lack of EID-related knowledge among caregivers of infants.

The authors went further and attributed the limited maternal knowledge about EID to the inadequacies in the healthcare workers' knowledge about EID.

Related to the caregiver's limited knowledge about EID, this study also found that there was a widespread perception among caregivers that HIV-exposed children with no symptoms of HIV infection are HIV-negative and therefore do not require HIV testing. This finding tallies with other studies in Kenya and South Africa which also found that some caregivers may not understand or see the benefit of testing their children for HIV when asymptomatic (Vreeman et al., 2010; Boender et al., 2012). A number of other qualitative studies in sub-Saharan Africa (SSA) exploring factors affecting EID also demonstrated a strong relationship between caregiver's perception of the health status of the child and uptake of EID (Peltzer et al., 2010; Adeniyi et al., 2015; Kiragu et al., 2008; Schacht et al., 2014; Kranzer et al., 2011; Yeap et al., 2010).

The misconception that healthy-looking children are HIV-negative has the effect of inhibiting the caregivers of such children from seeking early testing, diagnosis and treatment. Studies have found that the relationship between symptomatic illness and EID-seeking behaviour of the caregivers is strong. Boender et al. (2012) reported that over 72% of children were brought for care with advanced HIV disease at their initial visit to the health centres while Hassan et al. (2011) revealed that more than 80% of the infants enrolling for EID were referred for care from acute or chronic clinic services. The findings of these two studies imply that the infants were being referred and enrolled when they were already very sick, a situation that could have been avoided if the infants had been tested for HIV early.

This study's finding that some caregivers wait until their infants are sick before seeking EID could be explained by the fact that caregiver's beliefs and health seeking behaviours influence infant's uptake of EID (Schacht et al., 2014) and since adults who are the caregivers of infants have been shown to seek voluntary counselling and testing for themselves after displaying symptoms of HIV (Nuwaha et al 2002) it is possible that they do the same for their HIV-exposed infants. It is also clear from the study findings that caregiver's comprehensive knowledge about HIV is limited since some were not aware that an HIV-exposed child without HIV symptoms can be HIV-positive and as a result denied them the chance to access EID. Findings from this study confirm the Uganda Demographic Health Survey (UDHS) study results that revealed that whereas almost all Ugandans have heard of HIV, only 38% of women and 43% of men have comprehensive knowledge of HIV

prevention and transmission. One of the measures for comprehensive knowledge of HIV includes awareness that a healthy looking person can have HIV (UBOS, 2011).

The success of the prevention and treatment of HIV strategies rely on early diagnosis of infants. The timing of the testing and diagnosis is therefore crucial. However, the current findings show that limited caregiver knowledge about the right timing for EID may account for their reluctance to seek the service (Woldesenbet et al., 2015) and yet early ART has a positive influence on mortality and morbidity of infants (Violari et al., 2008). The findings suggest that maternal knowledge of EID is an important factor affecting uptake of EID.

### **5.2.2 Knowledge about the protective nature of PMTCT practices**

In Uganda, pregnant mothers who are HIV-positive access PMTCT services when they deliver from a health facility. In this study, the respondents viewed adherence to PMTCT practices as key to having an HIV-negative child. As a result, some of the caregivers found it unnecessary to take their children for HIV testing because they believed that the PMTCT ensured their children were negative. This finding tallies with that of a South African study in which respondents exhibited a sense of confidence that their infants were HIV-negative since they had complied with PMTCT requirements and therefore there was no risk of HIV transmission to the infant (Peltzer et al., 2010).

Health workers at health facilities are in the frontline of providing information to clients, including pregnant mothers and other caregivers. Some caregivers, especially those who returned their infants for HIV testing, recognised the health workers as a source of HIV information, caregivers who never returned their infants for testing claimed that the health workers did not impart to them enough knowledge about EID and PMTCT. This could explain the perception among some caregivers that the PMTCT practices are fully effective, a finding consistent with that of another study in South Africa which also attributed misperceptions about PMTCT to limited caregiver knowledge about the extent to which PMTCT interventions are protective (Yeap et. al., 2009). Limited knowledge about PMTCT was also exhibited in a study in Uganda where 12% of women interviewed did not think it was possible for a mother to pass on the virus to an unborn baby if the mother followed PMTCT guidelines (Bajunirwe & Muzoora, 2005). Low or incomplete maternal knowledge about PMTCT has a potentially negative effect on EID uptake as this study and previous studies (Makau et al., 2015; Woldesenbet et al., 2015) suggest.

### **5.2.3 Fatalistic beliefs about HIV**

Fear of a positive result for the child was found to be a de-motivator to HIV testing for infants in the current study. The caregivers were either not emotionally ready for a positive result or had some fatalistic beliefs that the HIV would progress faster to AIDS if their infants were tested for HIV and as a result believed the child would die soon after the test. This finding is not unique to Uganda with previous studies in southern Africa having had similar results. A study in South Africa found that caregivers believed that getting to know the child's HIV status would result in faster progression of the sickness (Yeap et al., 2010) while another study in Malawi revealed that an infant with an HIV-positive status would make the caregivers worried all the time and this might shorten the life of the baby (Donahue et al., 2012).

This study established that the basis of the respondents' fatalistic beliefs lay in their perception that HIV was incurable and as a result they had fears about having a child who is sickly all the time with no hope of healing. This finding is similar to those reported in South African studies which attributed caregiver's failure to seek EID for their infants to the fear that the child will fall sick; the fear that the child might die or the fear of living with an HIV-positive child (Adeniyi et al., 2015). In line with findings from the current study, caregivers in a study in Mozambique also associated HIV with death and as a result found no reason to test their children for HIV (Schacht et al., 2014).

A study in Mozambique found that these fatalistic beliefs persisted despite ART access probably because the claim that HIV was fatal was emphasized as an approach to advocate for safer behaviours in HIV prevention campaigns in the early years of the onset of HIV (Schacht et al., 2014). It can be concluded that these fatalistic beliefs about HIV still persist because some caregivers are not aware of new developments about the efficacy of paediatric HIV treatment considering that in Uganda, like in other SSA countries, HIV treatment for children became available later than that for adults.

Warwick (2006) and Phakathi et al. (2011) argue that ART availability and belief in its benefits can have a positive impact on the willingness of adults to be tested for HIV. However, findings from the current study suggest that, despite the increase in the availability of paediatric ART in Uganda, there are some caregivers who are reluctant to take their infants for EID, demonstrating perhaps that the caregivers' ability to decide to test their children for HIV remains constrained by their lack of general knowledge of HIV or low awareness of the

availability of paediatric HIV prevention and treatment services. Another possible explanation for the relationship between low uptake of EID and ART is offered by Jürgensen et al. (2012) who argue that even though ART has improved the health status of HIV-positive people, changing HIV from a fatal to a chronic condition, the fact that it is not a cure decreases people's incentive to test.

Despite the fatalistic belief of some caregivers in the current study, there were some caregivers who took children for HIV testing after observing the health status of other HIV-positive children improve while on ART. A similar finding was made in a study in Mozambique where caregivers became hopeful about their HIV-exposed children when they saw the health of other HIV-infected people improve due to treatment (Schacht et al., 2014). Knowledge that caregivers gain from observing the improvement in the health status of HIV-exposed children on ART is therefore a motivator for EID.

#### **5.2.4 Maternal receipt of ART**

Some respondents in this study were mothers who were themselves on ART. It was found that maternal receipt of ART had the potential to influence the mother's uptake of EID. Since women on ART made regular visits to the health facilities for refills of their medication, they were more likely to interface with health workers who inquired about the wellbeing of their infants. Constant follow up from health workers seemed to induce them to return their children for HIV testing, highlighting the importance of having mothers on ART as a gateway to acceptance of EID for HIV since the mothers seemed to serve as index clients to their HIV-exposed infants. This finding is supported by a study in Malawi where testing targeted at family members of index clients was found to be an effective approach for early case finding for HIV-exposed and HIV-infected children (Cohen et al., 2010). Equally, a study in Mozambique found that almost all (95%) of mothers who sought EID services with their infants were themselves enrolled in the ART clinic. Mothers on ART were said to have a better understanding of their HIV status and because of the regular visits to the clinic chances of identifying their HIV-exposed infants were higher (Cook et al., 2011). Meanwhile, in a study in Malawi, women who were not taking ART were found to have limited awareness about the availability of paediatric ART and the importance of early HIV testing for infants (Donahue et al., 2012), helping to reinforce the argument that improving the mother's access to services and indirectly information can have a positive influence on EID uptake.

From the findings in this study it is clear that mother's access to ART services and information and receipt of ART has a positive influence on EID uptake for their infants.

## **5.2.5 Other individual factors that influenced EID uptake**

### ***5.2.5.1 Influence of disclosure on EID uptake***

In this study, disclosure of HIV status to partners and close family members was perceived as both a facilitator and barrier to EID uptake. Participant's felt that voluntary disclosure was a facilitator while unintended disclosure by community members was a barrier to EID uptake. A few of the caregivers revealed that voluntary disclosure of their HIV status to spouses and close family members was one of the facilitators for uptake of HIV testing for their infants. Disclosure of status meant women could ensure moral and or financial support since it eliminated the idea of secrecy making it possible for them to test their children at the recommended time. This finding is supported by research in South Africa which revealed that women who disclosed their HIV test result were two and a half times more likely to opt for EID than those who did not disclose (Peltzer et al., 2010).

There were however some caregivers who found it difficult to access EID for their infants because they had not disclosed their HIV status to their partners due to fear of emotional and physical abuse. Non-disclosure as a deterrent to EID uptake was also revealed in studies in Kenya, Namibia and Nigeria among women living with HIV (ICWLHIV & GNP, 2015; OPHID, 2014; Motswere-Chirwa et al., 2014; Peltzer et al., 2010; Boender et al., 2012).

Caregivers were also afraid of the subsequent stigmatisation by the community when their positive test results became known after taking their infants for EID. This finding is consistent with that of a study in Kenya where over 30% of children were not returned to the clinic since their guardians had not disclosed their own status and were therefore afraid of stigma from the community and family due to their status and that of the child, (Braitstein et al., 2011) and a South African study where fear of community stigma was cited as one of the reasons for not requesting EID (Woldesenbet et al., 2015).

This study found that part of the stigma from the community was based on misinformation about HIV. For instance, some caregivers feared that community members would stigmatise their kids due to fear of HIV infection. These findings are supported by Kalichman and Simbayi (2003) who also cited wrong information about HIV as a cause of stigma.

From the findings and previous studies reviewed it is evident that fear of disclosure and the resulting stigma and discrimination negatively influence EID uptake. Some of the fears are based on ignorance and misconceptions about HIV.

### **5.3 Socio-cultural factors**

In this study, belief in faith healing and observance of cultural norms regarding post-delivery practices were provided by respondents as factors that negatively influenced EID uptake. Caregivers mentioned that there was no need to test their children for HIV since they were healed by faith through prayers. Negative influence of religion on EID uptake was also cited in studies in Zimbabwe and Kenya (OPHID, 2014; Wachira et al., 2012).

Another social factor that was mentioned by a few caregivers is the influence of post-delivery cultural norms that dictate that mothers should not leave their homes with a new born until after the elapse of a certain period of time. Due to observance of cultural beliefs relating to child birth, some care-givers failed to take their infants for EID for HIV. This finding collates with those in a study among HIV-positive women in Namibia, Kenya and Nigeria where respondents were worried of being questioned for taking infants away from home before the culturally acceptable period elapsed and therefore missed out taking their infants for HIV testing (ICWLHIV & GNP, 2015) and in Zimbabwe where the cultural requirement to deliver away from home made it difficult to access EID (OPHID, 2014).

In this study, social support from people in the community who include peers, selected family members, and members of PLWH support groups positively influenced decisions to take infants for HIV testing. These findings are supported by studies in South Africa and in Kenya which revealed that social support groups were a source of emotional support and information on EID resulting in uptake of EID (Peltzer et al., 2010; Makau et al., 2015). Hassan et al. (2011) also argue that lack of support structures to facilitate disclosure and deal with stigma inhibited HIV testing for infants. Similarly, Schacht et al. (2014) state that lack of emotional and social support from community members external to the family of the child, for instance, neighbours and other influential people in the community, hindered access to EID. On the contrary, Wachira et al. (2012) mention that community systems and structures were found to play a less important role in supporting caregivers since HIV-positive mothers opted to keep matters pertaining to their HIV status and that of their children.

These findings show that, in as far as contributing to the community uptake of EID, traditional community systems and structures in Uganda play a mixed role; supportive in

some instances but dissuading in other instances. Decisions to take children for EID are influenced by individuals and in some instances by the social network.

### **5.3.1 Influence of society's expectations of a responsible mother**

Some caregivers felt that taking their children for HIV testing, just like taking them for medical attention for any other health condition, was “a sign of being a good and responsible mother who cares about the health of her child”. The literature reviewed did not show any findings that directly link the idea of “being a good and responsible mother” to increased EID uptake so this finding, in as far as the relevant literature reviewed indicates, is new. However, one study in rural Uganda had alluded to the notion that responsible motherhood was a reason mothers sought HIV testing for themselves during antenatal care so as to protect their unborn babies and, in that way, fulfil societal expectations that good mothers protect their infants. Pregnant mothers who did not test for HIV in order to protect their babies were perceived as negligent (Mumtaz et al., 2013).

The mothers' perceived social obligation, this study has shown, has expanded beyond the pregnant mother testing herself for HIV to include taking her new-born infant for EID at the right time. It is evident social values associated with motherhood are changing and now include HIV testing for infants and adults as Mumtaz et al. have argued. Much as the fear of stigmatisation has been said to be a key barrier to the uptake of HIV testing, this study has revealed that the caregiver's felt social compulsion to protect their infants from HIV infection overcame the caregiver's fear of stigma. This suggests that taking advantage of mothers' innate desire to protect their HIV-exposed babies and keep them healthy might be one of the ways to motivate them to seek and accept EID for HIV for their infants.

### **5.4 Influence of socio-economic factors on EID uptake**

The socio-economic factors that could act as barriers to the uptake of EID by caregivers of new-born infants include distance to the clinic and transport costs between their home and the health facility. This finding is consistent with the findings of several other studies in sub-Saharan Africa (Peltzer et al., 2010; Makau et al., 2011; Boender et al., 2012; Schacht et al., 2014; ICWLHIV & GNP, 2015) which provide evidence that caregivers who stayed far away from the clinic and those who depended on their spouses for financial support were less likely to send their children to a health facility for EID.

A majority of caregivers interviewed who never took children back for HIV testing had at least primary school education. A study in Malawi noted that parents of infants lost to follow

up were less educated (Ioannidis et al., 1999). The highest level of schooling attained by the caregivers in this study is important for analysing the factors influencing the uptake of EID because maternal education has been found to enhance communication between the mothers and health care providers as well as improving the ability to retain information resulting in better implementation of recommended interventions (Hamadani et al., 2006). It is possible that maternal education could have a positive effect on EID uptake though it is difficult to draw any conclusions based on the profile of respondents sampled in this study.

Caregivers in this study mentioned that their lack of financial autonomy made it difficult to make decisions regarding health care seeking for themselves and their infants. Since the majority of caregivers in this study did not have any form of sustainable source of income of their own with most of them involved in casual labour, most of them mentioned that they depended on their husbands for finances and they as a result found it difficult to access EID services. Yet studies in Kenya, Uganda and Mozambique (Makau et al., 2015; Boender et al., 2012; Cook et al., 2011) revealed that there is a relationship between maternal independent source of income and uptake of EID services: the more independent a woman is in terms of income, the more likely she will seek EID for her child. However, according to the UDHS (2011), husbands were the major decision makers on matters pertaining to women's health care and only 23% of married women reportedly make independent health care decisions. Another study by Bwambale et al. (2008) found that most decisions pertaining to health-seeking behaviour within the family were said to be determined by the men and whatever decisions they make were normally not challenged. Effectively, it means the decision to take or not to take the infant for EID rests with the man, not the woman, particularly in the case of a woman who is financially dependent on her husband.

The findings in this study show that the effect of the financial burden on caregivers outweighed their strength of their desire to take their children to the clinic. As would be expected, some instead sacrificed health care for other basic necessities, a finding that tallies with the UDHS (2011) where almost 50% of women interviewed indicated that getting money for treatment would be a problem in accessing health care. It is therefore not surprising that free HIV testing was a motivator for some of the women to seek EID services for some of the caregivers in this study, a view that was also expressed in a study in Mozambique (Schacht et al., 2014).

For those caregivers that had a source of income their busy schedule and demanding work engagements as they laboured to earn money to survive were barriers to seeking HIV testing

for their infants. This finding agrees with a study in Kenya which showed that some women find it difficult to take time off doing the work that earns them a living in order to take their children to a health facility for HIV testing (Braitstein et al., 2011).

This study shows that financial constraints experienced by caregivers affect their ability to seek EID services for their infants. Though EID services are free the cost of transport to and from the health facility poses a burden on caregivers who are financially constrained.

## **5.5 Health facility factors**

### ***5.5.1 Negative attitudes of health workers at the facility***

In the current study, like in other studies in SSA (ICWLHIV & GNP, 2015; Kiragu et al., 2008; Varga et al. 2008; Yeap et al., 2010), the negative attitudes of health workers towards clients seeking HIV testing services and the lack of confidentiality were found to be among the factors that may inhibit uptake of EID. Findings from this study show that people's experiences with the health system in terms of their perceptions of health worker confidentiality and attitudes affect uptake of HIV testing (Gilson, 2003) underscoring the importance of positive demeanour of health workers.

### **5.5.2 Lack of sufficient information on EID**

In this study, some caregivers mentioned that lack of sufficient information on EID inhibited them from taking their infants for testing. At the health facility, they claimed their efforts to ask questions were sometimes frustrated by the health workers. These findings can be corroborated with those in a study in Kenya which revealed that, because service providers did not sufficiently cover the EID module during their antenatal and PMTCT training, they lacked adequate knowledge to impart to caregivers who visit the health facilities (Hassan et al., 2012). Studies in South Africa also demonstrated lack of adequate information from health workers as a barrier to EID uptake (Yeap et al., 2010; Horwood et al., 2010). So the claim of the caregivers of not being provided sufficient EID information has a basis.

However, although the literature reviewed seems to suggest that lack of knowledge and training about paediatric HIV makes some health workers incapable of recommending and imparting information about EID for HIV to those who need it (Phelps et al., 2013; Horwood et al., 2010), in this study caregiver respondents did not allude to lack of training. Instead some of the caregivers in this study attributed the health worker's apparent negative attitudes to the heavy work load that they health workers have to deal with. Other studies in SSA (Bwirire et al., 2008; Day et al. 2003; Van Dyk & van Dyk 2003) support this heavy work

load argument because it attributed the negative attitudes health workers portray to the low morale resulting from heavy workloads.

From the discussion, lack of sufficient information on EID seems to have a negative influence on uptake of EID. Heavy workload of the health workers makes it difficult for them to impart sufficient information to caregivers to help them make informed decisions about EID.

### **5.5.3 Long waiting times at the facility**

One of the other factors mentioned by caregivers as a deterrent from seeking HIV testing services for infants early were the long waiting times at the hospital. Whereas some caregivers found long waiting times not to be a problem and were ready to wait for a substantial amount of time, there were those who associated long waiting times with an increased risk of compromising confidentiality. These findings agree with studies in South Africa, Mozambique and one among HIV-positive women in Namibia, Kenya and Nigeria where long lines and overcrowding were also reported as a barrier to EID (Yeap et al., 2010; Schacht et al., 2014; ICWLHIV & GNP, 2015). Understandably, the basis for this consideration could relate to the fact that longer waiting times at a health facility imply foregoing numerous other activities such as caring for other children, household chores, and potential loss of income from business or casual work.

### **5.6 Summary of the discussion**

This chapter reveals that there are multiple factors that continue to impede caregivers of children at risk of HIV from accessing EID. At the individual or caregiver level, the impeding factors include fear of the stigma and discrimination that would result from unintended disclosure; the general fear of HIV-positive results; denial of status particularly if it is positive; maternal receipt of ART and incomplete knowledge about the protective nature of PMTCT practices. Economic factors discussed include lack of transport to the facility and the caregiver's failure to take time off their busy schedule to seek EID. At the health facility, the impeding factors include the unwelcoming attitudes of health workers, long waiting times and fear by the caregivers that the health workers lack confidentiality. Social-cultural factors, including the caregiver's health-related religious and cultural beliefs as well as the level of anticipated social support after disclosure, affect EID uptake. Most of the study findings confirm that factors affecting EID in Uganda are similar to those found in EID studies in other sub-Saharan countries as per the literature review. The findings in the current study are

supported by other studies conducted in the region and these have implications for future work in this context.

### **5. 7 Limitations of the study**

During this study it was very difficult to locate and interview caregivers who did not bring their children back for HIV testing. The alternative route to them was the telephone contacts in their personal records they provided the hospital during antenatal visits. However, these records presented challenges: some bore wrong telephone numbers; others were telephone numbers of treatment supporters who were partners reluctant to have the caregivers participate in the study while others just switched off their phones after agreeing to participate in the interview. To protect the initial representativeness of the study sample and maintain integrity of the data collected, peer mothers who are also HIV-positive were used to encourage the caregivers to participate in the interview. The peer mothers shared their story and experiences with the caregivers that they managed to contact and were able to convince some to participate.

Although the researcher explained the importance of the study during the informed consent process to reduce any potential bias, it is still possible that some of the responses from some of the HIV-positive mothers who failed to return their children for HIV testing might have been biased since the respondents might have felt victimised after learning about the purpose of the study. Yet another concern is that the purposively selected HIV-positive mothers who delivered at the selected health facility may not adequately reflect the circumstances of HIV-positive women who do not frequent health facilities and as a result the findings may not be representative of both categories of caregivers. Nevertheless, interview data from peer mothers provided some insight into the views of women who do not deliver in health facilities.

The study occurred in a specific geographical and cultural area and therefore its findings may not be generalized to other geographical and cultural regions. Logistical and financial constraints compelled the researcher to focus on tracing and interviewing mother infant pairs living close to the hospital in Wakiso District. The findings therefore cannot be generalized to those who had moved or were residing outside the hospital reach. Moreover, this particular study site was a public sector government hospital setting. Although the interviews are likely to have encountered the challenges that most caregivers who are HIV-positive face in both public and private settings, the views presented, especially those of key informants, may not

be representative of private sector patients. Future research in this area should therefore seek to conduct studies in both public and private sector facilities.

Some of the caregivers who returned their children for testing were interviewed near the facility where they delivered and obtained PMTCT and antenatal services. These caregivers could have been less honest about their negative experiences in care for fear of this information being revealed to the care providers at the facility. There is a possibility of social desirability bias in the interview responses. Besides, for the interviews conducted in the local Luganda language, the researcher had to rely only on transcripts and cultural explanations provided by the research assistant. The researcher was aware of the potential limitation and therefore ensured accurate transcriptions and discussion of understandings and findings with the research assistant.

The study population was homogenous with only female caregivers. The views presented therefore do not include those of male caregivers. However, in Uganda, caregiving is predominantly the duty and responsibility of women. In view of this cultural context of the study, women caregivers provide an insight into the views of the population that normally provides majority of child care within Uganda. This, however, should not be taken to mean men play a minimal role in caregiving. This study may not clearly explain the role of male partners of women caregivers in decisions regarding EID for infants since the male partners were not interviewed. Further research must address this limitation.

## **CHAPTER 6: CONCLUSION AND RECOMMENDATIONS**

### **6.1 Conclusion**

This study explored facilitators and barriers to early infant diagnosis (EID) for HIV-exposed infants of women who gave birth at Entebbe hospital, in Wakiso District, Uganda. Respondents provided information that showed that the uptake of EID by caregivers is influenced by a variety of factors. While some of these factors explored facilitated the uptake of EID for HIV in infants, others factors were found to act as barriers.

Like the barriers identified, the facilitators to EID uptake were found to exist at the caregiver or individual level and at the health facility or institutional level. Some of the facilitators were of socio-cultural nature, while others were socio-economic. At the caregiver's individual level, the maternal receipt of ART was found to facilitate the uptake of EID since mothers on ART seemed to be motivated to seek EID through the frequent reminders by health workers with whom they interface. This study proved what other similar studies had found earlier: mothers on ART are index clients for their infants. Therefore, besides facilitating EID uptake, ensuring early access to HIV services by HIV-positive mothers offers opportunity for early case finding for HIV-exposed and HIV-infected children.

From the socio-cultural perspective, the caregiver's urge to fulfil the societal expectation that good and responsible mothers protect their infants by testing them for HIV was identified as a facilitator. This particular finding suggests that social values associated with motherhood are changing to include HIV testing for infants and adults. Even though fear of stigma is still a key barrier to EID uptake, this study has revealed that the caregiver's felt social obligation to protect their infants from HIV infection prevailed over the caregiver's fear of stigma. It can be concluded here that strategies designed to exploit the mothers' innate desire to protect their HIV-exposed babies and keep them healthy could effectively increase uptake of EID for HIV. It must however be observed that, as this study found, social support from individuals and the community remains an important denominator of all the identified facilitators to EID uptake. Therefore, any mobilisation to increase EID uptake has to target both individual caregivers and those who are known or believed to influence them.

The study also identified several barriers to EID uptake at the individual level. These include the influence of limited maternal knowledge and awareness about uptake of EID; the caregiver's fatalistic beliefs about HIV; limited knowledge about the protective nature of PMTCT practices; the mother's perception about the health status of HIV-exposed child; and

the fear of the stigma and discrimination that result from disclosure. The caregiver's lack of adequate and comprehensive knowledge and information about EID underlie most of these barriers, emphasizing the importance of ensuring that caregivers access the EID information they ought to have in order to help them make informed decisions.

Still at the individual level, this study also revealed that some of the factors affecting EID uptake for infants were similar to those that affect the uptake of VCT for adults. For instance, the caregivers' perception that the atmosphere of the health facility that offer EID services was unfriendly was found to be one of the factors that discourage them from accessing EID services from such facilities; the same factor that Bwambale and others (2008) had found was driving adults, especially the men, to seek VCT services in places outside their home with counsellors who do not know them due to fear of being identified and labelled as HIV victims. This study therefore shows that the factors that inhibit adults from seeking HIV services for themselves, also inhibit them from accessing EID for the HIV-exposed infants in their care. Any interventions to increase EID uptake by caregivers should therefore tackle the attitudes that define their health-seeking behaviours.

Though spirituality has been found to be good at promoting health (Wachira et al. 2012), this study confirms that it can have adverse effects on paediatric HIV prevention and post-delivery practices if not combined with biomedical interventions like EID. This study found that the negative influence of religion and post-delivery cultural beliefs and practices inhibited caregivers from EID uptake. In order for health workers to get insights into how to tackle impediments to accessing HIV services, it is critically important, as this study reveals, that an integrated approach to culture and spirituality in paediatric care is necessary, as has been recommended by McEvoy (2003).

The barriers to EID were not only of social nature but others were also socio-economic. For example, in instances where some of the caregivers in the study were financially dependent on their spouses, transport costs to and from the health facility became a barrier to EID uptake even though EID services are provided free of charge. The effect of this financial dependency was more severe and noticeable if accessing EID at the health facilities involved the financially-dependent caregiver travelling over long distances.

The findings from this study has shown that the uptake of EID by caregivers at the selected study site in Entebbe, Wakiso District, is influenced by a variety of socio-cultural and socio-economic factors at the individual and the health facility levels. Yet it has already been

confirmed that early ART has a positive influence on mortality and morbidity of infants (Violari et al., 2008) and, consequently, WHO and the national guidelines recommend that treatment for all HIV infected children should be done when they are under 2 years (WHO, 2015). However, in order for this WHO target to be met, the researcher recommends that measures must be put in place to address the barriers to EID uptake at each of the levels where they have been found to operate while reinforcing the factors that this study has identified as facilitators to the uptake of EID.

## **6.2 Recommendations**

In view of the results of the research and the conclusions drawn above, the study presents the following recommendations to improve uptake of EID services:

### **6.2.1 Interventions to address the challenge of disclosure and stigma**

This study identified fear of disclosure and the resulting stigma and discrimination as factors affecting EID uptake. The health promotion division of the Ministry of Health should conduct continuous health education campaigns that aim at reducing the stigma towards HIV-positive mothers within the community. Since it has been revealed that knowledge about HIV is necessary but not sufficient to address stigma (Wolfe et al., 2005), the Ministry of Health should augment health education campaigns with national and regional policies that protect the rights of all persons living with HIV and mandate all supervisors of maternal, neonatal and child health facilities to ensure that treatment is humane.

Additionally, within the health facility setting, provision of HIV testing services should be combined with screening for other health conditions that currently do not carry the kind of stigma associated with being seen obtaining HIV testing services. Health workers should conduct disclosure-focused counselling sessions that emphasize the benefits of disclosing, how to disclose and when and to whom. This should lower the fear levels in caregivers and raise their propensity to seek HIV services for themselves and consequently for the HIV-exposed infants in their care.

### **6.2.2 Interventions to address the socio-economic factors**

The main economic factors that influence uptake of HIV testing for infants are busy work schedule of the caregivers and lack of transport. The Ministry of Health should consider taking EID services closer to those who need them (Mlay, Lgina & Becker, 2008) through, for instance, the home-based testing strategy in order to make testing cheaper and convenient for poorer communities (Wolf et al., 2005; Helleringer et al., 2009).

Additionally, integration of EID services with other child health services like immunisation would make follow up and testing of children more accessible (Goodson et al., 2013; Rollins et al., 2009) since integration of services has been found to reduce expenses for caregivers (Ndiritu et al., 2006).

Male involvement in HIV testing for infants should be promoted since men are key decision makers within homes and in most cases they provide the financial support that is needed for care-giving.

### **6.2.3 Addressing socio-cultural factors**

Findings from this study show that caregivers may miss out on EID for their infants due to their belief in faith healing. Though the researcher recognizes that spirituality has influence in promoting health, it is bound to have adverse effects on paediatric HIV prevention care and treatment if it is not integrated with HIV care and treatment. The researcher therefore recommends an integrated approach to spirituality in paediatric care. In this respect, health facilities should consider working with faith leaders as they might be good sources for reaching out and referring HIV-positive children and giving psychosocial support.

### **6.2.4 Strengthening health systems to support increased EID uptake**

As caregivers, mothers on ART were found to be facilitators of EID uptake for infants and the children under their care have several contacts with the health system through different service delivery points. In order to facilitate follow up of HIV-exposed infants, provider-initiated HIV testing and counselling (PITC) where the health care worker advises that children undergo voluntary testing at all points of contact should be encouraged and promoted. Besides, the PITC services should be integrated with other services for children like immunization so that caregivers can access the services.

Negative attitudes of the health workers towards their clients were found to affect EID uptake. This suggests that health workers should be continuously trained in effective interpersonal and communication skills to improve health worker-patient relationship communication skills/counselling skills so that they appropriately counsel and motivate care takers to take their infants for HIV testing at the recommended times. If health workers are targeted in internal Continuing Professional Development (CPD) courses, they will be motivated to participate in such trainings. An assessment of the curriculum for undergraduate health training institutions for health professions should also be undertaken to devise ways of

improving existing courses in effective communication, professional ethics and professionalism.

There is also need to reinforce the positive attitudes of health workers so that they provide a conducive environment, where caregivers are comfortable bringing their infants for testing at the recommended time. If due to reasons beyond their control caregivers do not fulfil their appointments, they need to know that they will be welcomed; not scolded for returning. When caregivers return to the EID service point, even later than planned, health workers must be ready to meet them.

There should be active tracing of mother–infant pairs after delivery. The counselling given during tracing visits should be strengthened. The VHTs are so well placed at the village level and so there should be deliberate plans to work with village health teams to support identification and tracking of HIV-exposed infants so that they may access EID at the recommended time. Particularly, there should be better linkage between PMTCT services and infant services so as to increase early testing of at risk children before they become sick.

#### **6.2.5 Improving caregiver knowledge and information about EID**

A number of barriers at the individual level were a result of inadequate caregiver knowledge about EID uptake. The health education and promotion division of the Ministry of Health, should reinforce messages about the importance of EID using success stories from caregivers who have positive experiences to share or messages of hope portraying mother-infant pairs that have benefited from EID and paediatric HIV treatment.

Health education needs to emphasize the fact that ART for children exists; it prolongs life and that life expectancy should not be curtailed by a positive result. Rather, by not testing, one risks an infant's premature death from advanced disease. Health education should also emphasize that PMTCT interventions do not provide 100% protection but there can be partial HIV transmission from mother to child even when fully adhere to ARV prophylaxis.

Moreover, there is need to reinforce messages on infant testing and diagnosis information in counselling and support services for PMTCT in order to support mothers to embrace EID. Such sessions should provide psychological and emotional support for mothers so that they can accept the infants' test results.

### **6.3 Proposed areas for further research**

Due to traditional gender-based allocation of responsibilities, care giving is predominantly female. In order to widen knowledge about factors affecting EID uptake, the researcher recommends further research that focuses on factors that influence male involvement in EID so as to address any existing gaps in understanding how to support HIV-positive mothers to access EID services for their infants. The researcher also recommends that further research be carried out on:

- the effect and role of religion on uptake of EID services in order to understand how religion can be used to supplement biomedical interventions;
- the influence of socio-cultural factors on EID uptake; and
- maternal education as a factor influencing EID uptake- a qualitative study.



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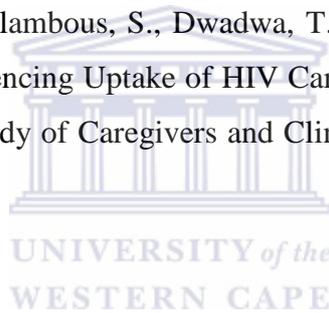
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## Appendix 1: Participant information sheet



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**Tel: +27 21-959 2809/2166 Fax: 27 21-9592872**

**E-mail: [soph-comm@uwc.ac.za](mailto:soph-comm@uwc.ac.za)**

**Project Title:** To explore the facilitators and barriers to HIV testing for infants of caregivers who delivered at Entebbe hospital, Wakiso district, Uganda.

### **What is this study about?**

This is a research project being conducted by Ruth Musekura at the University of the Western Cape. We are inviting you to participate in this research project because you have experience with Infants exposed to HIV. You have information relevant to the achievement of the objectives of the study.

### **What will I be asked to do if I agree to participate?**

If you agree to be part of the study you will be requested to sign a consent form indicating that you agree to participate. You are free to decide whether you would like to be part of the study or not. If you decide to take part, you can still withdraw at any time without telling us why. Your withdrawal from the study will not have any negative implications for you. We however hope that you will participate in this study since the findings will provide the Ministry of Health and the district management team with ideas for scaling up early HIV testing for infants.

You will be asked to participate in an individual interview that will take place at a place and time that you choose. The interview will not take more than 1 hour. Your participation in this study is out of your free will. Other caregivers of children exposed to HIV will be asked questions similar to yours.

You will be asked questions about your experiences with HIV testing for infants especially what you think makes people take their infants for testing and why some caregivers do not do so.

**Would my participation in this study be kept confidential?**

We will try our best to keep your personal information confidential. To help protect your confidentiality, your name will not be used. We will assign a code or number to the information you give us. The information collected will be kept in a locked place and will be destroyed when the research is finalized. Only the researcher will be able to access the information that is collected from you. The information in the final report will not be attached to individual study participants.

**What are the risks of this research?**

When you participate in the study there might be some issues which we will talk about that might be difficult or sensitive. If at any point you feel uncomfortable answering any question please let me know. In case you need to take a break during the study please let me know.

**What are the benefits of this research?**

This research is not designed to help you personally, but the results may help the investigator learn more about what motivates or demotivates caregivers from taking infants for HIV testing.

The benefits to you include informing program managers about the factors that stop caregivers like you from taking infants for HIV testing. Program managers need to get your first hand experiences in order to plan for effective program to increase uptake of HIV testing for infants.

We hope that, in the future, other people might benefit from this study through improved understanding of factors that affect or encourage caregivers of HIV-exposed children from going for early HIV testing.

**Do I have to be in this research and may I stop participating at any time?**

Your participation in this research is totally voluntary. You are free to choose not to take part at all. In case you decide to participate in this research, you may stop participating at any time. In case you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify. Any

participants that are affected by this study will be referred to the nearest health facility for counselling. In case there are children that require care, appropriate referrals will be made.

### **What if I have questions?**

This research is being conducted by *Ruth Musekura of the Faculty of Community & Health Sciences* at the University of the Western Cape .If you have any questions about the research study itself, please contact Ruth Musekura at: P.O Box 11001, Kampala, Uganda. Telephone: 256 71 2 200396 or 077 765101 and the Principal Investigator; Dr Lucia Knight on email; lknight@uwc.ac.za . Telephone + 27 (0) 21 959 22 43

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Prof Helene Schneider  
School of Public Health  
University of the Western Cape  
Private Bag X17  
Bellville 7535  
[hschneider@uwc.ac.za](mailto:hschneider@uwc.ac.za)



Dean of the Faculty of Community and Health Sciences:

Prof Jose Frantz  
University of the Western Cape  
Private Bag X17  
Bellville 7535  
[chs-deansoffice@uwc.ac.za](mailto:chs-deansoffice@uwc.ac.za)

This research has been approved by the University of the Western Cape's

## Appendix 2: Participant Information sheet translated into Luganda



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### **INFORMATION SHEET**

Omulamwa gwa Ppulojekiti: okwekenneenya ebireetera n'ebiremesa okukebera abaana abawere abazaalibwa ku Ddwaliro ly'Entebbe, Central Region 1, Uganda Akawuka ka Siriimu

#### **Okunoonyereza kuno kuli ku ki?**

Okunoonyereza kuno kukolebwa Ruth Musekura ku Yunivaasite ya Western Cape. Tukasaba okwetaba mu kunoonyereza kuno olwokuba olina obumanyirivu ku baana abawere abali mu katyabaga k'Akawuka ka Siriimu. Olina byomanyi ebyomugaso eri okutuukirisa ebigererwa by'okunoonyereza kuno.

#### **Biki ebijja okumbuzibwa singa nzikiriza okukwetabamu?**

Bwokkiriza okwetaba mu kunoonyereza kuno ojja kusabibwa okussa omukon ku kiwandiiko ekikakasa nti okkirizza okukwetabamu. Oli waddembe okusalawo okwetaba mu kunoonyereza oba nedda. Bwosalawo okukwetabamu, oba okyasobola okukuvaamu obudde bwonna nga totubuulidde lwaki. Okuvaamu kwo tekulina kyabulabe kwekukuleetera. Naye tusuubira nti ojja kwetaba mu kunoonyereza kuno olwokuba ebinakuvaamu bijja kuwa minisitule y'eby'obulamu n'abakulembeze ba disitulikiti amagezi ku kutumbula okukebera amangu abaana abawere Akawuka ka Siriimu.

Ojja kusabibwa okwetaba mu kubuuzibwa okwa sekinoomu okujja okubeerawo mu kifo nesaawa z'onosalawo. Okubuuzibwa kuno tekutwale budde busukka mu ssaawa emu (1 HR). okwenyigira kwo mu kunoonyereza kuno kwa kyeyagalire. Abalabirira abaana abalala abali mu katyabaga k'Akawuka ka Siriimu nabo bajja kubuuzibwa ebibuuzo ebifaanana ebikubuuziddwa.

Ojja kubuuzibwa ebibuuzo ebikwata ku bumanyirivu bwo mu ky'okukebera abaana abawere Akawuka ka Siriimu naddala ki ky'olwooza ekireetera abantu okutwala abaana baabwe abawere okukeberegwa ne lwaki abamu tebatwala.

### **Okwenyigira kwange mu kunoonyereza kuno kunaakumibwa nga kwa kyaama?**

Tujja kukola kyonna kyetusobola okulaba nti ebikukwatako bikuumibwa nga bya kyaama. Okwongera okukakasa nti bikuumibwa nga bya kyaama, amannyago tegajja kukozebwa. Tujja kussa kkoodi oba enamba ku by'onotugamba. Ebinakunganyizibwa bijja kuumibwa mu kifo ekisibe era bijja kusaanyizibwawo nga okunoonyereza kukomekkerezeddwa.

Oyo yekka anoonyereza yajja okusobola okulaba ku bikungaanyizibwa okuva gyooli. Ebinaabera mu alipoota enkulu tebijja kukwanyizibwa ku muntu yenna eyetabye mu kunoonyereza.

### **Biki ebyekengerwa mu kunoonyereza kuno?**

Bwewetaba mu kunoonyereza kuno tuyinza okwogera ku bintu ebimu ebiyinza okuba ebizibu oba ebitali byangu kwogerako. Akadde konna bwotawulira mirembe kuddamu kibuuzo kyoona nsaba ombuulire. Bwoyagala okummulamu mumasekkati g'okunonyereza nsaba ombuulire.

### **Okunoonyereza kuno kulino miganyulo ki?**

Okunoonyereza kuno tekukoledwa kukuyamba nga sekinoomu, wabula ebinakuvaamu biyinza okuyamba anoonyereza okumanya ebisingawo ku biki ebireetera abalabirira abaana abawere okubatwala okukeberegwa Akawuka ka Siriimu oba obutabatwala.

Emiganyulo gyooli mulimu okutegeeza abakulira pulogulaamu biki ebiremesa abalabirira abaana nga ggwe okutwala abaana abawere okukeberegwa Akawuka ka Siriimu. Abakulira pulogulaamu betaaga okuwulira okuva gyooli okusobola okuteekateeka pulogulaamu ezikola obulungi mu kutumbula eky'okukebera abaana abawere Akawuka ka Siriimu.

Tusuubira nti gyebujja, abantu abalala bayinza okuganyulwa mu kunoonyereza kuno okuyita mu kutegeera biki ebireetera abalabirira abaana abali mu katyabaga k' Akawuka ka Siriimu obutabatwala mangu kukeberegwa Kawuka ka Siriimu.

### **Nteekeddwa okubeera mu kunoonyereza kuno era nsobola okukomya okukwetabamu kwange akadde konna?**

Okwetabakwo mu kunoonyereza kuno kwa kyeyagalire. Oli waddembe okusalawo obutakenyigiramu wadde. Bwosalawo okwetaba mu kunoonyereza kuno, osobola okukuvaamu akadde konna. Bwosalawo obuteetaba mu kunoonyereza kuno, oba bwosalawo okukuvaamu akadde konna, tojja kubonerezebwa oba kuggibwaako miganyulo gyoteekeddwa kufuna. Abeetaba mu kunoonyereza kuno bonna abanaakosebwa bajja kusindikibwa ku ddwaliro erisinga okubeera okumpi basobole okubudaabubudibwa. Bwewanabeerawo abaana abetaaga okufibwaako, bajja kusindikibwa mu bifo ebituufu nga bwekisoboka.

### **Singa mbeera n'ebibuuzo?**

Okunoonyereza kuno kukolebwa Ruth Musekura owa Faculty ya Community & Health Sciences ku Yunivaasite ya Western Cape. Bwobera nekibuuzo kyonna ekikwata ku kunoonyereza, tuukirira Ruth Musekura ku P.O Box 11001, Kampala, Uganda. Essimu: 256 71 2 200396 n'Akulira okunoonyereza (Principal Investigator); Dr Lucia Knight ku email; lknight@uwc.ac.za . Essimu + 27 (0) 21 959 22 43

Bwobera nekibuuzo ekikwata ku kunoonyereza kuno ne ku ddembe lyo nga eyetabye mu kunoonyereza, oba bwoba oyagala okulopa ebuzibu bwonna obukutuuseeko obekuusa ku kunoonyereza, tuukirira:

Prof Helene Schneider  
School of Public Health  
University of the Western Cape  
Private Bag X17  
Bellville 7535  
[hschneider@uwc.ac.za](mailto:hschneider@uwc.ac.za)

Dean of the Faculty of Community and Health Sciences:

Prof Jose Frantz

University of the Western Cape ,Private Bag X17, Bellville 7535 ,

### Appendix 3: Consent



#### UNIVERSITY OF THE WESTERN CAPE

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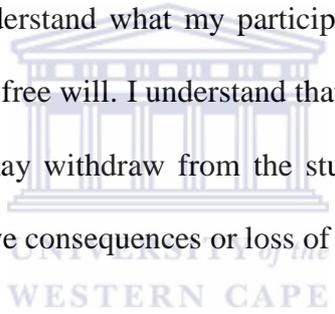
Tel: +27 21-959 2809/2166 Fax: 27 21-9592872

E-mail: [soph-comm@uwc.ac.za](mailto:soph-comm@uwc.ac.za)

#### CONSENT FORM

**Title of Research Project:** Facilitators and barriers to HIV testing for infants of caregivers who delivered at Entebbe Hospital, Wakiso District, Uganda.

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.



**Participant's name.....**

**Participant's signature.....**

**Date:**

**Appendix 4: Consent form translated in Luganda.**



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**E-mail: [soph-comm@uwc.ac.za](mailto:soph-comm@uwc.ac.za)**

**EBBALUWA EGABA OLUKUSA**

Omulamwa gwa Ppulojekiti: okwekenneenya Ebireetera n'ebiremesa okukebera abaana abawere abazaalibwa ku Ddwaliro ly'Entebbe, Central Region 1, Uganda Akawuka ka Siriimu.

Okunoonyereza kunyinyonyoddwa mu lulimi lwentegeera era nzikirizza okukwetabamu awatali kukakibwa.

Ebibuuzo byange ebikwata ku kunoonyereza bididdwamu. Kutegeera kwange nti ebinkwatako ng'omuntu tebijja kubuulirwa muntu mulala era nti nsobola okuva mu kunoonyereza akadde konna awatali kuwa nsonga era kino tekijja kunkosa mu ngeri yonna.

Amannya g'agaba olukusa.....

Omukono gw'agaba olukusa.....

Ennaku z'omwezi.....

## Appendix 5: Health worker key informant interview guide

1. Date of Interview: -----/-----/-----

dd mm yyyy

2. Health facility name: \_\_\_\_\_

3. Department / Section \_\_\_\_\_

4. Cadre of interviewee: \_\_\_\_\_

5. Position at the health care facility: \_\_\_\_\_

6. Gender of interviewee: \_\_\_\_\_



7. Duration working in section (Qn3)

0- 4 weeks

1 – 6 months

7- 12 months

Over 12 months

## Questions for health care workers

In Uganda, currently about 20,600 children get infected with HIV every year.

- 1 How do you think children get HIV? And how can HIV-positive mothers transmit HIV to their babies?
- 2 What can be done to prevent HIV-positive mothers from transmitting HIV to their babies?
- 3 Tell me what you know about the process for testing infants  
Probe: How often are caregivers supposed to bring their HIV-exposed infants to the health facility to receive care?
- 4 Tell me about the services caregivers of HIV-exposed children are supposed to receive when they come for care at your facility?
- 5 Research shows that some caregivers do not bring their HIV-exposed infants for testing
  - a. What could be some of the reasons some caregivers don't bring their infants for HIV tests? Do you have a personal experience you would like to share?
  - b. What do you think might be happening at home that could prevent them from returning to bring their infants for HIV test? Probe for the environmental factors at home and caregiver factors (Fear, partner support, financial limitations)
  - c. What do you think are some of factors at health facilities that could be preventing or discouraging them from returning to bring their infants for HIV testing?
  - d. What do you think could be some of the community factors that prevent caregivers from bringing their children for HIV testing? (Probe for stigma)
  - e. For those that bring their children for testing, what do you think are some of the motivating factors?
- 6 If an HIV test is not done and the child is positive, the child could fall sick and could die without being tested and miss out on the chance for treatment and therefore living longer would have been lost. What do you think should be done to ensure that caregivers bring their infants for HIV testing?

- f. What can the health care workers do?
  - g. What can the caregivers do?
  - h. What can the community leaders do?
  - i. What should government do?
- 7 Any other comment on this subject area?



## Appendix 6: In-Depth Interview Guide (Caregivers)

Date of Interview: -----/-----/----- 2. Participant No:

ddmmyyyy

1. To start with I would like to get some demographic information from you. Is that okay?

Respondent's relationship to child.

(Probe for whether respondent is Biological parent who returned child for testing or Biological parents who did not return child for testing / Caregiver who brought back child for testing / Caregiver that did not bring back child for testing / Grand parent who brought back child for testing Grand parent who never brought back child for testing)

Sex :

Age :

Education level

Probe for: primary level, Secondary level, Tertiary level, None :

Marital status

Probe for Single, Married, Divorced, Widowed :

Employment status

Probe for: Formal employment, Business, farmer, Not employed

Distance to the Hospital:

---

Questions for both types of caregivers.

1. What do you think are the key health problems of infants in your community?(List what is mentioned spontaneously)

Probe for diarrhoea, pneumonia, HIV

3. Can you tell me about how decisions about infants' health are made in your household?

**Probe** for – mother alone, husband, both mother and husband, extended family)

**Probe:** If reluctant to mention about own household ask about community.

4 How does your family decide where and when medical treatment is sought?

**Probe:** Who in the community do you ask if you are not sure?

5 Where do you take your infants for check up in your community?

First, why?

Second, why?

**Probe for:** Government clinic, Government hospital, faith leaders, traditional healers?

**Probe** If reluctant to mention about self ask about caregivers of infants in the community

6 Can you tell me about what you think the main reasons are that a parent might not go to a health facility when a child is not well?

**Probe** for transport, cost reasons. Fear.

### **PMTCT**

7 Can you tell me about your birth experience?

**Probe :** access to PMTCT

**Probe :** What information did you receive about HIV testing for the baby?

**Probe:** Who provided information about HIV testing for the baby?

### **Access to health services for infant**

8. Did you visit the clinic after delivery for your child's immunization or other child health services ?

If yes-Tell me about your experience while seeking services for the baby. Probe for positive / negative experiences. Probe: Why did you go? How old was the baby? Factors that motivated caregiver to go.

If no, Probe for reasons why not, probe for individual community and health facility factors.

Probe: Ask if they plan to go in the future and have they been in the past with other children?

### **HIV testing for infants**

#### **A. Opening statement for caregivers who have not as yet brought babies for testing**

You have been selected to be part of this study because you have HIV in your family and therefore it is possible that your child needs to be tested for HIV. We know you have not been able to test your child for HIV. We are not chasing you and we don't want to make you feel bad or pestered for not testing your child, we just want to try and understand how best we can provide services for you and your child. After this interview we will provide you with information about how and where to get your child tested if that is something you would like to do. In the meantime we would like to ask you some questions about some of your experiences and information that may affect your decision to attend a health facility for your infant's health.

9 After delivery of your last baby were you given information about HIV testing for your baby?

**Probe:** If yes who gave you the information, what information were you given, how did you feel about the information you were given? What did you do after receiving the information?

**Probe:** to see whether they visited the clinic and had the child tested

**Probe** reasons for not going .Probe for individual, community and health facility factors

**Probe** – Feelings about getting your child tested?

10 Can you tell me about any past bad experiences that may influence the way that you feel about testing your child?

**Probe for** – Stigma, fear of disclosure, health facility factors, child not sick, treatment for children not available.

#### **B. Opening statement for caregivers who brought back babies for testing**

We know that you have tested your child for HIV or we know that you haven't been able to test your child for HIV yet. If not we are not chasing you and we don't want to make you feel bad or pestered for not testing your child we just want to try and understand how best we can provide services for you and your child.

9. After delivery of your last baby were you given information about HIV testing for your baby?

**Probe :** If yes who gave you the information , what information were you given, How did you feel about the information you were given? What did you do after receiving the information

**Probe** to see when they visited the clinic and had the child tested.

**Probe** reasons for going . Probe for individual, community and health facility factors- you can ask specific probing questions like how do you feel about getting your child tested?

10. After taking your baby for testing Do you have any regrets or are you happy you went?

11. What do you think are the benefits for taking your baby for HIV testing?

**Probe** for Benefits to the caregiver, baby **Probe** for experiences at the health facility

### **Questions for both types of caregivers.**

Research shows that some Caregivers do not bring back their children for HIV testing.

13. What could be some of the reasons some mothers don't bring back their children for testing?

**Probe:** What do you think might be happening at home that could prevent them from bringing their children for testing?

**Probe:** What could be happening within the community that prevents mothers from bringing their children? (Probe: Stigma, Fear of disclosure, Lack of supportive mechanisms within the community)

14. What do you think are some of factors at health facilities that could be preventing or discouraging them from bringing their children for HIV testing?

**Probe for:** Negative attitudes from the health workers, Lack of confidentiality, costs, distance

15. If an HIV test is not done and a child is positive he or she can fall very sick and could die because the chance for treatment and therefore living longer is lost.

- a. What do you think should be done to ensure that mothers bring their children for testing?
- b. What can the health care workers do?
- c. What can the caregivers do?

- d. What can community leaders do?
- e. What can government do?

**Closing :**

These are all the questions I have. Thank you very much for answering our questions. Do you have any questions or comments you would like to make about what we talked about? Is there anything else you would like to tell us?

THANK YOU SO MUCH FOR YOUR TIME



## Appendix 7: Caregiver Interview Guide Translated in Luganda

Olunaku lw'oubuuzibwa...../...../..... 2. Enamba y'eyetabyemu

1 Okusookera ddala njagala kumanya ebikukwatako. Tekirina mutawana?

Oluganda wakati w'addamu ebibuuzo n'omwana

(buuza oba addamu ebibuuzo yazaalira ddala omwana eyakumyayo omwana okukeberegwa oba atamukomyayo kukeberegwa/alabirira omwana eyamukomyayo okukeberegwa oba ataamukomyayo kukeberegwa/ jjaja eyakomyayo omwana okukeberegwa oba ataamukomyayo kukeberegwa)

Ekikukla :

Emyaka :

Obuyigirize

Buuza oba: ppulayimale, ssekendule, ssomero ly'abakulu, teyasoma:

Embeera y'obufumbo :

Buuza oba Tawasangako/tafumbirwangako, yayawukano ne mukyalawe/bba, Namwandu/ssemwandu

Eby'emirimu

Buuza oba: alina omulimu, munabizineesi, mulimi, talina kyakola

Olugendo okutuuka ku ddwaliro:

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Ebibuuzo by'ebika by'abalabirira abaana byombi

2 Olowooza bizibu ki eby'obulamu eby'abaana abawere ebisinga obukulu mu kitundu kyo? (Wandiika ebimenyedwa)

Buuza ku Kiddukano, lubyamira/nimooniya, Akawuka ka Siriimu

3 Osobola okumbuulira engeri okusalawo ku by'obulamu bw'omwana ono gyekukolebwa mu maka muno?

Buuza-maama yekka, mwami, maama n'omwami bombi, amaka gonna)

Buuza: bwaba tayagala kwogera ku makaage buuza ku bikwata ku kitundu

- 4 Amakaago gasalawo gatywa wa era ddi obujjanjabi lwebunoonyezebwa?  
Buuza: Ani gwemubuuza mu kitundu bwemuba temwekakasa?
- 5 Wa gyemutwala abaana bammwe abawere okukeberegwa mu kintundu kyammwe?  
First, why? Ekisooka, lwaki?  
Second, why? Eky'okubiri, lwaki?  
Buuza oba: kkiriniki ya gavumenti, ddwaliro lya gavumenti, bakulembeze b'enzikiriza, basawo bannansi?  
Buuza: bwaba tayagala kweyogerako, buuza ku balabirira abaana abawere mu kitundu
- 6 Osobola okumbuulira ku nsonga ezisinga obukulu ezigaana omuzaade okutwala omwana mu ddwaliro nga mulwadde?

Buuza ku bikwata ku ntambula, esimbi, okutya

#### **Okuziyiza maama okusiiga omwana Akawuka ka Siriimu**

- 7 Nsaba ombuulire ku byewayitamu ng'ozala  
Buuza ebikwata ku kutuukirira ekola y'okuziyiza maama okusiiga omwana Akawuka ka Siriimu

Buuza: Bubaka ki bwewafuna ku kukebera omwana omuwere Akawuka ka Siriimu?

Buuza: Ani eyakuwa obubaka obukwata ku kukebera omwana omuwere Akawuka ka Siriimu?

#### **Okutuukirira empeereza z'ebya'obulamu eri omwana omuwere**

- 8 Oluvannyuma lw'okuzaala wakyalirako kkiliniki okugemesa omwanawo oba okufuna empeereza endala zonna ezikwata ku by'obulamu bw'omwana?  
Oba ye-mbuulira biki byewayitamu nga onoonya empeereza eri omwana. Buuza ebirungi nebibi. Buuza: lwaki wagenda? Omwana yali yenkanaki obukulu? Biki ebyaleetera alabirira omwana okugenda?

Oba nedda, buuza ensonga lwaki, buuza ensonga ezeekuusa ku kitundu n'eddwaliro.

Buuz: oba bateekateeka okugenda gyebujja era emabega baali babaddeko n'abaana?

### **Okukebera abaana abawere Akawuka ka Siriimu**

Okwogera okuggulawo eri abalabirira abaana abatannabatwala kukeberegwa

Olondebbwa okwetaba mu kunoonyereza kuno olwokuba mulina Akawuka ka Siriimu mu maka gammwe era kisoboka nti omwana wammwe yetaaga okukeberegwa Akawuka ka Siriimu. Tukimanyi obadde tonnasobola kukebeza mwanawo Kawuka ka Siriimu. Tetukutambilirako era tetwagala kukuleetera kuwulira bubi olw'obutakebeza mwanawo, twagala kugezaako kutegeera ngeri ki esinga obulungi gyetusobola okutuusa empeereza eri ggwe n'omwanawo. Oluvannyuma lw'okubuuzibwa kuno tujja kukuwa obubaka ku ngeri ne wa ew'okukuberera omwanawo singa kino ky'ekintu kyoyagala okukola. Naye kati twagala tukubuuzeeeyo ebibuuzo ku byewali oyiseemu na biki ebiyinza okukosa okusalawo kwo ku kugenda mu ddwaliro ku byekuusa ku bulamu bw'omwanawo.

- 9 Oluvannyuma lw'okuzaala omwanawoeyasembayo, waweebwa obubaka obukwata ku kukebera omwanawo Akawuka ka Siriimu?

Buuz: Oba ye, ani eyakuwa obubaka, bubaki ki obwakuweebwa, obubaka bwewaweebwa bwakuyisa butya? Ki kyewakola oluvannyuma lwokufuna obubaka?

Buuz okulaba oba baakyalira kkililiki era omwana nakeberegwa

Buuz ensonga ezaabagaana okugenda. buuz ensonga ezeekuusa muntu sekinoomu, ku kitundu n'eddwaliro.

- 10 Buuz-engeri gy'owuliramu ku ky'okukebeza omwanawo?

Nsaba obuulire ku byewali oyiseemu ebitaali birunngi ebiyinza okukosa engeri gyowuliramu ku ky'okuberera omwanawo?

- 11 Buuz ku –Kusosolwa, okutya okweyabiza abantu, ebyekuusa ku ddwaliro, omwana obutaba mulwadde, obujjanjabi bw'abaana obutabeerawo.

### **Okwogera okuggulawo eri abalabirira abaana abaabakomyawo okukeberegwa**

Tukimanyi nti wakebeza omwanawo Akawuka ka Siriimu oba tukimanyi nti obadde tonnasobola kukebeza mwanawo Kawuka ka Siriimu. Bwoba tonnaba

tetukutambilirako era tetwagala kukuleetera kuwulira bubu olw'obutakebeza mwanawo, twagala kugezaako kutegeera ngeri ki esinga obulungi gyetusobola okutuusa empeereza eri ggwe n'omwanawo.

8. Oluvannyuma lw'okuzaala omwanawoeyasembayo, waweebwa obubaka obukwata ku kukebera omwanawo Akawuka ka Siriimu?

Buuzi: Oba ye, ani eyakuwa obubaka, bubaki ki obwakuweebwa, obubaka bwewaweebwa bwakuyisa butya? Ki kyewakola oluvannyuma lwokufuna obubaka?

Buuzi okulaba oba baakyalira kkilini era omwana nakeberegwa

Buuzi ensonga ezaabaleetera okugenda. buuzi ensonga ezeekuusa muntu sekinoomu, ku kitundu n'eddwaliro.- osbola okubuuzi ebibuuzo nga owulira otya ku ky'okukebeza omwanawo?

- 9 Oluvannyuma lw'okutwala omwanawo okukeberegwa, olina kyewejjusa oba oli musanyufu nti wagenda?

- 10 Olowooza emigaso gy'okutwala omwanawo okukeberegwa Akawuka ka Siriimu gyegiriwa?

Buuzi: emigaso eri alabirira omwana. Emigaso eri omwana. Buuzi ebyaliwo ku ddwaliro?

- 11 Ebibuuzo eri abalabirira abaana ab'ebika byombi

Okunoonyereza kulaga nti abalabirira abaana abamu tebabakomyawo kukeberegwa Kawuka ka Siriimu

- 12 Nsonga ki ezimu ezigaana abalabirira abaana abawere okubaleeta okukeberegwa Akawuka ka Siriimu?

Buuzi: Olowooza biki ebibeerawo ewaka ebiyinja okubagaana okutwala abaana baabwe abawere okukeberegwa Akawuka ka Siriimu?

Buuzi: Olowooza bintu ki mu bitundu gyebabeera ebiyinja okugaana ba maama b'abaana okubaleeta okukeberegwa Akawuka ka Siriimu? (Buuzi okusosolwa/okuboolebwa, okutya okweyabiza abantu, obutabaawo ngeri yakubayamba mu bitundu)

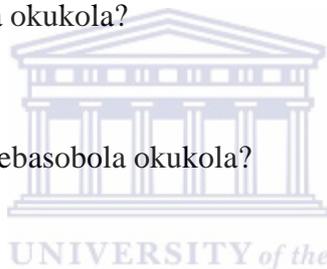
- 13 Olowooza bintu ki ku malwaliro ebiyinza okubagaana okukomyawo abaana baabwe abawere kukeberegwa Akawuka ka Siriimu?

Buuza: Empisa z'abasawo embi, abasawo obutakuuma bibagambiddwa nga bya kyaama, ensimbi, olugendo okugenda ku ddwaliro

- 14 Singa omwana takeberegwa Kawuka ka Siriimu ate nga akalina, omwana ayinza okulwala era naafa era nafiirwa omukisa gw'obujjanjabi n'okuwangaala.

- 15 Olowooza ki ekiteekeddwa okukolebwa okukaksa nti ba maama baleeta abaana baabwe okukeberegwa?

Biki abasawo byebasobola okukola?



Biki abalabirira abaana byebasobola okukola?

Biki abakulembeze by'ekitundu byebasobola okukola?

Biki Gavumenti byesobola okukola?

### **Okukomekkereza**

Ebyo by'ebibuuzo byembadde nabyo. Weebale nnyo okubiddamu. Olinayo ky'obuuza oba kyoyagala okwongera kwebyo byetwogeddeko? Olinayo ekintu ekirala kyonna kyewandyagadde okutugamba?

WEEBALE NNYO OLWOBUDDEBWO

## Appendix 8: Key Informant Interview Guide (other – Peer mother )

1. Date of Interview: -----/-----/-----  
dd mm yyyy
2. Organization: \_\_\_\_\_
- 3 Position of interviewee: \_\_\_\_\_
- 4 Gender of interviewee: \_\_\_\_\_

### Questions

In Uganda, currently about 20,600 children get infected with HIV every year.

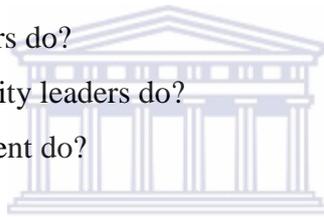
- 1 How do you think children get HIV? Probe: And how can HIV-positive mothers transmit HIV to their babies?
- 2 What do you think can be done to prevent HIV-positive mothers from transmitting HIV to their babies?
- 3 HIV testing for infants less than 12 months is different from one done for adults. Tell me what you know about the process for testing infants of HIV positive mothers
- 4 Research shows that caregivers do not bring HIV exposed children for testing at regional referral hospitals and facilities that provide specialised care for HIV after they are born.
  - a. What could be some of the reasons some caregivers don't bring back children for testing? Do you have a personal experience you would like to share?
  - b. What do you think might be happening at home that could prevent them from bringing children for testing? Probe for the environmental factors at home and

caregiver factors (Probe: lack of knowledge about testing services, Fear, financial costs, distance to health facility)

- c. What do you think are some of factors at health facilities that could be preventing or discouraging them from bringing back children for HIV testing ?
- d. What do you are some of the community factors that prevent caregivers from bringing back their children for HIV testing?
- e. For those that bring back children for testing , what do you think are some of the motivating factors?

5 If an HIV test is not done and the child is positive, the child could fall sick and die because the chance for treatment and therefore living longer is missed. What do you think should be done to ensure that caregivers bring back their infants HIV testing ?

- a. What can the health care workers do?
- b. What can the caregivers do?
- c. What can the community leaders do?
- d. What should government do?



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6 Any other comment on this subject area?

THANK YOU SO MUCH FOR YOUR TIME





