

Access to Prevention of Mother to Child Transmission of HIV-1 Services in Kenya:  
Social and Structural Determinants

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**Abstract**

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**Introduction:** Interventions to prevent mother-to-child transmission (PMTCT) of HIV are remarkably efficacious. However, although PMTCT coverage has increased, there remain gaps between availability of PMTCT services and *uptake* of PMTCT interventions. It is critical to determine modifiable individual, social and programmatic barriers to delivery of PMTCT.

**Methods:** To assess rates and correlates of PMTCT uptake, a cross-sectional community-based survey among women of child-bearing age was performed in the Health Demographic Surveillance System (HDSS) in Nyanza Province, Kenya. Concurrently, a cross-sectional survey assessing service capacity for PMTCT was performed at 40 maternal health facilities in the region.

**Results:** Antenatal care (ANC) attendance was associated with education (OR 6.7; 95%CI 2.0-22.9) and fewer prior pregnancies (OR 0.8; 95%CI 0.7-0.9). Most (87%) women attending ANC

were HIV tested. Maternal HIV testing was associated with better socioeconomic status, partner HIV testing and absence of shame if associated with someone with HIV. Among 216 HIV-seropositive women, 82% took PMTCT antiretrovirals (ARVs). Maternal ARV use was associated with HIV-tested partner (OR 2.7; 95%CI 1.3-5.9), number of ANC visits (OR 1.7; 95%CI 1.2-2.4) and shame (OR 0.5; 95% CI 0.3-0.9). Receipt of ARVs during labor was associated with facility delivery ( $p < 0.03$ ).

HIV-positive women were more likely to deliver at a health facility than HIV-negative women ( $p < 0.001$ ) and traveled longer to delivery care. Women who bypassed nearby facilities traveled to higher tier facilities offering more comprehensive services.

Among 40 ANC facilities surveyed, 95% offered HIV testing. Approximately half of facilities (55%) reported offering HIV testing to families of women tested. Thirty-three facilities (83%) reported offering PMTCT services; 60% had CD4 count measurement capability and infant PCR testing access. Median time to CD4 result was one week (IQR 2-14 days) and time to PCR was 3 weeks (IQR 14 to 30 days).

**Conclusions:** Interventions that may improve uptake of PMTCT include facilitation of partner involvement, promotion of facility delivery, and HIV-specific educational interventions.

Opportunities exist in maternal counseling or peer support, as well as media campaigns for stigma reduction. At the health-services level, family testing and implementation of point-of-care services at lower-tier facilities may further improve uptake of PMTCT services.

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## Glossary

ANC	Antenatal Care
ART	Antiretroviral Therapy
ARVs	Antiretroviral Medications
BMHSU	Behavioral Model of Health Services Use
CDC	Centers for Disease Control
GIS	Geographical Information System
GPS	Global Positioning System
HDSS	Health Demographic Surveillance System
HDSA	Health Demographic Surveillance Area
KeFA	A Kenya Free of AIDS Study
KEMRI	Kenya Medical Research Institute
MCH	Maternal Child Health
PMTCT	Prevention of Mother to Child Transmission
POCT	Point-of-care Testing
TBA	Traditional Birth Attendant
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UW	The University of Washington
UoN	The University of Nairobi
VCT	Voluntary Counseling & Testing
WHO	World Health Organization

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## Introduction

Prevention of mother-to-child transmission of HIV (PMTCT) programs are being scaled up throughout Africa to deliver HIV testing to pregnant women, and to provide antiretroviral therapy (ART) and counseling on infant feeding choices to prevent infant HIV infection, all with a vision toward elimination of pediatric HIV by 2015.<sup>1</sup> Despite markedly expanded PMTCT coverage there are residual gaps between service availability and uptake. In order to reap the benefits of interventions to prevent infant HIV infection, it is critical to determine modifiable individual, social and programmatic barriers to delivery of PMTCT.

### Mother to Child Transmission of HIV

The HIV virus can be transmitted from mother to infant throughout the three stages of pregnancy: the antenatal period, during labor and delivery and through breastfeeding during the postpartum period. Overall, among breastfeeding women, transmission rates are approximately 35% with no intervention: 10% intrauterine, 20% intrapartum and 5-10% during breastfeeding, with increasing risk as duration of breastfeeding continues.<sup>2,3</sup> This risk of transmission is significantly decreased with administration of PMTCT. Single-dose nevirapine can reduce HIV transmission by up to 50% in a breastfeeding population<sup>4</sup> with rates of transmission below 5% among those utilizing combination ART.<sup>5-8</sup> For PMTCT to be most effective, it must be administered throughout all three stages of potential transmission. Since initiation of PMTCT practices, the US Centers for Disease Control (CDC) indicates that the number of US perinatal AIDS cases has decreased sharply, a 95% decrease in new infections.<sup>9</sup> Despite this remarkable progress in efficacy of HIV prevention, the full public health benefit of PMTCT has not yet been realized in resource-limited settings. The World Health Organization (WHO) estimated that in 2010, in low and middle income countries, only 35% of pregnant women

received HIV testing, and less than half accessed antiretroviral medication (ARVs) for PMTCT worldwide.<sup>10</sup>

### Conceptual Framework

Access to, and engagement in health services for HIV treatment and prevention are critical for program effectiveness.<sup>11-13</sup> In PMTCT programs, women must engage in a continuum of care that begins with uptake of HIV-testing during antenatal care (ANC) and continues through the breastfeeding period (Figure 0.1).<sup>14,15</sup>

Factors that influence PMTCT uptake can be categorized and organized via a conceptual model within the framework of the Andersen Behavioral Model of Health Services Use (BMHSU) (Figure 0.2).<sup>16-18</sup> This model has previously been used in identifying barriers to HIV care, and it enables targeted modification of barriers both at the individual and environmental levels.<sup>12,19</sup> In the BMHSU, external or environmental factors interact with individual factors of person, resources and need, leading to health behaviors and ultimate health outcomes. Applied to PMTCT, individual factors include education, socioeconomic status, HIV knowledge and partner support (Chapter 1). The environment is divided into two aspects: the contextual social environment consisting of community norms, beliefs and stigma/discrimination (Chapter 2); and the health services environment, consisting of provider attitudes, treatment policies, available services, and geographic location (Chapter 3). Both environmental and individual factors work directly on health outcomes such as risk of infection and infant survival, but also act in the pathway through health behaviors. Health behavior can be classified as personal practices, such as self-care or use of traditional healers; it can also be related to health services use such as ANC, voluntary counseling and testing (VCT), skilled delivery and HIV medication.

### A Kenya Free of AIDS

The Kenya Free of AIDS (KeFA) study (R24 HD056799) aims to build capacity for rigorous social and behavioral science research on HIV/AIDS linking the University of Washington and

the University of Nairobi Centre for HIV Prevention and Research. The goal is to develop more effective HIV prevention strategies through interdisciplinary collaboration. The project has supported four foundational pilot studies and three seed grants that partner biomedical, social and behavioral scientists. This dissertation addresses the original aims of Foundational Project 2, "PMTCT: From Unmet Need to Unused Service", exploring cultural, social, and policy barriers to uptake of PMTCT. For our first aim in Project 2, Dr. John Kinuthia surveyed 2,700 women in 6 Maternal Child Health (MCH) sites at 6 week postpartum immunization visits. In this study, a complementary community-based assessment of women of childbearing age was conducted in a rural region of Nyanza Province, Kenya in order to comprehensively determine PMTCT coverage, including women who never received ANC services or attended MCH clinics. Concurrently, a cross-sectional enumeration and detailed survey of the available PMTCT and ANC services was performed. Through these cross-sectional studies, we are able to assess the availability and locations of PMTCT services and to describe attributes, attitudes and behaviors of women who accessed PMTCT compared to those who did not. Associations with uptake of PMTCT and potential barriers including stigma, institutional capacity, and knowledge were assessed through statistical analyses.

In addition to the three manuscripts included here, this study, involving a collaboration between the University of Washington, the University of Nairobi, the Kenya Medical Research Institute and the US Centers for Disease Control, has yielded other important findings related to MCH in the region including correlates of facility delivery, cultural infant feeding practices, and rates and correlates of miscarriage among the study population.

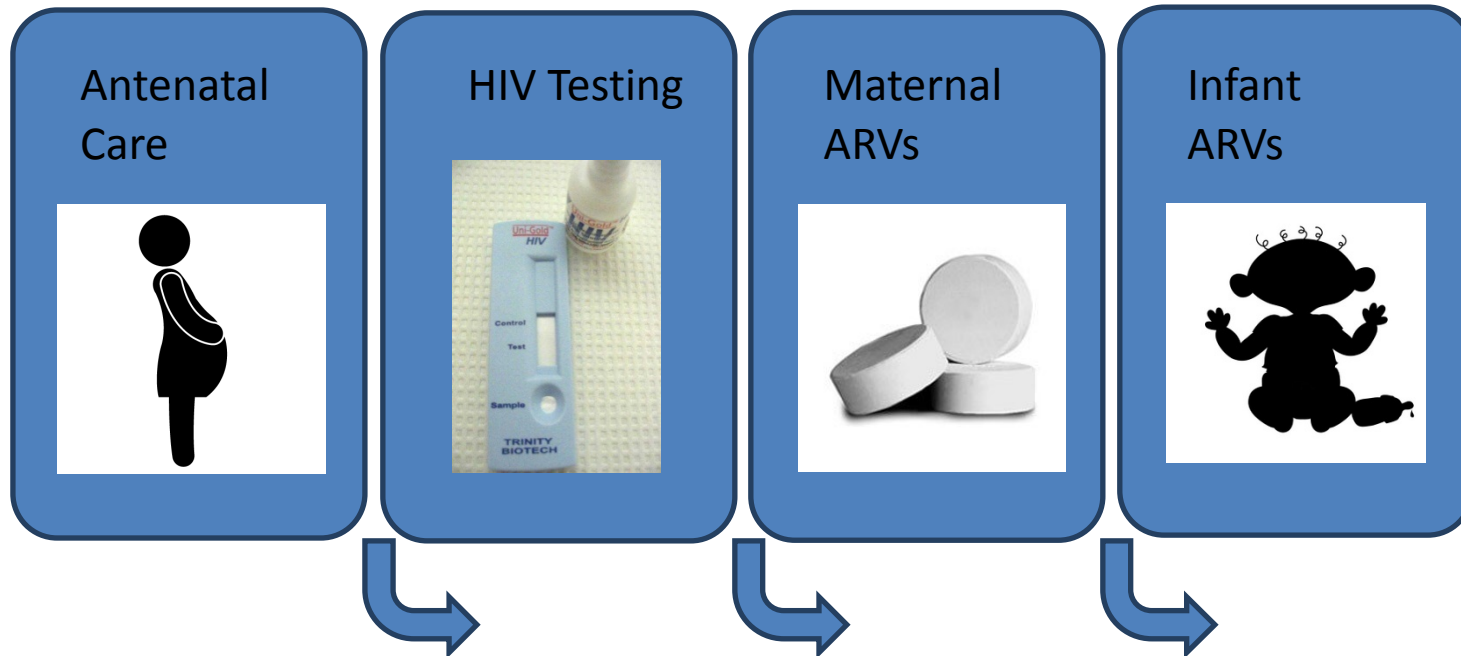
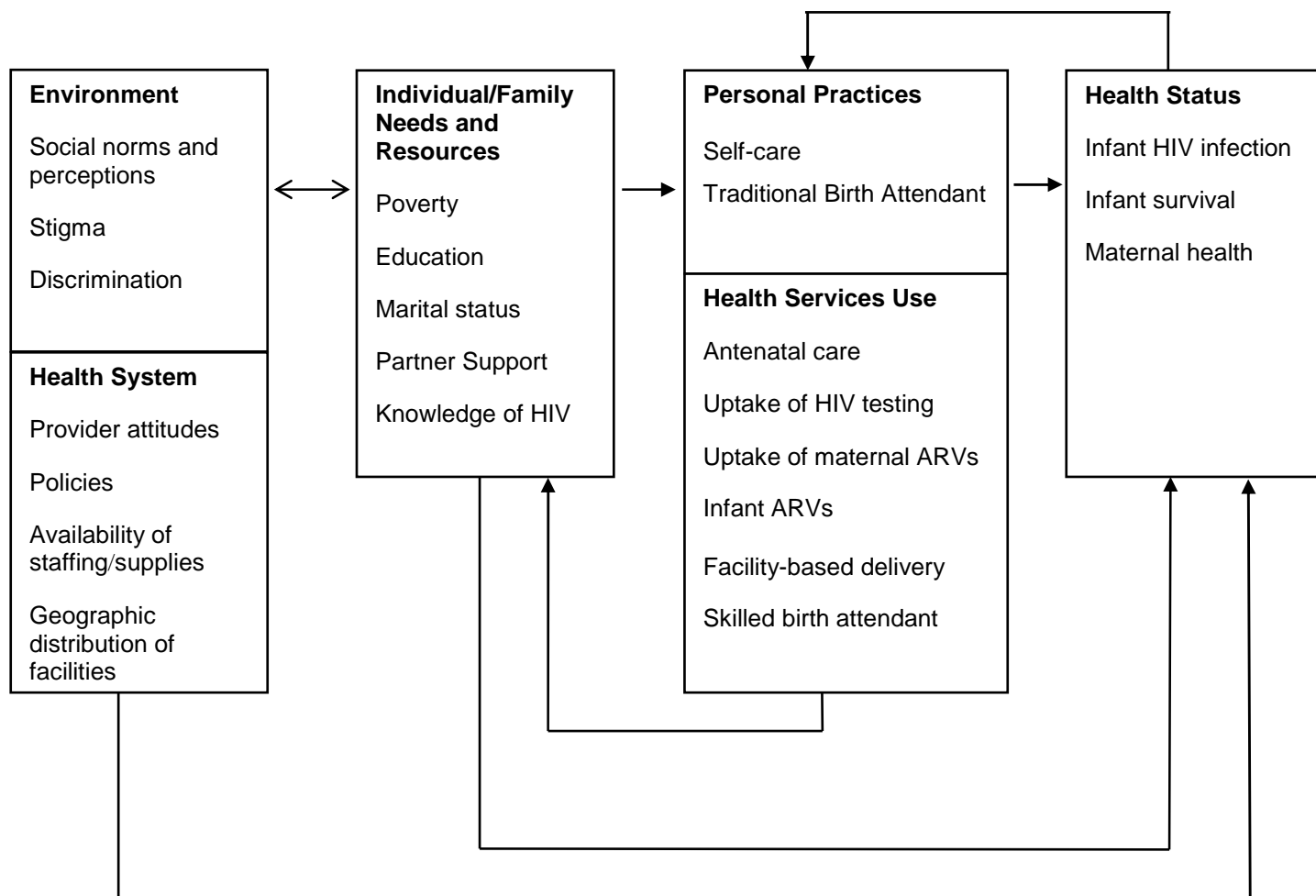


Figure 0.1: Loss to Care along the PMTCT Cascade



**Figure 0.2: Model of access to PMTCT adapted from Andersen, et al, 1995**

## Chapter 1. Partner Factors, Maternal Care, and HIV Knowledge Facilitate Uptake of PMTCT: A Community-Based Survey in Western Kenya

### 1.1 Background

Global elimination of mother to child transmission is targeted for 2015, and is an initiative which will require strategic improvements in service delivery.<sup>1</sup> As prevention of mother-to-child HIV transmission (PMTCT) interventions have expanded globally including in Sub-Saharan Africa, challenges in delivery and uptake of services persist. The World Health Organization (WHO) estimated that in 2010, in low and middle income countries, 35% of pregnant women received HIV testing, and less than half accessed ARVs for MTCT worldwide.<sup>10</sup> To meet elimination goals, a focus on PMTCT in Africa is critical; in 2010, 350,000 children in sub-Saharan Africa were *newly* infected with HIV, in contrast to the <500 new pediatric infections in all industrialized countries combined.<sup>10</sup>

Delivery of PMTCT involves a cascade of interventions, which begins with HIV testing pregnant women at initiation of antenatal care (ANC) and involves delivery of antiretrovirals (ARVs) throughout pregnancy and the postpartum period to prevent vertical HIV transmission. Kenya has made great strides in PMTCT service delivery, with receipt of ARVs among HIV-infected pregnant women more than tripling from 20% uptake in 2005<sup>20</sup>, to 56% in 2008<sup>21</sup>, and 73% in 2009.<sup>22</sup> While the number of new child HIV infections in Kenya have decreased since the introduction of PMTCT, absolute numbers remain high (>22,000 in 2009).<sup>23</sup> Recent estimates of transmission rates, while  $\leq 5\%$  in clinical trial settings,<sup>24-27</sup> range from 8 - 27%.<sup>23,28,29</sup>

Expansion of PMTCT services in Kenya faces some persistent barriers due to a variety of social, cultural, programmatic, logistical and policy challenges seen in other sub-Saharan countries.<sup>30-36</sup> Most PMTCT assessments are clinic-based. There are few community-based studies evaluating PMTCT services that sample a broad population of mothers, including those

who never accessed clinics. Clinic-based evaluations exclude those who never accessed care at all, arguably the most vulnerable population in service delivery. A recent study based in Uganda noted marked differences in PMTCT uptake estimates between clinic-based versus community-based surveys; the national clinic-based PMTCT uptake estimate was 80%, which was substantially higher than PMTCT uptake (60%) observed in a community-based survey.<sup>37</sup> In order to assess PMTCT service uptake and barriers to service delivery, we conducted a community-based survey of Kenyan women who had been pregnant during the past year.

## **1.2 Methods**

### Study Design

A cross-sectional community-level survey assessing knowledge and uptake of PMTCT services among women of child-bearing age was performed in the Health Demographic Surveillance System (HDSS) area in Nyanza Province, Kenya.

### Study Population

Women, maternal age 14 and older (the age of emancipation in Kenya for mothers), who resided in the HDSS area and had delivered a baby within the previous year (January to December 2010) were recruited.

### Study Location

The HDSS covers 383 villages with a population of approximately 220,000. Three regions make up this area: Karemo, Gem and Asembo. All three are regions are rural. The HDSS was launched in September 2001 by the US Centers for Disease Control and Prevention (CDC) in collaboration with the Kenya Medical Research Institute (KEMRI) and serves as a community-based platform. The HDSS provides demographic and health information as well as disease- or

intervention-specific information.<sup>38</sup> Since its inception, the HDSS has collected eleven years of data, including 5 years of self-reported HIV status and marital information among residents of the area. Home-based, counseling and testing (HBCT) of the HDSS population has been conducted since 2008, but had not been rolled out in all areas at the time of the study.

### Sampling

A random sample of eligible women in areas where HBCT had not yet been conducted was obtained, and village reporters were utilized to locate participants. In areas where HBCT had previously been conducted, an additional list of all HIV-positive mothers who knew their HIV status prior to delivery was generated to better define factors influencing the PMTCT cascade.

### Data Collection

Village reporters are community liaisons hired by the HDSS. In this case, trained fieldworkers were assigned a list of IDs and locations for all selected participants. Village reporters assisted fieldworkers to locate the mother participant and introduce the study. Fieldworkers administered surveys and recorded GPS location on hand-held PDAs using electronic forms (Pendragon Software Corporation, Buffalo Grove, IL); paper forms were used as a back-up. Mothers' surveys were adapted from clinic-based surveys used previously in this region.<sup>39</sup> Women were surveyed regarding their knowledge, opinions and use of PMTCT services and antenatal care (ANC) at last pregnancy.

Outcomes of interest included whether or not women accessed ANC, HIV testing, maternal ARVs for PMTCT, infant ARVs and infant testing. Uptake of HIV testing was assessed among women who accessed antenatal care, and PMTCT outcomes were assessed among all HIV positive women. Important co-factors included demographics such as age, education, and marital status as well as knowledge about HIV and disease transmission. Due to the inherent limitations in determining income through household surveys in resource-poor settings, asset-

based indicators (ownership of goods, roof type) were used as measures of socioeconomic status. Fieldworkers were blinded to HIV status of participants, thus self-reported HIV status was used.

### Data Analysis

Descriptive proportions of those accessing services in the PMTCT cascade were generated. Data analysis utilized chi-squared analyses for comparison of proportions using STATA (STATACorp, College Station, Texas). Wilcoxon rank sum tests were used for comparisons where data were not normally distributed and Fisher's exact test was used when cells were less than ten. Logistic regression was used to define correlates of accessing levels of care in the PMTCT cascade.

HIV-positive mothers sampled from the HBCT-communities were combined with the HIV-positive women from the general community sample for additional power further along the cascade, as HIV status in both groups was self-reported.

### Ethical Considerations

Prior to study start, community engagement activities were held targeting the area senior medical officers, the local community advisory board, the village reporters, chiefs and assistant chiefs. Informed consent was obtained from all participants, both to participate in the study and also to have their data from these surveys linked to their HDSS record. The study was approved by the University of Washington Institutional Review Board (#36022) and the Kenya Medical Research Institute Ethical Review Committee (#1714).

## 1.3 Results

### Population Characteristics of the Random Sample of Women

A random sample of 523 women was identified, 437 were located, and 405 agreed to participate in the survey. Among the 405 women, most were married (79% monogamous and 17% polygamous) (Table 1.1). The majority were of poor socioeconomic status; 42% held a salaried job, and less than half of the women completed a primary education. The median number of mobile phones per household was 1 (IQR 1-1.5), with 71% of women reporting one or more phones in the household. Under half of households reported cattle ownership (median 0, IQR 0-2), and > 90% of households did not own a television or refrigerator. Less than half had better than a grass roof (a marker of somewhat higher socioeconomic status), and the majority of these were tin.

Women reported a median of 4 (IQR 3-6) pregnancies. Although uptake of ANC was high (94%), most women started ANC late (median 5 months gestation at first ANC visit, IQR 4-6) and completed less than the recommended four ANC visits (median 3 visits, IQR 3-4). Uptake of skilled delivery, defined as a doctor, nurse or midwife, was low (44%), with 20% reporting no assistance at all. Less than half delivered at a health facility. Among those who did not deliver at a health facility (n=235), 89% delivered at home, 5% delivered at the location of a traditional birth attendant, and 6% reported delivering on the road on the way to a health facility.

### PMTCT Cascade

Most (94%) women from the random sample attended ANC during the last pregnancy, and among these 379 ANC attendees, 362 (96%) were not already known to be HIV-positive prior to their last pregnancy. Among those attending ANC and not previously known HIV-positive, 89% (322/362) reported being offered an HIV test, of whom, the majority (98%) accepted testing (Figure 1.1). The majority of testing (89%) took place at the first ANC visit. Altogether 87%

(314/362) of women attending ANC who were not previously known to be HIV-positive reported being tested for HIV. Among all women with previously unknown HIV status, regardless of antenatal care attendance, 84% reported HIV testing. Among the 314 women attending ANC tested for HIV, eleven (3%) declined to reveal their status, 279 (84%) reported they were HIV-negative, and 24 (7%) reported testing positive. Adding two women who reported being tested later and the seventeen known to already be positive, the estimated self-reported prevalence in this population was 13%, slightly lower than the 2009 Demographic Health Survey (DHS) prevalence of 16% among women in Nyanza province.<sup>40</sup>

An additional sample of 275 HIV-positive women (status known to sampling team via HBCT) was identified, of whom, 247 consented to participate; however, only 173 reported to fieldworkers that they were HIV-positive. Analyses of data from self-reported HIV-positive participants included 43 from the random sample and 173 from the HIV-positive HBCT sample to total 216.

Among these 216 HIV-positive women, 82% reported receipt of maternal ARVs at any time point (prenatal, labor and delivery, or postpartum). Uptake was lowest during the labor and delivery time point (62% compared to 72% prenatal and 72% postpartum). In bivariate analyses, delivery at a health facility was significantly associated with receipt of ARVs at the labor and delivery time point (69% at facility deliveries versus 55% uptake at non-facility deliveries,  $p < 0.03$ ). In addition, 79% of HIV positive women reported administering infant ARVs for prevention of HIV transmission to their child at any time.

#### Infant Antiretrovirals and Testing

Administration of infant ARVs for PMTCT was significantly associated with maternal ARV uptake. A small proportion (26%) of women who did not take maternal PMTCT ARVs reported that their infant received ARVs vs. 92% of women who took maternal ARVs ( $p < 0.001$ ). Among the 81% (176/216) of infants tested for HIV, 11% of mothers reported that their infant was HIV-

positive and 76% reported that the infant was negative. Timing of infant HIV diagnosis was not reported. Six percent of women declined to report their child's HIV status, and another 7% stated that they did not remember the test results. Among the 19 positive infants, fifteen (79%) were receiving care and treatment for HIV. One child died prior to receiving treatment. Among the other 3 HIV-infected infants who did not get treatment, fear of others finding out (n=1), denial (n=1), being unaware of treatment (n=2) were all reported as reasons for not accessing treatment for their child. Multiple reasons were listed by some mothers.

#### Correlates of Uptake: ANC

Factors associated with uptake of ANC at most recent pregnancy among women in the random community sample are detailed in Table 1.2. In bivariate analyses, completion of primary education was associated with increased likelihood of uptake of ANC (OR 6.7; 95%CI 2.0-22.9) and increasing numbers of previous pregnancies were associated with a decreased likelihood of accessing ANC (OR 0.8; 95%CI 0.7-0.9).

#### Correlates of Uptake: HIV Testing

Eighty seven percent of 362 women in the random sample who accessed ANC and were not previously known to be HIV-positive were tested for HIV during their most recent pregnancy. Factors associated with uptake of HIV testing were being a housewife (OR 2.4; 95%CI 1.1-5.2) or employed (OR 2.7; 95%CI 1.3-6.0) compared to unemployed, household ownership of at least one cow (OR 2.0; 95%CI 1.0-3.7) and mobile phone (OR 3.1; 95%CI 1.7-5.7), roof type of iron sheet or better (OR 2.2; 95%CI 1.0-4.9) report that their partner was tested for HIV (OR 2.7; 95%CI 1.4-5.1), and knowledge of HIV prevention (OR 2.0; 95%CI 1.1-3.9) and prevention of mother to child transmission (OR 2.3; 95%CI 1.2-4.4) (Table 1.3).

### Correlates of Uptake: Maternal Antiretrovirals

Factors associated with uptake of maternal ARVs among all HIV-positive women at any time point are described in Table 1.4. In bivariate analyses, report that their partner was tested for HIV (OR 2.7; 95%CI 1.3-5.9) and number of ANC visits (OR 1.7; 95%CI 1.2-2.4) were associated with increased likelihood of uptake of ARVs. Among those who knew their partner's status, having an HIV-positive partner was associated with uptake of maternal ARVs.

Correlates of uptake of all three maternal ARVs include education (OR 2.2; 95%CI 1.3-3.8), knowledge of HIV prevention in general (OR 5.0; 95% CI 1.8-14.1), and knowledge of PMTCT (OR 1.9; 95%CI 1.0-3.4) (Table 5). These were primarily driven by uptake in the peripartum period.

## **1.4 Discussion**

In this community-based study of recently pregnant women in western Kenya, rates of uptake of ANC, HIV testing and PMTCT were high. Among women with unknown HIV status surveyed in this study, 84% reported receiving HIV testing during pregnancy. Almost all women attended ANC (94%) and among ANC attendees, HIV testing was reported by almost 90% of mothers. This is particularly encouraging data because it is derived from a community rather than a clinic-based study. Most PMTCT program assessments have been clinic-based; there are few community surveys of PMTCT performance. Our study contrasts with a Ugandan study, which measured much lower PMTCT performance in community-based than clinic-based environments.

Our findings reflect remarkable progress by the Kenyan national PMTCT program. As early as 2008, the Kenyan National AIDS Control Council reported that 10,000 (1/3) of government health workers had been trained in delivery of PMTCT. In addition, PMTCT had been introduced to more than 80% of antenatal care facilities through the Ministry of Health, and over

1,000 sites offered PMTCT.<sup>41</sup> Our data suggest that these investments have translated into wide community PMTCT coverage. However, it remains critical to build on progress of the PMTCT program by identifying further enhancements.

We assessed performance of the PMTCT program throughout the cascade and identified cofactors for uptake or barriers. Socioeconomic indicators influenced uptake of interventions throughout the PMTCT cascade. Education was associated both with uptake of ANC and of maternal ARVs at all three time points; and socioeconomic status, as reflected by phone or cattle ownership or roof type, influenced uptake of interventions. Mobile phone ownership or access was significantly associated both with HIV testing and ARV use. Mobile phone ownership may be a proxy for other cofactors that influence PMTCT uptake. Only ~70% of women reported having mobile phone availability in the household, and the majority of these were shared. Recently, there has been increased enthusiasm for mobile phones as a tool in *mHealth* applications to improve maternal child health and potentially PMTCT.<sup>42-44</sup> Our study suggests that women without mobile phones may be the ones most in need of additional intervention to support PMTCT, and *mHealth* interventions may need to provide mobile phones to fully realize impact.

Maternal failure to access ANC, which is an entry point for detection of HIV and referral to PMTCT services, is often a limiting factor in accessing HIV testing and subsequent delivery of PMTCT. Our observed uptake of ANC was similar to the 2008/9 Kenya DHS estimates (92% in the DHS and 94% in this survey).<sup>40</sup> Our finding that failure to access ANC was associated with higher numbers of previous pregnancies may be due to a variety of factors: lack of perceived need, time unavailability with many children, or dissatisfaction with ANC in previous pregnancies.

Central to the delivery of PMTCT interventions is awareness of one's HIV status, and even among women who access ANC, challenges exist in the uptake of testing. We found higher

uptake of HIV testing than in a previous Kenyan national survey ~5 years ago.<sup>45</sup> In the Kenyan 2007 Kenya AIDS Indicator Survey (KAIS), 82% of women in their third trimester had attended ANC at least once, 18% of whom reported that they were not tested for HIV. We found that 94% of women reported attending ANC, of whom 13% did not have an HIV test. In our study, most HIV tests (~90%) were at the first ANC visit, allowing early PMTCT ARV initiation consistent with WHO guidelines. However, women presented later in ANC (median 20 weeks) than ideal (PMTCT should start by 14 weeks gestation). Hence systems to encourage earlier first ANC visits, or HIV testing outside clinic settings with referral to care, will be important to fully realize benefits of PMTCT.

Similar to our previous clinic-based study, we found access to facility-based healthcare during childbirth was associated with uptake of PMTCT ARVs.<sup>34</sup> This suggests that recent efforts to enhance skilled birth attendance to improve maternal and child health should result in improvements in delivering peripartum ARVs for PMTCT. Despite these efforts, in Kenya, access to facility delivery has only minimally improved (41% in 2003 and 44% in 2008-9).<sup>40</sup> It is plausible that for women not accessing facility delivery, Option B PMTCT (starting pregnant women on triple antiretroviral therapy) may retain more preventive efficacy than Option A, which requires peripartum nevirapine administration to additionally suppress maternal virus.<sup>46</sup> However, for either Option, facility delivery is likely to be superior to home delivery for peripartum ARV administration.

Awareness of partner HIV test was associated with uptake of maternal HIV testing and ARVs in our study. Male partners are sometimes tested during the pregnancy<sup>47</sup>, indicating that maternal HIV testing in antenatal care may promote male partner testing or vice versa. Our study did not specify the time of partner testing so we are unable to know which came first. However, in other studies, both males and females identify lack of disclosure of HIV diagnosis to a partner as a major obstacle for women in accessing care.<sup>48,49</sup> In a study of four African countries, only 37%

of HIV-positive pregnant women had disclosed to their husband.<sup>49</sup> Other studies have found similar associations between partner disclosure<sup>50</sup>, social support from a spouse<sup>51</sup>, and partner attendance at antenatal HIV counseling and testing<sup>52</sup> and uptake of or adherence to PMTCT. Gender roles which inhibit women's empowerment may also pose a barrier to partner disclosure of HIV status subsequent uptake of HIV services.<sup>53</sup> These data suggest that interventions that target partner involvement in care may promote uptake of PMTCT.

This analysis had several strengths in that it utilized a community-based approach to assess uptake of health services. Regional home-based counseling and testing in the HDSS further allowed for increased sampling of HIV-positive women. Limitations include reliance on self-report of HIV status and uptake of HIV/PMTCT services, as results may have been influenced by stigma or social desirability bias; the cross-sectional nature of the survey; and generalizability to other settings.

## **1.5 Conclusion**

We found high levels of PMTCT uptake in this survey. This is particularly encouraging data because it is derived from a community, rather than a clinic-based, study. There are opportunities for involving partners in improving maternal uptake of PMTCT services, however this must be implemented in a way as to not further marginalize women without partner support. The primary gap in delivery of maternal ARVs was during the labor and delivery period. Movement toward Option B/B+ policies or provision of labor ART dosing for Option A in a population where home deliveries are common may improve uptake failures during delivery. Other opportunities for intervention in the region include improving knowledge of HIV prevention and efforts to decrease stigma, particularly feelings of shame, associated with HIV.

**Table 1.1 Population and Sample**

<i>Participant Characteristic</i>	<i>Random Community Sample</i> N=405	<i>HIV+ Mothers*</i> N=216
<b>Demographic Information</b>		
Age	25 (22-30)	29 (25-32)
Years of residence in village	7.2 (3.5-12)	9.5 (5-14)
Marital status		
Married monogamous	318 (78.5)	159 (73.6)
Married polygamous	60 (14.8)	35 (16.2)
Single	17 (4.2)	7 (3.2)
Widowed	10 (2.5)	15 (6.9)
Occupation		
Unemployed	71 (17.5)	39 (18.1)
Housewife	163 (40.3)	98 (45.4)
Salaried job	170 (42.0)	77 (35.7)
Completed primary education	184 (45.4)	112 (51.9)
Cattle ownership (one or > in household)	192 (47.4)	89 (41.2)
Mobile phone ownership (one or > in household)	289 (71.4)	152 (70.4)
Roof type		
Grass	288 (71.1)	120 (55.6)
Corrugated iron sheet or better	116 (28.6)	96 (44.4)
<b>Pregnancy Information</b>		
Number of times pregnant	4 (3-6)	4 (3-6)
Any antenatal care last pregnancy	379 (93.6)	209 (96.8)
Number of ANC visits	3 (3-4)	3 (3-4)
Timing of first ANC visit (months pregnant)	5 (4-6)	5 (4-6)
Transport time to ANC (hours)	1 (0.5-1.5)	1 (0.5-1.5)
<b>HIV Testing</b>		
HIV tested last pregnancy	340 (84.0)	--
HIV test at first ANC visit (among those tested)	304 (89.4)	--
Tested at government facility (among those tested)	293 (86.2)	--
<b>Delivery Care</b>		
Facility delivery	170 (42.0)	101 (46.8)
Skilled attendant at delivery	176 (43.5)	101 (46.8)
Vaginal delivery (no instruments)	383 (95.3)	203 (94.0)
<b>Knowledge and Beliefs</b>		
Is there any way to prevent HIV	298 (73.6)	192 (88.9)
Can pregnant women give HIV to baby	261 (64.4)	172 (79.6)
Can prevent MTCT of HIV	210 (51.9)	158 (73.2)

\*Includes 43 mothers from random community sample and 173 mothers from HBTC

**Table 1.2 Factors associated with access to ANC at last pregnancy**  
Among all mothers in the community sample (n=405)

	<b>No ANC</b> 26 (6.4%)	<b>ANC</b> 379 (93.6%)	<b>OR (95%CI)</b>
<b>Demographic Information</b>			
Age	27 (23-32)	25 (22-30)	
Years of residence in village	9 (4-13)	7 (3.5-11.3)	
Marital status			
Married monogamous	22 (84.6)	296 (78.1)	
Married polygamous	3 (11.5)	57 (15.0)	
Single	0 (0.0)	17 (4.5)	
Widowed	1 (3.9)	9 (2.4)	
Occupation			
Unemployed	6 (23.1)	65 (17.2)	
Housewife	11 (42.3)	152 (40.2)	
Employed	9 (34.6)	161 (42.6)	
Completed primary education	3 (12.0)	181 (47.9)	6.74 (1.98-22.89) <sup>¥</sup>
Cattle ownership (one or > in household)	13 (50.0)	179 (47.5)	
Mobile phone ownership (one or > in household)	15 (57.7)	274 (72.5)	
Roof type			
Grass	19 (73.1)	269 (71.2)	
Corrugated iron sheet or better	7 (26.9)	109 (28.8)	
<b>Pregnancy and HIV</b>			
Number of times pregnant	5 (4-7)	4 (3-6)	0.79 (0.69-0.90) <sup>‡</sup>
HIV status (Self report, n=361)			
Negative	17 (100.0)	301 (87.5)	
Positive	0 (0.0)	43 (12.5)	
<b>Knowledge and Beliefs</b>			
Is there any way to prevent HIV	15 (60.0)	283 (75.1) <sup>*</sup>	
Can pregnant women give HIV to baby	14 (56.0)	247 (65.3)	
Can prevent MTCT of HIV	10 (71.4)	200 (81.3)	

\* p<0.10, † p<0.05, ‡ p<0.01, ¥ p<0.001

**Table 1.3 Factors associated with uptake of HIV testing at last pregnancy***Among women who were not known positive and attended ANC in community sample (n=362)*

	<b>No HIV Test</b> 48 (13.3%)	<b>HIV Tested</b> 314 (86.7%)	<b>OR (95%CI)</b>
<b>Demographic Information</b>			
Age	24.5 (22-28)	25 (22-30)	
Years of residence in village	7 (3.5-10.3)	7 (3.3-11.5)	
Marital status			
Married monogamous	34 (70.8)	250 (79.6)	
Married polygamous	12 (25.0)	43 (13.7)	
Single	2 (4.2)	15 (4.8)	
Widowed	0 (0.0)	6 (1.9)	
Occupation			
Unemployed	15 (31.3)	47 (15.0)	Ref
Housewife	17 (35.4)	129 (41.2)	2.42 (1.12-5.23) <sup>†</sup>
Employed	16 (33.3)	137 (43.8)	2.73 (1.25-5.95) <sup>†</sup>
Completed primary education	19 (39.6)	154 (49.2)	
Cattle ownership (one or > in household)	16 (33.3)	154 (49.4)	1.95 (1.03-3.70) <sup>†</sup>
Mobile phone ownership (one or > in household)	24 (50.0)	236 (75.4)	3.06 (1.65-5.71) <sup>¥</sup>
Roof type			
Grass	40 (83.3)	217 (69.3)	Ref
Corrugated iron sheet or better	8 (16.7)	96 (30.7)	2.21 (1.00-4.90) <sup>*</sup>
<b>Pregnancy and HIV Testing</b>			
Number of times pregnant	3 (3-4.5)	4 (3-6)	
Partner tested for HIV	16 (36.4)	179 (60.3)	2.65 (1.38-5.12) <sup>‡</sup>
Partner HIV positive	1 (6.7)	19 (11.0)	
<b>Knowledge and Beliefs</b>			
Is there any way to prevent HIV	29 (61.7)	240 (76.7)	2.04 (1.07-3.88) <sup>†</sup>
Can pregnant women give HIV to baby	28 (59.6)	205 (65.3)	
Can prevent MTCT of HIV	16 (34.0)	171 (54.6)	2.33 (1.23-4.44) <sup>‡</sup>

\* p&lt;0.10, † p&lt;0.05, ‡ p&lt;0.01, ¥ p&lt;0.001

**Table 1.4 Factors associated with uptake of Maternal ARVs***Among all self-reported HIV-positive women in the community and HBCT samples (n=216)*

	<b>No mARVs</b> 39 (18.1%)	<b>mARVs</b> 177 (81.9%)	<b>OR (95%CI)</b>
<b>Demographic</b>			
Age	26 (23-33)	29 (25-32)	1.05 (0.98-1.13)*
Marital status			
Married monogamous	27 (69.2)	132 (74.6)	
Married polygamous	7 (18.0)	28 (15.8)	
Single	2 (5.1)	5 (2.8)	
Widowed	3 (7.7)	12 (6.8)	
Occupation			
Unemployed	7 (18.0)	32 (18.3)	
Housewife	22 (56.4)	76 (43.4)	
Employed	10 (25.6)	67 (38.3)	
Completed primary education	16 (41.0)	96 (54.2)	
Cattle ownership (one or > in household)	19 (48.7)	70 (39.6)	
Mobile phone ownership (one or > in household)	27 (69.2)	125 (70.6)	
Roof type			
Grass	23 (59.0)	97 (54.8)	
Corrugated iron sheet or better	16 (41.0)	80 (45.2)	
<b>Pregnancy information</b>			
Number of times pregnant	4 (3-6)	4 (3-6)	
ANC during last pregnancy	36 (92.3)	173 (97.8)	3.60 (0.77-16.80)*
Timing of first ANC (months pregnant)	6 (5-7)	5 (4-6)	
Number of ANC visits (among those seeking ANC)	3 (2-4)	4 (3-5)	1.70 (1.21-2.39)‡
<b>HIV testing</b>			
Timing of first HIV Testing			
After learned was pregnant	28 (71.8)	98 (55.4)	Ref
Before learned was pregnant	11 (28.2)	79 (44.6)	2.05(0.96-4.38)*
Partner tested for HIV	18 (52.9)	117 (75.5)	2.74 (1.27-5.89)‡
Partner HIV positive (among those who knew partner status, n=129)	8 (44.4)	84 (75.7)	3.89 (1.39-10.85)‡
<b>Delivery Care</b>			
Facility delivery	13 (33.3)	88 (49.7)	1.98 (0.95-4.10)*
Skilled provider at delivery	13 (33.3)	88 (50.6)	2.05 (0.99-4.24)*
<b>Knowledge and beliefs</b>			
Is there any way to prevent HIV	31 (81.6)	161 (91.0)	2.27 (0.86-5.99)*
Can pregnant women give HIV to baby	29 (74.4)	143 (81.3)	
Can prevent MTCT of HIV	26 (66.7)	132 (75.4)	

\* p&lt;0.10, † p&lt;0.05, ‡ p&lt;0.01, ¥ p&lt;0.001

**Table 1.5 Factors associated with uptake of Maternal ARVs at all three time points**  
*Among all self-reported HIV-positive women in the community and HBCT samples (n=216)*

	<b>No or some mARVs</b> 99 (45.8)	<b>Full course mARVs*</b> 117 (54.2)	<b>OR (95%CI)</b>
<b>Demographic Information</b>			
Age	28 (25-32)	29 (25-32)	
Marital status			
Married monogamous	71 (71.7)	88 (75.2)	
Married polygamous	16 (16.2)	19 (16.2)	
Single	4 (4.0)	3 (2.6)	
Widowed	8 (8.1)	7 (6.0)	
Occupation			
Unemployed	17 (17.4)	22 (19.0)*	Ref
Housewife	53 (54.1)	45 (38.8)	0.66 (0.31-1.39)
Employed	28 (28.6)	49 (42.2)	1.35 (0.62-2.96)
Completed primary education	41 (41.1)	71 (60.7)	2.18 (1.27-3.77) <sup>‡</sup>
Cattle ownership (one or > in household)	40 (40.4)	49 (41.9)	
Mobile phone ownership (one or > in household)	64 (64.7)	88 (75.2)	1.66 (0.92-2.99)*
Roof type			
Grass	56 (56.6)	64 (54.7)	
Corrugated iron sheet or better	43 (43.4)	53 (45.3)	
<b>Pregnancy Information</b>			
Number of times pregnant	4 (3-6)	4 (3-6)	
ANC during last pregnancy	94 (95.0)	115 (98.3)	
Timing of first ANC (months pregnant)	5 (4-6)	5 (4-6)	
Number of ANC visits (among those seeking ANC)	3 (3-4)	4 (3-4)	
<b>HIV Testing</b>			
Partner tested for HIV	59 (67.8)	76 (74.5)	
Partner HIV positive (among those who knew partner status, n=129)	37 (63.8)	55 (77.5)	
Timing of first HIV Testing			
After learned was pregnant	62 (62.6)	64 (54.7)	
Before learned was pregnant	37 (37.4)	53 (45.3)	
<b>Delivery Care</b>			
Facility delivery	41 (41.4)	60 (51.3)	
Skilled provider at delivery	40 (40.8)	61 (53.0)	1.64 (0.95-2.82)*
<b>Knowledge and Beliefs</b>			
Is there any way to prevent HIV	80 (81.6)	112 (95.7)	5.04 (1.80-14.14) <sup>‡</sup>
Can pregnant women give HIV to baby	74 (75.5)	98 (83.8)	
Can prevent MTCT of HIV	66 (67.4)	92 (79.3)	1.86 (1.00-3.44) <sup>†</sup>

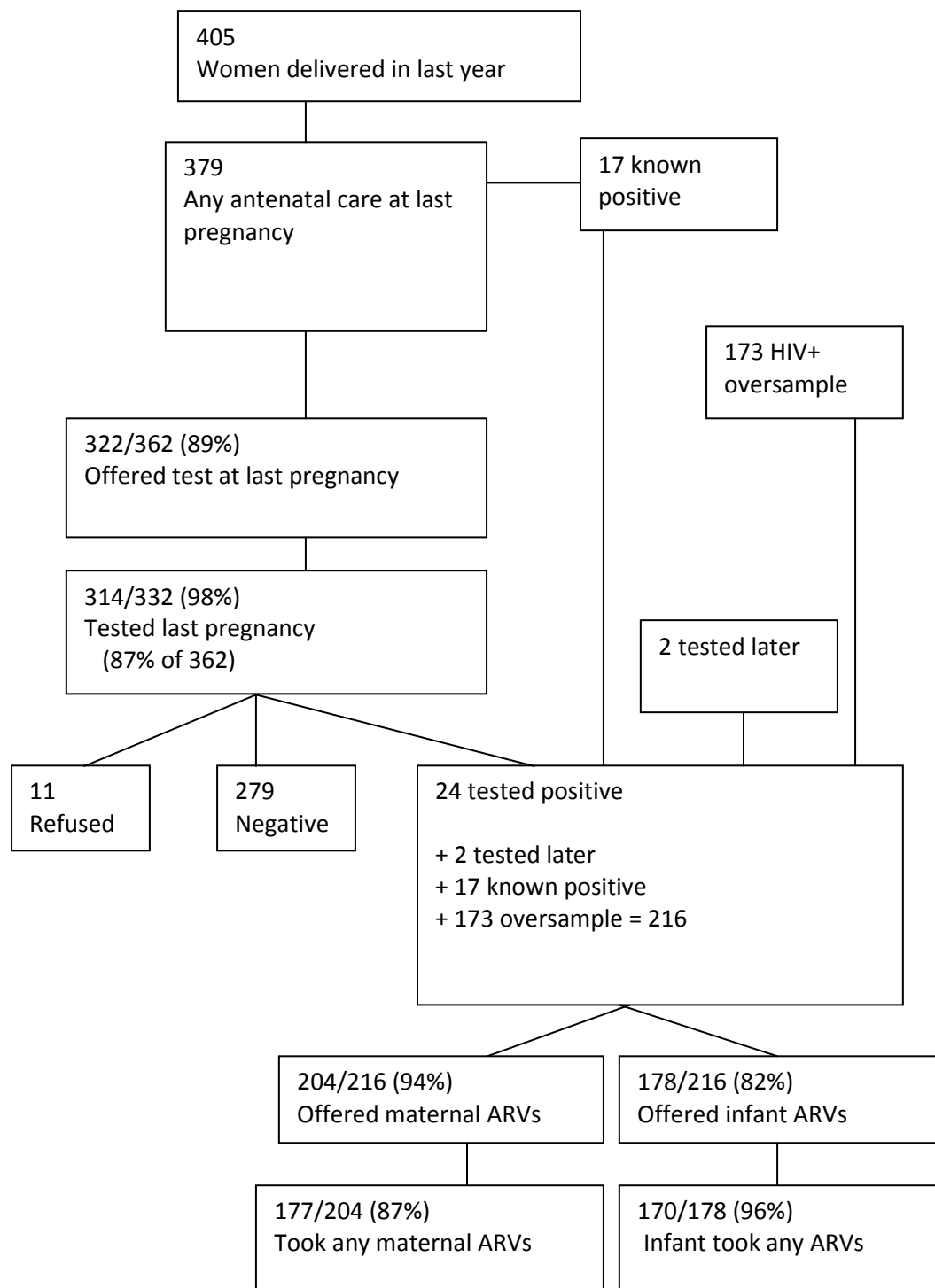
\* p<0.10, † p<0.05, ‡ p<0.01, ¥ p<0.001

**Table 1.6 Summary of odds ratios for likelihood of accessing care across the PMTCT cascade**

	<b>ANC</b> OR (95%CI)	<b>HIV Testing</b> OR (95%CI)	<b>mARVs</b> OR (95%CI)	<b>All 3 mARVs</b> OR (95%CI)
<b>Demographic Information</b>				
Occupation				
Unemployed			Ref	
Housewife		2.42 (1.12-5.23) <sup>†</sup>		
Employed		2.73 (1.25-5.95) <sup>†</sup>		
Completed primary education	6.74 (1.98-22.89) <sup>¥</sup>			2.18 (1.27-3.77) <sup>‡</sup>
Cattle ownership (one or > in household)		1.95 (1.03-3.70) <sup>†</sup>		
Mobile phone ownership (one or > in household)		3.06 (1.65-5.71) <sup>¥</sup>		1.66 (0.92-2.99) <sup>*</sup>
Roof type				
Grass			Ref	
Corrugated iron sheet or better		2.21 (1.00-4.90) <sup>*</sup>		
<b>Pregnancy Information</b>				
Number of times pregnant	0.79 (0.69-0.90) <sup>‡</sup>			
ANC during last pregnancy			3.60 (0.77-16.80) <sup>*</sup>	
Number of ANC visits (among those seeking ANC)			1.70 (1.21-2.39) <sup>‡</sup>	
<b>HIV Testing</b>				
Timing of first HIV Testing				
After learned was pregnant			Ref	
Before learned was pregnant			2.05(0.96-4.38) <sup>*</sup>	
Partner tested for HIV		2.65 (1.38-5.12) <sup>‡</sup>	2.74 (1.27-5.89) <sup>‡</sup>	
Partner HIV positive (among those who knew partner status, n=129)			3.89 (1.39-10.85) <sup>‡</sup>	
<b>Delivery Care</b>				
Facility delivery			1.98 (0.95-4.10) <sup>*</sup>	
Skilled provider at delivery			2.05 (0.99-4.24) <sup>*</sup>	1.64 (0.95-2.82) <sup>*</sup>
<b>Knowledge and Beliefs</b>				
Is there any way to prevent HIV		2.04 (1.07-3.88) <sup>†</sup>	2.27 (0.86-5.99) <sup>*</sup>	5.04 (1.80-14.14) <sup>‡</sup>
Can pregnant women give HIV to baby				
Can prevent MTCT of HIV		2.33 (1.23-4.44) <sup>‡</sup>		1.86 (1.00-3.44) <sup>†</sup>

Note: Samples for each column described in previous tables

\* p<0.10, † p<0.05, ‡ p<0.01, ¥ p<0.001



**Figure 1.1 Cascade of PMTCT**

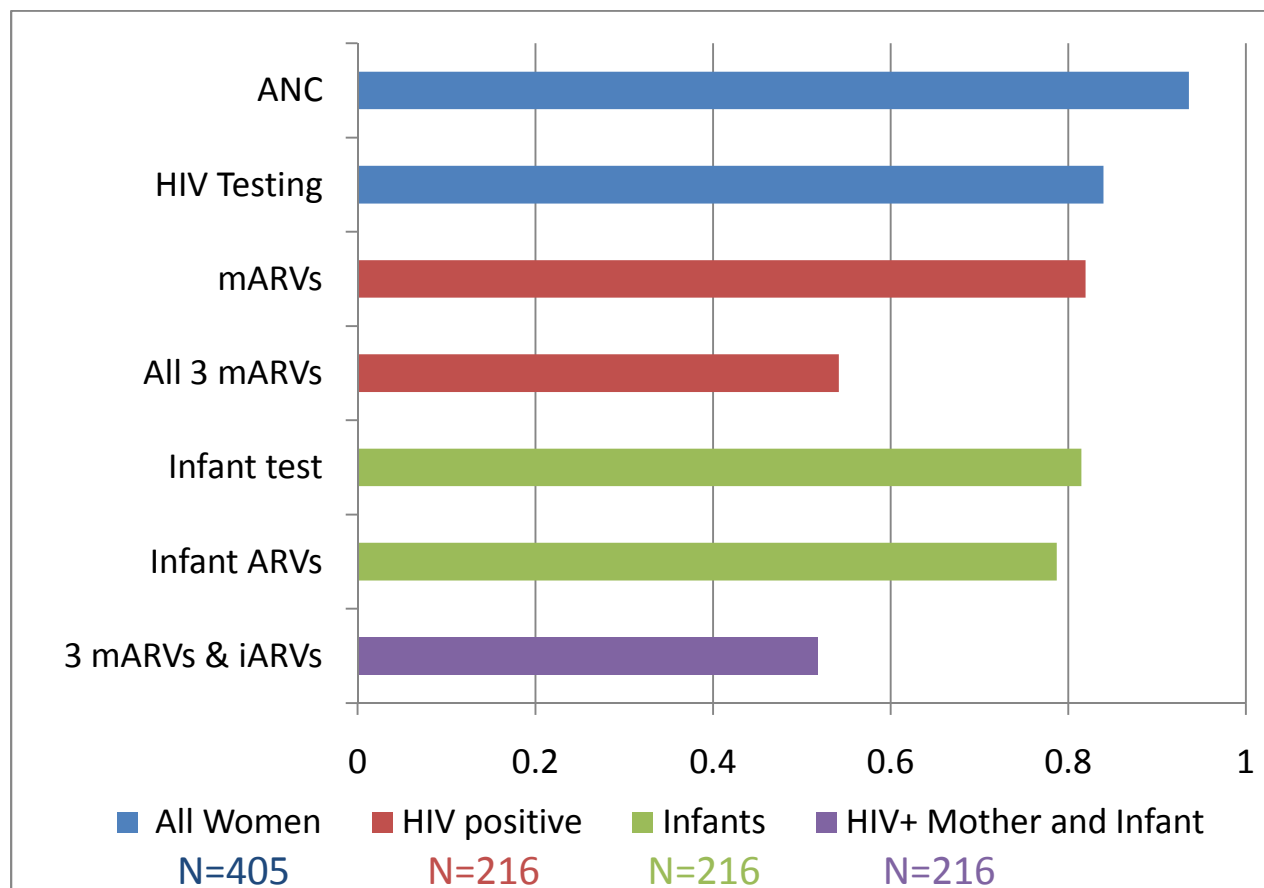


Figure 1.2 Uptake throughout cascade of PMTCT Services

## Chapter 2. Community Perceptions and Social Barriers to Engaging in PMTCT Programs in Western Kenya

### 2.1 Background

Interventions to prevent mother-to-child transmission (PMTCT) of HIV are remarkably efficacious<sup>24-27</sup>, the success of which has inspired a global plan to eliminate new pediatric HIV infections by 90%.<sup>1</sup> While scale-up of PMTCT services has been expansive, the World Health Organization (WHO) estimates that in sub-Saharan Africa, only 42% of pregnant women receive an HIV test and half of HIV-infected pregnant women receive effective antiretroviral regimens for PMTCT.<sup>10</sup>

Health behavior theories cite cultural and environmental factors including social norms, attitudes, and expected social acceptance as motivators or barriers to uptake of health services.<sup>18,54</sup> Literature in sub-Saharan Africa demonstrates a combination of health systems barriers to uptake of PMTCT, as well as widely perceived HIV-stigma and social or family influences.<sup>35,39,48,50,55</sup> While much of the HIV literature describes stigma and discrimination as a single concept, Nyblade et al specified four distinct domains of stigma: fear of casual contact; moral values of shame, blame and judgment; discrimination, and disclosure.<sup>56</sup> Understanding which stigma domain is affecting PMTCT uptake may be critical in targeting interventions to the appropriate underlying cause.

Furthermore, few quantitative measures of HIV discrimination in Sub-Saharan Africa are available, and little is known about the prevalence of HIV-related abuse or domestic violence, and to what extent these occurrences factor into uptake of services.

Understanding the social and contextual landscape of PMTCT uptake from a community perspective is necessary to design appropriate theory-based interventions that address the primary drivers of health behavior within a cultural or regional context. In this study, we aim to

quantitatively and qualitatively evaluate social factors influencing uptake of PMTCT in a region of Western Kenya, including referral to care, community acceptability of services and perceptions of barriers to uptake. We further aim to assess associations of stigma (moral values and discrimination) with outcomes of uptake of services along the PMTCT cascade.

## **2.2 Methods**

### Study design

In order to assess the contextual environment of access to (and uptake of) PMTCT services in western Kenya, we conducted a cross-sectional survey of mothers who recently delivered an infant and lived in the Kenya Health Demographic and Surveillance System (HDSS) area. Using HDSS population data, we were able to randomly sample women who had delivered within the last year (January to December, 2011) as well as an oversample of HIV-positive women in regions of the HDSS where home-based HIV counseling and testing had been recently rolled out.

### Data collection

Quantitative and qualitative information was collected in face to face interviews by trained fieldworkers. In addition to questions of socio-demographics, uptake of health services and knowledge of PMTCT, women were asked to describe their perceptions of why women in the community do or do not engage in PMTCT care. Eligible women were asked to respond to open-ended questions, which were entered in handheld PDAs by trained fieldworkers. Multiple answers were accepted. Women were additionally asked hypothetical questions such as “if you were diagnosed with HIV, would you seek care at the same facility for your next pregnancy?” Stigma questions focused on the community-level indicators derived from a validated toolkit within the domains of moral values of shame and blame/judgment and enacted stigma or

discrimination.<sup>56</sup> To assess discrimination, women were asked if they had ever known someone in the community that had any of a list of discriminatory acts happen to them because of HIV/AIDS in the last year. Additional questions on known domestic violence and abuse were included.

Outcomes of interest along the cascade of PMTCT services included uptake of antenatal care; HIV testing among women attending antenatal care (ANC) who are not previously known to be HIV positive; and uptake of maternal and infant antiretrovirals (ARVs) and of infant HIV testing among HIV positive women.

#### Data analysis

Quantitative information was analyzed using STATA software (STATA Corp, College Station, TX). Proportions were assessed using chi-squared tests of significance with Fisher's exact test where cell numbers were less than 10, and logistic regression was used to determine odds ratios. Wilcoxon rank-sum tests were used for comparing distributions of linear data.

Qualitative responses were translated from the local Luo language to English by the study team, then coded into themes and validated by the lead author and a Kenyan social scientist.

#### Ethical considerations

Informed consent was obtained from all participants, both to participate in the study and also to have their data from these surveys linked to their HDSS record. The study was approved by the University of Washington Institutional Review Board (#36022) and the Kenya Medical Research Institute Ethical Review Committee (#1714).

## 2.3 Results

### Sample and population

Two populations are described: 1) a random sample of women who delivered in the last year and reside in the HDSS area (n=405), and 2) a second group including all HIV-positive women in the community sample (n=43) plus women identified as HIV-positive in adjacent HDSS regions where home-based counseling and testing previously had taken place (n=173) to total 216 HIV-positive women. All women were included in analyses if they self-reported being HIV-positive.

### Social Factors Influencing Access to Care

#### *Referral to Care*

There was high uptake of ANC (94%) and moderate to low uptake of facility delivery (42%). Women who attended ANC were referred by advertisements (36%), friends or relatives (31%) or went because it was the same facility utilized in a previous pregnancy (31%). Few (<5%) chose an ANC facility based on health worker referral. Referrals for delivery care were 31% via advertising, 31% based on experiences at previous pregnancy, 23% were referred by a friend or relative and 15% health worker referral. Proportions among HIV-positive women and the community sample were similar for referrals to care.

#### *Acceptability of services*

Among women who responded to survey questions regarding acceptability of services (n=395 in the community sample and n=213 in the HIV-positive sample), there was high reported acceptability of PMTCT (Table 2.1). Almost all (>95%) of women in both the random community sample and in the HIV-positive group stated that they would opt for pregnancy care at a facility that offers HIV testing and would accept HIV testing if it was offered. A substantial number of women (33% in the random sample and 47% of HIV-positive women) reported that they would

want to get pregnant again if they were told that they had HIV. Most (>90% in the community sample and >95% in the HIV-positive sample) reported that if they were pregnant and HIV positive, they would go to the same ANC and delivery provider and would be willing to take medicine to prevent the baby acquiring HIV. Women who accessed a skilled provider for assistance at delivery were equally likely to be willing to return to the same provider as women who did not have skilled care, both in the community sample (97% and 94% respectively) and among HIV-positive women (100% and 98%).

Among the ten women in the community sample (3%) who reported that they would be unwilling to take ARVs for PMTCT, issues of stigma and confidentiality (n=6), fear of medication (n=4), logistical issues of cost and time (n=4) and lack of social acceptability either by husbands (n=3) or others in the community (n=1) were reported. Among the two HIV-positive women who said that they would be unwilling to take ARVs for PMTCT, only one woman was willing to provide a reason. She cited stigma and confidentiality as a barrier and she also stated that since her own life has now been shortened by HIV, there would be no need to help the child, because it will suffer after its mother's death.

### Perceived Barriers to Uptake

Prior to disclosing their own HIV status, all women were asked to identify reasons that they thought HIV-positive women might choose not to get tested for HIV, do not want their babies to get tested, or choose not to take ARVs for PMTCT. Several cross-cutting themes were identified, summarized quantitatively and qualitatively in Tables 2.2 and 2.3 respectively.

#### *Stigma or fear of disclosure*

Stigma and fear of disclosure of one's HIV status was cited most frequently as a response to each of the three questions. Women reported both a sense of shame as well as concern over

confidentiality as potential barriers to uptake. They also noted not just that “people will know status”, but also a fear of gossip and a, “guilt of how people talk”.

### *Denial*

Denial, or not wanting to know one’s status, was frequently cited as a perceived reason not to test both the mother and infant, ranking second only to stigma and fear of disclosure. However, it was not commonly endorsed as a reason to not take ARVs.

### *Concerns over family or husband acceptance*

Both women in the community sample and HIV-positive women reported perception of fear that a woman’s husband would not approve of HIV testing or treatment of the infant. While the majority of women specified a fear of partner disapproval, one woman also specified a “fear of family break-ups” more generally, related to uptake of maternal HIV testing. Another indicated potential abandonment by families, in that “you can be sent away after the test result”.

### *Lack of knowledge*

A lack of knowledge was also commonly cited as a barrier to HIV testing of both the mother and infant. The theme consisted of similar but distinct concepts, which included ignorance or lack of awareness of interventions (“some believe that there is no way they can prevent the baby from being infected”), lack of appreciation for the perceived benefit of the intervention (“not aware of the benefits they get from taking drugs”), and also having a lower level of education.

### *Logistical concerns*

Logistical concerns such as cost or time required to access testing and medication were not commonly reported, particularly for maternal HIV testing. Just under half of women in the community (48%) and HIV-positive women (45%) reported knowing the cost of an HIV test, though most HIV-positive women (98%) and women in the community (90%) who did not know the cost of a test suspected that it was free.

### *Despondency or despair*

Several women reported themes of despondency or despair. These included concepts of stress and worry about implications of a positive test result, survival of mother and child, as well as family relationships. There was a clear awareness of the linkage between the well-being of the mother and the long-term survival of the child living in sub-Saharan Africa. In regards to uptake of maternal HIV testing, women reported “stress” over a child’s survival if the mother was found to be positive. A perceived fatalism was also described related to uptake of PMTCT. One statement was, “even if they take the medicine, they will still die” or “some prefer ending their lives”. Others said that some women may “prefer dying to taking medicine” or that women may find “death to be the only solution for both the mother and child”. Perceptions of despondency and despair were reported at a similar frequency among both HIV-positive women and women in the community sample.

### *Difficulty with or fear of medications*

Difficulty taking or a fear of medications was reported by approximately a quarter of HIV-positive women (24%) as well as a large number of women in the community (29%). Women reported both a fear of harm to the mother and/or child, awareness or concern about side effects or size of the pills, and a concern that women who are very poor may not be able to afford food to take with the medication.

### *Guilt*

Guilt was primarily described as a perceived factor influencing women who do not want to test their baby for HIV. Twenty-seven percent of women in the community sample and 29% of HIV-positive women cited guilt as a reason to refuse HIV-testing of the infant.

### Stigma: Discrimination

Proportions of women reporting knowledge of discrimination and abuse are detailed in Table 2.4. Twenty percent of women in the community and 28% of HIV-positive women reported knowing someone that has experienced one of the forms of discrimination because of HIV in the past year. The most commonly cited forms of discrimination were verbal with 19% of women in the community sample reporting knowing people with HIV who were gossiped about, and 12% reporting knowing people with HIV who were teased or sworn at. Among HIV-positive women, 27% knew someone who was gossiped about and 10% knew someone who was teased or sworn at because of HIV. Twenty-three percent of women in the community sample, and only one-third of women who later reported being HIV-positive, reported knowing someone with HIV. Among them, the majority knew of someone that had experienced discrimination because of HIV (86% in both groups).

Knowledge of discrimination was not significantly associated with decreased uptake of ANC (19% reported discrimination among those who did and did not access ANC) among women in the community sample (Table 2.5). Among women who attend ANC and did not previously know their HIV status, reports of discrimination were more common among those who accessed maternal HIV testing than those who did not (OR 2.18; 95%CI 1.0-8.1). Among all HIV-positive women, report of known discrimination was similar among those who accessed any maternal ARVs for PMTCT (28%) and those who did not (28%). There was also no significant difference in uptake of maternal ARVs at all three time points (antenatal, during labor and postpartum), infant HIV testing or infant ARVs associated with known or observed discrimination.

### Household or Partner Violence and Abuse

Reports of mistreatment or abuse were not uncommon among those who knew someone with HIV (Table 2.4). Thirty-eight percent of women in the community sample and 23% of HIV-positive women who knew anyone with HIV reported knowledge of mistreatment or abuse.

Mistreatment by spouse other than physical violence (26% community, 20% HIV-positive) and isolation within the household (22% community, 10% HIV-positive) were the most commonly cited forms of abuse in each population.

Knowledge of violence or abuse was not associated with uptake of ANC (9% among those who accessed ANC and 8% among those who did not) (Table 2.5). Among women who accessed ANC and did not previously know their HIV status, 9% of those accepting HIV testing and 4% of those not accepting HIV testing reported knowledge of abuse ( $p=0.44$ ). Among all HIV-positive women there was also no significant association between knowledge of abuse and uptake of maternal ARVs, infant testing or infant ARVs for PMTCT.

#### Blame, judgment and shame

Values-based stigma was high in the region, with 89% of women indicating blame or judgment of people with HIV and 46% indicating that they would feel shame if they were associated with someone with HIV. Levels were lower, though still remarkable (86% indicating blame or judgment of people with HIV and 34% indicating they would feel shame), among HIV-positive women. Stigma indicators related to feeling shame if they were associated with someone with HIV were significantly associated with decreased likelihood of maternal HIV testing (OR 0.5; 95%CI 0.3-0.9), infant HIV testing (OR 0.4; 95%CI 0.2-0.9) and decreased uptake of maternal ARVs at all three time points (OR 0.5; 95%CI 0.3-0.9) (Table 2.5). Blame or judgment was not significantly associated with uptake of any of the outcomes.

## **2.4 Discussion**

This mixed-methods landscape analysis provides insight into the social context, perceived notions and sources of information related to uptake of PMTCT; prevalence of stigma,

discrimination and abuse related to HIV; and social barriers to HIV services for pregnant women in a region of Western Kenya.

Engagement in HIV services was highly acceptable among this population in Western Kenya. Women reported high levels of willingness to return to their same care provider for services if they were found to be HIV positive, however more than half of these were seeking delivery care from unskilled providers outside of health facilities. Given that facility delivery has been associated with uptake of maternal ARVs during delivery<sup>39</sup>, it is possible that further improvements in uptake could be seen by changing the delivery protocol for PMTCT, increasing uptake of skilled or facility delivery care among pregnant women, or expanding delivery/referral of PMTCT services to include unskilled providers at a culturally acceptable level. Previous studies have demonstrated willingness of traditional birth attendants (TBAs) to participate in PMTCT services and referral, as well as a high level of satisfaction among women accessing TBAs.<sup>57-59</sup>

Many women reported selecting their care provider as a result of advertising. Approximately one third of women in both the community sample and the HIV-positive group said that they were referred to ANC and delivery providers through advertisements. Mass media campaigns have shown promise in increasing uptake of HIV testing<sup>60</sup> and uptake of condoms<sup>61</sup>, as well as reduction of stigma<sup>62</sup>, in the region, and may help to further improve uptake of skilled delivery and PMTCT.

We found that stigma, both externalized and internalized, was prevalent in this community-based survey. Intriguingly, judgment and blame was similar in prevalence among women living with HIV (86%) as in the general sample of women. Shame about HIV was less prevalent and was significantly associated with being less likely to get HIV tested or take ARVs.

Discrimination was also highly prevalent in this population. However, having observed discrimination did not correlate with decreased uptake of ANC and PMTCT services. This

suggests that observation or knowledge of discrimination, though often measured together with individual-level stigma, is distinct from actually internalizing feelings of shame which appear to be more influential in PMTCT uptake. This is consistent with findings in Zimbabwe in which internalized stigma was significantly associated with decreased uptake of HIV testing, while observed discrimination and knowing someone with HIV was associated with increased uptake.<sup>63</sup> A cohort study in South Africa also found that internalized stigma decreased after initiation of antiretroviral therapy, even while experiences of discrimination increased over time.<sup>64</sup> Our findings trending toward increased uptake associated with more knowledge of discrimination could be explained by discrimination observed in a clinic setting, thus women accessing care may have been more likely to report it.

There are few rigorous evaluations of stigma reduction interventions,<sup>65</sup> but there appears to be promise in media campaigns as well as cognitive behavioral and mentor mother program delivery.<sup>62,66</sup> Social marketing campaigns and counseling interventions advocating for uptake of PMTCT may wish to specifically target messages to decrease internalized values stigma such as shame.

Considering the high prevalence of HIV in Nyanza province, it was surprising how few women reported knowing someone with HIV, especially the HIV-positive women. This could be related to stigma in either not wanting to acknowledge knowing someone with HIV, or knowing someone who has not disclosed their HIV status. This indicates both a reluctance of disclosure as well as an absence of peer support. The need for peer support may also be reflected in the comments related to despondency and despair as perceived barriers to uptake of PMTCT services. The concept of stress was frequently endorsed. And while comments on more severe depression were not common, the fatalism and despair reflected in some of the comments, particularly those who expressed ideas that nothing could be done for mother or child so death

was a better option, was striking. This suggests a potential severity of mental health concerns that may not be currently addressed within the current care system.

Another community-wide awareness was the difficulty with medication and the linkage between food/nutrition and ability to take meds. Fear of medication side-effects was widely perceived, and preemptive conversations about the medications on the part of health care workers at time of testing and referral may help to alleviate some fears.

There were several strengths and limitations of this survey. The community-based platform allowed for assessment of opinions and behavior of both women who did and did not engage in formal health care services, thus providing more generalizable information within the region.

The mixed-methods approach helped to both quantify prevalence of discrimination and abuse, as well as to understand more nuanced perceptions of barriers to care. A limitation is the cross-sectional nature of the study, thus the inability to assess the temporal relationship between measured factors and uptake of PMTCT services.

## **2.5 Conclusion**

This analysis identifies the social landscape and perceived barriers to uptake of PMTCT and subsequent elimination of mother to child transmission. This manuscript highlights perceived needs and opportunities for social support of individuals living with HIV in order to enable them to engage in care and live healthy lives, including peer support, counseling, advertising or marketing, and social awareness.

**Table 2.1 Social Norms: Acceptability of Care**

	<i>Random Community</i> N=395	<i>HIV-positive Women</i> N=213
<b>If you.....</b>		
Could choose between a facility that offers testing or does not?	383 (97.0)	211 (99.1)
Became pregnant again, would you accept HIV testing if offered?	389 (98.5)	213 (100.0)
Were told you have HIV, would you want to get pregnant?	132 (33.4)	99 (46.5)
If you were told you had HIV, would you go to the same provider for ANC in the next pregnancy?	368 (93.2)	209 (98.1)
If you were told you had HIV, would you go to the same provider for delivery in the next pregnancy?	375 (94.9)	211 (99.1)
Were pregnant and HIV+, would you be willing to take medicine to prevent the baby getting infected?	385 (97.5)	211 (99.1)

\* 10 in random sample and 3 in HIV-positive sample excluded for missing data

Table 2.2 Perceived Barriers to Uptake of Testing and PMTCT

	<i>Random Community</i> N=405	<i>HIV-positive Women</i> N=216
<b>Why do you think some women...</b>		
<b>Choose not to get tested for HIV</b>		
Stigma or fear of disclosure	260 (64.2)	161 (74.5)
Denial / Don't want to know	230 (56.8)	144 (66.7)
Husband would not like it	61 (15.1)	56 (25.9)
Lack of knowledge	42 (10.4)	23 (10.7)
Despondency or despair	23 (5.7)	12 (5.6)
Feel guilty	12 (3.0)	3 (1.4)
Logistical concerns (cost/time)	6 (1.5)	2 (0.9)
Worried about medications	0 (0.0)	4 (1.9)
Fear of family break-ups	1 (0.0)	0 (0.0)
<b>Who are HIV+ do not want to test their babies for HIV</b>		
Stigma or fear of disclosure	197 (48.6)	120 (55.6)
Denial / Don't want to know	193 (47.7)	118 (54.6)
Feel guilty	111 (27.4)	63 (29.2)
Lack of knowledge	65 (16.1)	34 (15.7)
Husband would not like it	48 (11.9)	34 (15.7)
Logistical concerns (cost/time)	11 (2.7)	3 (1.4)
Despondency or despair	3 (0.7)	1 (0.5)
<b>Who know that they have HIV choose not to take medicine to prevent the baby getting infected</b>		
Stigma or fear of disclosure	164 (40.5)	100 (46.3)
Fear of or difficulty with medication	116 (28.6)	53 (24.5)
Logistical concerns (cost/time)	14 (3.5)	5 (2.3)
Feel guilty	4 (1.0)	2 (0.9)
Lack of knowledge	18 (4.4)	5 (2.3)
Denial	3 (0.7)	0 (0.0)
Despondency or despair	10 (2.5)	2 (0.9)
Husband would not like it	46 (11.4)	28 (13.0)
Health worker advice	1 (0.0)	0 (0.0)

**Table 2.3 Sample Quotes**

<b>Maternal HIV Testing</b>	
Stigma, discrimination, and fear of disclosure	Wants to be secret Confidentiality is not guaranteed Fear of discrimination A lot of shame
Lack of knowledge	Ignorance They don't know the benefits
Despondency or despair	To avoid stress Afraid of the stress of the outcome Fear of shock Stress of soon she will die Stress of awareness of child survival
Worried about medication	Afraid of medicine
Family relationships	Bring problems in the family
<b>Infant HIV Testing</b>	
Stigma, discrimination, and fear of disclosure	Fear of stigmatization Can be sent away after test result
Lack of knowledge	Depends on peoples understanding Believe it's for adults Ignorance Fear the blood test can cause their babies to have insufficient blood
Despondency or despair	Fear of death The child will still die even if it is tested
<b>Infant ARVs for PMTCT</b>	
Stigma, discrimination, and fear of disclosure	People will know status Guilt of how people talk
Difficulty with medication	Medicine requires a balanced diet which they cannot afford The medicine needs a lot of food Taking drugs is a problem Size of medicine
Lack of knowledge	Not aware of the benefits they get from taking drugs Some believe that there is no way they can prevent the baby from being infected
Denial	Self-denial: they do not want to accept the fact that they have HIV
Despondency or despair	Stress Too much thoughts Some prefer ending their lives, not caring about the child they are carrying Prefer dying to taking medicine Even if they take medicine, they will still die People's emotional strength varies

**Table 2.4 Knowledge of someone with HIV/AIDS that experience abuse or discrimination in the last year**

<b>Knowledge of Discrimination or Abuse</b>	Among those in community who know someone with HIV (n=92, 23%)	Among all in community (n=405)	Among positive women who know someone with HIV (n=69, 32%)	Among all HIV-positive women (n=215)
	n(%)	n(%)	n(%)	n(%)
<b>Discrimination</b>				
Excluded from social gathering	16 (17.4)	16 (4.0)	7 (10.1)	7 (3.3)
Lost customers or lost a job	15 (16.3)	15 (3.7)	5 (7.3)	5 (2.3)
Abandoned by family/sent away	16 (17.4)	16 (4.0)	8 (11.6)	8 (3.7)
Abandoned by spouse or partner	30 (32.6)	30 (7.4)	15 (21.7)	15 (7.0)
Teased or sworn at	48 (52.2)	48 (11.9)	22 (31.9)	22 (10.2)
Lost respect or standing within the family	21 (22.8)	21 (5.2)	10 (14.5)	10 (4.7)
Lost respect or standing within the community	22 (22.8)	22 (5.4)	6 (8.6)	6 (2.8)
Gossiped about	78 (83.7)	78 (19.3)	57 (81.4)	57 (26.5)
<b>TOTAL MEASURE*</b>	<b>79 (85.9)</b>	<b>79 (19.5)</b>	<b>60 (85.7)</b>	<b>60 (27.9)</b>
<b>Abuse or mistreatment</b>				
Mistreated by spouse or partner	24 (26.1)	24 (5.9)	14 (20.0)	14 (6.5)
Physically harmed by spouse partner	14 (15.2)	14 (3.5)	4 (5.7)	4 (1.9)
Physically harmed by other person	10 (10.9)	10 (2.5)	2 (2.9)	2 (1.0)
Isolated within the household	20 (21.7)	20 (4.9)	7 (10.0)	7 (3.3)
<b>TOTAL MEASURE*</b>	<b>35 (38.0)</b>	<b>35 (8.6)</b>	<b>16 (22.9)</b>	<b>16 (7.4)</b>

\* Calculated if selected any of the above indicators

**Table 2.5 Stigma and Uptake of Care along the PMTCT Cascade**

	<b>No uptake</b> n(%)	<b>Uptake</b> n(%)	<b>OR (95%CI)</b>
<b>Attendance at ANC</b>			
Judge or blame persons with HIV for their illness	25 (96.2)	337 (88.9)	
Shame if they associated with someone with HIV	14 (53.9)	174 (45.9)	
Known or observed discrimination	5 (19.2)	74 (19.5)	
Known or observed mistreatment or abuse	2 (7.7)	33 (8.7)	
<b>HIV Testing</b>			
Judge or blame persons with HIV for their illness	45 (93.8)	279 (88.9)	
Shame if they associated with someone with HIV	30 (62.5)	137 (43.6)	0.46 (0.25-0.87) <sup>†</sup>
Known or observed discrimination	4 (8.3)	64 (20.4)	
Known or observed mistreatment or abuse	2 (4.2)	28 (8.9)	
<b>Any Maternal Antiretrovirals for PMTCT</b>			
Judge or blame persons with HIV for their illness	31 (79.5)	154 (87.0)	
Shame if they associated with someone with HIV	18 (47.4)	56 (31.6)	0.51 (0.25-1.05) <sup>*</sup>
Known or observed discrimination	11 (29.0)	49 (27.7)	
Known or observed mistreatment or abuse	4 (10.5)	12 (6.8)	
<b>Maternal Antiretrovirals for PMTCT during prenatal, delivery AND postpartum periods</b>			
Judge or blame persons with HIV for their illness	83 (83.8)	102 (87.2)	
Shame if they associated with someone with HIV	42 (42.9)	32 (27.4)	0.50 (0.28-0.89) <sup>†</sup>
Known or observed discrimination	24 (24.5)	36 (30.8)	
Known or observed mistreatment or abuse	9 (9.2)	7 (6.0)	
<b>Infant HIV Testing</b>			
Judge or blame persons with HIV for their illness	29 (78.4)	154 (87.5)	
Shame if they associated with someone with HIV	19 (51.4)	55 (31.3)	0.43 (0.21-0.88) <sup>†</sup>
Known or observed discrimination	6 (16.2)	53 (30.1)	
Known or observed mistreatment or abuse	3 (8.1)	13 (7.4)	
<b>Infant Antiretrovirals for PMTCT</b>			
Judge or blame persons with HIV for their illness	36 (83.7)	147 (86.5)	
Shame if they associated with someone with HIV	19 (44.2)	55 (32.6)	
Known or observed discrimination	11 (25.6)	49 (29.0)	
Known or observed mistreatment or abuse	3 (7.0)	13 (7.7)	

\* p&lt;0.10, † p&lt;0.05

## Chapter 3. Prevention of Mother to Child Transmission of HIV Services in Western Kenya: Mapping and Identifying Service Gaps

### 3.1 Background

Health systems in sub-Saharan Africa have experienced dramatic expansion of HIV prevention and treatment services since the introduction of antiretroviral therapy (ART) and multilateral donor funds such as the President's Plan for AIDS Relief (PEPFAR) and the Global Fund. While scale-up has led to increased delivery of prevention of mother to child transmission of HIV (PMTCT) interventions, challenges persist in the capacity of health systems to reach those most vulnerable and at greatest need, in delivering care in a comprehensive and integrated manner, and in an adequate scale to effectively eliminate new pediatric HIV infections.<sup>67</sup>

Structural facility or health systems level factors have been identified as playing a role in determining maternal uptake of PMTCT<sup>35,68-70</sup> and transition to long-term ART.<sup>71-73</sup> Although increasingly efficacious antiretroviral (ARV) regimens have been introduced to prevent mother to child transmission, modeling estimates demonstrate only marginal decreases in vertical transmission rates by improving regimen efficacy at current health system performance levels.<sup>74</sup> Improving health system performance, and thus increasing access to PMTCT, has significantly more impact in lowering rates of transmission and numbers of new infant HIV infections.

In addition to quantity and quality of services offered, geographic location of health services has been identified as a barrier to uptake of health care in general, and HIV care more specifically.<sup>30</sup> Geographical Information System (GIS) mapping has been demonstrated to be a potentially important tool to identify service gaps or underserved areas, and to calculate distance to delivery of HIV care and prevention services.<sup>75-78</sup> This technique has not yet been implemented for assessing access to PMTCT services in rural Kenya.

The aim of this study was to characterize the service provision landscape in delivering maternal child health (MCH) and PMTCT services in rural Western Kenya. The mapping and description of PMTCT service provision, linked together with maternal household survey data, also enabled assessment of whether availability of PMTCT services is related to its utilization and uptake.

## **3.2 Methods**

### Study Design

A cross-sectional survey assessing policies, practice and service capacity for PMTCT was performed at 40 maternal health facilities in the Health Demographic Surveillance System (HDSS) area in Nyanza Province, Kenya. Concurrently, a community-based survey of women in the region who recently delivered an infant was conducted in order to assess which health facility, if any, women attended at last pregnancy, as well as rates and correlates of uptake of PMTCT services.

### Study Population

Two key populations were surveyed in this study. One population included service providers at a health facility or private practice who offered antenatal care (ANC), delivery or PMTCT services in the HDSS area. A single provider from each identified facility, specifically the individual who was most often responsible for PMTCT services at the facility, usually a nurse, was identified. The health system in Kenya consists of dispensaries at the lowest tier, with increasing levels of care in health centers, nursing homes, district and provincial hospital facilities.<sup>79</sup> Dispensaries are staffed by nurses and medical assistants and can provide antenatal care, treatment for simple medical problems and assistance with normal deliveries. The second population included women maternal age 14 and older, the age of emancipation in Kenya for mothers. Women who resided in the HDSS area and had delivered an infant within

the previous year (January to December 2010) were eligible to participate. The sampled populations of women from the random community sample, as well as the HIV-positive oversample in regions where home-based counseling and testing had taken place, are identified in Figure 3.1.

### Study Location

The HDSS covers 383 villages with a population of approximately 220,000 in Nyanza Province, Kenya. Three regions make up this area: Karemo, Gem and Asembo. All three regions are rural. The HDSS was launched in September 2001 by the US Centers for Disease Control and Prevention (CDC) in collaboration with the Kenya Medical Research Institute (KEMRI) and serves as a community-based platform for monitoring health status. The HDSS provides demographic and health information as well as disease- or intervention-specific information.<sup>38</sup>

### Sampling

A comprehensive list of all public and private facilities in the HDSS region was generated prior to the start of this study. The study team accessed a number of sources to comprehensively identify all providers of maternal health in the HDSS. These included meetings with District AIDS and STI Coordinators and District Medical Officers, area program managers of non-government organizations (NGOs) supporting local facilities in implementation of PMTCT, the eHealth-Kenya database website<sup>80</sup>, and local HIV research study and community mobilization coordinators.

For the maternal surveys, a random sample of women who delivered an infant in the previous year was generated. A second comprehensive sample of known HIV-positive women from an adjacent area in the HDSS, where home-based counseling and testing had been recently implemented, was also generated in order to provide additional power to detect associations further along the PMTCT cascade.

### Data Collection

Surveys of the health facilities and women in the community were conducted simultaneously in early 2011. Health care provider surveys included questions about the type of services offered, institutional protocols and policies, ARV availability, provider-level stigma, and institutional capacity. The surveys were administered by field workers and took approximately 30-35 minutes to complete. The surveys were developed by a panel of service experts including a Kenyan OB/GYN, a Kenyan Global AIDS Program physician, a Kenyan PMTCT Technical Advisor from the Global AIDS Program, and a member of the survey team that conducted the 2004 Kenya Service Provision Assessment Survey. Provider stigma questions were adopted from a validated toolkit and addressed domains of discrimination, and values of shame, blame and judgment.<sup>56</sup>

Mothers' surveys included information on the health facility she accessed for both ANC and delivery care at last pregnancy, as well as outcomes of uptake of care along the PMTCT cascade: antenatal care, maternal HIV testing, maternal and infant antiretrovirals, and infant HIV testing.

Fieldworkers administered surveys and recorded GPS location on hand-held PDAs using electronic forms (Pendragon Software Corporation, Buffalo Grove, IL). Fieldworkers were blinded to HIV status of community participants, even when status was known to the sampling team, thus self-report of HIV status was used for all analyses.

### Data Analysis

Data analysis utilized chi-squared analyses for comparisons of proportions using STATA (STATA Corp, College Station, Texas), Wilcoxon rank sum tests were used for comparisons where data were not normally distributed, and Fisher's exact test was used when cells were less than ten. Women in the community sample reported the health facility they attended at last pregnancy and this information was used to link facility-level data to maternal outcomes. GIS

information was mapped using ArcGIS software (Esri, Redlands, California).

### Ethical Considerations

Prior to study start, community engagement activities were held targeting the area senior medical officers, the local community advisory board, the village reporters, chiefs and assistant chiefs. Letters of support were obtained from area district and province medical officers, and the study was approved by the University of Washington Institutional Review Board (#36022) and the Kenya Medical Research Institute Ethical Review Committee (#1714). Informed consent was obtained from all participants, and women in the community consented both to participate in the study and also to have their data from these surveys linked to their HDSS record.

## **3.3 Results**

### Services and Characteristics of Maternal Health Facilities

Public, private and mission facilities were included and a total of 41 facilities were identified. One service provider from a NGO-facility declined to participate, resulting in a sample of 40 providers (Table 3.1). Figures 3.2a and 3.2b identify facilities by type of facility and the MCH/PMTCT services offered at each. Most facilities were public government facilities (80%), with lower tier dispensaries being the most prevalent (70%). All facilities offered general medical services, including ANC. Other services included family planning (95%), sexually transmitted infection services (93%), and tuberculosis care (75%). Providers estimated seeing a median of 40 women for antenatal services in the last month (Range 3-400). Population density in the random sample of women relative to service availability is shown in Figure 3.3. Most health facilities appear close to population centers, though only one of these is a hospital and it is not a government operated facility.

### HIV Testing

Among all facilities, 38 (95%) offered HIV testing (Table 3.2). The two that did not offer HIV testing were both private clinics. Among facilities offering any testing services, nearly all (95%) had a standard protocol for testing in place. All but one stated that testing was offered at the time of visit, whereas one facility required women to make an appointment for a test at a later time. Just over half of facilities (55%) reported offering HIV testing to families (partners and children) to all individuals tested. Among 32 facilities that provided partner HIV testing if requested, providers estimated actually testing only a small number of (median 2; IQR 0-5) male partners each month. Testing was free at all facilities.

### Labor and Delivery

Delivery services were offered at 85% of facilities. Estimates of proportions of women who returned to their facility for delivery care after ANC were low (median 22.5; IQR 10-42.5). Two of the facilities were able to perform cesarean sections on-site. Ninety-five percent of delivery facilities offered HIV testing for women not tested prenatally, and 80% regularly offered ARVs for PMTCT to women delivering on-site.

### PMTCT services for pregnant women

Thirty-three facilities (83%) reported offering some PMTCT services for pregnant women (Table 3.3), with a lower number (26 facilities; 65%) reported offering ARVs for mothers and infants through the breastfeeding period. Among facilities offering PMTCT, most (67%) used WHO stage and CD4 count to assess criteria for ART versus PMTCT. Only one facility used WHO stage only. Single-dose nevirapine administration was still common (39%), while adherence to WHO Option A was reported at 27% of facilities and Option B guidelines were reported at 24% of facilities. However, 64% of PMTCT facilities (n=21) reported a change in PMTCT practices in the last six months, with the majority of these (n=17) reporting change to a more comprehensive

regimen. All facilities following Option B guidelines and 89% of facilities following Option A had CD4 testing available. Seventy-five percent of facilities following Option B and 100% of facilities following Option A were government operated.

The majority of (88%) facilities allowed women to take antiretroviral medication home for self-administration after delivery. The four that did not reported they standardly provided medication between 2 and 4 months gestation in clinic. All but one facility offered counseling on maternal nutrition, and 83% had cotrimoxazole prophylaxis available for pregnant women.

#### PMTCT services for infants

Eighty-five percent (n=34/40) of facilities reported that ARVs for PMTCT were available for infants (Table 3.3). Ninety-seven percent (n=33/34) of these reported that providing mothers with ARVs to administer to the child after delivery was standard practice. Among all facilities, 83% offered cotrimoxazole prophylaxis to infants. All but one facility offered counseling on infant feeding to pregnant women, and all but one of these reported recommending exclusive breastfeeding for six months. Only one sub-district hospital, the highest tier public facility in the survey region, offered breast milk substitute services. Substitutes were provided free of charge, though the facility reported lack of supply sometimes (scale: often, sometimes, rarely, never).

#### Laboratory Services

Most facilities (95%) reported having some laboratory services available to pregnant women. Sixty percent had CD4 counts available, only two of these were on-site; and sixty percent had PCR available; all of which were sent to a central laboratory in Kisumu. Median time to CD4 result was one week (IQR 2-14 days) and time to PCR was a median of 3 weeks (IQR 14 to 30 days). No private clinics offered CD4 testing or infant PCR. Other facilities not offering CD4 or PCR testing included 11 dispensaries and a private hospital.

### Provider Attitudes

Seven providers (18%) endorsed attitudes of judgment of individuals with HIV, with the majority of these (n=5) agreeing with the statement that HIV is a punishment for bad behavior (Table 3.4). Of the three values (judgment, blame and shame), providers most often agreed with values of blame, specifically that promiscuous men were the ones that spread HIV in the community (28%). Few providers agreed with statements of feeling ashamed if someone in the family had HIV (10%) or if they themselves were infected (3%). Observed discrimination towards clients by health providers was common (75%), though this generally consisted of extra precautions with instruments (50%) or using latex gloves in non-invasive exams (45%). Only one facility, a public dispensary, reported observing providers gossiping about patient HIV status.

### Distance to Care - Random Sample

Among women in the random community sample (n=405), 83% were matched to an interviewed facility. Distance data between women and the facility they attended was available on 92% of those with facility information. Distance data was unavailable if GPS location was missing from the mothers (n=29) or if mothers accessed facilities outside of the DSS area (n=40) or if women did not attend ANC (n=25). Women without matched facility data and women missing distance data were not significantly different in socioeconomic status or outcomes of HIV testing and maternal ARV uptake than those who were not missing facility or distance information.

Among women who attended ANC, the median distance to attended facility was 2.3 kilometers (IQR 1.5-3.5) in the random community sample, and the majority of women (87%) walked to their ANC appointment (Table 3.5). Median distance to attended delivery facility was 2.1 kilometers (IQR 1.3-3.9), and over half of women (53%) walked to their delivery facility. Travel time to both ANC and delivery facilities was approximately one hour.

HIV-positive women were more likely to deliver at a health facility (70%) than HIV-negative women (40%) ( $p < 0.001$ ). Among women that attended health facilities, HIV-positive women traveled longer to delivery care than negative women, median 0.5 hours (IQR 0.3-1.5) among HIV-negative women and 1.5 hours (IQR 0.75-2) among HIV-positive women. There was no difference in travel time to ANC facility.

### Choice of facility

Straight line distances to care from woman's home to the care facility she attended are shown for both ANC (Figure 3.4) and delivery services (Figure 3.5). Although women did not always attend the closest facility, the women who bypassed nearby facilities generally traveled to either a higher tier facility, or a facility that offered more comprehensive services. Among all HIV-positive women, maternal stigma (shame) was not associated with distance to ANC or delivery provider.

Twelve of the 40 facilities were not attended by any women who participated in the survey. Seventy-eight percent of public facilities were attended by surveyed women versus 38% of private ( $p < 0.03$ ). Facilities not attended by women in the survey included 7 dispensaries, 1 district hospital, 1 private clinic, 2 private hospitals, and 1 sub-district hospital, and this distribution was similar to facilities attended. Many of the facilities not attended were located near the borders of the survey area or had fewer services to offer. Facilities offering CD4 and PCR testing were more commonly accessed (79% and 83% respectively) than facilities who did not (21% and 17%) ( $p = 0.06$  and  $0.01$ ).

No HIV-positive women attended private clinics. HIV-positive women who attended the mission-based hospital facilities in the region for ANC had significantly higher uptake of maternal ARVs (97%) than those who attended government facilities (80%) ( $p = 0.03$ ); the same was true for uptake of infant ARVs with 100% of those attending mission facilities administering infant ARVs compared to 77% of those attending government facilities ( $p < 0.001$ ).

### 3.4 Discussion

In this survey, we comprehensively mapped and assessed all facilities offering PMTCT, including public, private and mission facilities, and linked this information to a community-based survey of women. We found generally high availability (>80%) of HIV testing, ARVs for PMTCT and cotrimoxazole provision, but identified several areas for potential enhancement. These include varied implementation of PMTCT interventions ranging from single-dose nevirapine to Option B, low levels of partner HIV testing, and long turn-around time for CD4 and infant PCR results. Provider-reported stigma was relatively low, though fear of occupational exposure appears to persist. Together, these findings identify several opportunities to enhance PMTCT services.

Maps of linkages between women and the facilities they attended highlight uptake patterns in access to care. Most women did not deliver at a facility, and HIV-positive women delivered in a facility more often, traveling further to deliver, than HIV-negative women. Maternal stigma was not associated with distance to care facility accessed, and bypassed facilities generally offered fewer services, suggesting that women are seeking a higher level of care and not necessarily avoiding clinics where they may be known in the community. Population density maps demonstrate that availability of health services corresponds to population centers, and could serve as useful tools for strategically planning locations of new facilities, or expanding available services, in areas where higher tier or more comprehensive services are limited.

HIV-testing was available at nearly all facilities, however testing was not frequently offered to other family members. Previous research has found an association between partner involvement and uptake of PMTCT and other HIV services,<sup>48,69,81,82</sup> thus this may be a method to increase uptake and adherence. However, how this is implemented in the context of empowerment issues<sup>83</sup> and intimate partner violence may require careful consideration.

Increasing testing of other children in the household may provide additional benefit for earlier initiation of pediatric antiretroviral therapy among children who are undiagnosed. Integrating family HIV testing services at clinics not currently offering these (~45%) and working with communities to increase acceptability and uptake of partner testing are priority areas that could improve PMTCT.

Availability of maternal PMTCT ARVs was high, and reports of changes to more comprehensive regimens were common, reflecting dynamic scale-up in the region over the past decade. The Kenyan Ministry of Health (MOH) reported that by 2008, PMTCT services had been introduced to more than 80% of antenatal care facilities and in 1,000 sites.<sup>41</sup> However, the varied PMTCT regimens we observed including single-dose nevirapine, Option A, and Option B illustrate the challenge of evenly adapting regimens during national scale-up. WHO PMTCT guidelines have rapidly changed during the past decade and Kenyan national policy has mirrored WHO guidelines. These changes, in turn, require extensive retraining and adaptations for implementation with resulting diversity in approaches as individual programs transition.

Although the facilities surveyed offered most services, opportunities exist for increasing comprehensive services at lower tier facilities. For example, implementing point-of-care testing (POCT) in facilities without links to laboratories, or where turn-around time for diagnostic tests is long, may enhance PMTCT. The average turnaround time for CD4 counts in facilities was one week, and delays compromise timely initiation of ART. Several studies have demonstrated that implementation of POC CD4 count tests significantly decreased loss to follow-up prior to ART initiation and reduced the median time from enrollment to ART initiation.<sup>72,84</sup> With PMTCT requiring a similar cascade of access, implementation at the MCH level may similarly promote prompt initiation of ARVs for PMTCT.

Despite frequent concerns about confidentiality and treatment by care providers among

women,<sup>69,73,85</sup> stigma among health providers was unexpectedly low. This is consistent with a 2009 study in South Africa,<sup>86</sup> in which provider attitudes toward individuals living with HIV were generally positive, but fear of occupational exposure persisted. Interventions to increase education about occupational HIV transmission and use of universal precautions may further alleviate unintended stigma resulting from differential treatment of HIV-positive clients.

This study was novel in its approach to use GIS mapping to assess PMTCT service availability in a rural community in Kenya, and in the ability to link data between the majority of women in the study area with the facilities they accessed. Limitations include the cross-sectional nature of the surveys, and relatively small sample size of facilities assessed.

### **3.5 Conclusion**

Availability of PMTCT services in Western Kenya has seen considerable expansion, though opportunities for improvement persist. Partner and family testing services, implementation of POCT, and provision of more comprehensive services in lower tier facilities all have potential impact in improving service delivery, uptake of PMTCT services by women and ultimate decreases in new pediatric HIV infections.

**Table 3.1. General Facility Information**

<i>Facility Information</i>	<b>N=40</b>
Type of facility	
District Hospital	2 (5.0)
Sub-district Hospital	3 (7.5)
Health Center	1 (2.5)
Dispensary	28 (70.0)
Mission Hospital	2 (5.0)
Private Clinic	2 (5.0)
Private Hospital	2 (5.0)
Managing authority	
Government	32 (80.0)
Mission/Church	4 (10.0)
NGO	1 (2.5)
Private for-profit	2 (5.0)
Other: MOH/NGO collaboration	1 (2.5)
Services offered	
General medical care	40 (100.0)
Pediatric care	39 (97.5)
Antenatal care	40 (100.0)
Family planning	38 (95.0)
STI services	37 (92.5)
TB care	30 (75.0)
Estimated number of women seen per month for ANC	40 (19-69)

**Table 3.2. HIV Testing Practices**

<i>HIV Testing</i>	<b>N=40</b>
Routine practice to recommend HIV test to all pregnant women	39 (97.5)
HIV testing offered at facility	38 (95.0)
Standard protocol for HIV testing	36 (94.7)
Provide service at time of visit	35 (97.2)
Make appointment for test at another time	1 (2.8)
Couples VCT performed if requested	35 (92.1)
Couples VCT offered to all individuals tested	23 (60.5)
Provide testing to male partners of pregnant women if requested	32 (80.0)
Family testing (partners and children) offered to all individuals tested	22 (55.0)
Estimated number of partners tested in last month	2 (0-5)

**Table 3.3: PMTCT Services for Pregnant Women and Infants**

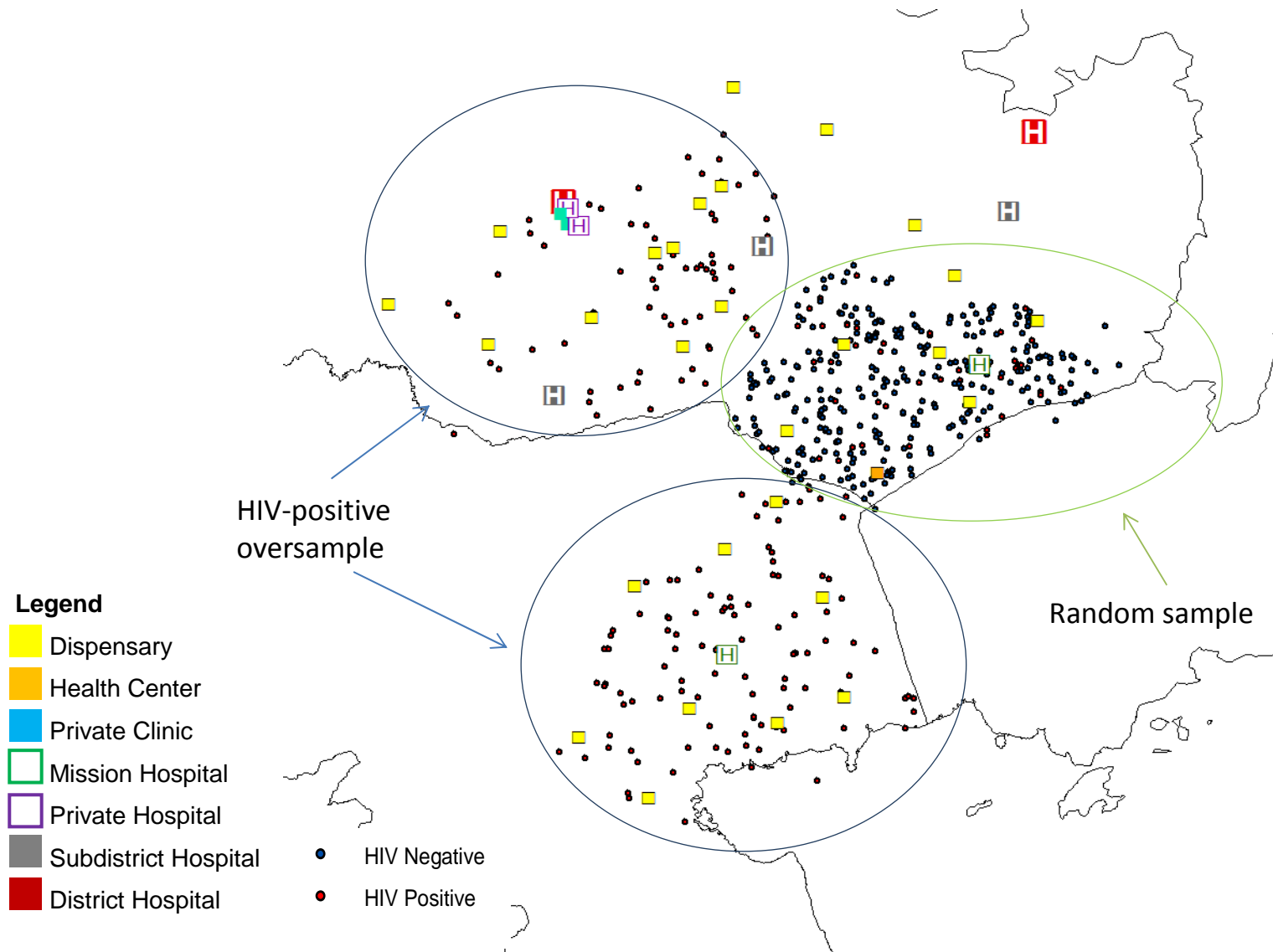
<b>PMTCT Services</b>	<b>n(%)</b>
<b>Antiretrovirals for Pregnant Women</b>	<b>N=33</b>
Criteria for ART versus PMTCT	
WHO Stage and CD4 Count	22 (66.7)
CD4 Count	10 (30.3)
WHO Stage	1 (3.0)
Deliver PMTCT: Give to women to self-administer	29 (87.9)
Deliver PMTCT: Give at x months pregnancy	20 (60.6)
Number of months	4 (3-5)
Deliver PMTCT: Give on-site during delivery	29 (87.9)
Facility PMTCT guidelines	
Single-dose nevirapine	10 (30.3)
Single-dose nevirapine plus tail	3 (9.1)
WHO Option A (Maternal AZT)	9 (27.3)
WHO Option B (Maternal triple ARV prophylaxis)	8 (24.2)
Tiered Combined	2 (6.1)
Change in PMTCT practices in last 6 months	21 (63.6)
Type of change (n=21)	
Earlier ART eligibility	3 (14.3)
More comprehensive regimen	17 (81.0)
AZT available	1 (4.8)
Offer combination ART for pregnant HIV-positive women	29 (87.9)
Maternal ARVs for PMTCT offered during breastfeeding	26 (78.8)
Infant ARVs for PMTCT offered during breastfeeding	26 (78.8)
<b>Antiretrovirals for Infants</b>	<b>N=34</b>
Deliver PMTCT: Give to women to self-administer after home delivery	33 (97.1)
Deliver PMTCT: Given to infants on-site after delivery	28 (82.4)
Deliver PMTCT: Provided to infants while breastfeeding	30 (88.2)
Offer PMTCT for free	34 (100.0)
<b>Infant Services</b>	<b>N=40</b>
Cotrimoxizole prophylaxis	33 (82.5)
Monitoring of growth and development	38 (95.0)
<b>Counseling on Infant Feeding</b>	<b>N=39</b>
All HIV+ women receive counseling on infant feeding	39 (100.0)
Recommend exclusive breastfeeding to all women x 6 months	38 (97.4)
Recommend replacement feeding	21 (53.9)

Table 3.4: Provider Attitudes

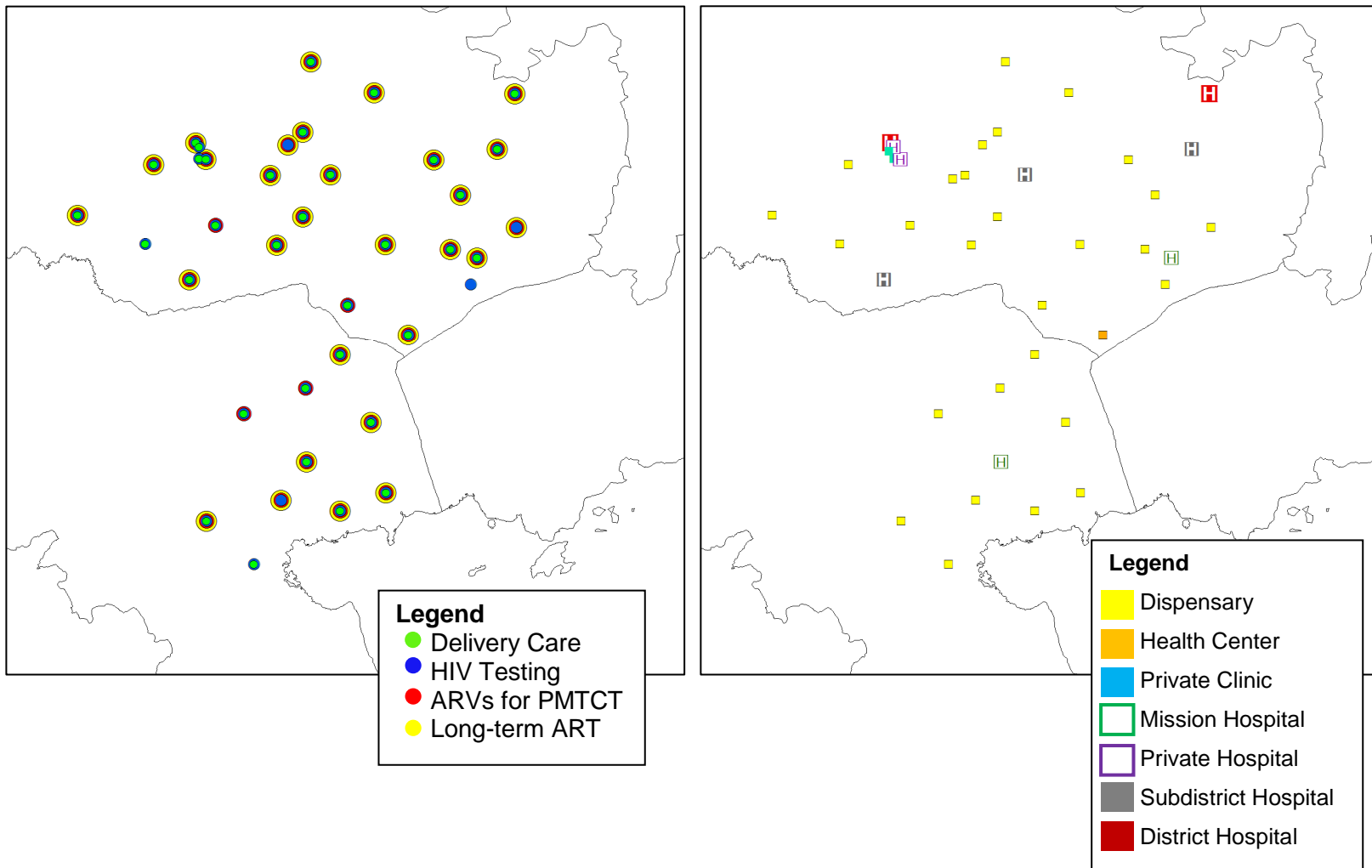
<i>Stigma Indicators</i>	<b>N=40</b> n(%)
<b>Judgment</b>	
HIV is a punishment from God	2 (5.0)
HIV is a punishment for bad behavior	5 (12.5)
People with HIV should be ashamed of themselves	1 (2.5)
<i>Judgment aggregate</i>	7 (17.5)
<b>Blame</b>	
Promiscuous men are the ones that spread HIV in our community	11 (27.5)
It is the prostitutes that spread HIV	6 (15.0)
<i>Blame aggregate</i>	12 (30.0)
<b>Shame</b>	
I would feel ashamed if I were infected with HIV	1 (2.5)
I would feel ashamed if someone in my family had HIV	4 (10.0)
<i>Shame aggregate</i>	4 (10.0)
<b>Discrimination</b>	
Receiving less care or attention than other patients	1 (2.5)
Extra precautions being taken with sterilization of instruments	20 (50.0)
Requiring HIV test prior to surgery	17 (42.5)
Using latex gloves on non-invasive exams	18 (45.0)
Testing for HIV without consent	1 (2.5)
Providers gossiping about HIV status	1 (2.5)
<i>Discrimination aggregate</i>	30 (75.0)

**Table 3.5: Distance to care facility**

<i>Distance to Care</i>	<i>Random Community N=405</i>
<b>Among those who attended ANC</b>	<b>N=379</b>
Travel time to reach ANC (n=362)	1 hour (0.5-1.5)
Typical mode of transport to ANC (n=377)	
Walk	327 (86.7)
Mini-bus	20 (5.3)
Other	30 (8.0)
Distance to ANC (n=311)	2.3 km (1.5-3.5)
<b>Among those who attended facility delivery</b>	<b>N=170</b>
Time to reach delivery facility (n=146)	0.9 hour (0.3-1.5)
Typical mode of transport to delivery facility	
Walk	90 (52.9)
Mini-bus	28 (16.5)
Motorcycle	31 (18.2)
Other	20 (11.8)
Distance to actual delivery (n=113)	2.1 (1.3-3.5)



**Figure 3.1 Map of Study Populations**



**Figure 3.2a Map of Surveyed Health Facilities by Services Offered**

**Figure 3.2b Map of Surveyed Health Facilities by Facility Type**

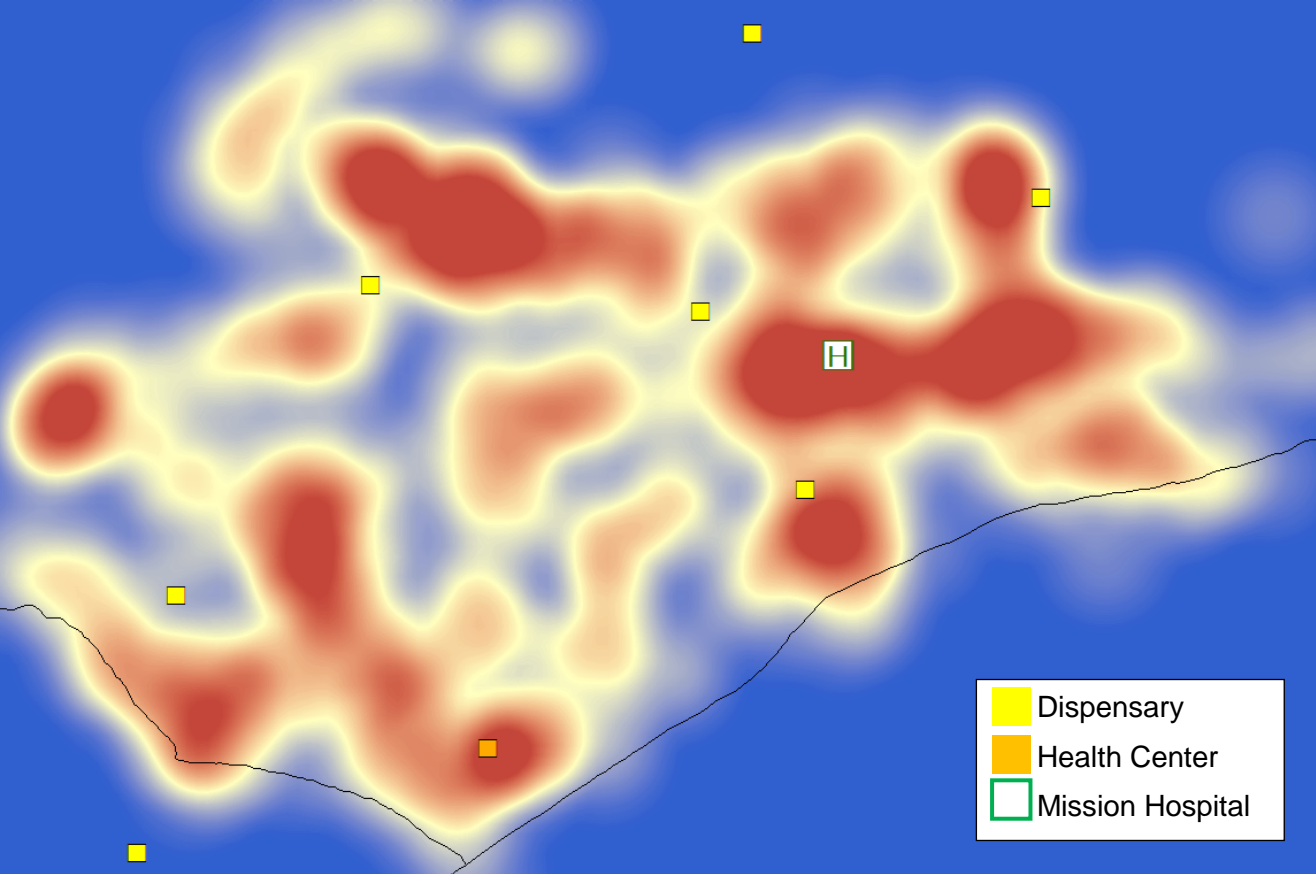
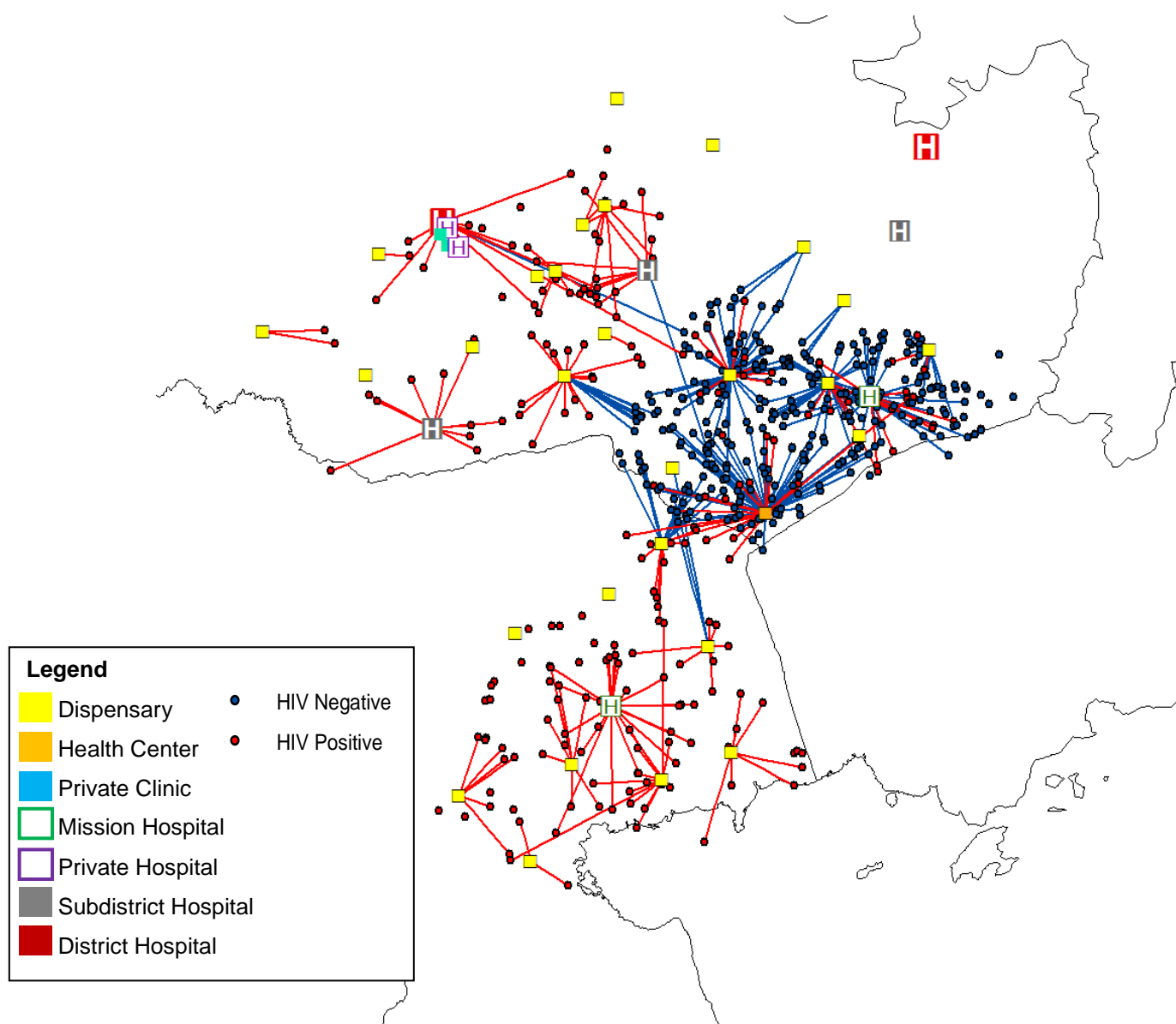
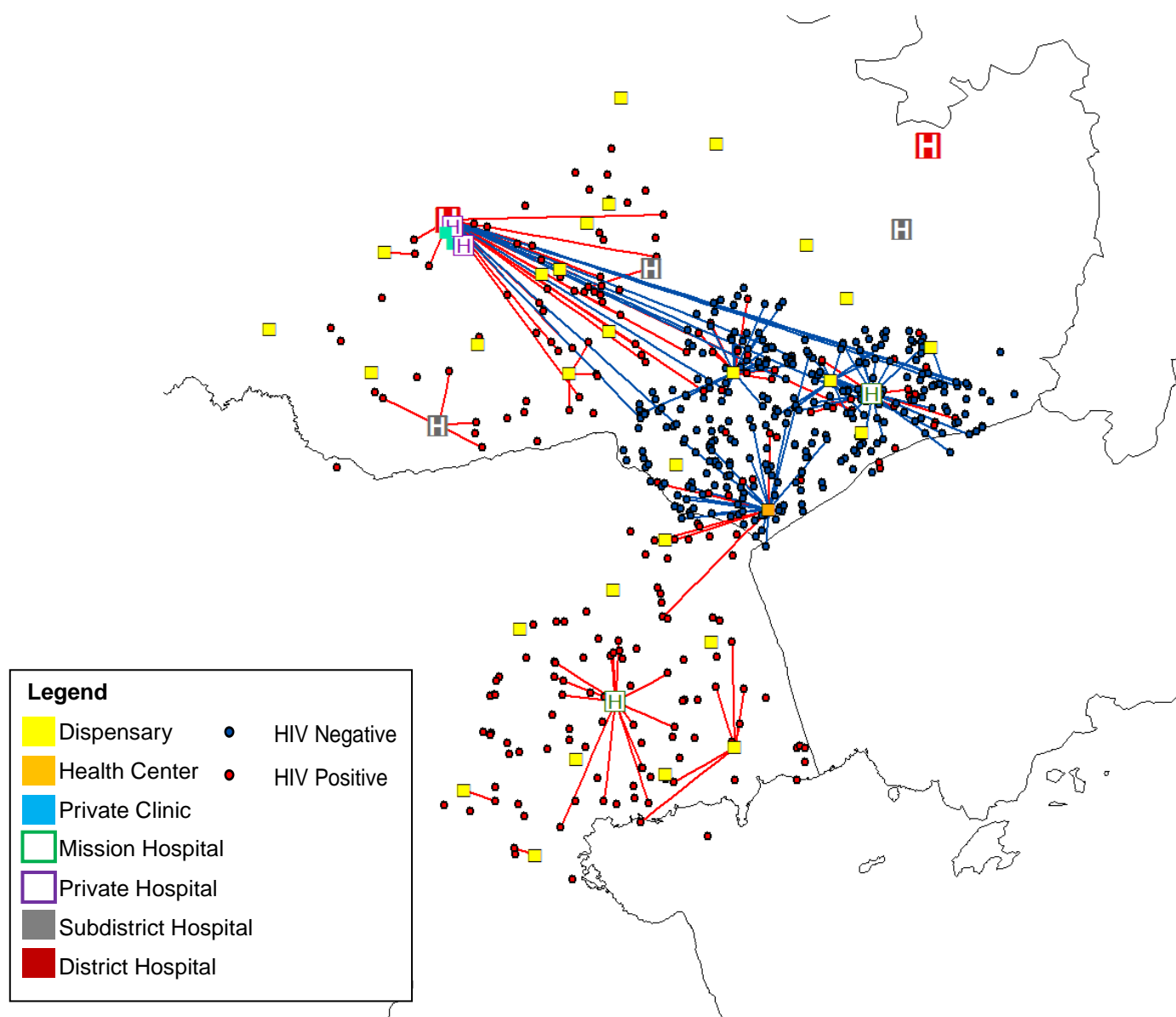


Figure 3.3 Map of Providers Relative to Population Density in the Random Sample



**Figure 3.4 Map of Antenatal Facilities Accessed**



**Figure 3.5 Map of Delivery Facilities Accessed**

## Conclusion

We found high levels of PMTCT availability and high levels of maternal PMTCT uptake in this community-based survey. These are encouraging findings, particularly since these data are derived from a community-based, as opposed to a clinic-based sample. Differences between these findings and previous clinic-based studies highlight the importance and value of assessing engagement in care from a community perspective.

The correlates of uptake we identified reflect challenges identified by UNAIDS in their framework for elimination of mother to child transmission by 2015<sup>1</sup>; further refining PMTCT services will require a commitment to improving structural factors such as education and poverty,; as well as comprehensive, integrated approaches to maternal and child health that utilize a family focus.

Despite significant improvements over time, challenges in implementation, and opportunities for improvement exist. In each of the Chapters, opportunities were identified related to each of the three components of the conceptual model: personal and family factors, social and community factors, and health services factors. Interventions that may improve access at the individual and family level include empowerment training for women to facilitate partner involvement, promotion of facility delivery, and HIV-specific educational interventions. At the social and community level, significant opportunities exist in maternal counseling or peer support, as well as media campaigns for stigma reduction. Finally, at the health services level, increased family testing outreach, and implementation of more comprehensive or point-of-care services at lower-tier facilities may further improve uptake of PMTCT services.

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## Curriculum Vitae

### EDUCATION

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#### University of Washington, Seattle, WA

Ph.D. Nursing, 2012

Dissertation: Access to Prevention of Mother to Child Transmission of HIV-1 Services in Kenya: Social and Structural Determinants

Committee: Brenda Zierler, Grace John-Stewart, Nancy Woods, Joachim Voss, Lisa Manhart

#### University of Washington, Seattle, WA

M.P.H. Health Services (Health & Policy Research Track), 2006

Thesis: Inclusion of Birth Control Teaching in Formal Sexual Education: Implications for Abstinence-Only Policy

#### Johns Hopkins University, Baltimore, MD

B.S.N. Nursing, 2000

#### University of Washington, Seattle, WA

B.A. Women Studies, 1996

### PUBLICATIONS

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McGrath CJ, Njoroge J, John-Stewart GC, **Kohler PK**, Benki-Nugent SF, Thiga JW, Etyang A, Chung MH. Increased incidence of symptomatic peripheral neuropathy among adults receiving stavudine versus zidovudine-based antiretroviral regimens in Kenya. *J Neurovirol.* 2012, in press.

**Kohler PK**, Chung MH, McGrath CJ, Benki-Nugent SF, Thiga JW, John-Stewart GC. Implementation of free cotrimoxazole prophylaxis improves clinic retention among antiretroviral therapy-ineligible clients in Kenya. *AIDS.* 2011 Aug 24;25(13):1657-61.

Benki-Nugent S, Chung MH, Ackers M, Richardson BA, McGrath CJ, **Kohler P**, Thiga J, Attwa M, John-Stewart GC. Knowing a sexual partner is HIV-1-uninfected is associated with higher condom use among HIV-1-infected adults in Kenya. *Sex Transm Dis.* 2011 Sep;38(9):808-10.

Otieno PA, **Kohler PK**, Bosire RK, Brown ER, Macharia SW, John-Stewart, GC. Determinants of failure to access care in mothers referred to HIV treatment programs in Nairobi, Kenya. *AIDS Care.* 2010 Jun;22(6):729-36.

Chung M, **Kohler P**, Attwa M, Thiga J, John-Stewart G. Comparing Clinic Retention Between Residents and Nonresidents of Kibera, Kenya. *J Acquir Immune Defic Syndr.* 2010 Mar 1;53(3)422-4.

**Kohler PK**, Manhart LE, Lafferty WE. Abstinence-only and comprehensive sex education and the initiation of sexual activity and teen pregnancy. *J Adolesc Health*. 2008 Apr;42(4):344-51.

Strote J, **Kohler P**. Transfer of care is associated with longer unsuccessful resuscitations. *Am J Emerg Med*. 2008 Feb;26(2):206-11.

## INVITED PRESENTATIONS

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**Kohler, PK**. Promoting Adolescent Reproductive Health: Domestic and Global Approaches to Sex Education, *Central Washington University, Department of Women Studies Keynote Address*, Ellensburg, Washington. April 25, 2012

## CONFERENCE PRESENTATIONS

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**Kohler P**, Okanda J, Kinuthia J, Olilo G, Odhiambo F, Mills L, Laserson K, John-Stewart G, Social and Structural Barriers to Uptake of PMTCT in Nyanza Province, Kenya: a Community-Based Survey. 2012 XIX International AIDS Conference in Washington DC, USA. *Travel scholarship and oral poster*.

**Kohler P**, Campos PE, Buendia C, Carcamo C, Garcia PJ, Hughes J, Mejia C, Garnett G, Holmes K. Health-seeking behaviours among female sex workers in a community randomized trial in Peru (The Peru-PREVEN Study). 2011 19th Biennial Conference of the International Society For Sexually Transmitted Diseases Research, Quebec City, Canada. *Travel scholarship and oral presentation*.

**Kohler PK**, Chung MH, Benki-Nugent S, McGrath C, Attwa M, Sakr S, John-Stewart, G. "Free Cotrimoxizole Substantially Improves Retention among ART-ineligible Clients in a Kenyan HIV Treatment Program." 2011 18<sup>th</sup> Conference on Retroviruses and Opportunistic Infections, Boston, Massachusetts. *Young Investigator Award, panel discussion and poster presentation*.

**Kohler PK**, Benki-Nugent S, Chung MH, John-Stewart GC. "Evaluation of ARV Treatment Scale-Up at a PEPFAR Funded Program in Kenya." 2009 University of Nairobi HIV/AIDS Collaborating Group Annual Meeting, Nairobi, Kenya. *Oral presentation*.

**Kohler PK**, Manhart LE, Lafferty WE. "Does Comprehensive Sex Education Increase the Likelihood that US Teens will engage in Sexual Activity?" 2007 International Society for STD Research, Seattle, Washington. *Oral presentation*.