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Maternal Influences to Vertical Transmission of HIV in Kenya and Uganda

A dissertation submitted in partial satisfaction of the requirements for the degree Doctor  
of Philosophy

in

Public Health (Global Health)

by

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2016

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The Dissertation of Julie N. Bergmann is approved, and it is acceptable in quality and form for publication on microfilm and electronically:

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Chair

University of California, San Diego

San Diego State University

2016

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Chapter 2, in part, is currently being prepared for submission for publication of the material. Bergmann JN; Newmann SJ; Bukusi EA; Stockman JK. The dissertation author was the primary investigator and author of this material.

Chapter 3, in full, is a reprint of the material as it appears in AIDS and Behavior 2016. Bergmann JN; Wanyenze R; Makumbi F; Naigino R; Kiene SM; Stockman JK, AIDS and Behavior, 2016. The dissertation author was the primary investigator and author of this paper.

Chapter 4, in part, has been submitted for publication of the material as it may appear in AIDS Care, 2016. Bergmann JN; Wanyenze R; Stockman JK, AIDS Care, 2016. The dissertation author was the primary investigator and author of this paper.



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4. Stockman JK, Syvertsen L, Robertson AM, Ludwig-Barron NT, Bergmann JN, & Palinkas LA. Women's perspectives on female-initiated barrier methods for the prevention of HIV in the context of methamphetamine use and partner violence. *Women's Health Issues*. 2014: 24(4), e397-e405.

### Publications Under Review

1. Brown M, Bergmann JN, Mackey TK, Eichbaum Q, McDougal L, & Novotny TE. Mapping Foreign Affairs and Global Public Health Competencies: Towards a Competency Model for Global Health Diplomacy. *Global Health Governance*. (submitted March 2016)
2. Bergmann JN, Wanyenze R, & Stockman JK. Understanding Patient Costs in Accessing Infant ART and HIV Health Services in Uganda. *AIDS Care*. (submitted May 2016)
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## Publications in Preparation

1. Brown M, Bergmann JN, & Novotny TE. Applied Global Health Diplomacy: Profile of Health Diplomats Accredited to the United States and Foreign Governments, a Qualitative Study.
2. Bergmann JN, Newmann SJ, Bukusi EA, & Stockman JK. Is Gender Equity Related to Female Contraceptive Use? Results from Kisumu, Kenya. *Contraception*. (submitted September 2016).

## Presentations

1. Bergmann, JN. Vertical Transmission of HIV in Uganda: Maternal Influences on Infant Infection. World AIDS Day, San Diego, CA., December 2015 (poster presentation)
2. Bergmann, JN. Vertical Transmission of HIV in Uganda: Maternal Influences on Infant Infection. Frontiers of Innovation Scholars Program Conference, San Diego, CA., November 2015 (poster presentation)
3. Bergmann JN, Barnes R, & Stockman JK. Prevalence of recent psychological abuse by type of sex partner among meth-using women. National Conference on Health and Domestic Violence, Washington D.C., March 2015 (poster presentation)

## ABSTRACT OF THE DISSERTATION

Maternal Influences on Vertical Transmission of HIV in Kenya and Uganda

by

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Doctor of Philosophy in Public Health (Global Health)

University of California, San Diego, 2016

San Diego State University, 2016

Professor Jamila K. Stockman, Chair

**Background:** Despite improved availability of antiretrovirals (ARVs) in sub-Saharan Africa (SSA), vertical HIV transmission continues to result in thousands of HIV-infected infants each year. Contributing to this are barriers to accessing medications and health services that women encounter throughout their reproductive lifespans. This includes before pregnancy (contraceptive non-use), during pregnancy (ARV non-adherence), peripartum (non-hospital deliveries), and postpartum (infant ARV non-use) periods. This dissertation sought to evaluate barriers to preventing vertical HIV transmission throughout women's reproductive lifespans.

**Objectives:** Specific aims include: 1) assessing associations between gender equitable attitudes and dual contraceptive use among couples with HIV; 2) evaluating

the association between maternal ARV adherence and infant ARV administration; and 3) enumerating patient costs of accessing infant HIV care.

**Methods:** Data from three studies were used to achieve these objectives. Aim 1 used cross-sectional data collected from 103 couples in Kenya. Aim 2 used data from a cross-sectional survey (n=384) and focus group discussions (FGDs) (n=6, 5-9 participants each) conducted with HIV-positive mothers in Uganda. Aim 3 used cross-sectional and FGD data from 49 HIV-positive mothers in Uganda.

**Results:** Aim 1 findings demonstrated that female and male partner gender equitable attitudes significantly interacted to influence dual contraceptive use (AOR: 1.02, 95% CI: 1.01-1.04). Aim 2 findings showed that infant ARV administration was significantly associated with lack of maternal ARV adherence (AOR: 3.55, 95% CI: 1.36-9.26) and maternal attendance in a support group (AOR: 2.50, 95% CI: 1.06-5.83). FGDs supported these quantitative findings, explaining how support group attendance facilitated ARV administration, while poor ARV health messaging contributed to lack of administration. Finally, aim 3 findings showed that the cost of attending one HIV clinic visit averaged \$5.46 USD (SD=\$3.63), which is equivalent to 3-4 days' income. FGDs identified that transportation costs, informal service charges, and opportunity costs contributed to this expense.

**Conclusions:** These results contribute to our understanding of influences on prevention of vertical HIV transmission in SSA. Several recommendations for intervention and further research were identified, including increasing male partner inclusion in reproductive healthcare and improving support for women with HIV. Additionally, cost analyses are needed to support policies assuring access to vertical HIV prevention programs.

## **Chapter 1: INTRODUCTION**

### **HIV in sub-Saharan Africa**

Despite great strides in combating the global HIV epidemic, sub-Saharan Africa (SSA) remains the most heavily impacted region in the world in terms of new HIV infections and overall prevalence.(1) In 2014, it was estimated that 25 million individuals throughout SSA were infected with HIV, representing 71% of the global HIV/AIDS burden.(2) In 2014, approximately 90% of pregnant women and children infected with HIV lived in SSA.(3) Women also remain disproportionately affected by HIV in SSA, accounting for 58% of people living with the disease in the region.(2) In much of SSA, children are particularly vulnerable, as around 13% of all new HIV infections can be attributed to vertical transmission.(2) Vertical transmission includes transmission of HIV to an infant during pregnancy, labor, delivery, or breastfeeding. Despite the effectiveness of antiretroviral (ARV) medications in preventing vertical transmission, which when administered and adhered to appropriately can reduce transmission to less than 5%,(4) access to ARV is not universal for individuals in SSA. In 2014, while 75% of pregnant HIV-positive women in SSA received ARVs, only 28% of children received the needed medication.(2) This dissertation will identify and explore barriers and facilitators to the elimination of vertical HIV transmission during different points in women's reproductive lifespans in Kenya and Uganda.

Both Kenya and Uganda have prioritized the prevention of mother to child HIV transmission (PMTCT) due to the high numbers of new infant infections in each country each year. In 2013, the incidence of HIV in Kenyan children was at 11%, while the rate among Ugandan children was at 12%.(5, 6) In Kenya, one identified barrier to preventing vertical transmission is HIV-positive women's inability to access and use contraception,

resulting in unintended pregnancies and HIV-exposed infants.(7) Thus, the research in Kenya aimed to understand contraceptive use among couples as a means to prevent unintended pregnancy among HIV-positive women. In Uganda, a new antiretroviral therapy (ART) protocol was adopted in 2012 to eliminate previously identified logistical barriers to accessing HIV medications; this protocol, developed by the World Health Organization, is referred to as Option B+.(8) This approach suggests that HIV-positive pregnant and post-partum women living in countries with generalized epidemics, like Uganda, be started on lifelong ART, regardless of their CD4 counts, and their infants be started on ART for the duration of breastfeeding, or for life if tested positive for HIV.(8) Given the increased access and availability of medications enabled by this program, research in Uganda aimed to evaluate the association between maternal ART adherence and administration of infant nevirapine, while also identifying remaining barriers to accessing pediatric HIV care.

### **Conceptual Framework**

Vertical transmission of HIV is a complex public health issue with no easy solution. Given the cultural and societal pressures exerted on HIV-positive women, using contraception, accessing care, and adhering to medication is not always feasible. Specifically, different barriers have been identified at different points in women's lives (Figure 1.1). The goal of this dissertation was to explore barriers and facilitators at each point. Prior to pregnancy, HIV-positive women may be at risk for future vertical transmission if they do not use contraception to prevent pregnancy. This may occur for many reasons, including because they do not know their HIV-status (due to fear of testing), they have not disclosed their status to their sexual partner, and/or they do not have the decision-making power necessary to demand contraceptive use (Aim 1).

Additionally, from pregnancy into the postpartum period, women are not always free to access ART or remain in care due to socio-cultural and economic barriers (e.g., costs, distance to clinics, fear of disclosure of HIV status to family, the community, etc.) (Aims 2 and 3).

### **Theoretical Framework**

Barriers to ART adherence and retention in PMTCT care for HIV-positive women and their infants are numerous, and studies have illuminated obstacles to care at each step in the PMTCT cascade (Figure 1.2). Busza et al.(9) use the socio-ecological framework to explain these barriers at different levels of social influence including the individual, family, community and socio-cultural environmental levels (Figure 1.3). An example of a barrier at the individual level is a woman lacking the necessary information to understand the importance of adhering to her own ART, while also administering ARV to her infant.(10) Family level factors may include an inability to access health services due to a lack of decision-making power or needed partner support; partner non-acceptance of contraceptive use; and not disclosing one's HIV status to one's partner/family, which may prevent autonomous access to services.(9) Community level factors may include stigmatization and discrimination from individuals outside the family, which make it difficult to openly attend HIV clinics and/or take medications.(11) Finally, socio-cultural environmental factors include gender norms in the society that prevent the use of reproductive health services (i.e., masculinity norms that prevent contraceptive use).

### **PMTCT Cascade of Care**

A pregnant woman's retention in care is a critical factor that predicts the future health of her children.(12) Mothers who are retained in care are more likely to be

tested/identified as HIV-positive, started on treatment, deliver in health facilities, and, in the case of exposure of their infants to HIV, have their child enrolled in pediatric HIV care.(9) However, the cascade effect (Figure 1.2) demonstrates that while most women access services during pregnancy, this sharply declines during the post-partum period.(13) This is a critical period as the rate of vertical transmission of HIV at six weeks of age is at 5%, but rises to 14% by the end of breastfeeding.(14) Thus, it is important to identify and reduce barriers that prevent women from continuing HIV/AIDS treatment as a component of preventing vertical transmission of HIV. When appropriately implemented, ART use among pregnant women and subsequent administration to their HIV-exposed infants has been shown to reduce vertical transmission from 15-45% to less than 5%.(15, 16) Despite the effectiveness of ART, it is estimated that only 15-30% of pregnant women appropriately adhere to ART.(17) In Kenya and Uganda, dropouts in the PMTCT cascade of care are common. In rural Kenya, only 52% of pregnant women have been tested for HIV,(18) and less than half of those eligible receive ART.(19) In Uganda, 65% of pregnant women have been tested for HIV, and of those testing positive and in need of ART, only 52% were shown to adhere to the necessary medication regimen.(20) Due to the simplified nature of Option B+, dropouts in the cascade of care may be reduced; however, this strategy may also bring new challenges in terms of long-term adherence and retention for women who otherwise feel healthy. *This dissertation aims to identify barriers or facilitating conditions women encounter in accessing and adhering to HIV/AIDS care throughout their reproductive lifespans.*

### **Pre-pregnancy Barriers: Contraceptive Use and Gender Equity in Kenya (Aim 1)**

A generalized HIV epidemic still exists in Kenya, as it is estimated that 6.1%(21) of the population is infected with HIV. Although ART has led to the improved health of infected individuals,(22) much remains to be accomplished to eliminate the disease,



especially to prevent vertical transmission. Moreover, among women in Kenya there is an expressed desire for decreased fertility and increased use of modern contraception (e.g., long acting reversible contraception).(23) Despite this desire, Kenya continues to report high rates of unintended pregnancies and unmet contraceptive needs among HIV-positive women.(23-25) Unmet need for contraception and resulting unintended pregnancies are estimated to be higher among HIV-positive women than among non-infected women.(7) Further, HIV-positive pregnant women are at higher risk for pregnancy-related complications due to their compromised immune systems and potential disease interactions, which increases their risk of death or disability.(25-27)

Lack of contraceptive use is in large part due to male partner resistance, which may prevent women from autonomously using contraception.(25, 28-34) Moreover, traditional masculinity notions and gender norms regarding acceptance of contraceptive use prevent many men from using contraception as desired.(35-39) Women are therefore deterred from using contraception autonomously due to fear of discovery of covert use and/or partner resistance to overt use.(36) Thus, improved gender equitable attitudes toward contraception, with less defined gender roles, may lead to increased contraceptive use.

*Aim 1 is to determine if each partner's gender equitable attitudes are associated with dual contraceptive use among couples in which the woman is HIV-positive (Paper 1).*

We hypothesize that couples with better gender equity attitudes will have increased dual contraceptive use. This aim will be achieved through a cross-sectional survey conducted among 103 couples in Kisumu, Kenya.

## **Pregnancy and Early Post-Partum Barriers: ARV Prophylaxis Administration in Infants in Uganda (Aim 2)**

Uganda is one of 22 countries that account for 75% of the global PMTCT service need.(40) Uganda has the highest HIV prevalence (7.2%) in East Africa.(41) Throughout SSA, including in Uganda, many HIV-infected infants die from HIV-related causes without ever being diagnosed or receiving care.(42) HIV-infected infants who have not been treated have a bleak future: 35% will die before 12 months and over 50% by two years of age.(43) Thus, early access to ARV is critical in preventing HIV infections among infants.(44-49) A study by Guay, et al., demonstrated that when nevirapine (a drug used for HIV prophylaxis) was administered within 72 hours of birth, vertical transmission was halved from 21.3% to 11.9%.(50, 51) Thus, understanding barriers to ARV administration and subsequent HIV care is critical in reducing vertical transmission. Because a mother's retention in care is a known influence on the future health of her children, (12) we desired to assess if her medication adherence also influenced that of her infant. Moreover, many maternal barriers to accessing infant care have been identified such as lack of service integration, shortage of medications, poor quality of HIV services, as well as fear of HIV status disclosure.(52) Given this, we also sought to explore how these and others influenced administration of infant ARV within our study population.

*Aim 2 is to determine if maternal ART adherence is associated with administration of infant antiretroviral prophylaxis (nevirapine) within 72 hours of birth. This study will also use qualitative methods to identify maternal barriers and facilitating conditions that influence nevirapine administration to their infants (Paper 2).*

We hypothesize that women who adhere to ART are more likely to administer nevirapine to their infant within 72 hours of birth. This study will utilize a mixed methods approach using quantitative data from a cross-sectional survey (n=384) and focus group discussions (n=6, 5-9 participants each) conducted with HIV-positive mothers in Uganda.

### **Post-partum Barriers: Women's Economic Dependence in Uganda (Aim 3)**

Ugandan gender roles contribute significantly to vertical transmission of HIV.(16, 53) Women's roles include childrearing and managing domestic affairs, while men are the traditional breadwinners.(54) This makes women financially dependent on their husbands, resulting in a lack of power over household resources and an inability to make decisions regarding the household.(55) This lack of power and financial solvency also results in women's inability to make demands on their husbands including accessing HIV care for exposed or infected infants.(53, 56) Furthermore, male spouses and their female relatives are traditionally the decision-makers regarding health matters.(55, 57-59) Only 38% of married women reported participating in decisions pertaining to their own healthcare, major household purchases, and visits to their family or relatives.(60) Lack of decision-making ability, including where to spend money, results in decreased PMTCT care enrollment for women and later, their children.(61) Given these gender roles, and the fact that most people in Uganda live at or below the poverty line, women are limited in their ability to pay for HIV care autonomously. While few studies have measured patient costs associated with accessing HIV care, those that have indicate costs can be high and thus, can inhibit access to services at the recommended level.(62) Patient costs include both direct (i.e., cost of testing, transportation) and indirect (i.e., loss of productivity) costs and may be a critical barrier

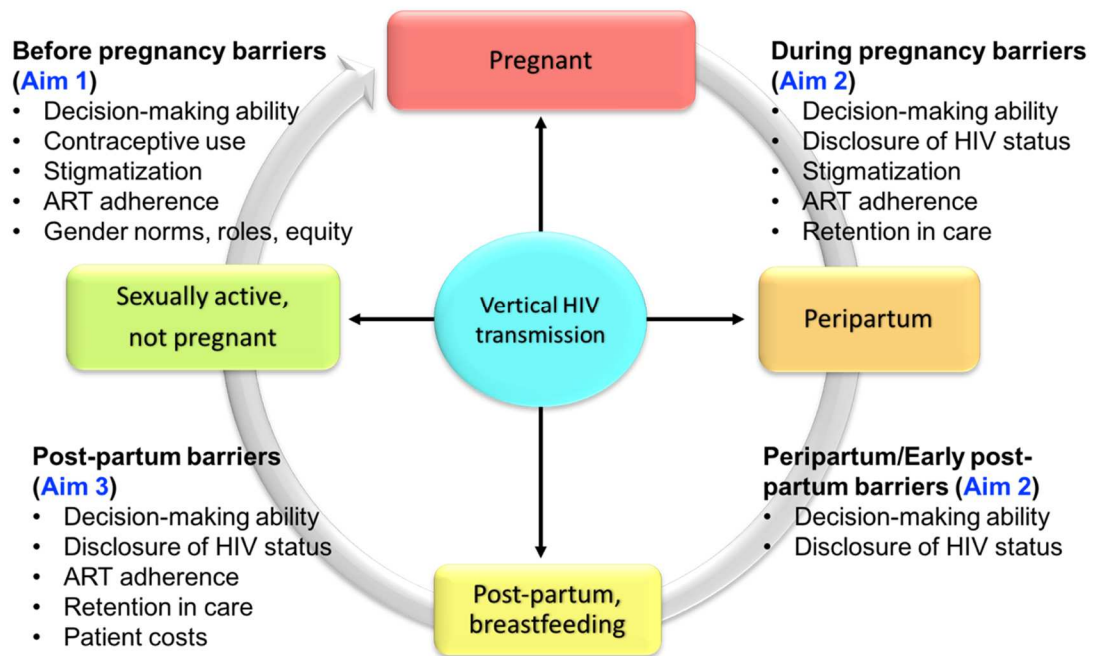
preventing women from autonomously bringing their children in to receive pediatric HIV services.

*Aim 3 is to quantify and define the costs HIV-positive women incur when accessing infant HIV services (Paper 3).*

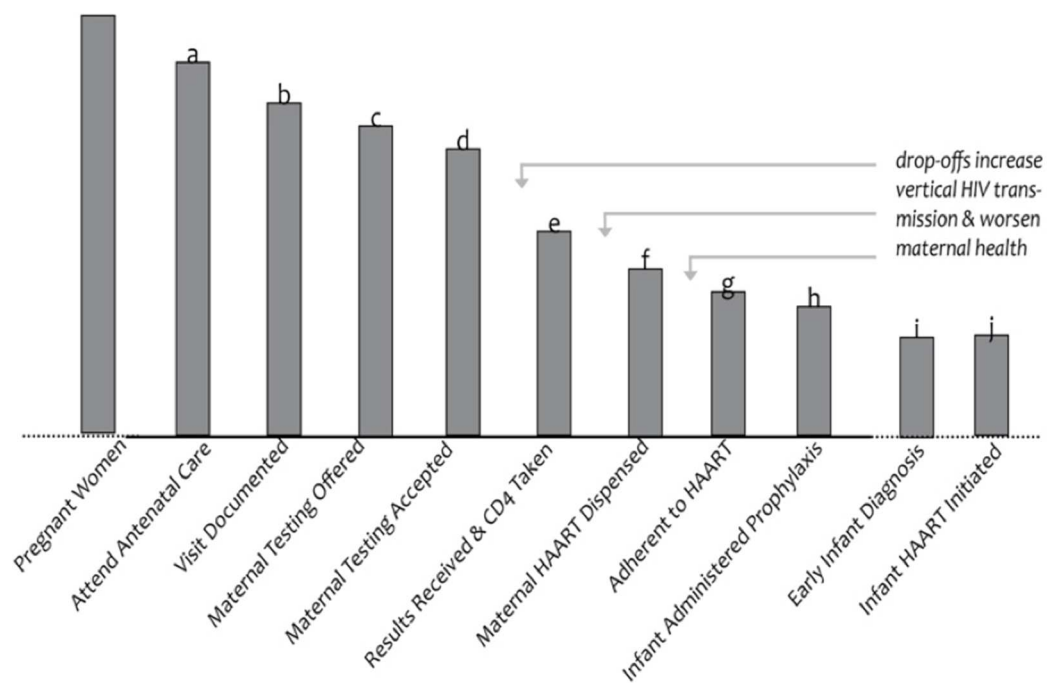
Aim 3 will be achieved through a mixed methods study that utilizes cross-sectional quantitative data and focus group discussions among 49 HIV-positive mothers in Uganda.

### **Rationale and Implications**

The elimination of mother to child transmission of HIV in SSA can be achieved if barriers preventing access to and utilization of health care and related services are identified and removed. This dissertation aims to identify and fill gaps in research on vertical transmission of HIV throughout women's reproductive lifespans. It will also assess different levels of social influence that prevent their access to and use of services. Women live in dynamic and complex communities that may create barriers that prevent them from accessing contraceptive technology and health care in general. Thus, designing programs and policies to address individual, couple, and community level barriers is critical in improving access to contraception and HIV/AIDS care in SSA. The results of this dissertation will also be used to suggest future research directions that the public health community should pursue to continue reducing vertical transmission of HIV in SSA.



**Figure 1.1: Conceptual Framework**



**Figure 1.2: Prevention of Mother to Child Transmission of HIV Cascade of Care**  
 adapted from Stringer et al., 2010



Figure 1.3: Socio-ecological framework for PMTCT adapted from Busza et al., 2012

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## **Chapter 2: Understanding Dual Contraceptive Use Among HIV-positive Women in Kisumu, Kenya: A Dyadic Analysis**

### **Abstract**

**Background:** Dual contraceptive use among HIV-positive women is critical in preventing unintended pregnancies as well as horizontal and vertical HIV transmission. Despite this, contraceptive uptake among HIV-positive individuals in Kenya remains low and traditional notions of gender roles have been identified as a critical barrier to use. This study seeks to identify the prevalence of dual contraception and to evaluate the association of gender equity attitudes and HIV-related variables with dual use among couples in Kenya.

**Methods:** This analysis is based on a cross-sectional survey of 103 couples in Kisumu, Kenya. Data were analyzed using bivariate and logistic regression. Our unit of analysis was the dyad (or couple), and our primary independent variable was the Gender Equitable Men (GEM) scale score. HIV-related variables (e.g., serostatus, disclosure of HIV status) were our secondary independent variables, and our dependent variable was dual contraceptive use.

**Results:** Among the 103 dyads, 59% reported using dual contraception. Multivariate regression findings showed a statistically significant interaction between female and male partner GEM scores and their association with dual contraceptive use (AOR: 1.02, 95% CI: 1.01-1.04). Additionally, women's disclosure of their HIV status was also associated with a dyad's dual contraceptive use (AOR: 2.70, 95% CI: 1.31-5.54).

**Conclusions:** Improving male gender equity attitudes may increase use of reproductive health services among women and their partners. Also, encouraging HIV disclosure may enable couples to make better-informed decisions regarding the need for

dual contraception. Interventions targeting men and adolescent boys to transform traditional gender attitudes and to educate them on reproductive health, HIV transmission, and their role in family planning are recommended. We also urge further research into factors that influence dyadic level decisions among HIV-positive couples.

## **Introduction**

In 2014, 25 million people in sub-Saharan Africa (SSA) were living with HIV/AIDS, which is approximately 71% of the global disease burden.(1) Women are of particular concern, as 58% of all individuals with HIV in SSA are female.(1) Kenya follows these trends. In 2012, 5.6% of the Kenyan population was infected with HIV (~2,500,000), with higher prevalence (6.9%) among women.(2) This is especially significant, as women are at risk for both horizontal transmission of HIV to sexual partners and vertical transmission to their infants. As a result of vertical transmission, 11% of new HIV infections in the country each year are among infants.(2) Compounding this problem is the fact that 40% of all pregnancies in Kenya are unintended (mistimed or unwanted).(3) Previous research indicates that women desire fewer children (actual fertility: 4.0 vs. desired fertility: 3.0) and that there are unmet contraceptive needs (desire to delay or prevent pregnancy is between 18-26%).(3, 4)

The World Health Organization recommends the use of dual contraceptive methods (consistent condom use coupled with a highly effective contraceptive method such as oral contraceptives and long-acting reversible contraceptives (LARC)) for HIV-positive persons who wish to prevent or delay pregnancy. As typical male condom use, by itself, is associated with an overall unintended pregnancy rate of 18%(5) and highly effective female contraceptive options (e.g., LARC) do not prevent the transmission of HIV, providers are urged to educate and counsel the use of dual methods. Dual use can

prevent not only unintended pregnancies, but also both horizontal and vertical transmission of HIV. Despite the necessity of dual contraception among HIV-positive women, little is known about these practices. The few studies in SSA that have reported on dual usage show that uptake varies widely from essentially none in Rwanda to approximately 20% in Zambia.(6-8)

Extensive research has been conducted to understand the unmet contraceptive need in Kenya,(9-13) and multiple studies have addressed the contribution of male partner resistance(9-11, 14-16) as well as gender equitable attitudes(12, 17-20) on contraceptive use. Traditional notions of masculinity significantly prevent male partners from using contraception or allowing their female partners the use of it.(12, 17-20) Inequitable male gender attitudes can act as a deterrent for women autonomously using contraception due to fear of discovery.(18) Despite previous research, no studies have assessed the relationship between gender equity attitudes and dual contraceptive use (e.g., how male/female partner's attitudes are associated with dual contraceptive use).

The first objective of our study was to identify the prevalence of dual contraceptive use within our sample. Additionally, given the lack of research on dyadic level influences, or factors that work at the level of the couple rather than at the individual level, we sought to evaluate how partner's gender equitable attitudes influenced their use of dual contraception. We hypothesized that more gender equitable attitudes among partners would increase the likelihood of dual contraceptive use. Moreover, given the high HIV prevalence in Kenya, we also evaluated if HIV-related variables, such as serostatus or disclosure of HIV status, were a secondary predictor of a couple's dual contraceptive use.

## **Methods**

### *Study Setting and Participants*

Kisumu, located in Nyanza Province in western Kenya, has the third highest HIV prevalence among all cities in the country (19.3%).<sup>(21)</sup> The province also reports a discrepancy between the actual fertility and desired fertility rates (4.5 vs. 3.0 per woman) and a high unmet need for contraception (32%).<sup>(3, 4)</sup> Moreover, while most Kenyan women attend antenatal care at some point in their pregnancy (96%), retention diminishes throughout the pregnancy, with only 58% attending the recommended four or more visits.<sup>(4)</sup> With only 55% of HIV-positive women in Kisumu delivering in health facilities,<sup>(21)</sup> accessing needed HIV medications during pregnancy and during peripartum may be challenging. Nevertheless, preventing unplanned pregnancies and reducing vertical transmission of HIV through providing consistent ART to HIV-infected mothers is critical to preventing HIV/AIDS in SSA. Further, understanding factors contributing to dual contraceptive use among this population is important in preventing transmission or reinfection between sex partners.

To understand correlates of dual contraceptive use among couples, we conducted a cross-sectional study in Kisumu from November 2015 – March 2016 using a convenience sample of clinic attendees. The study was conducted at five clinics in Kisumu County: Lumumba Health Center, Kisumu District Hospital, Railways Clinic, Rabour Health Center, and Nya'gande Health Center. To be eligible, both partners in the couple had to participate in the study. Eligible female participants were HIV-positive, initiated on antiretroviral therapy (ART), 18-45 years of age, not pregnant, but able to conceive, and in a sexual relationship. Eligible male participants were in a sexual relationship with the female participant and not sterilized. Men could be HIV-positive or negative.



### *Procedures*

All women were recruited from ART clinic waiting areas after their clinic visit and solicited for participation. If women were eligible and interested in participating in the study, they contacted their male partners to be screened for eligibility. If both partners were eligible and interested, the couple was recruited into the study. Data were gathered through face-to-face, paper-based, 60-minute interviews with a gender-matched interviewer (i.e., men interviewed men) and conducted in either English or in the local language of Dhulou. Male and female partner interviews took place in private locations of the participant's choosing (e.g., their homes). Participants received 300 Kenyan Shillings (KSH) (~3 USD) for their time. Written consent was obtained from all participants. The study protocol was reviewed and approved by the Institutional Review Boards (IRBs) at the University of California, San Diego (Protocol #151006) and the Kenyan Medical Research Institute (KEMRI) (Protocol #0025).

### *Data Analysis*

#### Measures

The level of analysis for this paper is at the dyadic (or couple) level. Thus, we included two levels of variables, those at the individual level (i.e., male partner or female partner) and others at the dyadic level. While all participants responded individually to each question, some variables were collapsed into dyadic responses (e.g., relationship length was reported for the couple rather than the individual). We have indicated how each variable was reported (i.e., individual vs. dyadic).

*Demographic variables* included age, having had children, number of children, education level, relationship length, marital status, and health facility. Age, number of children, and relationship length were coded as continuous variables. Education and

health facility were treated as categorical variables, while having had children and marital status were represented by dichotomous variables. Having had children, relationship length, marital status, and health facility were coded at the dyadic level; all other variables were reported at the individual level.

*Fertility Variables.* As dual contraceptive use was our dependent variable, we included several fertility variables to account for potential confounding in our model. These included the female partner's fertility intentions, male partner's fertility intentions, female's belief regarding her male partner's fertility intentions, male partner's belief regarding his female partner's fertility intentions, female partner's desired time until next child, and male partner's desired time until next child. All intention variables were coded as categorical (yes, no, or undecided) and at the individual level. All time variables were coded as continuous and at the individual level.

*Gender Equitable Men (GEM) Score (primary independent variable).* The GEM scale(22) was used to assess gender equitable attitudes and notions among participants. The scale consists of 24-items, with an internal consistency of  $\alpha = 0.81$ , and was developed to examine perceptions of gender norms regarding sexual and reproductive health, intimate relationships, and violence among both men and women.(22) The scale has demonstrated that higher GEM scores are associated with contraceptive use among both men and women.(13, 22) Higher scores indicate more equitable attitudes. Responses were coded as continuous and reported at the individual level. Given the dyadic focus of this paper, we specifically sought to examine partner scores interacted. As such, each partner's response was centered and used to create an interaction term.

*HIV Variables (secondary independent variables).* We included male partner's HIV status (categorical), time since HIV diagnosis (continuous), if HIV status was

disclosed to one's partner (dichotomous), and the total types of people (i.e., partner, parent, sibling, child, etc.) to whom participants had disclosed their HIV status (continuous). All responses were recorded at the individual level.

*Dual Contraceptive Use (dependent variable)*. Female and male participants responded to gender-specific contraceptive questions. Women were asked if they used any form of female contraception (e.g., intrauterine devices, oral contraceptives), while men were asked if they used condoms during sexual intercourse with their partner (responses were dichotomous). Ten percent of female responses were verified through patient records. If both participants responded positively, dyadic responses were coded as yes.

#### Statistical Analysis

The distribution of each variable was examined prior to analyses. Dual contraceptive use was the dependent variable, GEM score was the primary independent variable, and HIV disclosure was the secondary independent variable. Wilcoxon Rank-Sum tests were used for non-parametric continuous variables, while a T-test was used to assess for differences on normally-distributed continuous variables. Chi-square tests were used to examine group differences for categorical variables. Logistic regression analyses were performed to identify HIV variables associated with dual contraceptive use. Factors with a  $<0.1$  p-value in the bivariate analyses were assessed for inclusion in the multivariate logistic regression. We assessed model fit using the Akaike Information Criterion (AIC). The final model included only variables that were significant at p-value  $\leq 0.05$ , and was adjusted for demographics and fertility intentions. All analyses were performed using STATA 14.1.

## Results

### *Participant Characteristics*

Among the 103 women, participants were on average 31 years old (standard deviation (SD)=6.2) and had 2.7 children (SD=1.6); 63% had received no formal education. Among the 103 male participants, average age was 38 years (SD=9.0) and mean number of children was 3.2 (SD=2.4); 53% had attended primary school or higher. Overall, 93% of couples were married, the average relationship length was 8.7 years (SD=7.4), and 8% reported having no children. Fifty-nine percent of dyads reported using dual contraception (Table 2.1).

### *Factors Associated with Dual Contraceptive Use*

Bivariate analyses showed that dyads in which male partners wanted more children and female partners were unsure of their partner's fertility intentions were significantly less likely to use dual contraception compared to their counterparts (OR: 0.33, 95% CI: 0.13-0.80, OR: 0.23, 95% CI: 0.07-0.82, respectively). Similarly, compared to dyads in which individuals did not want any additional children, female partners who wanted a child within the next two years (OR: 0.35, 95% CI: 0.12-0.99) and male partners who wanted children anytime in the future or were unsure about wanting future children were significantly less likely to use dual contraception (<2 years, OR: 0.11, 95% CI: 0.03-0.43, 3-6 years, OR: 0.18, 95% CI: 0.05-0.64, unsure, OR: 0.12, 95% CI: 0.03-0.59) (Table 2.2).

Controlling for marital status, relationship length, children, age of both partners, education level, male partner's HIV status, fertility intentions and timing, and health care facility, we found several variables to be independently associated with dual contraceptive use. Foremost, there was a statistically significant interaction term

between female and male partner GEM scores on dual contraceptive use (AOR: 1.02, 95% CI: 1.01-1.04). When male GEM score was at the mean, for each point increase in female GEM score, the likelihood of dual contraceptive use increased by 5%.

Additionally, when female GEM score was at the mean, for each point increase in male GEM score, the likelihood of dual contraceptive use increased by 2%. Moreover, for each additional type of person to whom women disclosed their HIV status, her dyad was 2.70 times more likely to use dual contraception (95% CI: 1.31-5.54) (Table 2.3).

## **Discussion**

This cross-sectional study sought to identify the prevalence of dual contraceptive use among HIV-positive women attending ART facilities in a Kenyan community. It also sought to understand how gender equitable attitudes related to couples' dual use of contraception. We found that more than half of the couples in our study reported using dual contraception and that the interaction between each partner's gender equitable attitudes were significantly associated with dual usage. Our results also demonstrated that female partners who disclosed their HIV status to more types of people were more likely to be in a dyad that engaged in dual contraceptive use.

Our results support previous findings that both female and male gender equitable attitudes are associated with contraceptive use.(13, 23-27) While our bivariate analyses showed that neither female nor male partner GEM scores significantly influenced a dyad's dual contraceptive use, we were able to ascertain directionality; higher GEM scores pointed toward increased odds of dual contraceptive use. Our multivariate analysis demonstrated a significant interaction between each partner's gender equitable attitudes and a couple's dual contraceptive use. Specifically, when both partners had more equitable attitudes, a greater effect was seen, which resulted in an increased odds

of dual contraceptive use. Moreover, the significant interaction term also indicates that the association between female or male GEM scores and dual use was influenced by the other partner's gender equity attitudes. This is a critical finding that demonstrates the importance of dyadic research. It also suggests that increasing gender equitable attitudes among men and women may subsequently influence the actions of their partner. These findings highlight the need to implement interventions with men that transform traditional attitudes on gender, rather than just provide education. No previous studies have assessed the relationship between GEM scores and dual contraceptive use nor have any studies assessed both partner's GEM scores on their joint contraceptive use. Given the novelty of these findings, we suggest further research to validate our results.

Our results showed that more liberal HIV disclosure behavior influenced dual contraception, which aligns with previous studies that demonstrated that disclosure to one's partner is associated with increased use of contraception.(28-30) Studies in Zambia, Ghana and Ethiopia, report that disclosure increases an individual's, as well as a couple's, ability to make informed decisions regarding fertility intentions and resulting contraceptive use.(28-30) We note that although we did assess if disclosing one's HIV status to one's partner was associated with dual contraceptive use, this was a non-significant finding. However, we believe that increased disclosure, above and beyond to one's partner, can lead to more social support and increased knowledge regarding risks of HIV transmission.(31) With more support and knowledge, individuals and couples can more easily make informed decisions regarding their fertility.

As expected, we found that fertility intentions were significantly associated with dual contraceptive use. Women who desired children soon, or men who wanted more children at any point in the future, had lower odds of reporting dual contraceptive use.

While this is intuitive, we note that it is important to take fertility intentions into consideration when designing interventions aimed at increasing dual contraceptive use among HIV-positive populations. Additionally, our findings from the bivariate analyses also demonstrate the importance of male partner fertility intentions on dual contraceptive use. It appears that if men desired more children or were uncertain in their intentions, dual contraception was less likely to be used. However, we did not find the reverse to be true. This discrepancy suggests that male intentions may override the female partner's desire to cease or delay childbearing. This finding seconds the need for gender transformative interventions that may lead to women having an equal voice in couple's reproductive intentions.

Our study had several limitations. First, we only interviewed women who attended at least one ART clinic visit. As such, we have no information on women who do not seek care nor do we have information from their partners. Individuals who have infrequent encounters with health care professionals may have fewer opportunities to learn about the need for dual contraception. Secondly, only women with a male sexual partner willing to participate were eligible for the study. Therefore, we know nothing about unwilling male partner's gender equitable attitudes, which may be lower than those who were willing to participate. Thirdly, our results may have differed if we targeted HIV-positive men and their partners for recruitment, rather than focusing on HIV-positive women. However, since around 80% of couples were sero-concordant, results may not have significantly differed. Next, all clinic sites were part of the Family AIDS Care & Education Services (FACES), where family planning is integrated into HIV care.<sup>(32)</sup> FACES patients may be uniquely knowledgeable about the need for dual contraception as compared to couples who access care elsewhere. This may explain the high prevalence of dual contraceptive use we found among our study sample.

Additionally, female partners may have had more opportunities to autonomously access female contraceptives compared to women who attend ART clinics where family planning is not integrated into care. Moreover, since our study was cross-sectional in design, we were unable to identify any temporal influences or changes in dual contraceptive use. Finally, all data were collected via self-report and therefore may be subject to recall and/or social desirability biases.

Despite these limitations, our study findings reinforce the relationship between gender equity and contraceptive use. Given the importance of both male and female actions to achieve dual contraception, we suggest developing an intervention that both transforms traditional notions of gender norms, in order to increase gender equity, and targets male knowledge and subsequent involvement in reproductive health. Previous research has found that men are not only willing to be included in family planning,(33) but also are amenable to contraceptive use when suggested by HIV providers.(11) Thus, we suggest a two-fold intervention. First, HIV providers should be urged to discuss family planning practices, HIV transmission, and the need for dual contraceptive use with men, as well as women, to educate them on their role and responsibility in reproductive health. Additionally, community-level health campaigns should be aimed at adolescent boys and young men to transform masculinity notions that negatively impact reproductive health or single out reproductive health as “women’s business”. Campaigns should also work to improve male gender equitable attitudes that prevent open discussion with sexual partners regarding reproductive health. As both partners contribute to dual contraceptive use, conversations regarding couples’ intentions and each partner’s role should be encouraged within couples.

Moreover, given the lack of knowledge regarding dual contraceptive use as well as individual level influences on dyadic level outcomes, we strongly recommend our



findings be further researched for validation and to identify additional areas for intervention. We suggest that further research into dyadic level fertility intentions, including if partners discuss their intentions with each other, as well as dyadic level knowledge regarding HIV transmission (i.e., does a couple have knowledge or do partners have different levels of knowledge regarding transmission) be conducted. Both areas may help shed light on communication between partners and how joint decisions are reached.

Dual contraceptive use not only safeguards male or female partner health by protecting against horizontal HIV transmission, but also can prevent unintended pregnancy and the subsequent risk of maternal death or disability encountered due to pregnancy. Further, eliminating unintended pregnancies through dual contraceptive use will also prevent vertical transmission of HIV. Despite the many benefits of dual usage, uptake remains low among HIV-positive populations. Our results support the evidence that improving gender equitable attitudes is critical to improving the uptake of contraception, and in our case, dual usage. However, dual usage requires communication between partners as well as joint action. Thus, we urge HIV researchers to focus reproductive health interventions at the dyadic level and to further explore how dyadic level decisions are impacted by partner communication and other individual level factors.

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Chapter 2, in part, is currently being prepared for submission for publication of the material. Bergmann JN; Newmann SJ; Bukusi EA; Stockman JK. The dissertation author was the primary investigator and author of this material.

**Table 2.1: Characteristics of Couples from Kisumu, Kenya enrolled in the Contraceptive Use among Couples Study by dual contraceptive use (N=103 couples)**

Variable			Dual No N= 42 (41%)	Dual Yes N=61 (59%)	P-value	Total <sup>a</sup> N=103 (%)
Mean Age (SD)	Female Partner		30.7 (6.9)	30.8 (5.8)	0.96	30.8 (6.2)
	Male Partner		38.1 (9.7)	38.0 (8.5)	0.97	38.1 (9.0)
Mean Number of Children (SD)	Female Partner		2.5 (1.6)	2.9 (1.5)	0.17	2.7 (1.6)
	Male Partner		3.2 (2.5)	3.2 (2.4)	0.85	3.2 (2.4)
HIV Status	Female Partner	Positive	42 (100)	61 (100)	---	103 (100)
		Negative	0 (0)	0 (0)	--	0 (0)
	Male Partner	Positive	32 (76)	47 (77)	0.95	79 (77)
		Negative	9 (21)	12 (20)		21 (20)
Unknown	1 (3)	2 (3)	3 (3)			
Highest level of education attended	Female Partner	No school	31 (74)	34 (56)	0.16	65 (63)
		Primary	9 (21)	20 (33)		29 (28)
		Secondary+	2 (5)	7 (11)		9 (9)
	Male Partner	No school	22 (55)	26 (42)	0.09	48 (47)
		Primary	18 (43)	23 (38)		41 (40)
		Secondary+	2 (2)	12 (20)		14 (13)
Do you want more children?	Female Partner	No	18 (43)	30 (49)	0.12	48 (46)
		Yes	18 (43)	29 (48)		47 (46)
		Not Sure	6 (14)	2 (3)		8 (8)
	Male Partner	No	9 (21)	26 (43)	<b>0.01</b>	35 (34)
		Yes	33 (79)	31 (51)		64 (62)
		Not Sure	0 (0)	4 (6)		4 (4)
Does your partner want more children?	Female Partner	No	13 (31)	28 (46)	0.06	41 (40)
		Yes	19 (45)	28 (46)		47 (46)
		Not Sure	10 (24)	5 (8)		15 (14)
	Male Partner	No	10 (24)	24 (39)	<b>0.02</b>	34 (33)
		Yes	32 (76)	32 (53)		64 (62)
		Not Sure	0 (0)	5 (8)		5 (5)
Disclosed HIV status to partner	Female Partner	Yes	41 (98)	57 (93)	0.33	98 (95)
		No	1 (2)	4 (7)		5 (5)
	Male Partner	Yes	31 (97)	44 (88)	0.16	75 (91)
		No	1 (3)	6 (12)		7 (9)
Mean Types of People HIV Status Disclosed to (SD)	Female Partner		2.2 (1.4)	2.7 (1.7)	0.08	2.5 (1.6)
	Male Partner		2.0 (1.3)	2.1 (1.4)	0.96	2.0 (1.4)

Table 2.1: Characteristics of Couples from Kisumu, Kenya, Continued

Variable			Dual No N= 42 (41%)	Dual Yes N=61 (59%)	P-value	Total <sup>a</sup> N=103 (%)
Time until next child	Female Partner	Now-2 years	13 (31)	9 (15)	0.12	22 (21)
		3-6 years	5 (12)	14 (23)		19 (18)
		6+ years	1 (2)	2 (3)		3 (3)
		Not sure	8 (19)	6 (10)		14 (14)
		None wanted	15 (36)	30 (49)		45 (44)
	Male Partner	Now-2 years	13 (31)	8 (13)	0.05	21 (20)
		3-6 years	18 (43)	22 (36)		40 (39)
		6+ years	0 (0)	3 (5)		3 (3)
		Not sure	7 (17)	5 (8)		12 (12)
		None wanted	4 (9)	23 (38)		27 (26)
Mean GEM scale score (SD)		Female Partner	47.1 (13.5)	51.3 (12.0)	0.12	49.6 (12.7)
		Male Partner	53.4 (9.9)	55.1 (11.3)	0.43	54.4 (10.7)
Mean relationship length (SD)		Dyad	9.0 (8.2)	8.5 (6.9)	0.95	8.7 (7.4)
Marital status	Dyad	Not Married	2 (5)	5 (8)	0.50	7 (7)
		Married	40 (95)	56 (92)		96 (93)
Has children	Dyad	No	6 (14)	2 (3)	0.04	8 (8)
		Yes	36 (86)	59 (97)		95 (92)
Facility	Dyad	Kisumu District Hospital	7 (17)	13 (22)	0.19	20 (19)
		Lumumba	20 (48)	30 (49)		50 (49)
		Nya'gande	4 (9)	2 (3)		6 (6)
		Rabour	11 (26)	11 (18)		22 (21)
		Railways	0 (0)	5 (8)		5 (5)

<sup>a</sup> Not all columns add to the total N as not every participant answered each question.

<sup>b</sup> SD=standard deviation

**Table 2.2: Bivariate analyses of associations with dual contraceptive use among couples in Kisumu, Kenya (N=103 couples)**

Variable			Unadjusted Odds Ratio	95% Confidence Interval	P-value
<b>Demographics</b>					
Age		Female Partner	1.00	0.94-1.07	0.96
		Male Partner	0.99	0.95-1.04	0.97
Highest level of education attended	Female Partner	No school		Ref	
		Primary	2.03	0.80-5.11	0.14
		Secondary+	3.19	0.62-16.54	0.17
	Male Partner	No school		Ref	
		Primary	1.08	0.47-2.50	0.86
		Secondary+	5.08	<b>1.02-25.17</b>	<b>0.05</b>
Relationship length		Dyad	1.00	0.94-1.06	0.99
Marital status	Dyad	Not Married		Ref	
		Married	0.56	0.10-3.03	0.50
Has children?	Dyad	No		Ref	
		Yes	4.92	0.94-25.69	0.06
<b>HIV Variables</b>					
Disclosed HIV status to partner		Female Partner	0.34	0.04-3.23	0.35
		Male Partner	0.24	0.03-2.10	0.19
Types of people HIV status disclosed to (e.g., partner, child, sibling, community member)		Female Partner	1.25	0.95-1.65	0.10
		Male Partner	1.40	0.65-3.02	0.40
Time since diagnosis		Female Partner	1.03	0.91-1.16	0.66
		Male Partner	0.98	0.89-1.07	0.59
<b>Fertility Variables</b>					
Do you want more children?	Female Partner	No		Ref	
		Yes	0.97	0.42-2.22	0.94
		Not Sure	0.20	0.04-1.10	0.06
	Male Partner <sup>b</sup>	No		Ref	
		Yes	0.33	<b>0.13-0.80</b>	<b>0.02</b>

**Table 2.2: Bivariate analyses of associations, Continued**

Variable			Unadjusted Odds Ratio	95% Confidence Interval	P-value
Does your partner want more children?	Female Partner	No		Ref	
		Yes	0.68	0.28-1.65	0.40
		Not Sure	0.23	<b>0.07-0.82</b>	<b>0.02</b>
	Male Partner <sup>b</sup>	No		Ref	
		Yes	0.42	0.17-1.01	0.05
Time until next child	Female Partner	None wanted		Ref	
		Now-2 years	0.35	<b>0.12-0.99</b>	<b>0.05</b>
		3-6 years	1.40	0.42-4.62	0.58
		6+ years	1.00	0.08-11.93	1.00
		Not sure	0.38	0.11-1.28	0.12
	Male Partner <sup>b</sup>	None wanted		Ref	
		Now-2 years	0.11	<b>0.03-0.43</b>	<b>0.001</b>
		3-6 years	0.18	<b>0.05-0.64</b>	<b>&lt;0.01</b>
		Not sure	0.12	<b>0.03-0.59</b>	<b>&lt;0.01</b>
		<b>Primary Predictor</b>			
Mean GEM scale score	Female Partner		1.03	0.99-1.06	0.11
	Male Partner		1.02	0.98-1.05	0.43

<sup>a</sup> Bold values are significant at the p=0.05 level

<sup>b</sup> Some categorical variables did not have adequate number of responses to be regressed for each category

**Table 2.3: Factors independently associated with dual contraceptive use among couples in Kisumu, Kenya (N=103 couples)**

<b>Variable</b>	<b>Adjusted Odds Ratio<sup>a</sup></b>	<b>95% Confidence Interval</b>	<b>P-value</b>
<b><i>Primary Independent Variable</i></b>			
Female Partner GEM Score (centered)	1.00	0.94-1.06	0.851
Male Partner GEM Score (centered)	1.03	0.93-1.15	0.535
Interaction between partners' GEM scores (centered)	1.02	1.01-1.04	<b>0.000</b>
<b><i>HIV Variable</i></b>			
Female partner disclosure to more types of individuals	2.70	1.31-5.54	<b>0.007</b>
<b><i>Fertility Variable</i></b>			
Male partner wanting more children	0.02	0.001-0.24	<b>0.003</b>
Female partner unsure when she wants next child	0.003	0.00-0.10	<b>0.001</b>

<sup>a</sup> Adjusted for marital status, relationship length, children, age for both partners, education level, male partner's HIV status and health care facility.

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## **CHAPTER 3: Maternal Influences on Access to and Use of Infant ARVs and HIV Health Services in Uganda**

### **Abstract**

**Background:** Vertical transmission of HIV is responsible for about 14% of new HIV cases reported each year in sub-Saharan Africa (SSA). Barriers that prevent women from accessing and using antiretroviral medications (ARVs) for themselves and their infants perpetuate the epidemic.

**Methods:** To identify influences on access to and use of infant HIV health services, specifically nevirapine administration to infants, we conducted a mixed methods study among HIV-positive women in Uganda. This included a cross-sectional survey (n=384) and focus group discussions (n=6, 5-9 participants each).

**Results:** Of the 384 women, 80% reported giving nevirapine to their infants within 72 hours of birth. Factors independently associated with nevirapine administration were lack of maternal adherence to ARVs (AOR: 3.55, 95% CI: 1.36-9.26) and attending a support group (AOR: 2.50, 95% CI: 1.06-5.83). Non-health facility births was inversely related to nevirapine use (AOR: 0.02, 95% CI: 0.003-0.09). Focus group discussions identified four themes impacting access and use: attending a support group, health care worker attitudes, partner support, and health messaging regarding ARVs.

**Conclusions:** Improving health care worker messaging regarding ARVs and providing women with needed support to access and administer infant ARV prophylaxis is critical to reducing mother to child transmission of HIV. Eliminating these barriers may save the lives of many HIV-exposed infants and reduce prevalence of HIV in SSA.

## Introduction

Despite significant progress in curbing the HIV/AIDS epidemic, the disease persists worldwide, with the greatest burden localized in sub-Saharan Africa (SSA). In 2014, 25.8 million individuals in SSA were HIV-infected, representing 70% of the worldwide burden of disease.(1) In the same year, more than 90% of pregnant women and 91% of children infected with HIV lived in SSA.(2) Fortunately, during that same year, 75% of pregnant HIV-positive women in SSA received antiretroviral therapy (ART) to prevent vertical transmission to their infants as compared to the 36% reported in 2009.(2)

Infants and children, however, are not as well served. When adhered to appropriately by the mother and provided immediately to the newborn infant, antiretroviral (ARV) medication can reduce vertical transmission to less than 5%.(3) Despite this, in 2013, only 28% of children in need of ARVs in Africa received the medication.(4) Early access to ART, including receiving ARV prophylaxis such as nevirapine (NVP) immediately after delivery for HIV-exposed infants, is critical in preventing vertical transmission and in increasing survival for those who become infected.(5-10) A study by Guay et al. in Uganda demonstrated that when NVP was administered within 72 hours of birth, vertical transmission was halved from 21.3% in the control group to 11.9% in the treatment group.(11, 12)

Despite its known effectiveness, there are few studies(13) demonstrating NVP use among infants, and even less about maternal influences on accessing and using HIV medications and services. The lack of information on barriers to infant HIV treatment, coupled with the low rates of ART coverage in SSA, motivated this study. We grounded our approach in the Socio-Ecological Framework as described by Busza et al.(14), which suggests barriers to accessing HIV care for HIV-positive pregnant women

at different levels of social influence (individual, family, and community). We hypothesized that these three levels would influence access to and use of NVP for infants. We aimed to quantitatively identify influences on mothers providing NVP immediately after birth in the Uganda setting. Further, to assist in the interpretation of our quantitative findings, we used qualitative methods to assess women's knowledge, attitudes, and experiences in accessing HIV health services and specifically in administering NVP to infants after birth.

## **Methods**

### *Study Design*

We conducted a mixed methods study in three districts in Uganda: Masaka, Luwero, and Mityana. HIV-positive women were recruited to participate in a longitudinal study from antenatal care (ANC) clinics at Masaka Regional Referral Hospital, Luwero Health Center IV (HC-IV), or Mityana Hospital. Women enrolled in the longitudinal study were then recruited to participate in focus group discussions (FGDs).

### *Study Setting*

Masaka, Luwero, and Mityana districts are located in the Central 1 region of Uganda where HIV prevalence among women is the highest in the country at 12.5%.<sup>(15)</sup> In Masaka, where the population is 296,649, 65% of individuals live in rural areas. Luwero, with a population of 458,158, has 79% of its people living in rural areas. And in Mityana, where the population is 331,266, 86% of individuals live in rural areas.<sup>(16)</sup> These three districts were selected for this study as they were prioritized for the initial rollout of Option B+ (treatment protocol in which HIV-positive women are initiated on ART for life and infants for the duration of breastfeeding or life if testing HIV-positive<sup>(17)</sup>)

in Uganda and have fully operational Option B+ programs. Thus, a cohort of women started on B+ could be identified.

### *Quantitative Component*

#### Sample Selection

This cross-sectional analysis used data from a convenience sample of 384 women enrolled in a longitudinal study assessing the implementation of Option B+ in Uganda. Eligible participants were pregnant, HIV-positive, and ART-naïve or initiated within four weeks of recruitment. Women found to be too ill to participate, due to pre-existing medical conditions, were excluded from participation. Data for this analysis were taken from the first follow-up survey administered after birth, collected during September 2014 – November 2015.

#### Procedures

All women were recruited from ANC clinic waiting areas after their clinic visit to participate in this study. Surveys were implemented at baseline with follow-up visits at months 2, 4, 6, 10, 14, and 18. Data were gathered through interviewer-administered, paper-based surveys. Interviews were conducted in the local language of Luganda and lasted approximately 60 minutes. Interviews took place in private spaces at the health facilities. Participants who came to the health facility to receive health care and participate in the study received 5,000 Ugandan Shillings (UGX) for their time, while those who came solely to complete a follow-up survey also received an additional 5,000 UGX for transportation costs (1USD=3475UGX). Written consent was obtained from all participants. The Option B+ study protocol was reviewed and approved by the Makerere University School of Public Health (Protocol #064) and the Uganda National Council of

Science and Technology (UNCST) (Registration #SS3153) Institutional Review Boards (IRBs).

#### Data Analysis

*Measures.* Measures are presented by the Socio-Ecological Framework(14) levels of social influence.

#### Individual level

*Demographics* included age, education, occupation, number of children, and marital status.

*Adherence measures:* Adherence was measured using multiple questions. Participants were asked to report the proportion of their ART medications taken in past month. Proportions were dichotomized to 95% and above, and less than 95% (the optimal threshold for viral suppression).(18) Participants were also asked to recall if they had missed any ART dose in the last 3 days or in the last 7 days. Responses were dichotomized (y/n).

#### Family Level

*Partner is HIV-positive:* Participants were asked if their current sexual partner was HIV-positive. Responses were dichotomized (y/n).

*Delivery Location:* Women were asked where they delivered their infant (health facility where study interviews are conducted, other health facility, at home, by traditional birth attendant, and other). Responses were collapsed into a dichotomous response (at a health facility or other location).

*Disclosure of HIV Status to Partner:* Participants were asked if they had disclosed their HIV status to their current sexual partner. Responses were dichotomized (y/n).

*Disclosure of HIV Status:* Participants were asked if they had disclosed their HIV status to anyone other than their partner. Responses were dichotomized (y/n).

*Nevirapine Use (dependent variable):* Women were asked if their infant received NVP within 72 hours of birth. Responses were dichotomous (y/n).

### Community Level

*Support Group:* Many types of support groups for HIV-positive women exist in Uganda. There are religious groups, groups facilitated by hospitals, community groups, etc. The goal of each group is to provide information about HIV, answer questions as needed, and to provide emotional support for those in need. We asked participants if they currently participated in any support group including family support groups, religious groups, community groups, or other groups. Response options were dichotomous (y/n).

### Statistical Analysis

The distribution of each variable was examined prior to analysis. Wilcoxon Rank Sum test was used for non-parametric continuous variables, while chi-square tests were used for categorical variables. Bivariate logistic regressions were performed to identify factors associated with NVP use within 72 hours of birth. Factors achieving a 0.1 p-value in the bivariate analysis were assessed for inclusion in the multivariate logistic regression. We assessed model fit using the Akaike Information Criterion (AIC). The final model was adjusted for demographics and included only variables with  $p < 0.05$ . All analyses were performed using STATA 14.1.

## *Qualitative Component*

### Sample Selection

Six FGDs were conducted in November 2015. Two were held in each district, with a total of 43 participants, 14 from Masaka, 16 from Mityana, and 13 from Luwero. All women participating in the longitudinal study who had given birth were eligible for FGD participation. All women we were able to reach agreed to participate.

### Procedures

We used contact information provided at baseline in the longitudinal study to contact women for FGD participation. Three lists were randomly generated of all participants; one list for each facility and the 10<sup>th</sup> name on each was contacted to participate. FGDs were conducted by trained study interviewers in Luganda, were held at health facilities in private spaces, and lasted 30-60 minutes. All FGDs were audio-recorded. Participants received 10,000 UGX for their time. Written consent was obtained from all participants. The FGD study protocol was reviewed and approved by Makerere University School of Public Health (Protocol #320), University of California, San Diego (Project #151007), and UNCST (Registration #SS3923) IRBs.

### Data Analysis

FGD audio-recordings were transcribed and then translated into English. Transcripts were uploaded into MAXQDA 11 for analysis. Our analysis was a four-step process. First, we reviewed all transcripts to develop a broad understanding of the content and at the same time, wrote short descriptive statements to document our impressions of topics/themes.(19) Second, we used these statements to identify emergent themes and to create open codes.(19, 20) All codes, *a priori* (i.e., determined



from theoretical framework/quantitative analysis) and *emergent themes* (i.e., open coding), were then used to create a codebook that included each code, a description of its content, its inclusion/exclusion criteria, and a text example.(19) Finally, we coded all transcripts using the codebook.

## **Results**

### *Quantitative Results*

#### Participant Characteristics

Among the 384 women, participants were on average 25 years of age (standard deviation=6.3), 50% had attended secondary school or higher, 81% were married, and 37% had at least two children before entering the study. Occupations varied, but the most common were farmers (20%), businesswomen (31%), and either housewives or unemployed (31%). Twenty percent of participants reported not providing NVP to their infants within 72 hours of birth (Table 3.1).

#### Factors Associated with NVP Use within 72 hours of Birth

Bivariate analyses showed that taking less than 95% of ART doses in a 30 day timeframe (OR: 3.29, 95% CI: 1.77-6.13), missing an ART dose in the last 3 days or in the last week (OR: 4.89, 95% CI: 2.47-9.70, OR: 3.70, 1.87-7.33, respectively), and participating in a support group (OR: 2.15, 95% CI: 1.24-3.74) were all positively associated with an infant receiving NVP after birth. Conversely, delivering at home (OR: 0.02, 95% CI: 0.004-0.08) was negatively associated with giving NVP to infants after birth (Table 3.2).

Controlling for age, marital status, education, number of children, disclosure of HIV status to partner, and health care facility, we found in our multivariate logistic

regression that women who took less than 95% of their ART doses in the past month had 3.55 greater odds of giving NVP to their infants after birth (95% CI: 1.36-9.26) and women who attended a support group had 2.50 greater odds of providing NVP to their infants after birth (95% CI: 1.06-5.83). On the other hand, women who delivered at home were 98% less likely to provide NVP to their infants after birth (95% CI: 0.003-0.09) (Table 3.3).

### *Qualitative Results*

#### Factors Influencing NVP Access and Use

##### Partner Level: Lack of Partner Support

Participants discussed how their male partners were largely unsupportive of their care seeking. While men may provide money, they do not want to be involved in health activities regarding the pregnancy or HIV care.

You see some men, when he knows that he made you pregnant he would give you money to go to the hospital but he would not go with you to the hospital even if you request him. He can never allow going there.

**Luwero, FGD #5**

Another participant echoed these sentiments and discussed how her husband refused to go to the health center with her unless the doctor specifically requested his attendance.

You see even when you are pregnant and tell your husband to go along with you to the hospital, if you do not tell him that the doctor requested you to take him along, he would never come. I would have to first tell him, 'The doctor said that before I receive drugs I must first go with you.' Our husbands are stubborn! The moment he knows that you delivered, what else does he need from you? Nothing. **Luwero, FGD #6**

### Community Level: Support Groups

Women discussed a variety of reasons they were involved in support groups.

Those who participated in a support group stated that the fiscal benefits of participation were critical to their ability to access health services for themselves and their infants.

The money from 'Cash Round [support group]' helps me to cater with transport or in case I fall sick or if the baby is sick such that we are able to go and receive treatment. **Masaka, FGD #2**

Others positively discussed the educational benefits that support groups provided.

The group is found here at the hospital and our doctors give us advice and counsel us so as we feel encouraged enough to keep healthy such that we are able to take care of our babies. **Luwero FGD #6**

Not all women participated in support groups. The overwhelming reason for lack of participation was the inability to pay the entrance fee associated with joining the group.

I do not have any group because the initiation part of all groups requires money yet I do not have money. **Mityana, FGD #3**

### Community Level: Health Care Worker Attitudes and Behaviors

Health care workers' behaviors greatly impacted women's desire and/or ability to access HIV services for themselves and their infants. Women reported that money, or some form of compensation (i.e., food), was demanded to access the free services.

Many of the participants echoed the sentiment.

I had...gone to get services for the baby but when I got there, the nurse told me, "First give us some money for a soda. You are just from seeing Nurse Susan, you must have some money." I ended up giving him 1000ush for him to work on me. **Mityana, FGD #4**

In addition to compensation, health care workers' attitudes towards HIV-positive women were often judgmental and rude. Several women commented on this, while many others expressed their non-verbal agreement.

Me, sometimes you may get a special challenge and you do not return on the set date, but on the other day you come the doctors insult you yet you have a reason as to why you didn't come that day. So for that day you missed and chose to come on a different day, the nurses yell so loudly at you in front of other patients that you get shamed in front of them. That is what hurts me most. **Luwero, FGD #5**

Moreover, participants indicated that they were expected to act in certain ways and when they did not, health care workers often belittled them. One woman commented that after receiving her HIV diagnosis, her nurse told her, "How come you are not crying?"

**Mityana, FGD #5**

#### Mixed Messages on ART

It was clear from the FGDs that women were told about the importance of ART and NVP during their ANC visits. However, women's knowledge regarding prevention of vertical transmission varied considerably. Some women thought that NVP use after delivery only, would prevent transmission and would guarantee a HIV-negative baby.

If immediately after delivery the baby gets the syrup, the baby comes out healthy and doesn't get the sickness. **Masaka, FGD #1**

Conversely, other women thought that their own adherence would lead to an HIV-negative baby and seemed to underappreciate the need for ART in HIV-exposed infants.

To prevent the baby from getting HIV is if you know that you are pregnant, you must go to the hospital to receive drugs and in that way you would give birth to a fine baby because you would have prevented the baby from getting the virus from within the womb. **Luwero, FGD #5**

None of the women discussed the need for maternal adherence followed by NVP immediately after delivery, with continued adherence for the HIV-exposed infant throughout the breastfeeding period and indefinitely for the infected mother.

## **Discussion**

This mixed methods study sought to identify and understand influences on mothers accessing and using infant HIV medication and health services. We found that 20% of participants did not provide NVP to their infants within 72 hours of birth. Additionally, our quantitative results showed that not adhering to ART and participating in a support group were associated with providing the infant NVP after birth. Conversely, women who delivered at home were unlikely to give NVP to their infants. In the context of the Socio-ecological Framework, our qualitative results supported these findings and added new insights not seen in the quantitative analysis. We found that support groups, lack of partner support, health care worker attitudes, and unclear health messages regarding ART influenced women's access to and use of HIV services and ARV prophylaxis for their infants.

At the individual level of social influence, focusing on the woman, we found, surprisingly, that a lack ART adherence was significantly associated with NVP use. One interpretation is that women who did not adhere to ART were more likely to give NVP to their infants to ensure that their infants did not get HIV. In FGDs there were mixed ideas about what prevents transmission between mothers and their infants. Some women discussed the idea that NVP in itself can prevent transmission, with no reference to the need for their own adherence during pregnancy. However, our finding can also be interpreted in reverse: women who adhered to ART were less likely to give NVP to their infants. This may suggest that women thought their own adherence to ART was

adequate to prevent vertical HIV transmission. FGDs revealed that several participants did indeed believe this. While we are not able to decisively determine the most appropriate interpretation, we can say that understanding how each medication contributes to the prevention of HIV transmission was unclear among participants.

Family level barriers were also identified in our study. We found that home-based deliveries and lack of male partner support made it less likely that an infant would receive NVP. Home deliveries, still common in Uganda,(21) do not have the same supplies readily available as at a health facility. Additionally, lack of male partner support can force women to act covertly or prevent them altogether from accessing and using needed services. Studies have shown that when male partners are actively involved, women are more likely to access and use HIV medications and services for both themselves and their infants.(22, 23)

We found several community level factors of importance. First, we found that involvement in support groups was significantly associated with using infant NVP. Note, in this case support group was a broad term subject to the participant's interpretation; support groups were comprised of any group providing women emotional or financial support. In FGDs, participants also highlighted the value of support groups by discussing how participation enabled them to pay for medication and to better understand medical directions. Our results are supported by previous studies in SSA, which suggest that support groups can be beneficial to HIV-positive women by helping them to accept their HIV status, by enabling them to gain knowledge about HIV, and by empowering them to take control of their situation.(24, 25)

Additionally, community level factors also include health systems issues such as health care worker attitudes and behaviors. Participants described how hurtful health care workers could be and how they acted as a deterrent in accessing medications and

HIV health services. In addition to issues with overcrowding and lack of privacy during health care visits,(26, 27) numerous studies have discussed the quality of care, specifically health care worker attitudes and behaviors,(28-31) which result in decreased attendance and access to medications.

ART adherence, previously mentioned as an individual level barrier, is also a community level factor. Our FGDs revealed that while health care workers were providing information regarding how to prevent HIV transmission, the take-home messages were less than clear. We note, standard of care at each facility was for mothers to administer NVP to their infants regardless of their own adherence to ART. While messages came from multiple staff members and we do not have a record of what was actually said, we do know that women from all three facilities had differing opinions on prevention. Incorrect or misinterpreted information is a critical health systems barrier to the elimination of mother to child transmission of HIV.(32)

A limitation of our study was that we only interviewed women who attended at least one ANC visit. As such, we have no information on women who did not come into ANC at all, which is unfortunate as these women probably experience the largest number of barriers to accessing infant health services. Additionally, given the nature of the interview schedule, women were frequently in touch with a study interviewer. Consequently, being continually asked questions regarding adherence and access to health services may either have acted as a reminder/nudge for women, resulting in increased adherence or service utilization, or may have contributed to social desirability bias. Also, as all data was collected via self-report, our results are vulnerable to recall and social desirability biases. Finally, while the amount compensation was approved by the Makerere University and UNCST IRBs, there is a possibility that the additional

income resulted in an improved ability access infant NVP and as such, may have unintentionally biased our results.

Despite these limitations, our study highlights key barriers to infant HIV health service utilization that should be intervened upon. We believe that clear and concise health messages regarding the necessary medication regimen to prevent vertical transmission need to be developed and tested for long-term patient understanding. Support groups may be one pathway to disseminate this information. However, boosting support group attendance and lowering initiation costs must first be addressed. Further, as not all women participate in support groups, an additional avenue for dissemination needs to be identified. Perhaps peer mentors or navigators who would work with women individually to better understand health care worker instructions would prove successful.(33) In addition to developing these interventions, we strongly urge further research in additional settings to corroborate and elaborate on our findings. Specifically, we suggest additional research to understand the identified trends regarding maternal ART adherence. We also suggest further research on access to and use of infant ARVs including infant NVP adherence and subsequent early infant diagnostic testing.

## **Conclusions**

Eliminating mother to child transmission of HIV will only be achieved if all HIV-positive pregnant women receive and adhere to ART and if all HIV-exposed infants receive ARV prophylaxis in a timely manner. While much has been published on the effectiveness of ART in preventing transmission(11, 12) and to a lesser extent, access issues related to some infant HIV services (i.e., early infant diagnosis)(34), little research reports on access or adherence prior to two months of age(35). Our results provide a first step in understanding and overcoming these barriers, specifically in the Ugandan



context. Additionally, understanding multiple levels of social influence in a local context can greatly help when designing interventions and programs to reach not just women, but also their partners and the greater communities in which they reside. Programs designed to be inclusive of these levels will bolster access and use and ultimately reduce HIV transmission rates.

### **Acknowledgement**

Chapter 3, in full, is a reprint of the material as it appears in *AIDS and Behavior* 2016. Bergmann JN; Wanyenze R; Makumbi F; Naigino R; Kiene SM; Stockman JK, *AIDS and Behavior*, 2016. The dissertation author was the primary investigator and author of this paper.

**Table 3.1: Characteristics of HIV-positive Women enrolled in the Implementation of Option B+ study in Uganda according to infant nevirapine (NVP) use (N=384)**

Variable		NVP Yes N=308 (80%)	NVP No N=76 (20%)	P- value	Total <sup>a</sup> (n=384)
Mean Age (standard deviation)		25 (4.3)	26 (10.2)	0.57	25 (6.3)
Highest level of education attended	No school	9 (3)	3 (4)	0.24	12 (3)
	Primary	140 (45)	42 (55)		182 (47)
	Secondary+	159 (52)	31 (41)		190 (50)
Marital status	Married	244 (79)	66 (87)	0.13	310 (81)
	Single, Divorced, or Widowed	64 (21)	10 (13)		74 (19)
Occupation	Farmer	49 (16)	28 (37)	<0.01	77 (20)
	Salaried position	23 (7)	3 (4)		26 (7)
	Business	104 (34)	17 (22)		121 (31)
	Causal Worker	14 (5)	4 (5)		18 (5)
	Housewife, Not Employed	97 (31)	22 (29)		119 (31)
	Other	21 (7)	2 (3)		23 (6)
Number of live children prior to entering the study	0	78 (26)	21 (28)	0.97	99 (26)
	1	84 (27)	21 (28)		105 (27)
	2	56 (18)	13 (17)		69 (18)
	3+	90 (29)	21 (28)		111 (29)
Health Facility	Masaka Hosp	113 (37)	22 (29)	0.50	135 (35)
	Luwero HC-IV	75 (24)	21 (28)		96 (25)
	Mityana Hosp	120 (39)	33 (43)		153 (40)
Attends any support group	Yes	139 (45)	21 (28)	0.01	160 (42)
	No	169 (55)	55 (72)		224 (58)
% of ART doses taken in the past month	≥95%	276 (83)	32 (60)	<0.01	308 (80)
	<95%	55 (17)	21 (40)		76 (20)
Missed an ART dose in last 3 days	Yes	27 (12)	21 (40)	<0.01	48 (18)
	No	195 (88)	31 (60)		226 (82)
Missed an ART dose in last 7 days	Yes	33 (16)	20 (42)	<0.01	53 (21)
	No	171 (84)	28 (58)		199 (79)
Current sexual partner HIV-positive	Yes	65 (54)	13 (50)	0.85	78 (53)
	No	56 (46)	13 (50)		69 (47)
Delivery location	Health facility	306 (99)	53 (73)	<0.01	359 (94)
	Elsewhere	2 (1)	20 (27)		22 (6)
Disclosed HIV status to partner	Yes	151 (58)	33 (60)	0.68	190 (58)
	No	116 (42)	22 (40)		138 (42)

**Table 3.1: Characteristics of HIV-positive Women, Continued**

Variable		NVP Yes N=308 (80%)	NVP No N=76 (20%)	P- value	Total <sup>a</sup> (n=384)
Disclosed HIV status to anyone	Yes	273 (89)	55 (72)	<b>&lt;0.01</b>	328 (86)
	No	34 (11)	21 (28)		55 (14)
Infant completed an early infant diagnostic (EID) test	Yes	255 (83)	53 (70)	<b>0.01</b>	308 (80)
	No	53 (17)	23 (30)		76 (20)
Result of infant's EID test	Negative	250 (98)	46 (87)	<b>0.00</b>	296 (97)
	Positive	4 (2)	6 (13)		10 (3)

<sup>a</sup> Not all columns add to the total N as not every participant answered each question.

**Table 3.2: Bivariate associations between HIV-positive mothers giving nevirapine to their infants immediately after birth in three districts in Uganda according to Socio-ecological Framework (N=384)**

Variable		Odds Ratio	95% Confidence Interval	P-value
<b>Individual Level of Social Influence</b>				
Age		1.02	0.98-1.05	0.93
Marital status	Married		Ref	
	Single, Divorced or Widowed	0.58	0.28-1.19	0.14
Highest level of education attended	None		Ref	
	Primary	0.9	0.23-3.48	0.88
	Secondary+	0.59	0.15-2.28	0.44
# of Children prior to start of study	0		Ref	
	1	0.93	0.47-1.83	0.83
	2	0.86	0.40-1.86	0.71
	3+	0.87	0.44-1.70	0.68
Took <95% of ART doses in past month		<b>3.29</b>	<b>1.77-6.13</b>	<b>&lt;0.01</b>
Missed an ART dose in last 3 days		<b>4.89</b>	<b>2.47-9.70</b>	<b>0.01</b>
Missed an ART dose in last 7 days		<b>3.70</b>	<b>1.87-7.33</b>	<b>&lt;0.01</b>
<b>Family Level of Social Influence</b>				
Current sexual partner HIV-positive		1.16	0.50-2.71	0.73
Delivered at home		<b>0.02</b>	<b>0.004-0.08</b>	<b>&lt;0.01</b>
Disclosed HIV status to partner		0.95	0.54-1.67	0.85
Disclosed HIV status to anyone		1.51	0.93-2.47	0.10
<b>Community Level of Social Influence</b>				
Currently in a support group		<b>2.15</b>	<b>1.24-3.74</b>	<b>&lt;0.01</b>

<sup>a</sup> Bolded values are significant at the p=0.05 level

**Table 3.3: Factors independently associated with mothers giving nevirapine to their infant immediately after birth among HIV-positive post-partum women in three districts in Uganda**

<b>Variable</b>	<b>Adjusted Odds Ratio<sup>a</sup></b>	<b>95% Confidence Interval</b>	<b>P-value</b>
Took <95% of ART doses in last 30 days	3.55	1.36-9.26	<b>0.01</b>
Delivered at home	0.02	0.003-0.09	<b>&lt;0.01</b>
Currently in a Support Group	2.50	1.06-5.83	<b>0.04</b>

<sup>a</sup> Adjusted for disclosure of HIV status to current partner, age, marital status, education level, number of children, and health care facility.

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## **CHAPTER 4: The Cost of Accessing Infant HIV Medications and HIV/AIDS Health Services in Uganda**

### **Abstract**

**Background:** Patient costs are a critical barrier to the elimination of mother to child HIV transmission. Despite the Ugandan government providing free public HIV services, infant antiretroviral (ARV) prophylaxis coverage remains low (25%). To understand costs incurred by mothers in accessing ARV prophylaxis for their infants, we conducted a mixed methods study to quantify costs and to qualitatively understand how costs influence access and use.

**Methods:** We used cross-sectional survey data and focus group discussions (FGDs) from 49 HIV-positive mothers in Uganda. Means and standard deviations were calculated for direct (e.g., transportation), indirect (e.g., opportunity costs, such as salary loss), and total costs involved in accessing infant HIV services. Transcripts from FGDs were reviewed and coded for theme identification.

**Results:** The cost of attending HIV clinic visits averaged \$5.46 USD (standard deviation (SD)=\$3.63). Direct costs totaled \$3.71 (SD=\$3.52), while indirect costs totaled \$1.75 (SD=\$0.32). FGDs identified three costs hindering access to HIV services: transportation costs, informal service charges, and opportunity costs.

**Conclusions:** All participants reported significant costs associated with accessing infant HIV services—the equivalent of 3-4 days' income. To address transportation and opportunity costs, policies need to be developed reducing the yearly number of clinic visits patients must attend for HIV services. Additionally, stricter policies and oversight should be implemented to prevent informal HIV service charges.

## Introduction

Uganda is classified as a high burden country in terms of HIV prevalence and incidence.(1) Despite this classification, Uganda has made significant strides in curbing the HIV/AIDS epidemic. In 2014, while 1.5 million individuals in the country were HIV-infected, only 6% of cases were attributed to new infections acquired during that year.(1) Further, in the same year, 51% of HIV-positive individuals in the country were on antiretroviral therapy (ART), up from 42% in 2013.(1) While much forward progress has been made in reducing new infections and treating those infected, less progress has been made in preventing vertical HIV transmission to infants. In 2014, only 25% of exposed infants received antiretroviral (ARV) prophylaxis (i.e., nevirapine) during their first 6 weeks of life; a substantial decrease from the 2013 coverage rate of 37%.(1)

In an effort to increase access to and use of HIV services, the Ugandan government committed to providing free HIV services to all infected individuals.(2) While much work has quantified the health system expenditure involved in providing ART in sub-Saharan Africa (SSA),(3-5) fewer studies have assessed the patient costs incurred in accessing the “free services”. One study in South Africa demonstrated that yearly costs incurred by patients seeking free HIV care can be as high as \$170 USD.(6) Similarly, a study in Malawi found free ART visits to be costly for patients, reporting that a clinic visit was about the equivalent of 75% of a Malawian’s daily income.(7) Both studies demonstrate that free ART services do not equate to free care.

Despite this, ART coverage rates for HIV-positive pregnant women in Uganda indicate that most are able to access services at some point during their pregnancies (94% received ART in 2014).(1) However, the low rates of infant ARV prophylaxis uptake may suggest that access becomes problematic post-partum for both mothers and their exposed infants. This study was conceived to understand the true financial burden

HIV-positive mothers face when accessing HIV treatment for their infants, as well as the nature of these costs. To that end, we aimed to quantify direct (e.g., transportation), indirect (e.g., opportunity costs, such as salary loss), and total costs incurred by mothers when accessing HIV services for their infants in Uganda. Further, to help explain the quantified expenses, we qualitatively evaluated women's experiences in accessing HIV health services.

## **Methods**

### *Study Design*

We conducted a mixed methods, cross-sectional study in three districts in Uganda (Masaka, Luwero, and Mityana). HIV-positive women participating in an ongoing longitudinal study assessing the uptake of Option B+ in Uganda were solicited for participation in this study. Women who participated in a quantitative face-to-face survey were then invited to participate in focus group discussions (FGDs). Written informed consent was obtained from all participants. Data were collected in November 2015. The study protocol was reviewed and approved by the Institutional Review Boards of Makerere University School of Public Health (Protocol #320), the University of California, San Diego (Project #151007), and the Uganda National Council of Science and Technology (Registration #SS3923).

### *Quantitative Component*

#### Sample Selection

This cross-sectional analysis involved a sample of 49 women previously enrolled in an ongoing longitudinal study. Pregnant women were originally recruited from antenatal care (ANC) visits, were HIV-positive, had initiated ART within 4 weeks of

recruitment, and were aged 15-49 years. All post-partum participants from the longitudinal study were eligible for the cross-sectional study.

### Procedures

We used contact information provided at baseline in the longitudinal study to contact women for participation in the cross-sectional study. Six lists were randomly generated of all participants, two lists for each district: one of women who had accessed infant ARV prophylaxis (nevirapine), and one of women who had not. We included this to understand the perspectives of women who utilize HIV services differently. From these lists, every 10<sup>th</sup> name was randomly selected to participate. All data were gathered through face-to-face interviews, were paper-based, were conducted in the local language of Luganda, and lasted approximately 10 minutes. Interviews took place in private spaces at the health facilities. Participants received 1,000 Ugandan Shillings (~\$.30 USD) for their time.

### Data Analysis

**Measures.** In addition to demographics, we collected direct and indirect costs.

**Direct Costs.** All expenses reported were in reference to participants' typical HIV clinic visit for their infants. If they had not accessed services for their infant, participants referenced costs of their own care. All amounts were reported in Ugandan Shillings and later converted to USD (1USD=3475UGX).

**Caretaker Cost.** Participants were asked how much they paid for a caretaker to watch or care for either a child or an elder while they attended a clinic visit.

*Transportation Cost.* Participants were as asked how much they paid for round trip transportation to the health center.

*Medication Fee.* Despite being free of charge, informal fees frequently require patients to pay for free medications. As such, we asked participants if they paid for any HIV-related medications (e.g., nevirapine, co-trimoxazole) and if so, how much. This question excluded any medications that were for purchase outside of the free HIV services (i.e., at private facilities).

*Service Fee.* Similarly, patients may be charged informal fees to access otherwise free HIV services. As such, we asked participants if they had to pay for any HIV-related services (e.g., early infant diagnosis test) and if so, how much they paid.

*Other Fees/Refreshment Cost.* Participants were asked if they paid for anything else during their visits and if so how much they paid (e.g., food and refreshments for themselves or for anyone else such as nurse or partner).

#### Indirect Costs

*Opportunity Costs.* As clinic visits typically require a full day, opportunity costs were calculated for one day of missed work. While clinic time was not reported in the quantitative survey, the qualitative portion of the study endorsed this method.

Participants were asked their profession; professions were then used to calculate daily salaries. Salary for farmers was determined based on the per capita GDP associated with agriculture (27% of total GDP in 2014(8) (equaling 7.3 Billion USD)). GDP per capita for farmers was generated by dividing the agricultural GDP by the number of Ugandans involved in agriculture (8.8 million workers).(9) That amount was then converted to a daily figure (totaling \$2.27/day). As housewives and informal merchants (i.e., sellers of goods, foods, etc.) are both part of the informal sector, both professions

were assigned the monthly salary for individuals in rural areas (all three districts are in rural locations), as published by the Uganda Bureau of Statistics.(10) Daily salaries were based on the published monthly rates and then converted to USD (totaling \$1.56/day).

### Statistical Analysis

The distribution of each variable was determined prior to analyses. We used Wilcoxon Rank Sum test for non-parametric continuous variables and Chi-square tests for categorical variables. Means and standard deviations were calculated for direct, indirect and total costs. All analyses were performed using STATA 14.1.

### *Qualitative Component*

#### Sample Selection

Six FGDs were conducted; two in each district, and a total of 43 of the 49 women who completed the quantitative survey participated. Fourteen women were from Masaka District, 16 from Mityana District, and 13 from Luwero District. The other six women were unable to stay for FGDs.

#### Procedures

Upon agreeing to participate in the cross-sectional study, participants were solicited for participation in the FGDs. FGDs were conducted by trained study interviewers in the Luganda language, were held in private spaces at health facilities, and lasted 30-60 minutes. All FGDs were audio-recorded. Participants received 10,000 Ugandan Shillings for their time.

FGD guides were informed from the literature and revised from discussions with the longitudinal study's interviewers regarding their experiences. The guides had two

main themes: 1) knowledge regarding vertical HIV transmission and how it is prevented, and 2) facilitators and/or barriers to accessing infant HIV services.

## Data Analysis

FGD audio-recordings were transcribed and then translated into English. Transcripts were uploaded into MAXQDA for analysis. Our analysis was a four-step process. First, we reviewed all transcripts to develop a broad understanding of content. During this process we developed short descriptive statements to document initial impressions of these topics/themes.<sup>(11)</sup> Second, we used these statements to identify emergent themes and to create open codes.<sup>(11, 12)</sup> *A priori themes* (i.e., created from our theoretical framework/quantitative analysis) and *emergent themes* (i.e., identified in open coding), were used to create a codebook that included a description of each code's content, inclusion/exclusion criteria, and a text example.<sup>(11)</sup> Finally, we coded all responses in the transcripts using the codebook.

## Results

### *Quantitative Results*

#### Participant Characteristics

Among the 49 participants, women were on average 25 years of age (standard deviation (SD)=5.7), 41% had attended either secondary school or higher, 84% were married, and 73% had at least one child prior to entering the study. Forty-three percent of participants self-identified as housewives, 31% sold goods, and 26% were farmers (Table 4.1).

## Patient Costs

All participants reported some form of direct and indirect costs. On average, direct costs equaled \$3.71 USD (SD=\$3.52) and indirect costs averaged \$1.75 (SD=\$0.32) for a total cost of \$5.46 (SD=\$3.63) (Table 4.2). While we did assess for group differences between participants who had accessed infant ARV prophylaxis and those who did not, no statistically significant differences were identified.

## *Qualitative Results*

### Types of Costs Experienced when Accessing Infant HIV Health Services

#### Direct Cost: Transportation

All participants incurred transportation costs. Women described that while they wanted to adhere to medications and follow medical instructions, they frequently did not have the money necessary to get to the clinic for medication refills or needed appointments.

Personally, the journey is so long for me. Now a time may reach when I have to return to the hospital, yet the maximum I can get in my wallet is 2,000ush or 1,000ush! So I would feel a challenge because of that situation since I wanted to bring back the baby but have no money. **FGD #1, Masaka**

Another woman discussed how keeping a clinic appointment is challenging when money is scarce. Women knew the necessity of attending scheduled appointments, but were unable to do so if they did not have the funds for transport.

The challenge I have gone through is when my appointment date to return this side is about to reach, I fail to get money for transport. **FGD #6, Luwero**



#### Direct Cost: Informal HIV service and medication charges

Most women reported experiencing informal HIV service fees. Participants who had not accessed infant HIV services stressed that these fees were critical in preventing them from accessing medications. Note, we exclude FGD number and location from these quotes to preserve anonymity of the participant and potentially of the health care worker involved.

There is a gentleman who always stations there, so there are times I usually go there when he is the only person who worked that day and he says, "If you do not have money for a soda I am not going to give you the baby's medicine." He has done that to me about thrice.

Yet another woman discussed how access to and use of services was prevented by health care workers' demands for *payment*.

During registration the doctor asks you for a 'soda' but when you tell her, "Doctor today I do not have any money" she then says, "Now I have been so busy, but now I am concentrating on you, don't you see that I have worked so much?" Then when you tell her, "I do not have money, but I will give you some another day when I come with money," she says, "No, I am tired."

#### Indirect Costs: Opportunity Costs

Time lost, and the resulting salary loss, was a recurring theme among the majority of women. Travel time (which can add to several hours round trip) in addition to overcrowding and an inadequate number of health care workers (which leads to excessive wait times), compounded to result in all day clinic visits. One woman summed up the struggle participants faced between accessing services and earning the money to pay for the services.

For example, us that are occupied with work, I may sometimes have customers' tasks to complete yet I have to come and pick drugs. So I find myself delaying yet I love my baby but also need the money. In that way I end up losing the work but only because I am yearning to save my baby's life. **FGD #6, Luwero**

In addition to lost time for each clinic visit, women also talked about experiencing stock outs when attempting to collect medications. Stock outs, when essential medications are unavailable at clinics, are unfortunately common in Uganda and can result in an inability to secure needed medications and can greatly influence adherence. When funds are scarce, wasting time and money to get to the clinic only to discover the medications are unavailable can also create disillusionment regarding access to care among patients and ultimately negatively impacts health.

It is still making the medicine available because you may use money to transport yourself all the way from Sembabule to come and pick drugs but when you reach here they tell you, 'there are no drugs now but come back tomorrow,' yet you do not have the money to transport you back there the next day, and yet even if they write it down for you to go and buy it, you do not have money. **FGD #2, Masaka**

## **Discussion**

This mixed methods study sought to quantify and understand the costs associated with accessing infant HIV treatment and health services. While there were no statistically significant differences between participants who accessed infant HIV prophylaxis and those who did not, the cost reported by all participants to access and use HIV services was significantly higher than “free”. Our qualitative results helped to explain these costs and highlighted how they prevented access. We found that transportation costs, informal HIV service and medication charges, and opportunity costs significantly contributed to the decision and ability to access infant HIV services.

Average daily income for a rural Ugandan is approximately \$1.56.(10) Participants reported that on average they spent \$5.46 for a single clinic visit—the equivalent of 3-4 days income, a significant expense for someone living on \$1.56 a day. Previous studies have demonstrated that the daily, yearly, and lifetime financial hardship due to HIV expenses can result in forgoing other essential expenditures (i.e., food,

school fees) and push already impoverished individuals into complete financial ruin.(13, 14)

FGDs highlighted the financial burden experienced due to transportation costs. Many women discussed wanting to attend a clinic to pick up medications, see doctors, etc., but were unable to do so because they simply did not have the funds necessary to get to the clinic. On average, we found that round-trip transportation cost \$1.89 or 35% of the total cost of a clinic visit. Several studies in SSA have assessed transport costs and found this to be a critical barrier in accessing care and typically the largest contributor to direct costs incurred by patients.(13-16) Further, studies have found that high direct costs, specifically for transport, can lead to low ART adherence.(7, 17, 18) Our study supported the hardship experienced by patients due to transportation costs and demonstrated that these expenses must be taken into consideration when developing guidelines for how frequently patients need to return to access HIV services.

While not all participants reported being forced to pay informal service fees, those who did stated that they were costly, unexpected, and frequently resulted in an inability to access services or medications. FGDs showed that many women arrived at health centers with the exact amount of money they knew would be necessary for the clinic visit (costs for transportation, food, etc.). When forced to pay additional fees for free services, women were not able to do so. Many studies in SSA have looked at informal fees (in some cases referred to as bribes) when accessing care.(19-24) While it can be argued that informal fees might make health care workers work harder as they feel they are being more adequately compensated for their time,(24) most studies found that health care workers demonstrated no additional effort when receiving informal compensation and that in settings where informal compensation was demanded, quality of care actually diminished among the health care workers who did not ask for

payments.(19, 22-24) Informal payments act to demotivate health care workers and discourage patients from accessing care. As such, policies aimed at increasing health care worker base salaries may alleviate the demands for informal compensation. Regardless of base pay, increased health care worker accountability and enforcing harsher punishments on those who do not adhere to the policy may remove this critical barrier in access to HIV care.

Time lost due to clinic visits is a critical economic barrier to accessing care. FGD participants overwhelmingly noted that a clinic visit required an entire day and that the time spent going to clinics was time that could not be spent working. Given the high costs associated with accessing care, participants were frequently forced to decide between earning the money to pay for visits or accessing the services. Compounding their frustration over lost time was the occurrence of medication stock outs, which required them to either come back another day or go without the needed medication. While indirect expenses, specifically opportunity costs, were half as much as direct expenses, they accounted for approximately 33% of the total cost of accessing care. Further, it has been demonstrated that the sicker individuals become, the more opportunity costs they experience, sometimes referred to as the 'medical poverty trap'.(25) Since indirect costs will always be present when both sick and relatively healthy individuals access care, they must be accounted for when developing policies to facilitate access to HIV services.

Our study had three main limitations. First, we only recruited participants who attended at least one ANC visit. While ANC attendance is high in Uganda (95%),(26) minimizing this limitation, we have no information on women who did not attend ANC at all during pregnancy. Given that women who do not access care probably experience the greatest barriers and perhaps even the greatest costs, our study most likely

underestimates the true cost incurred in accessing care among HIV-positive mothers. Secondly, a larger sample size may have allowed us to detect a statistically significant difference between the women who accessed infant ARV prophylaxis and those who did not. However, this was not our main objective. Instead we were primarily interested in understanding patient costs in general, rather comparing groups. Finally, assigning standardized indirect costs by profession could either have resulted in under or overestimating participant wages. However, as none of the women reported a formal profession, and most did not engage in activities that actively brought cash into the household, our method enabled us to assign value to non-cash earning activities (i.e., gardening, childcare, etc.) and provide an opportunity cost for all participants.

Despite these limitations, our study identified several key costs and further explained how they impact access to HIV health services. These costs can and should be addressed at the policy level in an effort to boost access rates and improve ART adherence. As our study population was largely from rural areas, distance to health facilities and associated costs were long and high. However, transportation costs will always exist. Given this, we recommend reducing the number of times women and their infants must return to health facilities for post-natal check-ups or pill collection. Currently, at most facilities in Uganda, post-partum women return with their child monthly for the first six-months post-birth and then every 2-3 months up until month 18 (women then continue to return every 2-3 months thereafter for their own health). However, for women who prove adherent and whose infants receive appropriate medications and services in a timely manner, return to the clinics should be reduced to 2-3 times a year. Further, informal health service fees not only prevent access, but disillusion patients from attempting to access services and medications at later dates. Policies must be

implemented that increase oversight and accountability of health care workers, which would eliminate their ability to require payment for free services.

### **Public Health Implications**

The elimination of mother to child transmission is possible, but only if barriers preventing mothers from accessing and utilizing HIV services for themselves and their infants are removed. While ART is free in Uganda, HIV services are not. We have identified several types of costs that patients in Uganda experience and have further elaborated on how they impact HIV-positive women's behaviors. Identifying these costs is the first step in their elimination. This study provides motivation for the development of new policies targeted at public ART facilities. The elimination of some, if not all, unexpected fees will not only improve access and adherence to ART, but will also ultimately decrease vertical transmission rates.

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**Table 4.1: Characteristics of HIV-positive women with HIV-exposed infants in Uganda**

<b>Variable</b>	<b>Total (n=49)</b>	
Mean Age (standard deviation)	25 (5.7)	
Education	No school	3 (6)
	Primary	26 (53)
	Secondary+	20 (41)
Marital Status	Married	41 (84)
	Not Married	8 (16)
Occupation	Housewife	21 (43)
	Informal Merchant	15 (31)
	Farmer	13 (26)
Number of Children	0	13 (27)
	1	12 (24)
	2	10 (20)
	3+	14 (29)
Health Facility	Masaka Hospital	15 (30)
	Luwero Health Center IV	15 (30)
	Mityana Hospital	19 (39)
Mean transportation time to and from clinic in minutes (standard deviation)	79 (79)	
Cost of transportation to clinic (standard deviation)	\$1.89 (\$1.89)	

**Table 4.2: Mean costs associated with HIV-positive mothers accessing infant HIV services in Uganda (N=49)**

<b>Type of Cost</b>	<b>Mean Cost (SD)</b>
Direct Mean Cost	\$3.71 (3.52)
Indirect Mean Cost	\$1.75 (0.32)
Total Mean Cost	\$5.46 (3.63)

SD: Standard deviation



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## **CHAPTER 5: DISCUSSION**

This dissertation sought to identify and understand barriers and facilitators to the prevention of vertical transmission of HIV in Kenya and Uganda. Given the economic disparities as well as cultural complexities (e.g., sexual relationship power) resulting from strictly defined gender roles in Sub-Saharan Africa (SSA), this dissertation assessed different levels of social influence, as outlined in the Socio-ecological Framework, to achieve these aims.(1) At the individual level, we sought to understand women's behaviors as they relate to accessing HIV care and medications for themselves and their infants. At the family level, we aimed to understand how equity attitudes between sexual partners contribute to potential HIV transmission. At the community level, we aimed to understand social and economic factors that prevent women from autonomously accessing infant HIV services. As women are often the first person to be identified as HIV-positive in a relationship and/or family unit, typically due to their contact with antenatal care where HIV testing is standard, they frequently are held accountable for bringing the disease into the household as well as for infecting any of their infants.(2) Because of this, a woman may choose to avoid HIV testing, not disclose her results to her partner, or not access and/or adhere to her HIV medications due to fear of discovery by her partner or family. All of these reasons contribute to the continuation of vertical transmission of HIV. Thus, it was imperative to understand the variety of barriers and facilitators to accessing and utilizing health services that women encounter throughout their reproductive lifespans.

## **Aim 1: Evaluating Gender Equity and Dual Contraceptive Use among Couples in Kenya**

The first aim of this dissertation was to identify influences to vertical transmission of HIV that women encounter before pregnancy and at the family and community levels of the Socio-ecological Framework. Many pregnancies among HIV-positive women each year in SSA are unintended (mistimed or unwanted) and bring about risk of vertical transmission of HIV. Previous research has identified the role that male partner resistance, masculinity notions, and gender equity contribute to contraceptive use and nonuse when there is an expressed desire to prevent or delay pregnancy.(3-8) Aim one sought to build from this work to understand how dyadic level, or couple level, decisions (in this case dual contraceptive use) are impacted by individual partner attitudes of gender equity and if these individual attitudes interact to influence the dyadic outcome.

Aim one results reiterated the association between gender equitable attitudes and contraceptive use.(9-14) However, our findings augmented previous research by identifying a significant interaction in gender equitable attitudes between partners on dual contraceptive use, which was a family level influencer per the Socio-ecological Framework. We found that each partner's attitudes interacted with the other's to significantly increase the odds of dual contraceptive use within the dyad. In other words, as both partner's attitudes about equity improved, there were greater odds of dual use as compared to when only one partner had more equitable attitudes. However, we note, we did not find an individual association between GEM scores and dual contraceptive use, further highlighting the importance of dyadic research. Moreover, aim one identified that when female partners disclosed their HIV status to more types of individuals (e.g., partners, parents, children, friends), they were more likely to be in a dyad that reported dual contraceptive use. This outcome was a family and community level influencer per

the Socio-ecological Framework. This finding reinforced previous results on HIV disclosure, which indicated that disclosure to one's sexual partner, for example, can result in increased support and encourage open communication between partners, leading to contraceptive use.(15-17) Our results again emphasize the need to include and educate men in reproductive health and family planning matters, including transmission of HIV, despite the cultural belief that these topics are typically "women's business". As men must actively participate for a couple to achieve dual contraceptive use, and male partner support can encourage female contraceptive use, we urge male partner inclusion in these matters. Additionally, our results provide evidence for targeting males with gender transformative campaigns to change their traditional attitudes on gender equity.

### **Aim 2: Evaluating Maternal Influences on Administration of Infant Antiretroviral (ARV) Prophylaxis**

The second aim of this dissertation was to understand facilitators and barriers to preventing vertical HIV transmission at the individual and community levels of the Socio-ecological Framework that HIV-positive women encounter while either pregnant or immediately after their pregnancy. Despite increased availability of HIV medications in SSA, only 28% of HIV-positive children in the region received ARVs in 2013.(18) While it is well known that early access to ARVs is critical in preventing vertical transmission,(19-24) little research has been conducted to understand administration of ARV prophylaxis in infants younger than 6-weeks of age. Aim two sought to address this gap and to understand how mothers' behaviors were associated with their infant receiving ARV prophylaxis at birth. Moreover, aim two also sought to elaborate on mothers' behaviors and actions through focus group discussions.

Aim two results demonstrate that maternal behaviors are significantly associated with infants receiving ARV prophylaxis immediately after birth. While intuitive, few studies have provided these results, with most research focusing on infant health and medication adherence after 6-weeks of life. Specifically, we found that maternal adherence to ART was negatively associated with administration of medication to infants, while maternal participation in a support group was positively associated with administration. Our results regarding support group attendance supported previous literature on community support for HIV-positive women. Studies have demonstrated that support groups can help empower women to accept their HIV status, while also helping them to learn to live with HIV.(25, 26) Our quantitative and qualitative results confirm this prior work and further suggest that support groups can provide women with assistance in learning to care for their HIV-exposed infants. This finding was a community level influencer per the Socio-ecological Framework. Conversely, literature on maternal adherence to ART has been associated with increased access to HIV services for exposed or infected infants (e.g., early infant diagnosis testing).(27) However, our quantitative results did not show this. Therefore, we relied on our focus group discussions to help explain this outcome. We found that HIV-positive pregnant women were given conflicting, confusing, and incomplete information regarding the need for infant HIV medication and maternal ART adherence. This is a major finding for the research on vertical transmission of HIV and is an individual and community level influencer per the Socio-ecological Framework. As both maternal and infant adherence are critical in preventing HIV transmission, this study provides strong evidence for the necessity of improving health care worker messaging regarding ARV adherence for women and their infants. It also provides evidence suggesting that programs aimed to

bolster support group participation may facilitate ARV administration to infants as well as provide pregnant women clarifications regarding health care worker ARV messaging.

### **Aim 3: Assessing Patient Costs for Access to Infant HIV Health Services**

The final aim of this dissertation was to quantify and identify the economic costs post-partum HIV-positive women incur when accessing needed HIV medications for their exposed or infected infants. This aim focused on the individual and community levels of social influence from the Socio-ecological Framework. Because most individuals live at or below the poverty line in SSA, many governments in the region, including Uganda, have pledged to provide free HIV health services to curb the epidemic.(28) While many studies have assessed the health system costs that SSA states incur in providing free services,(29-31) very few have quantified patient costs. The few studies that have, estimate yearly costs to be as high as \$170 USD, (32) as in the case of South Africa, or around 75% of one's income,(33) as in the case of Malawi. Given this, aim three sought to identify the total cost of accessing infant HIV care in Uganda for the purpose of identifying areas in which policy reforms may be created to help alleviate the financial burden.

Aim three results provide additional evidence that HIV health services are not free to access. We found that HIV-positive women incur an expense of \$5.46 USD (standard deviation=\$3.63) per clinic visit; the equivalent of 3-4 days' income. To explain incurred costs, we held focus group discussions and found that three costs played a significant role in the total expense: 1) transportation costs, 2) informal service charges, and 3) opportunity costs. The first two costs are community level influencers per the Socio-ecological Framework, and the third cost is an individual level influencer. We found transportation costs to be approximately 35% of the total clinic costs. This finding

supports previous research demonstrating that transportation costs are a critical barrier to accessing care.(34-37) Moreover, given the frequent supply shortages clinics experience in SSA, opportunity costs, costs associated with loss of work, contribute significantly to patients being lost to care as patients may choose not to return since medications may not be available. Finally, informal service fees are the main finding of aim three and another key result of this dissertation work. We found that health care workers frequently required payment for free services, which our participants were unable to afford. Previous studies have shown that quality of care not only remains static if informal fees are paid, but will actually diminish among the health care workers who did not ask for payments.(38-41) To eliminate vertical transmission of HIV, results such as those from aim three, must be addressed. Our findings urge for policy reform regarding oversight of health care workers to prevent informal fees. Additionally, our results also suggest that salaries for health care workers may not be adequate to compensate for their workload. Given the numerous encounters HIV-positive mothers will have with health care services throughout their reproductive lifespans, either for HIV related care, reproductive health, or their children's care, costs will play a significant role in their ability to seek medical attention. Therefore, this dissertation provides evidence for policy reform targeted at alleviating the burden of patient costs.

### **Dissertation Limitations and Achievements**

This dissertation had several overarching limitations. Foremost, all data were self-report and therefore may be subject to recall and/or social desirability biases. However, we did attempt to negate this by assessing clinic records to verify female contraceptive use, ART adherence, and ARV prophylaxis administration. Additionally, data were not population-based, instead convenience samples and therefore, our results



are not generalizable to the greater population. Moreover, as all three aims employed cross-sectional designs, we were unable to identify any temporal influences in contraceptive use, maternal ART adherence, or wage fluctuations. Moreover, only women who attended health clinics were recruited to participate and as such, we have no information on women who do not seek care. Thus, it is possible that non-care seekers experience more or different types of barriers to accessing care. Despite the limitations, this dissertation provides much needed evidence on behaviors that act as barriers and facilitators to preventing vertical transmission of HIV.

Despite the plethora of data and literature explaining the current state of the HIV epidemic in SSA, little is known about the topics addressed in this dissertation. This dissertation address four main gaps in the current literature. First, aim one provided much needed data on the prevalence of dual contraceptive use among an HIV-positive sample in Kenya while also exploring correlates to use. Given the World Health Organization guidelines on contraceptive use among HIV-positive individuals, a surprising lack of research exists on dual use, specifically in Kenya. Secondly, aim one also presented dyadic level data on contraceptive use, which demonstrated the need to include both partners in analyses on actions or decisions that are taken or made jointly. As partners in sexual relationships are influenced by each other, it stands to reason that both partners must be included in such analyses. Next, aim two identified facilitators and barriers to administration of ARV prophylaxis to infants prior to 2 months of age. Until this study, to our knowledge almost no research addressed access or adherence to HIV medications for infants immediately after birth. Given the necessity of infants receiving and adhering to ARVs to prevent HIV transmission, it is critical that this gap be filled.(42) Finally, aim three quantified an estimated cost of attendance for each pediatric HIV clinic visit. Since most individuals in Uganda live at or below the poverty line, it is essential that

actual costs of care be understood in order to identify economic reliefs that can help increase access. This dissertation explored different points in women's reproductive lifespans in which barriers or facilitators to the prevention of vertical transmission can occur. It provided evidence in each identified case, and also suggested areas for intervention that may serve to halt mother to child transmission of HIV.

### **Practice and Policy Implications**

Results from aim one lead us to suggest developing an intervention that both transforms traditional notions of gender norms in order to increase gender equity and targets male knowledge and subsequent involvement in reproductive health. We suggest a two-fold intervention. First, HIV providers should be urged to discuss family planning practices, HIV transmission, and the need for dual contraceptive use with men, as well as women, to educate them on their role and responsibility in reproductive health. Additionally, community-level health campaigns should be aimed at adolescent boys and young men to transform masculinity notions that negatively impact reproductive health or single out reproductive health as "women's business". Campaigns should also work to improve male gender equitable attitudes that prevent open discussion with sexual partners regarding reproductive health. As both partners contribute to dual contraceptive use, conversations regarding couples' intentions and each partner's role should be encouraged within couples.

Results from aim two lead us to suggest developing clear and concise health messages regarding the necessary medication regimen to prevent vertical transmission need to be developed and tested for long-term patient understanding. Support groups may be one pathway to disseminate this information. An additional pathway may be the

use of peer mentors or navigators who would work with women individually to better understand health care worker instructions.

Finally, aim 3 results lead us to recommend reducing the number of times women and their infants must return to health facilities for post-natal check-ups or pill collection. Currently, at most facilities in Uganda, post-partum women return with their child monthly for the first six-months post-birth and then every 2-3 months up until month 18 (women then continue to return every 2-3 months thereafter for their own health). However, for women who prove adherent and whose infants receive appropriate medications and services in a timely manner, return to the clinics should be reduced to 2-3 times a year. Further, informal health service fees not only prevent access, but disillusion patients from attempting to access services and medications at later dates. Policies must be implemented that increase oversight and accountability of health care workers, which would eliminate their ability to require payment for free services.

### **Areas for Future Research**

The elimination of mother to child transmission of HIV can be achieved if barriers preventing access and utilization of health care and related services are identified and removed. This dissertation identified and filled several gaps in the field of vertical transmission of HIV. It looked at different points in women's reproductive lifespans in which intervention may prevent the transmission of HIV either in the future or the present. Given the scarcity of information on many of the aforementioned topics, we strongly suggest that further work be undertaken to verify our results. Specifically, we suggest further research on dual contraceptive use as a pathway to prevention of vertical transmission. Identifying factors associated with dual use, such as knowledge, retention in care, etc., may be critical in creating interventions to improve use. We also

urge for research on influences to dyadic level decisions regarding contraceptive use as well as access to infant HIV services. Better understanding couple-level knowledge regarding pregnancy prevention methods and how to prevent transmission of HIV may inform interventions in both the fields of family planning and vertical transmission of HIV research.

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