



# Understanding the Barriers to Antiretroviral Therapy (ART) Initiation for HIV-Positive Children 2-18 Months of Age in Swaziland



MINISTRY OF HEALTH PEDIATRIC ART  
PROGRAM STUDY REPORT

OCTOBER 2016

## ACKNOWLEDGEMENTS

We thank the caregivers of the children for participating in this study and the data clerks and interviewers for their invaluable assistance in collecting the data. This study was supported by the National Institutes of Health (NIH) funded Minority Health International Research Training Program (MHIRT), grant no. T37-MD001448, from the National Institute on Minority Health and Health Disparities, Bethesda, MD, USA, University of Alabama in Birmingham (UAB), the United Nations Children’s Fund (UNICEF) - Swaziland Country Office, the Ministry of Health (MOH) Pediatric ART Program, the Baylor College of Medicine Children’s Foundation – Swaziland (BCMCF-SD), The Clinton Health Access Initiative (CHAI) - Swaziland and the President’s Emergency Plan for AIDS Relief (PEPFAR)-Swaziland. We thank Ms. Katharine Bodnar for helping to create the Access database, Musa Malinga for conducting the qualitative analysis and Ms. Elizabeth Swanton for helping with the protocol development and the analysis of facility level data to determine site selection.

This study was commissioned by the Pediatric ART Technical Working group and led by Nobuhle Mthethwa (MOH), Dr. Peter Preko (CTS Global assigned to CDC/PEPFAR) and Prof. Puline Jolly (UAB) as the principal investigators.

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# 1. EXECUTIVE SUMMARY

Without antiretroviral therapy (ART), a third of HIV-infected children will die before the age of one and more than half are expected to die before the age of two.<sup>1,2,3</sup> However studies show that early initiation of ART has better clinical and immunological outcomes than deferred ART among HIV-infected children, and can potentially reduce the rates of mortality associated with HIV.<sup>5</sup> Early initiation of ART has been shown to significantly reduce early infant mortality by 76% and HIV disease progression by 75%.<sup>6</sup> Multiple studies in Southern Africa have highlighted the challenges of early initiation of ART among children and the vital need to initiate early HIV diagnosis and early ART to reduce infant mortality.<sup>1,2,4,6-11</sup>

In 2007 the Ministry of Health (MOH) initiated early infant diagnosis (EID), testing of HIV-exposed infants at 6-8 weeks of age as part of the routine 6-week postnatal visit and under-five healthcare in Swaziland, which helped in identifying HIV infected children and led to doubling the number of children receiving HIV treatment.<sup>22</sup> Although the 2010 Swaziland Paediatric HIV Management Guidelines recommended that all children less than 24 months with confirmed HIV positive results be initiated on ART regardless of their immunological or clinical stage<sup>20</sup>; just about half of HIV-positive infants under 1yr was on treatment by 2012.

This study was designed to track all children with HIV DNA PCR positive results to document their actual outcome and to identify barriers to initiating children on ART following diagnosis of HIV; with the aim of understanding the socio-ecological barriers to early ART initiation for HIV-positive children (<18 months of age) in Swaziland.

The specific objectives of the study included: i) Identify individual factors (socio-demographics, access to health care, health seeking behaviours, perception of HIV & ART) associated with lack of uptake of ART by children 2-18 months diagnosed HIV-positive by HIV DNA PCR; ii) Identify interpersonal factors (support structures, relationship with healthcare providers) associated with lack of uptake of ART by children 2-18 months diagnosed HIV-positive by HIV DNA PCR; iii) Identify organizational factors (facility type, DBS hotline use, Results delivery, tracing methods, ART services, etc.) associated with lack of uptake of ART by children 2-18 months diagnosed HIV+ by HIV DNA PCR.

The findings from this study would be used to design interventions to improve the national Paediatric ART interventions including service delivery approaches related to efficient patient enrolment and retention, which would improve outcomes for these children.

The study was a retrospective case control study targeting children aged 2-18 months who tested positive for HIV through DNA PCR analysis between January 2011 and December 2012 at 11 sites across all four regions in Swaziland. Site selection was purposefully done to cover facilities with high volume HIV DNA PCR positive test results. The 11 sites represented 76% of all positive DNA PRC test results in the country. Cases were children 2 to 18 months, who tested positive for HIV using DNA PCR who were not documented to have initiated on ART between January 2011 and December 2012,; while Controls were children, aged 2 to 18 months, who tested positive for HIV using DNA PCR, who were documented to have initiated ART between the same period. Children who were not within the age 2-18 months, did not live in Swaziland, and/or had an unknown HIV-status, were excluded from the study.

The study found that different factors at individual; interpersonal and organizational level play major role in the decision to initiate a child on ART. This study highlights the biggest barriers to ART initiation among children aged 2-18 months include: behaviour and attitudes among both HCW and caregivers such as lack of disclosure, stigma and discrimination, and irregular attendance at health care facilities.

## Key Recommendations:

1. **Key recommendations to address caregiver factors**
  - Active patient follow up must be implemented by all facilities in line with the national referral, linkages and retention
  - Strengthen/reinforce the role of social workers in implementing the Children Protection and Welfare ACT to ensure appropriate action can be taken where the parent/primary caregiver delays critical services for children
  - Male involvement through couple counselling to help spouses accept and cope better with HIV status of their children
2. **Key recommendations to address interpersonal factors**
  - Strengthen training and supervision around customer care, stigma and discrimination.
  - Supervisors should ensure there is a system in place at each facility for patient feedback and follow-up with HCW on issues arising.
  - Training and skills transfer on disclosure techniques for nurses and social workers is critical so that they can support caregivers to disclose to partners and/or relevant family members...
  - Implement patient reminder interventions (sms, calls) to help caregivers keep appointments and to demonstrate that HCWs care about their wellbeing
3. **Key recommendations to address organizational factors**
  - To improve patient tracking at the facility, HCWs are encouraged to improve documentation of client contact information
  - When delivering the child's HIV test results, the counselling process should include why infants need early ART initiation, the process of initiation and what is expected of the caregiver

## 2. BACKGROUND

### 1.1 Paediatric HIV and Antiretroviral Therapy

Studies show that early initiation of ART has better clinical and immunological outcomes than deferred ART among HIV-infected children, and can potentially reduce the rates of mortality associated with HIV.<sup>5</sup> Without antiretroviral therapy (ART), a third of HIV-infected children will die before the age of one and more than half are expected to die before the age of two.<sup>1,2,3</sup> Therefore, the initiation of ART is crucial for the health and longevity of infants and children.<sup>4</sup> Early initiation of ART has also been shown to significantly reduce early infant mortality by 76% and HIV disease progression by 75%.<sup>6</sup> Multiple studies have highlighted the challenges of early initiation of ART among children and the vital need to initiate early HIV diagnosis and early ART to reduce infant mortality in Southern Africa.<sup>1,2,4,6-11</sup>

### 1.2 Prevention of Mother to Child Transmission (PMTCT) of HIV and Paediatric HIV in Swaziland Prior to 2013

With an adult HIV prevalence of 26%, Swaziland has the highest prevalence of HIV infection in the world.<sup>12,13</sup> The 2010 Antenatal Care Sentinel Surveillance Report revealed that the burden of HIV disease is even greater among pregnant women with a prevalence of approximately 41%.<sup>14</sup> HIV-positive pregnant women in Swaziland give birth to over 13,000 HIV-exposed infants each year<sup>15</sup> and, although antenatal care (ANC) coverage is almost universal, with 97% women attending ANC services at least once<sup>16</sup>, only 28% of pregnant women attended ANC during their first trimester in 2010. Early ANC attendance is crucial for the initiation of care among HIV-positive mothers.<sup>17</sup> Since HIV disease is a high contributor of maternal and child mortality in Swaziland (47% of MMR and 23% of U5yrMR contributes to by HIV and AIDS)<sup>3,4,17</sup> the scale-up of prevention of mother-to-child transmission of HIV (PMTCT) is a priority for the government of Swaziland.<sup>15,18</sup>

The 2010 Swaziland Paediatric HIV Management Guidelines recommended that all children less than 24 months with confirmed HIV positive results be initiated on ART regardless of their immunological or clinical stage<sup>20</sup>. Though Swaziland has achieved high ART coverage rates among adults (87%, 2012), increased coverage of ART for eligible children is still needed.<sup>21</sup>

In 2007 the Ministry of Health (MOH) initiated early infant diagnosis (EID), testing of HIV-exposed infants at 6-8 weeks of age as part of the routine 6-week postnatal visit and under-five healthcare in Swaziland, which helped in identifying HIV infected children and led to doubling the number of children receiving HIV treatment.<sup>22</sup> However, almost half of children still did not have access with 14,000 children (0-14 years old) eligible for ART in 2012 and 54% were actually receiving ART. Despite years of efforts, almost half of HIV-positive children under the age of 1 eligible for ART in 2012 had not initiated treatment.<sup>22</sup>

Therefore, this study was designed to track all patients with HIV DNA PCR positive results to document their actual outcome (ART initiation, Did Not Initiate ART, Loss to Follow up, Death) , and to identify barriers to initiating children on ART following diagnosis of HIV.

The findings from this study will be used to design interventions to improve the national program and therefore improve outcomes for these children. Health interventions, promotions and campaigns can modify risks and motivate parents/guardian to seek treatment and reduce infant mortality from HIV. In addition, the findings from the study could lead to the development of improved HIV service delivery strategies/approaches related to efficient paediatric ART enrolment and provision.

### **1.3 Aim and Objectives**

#### **Aim**

With the limited studies examining ART initiation among children in Swaziland, the aim of this study was to understand the socio-ecological barriers to early ART initiation for HIV-positive children (<18 months of age) in Swaziland.

#### **Primary Objective**

The primary objective of this study was to understand the specific barriers to early ART initiation among children (<18 months of age), who have been diagnosed with HIV in Swaziland.

#### **Secondary Objectives**

1. Identify individual factors (socio-demographics, access to health care, health seeking behaviours, perception of HIV & ART) associated with lack of uptake of ART by children 2-18 months diagnosed HIV-positive by HIV DNA PCR.
2. Identify interpersonal factors (support structures, relationship with healthcare providers) associated with lack of uptake of ART by children 2-18 months diagnosed HIV-positive by HIV DNA PCR.
3. Identify organizational factors (facility type, DBS hotline use, Results delivery, tracing methods, ART services, etc.) associated with lack of uptake of ART by children 2-18 months diagnosed HIV+ by HIV DNA PCR.

### 3. METHODOLOGY

#### 3.1 Study Design, Study Population & Sampling Method

##### Study design

The study was a retrospective case control study. The study population included children aged 2-18 months who tested positive for HIV through DNA PCR analysis between January 2011 and December 2012 at any of the following 11 sites across all four regions in Swaziland (Hhohho, Manzini, Lubombo, and Shiselweni):

Baylor Mbabane COE	Luyengo Clinic	Good Shepherd Hospital	Nhlangano PHU
Baylor RFM	Lobamba Clinic	King Sobhuza II (KS II) PHU	Horo Clinic
Baylor Hlatikhulu	Siphofaneni Clinic	Matsapha MSF Clinic	

These sites were purposefully selected based on the relatively high volume of positive HIV DNA PCR tests results from each site during the January 2011 and December 2012 eligibility time period. These 11 sites represent 76% of all positive DNA PRC test results in the country during this time period. In addition, these sites are representative of both rural and urban facilities.

##### Sample Size

Thirty-six (36) cases and 191 controls were enrolled in the study and completed a questionnaire-based interview, and 14 cases and 17 controls participated in a FGD. This was similar to one used in an identified another study which observed the barriers to ART initiation that was presented at a conference in July 2014 that had 45 cases (those who did not initiate) and 148 controls (ART initiated).

##### Sampling Methodology

Of the caregivers interviewed, based on the register level data there were 64 cases and 174 controls; however, when asked in the questionnaire based interview if the child had been initiated on ART, 29 cases self-reported that their child had initiated ART, and 11 controls self-reported that their child had not initiated the child on ART. Given this inconsistency, and inability to rely on register data (the patient may have discontinued treatment) or self-reported data (the caregivers may have thought it socially desirable to have initiated their child) an attempt was made to re-contact these caregivers, however only 11 controls were successfully re-contacted (14 of the cases had died, and the study team deemed it unethical to re-contact the caregivers; 15 cases were unable to be re-contacted). The 29 cases that could not be re-contacted were dropped from the analysis. Therefore, the final sample resulted in 36 cases and 191 controls.

##### Inclusion and Exclusion Criteria

- Cases: HIV-exposed children, aged 2 to 18 months, who tested positive for HIV using DNA PCR between January 2011 and December 2012, who were not documented to have initiated on ART.



- Controls: HIV-exposed children, aged 2 to 18 months, who tested positive for HIV using DNA PCR between January 2011 and December 2012, who were documented to have initiated on ART.
- Children who were not within the aged 2-18 months, did not live in Swaziland, and/or had an unknown HIV-status, were excluded from the study.

### **3.2 Study procedures**

Study data was collected in two parts: 1) Initial data extraction from facility-based patient registers to identify the study population; followed by 2) structured interviews and focus group discussion sessions with the caregivers of the study population. These two procedures are described in detail below.

#### **3.2.1 Initial data extraction**

A retrospective record review of each HIV-positive child was conducted using facility registers (DNA PCR Logbook and/or Sample Transportation Logbook, the Under 5 Child Welfare Register, Electronic Medical Record (EMR) systems and Patient HIV Chronic Care files) as well as follow up with clinic staff, as reference documents. The record review was carried out at the 11 pre-selected for the study. For children that met the study criteria, patient information was extracted, including patient name, caregiver contact information, date of birth, date of the DNA PCR test, date the DNA PCR test result was given to caregiver, ART initiation (yes/no), date of ART initiation, and ART patient number. Caregivers of eligible children were then contacted for enrolment in the study.

#### **3.2.2 Enrolment of participants**

Potential participants were caregivers of each HIV-positive child identified during the initial data extraction. Potential participants were contacted via telephone and were invited to participate in the study using a call script. If the participant agreed to be part of the study, he/she was scheduled for an interview or a focus group discussion (FGD) session.

For caregivers not reached on the first attempt, a maximum of four additional attempts were made to contact the caregiver at varying times of day. If after the fifth attempt the caregiver could not be reached, the participant was considered “not available”. If the participant declined, if the contact number from the facility was incorrect (i.e., never heard of primary caregiver or child), or if the contact number was no longer in service, no further attempts to contact the caregiver were made.

Participants were officially enrolled when they arrived for the interview or the FGD.

#### **3.2.3 Facility level survey**

Facility-level data was collected to obtain organizational information. The survey focused on the number of staff at each facility, facility type, use of the DBS hotline, DBS results delivery, tracing methods used, and PMTCT and ART service provision that were available and used in 2012, to align with the study population testing time period defined in the inclusion criteria.

### **3.3 Data collection**

#### **3.3.1 Questionnaire-based interview**

Caregivers were interviewed at the selected facilities or at a place of convenience. Data collectors obtained written consent and facilitated the questionnaire with the caregivers. Questionnaire based -interviews were conducted in siSwati or English, depending on the participant's language preference (*see attached in Annex 1 &2*). The questionnaire focused on socio-demographic characteristics (age of caregiver, religion, number of children, etc.), access to health care and health seeking behaviours (access to clinic, limitations of access, facility attendance, immunization, etc.), caregiver health (substance use, HIV status, ART adherence), child HIV status & ART enrolment (counselling on child's HIV status, reasons for not enrolling) and interpersonal factors (availability of support groups, relationship with caregiver). All caregivers were given transport reimbursement after the interview.

#### **3.3.2 Focus Group Discussions (FGDs)**

Four FGDs were conducted: two among caregivers of cases (HIV-positive children not initiated on ART) and two among caregivers of controls (HIV-positive children initiated on ART). FGDs were conducted in siSwati, the language of general communication in Swaziland. Each focus group had 7-10 participants and lasted approximately 120 minutes. Moderators of the FGDs were data collectors or qualitative researchers who had been trained in focus group techniques. Each FGD was facilitated by a moderator who was assisted by one note taker. All of the discussion sessions were recorded with permission of the participants. Following completion of Informed Consent Forms and Audiotape Releases, each session was conducted using a discussion guide as follows: (1) Welcome & Introductions; (2) Introduction of the project & purpose of the focus group; (3) Establishment of ground rules; (4) Questions & Answers regarding the focus group process; (5) Posing of 6-8 specific focus group questions; (6) Summary of focus group content; (7) Elicitation of final thoughts; and (8) Closing. The FGDs were focused on the feelings and thoughts towards HIV and ART, the barriers and facilitators to ART initiation of children, the health services in the community and the nearby facilities, and suggestions on how to improve the access to ART among children less than 2 years. All participants were given transport reimbursement.

#### **3.3.3 Facility level survey**

The senior nurse from each site visited was asked to fill out a facility-level survey to obtain organizational/facility level information.

### **3.4 Data Analysis**

#### **3.4.1 Quantitative Data from Questionnaire-based Interview and Facility Survey**

Data was captured in Microsoft Access 2007 and Excel 2007 (Microsoft Corporation, Redmond WA). The quantitative data were analysed using Stata 12.1 (StataCorp. LP, College Station, TX) and the level of significance

for all tests was 0.05. For categorical variables, Chi-square tests were performed to compare cases and controls, and for continuous variables, t-tests were performed. Univariate logistic regression models were used to further investigate differences between cases and controls. Variables from descriptive analyses that resulted in a statistically significant difference between cases and controls ( $p < 0.05$ ) were further investigated with logistic regression models. Furthermore, variables that resulted in significant odds ratios during the univariate analysis were further investigated in a logistic regression model adjusted for death of the child.

### **3.4.2 Qualitative data from FGDs**

FGDs were transcribed verbatim, and translated into English by data collectors. One qualitative researcher analysed the transcripts, with the help of the study team. The researcher was in-country and familiar with Swaziland culture and clinical practices. FGDs were coded using a code book that was derived from the questions of the study, as well as through multiple readings of the FGDs transcripts. The themes used to code the transcript were: (1) Overall impression/perspective/thoughts of HIV; (2) Barriers to ART initiation; (3) Pregnancy and ART initiation; (4) ART accessibility; (5) Service delivery in relation to ART; (6) Suggestions to improve ART initiation and access. ATLAS.ti 7.5 (Scientific Software Development GmbH, Berlin) was used to support and verify themes. Among all themes, special attention was paid to any differences and similarities between the cases and the controls.

### **3.5 Ethical considerations**

The Institutional Review Board (IRB) of the University of Alabama at Birmingham and the Swaziland Scientific and Ethics Committee reviewed and approved the study protocol before its implementation. Mothers/caregivers were given a consent form to read and they were encouraged to ask the researchers questions regarding the process of the study. The consent form was read to mothers/caregivers who were unable to read and they were requested to sign their names, or an 'X' if they were unable to write, signifying their agreement to participate in the study. The research staff was trained and sensitized to ensure confidentiality, voluntary participation and comfort of the participants at all times. Participants were told that they were in no way obligated to answer any questions that made them feel uncomfortable.

All data collected from the participants were kept confidential. Once all data were collected and verified they were de-identified prior to analysis. All data were stored on secured computers and in locked cabinets to which only research staff had access.

## 4. RESULTS

### 4.1 Data extraction

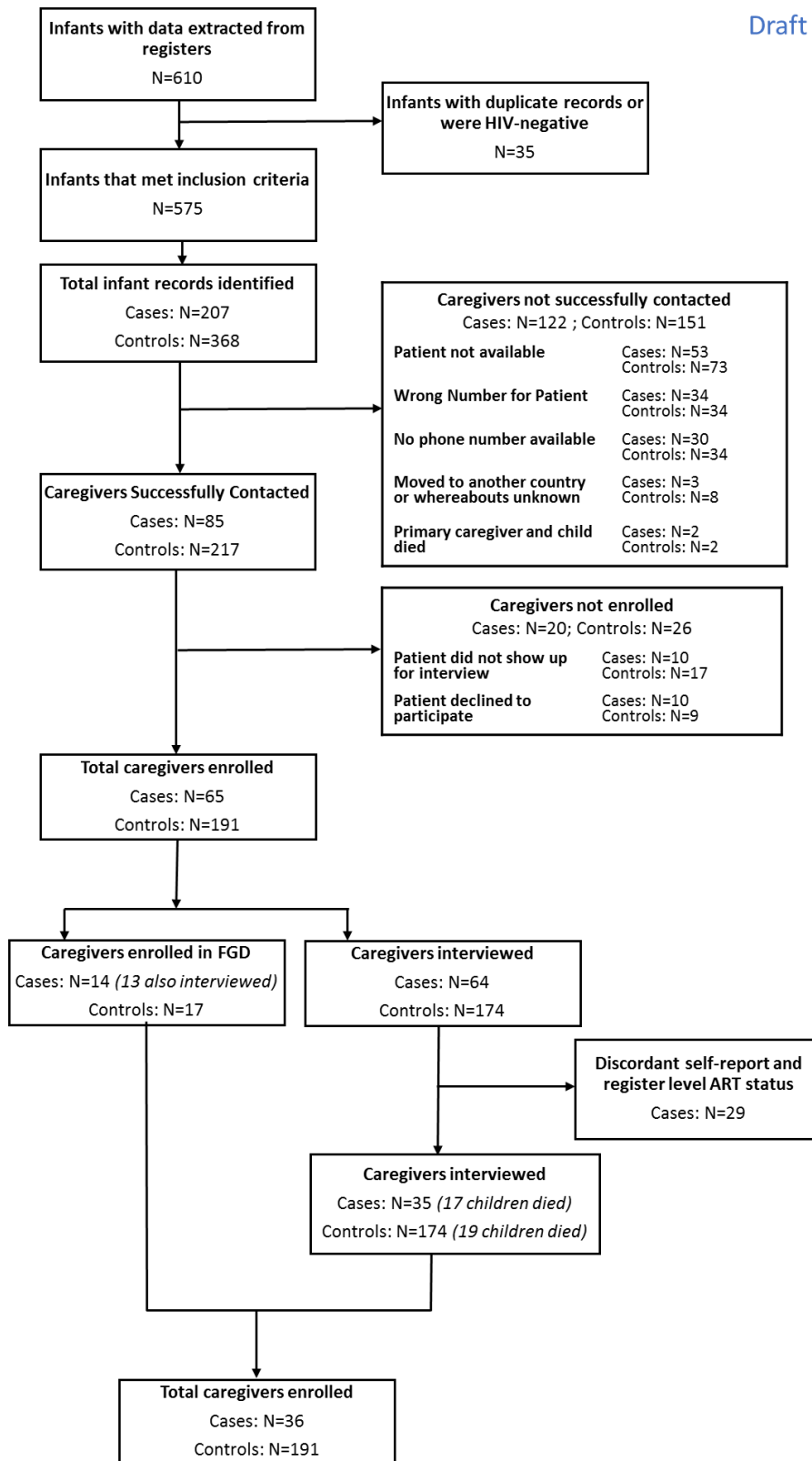
From the 11 sites, patient data and caregiver contact information was extracted for 610 HIV-positive children that met the inclusion criteria. Figure 1 illustrates the data extraction process and the total number of cases and controls identified, and the final number of cases and controls enrolled in the study. Of those who could not be successfully contacted, more than 40% of cases and controls were “not available” (no answer after 10 rings, number not in service, phone was turned off or out of service coverage); more than 20% did not have a phone number available for a caregiver in the facility files; and more than 20% was a wrong number (either incorrect in the clinic register, or inactive for >6 months). No caregivers were successfully enrolled from Siphofanini clinic, and therefore all caregivers were enrolled from the remaining 10 facilities.

Of the caregivers interviewed, based on the register level data there were 64 cases and 174 controls; however, when asked in the questionnaire based interview if the child had been initiated on ART, 29 cases self-reported that their child had initiated ART, and 11 controls self-reported that their child had not initiated the child on ART. Given this inconsistency, and inability to rely on register data (the patient may have discontinued treatment) or self-reported data (the caregivers may have thought it socially desirable to have initiated their child) an attempt was made to re-contact these caregivers, however only 11 controls were successfully re-contacted (14 of the cases had died, and the study team deemed it unethical to re-contact the caregivers; 15 cases were unable to be re-contacted). The 29 cases that could not be re-contacted were dropped from the analysis. Therefore, the final sample resulted in 36 cases and 191 controls.

Figure 1. Data Extraction Flow Chart

Draft 2

4.2



## 4.2 Quantitative Findings from Questionnaire-based Interview

35 cases and 174 controls were enrolled in the study and completed a questionnaire-based interview, and 14 cases and 17 controls participated in a FGD. Of those interviewed, 17 cases (49%) interviews 19 controls (11%) were reported to have died by the caregivers, though the outcome of the child did not affect participation in the study.

### 4.2.1 Individual Factors: Socio-demographic factors

Table 1 shows the socio-demographic characteristics of the caregivers. For both cases and controls, the average caregiver for the child was a female, were the child's primary caregiver, and the biological mother. The average caregiver was 30 and 34 years of age for cases and controls, respectively. For cases and controls combined, most caregivers were from Manzini region, followed by Hhohho, Lubombo and Shiselweni (38%, 27%, 25%, 10%, respectively)<sup>1</sup>, and although there was no significant difference in the regional distribution, there was a difference in the proportion of caregivers that have moved since the time of the child's HIV test (26% for cases vs. 10% for control,  $p=0.01$ ). A caregiver who has moved since the time of the child's HIV test was 3.17 times more likely to have not initiated their child on ART (95% CI: 1.28-7.89). There was no significant difference between cases and controls for sex of caregiver, relationship to child, marital status, religion, size of household, homeownership, level of education, current employment status, monthly employment income, and source of income if unemployed.

Table 1: Socio-demographic characteristics	Child Initiated on ART				P-value
	No (Case); N=35		Yes (Control); N=174		
	N	%	N	%	
<b>Sex of caregiver</b>					
Female	35	100%	159	91%	0.07
<b>Age of interviewee at the time of interview, years</b>	31.7	-	33.8	-	0.36
<b>Primary Caregiver</b>	35	100%	169	97%	0.31
<b>Caregiver Relationship to Child</b>					
Biological Mother	32	91%	131	76%	0.19
Father	0	0%	13	8%	
Grandparents	2	6%	19	11%	
Others	1	3%	10	6%	
<b>Region living now</b>					
Hhohho	14	40%	43	25%	0.25
Manzini	10	29%	69	40%	
Lubombo	9	26%	44	25%	
Shiselweni	2	6%	18	10%	
<b>Moved since child's HIV test</b>	9	26%	17	10%	0.01*
<b>Marital status</b>					
Single/ Divorced/ Widowed	18	51%	92	53%	0.33
Married	17	49%	71	41%	
Cohabiting	0	0%	9	5%	
<b>Religion</b>					
Christian	24	69%	94	54%	0.11

<sup>1</sup> E-NSF 2014 -2018

Table 1: Socio-demographic characteristics	Child Initiated on ART				P-value
	No (Case); N=35		Yes (Control); N=174		
	N	%	N	%	
Others	11	31%	80	46%	
<b>Size of Household</b>					
<=4 people	16	46%	69	40%	
>4 people	19	54%	105	60%	
<b>Number of children living in household</b>					
0 children	4	11%	6	3%	0.13
1-4 children	25	71%	128	74%	
>4 children	6	17%	38	22%	
<b>Homeownership</b>					
Own Home	13	37%	76	44%	0.83
Rent	11	31%	43	25%	
House on family property	8	23%	42	24%	
Live with family/friends' houses	3	9%	13	7%	
<b>Highest level of education</b>					
Primary/Not attended school	9	26%	74	43%	0.18
Secondary/ Vocational	14	40%	52	30%	
High School or higher	12	34%	48	28%	
<b>Current employment status</b>					
Employed/ Self- employed	11	31%	80	46%	0.11
Unemployed	24	69%	94	54%	
<b>Monthly income</b>					
<E500	2	15%	12	13%	0.66
E500-1200	8	62%	47	51%	
>E1200	3	23%	33	36%	
<b>Source of income if unemployed</b>					
Partner / Family / Church/ Grants	20	83%	72	77%	0.48

\* indicates significant relationship with  $p < 0.05$

#### 4.2.2 Individual Factors: Access to Healthcare, Health Seeking Behaviours, Relationship with Caregivers Health Facility

Caregivers were successfully enrolled from the 10 health facilities listed in the table below. The proportion of cases and controls found at each facility is listed below. In all facilities, the majority participants were caregivers of controls; however a statistically significant difference was found between the facility where the child's DNA PCR sample was taken and with the number of cases and controls at that facility as shown in Table 2. The facility attended by the caregiver also had a significant effect, after adjusting for death of the child. In one facility, caregivers who attended were 3.25 times more likely to have not initiated their child on ART if compared to children seen at the mother facility (95% CI: 1.05-10.08). In addition, compared to caregivers who attended one hospital compared to another, caregivers who attended one were 20% or 5 times more likely to have initiated their child on ART (OR 0.20 95%CI 0.05-0.78) compared to the other hospital.

Table 2. Cases and Controls by Facility	<i>Child initiated on ART</i>				P-value
	No (Case); N=35		Yes (Control); N=174		
	N	%	N	%	
<b>Facility Attended</b>					
Baylor Mbabane COE	11	22%	39	78%	<0.001*
Baylor RFM	12	43%	15	57%	
Baylor Hlatikhulu	0	0%	4	100%	
Good Shepherd Hospital	4	8%	46	92%	
Horo Clinic	1	14%	6	86%	
KSII PHU	1	4%	22	96%	
Lobamba Clinic	2	50%	2	50%	
Luyengo Clinic	0	0%	22	100%	
Matsapha MSF Clinic	3	27%	8	73%	
Nhlangano PHU	1	10%	9	90%	

\* indicates significant relationship with  $p < 0.05$

### **Access to Healthcare**

Caregivers were asked about their access to health care facilities. A significant difference in time to the nearest clinic was observed between cases and controls ( $p=0.02$ ) with a greater proportion of controls (34%) reported travelling more than 60 minutes to the nearest clinic compared with cases (14%). With respect to access to healthcare, a caregiver that lived less than 30 minutes from a health care facility was 4.01 times more likely to have not initiated their child on ART, compared to someone who lived more than 60 minutes from their health care facility (95% CI: 1.39-11.54); Caregivers did not differ in their mode of transportation to the clinic, nor on cost of attending a health visit (transport, food, health service fees). When caregivers were asked to report what limited their access to healthcare, 23% of cases compared to 10% of controls, reported that there were no limitations to accessing care ( $p=0.03$ ). However, caregivers who reported no limitations to accessing care were 2.73 times more likely to have not initiated their child on ART (95% CI: 1.08 - 6.96). A significantly higher proportion of controls (22%) indicated “distance to healthcare facility” as a limitation to accessing health care compared to cases (6%;  $p=0.04$ ). Although not statistically significant, the majority of cases and controls reported “getting money for transport” as a limitation to accessing health care, followed by “concern of available medications”, and “work commitments”. Additional results regarding access to health care are presented in Table 3.



### ***Health Seeking Behaviour***

The majority of caregivers, both case- and control-caregivers, reported attending a health care facility for their own health care at least once every 3 months (71% and 81% respectively; no significant difference); however, there was a significant difference with respect to appointment keeping, with the majority of control-caregivers (89%) reporting that they always keep appointments compared to 74% of case-caregivers ( $p=0.02$ ). Looking at caregiver access to care, compared to caregivers who always kept their appointments, caregivers who never kept their appointments were 2.9 times more likely to have not initiated their child on ART (95% CI: 1.18 - 7.16). With respect to the child's health care visits, case-caregivers were significantly different than control-caregivers ( $p<0.001$ ); with a greater proportion of case-caregivers never bringing their child to the clinic or only bringing the child when sick (29% vs 6%). Children who were never taken to the health facility were 5.08 times more likely to have not been initiated on ART compared to children who were taken to the facility every month (95% CI: 1.80 - 14.35). In addition, although cases and controls were nearly identical in their self-reported immunization status from birth to week 10 (~97%), there was a significant drop in the number of cases returning for vaccines after week 14 (91%), which steadily decreased up to 18 months (51%), compared to controls who maintained greater than 90% coverage ( $p < 0.001$ ) as shown in Table 3 below. It is important to note that children who had received their 6-18month vaccinations were 3.46-9.33 times more likely to have been initiated on ART (respectively).

Table 3. Access to Health Care and Health Seeking Behaviors	Child initiated on ART				P-value
	No (Case); N=35		Yes (Control); N=174		
	N	%	N	%	
<b>Access to Health Care Services</b>					
<b>Time to nearest clinic</b>					
≤ 30 minutes	18	51%	53	30%	0.02*
31-60 minutes	12	34%	62	36%	
> 60 minutes	5	14%	59	34%	
<b>Mode of transportation to nearest clinic</b>					
Public Transportation	21	60%	135	78%	0.09
Other/ Walk	13	37%	36	21%	
Personal Car	1	3%	3	2%	
<b>Cost of attending the clinic</b> (transport, food, health fee)	31.57	-	40.56	-	0.07
<b>Limitations to accessing health care</b>					
Money for transport	18	55%	116	67%	0.18
Distance to health facility/clinic	2	6%	38	22%	0.04*
Concern that there may be no medication available	3	9%	9	5%	0.38
Work commitment	1	3%	12	7%	0.40
No limitations	8	23%	17	10%	0.03*
<b>Health Seeking Behaviors</b>					
<b>Caregiver health care facility attendance</b>					
Never	4	11%	9	5%	0.31
Attends Regularly (≥3 visits per year)	25	71%	140	81%	
Does not attend regularly (< 3 visits per year)	6	17%	24	14%	
<b>Caregiver's appointment-keeping behavior</b>					
Never / Rarely / Sometimes	9	26%	18	11%	0.02*
Always	26	74%	151	89%	
<b>Child health care facility attendance</b>					
Never/Only when sick	9	29%	10	6%	<0.001*
Every Month	17	55%	96	56%	
Every Two Months	4	13%	45	26%	
Once Every 3 months or more	1	3%	20	12%	
<b>Child immunization coverage</b>					
At Birth (BCG;OPV 0)	34	97%	168	97%	0.86
6 weeks (DPT/HBV; OPV 1)	34	97%	169	97%	1.00
10 weeks (DPT/HBV 2; OPV 2)	34	97%	167	96%	0.74
14 weeks (DPT/HBV 3; OPV 3)	32	91%	166	95%	0.34
6 months (Vitamin A)	30	86%	166	95%	0.03*
9 months (Measles)	24	69%	163	94%	<0.001*
12 months (Vitamin A; Albendazole)	20	57%	161	93%	<0.001*
18 months (OPV 4; Measles; Vitamin A)	18	51%	158	91%	<0.001*
I don't know	1	3%	4	2%	0.84

\* indicates significant relationship with p<0.05

#### 4.2.3 Individual Factors: Caregiver Health, Behaviours, Maternal Health, HIV status, & ART Enrolment

##### **Caregiver Health Behaviours**

More control-caregivers reported to “always adhering to their medical treatment” ( $p=0.06$ ).

##### **Maternal and Reproductive Health**

Alcohol use during pregnancy was also significantly different between case- and control-caregivers (13% vs 3%, respectively;  $p=0.03$ ). With respect to maternal health factors, caregivers who reported using alcohol during pregnancy were 4.50 times more likely to not have initiated their child on ART (95%CI 1.06-19.09).

There was no difference between the number of ANC visits the mothers attended, the time of their first ANC visit, whether their pregnancy was planned, or use of contraception. In general, the majority of mothers were attending at least 3 ANC visits, and the majority of mothers attended their first ANC visit during their second trimester. Only 16% of case- and 25% of control-caregivers reported that their pregnancy was planned, and less than 35% of all caregivers reported using contraception at the time of pregnancy.

##### **Caregiver HIV Status & ART Enrolment**

Table 4 presents the results from caregivers regarding caregiver health behaviours and health status. The majority of case-(97%) and control-caregivers (98%) reported knowing their HIV status, and the majority of case- (87%) and control-caregivers (92%) reported having disclosed their HIV status to at least 1 family member. However, although not significantly different among case- and control-caregivers, only 60% and 62% (respectively) reported having disclosed to their partner; only 40% and 47% (respectively) to their mother; and 7% and 0% (respectively) to their in-laws.

Table 4. Caregiver Health Behaviors, HIV status, & ART enrollment	Child initiated on ART				P-value
	No (Case); N=35		Yes (Control); N=174		
	N	%	N	%	
<b>Caregiver Health Behaviors</b>					
<b>Adherence to medical treatment</b>					
Always	24	80%	151	92%	0.06
Rarely / Sometimes	6	20%	14	8%	
<b>Maternal &amp; Sexual Reproductive Health</b>					
<b>Alcohol use during pregnancy</b>	4	13%	4	3%	0.03*
<b>Antenatal care (ANC) visits</b>					0.52
<3 times	4	13%	12	9%	
3-8 times	27	84%	105	82%	
>8 times	1	3%	11	9%	
<b>Time of first ANC visit</b>					0.80
First Trimester	9	28%	34	26%	
Second Trimester	16	50%	74	57%	
Third Trimester	6	19%	18	14%	
Labor Ward/Never	1	3%	2	2%	

Table 4. Caregiver Health Behaviors, HIV status, & ART enrollment	Child initiated on ART				P-value
	No (Case); N=35		Yes (Control); N=174		
	N	%	N	%	
Planned pregnancy	5	16%	32	25%	0.28
Use of contraceptive at time of pregnancy	10	31%	31	24%	0.40
Mother was a victim of sexual violence	4	13%	6	5%	0.10
<b>Caregiver HIV Health Status &amp; ART Enrollment</b>					
HIV status known	34	97%	171	98%	0.67
Disclosed HIV status to study team (HIV+ or HIV-)	32	94%	168	98%	0.15
Prefer not to answer	2	6%	3	2%	
Year of HIV diagnosis					0.52
≤2005	1	4%	8	7%	
2006-2010	15	54%	52	42%	
≥2011	12	43%	63	51%	
ART use during pregnancy	19	61%	62	48%	0.17
Always adherent to ART	11	85%	91	94%	0.22
Disclosure of HIV status	27	87%	140	92%	0.44
Partner	21	60%	108	62%	0.82
Mother	14	40%	81	47%	0.48
In-law	11	7%	0	0%	0.13
Children	1	3%	9	6%	0.57
Family unaccepting of HIV	2	7%	18	13%	0.41
Experienced HIV stigma	3	10%	22	14%	0.56

\* indicates significant relationship with  $p < 0.05$

### **Child HIV status & ART enrolment**

Table 5 demonstrates information regarding the child's HIV status and ART enrolment. A significantly larger proportion of control-caregivers (76%) strongly agreed that it is important to enrol children living with HIV on ART compared to cases (38%,  $p < 0.001$ ). There was no difference in the self-reported time the health care worker (HCW) spent discussing the child's HIV results with the caregiver; however, when case-caregivers were asked reasons for not starting the child on ART, 27.5% reported that they did not understand the process of ART enrolment (14%), or that nurses did not explain what they were meant to do (11%). Case-caregivers also reported that they did not initiate their child because they thought their child was not sick (23%), they feared disclosing their or their child's HIV status (17.5%), they did not trust HIV medications (10%), or they were in denial of their child's HIV status (6%). Only 6% reported that they had to get permission from their partner before initiating the child, and 50% reported that they were not able to initiate their child on ART, either because their child died before initiating ART (31%), or that their child was not eligible for ART because they were just initiated on TB treatment (19%). Among control-caregivers, only 16% indicated that their child experienced side effects due to ART.

Table 5. Child's HIV status & ART enrollment	Child initiated on ART				P-value
	No (Case); N=35		Yes (Control); N=174		
	N	%	N	%	
<b>How much time was spent explaining child's HIV results</b>					0.40
<=20 minutes	9	26%	29	17%	
>20 minutes	24	71%	132	76%	
None, they did not explain	1	3%	5	3%	
I don't know	0	0%	7	4%	
<b>Caregivers who strongly agreed that it is important to enroll HIV-positive children on ART</b>	13	38%	131	76%	<0.001*
<b>Child experienced ART side effects (Controls only)</b>	-	-	28	16%	-
<b>Reasons for not starting the child on ART (Cases only)</b>					
Child died before ART initiation	11	31%	-	-	-
The child is not eligible or was on TB treatment	7	19%	-	-	-
The child is not sick	8	23%	-	-	-
Fear of disclosure my/the child's HIV status	6	17%	-	-	-
Do not understand the HIV enrollment process	5	14%	-	-	-
The nurses did not explain	4	11%	-	-	-
I don't trust HIV medications/ ART is harmful	2	6%	-	-	-
Denial of the child's HIV status	2	6%	-	-	-
Need permission from partner	2	6%	-	-	-

\* indicates significant relationship with  $p < 0.05$

#### 4.2.4 Interpersonal factors: Support networks

There were no significant differences between case- and control-caregivers for support networks (Table 6). Only 9% of both case- and control-caregivers received additional support for their child's care. The majority of case- and control-caregivers reported attending religious services regularly, and of those, the majority said their religious affiliation was accepting of HIV-positive individuals. When asked about the availability of support groups, only 9% of case- and 22% of control-caregivers reported that support groups were available ( $p=0.09$ ). Of those who knew support groups were available, 67% of case and 55% of controls said they attended; however, of those that attended more than 95% in both groups said they found the support groups helpful.

#### 4.2.5 Interpersonal factors: Relationship with health care providers

When asked to rate their relationship with their health care provider, the relationship ratings was significantly different between case- and control-caregivers ( $p=0.01$ ). For case-caregivers, 9% reported having a poor or very poor relationship with their doctor or nurse, compared to only 1% of control-caregivers, while 94% of control-care-givers describe an excellent relationship with the care giver compared to 83% for case-caregivers. Caregivers who reported having a poor or very poor relationship with their healthcare provider were 16.98 times more likely to not have initiated their child on ART (95% 1.71-168.78).

There was however no significant difference found between the two groups for the relationship rating with other clinic staff (expert client, receptionist, etc.).

Table 6. Interpersonal factors as barriers to ART initiation	Child initiated on ART				P-value
	No (Case); N=35		Yes (Control); N=174		
	N	%	N	%	
<b>Support Networks</b>					
Caregivers receiving additional support for child's care (financial, food, clothing, other)	3	9%	15	9%	0.99
Caregivers regularly attending religious services	33	94%	164	94%	0.99
Religious affiliation accepting of HIV+ individuals	22	63%	121	71%	0.53
<b>Availability of HIV support groups</b>					
No	24	69%	87	50%	0.09
Don't Know	8	23%	49	28%	
Yes	3	9%	38	22%	
If yes, do you attend?	2	67%	21	55%	0.70
If you attend, do you find it helpful?	2	100%	20	95%	0.26
<b>Relationship with Healthcare facility</b>					
<b>Relationship with doctor or nurse</b>					
Excellent / Good	29	83%	164	94%	0.01*
Average	3	9%	9	5%	
Poor / Very Poor	3	9%	1	1%	
<b>Relationship with other clinic staff (expert client, administration etc.)</b>					
Excellent / Good	29	83%	159	91%	0.20
Average	5	14%	10	6%	
Poor / Very Poor	1	3%	5	3%	

\* indicates significant relationship with  $p < 0.05$

#### 4.2.6 Organizational Factors

Of the 10 sites included in the study, in 2012 the majority of sites were Baby Facilities (defined as facilities that did not have onsite electronic ART database, 55%), that utilized the DBS toll-free hotline to receive EID results from the National Referral Laboratory (82%), and that performed on-site initiation of paediatric ART clients (100%). ART initiations were performed by Nurse-Led ART Initiations (NARTIS) trained nurses at 45% of facilities, by visiting doctors at 27% of facilities, or by a combination of NARTIS trained or visiting doctors at the remaining 27% of facilities. All 10 facilities reported providing PMTCT services, paediatric ART initiation, and providing patient tracing procedures by phone call only (55%) or a combination of phone calls and home visits (45%). Additionally, 64% of sites reported that in 2012, the nurses within the facility were confident or very confident initiating children on ART. Nurse confidence in providing ART initiation services for children was the only statistically significant difference between facilities with more cases than controls ( $p=0.03$ ; Table 7).

Table 7. Facility Data by Case Control Status	Child initiated on ART				P-value
	No (Case); N=35		Yes (Control); N=174		
	N	%	N	%	
<b>Tracing mechanism used by facility</b>					
Phone call	8	23%	51	29%	0.44
Phone call + home visit	27	77%	123	71%	
<b>Facility used DBS hotline to receive EID results</b>	33	97%	146	87%	0.89
<b>Facility experienced pediatric ARV stock outs</b>	4	13%	34	29%	0.09
<b>Nurse confidence with providing pediatric ART initiation</b>					
Not at all confident	3	9%	8	5%	0.03*
A bit confident	6	17%	48	28%	
Confident	2	6%	37	21%	
Very confident	24	69%	81	47%	

## 4.2.7 Results from Univariate and adjusted logistic regression models

(Results descriptions of logistics regressions are incorporated in the respective text above)

Table 8: Logistic regressions	Univariate		Adjusted (controlling for those who died)	
	OR	95% Confidence Interval	OR	95% Confidence Interval
<b>Socio-demographics</b>				
Moved since child's HIV test	3.17	(1.28 - 7.89)*	1.91	(0.69 - 5.28)
<b>Access to Healthcare and Health Seeking Behaviors</b>				
Facility Attended (reference= Baylor COE)				
Good Shepherd	0.308	(0.09 - 1.04)	0.2	(0.05 - 0.78)*
Hlatikhulu	-	-	-	-
Horo	0.591	(0.06 - 5.44)	1.15	(0.12 - 11.16)
KS II	0.161	(0.02 - 1.33)	0.24	(0.03 - 2.15)
Lobamba	3.45	(0.44 - 28.13)	2.17	(0.19 - 24.43)
Luyengo	-	-	-	-
Matsapha MSF	1.32	(0.30 - 5.88)	2.01	(0.40 - 10.10)
Nhlangano PHU	0.394	(0.97 - 7.26)	0.32	(0.03 - 3.40)
RFM	2.65	(0.97 - 7.25)	3.25	(1.05 - 10.08)*
Time to nearest clinic (reference = >60 minutes)				
<= 30 minutes	4.01	(1.39 - 11.54)*	5.82	(1.80 - 18.81)*
31 - 60 minutes	2.28	(0.76 - 6.88)	2.74	(0.83-9.02)
Self-reported limitations to accessing healthcare				
Distance to Healthcare	0.23	(0.05 - 1.01)		
None	2.73	(1.08 - 6.96)*		
Caregiver appointment keeping (reference = Always)				
Never/Rarely/Sometimes	2.9	(1.18 - 7.16)*	2.67	(0.99 - 7.21)
Child health care facility attendance (reference= >=every month)				
Every Two Months	0.50	(0.16 - 1.58)	0.78	(0.22 - 2.68)
Once in every 3 months - 1 year	0.28	(0.36 - 2.24)	0.64	(0.08-5.47)
Never	5.08	(1.80 - 14.35)*	6.02	(1.84-19.73)*
Child Immunization Coverage - Not immunized vs. Immunized				
At Birth (BCG;OPV 0)	0.82	(0.10-7.06)	0.57	(0.06-5.75)
6 weeks (DPT/HBV; OPV 1)	0.99	(0.11-8.78)	0.62	(0.06-6.61)
10 weeks (DPT/HBV 2; OPV 2)	0.7	(0.08-5.89)	0.52	(0.53 -5.10)
14 weeks (DPT/HBV 3; OPV 3)	1.94	(0.49 - 7.73)	2.12	(0.47-9.56)
6 months (Vitamin A)	3.46	(1.06 - 11.29)*	3	(0.81-11.12)
9 months (Measles)	6.79	(2.66-17.37)*	4.56	(1.63-12.77)*
12 months (Vitamin A; Albendazole)	9.29	(3.87-22.31)*	5.2	(1.97 - 13.70)*
18 months (OPV 4; Measles; Vitamin A)	9.33	(4.03-21.58)*	5.21	(2.03-12.35)*
<b>Caregiver Health</b>				
Substance use				
Drinking while Pregnant	4.5	(1.06-19.09)*	6.96	(1.48-32.58)
<b>Interpersonal Factors</b>				
Relationship with healthcare provider (Excellent / Good)				
Poor/Very Poor	16.96	(1.71-168.78)*	7.65	(0.61 - 95.16)
Average	1.88	(0.48 - 7.38)	2.58	(0.61-10.96)

### 4.3 Qualitative Findings from FGDs

Thirty-one caregivers (14 cases and 17 controls) participated in four FGDs: two among case-caregivers and two among control-caregivers. Themes identified from the focus group sessions were grouped in accordance with the questions listed in the study. The barriers to ART initiation were further classified according to the objectives of the study: (1) maternal/family socio-demographic factors, (2) interpersonal factors, and (3) organizational factors. Quotations from the respondents are indicated in a smaller font to substantiate the narrations of the themes. All groups consisted of only female caregivers; quotations reflect views of case- and control-caregivers.

#### 4.3.1 Individual factors

##### Socio-demographic Characteristics

##### Distance to clinic and Monetary restrictions

The distance to health facilities coupled with lack of transport and cost of transport were mentioned as barriers to ART initiation. When paediatric ART services are not available at the local clinic, caregivers have to travel to a clinic at a greater distance from their homes, while some caregivers go to a clinic further away due to fear of discrimination and stigma. In addition, lack of money was mentioned as a barrier to accessing the facility as well as initiating the child if there wasn't enough money for food for the child.

*Control - caregiver: "The clinic is very far and there is no transport so you have to walk long distances".*

*Control -caregiver: "Clinic is far and you take 3 hours or more to get to the clinic".*

*Case -caregiver: "In some areas, the services are still missing [...] Most of the time I have to come here [Baylor COE]. There are children at different homes whom their parents can't afford to come to Baylor. When the mother doesn't have money to bring child to Baylor, she stays at home and a gap is created resulting in child not taking pills correctly."*

*Case-caregiver: "I think it's because of lack of money, because I can fetch the medication but if we do not have enough food to go with the medication, it becomes a problem. Because once I initiate him on treatment, he must not stop taking it, so it's better [to not initiate the child on treatment]"*

##### Age of mother

Teenage pregnancies could prevent a young mother from accessing ART. Since many teenage mothers do not plan their pregnancy, they often struggle to take proper care of themselves during pregnancy, may be unaware of their HIV status, and are unprepared to care for their child.

*Case-caregiver: "I think the other problem relates [...] teenagers who get pregnant while still school-going. For instance If I get into a relationship for the first time, I get pregnant, I am young and still want to explore my youth stage and enjoy it-so when I deliver an HIV-positive baby, I won't have time to take care of the baby because I was not even ready to have one. So in my enjoying my youth stage, I will only take care of the child and give the treatment when I have remembered, if I don't remember, he will miss the dose because to me he will still be*



healthy looking. Hence the child will have a problem health-wise as he may be missing doses at times under the care of the teenage mother”.

### Access to early ART initiation

Case- and control-caregivers differed on their thoughts and experiences with respect to access to ART initiation. Cases reported that they arrived at the facility when the child was already sick, resulting in the death of the child before initiation on ART. While control-caregivers reported that access to ART was very easy. The difference between these two groups were reported to be that HCW gave control-caregivers the required attention and services that helped to ease the ART initiation process.

**Case - caregiver:** *“It was found that I came late. The baby was already sick. They gave us a day to come back for sessions before initiation. That same day, he died. I then came back alone for the sessions.”*

**Case-caregiver:** *“He was tested at 6 weeks ... and was positive. They told me to come to Baylor...We were then admitted at Mbabane government hospital because he was sick. On the date when he was supposed to return to Baylor, we were still in hospital. I told them at the hospital that we were supposed to return to Baylor for initiation today, they told me they won’t discharge us until the baby was well... He passed away without starting treatment.”*

**Case - caregiver:** *“[my child] was found to be positive and the illness was at an advanced stage. They started him on TB treatment first but he died while still on TB treatment.”*

Control-caregivers mentioned that the access to free and good quality ART drugs helped the initiation of their children on treatment.

**Control-caregiver:** *“I am grateful to government for making sure that everyone gets the pills by making them free of charge. If ART’s were sold then more and more people would die so that’s why I am grateful to the government of Swaziland”.*

**Control- caregiver:** *“The Health Ministry has been of great help indeed in such a way that we do not know how to say thank you. For example if a child starts treatment at an early age of 2 months old, the child will grow up healthy and maybe reach 10 years old without any indication that the child is living with a virus in his/her body. That’s why I would like to encourage the Ministry of Health to continue with their good work”.*

### Unplanned pregnancy and ART initiation

Caregivers reported that their pregnancies were not planned. Some reported that they were using contraceptives during the period that the pregnancy occurred and wondered how they got pregnant. The unplanned pregnancies resulted in the mothers attending their first ANC visit late, and thus, being tested for HIV and initiating ART late in the pregnancy.

**Control- caregiver:** *“I did not plan to have a kid, it just happened. I was stressed when I found out that I was also HIV positive”.*

### Perceptions on Antiretroviral Therapy (ART)

Both case- and control-caregivers knew that taking ART during pregnancy prevented HIV transmission from mother to child. Relevant quotes from caregivers are as follows:

**Case - caregiver:** “They [ARVs] really help a great deal. They took great care of me when I was doing my ANC visits at Nazarene; even during labour I visited another clinic where I was also given the intrapartum dose. The baby came out negative”. (referring to another HIV-negative child)

**Case- caregiver:** “They [ARVs] are ok because I was using them for my previous babies and they are all negative.” (referring to other children)

**Case-caregiver:** “I found them [ARVs] very helpful during the child I gave birth to in 2013 and my child is negative”. (referring to her other child)

However, a few control respondents reported that ART during pregnancy was not helpful as they gave birth to HIV-positive babies. A quote from one participant follows:

**Control - caregiver:** “They [ARVs ] were not helpful because my child was born positive”.

**Control - caregiver :** “They [ARVs] are helpful and sometimes not because some give birth to negative babies but others to positive ones even though they were all taking the same medication”.

Case-caregivers emphasized their knowledge that ART resulted in better health for both themselves and their children. Furthermore, control-caregivers reported that ART was very helpful since children who started ART showed enormous improvement especially when they were in a critical condition before ART.

**Control - caregiver:** “I think they [ARVs] are really helpful because ART helped my child back to health when I had no hope at all.”

**Control caregiver:** “I really think ART helps because once a child start taking them maybe after being sick, then you cannot tell the difference between a child who is HIV positive and the one who is negative. ART does really help the child’s CD4 count not to drop so the child stays healthy”.

However, some case-caregivers emphasised the challenges and their concerns with ART treatment for other children, including children refusing to take their medication due to the bitter taste or to treatment fatigue.

**Case caregiver:** “He has become difficult with taking his medication; when you remind him to take his medication he tells you he has taken his medication or he tells you to make the others take the pills as well.” (referring to the child of her aunt)

**Case caregiver:** “The syrup however, is bitter, he sometimes doesn’t want to take it.”

#### 4.3.2 Interpersonal factors

##### Disclosure

Among other barriers highlighted in the FGDs was the failure of the mother to disclose her, or her child’s positive HIV status to her partner. Many reasons for not disclosing were cited by the caregivers, including the child was of a previous relationship, or the mother was scared of losing her partner. It also transpired that partners became a problem as some refused to discuss this topic with their wives. Alternatively, both partners would pretend they were HIV-negative and secretly take medication. Hence, the parents were not able to discuss the HIV status of their child, let alone the initiation of their child on ART.

**Case caregiver:** “Very true, sometimes the husband may be taking the treatment secretly and will only disclose when you tell him that you are also starting ART”.

**Case Caregiver:** “I am married; sometimes you do tell your husband and you find that he doesn’t listen. Every time you try to tell him about HIV and what they are saying at the clinic, he just shuts off and pushes away the issue.

*Those are the cases where you find that you get scared to take care of the baby; you do it secretly because he just doesn't want to entertain anything that relates to HIV and ART. So when you do things secretly, you are not at ease because even when it's time for medication while your husband is also present, you won't get a chance and you will miss the dose because you are afraid of him."*

**Case Caregiver:** *"I tested positive when I was pregnant. Then my partner died and I got into a relationship with another man. Since we were in love, we never told each other about our HIV statuses. It became a very big problem when I had to start cotrimoxazole prophylaxis he was always in the house when I had to take my tablet. I was so disturbed emotionally by this situation because even when I wanted to take the tablets under the table, he was always around. I used to hide my tablets".*

**Case Caregiver:** *"When [my husband] learned our baby was positive, he accused me of killing our baby and he left."*

It was further discussed that since a lot of lies and secrets engulf families, mothers of HIV-positive children do not disclose their status to their family members, who sometimes are the primary caregivers of the children. Therefore, follow up visits attended by other family members may be compromised, as the importance of HIV testing and treatment is not emphasised by the mothers to family members and patients may even default when left in their care. Caregivers reported that such behaviour was linked to fear of discrimination and to denial.

**Case Caregiver:** *"Mine is 4 years now. I think the problem is fear to disclose because my child is 4 years now and I don't stay with him because he doesn't belong where I eventually got married. So he stays with my mother but I have not disclosed my status to my mother even now. When I have to bring him to the clinic, I usually send for him. Even now, he was supposed to come for his refills but I didn't bring him because I am scared to disclose to my mother and that stresses me. So I can't tell my mother, at the same time I cannot bring him with me to my marital home to stay with me". (referring to another child)*

**Case Caregiver:** *"My mother took the pills and I told her how to give it to the child. When she asked what the pills are for since I keep giving them to the child, I told her they are for boosting the child. So, besides money, the other issue is the fear of disclosure... the fear of coming out and telling your family about your status, especially when you know the kind of people your family is" (referring to another child)*

### **Discrimination and fear of stigma**

Cases reported that discrimination was still a major challenge in accessing ART or enrolling children on ART. Many control-and case-caregivers, reported being discriminated against due to their HIV status.

**Case Caregiver:** *"When you have [HIV], you are regarded as promiscuous. Then they gossip about you. When I take my pills, I do so in private. My pills are under the bed. I am scared my friend might visit me and find my pills in the open and gossip about me in the community"*

**Case Caregiver:** *"There is still discrimination. Like if you are a wife, your in-laws would say, this promiscuous woman came with the virus and infected my child. They talk all kinds of negative things that emotionally hurt you. Most of us end up hiding our status."*

**Case Caregiver:** *"I don't want my child to be known that he or she is positive. There is no one that I can talk to as my supporter. It's just a thing of my own that my child is positive and if I talk to someone she will say aghh...This one and her child are both drinking the tablets. You see?" (When providing reasons for not bringing a treatment supporter to initiate her child on ART)*

**Case Caregiver:** “Yes you can be self-determined to take the pills because this is your life-however in my case I got discouraged because it was a family member that started discriminating and telling people about my status.”

**Case Caregiver:** “I think people have the information about HIV, but the problem is discrimination. When we see someone queuing to take ART we start asking people if they have seen so and so queuing for ART or have you heard X’s bag making the sound of ART ricocheting in their containers. Or have you seen so and so, he is wasted due to the virus, “have you seen the rashes?” the problem is that people start discriminating based on status so people get afraid to enrol on treatment.”

## Relationship with HCW

Both case- and control-caregivers recalled receiving unfair treatment from health care workers (HCWs). Examples of poor treatment included HCWs shouting at patients, HCWs gossiping about clients, delayed service provision and unnecessarily long waiting times.

**Control Caregiver:** “...But they [HCW] treat us like idiots. Most of the nurses, especially at one facility are really rude they do not know how to treat people. I once had a problem with my child... and I tried to get help at another facility but one of the nurses was rude and couldn’t help me”.

**Case Caregiver:** “I think finding people [HCW] of the right attitude, who are approachable, is very important to us when we come to the health facilities. When you get ill-treated by a person at the Health Centre, you get demotivated even to come back for refills just because the image of that person who treated you badly comes to mind. You start thinking twice.”

**Case Caregiver:** “Sometimes you find someone [a HCW] who will talk as if she knows how you got the HIV and she will be saying all kind of hurtful things, while he/she is not even aware how you got the HIV and the way you got it could be even painful to you too. If you are a short-tempered person, you can stop going to that facility because of the annoying attitude. Health facilities are supposed to be a place where we get comforted but sometimes you find yourself deciding to stay home with the child just because of the attitude of some healthcare workers”

**Case Caregiver:** “We are not treated well, you sometimes wish to change facility and go somewhere where you will be welcomed and free to talk about whatever is troubling you.”

**Case Caregiver:** “I come from Lobamba, but I can never go there to collect my pills, even though I live next to the clinic. That’s why I chose Baylor because they know how to treat a person well. If I can run short of money to come here, I would stay at home until I find money to come back here.”

Caregivers also reported fear of returning to the facility after a missed or skipped appointment, because they might be ill-treated.

**Case Caregiver:** “With me here is the ART booklet; I was supposed to come back to the facility on the 14th of January 2015. I am so afraid, and I am now even afraid of bringing the child to the clinic because he has missed his appointment date.”

### 4.3.3 Organizational Factors

#### Long waiting times

Both case and control-caregivers reported long waiting times being a barrier to accessing health care services.

**Case Caregiver:** *"Sometimes you get there at 7 am or 6 am [in the morning] and the lines are too long. Then at 10 am they [HCW] leave you waiting and go for tea break. You had said you will be back at work at 10 am. Even at 1pm they [HCW] also leave and go for lunch. When you start to talk they tell you, you should have come earlier in the morning."*

**Control Caregiver:** *"... sometimes you wait for more than 2 hours and the nurses would not help you until it suits them and there's nothing to do or say because they might end up not helping you at all".*

#### Lack of counselling and education from HCW

Case-caregivers reported that the HCWs did not spend enough time explaining health conditions and treatments to the clients. Many case-caregivers did not understand the process of ART initiation for themselves and their children. They did not understand the need to bring treatment supporters to their appointment, as well as the reasons why their children could not be initiated on treatment on the same day. It also seemed that the HCWs did not have time to educate and counsel the clients, thus the clients did not feel free to talk and ask questions.

**Case Caregiver:** *"So I went a bit later to hospital. I don't know whether they gave me the prophylaxis, because they just gave me a lot of pills and I assumed it was just the routine pills you take when pregnant."*

**Case Caregiver:** *"It's like they are in a hurry when attending patients. They don't have time to sit down and talk to you."*

**Case Caregiver:** *At the clinic I was attending, I was never counselled on how to take care of myself and my baby when you are HIV-positive, when to start attending antenatal care, and the need to deliver in a hospital setting was never emphasized, breastfeeding duration or anything relating to treatment received to try and prevent the child from getting HIV vertically. Furthermore, I delayed testing my baby for HIV; I tested him for HIV when he was already very sick."*

**Case Caregiver:** *"Mine also died. I felt so much pain. I didn't know it was possible to give birth to a positive baby."*

**Denial** was also highlighted by caregivers, and is likely due to limited education related to HIV.

**Case Caregiver:** *"I always say that I am the one who killed my baby. If only I had accepted my status. [...] Until you are properly educated about HIV, you struggle with denial."*

**Control Caregiver:** *"I think most parents are in denial. They do not want to accept their status and their children's even when they try counselling them at clinics."*

**Case Caregiver:** *"A lot of people are afraid of AIDS. My sister had a positive baby. She refused to believe, gave the baby to my mother and didn't breastfeed. After 9 months, the baby was still not crawling, walking, he was sick."*

There was a difference found between case- and control-caregivers as control-caregivers reported that they were sensitized by healthcare or community workers about the importance of accepting a child's HIV-positive status and providing extra care and loving them. It was also reported that some service providers gave them the required attention and services and hence access to ART was made easier. This indicates that proper education and support from a HCW could increase the linkage to care.

**Control Caregiver:** *“I was encouraged by an Expert Client at one facility and she even made an example about her own child who is 7 years old and healthy and that made me decide to start my child on ART.”*

**Control Caregiver:** *“I was taught about the advantages of starting the child on ART and why I should and I really understood all that was taught so then I made up my mind.”*

### **Lack of privacy and confidentiality**

The caregivers pointed out that local HCWs lacked confidentiality as they often disclosed the HIV status of their patients to other community members. As a result caregivers would leave one clinic for another in an attempt to gain privacy and confidentiality, often compromising the treatment routine and leading to missed appointments.

**Control Caregiver:** *“There is no privacy, for example in some facilities, there is a place to get your ART and it is outside in the mobile containers so if you go there everyone just know that you are HIV-positive.”*

**Case Caregiver:** *“There was a nurse who used to tell other visiting patients about my status. When I left her room, she would tell the next client that I had come to refill my ART. ”*

**Case Caregiver:** *“My friend said: “we are supposed to go to clinics where they in turn gossip about us?” Then I advised her to change clinics, but she thought nurses were all the same, you would expect that they were taught about confidentiality. I think some nurses need to be educated about confidentiality.”*

**Case Caregiver:** *“It is difficult to take treatment from your local clinic and even the nurses, some of them may be ignorant on issues of confidentiality...”*

## 4. DISCUSSION

This study highlighted several barriers that caregivers face when initiating their HIV-positive children (aged 2-18 months) on ART. Below is a discussion of the findings and recommendations for the way forward.

### 4.1 Individual Factors associated with lack of uptake of ART by HIV Infected children 2-18 months

#### Socio-demographic Factors

Case- and control-caregivers were similar on nearly all sociodemographic factors, indicating that the caregiver's sex, age, region of residence, religion, marital status, education level, employment status, and income were not factors associated with initiating a child on ART. For cases and controls combined, most caregivers were from Manzini region, followed by Hhohho, Lubombo and Shiselweni (38%, 27%, 25%, 10%, respectively), an observation which follows the regional HIV disease burden, therefore something to be expected<sup>2</sup>.

#### Access to Healthcare

Physical access to healthcare was also not a sufficient barrier to initiating children on ART, as control-caregivers were found to still travel the distance needed to initiate their child on ART, be it for logistic or personal factors; however the findings also showed that caregivers that have moved since the time of the child's HIV test were less likely to initiate ART.

Although both case- and control-caregivers reported that the limitations to accessing care was based on lack of money and distance to the facility, caregivers that lived less than 30 minutes from their nearest facility were 4 times more likely to not initiate their child on ART, compared to caregivers who lived 60 minutes or more from the clinic. From the focus group discussions, caregivers further explained that the difficulty with seeking treatment at their local healthcare facilities as compared to facilities that are further away is due to privacy concerns or unavailability of Paediatric ART services.

Interestingly, caregivers that reported "No limitations" to accessing care were 2.73 times more likely to not initiate their child on ART. This suggests that the physical barriers to accessing care are minimal, and other factors may play a greater role in a child's ART initiation, such as stigma and discrimination, provider attitudes or non-disclosure to partners as explained in the FGD.

#### Health seeking behaviours

Some health seeking behaviours were associated with ART initiation. Caregivers that kept their own appointments were nearly three times more likely to initiate their child on ART compared to caregivers that did not always keep their appointments (CI: 1.18 - 7.16). In addition, children who were only taken to a healthcare facility when they were sick were five times more likely to have not been initiated on ART compared to children who attended the facility at least once per month (CI: 1.80 - 14.35). Furthermore, as a more reliable proxy for

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<sup>2</sup> The extended national strategic framework for HIV 2014-2018

children's healthcare visits from birth to 18 months, children who had received their 6, 9, 12, and 18 month immunizations were 3-9 times more likely (3-5 times more likely, when controlled for the mortality; see Table 8) to have initiated on ART compared to children who had not received their immunizations. Although not statistically significant, greater proportion of case-caregivers (61%) were on ART during pregnancy compared to control-caregivers (48%) but are less likely to adhere to treatment (85% vs 94%).

Finally, the primary reason for not initiating the child on ART, as reported by case-caregivers, was due the child's death prior. However, the cause of death was not clear, nor the lag time between diagnosis and time of death. This could have been due to arriving at the facility very late in disease progression, only once the child was very sick, with multiple OI's including TB, resulting in the child not being able to initiate ART before they passed away.

### **Maternal health behaviours**

Some maternal health behaviours were also risk factors for not initiating a child on ART. Among the mothers who participated in the study, only 16% of case- and 25% of control-mothers reported having planned their pregnancy; yet, only 31% of case- and 24% of control-mothers were using contraception at the time of the pregnancy. This was re-iterated through the FGDs where the majority of women reported that their pregnancies were not planned, that they were not using contraception, and that their unplanned pregnancies resulted in their late first ANC visit. These findings are not new, as the unmet need among pregnant women living with HIV was 66% in 2010<sup>3</sup>. This suggests a need for improved contraception education for all women of reproductive age especially during; prenatal care, ANC, routine treatment refills and post-natal care.

Teenage pregnancy was also highlighted in the FGD as a potential perceived risk factor for not initiating a child on ART. It was perceived that with teenage mothers are not ready for the responsibility of being a parent, let alone a parent of an HIV-positive child.

Furthermore, mothers who consumed alcohol during pregnancy were 4 times more likely to not initiate their children on ART compared to women who did not drink alcohol during pregnancy.

In general women in Swaziland would benefit from comprehensive education on health and sexuality. The Ministry of Education and Training is rolling out its new Life Skills Education Programme in conjunction with the Ministry of Health which includes a comprehensive sexuality education component which will be a great source of sexual health education for in school youth. The introduction of the Life Skills curriculum into secondary schools and development of a similar curriculum for primary school learners should be accelerated.

With respect to teenage pregnancy, HCWs need to be educated on the provision of youth friendly services, an initiative that the Sexual and Reproductive Health Unit (SRHU), and this should be coupled with and the integration of family planning into these services. Contraception should be available to youth 12 years of age and older, to be harmonized with the new age of consent for HIV testing<sup>4</sup>. The National Policy on Sexual and

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<sup>3</sup> Swaziland Multiple Cluster Indicator survey (MICS) 2014

<sup>4</sup> 2015 National Integrated HIV Management Guidelines



Reproductive Health states that comprehensive education, information, and services shall be provided to all children, adolescents, and young people; however, there is no documentation regarding to age of the youth for access to contraception, it is recommended that this is updated upon the next revision of this document. A recommendation for future research would be to focus on young mothers, as this study was unable to capture the complexities of this issue.

#### **4.2 Interpersonal factors associated with lack of uptake of ART by HIV Infected children 2-18 months**

Interpersonal factors were highlighted as one of the biggest barriers to caregivers initiating their children on ART.

##### **Relationship with Health Care Providers**

A client's relationship with a healthcare worker may have many implications for client satisfaction and retention, especially when a patient is HIV-positive, and pregnant. Although the confidence interval was quite wide (2-169), caregivers who had a "very poor or poor" relationship with their healthcare provider (doctor or nurse) were 17 times more likely to not initiate their child on ART compared to caregivers who reported having an "excellent or good" relationship with their healthcare provider. Although quantitative data suggests that there are only issues at one facility, only 11 of 183 facilities in the country were observed in this study, and attitudes and behaviours of health care workers should be observed more closely at all facilities. Focus group discussions further reiterated and elaborated on many issues experienced by both case- and control-caregivers at health facilities, reporting that they are "treated like idiots", "nurses are rude", and that "nurses need to be educated about confidentiality". Case-caregivers reported that when you are ill-treated by a HCW, you are demotivated to come back to the facility, for your own care or for your child's care, and that you will decide to stay home with the child, or choose to go to another facility (leading to LTFU, if the patient is not transferred properly). It was also reported that caregivers are reluctant to attend the facility once they have missed an appointment for fear of reprimand and rough treatment by HCWs. A healthcare facility should be cognisant of a patient's right charter, and the importance of customer care and the difference between being firm and being disrespectful<sup>5</sup>

A perceived lack of privacy and confidentiality by health care providers was mentioned as a barrier to ART initiation and they preferred attending a facility where the health care provider does not know the client or any of their family or friends. This echoes the previous finding that patients prefer to seek care at a facility that is further away to ensure privacy while accessing health services.

##### **Support groups**

Support groups are a place where caregivers with HIV-positive children can get together and discuss challenges and to simply have someone to talk to who is going through the same situation (peer support). Although there

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<sup>5</sup> The MOH Rights of a patient charter

was no difference between case- and control-caregivers, the majority of caregivers said there were not any support groups available, or that they did not know if there were support groups available for parents of a child living with HIV (91% of case-caregivers, 78% of control caregivers). This sheds light on a need within the country, for more support groups working with HIV-positive mothers, and families of HIV-positive children.

### **Disclosure, Stigma and Discrimination**

This study highlighted the issues that still exist in Swaziland regarding disclosure of ones HIV status. Again, although there was no difference between the proportions of case- and control-caregivers that had disclosed their HIV status to *someone*, less than two-thirds of all caregivers disclosed their HIV status to their partner. Non-disclosure to partners was greatly emphasized through the FGDs, and case-caregivers reported that they had not disclosed their HIV status because they were afraid to lose their partner or that they would be stigmatized. It was also clear that in some relationships, both partners keep their HIV status from one another, with one case-caregiver stating that “since we were in love we never told each other about our HIV status”.

During the FGDs, case-caregivers recommended greater male involvement to aid in initiation of a child on ART. It was suggested that men need to be involved from the beginning of the initiation process and disclosure of the mother’s HIV status should be facilitated by the nurses so that the father may also be educated on the child’s HIV status and can assist with the child’s ART enrolment.

Disclosure to other family members was also quite low, with only 43% of case- and 51% of control-caregivers disclosing their HIV status to their mother, who was likely to be taking care of the child when the biological mother was not available. Through FGDs, case-caregivers also emphasized that they did not disclose their HIV status to their family and their mothers even when they were the child’s primary caregiver. As a result of non-disclosure to family members, immediate compulsions of a caregiver to maintain secrecy regarding their own HIV status could outweigh obligations for the child to be initiated and retained on ART.

Disclosure issues all relate back to the fear of discrimination and stigma. Although few caregivers reported experiencing stigma and discrimination through the interviews, strong messages were relayed in the FGDs, indicating that stigma and discrimination are major issues in Swaziland. Caregivers reported they are regarded as promiscuous, and they are isolated from their community. With the education that has been done, stigma and discrimination remain a challenge in Swaziland.

### **4.3 Organizational factors associated with lack of uptake of ART by HIV Infected children 2-18 months**

#### **Loss To Follow Up of clients at the Facility**

One of the major findings from this study is that majority of the caregivers were not reachable with contact information available in routine facility registers, with 59% of the cases and 45% of the controls not successfully contacted. The main reasons were that caregivers were not available (41%), it was a wrong number (22%), or there was no contact information available at the clinic-level (21%).

### **Caregivers understanding of the HIV diagnosis and ART enrolment process**

One of the primary reasons provided for not initiating the child on ART was that the caregiver did not understand the ART enrolment process, or that the nurse did not explain what was needed in order to initiate the child. However, there was no difference between cases and controls regarding the time spent explaining the child's HIV test results, which could imply that the current pre-ART counselling process is not entirely effective or consistent and certain caregivers may need more time to complete the process. Similarly, when asked if they think it is important to enrol HIV-positive children on ART, only 38% of case caregivers reported that they strongly agreed. This could be due to the caregiver not being aware of the benefits of early ART initiation, and not being fully educated on what is needed for the child when they are found to be HIV-positive. Finally, nearly one in four caregivers reported they did not initiate their child because they reported the child was not sick, and through FGDs, it was clear that some cases were in denial of their child's HIV status. In this study, denial and lack of awareness of benefits of early initiation in children led to some instances of delayed presentation at the facility, and it is well known that the risk of mortality increases exponentially every year a HIV-positive child is not initiated on ART (Newell et al, Lancet 2014).

### **Long waiting times**

Long waiting times at the facility were highlighted by both case- and control-caregivers as a barrier to accessing care. Caregivers reported that they would arrive at the facility at 6 or 7 am only to spend the better part of the day waiting to receive care. These long waiting times are some of the reasons that mothers send their children with other caregivers while they head back to work. Although there was no difference between case- and control- caregivers regarding waiting times, keeping children and mothers together in care can help improve survival rates among HIV positive women and their children. Thus, reducing waiting times would be a significant improvement for many mothers and caregivers attending healthcare facilities for a variety of health services.

### **4.4 Limitations**

There could have been a bias with sampling of caregivers in that the study team was only able to contact 41% of case- and 59% of control-caregivers. However, this would have resulted in a non-differential misclassification as there is no reason to believe that the cause of a caregiver not being contacted (wrong number, out of range, not in service) would be related to their case or control status. In addition to sampling bias, a potential participation bias could have occurred, in that, of those contacted 76% of case- and 88% of control-caregivers agreed to participate in the study. This could result in a bias if the cases that chose to participate in the study were different from those who refused to participate. However, there were only 10% of controls that declined to participate in the study, the others were simply not available to participate at the time of data collection so the study team believes that this should not have affected the results of this study.

When interviewing human subjects, there is always a risk of social desirability bias, where caregivers may have responded with what they thought the interviewer wanted to hear. The study team strived to reduce this bias

by assuring that the information collected was anonymous. Similarly, they may have been a risk of recall bias considering the time lapse between positive DBS results and time of the study; however the interviewers used more probe questions among the caregivers to minimize this. In addition, the study team decided to correct for potential misclassification by dropping the 29 caregiver interviews where the clients ART status could not be confirmed, as the team expected that self-reporting ART initiation was likely a product of social desirability.

In addition, as with all qualitative research, the role of the facilitators is a source of potential bias as they could potentially lead the discussion and the responses. However, facilitators were trained in focus group methods before the study in an attempt to mitigate undue influence by moderators on participant responses. While focus groups are useful for understanding community attitudes, a certain inevitable amount of bias occurs through group dynamics. Caregivers may be reluctant to voice opposing views, or the most assertive participant may disproportionately affect the results. It is also important to note that though the study had a 4<sup>th</sup> objective on *quantifying the losses of HIV-positive infants along each point of the continuum of paediatric HIV care from DNA PCR sample collection to ART initiation*; data was not able to be collected to analyse it appropriately, thus it was omitted from the final results. Though it make the study requirements, due to the small number cases (those who did not initiate) some analyses could not be made

Despite such limitations, this study not only shed light on the barriers to ART initiation among children age 2-18 months but also provided suggestions to improve access to ART for caregivers of HIV-positive children in Swaziland.

## 5. CONCLUSIONS & RECOMMENDATIONS

In conclusion, different factors at individual; interpersonal and organizational level play a major role in the decision to initiate a child on ART. This study highlighted that the biggest barriers to ART initiation among children aged 2-18 months were in relation to behaviour and attitudes among both HCW and clients/caregivers (such as issues lack of disclosure of one's HIV status, stigma and discrimination (self; and communal), irregular attendance at health care facilities) rather than the barriers being related to services availability (such as access to care, and sociodemographic factors). Although physical access to healthcare was not a sufficient barrier to initiating children on ART, as control-caregivers were found to still travel the long distance needed to initiate their child on ART, be it for logistic or personal factors; the findings also showed that caregivers that have moved since the time of the child's HIV test were four times less likely to initiate ART. The high unmet need of FP reported in this study suggests a need for improved contraception education for all women of reproductive age especially during; prenatal care, ANC, routine treatment refills and post-natal care. Interpersonal factors were highlighted as one of the biggest barriers to caregivers initiating their children on ART. A client's relationship with a healthcare worker may have many implications for client satisfaction and retention, especially when a patient is HIV-positive, and pregnant. A healthcare facility should be cognisant of a patient's right charter, and the importance of customer care and the difference between being firm and being disrespectful. Nearly one in four caregivers reported that they did not initiate their child because they reported the child was not sick, and through FGDs, it was clear that some cases were in denial of their child's HIV status. In this study, denial and lack of awareness of benefits of early initiation in children led to some instances of delayed presentation at the facility, and it is well known that the risk of mortality increases exponentially every year a HIV-positive child is not initiated on ART. Long waiting times at the facility were highlighted by both case- and control-caregivers as a barrier to accessing care. Caregivers reported that they would arrive at the facility at 6 or 7 am only to spend the better part of the day waiting to receive care.

Despite such limitations, this study not only shed light on the barriers to ART initiation among children age 2-18 months but also provided suggestions to improve access to ART for caregivers of HIV-positive children in Swaziland. The recommendations are as follows:

### **Individual Factors associated with lack of uptake of ART by HIV Infected children 2-18 months**

1. Caregivers and children should be actively followed-up by HCWs who should ensure that clients who have not received care at their facility are enrolled in care at another facility.
2. A clear SOP must be in place, a suggestion is to incorporate an active case finding of children who have tested DNA PCR positive into the country's EID SOP that is already in existence.
3. When early ART initiation is done; HCWs should ascertain if client will be moving and transfer the patient appropriately if they will be moving, to enhance improved access and adherence to treatment.
4. Similarly all DBS positive patients should tracked/followed up, even if they have moved.

5. As per the Child Protection and Welfare Act of 2012, if the caregiver is not providing the child with appropriate care including delayed HIV testing and treatment, a social worker needs to get involved in order to assign a second primary caregiver. MOH need to strengthen/reinforce the role of social workers in implementing the Children Protection and Welfare ACT
6. Given the high proportion of unplanned pregnancies and the low proportion of contraception use among caregivers, family planning-HIV integration should be strengthened. Whether the integration be “same-room” or “same-roof”, this can include both long-term and short-term methods. For example, injectable FP methods and ARVs can be offered in the same-room, while IUDs and ARVs could be offered under the same-roof.
7. To prevent alcohol consumption during pregnancy, additional education should be provided to women during ANC visits about the risks of alcohol consumption.

### **Interpersonal factors associated with lack of uptake of ART by HIV Infected children 2-18 months**

1. Customer care needs to be strengthened to objectively deal with difficult situations. A system should be put in place to identify service providers that are negatively impacting customer care.
2. Supervisors should ensure there is a system in place at each facility for patient feedback and follow-up with HCW on issues arising. This may include a suggestion box and/or patient satisfaction surveys.
3. MOH should aim to make facility based support groups available at more facilities and inform clients of the availability of these support groups, as currently support groups are not wide spread across the country’s health facilities. In addition, these support groups should be more structured with positive living tool kits and trained facilitators that can translate into acquisition of life saving behaviours such as adherence, early enrolment on ART, use of FP etc.
4. Disclosure is clearly a major concern in Swaziland and nurses and or social workers should be facilitating disclosure to not only to partners but to family members and other caregivers as well. In general discrimination needs to be addressed at all levels. With respect to the paediatric ART program, PMTCT program mentorship tools mention that “we [HCW] can help you talk to your partner about your HIV status”, however, this should be a strengthened, and support for partner disclosure should be a key role of HCWs. In the event that partners are unwilling to peacefully accept the HIV-status of the caregiver or child, additional support from social workers can be enlisted. HCWs should be provided with the relevant resources and protocols to engage the Department of Social Welfare when needed.
5. With respect to stigma and discrimination, Swaziland as a country needs to improve in its empowerment of people living with HIV to feel comfortable with their status. The positive living campaign has been very strong in other countries in the region. If more public figures were able to come out and promote positive living, it would have drastic implications for all those infected and affected by HIV.

## **Organizational factors associated with lack of uptake of ART by HIV Infected children 2-18 months**

- 1.** To reduce loss To Follow Up of clients at the Facility, facilities are encouraged to improve documentation of client contact information. Every client should have an active phone number(s) where they can be contacted documented in all the relevant facility-based tools (e.g. Under 5 register, DNA PCR logbook, chronic care file, etc.). At each follow-up visit, the HCW should confirm that the contact information has not changed and in the event of a change, document any updates, and potentially even call the client to ensure that the information given was correct. This is particularly important for any child getting a DBS where we know we will need to contact the caregiver with the results. In addition, alternative methods of contacting caregivers should be investigated.
- 2.** When delivering the child's HIV test results, the counselling process should involve not only the HCW simply telling caregivers what is required for the ART initiation process, but also having the HCW ensure that the caregiver understands the process. This could be done by having the caregiver have an interactive discussion with the client where reflective listening ensures complete understanding. This education could be enhanced by the development and implementation of new job aids. These job aids can address the importance of starting an HIV positive child on ART as soon as possible, that not every child show HIV symptoms, and if the child isn't showing symptoms it doesn't mean the child is not sick. The newly updated Early Infant Diagnosis Standard Operating Procedures document<sup>6</sup> provides clear messages on how and what to counsel the caregiver on when their child tests positive. Nurses should be trained on the messages provided in this document, and are encouraged to seek guidance when counselling caregivers on HIV education and ART initiation at PNC visits.
- 3.** To reduce on the long waiting times, the MOH is strengthening attendance of mothers at health facilities with their children through the introduction of Mother Baby Pair services and approach to care. The purpose of this initiative is to reduce the waiting time, and the number of queues that a mother has to join before receiving care for herself and her baby. This approach will be rolled out nationally throughout 2016. Strengthening and supporting the Mother Baby Pair (MBP) services, and conducting operational assessments periodically to determine the successes and challenges to the program may address the long waiting times.
- 4.** Increase sensitization of caregivers through morning health education sessions at the clinics and conduct a time-in-motion study to determine the benefits of offering services together for both the caregiver and healthcare provider to aid monitor this process.

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<sup>6</sup> National Early Infant Diagnosis Standard Operating Procedures 2015

## Recommendations from caregivers

During the FGDs, the respondents shared some recommendations to decrease the barriers to ART initiation among children in Swaziland.

### Education and counselling

The caregivers stressed the need to invest in counselling for primary caregivers of the children who are eligible for or on ART. **Case Caregiver:** *“When we get time, we should also attend the health education talks in clinics. They greatly help. I go there every day.”*

**Case Caregiver:** *“I think there is need to invest in counselling for primary caregivers of the children. They need to be aware of everything related to management of the child and the treatment related matters”*

### Male involvement

Caregivers also expressed the importance of including partners in the provision of healthcare services. For instance, they recommended that the clinics invite the partners of pregnant women so that both could be educated on the importance of ART and HIV in general. Asking the Rural Health Motivators to visit homes to educate men on the issues of ART was also presented as a way to improve access to ART for the parents and the child.

**Case Caregiver:** *“It would be good if the man would be invited to come to the facility before the child is initiated and have everything explained, so that they can understand the issues involved here. So long as I do things secretly, it will be difficult for the child to be adherent, especially if I visit my partner at his place.”*

**Case Caregiver:** *“At the very least, we could have the Rural Health Motivators visit our homes to educate our men on these issues.”*

**Case Caregiver:** *“I think when you are pregnant, nurses must make it a point to check if you have disclosed to your partner. If not, then they need to facilitate that process and further educate both of you. When the child gets tested, we should be encouraged to come together for results. We need to involve men from the beginning.”*

### Disclosure counselling

In terms of disclosure, the caregivers recommended that the nurses should ensure that all pregnant women disclose their HIV status to their partners by facilitating the process and further educating both partners.

**Case Caregiver:** *“I advise you that you request the nurses to facilitate the disclosure process for you. [...] That’s what I did with my sister when she was scared to tell my mother that her child is positive. They helped explain everything even that the child will have to start TB treatment.”*

### Enforce confidentiality and privacy

Caregivers in the discussions also underlined that the nurses needed to be trained on issues of confidentiality and customer care at the facility. One participant recommended that ART should be provided in consultation



rooms in order to promote privacy and confidentiality of treatment. Respondents regarded privacy and confidentiality as paramount in the daily service provision routines.

**Case Caregiver:** *“It would be advantageous if we refilled our medication from the nurses consultation rooms as well; so that when you get into the nurses’ consultation room, you will get your package there as well and simply go home.”*

### **Following up on patients and reminding them of their appointment**

Some respondents highlighted that receiving follow-up calls from healthcare workers would be really helpful.

**Case Caregiver:** *“Is there a way the facility can make follow-ups on patients and children? Especially if you were supposed to come back for an appointment and you don’t show up. If they can call and find out the reasons why you couldn’t attend your appointments. Like in my case, if someone called to find out why I couldn’t bring the baby for initiation on the agreed date. Because you find that some are short of money to return, then ways of helping that person can be sought.”*

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# ANNEX 1: STUDY QUESTIONNAIRE:

**TITLE OF RESEARCH: Understanding the Barriers to ART initiation for HIV positive Children 2-18 months of age in Swaziland**

Original Date (mm/dd/yyyy):	Date Revised (mm/dd/yyyy):
ID Code:	Investigator:

All questions contained in this questionnaire are strictly confidential

<b>SECTION I. MOTHER/CAREGIVER SOCIO-DEMOGRAPHIC BACKGROUND</b>	
1. Are you the primary caregiver of the child?	<input type="checkbox"/> Yes <input type="checkbox"/> No
2. What is your relationship with the child?	<input type="checkbox"/> Biological Mother <input type="checkbox"/> Grandparent <input type="checkbox"/> Biological Father <input type="checkbox"/> Guardian/Caretaker <input type="checkbox"/> Other, specify: _____
3. Date of birth (dd/mm/yyyy):	_____/_____/_____
4. Age:	<input type="checkbox"/> < 19 <input type="checkbox"/> 30 – 34 <input type="checkbox"/> 20 – 24 <input type="checkbox"/> 35 – 39 <input type="checkbox"/> 25 – 29 <input type="checkbox"/> > 39
5. Sex:	<input type="checkbox"/> Female <input type="checkbox"/> Male
6. In what region do you live now?	<input type="checkbox"/> Hhohho <input type="checkbox"/> Manzini <input type="checkbox"/> Lubombo <input type="checkbox"/> Shiselweni
7. What is the name of the community in which you live?	_____
8. What is your marital status?	<input type="checkbox"/> Single <input type="checkbox"/> Widowed <input type="checkbox"/> Married <input type="checkbox"/> Cohabiting <input type="checkbox"/> Other, specify: _____
9. Religion:	<input type="checkbox"/> Christian <input type="checkbox"/> Muslim <input type="checkbox"/> Zionist <input type="checkbox"/> Traditional <input type="checkbox"/> Other, specify: _____
10. How many children do you care for?	_____
11. Number of people living in your household (include yourself):	<input type="checkbox"/> 1 – 2 <input type="checkbox"/> 3 – 4 <input type="checkbox"/> 5 – 6 <input type="checkbox"/> > 6
12. How many children (aged 0 to 17 years) live in your household?	<input type="checkbox"/> 0 <input type="checkbox"/> 5 – 6 <input type="checkbox"/> 1 – 2 <input type="checkbox"/> > 6 <input type="checkbox"/> 3 – 4
13. What ages does your child(ren) fall?	<input type="checkbox"/> 0 – 2 years <input type="checkbox"/> 6 – 10 years <input type="checkbox"/> 3 – 5 years <input type="checkbox"/> 11 - 17
14. How would you describe your living situation?	<input type="checkbox"/> Own Home <input type="checkbox"/> Rent <input type="checkbox"/> Live with other family/friend <input type="checkbox"/> Other, specify: _____
15. What is the main material that your home is made of?	<input type="checkbox"/> Stick and Mud <input type="checkbox"/> Wood <input type="checkbox"/> Cement <input type="checkbox"/> Stones <input type="checkbox"/> Other, specify: _____

16. What is the main material that the floor in your home is made of?	<input type="checkbox"/> Cement <input type="checkbox"/> Cow dung <input type="checkbox"/> Dirt	<input type="checkbox"/> Tiles <input type="checkbox"/> Wood <input type="checkbox"/> Other, specify: _____
17. Please indicate what energy source you use for cooking.	<input type="checkbox"/> Wood <input type="checkbox"/> Gas <input type="checkbox"/> Electricity	<input type="checkbox"/> Coal <input type="checkbox"/> Kerosene <input type="checkbox"/> Other, specify: _____
18. Please check all the service(s) you have within your household.	<input type="checkbox"/> Water Supply <input type="checkbox"/> Electricity <input type="checkbox"/> Television <input type="checkbox"/> Washer	<input type="checkbox"/> Radio <input type="checkbox"/> Refrigerator <input type="checkbox"/> Water heater <input type="checkbox"/> Other, specify: _____
19. What is the principal sanitary system used by your household members?	<input type="checkbox"/> Flushing Toilet <input type="checkbox"/> Pit Latrine <input type="checkbox"/> None <input type="checkbox"/> Other, specify: _____	
20. What is the principal garbage disposal system used by your household members?	<input type="checkbox"/> Open dumping <input type="checkbox"/> Burning <input type="checkbox"/> Truck collects it (Municipal) <input type="checkbox"/> Burial <input type="checkbox"/> Other, specify: _____	
21. What is your highest level of education completed? Check one.	<input type="checkbox"/> Primary <input type="checkbox"/> Secondary <input type="checkbox"/> Vocational <input type="checkbox"/> Tertiary (University, Technical) <input type="checkbox"/> I did not attend school	
22. What is your current employment status?	<input type="checkbox"/> Employed <input type="checkbox"/> Self-Employed <input type="checkbox"/> Partially Employed <input type="checkbox"/> Unemployed (if selected, skip to question 25)	
23. What is your occupation? Check all that apply.	<input type="checkbox"/> Laborer (housekeeper, vender, field worker) <input type="checkbox"/> Skilled worker (weaver, painter, mechanic) <input type="checkbox"/> Clerical <input type="checkbox"/> Professional (doctor, nurse, teacher) <input type="checkbox"/> Own business <input type="checkbox"/> Other, specify: _____	
24. If employed, what is your monthly income?	<input type="checkbox"/> < E500 <input type="checkbox"/> E500 – 1200 <input type="checkbox"/> E1201 – 3300 <input type="checkbox"/> > E3300 <input type="checkbox"/> I am not employed	
25. If not employed, what is your source of income? Check all that apply. Skip question if employed.	<input type="checkbox"/> Social grants <input type="checkbox"/> Partner <input type="checkbox"/> Other, specify: _____	<input type="checkbox"/> Family <input type="checkbox"/> Church

26. Please list all family members who work and contribute to your household, their occupation, and monthly income.

Relation to infant	Occupation	Monthly Income

**SECTION II. MOTHER/CAREGIVER INFORMATION**

**Interpersonal Factors/Social Support**

27. Does your child receive financial support from other family members/relatives?	<input type="checkbox"/> Yes <input type="checkbox"/> No (if selected, skip to question 29)
28. List all family members (including yourself) who provide financial support for your child by the relationship he/she has with the child (e.g. grandmother, father, mother).	
29. Do you receive additional support (financial, food) for your child's care (e.g. ministry, community, church, other)?	<input type="checkbox"/> Yes <input type="checkbox"/> No (if selected, skip to question 31)
30. What is your source of additional support or your child?	<input type="checkbox"/> Ministry <input type="checkbox"/> Community <input type="checkbox"/> Church <input type="checkbox"/> Other, specify: _____
31. Do you attend religious services regularly?	<input type="checkbox"/> Yes <input type="checkbox"/> No
32. Is your religious affiliation accepting of HIV positive individuals?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I do not have a religious faith
33. Does your religious affiliation have a negative view on HIV/AIDS?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I do not have a religious faith
34. Are HIV support groups available in your community?	<input type="checkbox"/> Yes <input type="checkbox"/> No (if selected, skip to questions 38)
35. Do you attend HIV support groups?	<input type="checkbox"/> Yes <input type="checkbox"/> No
36. What kind of support do you receive in your HIV support group(s)? Check all that apply.	<input type="checkbox"/> Educational/Preventive <input type="checkbox"/> Financial <input type="checkbox"/> Food/Nutritional <input type="checkbox"/> Emotional Support/Counseling <input type="checkbox"/> Other, specify: _____
37. Do you find the support group(s) helpful?	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>Maternal HIV Status</b>	
38. If you are HIV-positive, when were you diagnosed (mm/yyyy)?	Month/Year: ____/_____ <input type="checkbox"/> I am not HIV-positive (if selected, skip to question 46)
39. Please indicate your last CD4 Count (if applicable).	<input type="checkbox"/> Less than 350 cells/mm3 <input type="checkbox"/> 350 – 499 cells/mm3 <input type="checkbox"/> 500 – 1000 cells/mm3 <input type="checkbox"/> more than 1000 cells/mm3 <input type="checkbox"/> Unknown
40. Do you take any medications to treat HIV (antiretroviral therapy)?	<input type="checkbox"/> Yes <input type="checkbox"/> No
41. If you are on antiretroviral therapy (ART), have you ever experienced side effects?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I am not on ART
42. Did you take any HIV medications during your pregnancy (e.g. ART prophylaxis)?	<input type="checkbox"/> Yes <input type="checkbox"/> No
43. Have you disclosed your HIV status to your family member(s)?	<input type="checkbox"/> Yes <input type="checkbox"/> No (if selected, skip question to 45)
44. Are your family member(s)	<input type="checkbox"/> Yes

accepting of your HIV status?	<input type="checkbox"/> No	
45. Have you ever felt isolated, discriminated against, or stigmatized based on your HIV status?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
<b>Barriers for health care</b>		
46. How long does it take you to get to the nearest clinic that can provide you with care?	<input type="checkbox"/> ≤ 30 minutes <input type="checkbox"/> 31 – 60 minutes <input type="checkbox"/> > 60	
47. What mode of transportation do you usually use to get to the clinic/hospital?	<input type="checkbox"/> Own car <input type="checkbox"/> Borrowed car <input type="checkbox"/> Taxi <input type="checkbox"/> Other, specify: _____	<input type="checkbox"/> Public Transportation <input type="checkbox"/> Hitch <input type="checkbox"/> Walk
48. Please estimate the average cost for each item when you visit the clinic.	E _____ Food E _____ Transport E _____ Co-Pay E _____ Other, specify: _____	
49. Please mark all the following barriers that limit your access to health care.		
	Yes	No
Distance of health facility	<input type="checkbox"/>	<input type="checkbox"/>
Getting money for transport to clinic/health facility	<input type="checkbox"/>	<input type="checkbox"/>
Concern that there may be no medication available	<input type="checkbox"/>	<input type="checkbox"/>
Not wanting to go alone	<input type="checkbox"/>	<input type="checkbox"/>
Healthcare provider may not be available	<input type="checkbox"/>	<input type="checkbox"/>
Not having a female healthcare provider	<input type="checkbox"/>	<input type="checkbox"/>
Stigma (fear of disclosure of HIV status)	<input type="checkbox"/>	<input type="checkbox"/>
Permission from partner	<input type="checkbox"/>	<input type="checkbox"/>
Non-disclosure to partner	<input type="checkbox"/>	<input type="checkbox"/>
Other, please specify: _____	<input type="checkbox"/>	<input type="checkbox"/>
<b>Quality of Health Services</b>		
50. Are you aware of the services available for your HIV-positive child?	<input type="checkbox"/> Yes <input type="checkbox"/> No (if selected, skip to question 52)	
51. How would you describe the availability of services for your HIV-positive child?	Excellent    Good    Average    Poor    Very Poor	
52. Are you aware of the drugs for your HIV-positive child?	<input type="checkbox"/> Yes <input type="checkbox"/> No (if selected, skip question 54)	
53. How would you describe drug availability for your HIV-positive child? Circle one.	Excellent    Good    Average    Poor    Very Poor	
54. How would you rate the relationship between you and your healthcare provider (e.g. doctor, nurse)? Circle one.	Excellent    Good    Average    Poor    Very Poor	
55. How would you rate the relationship between you and other clinic staff (e.g. receptionist)? Circle one.	Excellent    Good    Average    Poor    Very Poor	
<b>Health-Seeking Behaviours</b>		
56. Do you have any health condition(s)? Check all that apply.	<input type="checkbox"/> None <input type="checkbox"/> Diabetes (Sugar) <input type="checkbox"/> Cancer <input type="checkbox"/> Anxiety/Depression <input type="checkbox"/> Hypertension (high blood pressure) <input type="checkbox"/> Tuberculosis <input type="checkbox"/> Other(s), specify: _____	
57. How often do you use or attend a health care	<input type="checkbox"/> Never	

facility?	<input type="checkbox"/> Once a month <input type="checkbox"/> Once every two months <input type="checkbox"/> Once every three months <input type="checkbox"/> Once every six months <input type="checkbox"/> Once a year <input type="checkbox"/> Other, specify: _____
58. What hospital(s)/clinic(s) do you attend? Check all that apply.	<input type="checkbox"/> Baylor Clinic <input type="checkbox"/> Good Shepherd Hospital <input type="checkbox"/> King Sobuza II (KS II) Clinic <input type="checkbox"/> Matsapha MSF Clinic <input type="checkbox"/> Nhlangano PHU <input type="checkbox"/> Luyengo Clinic <input type="checkbox"/> Lobamba Clinic <input type="checkbox"/> Siphofaneni Clinic <input type="checkbox"/> Horo Clinic <input type="checkbox"/> Other(s), specify: _____
59. When was the last time you attended the clinic/hospital (mm/yyyy)?	_____ / _____
<b>SECTION III. MATERNAL HEALTH</b>	
<i>Only to be answered by the biological mother of the HIV-positive child of interest.</i>	
<b>Substance use (Alcohol, smoking, homebrew, others)</b>	
60. Do you use alcohol (or homebrew)?	<input type="checkbox"/> Yes <input type="checkbox"/> No (if selected, skip to question 62)
61. How often do you drink alcohol or homebrew?	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Other, specify: _____
62. Did you drink during your pregnancy with the child?	<input type="checkbox"/> Yes <input type="checkbox"/> No (if selected, skip to question 64)
63. How often do you drink alcohol or homebrew while pregnant with the child?	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Other, specify: _____
64. How often do you smoke?	<input type="checkbox"/> Never <input type="checkbox"/> Occasionally <input type="checkbox"/> Regularly
65. Did you smoke during your pregnancy with the child?	<input type="checkbox"/> Yes <input type="checkbox"/> No (if selected, skip to question 67)
66. How often did you smoke during your pregnancy with the child?	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Other, specify: _____
67. Do you use marijuana or other addictive substances?	<input type="checkbox"/> Yes <input type="checkbox"/> No (if selected, skip to question 69)
68. How often do you use these drugs?	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Other, specify: _____
69. Did you use any addictive substances during your pregnancy with the child?	<input type="checkbox"/> Yes <input type="checkbox"/> No (if selected, skip to question 71)
70. How often did you use these drugs during your pregnancy with the child?	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Monthly <input type="checkbox"/> Other, specify: _____

### Personal Health and Reproductive Practices

71. Do you have any health condition(s)? Check all that apply.	<input type="checkbox"/> None <input type="checkbox"/> Diabetes (Sugar) <input type="checkbox"/> Cancer <input type="checkbox"/> Anxiety/Depression <input type="checkbox"/> Hypertension (high blood pressure) <input type="checkbox"/> Tuberculosis <input type="checkbox"/> Other(s), specify:
72. During your pregnancy with the HIV-positive child, how many times did you attend antenatal care?	<input type="checkbox"/> 0 <span style="margin-left: 300px;"><input type="checkbox"/> 5 – 8</span> <input type="checkbox"/> 1 – 2 <span style="margin-left: 250px;"><input type="checkbox"/> &gt; 8</span> <input type="checkbox"/> 3 – 4
73. How far along were you in your pregnancy when you had your first antenatal care visit for the child? Check one.	<input type="checkbox"/> First trimester (1-12 weeks) <input type="checkbox"/> Second trimester (13-28 weeks) <input type="checkbox"/> Third trimester (29-40 weeks) <input type="checkbox"/> None/Visited at labor
74. Was your infant planned?	<input type="checkbox"/> Yes <b>(if selected, skip to question 78)</b> <input type="checkbox"/> No
75. Were you using contraceptives when you conceived the child?	<input type="checkbox"/> Yes <input type="checkbox"/> No
76. Have you ever been the victim of sexual violence?	<input type="checkbox"/> Yes <input type="checkbox"/> No <b>(if selected, skip to question 78)</b>
77. Was your HIV-positive child conceived as a result of a sexual violence act?	<input type="checkbox"/> Yes <input type="checkbox"/> No

### SECTION IV. CHILD HEALTH INFORMATION

78. How often do you take your child to the clinic?	<input type="checkbox"/> Never <input type="checkbox"/> Every three months <input type="checkbox"/> Every six months <input type="checkbox"/> Once a year <input type="checkbox"/> Other, specify: _____
79. Did you ever receive your child's HIV test results?	<input type="checkbox"/> Yes <input type="checkbox"/> No <b>(if selected, skip to question 84)</b>
80. How were you given your child's HIV test results? Check all that apply.	<input type="checkbox"/> By appointment at the clinic <input type="checkbox"/> I never received the results <input type="checkbox"/> Other, specify: _____
81. How much time was spent explaining your infant's results?	<input type="checkbox"/> < 10 minutes <span style="margin-left: 150px;"><input type="checkbox"/> 21 - 30 minutes</span> <input type="checkbox"/> 10 - 20 minutes <span style="margin-left: 150px;"><input type="checkbox"/> &gt; 30 minutes</span> <input type="checkbox"/> None, they did not explain
82. How many of your other children have been diagnosed with HIV?	<input type="checkbox"/> 0 <span style="margin-left: 250px;"><input type="checkbox"/> 4</span> <input type="checkbox"/> 1 <span style="margin-left: 250px;"><input type="checkbox"/> &gt; 4</span> <input type="checkbox"/> 2 <span style="margin-left: 250px;"><input type="checkbox"/> I have no other children</span> <input type="checkbox"/> 3
83. How many of your other children are enrolled in antiretroviral therapy (ART)?	<input type="checkbox"/> 0 <span style="margin-left: 250px;"><input type="checkbox"/> 4</span> <input type="checkbox"/> 1 <span style="margin-left: 250px;"><input type="checkbox"/> &gt; 4</span> <input type="checkbox"/> 2 <span style="margin-left: 250px;"><input type="checkbox"/> I have no other children</span> <input type="checkbox"/> 3
84. Has your child received his/her immunizations?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I don't know
85. Is your child up to date on his/her vaccines?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I don't know
86. When was the last time that your child was sick (mm/yyyy)?	Date of last sickness: _____/_____/_____ <input type="checkbox"/> No previous sickness <b>(if selected, skip to question 92)</b>



87. What was your infant's illness/condition (e.g. diarrhea, flu, etc.)?	<input type="checkbox"/> Diarrhea <input type="checkbox"/> Flu <input type="checkbox"/> Measles <input type="checkbox"/> Other, specify: _____	<input type="checkbox"/> Chickenpox <input type="checkbox"/> I don't know
88. Did you take your infant to the clinic/hospital to get health care during his/her last sickness?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
89. Was your infant hospitalized during his/her illness?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
90. If your child was hospitalized, for how long? Check one.	<input type="checkbox"/> Less than one week <input type="checkbox"/> One week <input type="checkbox"/> More than one week	
91. Did your infant receive any treatment (e.g. antibiotics) following his/her illness?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
92. Is your infant enrolled in antiretroviral therapy (ART)?	<input type="checkbox"/> Yes <b>(if selected, skip question 96)</b> <input type="checkbox"/> No <b>(if selected, skip to question 96)</b>	
93. Has your child had any side effects from ART?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
94. Explain your reasons why you decided to enroll your child in ART.	<input type="checkbox"/> The clinic staff explained the benefits of ART <input type="checkbox"/> Advised by family member(s) <input type="checkbox"/> Other, specify: _____	
95. I feel that it is important to enroll my infant in antiretroviral therapy. Circle one.	Strongly Agree   Agree   Neutral   Disagree   Easy   Strongly Disagree	
96. What are some reasons for not enrolling your child in ART? Check all that apply.		
<input type="checkbox"/> Do not have enough money to make clinic visits <input type="checkbox"/> Transportation Barriers (clinics are too far, etc.) <input type="checkbox"/> There may be no medication available <input type="checkbox"/> Health care provider may not be available <input type="checkbox"/> Permission from partner <input type="checkbox"/> Non-disclosure of HIV status to partner <input type="checkbox"/> Child is not sick <input type="checkbox"/> I don't trust HIV medications <input type="checkbox"/> Religious beliefs/practices <input type="checkbox"/> Unaware of ART <input type="checkbox"/> Inadequately informed about ART <input type="checkbox"/> Low quality of health services offered to my child		
<input type="checkbox"/> Fear of disclosure of my child's HIV status <input type="checkbox"/> Fear of disclosure of my own HIV status <input type="checkbox"/> Do not understand the process of ART enrollment <input type="checkbox"/> HIV medications will harm my child <input type="checkbox"/> My child may experience side effects from ART <input type="checkbox"/> Distance of health facility <input type="checkbox"/> Distance of pharmacy for medications <input type="checkbox"/> Healthcare provider may not be available <input type="checkbox"/> Stigma (fear of disclosure of HIV status) <input type="checkbox"/> My age/physical condition <input type="checkbox"/> My health status <input type="checkbox"/> Other(s), specify: _____		

## ANNEX 2: BARRIERS TO ART INITIATION RECRUITMENT CALL SCRIPT

### Barriers to ART Initiation Recruitment Call Script

#### Interviews

Hello, my name is \_\_\_\_\_ (*speak slowly and make sure the participant hears and understands your name*) from (name of clinic you are calling from). I am a research assistant on a study conducted by ..... designed to understand Child Health Care. May I have a few minutes of your time to discuss how you can take part in the study?

*If potential participant agrees, continue with the call script. If not, thank them for their time and call another potential participant.*

We would like to interview the mothers/caregivers about Child Health Care. If you participate in this study, we will reimburse your transportation costs to (provide name and location of clinic). The interview should take about 45 minutes. Are you interested in participating in the research study?

*If potential participant agrees to be interviewed, proceed with the remainder of the call script.*

Are you available any time this week to attend the interview session in (provide name and location of clinic)?

*If participant can come, schedule a time and date for her to come in for the interview. Keep a record of the scheduled interview time. Please emphasize that the participant **must** provide a receipt or ticket documenting their transportation costs. Also, verify the date, time, and location that the participant has agreed to come in to be interviewed before ending the call.*

Please bring your ticket so that I can repay you for your transportation costs to the clinic. So I will see you on (day and date of interview) at (name and location of clinic). Do you have any questions?

Thank you for your time and see you soon. Have a good day.

#### Focus Groups

Hello, my name is \_\_\_\_\_ (*speak slowly and make sure the participant hears and understands your name*) from (name of clinic you are calling from). I am a research assistant on a study conducted by ..... designed to find out reasons for non-enrollment of HIV-positive infants on HIV treatment in Swaziland. May I have a few minutes of your time to discuss how you can take part in the study?

*If potential participant agrees, continue with the call script. If not, thank them for their time and call another potential participant.*

We are looking for caregivers of HIV-positive infants to participate in focus group discussion sessions. The information will be used to improve health programs to increase HIV treatment for infants. If you participate in this study, we will reimburse your transportation costs to (provide name and location of clinic). You will also be provided with snacks during the session which should take about 2 hours. Are you interested in participating in the research study?

*If potential participant agrees to be interviewed, proceed with the remainder of the call script.*

Are you available to attend the focus group session on (day and date of focus group session) at (name of clinic)?

*If participant can come, schedule a time and date for them to come in for the interview. Keep a record of the scheduled interview time. Please emphasize that the participant **must** provide a receipt or ticket documenting their transportation costs. Also, verify the date, time, and location that the participant has agreed to come in to be interviewed before ending the call.*

Please bring your ticket so that you can be paid for your transportation costs to the clinic. So I will see you on (day and date of focus group) at (name and location of clinic). Do you have any questions?

Thank you for your time and see you soon. Have a good day.

