1-1-2014

Perspectives of HIV + Women on the Mother to Child Transmission of HIV in Addis Ababa, Ethiopia

Kimberly Anne Fleek
University of South Florida, kfleek@gmail.com

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Perspectives of HIV+ Women on the Prevention of Mother to Child Transmission of HIV in Addis Ababa, Ethiopia

by

Kimberly A. Fleek

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy
Department of Global Health College of Public Health University of South Florida

Major Professor: Jaime Corvin, PhD
Julie Baldwin, PhD
Ricardo Izurieta, MD, PhD
Eknath Naik, MD, PhD

Date of Approval:
October 3, 2014

Keywords: PMTCT, vertical transmission, PLHIV, adherence, peer counselor

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DEDICATION

This work is dedicated to the many women living with HIV in Ethiopia and around the world. Your courage and strength inspire and enable me to hope for a better future for you and your children.
ACKNOWLEDGMENTS

This research work and the completion of my PhD was not a solo endeavor: it is a reflection of the combined efforts of many people. Although the following acknowledgements aim to recognize the work of these individuals, they are not truly adequate to express my appreciation for those who have contributed so greatly to my life over the last few years.

To my dissertation committee: Thank you to Dr Jaime Corvin, Dr Julie Baldwin, Dr Ricardo Izurieta and Dr Eknath Naik for their support and direction during all phases of this endeavor. Their wisdom helped me to craft a feasible research study, and their guidance enabled me to turn the results into something that I hope leads to positive change for Ethiopian children in the future. Thank you to each of them for offering their time, their coveted expertise, and their encouragement in completing this process. A special thank you to Dr Corvin for taking on the arduous task of being my major professor and for spending countless hours helping me revise working drafts of the manuscript. Her kindness and support was invaluable in keeping me motivated to see this journey through to completion.

To others in the university: A special thank you goes to Dr Ran Nisbett, my advisor in my initial years of public health study. I learned volumes from him, both through taking his courses and through many conversations held sitting in his office. His passion for making research translate to global health practice that impacts communities continues to inspire me and is something I seek to emulate in my career. Thank you to the many other professors whose courses
gave me the necessary foundation for my research, and thank you to Dr Getachew Dagne for making the initial connection for me into Addis Ababa. A special thanks to Ms. Jessica Grossman for her wonderfully helpful attitude, for answering multitudes of emails over the years about administrative issues and the whole PhD process, and for completing last-minute tasks for me while I was out of the country on more than one occasion.

To the community in Addis Ababa: Thank you to my research assistant and to the amazing individuals who are working tirelessly in organizations serving women living with HIV and their children. The staff of the two organizations with whom I worked welcomed me, introduced me to research participants, offered me daily support in adapting to a new environment, and inspired me with their faithful and joyful service. This research would simply not have been completed without their support, and my hope is that the results will bring great benefits to their communities in the future. Thank you to the faculty at AAU for also welcoming me, offering their support, and helping me make connections with the health departments in the city. Finally, I am humbled by the incredible openness of each of the women in sharing their stories and lives with me. I am truly grateful.

To my dear friends and family: So many of my friends and those in my family have offered me words of advice, prayer, and encouragement over the last several years, and their support has been absolutely invaluable. I have incredible appreciation for them for walking with me through this process, for cheering me on, for being patient with me on the difficult days, and for consistently reminding me of why I choose to do this kind of work. Their loving presence in my life is a daily reminder of God who is the source of all my strength and hope; it is to Him that I am the most grateful of all.
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ABSTRACT

*Purpose and rationale:* In 2012, an estimated 9,500 infants in Ethiopia were born with HIV. Mortality for these infants is high, and preventing infection offers the best hope for reducing the childhood death rates. Effective measures exist which can reduce the likelihood of a child acquiring HIV from its mother to less than 2%, and the necessary anti-retroviral medications are free and accessible to Ethiopian women. However, Prevention of Mother to Child Transmission of HIV (PMTCT) efforts in the country have not kept pace with the global reduction in infant infections over the last decade, and the Ethiopian MTCT rate was still 20% in 2012. Although a large number of women are getting tested for HIV during pregnancy, only 41% of eligible women in the country complete PMTCT therapy. The purpose of this exploratory study was to elicit the perspectives of HIV+ mothers on the unique socio-contextual factors which affect them during pregnancy, both positively and negatively, including the beliefs, attitudes, cultural norms and individuals who have influence over their reproductive health decisions. *Methods:* The mixed-methods study was done at a community level in Addis Ababa, Ethiopia. With the assistance of several large networks of people living with HIV (PLHIV), PLHIV mothers who have a child at least one year of age were recruited by mixed purposeful sampling; various socio-economic demographics were represented. In-depth interviews, focus groups and surveys were then completed in Amharic with a research assistant translating to English. *Results:* 98 women in total took part in the study: 23 completed interviews, 28 participated in focus groups, and 49 completed additional surveys. The greatest barriers to PMTCT completion identified were: feelings of hopelessness and carelessness, a general lack of
understanding of the efficacy of ARVs, negative religious influences, stigma and poverty. The strongest facilitators to PMTCT use expressed by the women were: PLHIV peer support, faith, and gaining hope. It was recommended that PLHIV mothers be utilized in all PMTCT planning and interventions in the future. *Implications:* Program managers and health officials can build on these findings to modify existing PMTCT programs and to develop innovative and effective new PMTCT interventions. This will ultimately result in increased PMTCT uptake and adherence amongst HIV + pregnant women and a reduction in infant HIV transmission.
SECTION I
INTRODUCTION

Purpose of the Study

The Government of Ethiopia has a stated goal of “eliminating pediatric HIV by 2015,” (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2012a). In order to facilitate that goal, the purpose of this study is to identify the barriers and facilitators which affect a woman’s adherence to PMTCT in Addis Ababa. Program managers and health officials can build on findings from the study to design innovative PMTCT approaches and improve existing interventions: this will ultimately result in increased PMTCT uptake and adherence amongst HIV+ pregnant women and a reduction in infant HIV transmission.

Organization of the Dissertation: Manuscript Format

This manuscript is presented in four sections and appendices in order to meet the requirements of the USF dissertation manuscript format.

The first section defines the background and significance of the study and its justification. Section I also includes the primary research question, theoretical framework, and methodology of the study, along with a glossary of terms that may be encountered throughout the document.

Sections II and III are individual manuscripts written for journal submission. Each manuscript incorporates condensed components of the background, theory and methods of the overall study, along with the data analysis, results and discussion targeted to the relevant questions being addressed in the manuscript. Manuscript One, “Perspectives of HIV+ Women on
PMTCT in Addis Ababa, Ethiopia-a SEM Model” incorporates results from both the quantitative and qualitative elements of the mixed-methods study. Manuscript Two, “Reducing PMTCT Attrition-the Advice of HIV+ Women in Addis Ababa” reports and expands on qualitative results that emerged from the study. Additional manuscripts are planned after the submission of this dissertation (see Section IV).

Section IV presents a summary of the overall quantitative and qualitative research findings. Conclusions and recommendations for further research are also drawn from this data analysis. The comprehensive literature review that was the background for this work is presented in Appendix A. Other appendices include the instruments and informed consent forms used in the study, in both English and Amharic translations, the IRB consent document, and the initial codebook used for data analysis.

Background and Significance

In 2012, 330,000 children were infected with HIV across the globe. Ninety percent of these children acquired the infection through “vertical transmission,” with their mothers passing the virus during pregnancy, delivery, or breastfeeding (UNAIDS, 2012b). This number is staggering in light of the fact that effective prophylactic medication for the Prevention of Mother to Child Transmission of HIV (PMTCT) is available. If the medication is used correctly, vertical transmission risk decreases to less than 2% (Lallemont, 2012). Use of these antiretroviral (ARV) medications has prevented over 350,000 childhood infections since 1995 (World Health Organization [WHO], 2011a). Yet vertical HIV transmission remains a true public health crisis, for more than 50% of newly infected children will die before their second birthday without appropriate care and treatment (WHO, 2007).
In the absence of interventions, the overall risk of MTCT is between 20-35%, but the risk level varies in different stages of pregnancy and breastfeeding. Estimated MTCT risk is between 5-10% during pregnancy (by placental transmission), 10-20% during labor and delivery, and 5-20% during breastfeeding (Tolle & Dewey, 2010). The overall risk for a non-breastfeeding mother who uses no intervention is approximately 20%. Six months of breastfeeding with no intervention will increase the risk to 30%, and 18-24 months of breastfeeding raises the MTCT risk to 35% (WHO, 2007).

An infant is at risk of acquiring HIV infection from conception to the cessation of breastfeeding (Tolle & Dewey, 2010). This extended risk period requires a lengthy prevention process, and it requires intervention at multiple steps. The process, which has been termed the “PMTCT Cascade,” begins at maternal HIV diagnosis, continues through pregnancy and delivery, extends through breastfeeding, and reaches completion when the infant is appropriately tested for HIV (WHO, UNAIDS, & UNICEF, 2011). Some of the intervention steps required along the cascade include HIV testing and counseling, CD4 testing, initiation of ARVs, nutritional counseling, adherence to medication, and infant HIV testing (Figure 1). Although each individual step may be fairly straightforward, trying to successfully navigate all the steps in the PMTCT continuum can seem complex and overwhelming to an HIV-infected mother. Outside influences such as social pressure, financial difficulties, and other responsibilities can further complicate the process, and many women do not complete all of the required steps as a result (WHO, 2010a). In fact, loss to follow up (attrition) from the system is a documented global problem, with adherence rates to every step of the cascade ranging from 99% to less than 1%. The global average for successful completion of the entire PMTCT system is 62% (UNAIDS, 2013).
UNICEF and WHO issued a joint proposal in 2007 entitled “Acceleration of Prevention of Mother-to-Child Transmission (PMTCT) and Scale up of Linkages to Paediatric HIV Care and Treatment.” As organizations such as PEPFAR took on increasing responsibility for scaling up distribution of ARVs in high priority countries (PEPFAR, 2010) and countries made national commitments to PMTCT efforts, the number of new HIV infections in children dropped worldwide by 43 percent between 2003 and 2011 (UNAIDS, 2012c). The distribution of these infections throughout that time remained highly concentrated in certain countries, the majority of which were in sub-Saharan Africa. With improving coverage and improving medication, vertical transmission rates of less than 2% became the global target as of 2011 and caused many leaders to being shifting their terminology from “Prevention” to “Elimination of Mother to Child Transmission” (eMTCT) (UNAIDS, 2011).

Although progress was made, the year 2011 still documented between 330,000 and 420,000 new infant HIV infections globally (Sullivan, Drobac, Thompson & Rodriguez, 2011; UNAIDS, 2012c). In 2011, UNGASS launched the “Global Plan,” an ambitious agenda that set a goal to eliminate all new infections among children by the year 2015 and to substantially reduce maternal mortality (UNAIDS, 2012b). Another goal under of the Global Plan is to provide ARVs
to 15 million people, a large percentage of whom will be pregnant women. The WHO issued a similar strategy that same year entitled “The Global Health Sector Strategy 2011-2015;” it includes a target goal of reducing vertical transmission by 90% worldwide (WHO, 2011a). In order to effectively reduce and eliminate infant HIV infections, four key strategies were identified and recommended: 1) reducing the transmission of HIV to women of childbearing age; 2) meeting the family planning needs of HIV + women; 3) offering appropriate ARVs to HIV infected women and their infants; and 4) ensuring the well-being and support of HIV + women and their families for treatment (UNAIDS, 2011a; WHO, 2011a). It was also recommended in this document that PLHIV be involved in planning HIV prevention services in order to increase the effectiveness of interventions (WHO, 2011a).

As a result of these commitments, the ARV coverage of pregnant women rose to 57% in low and middle income countries by 2012, an enormous improvement over previous years (UNAIDS, 2012c). There was a 52% decline in new HIV infections among children from 2001-2012, preventing more than 670,000 children from acquiring HIV from 2009 to 2012 (UNAIDS, 2013). In sub-Saharan Africa, the overall PMTCT coverage was estimated at 59% (UNAIDS, 2012b). Even across Africa, however, the rates of maternal ARV coverage are highly variable, ranging from over 90% in Botswana and South Africa to less than 25% Chad and Ethiopia (UNAIDS, 2012d).

The scale-up of ARV coverage for exposed infants has not been as successful, although it has also shown some improvement. Among the estimated 1.49 million infants who were born to mothers living with HIV in 2011, 42% received prophylactic ARVs, an increase from 32% in 2009 (WHO, 2011b). In sub-Saharan Africa, where approximately 90% of HIV infected children live, the percentage of eligible infants who received appropriate ARVs was up to 54%
As expected, countries which have the most improved coverage of maternal ARV services have also seen the greatest reductions in the number of new childhood HIV infections.

**WHO PMTCT Guidelines**

As the medical evidence for appropriate therapy changed and the spectrum of HIV medications has expanded, the WHO took on the role of providing international guidance on appropriate therapy for HIV infected pregnant women and their infants. The first PMTCT guidelines issued by the WHO were introduced in 2001 and have undergone continual revision as the HIV epidemic evolved. A summary of guidelines issued in 2004, 2006, 2010, and 2012 are included in Appendix B. The comprehensive WHO guidelines also include detailed variations on these recommendations for treating women who are anemic, co-infected with tuberculosis, or infected with the HIV-2 strain (WHO, 2010b). In addition to medication recommendations, the WHO has issued over 16 documents and recommendations on infant feeding practices for HIV+ women over the last several decades. The most recent infant feeding guidelines, released in 2010, state that HIV + mothers who are on ARVs should exclusively breastfeed their infants for the first six months of life. They should continue breastfeeding and add complementary food for the first 12 months of life, and commercial infant formula should only be given as replacement feeding if AFASS (acceptable, feasible, affordable, sustainable, and safe) criteria are met. Finally, all cessation of breastfeeding should be done gradually, over a period of a month or more (WHO, 2010b).

In 2010, the PMTCT guidelines emphasized three main points: 1) earlier ART for a larger group of HIV+ pregnant women to benefit both the health of the mother and prevent HIV
transmission to her child during pregnancy; 2) longer provision of ARV prophylaxis for HIV+ pregnant women who do not need ART for their own health to reduce MTCT risk; and 3) provision of ARVs to the mother or child to reduce the risk of HIV transmission during the breastfeeding period. Under the new recommendations, the CD4 count which would make a woman eligible for ART for her own therapy was raised from 200 to 350; this would include approximately 40% of HIV+ pregnant women worldwide. Pregnant women with CD4 counts less than 350 are at the highest risk of transmission at any time in the PMTCT continuum, and they account for greater than 75% of the MTCT risk. Over 85% of maternal deaths within 2 years of delivery also occur in this group of women, and maternal survival plays a key role in infant survival. The earlier initiation of ART offered a strong benefit to both maternal health and child survival, and a triple therapy HAART regimen was to be started as soon as diagnosed during pregnancy in these women. Their infants would receive NVP or AZT for 4-6 weeks, regardless of when their mother began ART.

For women who were not eligible for ART for their own health, ARV prophylaxis for PMTCT was to be started under these guidelines at 14 weeks of gestation, or as soon as possible, through one of two options. The choice of which prophylactic regimen to use was to be guided by country choice (WHO, 2010c). Under “Option A,” AZT is given to the mother twice daily beginning at 14 weeks of gestation. Infants receive daily NVP or AZT for either 6 weeks or until one week following the cessation of breastfeeding. The second option for PMTCT prophylaxis, “Option B,” begins HAART triple therapy for pregnant women, even if they are not eligible for therapy for their own ongoing care. If the mother is treated with HAART during pregnancy, no additional treatment is required in the intra-partum period. Infants are given daily
NVP or AZT from birth until 6 weeks of age, regardless of breastfeeding status. All infants under the 2010 guidelines should be PCR tested at 6 weeks and treated as appropriate.

“Option B+”, first introduced and implemented in Malawi by their government in 2011, calls for a radical departure from former PMTCT thinking. Under Option B+, all HIV-infected pregnant women initiate lifelong ART at diagnosis, irrespective of their clinical or immunologic status. This option promotes inclusion with other MCH services, and ART is initiated earlier in pregnancy for most women since CD4 testing is not required. Option B+ has been recommended for many of the same reasons as Option B: the higher MTCT risk in mothers with CD4< 350, the large percentage of pregnant women who qualify for ART (over 40%), the faster reduction in HIV viral load which leads to decreased transmission rates, and improved maternal health. The recommendation to continue HAART after delivery regardless of the mother’s CD4 count is another new element of Option B+, and its proponents offer several suggestions for its potential benefits. The use of lifelong HAART will improve maternal health and survival, which will also have an indirect effect on reducing under-5 mortality (United Nations Children’s Fund [UNICEF], 2012). Additionally, long-term HAART may reduce MTCT risk early in future pregnancies. A 96 % reduction in horizontal HIV transmission to sero-discordant, HIV-negative partners was seen when individuals with CD4 counts of 350–550 cells started ART (Cohen et al., 2011); lifelong HAART is therefore likely to provide primary prevention benefits to sexual partners as well (UNICEF, 2012).

In 2012, WHO issued an endorsement of Option B+ and highlighted the decreased MTCT risk, decreased maternal mortality risk, and simplification of the medication regimen for patients as key supporting evidence. The guidelines also pointed out that simplifying the delivery regimens offers an advantage to health systems by eliminating the increased demands for CD4
testing or clinical staging (WHO, 2010d; Karim et al., 2011). Some concerns exist about the safety of both Option B and Option B +, however, since the effects of long term exposure to HAART early in life may have on an infant are not well known. What effect long term ARV use may have on the quantity or quality of breast milk production is also unclear, and there has been some evidence of the risk of antiretroviral drug resistance increasing among failed cases of HIV prophylaxis (Young et al., 2011; Chi et al., 2012).

By 2012, many Ministries of Health in the region were beginning to endorse universal antiretroviral treatment or prophylaxis for HIV-infected pregnant women and the use of Option B. Lack of adherence to Option A for both mother and infant, complications in health system delivery mechanisms, and the necessity for a delivery attended by a skilled health care worker were commonly cited reasons for the shift (UNICEF, 2012). In addition, Option B is more amenable to the goal of many PMTCT programs to integrate PMTCT with other health services. Health worker training can be simplified with Option B, and the introduction of a generic fixed dose combination of TDF/3TC/EFV in 2009 made concerns over cost less relevant (UNICEF, 2012; Chi et al., 2012). The growing support for Option B was a key starting point for potential transitioning to the 2012 addition of Option B +. As of 2013, Angola, DRC, Lesotho, Malawi, Mozambique, Namibia, Uganda, Tanzania, Zambia, Zimbabwe, and Rwanda, had all adopted Option B+; Cameroon, Kenya, South Africa, and Swaziland were piloting sites to evaluate Option B+ (IATT, 2013). Ethiopia shifted from Option A and began the roll-out of Option B + in the summer of 2013, with national implementation beginning in December of 2013 (Ethiopia Ministry of Health [MOH], 2013a).
Global Challenges and Progress in PMTCT

Although the scientific advances in ARVs have been enormous, many PMTCT systems are still failing to promote the reduction rates in infant HIV transmission being called for in the global community. A breakdown in any one of the steps along the PMTCT cascade can result in infant HIV transmission, and each woman must adhere faithfully to the entire continuum of care. The process starts when she gets tested for HIV, after which she must receive the test results, initiate treatment or prophylaxis, and adhere to the prescribed medications for the correct duration of time. Mothers must also give their exposed infants the proper ARV prophylaxis regimens and bring them for early HIV testing, ensuring prompt treatment if they are found to be infected. Systematic breakdowns are common along many points in the pathway; each can increase loss to follow-up (LTF) and reduce PMTCT program impact. It has been noted by health system researchers that the continual introduction of more effective ARV combination treatments will fail to yield high reductions in the number of childhood HIV infections in the absence of better performance at each step of the PMTCT continuum (Verani, Hurley & Borse, 2013).

A meta-analysis of 44 studies in Africa and 75,172 HIV-infected pregnant women highlighted the problem of LTF in the PMTCT system. While 94% of pregnant women in the analysis accepted HIV testing under the opt-out approach, only 70% of those identified as HIV-positive initiated any form of ART (Wettstein et al., 2012). In many PMTCT programs, women were either not tested quickly for HAART eligibility, or they did not receive their results on the same day and failed to return (Chi et al., 2012). Among those mothers who did learn that they qualified for HAART for their own health, only 62% initiated treatment (Wettstein et al., 2012). Of all pregnant women living with HIV in low and middle income countries in 2010, only 48%
received an effective PMTCT regimen (excluding single-dose NVP) (WHO, UNAIDS & UNICEF, 2011). Finally, only 64% of HIV exposed infants had early HIV testing performed, and an even smaller percentage of infected infants received ART (Wettstein et al, 2012; Elisabeth Glaser Pediatric AIDS Foundation [EGPAF], 2013). Although adherence varies greatly across countries and programs, this analysis confirms that newer and more effective PMTCT approaches are required on a global scale. Every point of possible attrition must be addressed.

**Barriers to PMTCT Uptake and Adherence**

Possible reasons for women not to follow the PMTCT system through to completion exist on many levels, and each woman’s situation is different. Systemic, social, cultural, and religious influences, as well as personal beliefs, may all contribute to the high rate of attrition along the PMTCT cascade, and these influences often overlap. In a large systematic review of PMTCT studies from 2000-2010, most of which were completed in sub-Saharan Africa, attrition along the PMTCT pathway was associated with stigma, economic concerns, lack of partner disclosure, and poor interactions with the medical community (Ferguson et al., 2012). Poverty, one of the most dominant influences on the lives of many African women, can also independently hinder access to health care and contributes to a myriad of social issues which each hinder PMTCT uptake (Ferguson et al., 2012). Lack of adequate knowledge about HIV and PMTCT is also a common problem, and mothers may not understand how to properly take PMTCT medications nor administer them correctly to their infants (Ahou et al., 2010).

Both barriers to PMTCT and successful interventions exist in the context of a culture, community, and social system, and these vary widely across settings (Busza et al., 2012). A systematic review of community based PMTCT interventions uncovered barriers to PMTCT
regimens including low risk perception, low motivation or self-efficacy, poor mental or physical health, household inequality, low levels of partner disclosure, and gender roles that do not prioritize women’s health (Busza et al., 2012). Also included were fear of partner violence (Otieno et al., 2010), religious or spiritual beliefs, difficulty in transportation and financial concerns, stigma, and a bad policy environment (Busza et al., 2012). Discontentment with the health care facility or providers is also common; this is expressed as “poor services,” and “dislike of the facility” (Otieno et al., 2010) or poor health care worker attitudes (Atwiine et al., 2013). Personal elements of other fears, lack of interest, or “not feeling ready,” are common in some sites (Atwiine et al., 2013; Duff et al., 2010; Otieno et al., 2010); religious ideals can have a large effect on the perception of risk of both acquiring and transmitting HIV as well (Smith, 2003).

Just as the barriers to PMTCT use are variable by location, certain elements of PMTCT interventions may be attractive to women in one culture but not in another. The value of partner support is well-documented in some locations, yet Ugandan women did not express that improving partner involvement would have any great influence on their reproductive health decisions (Ahou et al., 2010). Kenyan woman stated that increased education, free services, and compassionate care were the three key factors that make PMTCT attractive in their own context (Duff et al., 2010). The incorporation of traditional and religious leaders in Zambia is credited with contributing to the incredible success of their PMTCT system (Torpey et al., 2010).

One rapidly growing trend in PMTCT interventions is the use of peer support groups or peer counselors. Many countries have introduced these groups for women who are HIV+, both prior to and during pregnancy; HIV+ women are even being included in the PMTCT workforce as counselors in a number of countries (EGPAF, 2013). These interventions have increased
adherence to PMTCT in a large scale review of several sites (Busza et al., 2012). The engagement of community support is also emerging as a promising intervention. Involving local leaders can encourage and prepare women for HIV testing and care when they enter the ANC system, and it can also promote PMTCT adherence for women who require care (EGPAF, 2013). Family focused care has proven to increase PMTCT uptake and adherence in various regions, but the results are not consistent across locations (Tonwe-Gold, Ekouevi & Bosse, 2009). Little has been studied regarding the potential use of other family or community supporters to encourage PMTCT uptake and adherence. Mothers, grandmothers, traditional birth attendants, or religious leaders may be effective in counseling or influencing HIV+ mothers to adhere to PMTCT if trained appropriately, and the potential for their use should be further explored (Young et al., 2011).

**Ethiopia**

Ethiopia is the second most populous country in sub-Saharan Africa, with an estimated population of 83 million people (UNAIDS, 2012a). The population growth rate in the country is 2.7% per year, explained primarily by the high fertility rate of 4.8 children per woman (UNFPA, 2010). The population structure is pyramidal, and 44% of citizens are under the age of 15 (UNAIDS, 2012a). With close to 84% of the population living in rural areas, Ethiopia is one of the least urbanized countries in the world. It is also one of the most struggling nations in the world economically, and almost 33% of the population lives below the international poverty line (UNAIDS, 2012a). The annual per capita income for Ethiopian citizens is less than $390 (UNAIDS, 2012a). A large number of Ethiopians have received little or no education: 52% of females and 38% of males have never attended school. Young girls are frequently denied access
to education in order to help generate family income or assist in domestic duties (von Massow, 2000). The number of girls attending school has risen rapidly, however: primary education for women increased from 11.8% in 2000 to 27.8% in 2011 (UNFPA, 2012). Only between 3% and 5% of the Ethiopian population have completed secondary education, although this number has been improving in among males in recent years (Ethiopian Central Statistical Agency [CSA], 2012). The same increase has not been seen in secondary education for the female population (UNFPA, 2012). In 2011, the national literacy rate for the country was 36%, yet only 23% of women were able to read (UNICEF, 2011).

The long-standing feudal system of government in Ethiopia was taken over by military force in 1974, after which the country suffered through nearly 20 years of political turmoil. After it became a federalist state in 1994, the country was divided into nine Regional States and two City Administrations (Figure 2). Each of these areas is subdivided into 817 administrative “woredas” (districts), which are further divided into “kebeles” (UNAIDS, 2012a). The kebele is the smallest unit of governance in the country, and there were over 15,000 of them in the country in 2012 (CSA, 2012). In addition to the regions defined by the government, the highly populous nation is divided by many different things: geography, economic resources, climate, ethnicity, religion, and language are among them. Within its borders, Ethiopia is home to more than 80 different ethnic groups (CSA, 2012). The two largest ethnic groups, Oromo and Amhara, number in the millions; Tigray is the next largest group and includes only a third as many people. Many ethnic groups are as small as 100 members or less. Over 80 different languages are spoken across the country, although Amharic is officially declared as the national tongue (CSA, 2012).
The average age of marriage for Ethiopian women is 16.5 years and for men is 21 years (CSA, 2012). Eleven percent of women are married to a man who has more than one wife, with two wives being the most common form of polygamy. Intergenerational sex is common: 21% of women ages 15-24 reported having sex with a man 10 years or older (CSA, 2012). This commonly takes place through the marriage of young girls to older men, and 10% of women will actually be married by the age of 15 (CSA, 2012). Although not as common as marriage, intergenerational sex takes place outside of marriage more often in urban locations. In Addis Ababa, many sexual relations between girls and older men were reported to be motivated by promises of employment, overseas travel, financial gain, or other gifts (Dugassa, 2005). Despite their engagement in early sexual activity, Ethiopian women are often hindered from discussing sexuality and health by cultural norms, and their ability to refuse or to advocate for protected sex may be limited (Cummings, Mengistu, Negash, Bekele & Ghile, 2006).
Across the country, 94% of women express difficulty in accessing health care. Health decisions are made for women exclusively by their husbands 25% of the time, while 61% feel they have to consult their husbands and gain his acceptance regarding health care decisions (CSA, 2012). Over 40% of women were not allowed to participate in decisions regarding finances for the household, which limits their access to money for health care. Although health care access is generally better in urban locations than in rural communities, 74% of women in Addis Ababa expressed difficulty in obtaining health care. The most common reasons reported for the difficulty were lack of money, failure to get their husband’s permission, difficulty with transportation or distance to the health facility, or a heavy workload at home (CSA, 2012; Cummings et al., 2006).

Fifty-eight percent of Ethiopian women will give birth by the age of 20. The fertility rate in the country is 4.8 children/woman of reproductive age, with rural women having a higher number of children (5.5) than urban women (2.6) (CSA, 2012). There has been a marked increase in contraceptive use over the last decade, from 8.2% in 2000 to 28.6% in 2011. Urbanization and an increase in primary education for females have encouraged contraceptive use, as has a decline in child mortality (UNFPA, 2012). There has also been strong government encouragement offered in favor of family planning, specifically advocating for the use of Implanon. Almost 12% of Ethiopian women have adopted this long-acting method of contraception, but the uptake has not been as great in urban areas (UNFPA, 2012).

The number of women who access ANC care during pregnancy has increased in the last decade, but it is still low. Thirty-four percent of women in the country reported having visited ANC at least once during their last pregnancy (CSA, 2012). When women in Addis Ababa were asked why they did not access ANC, the majority (68%) said that it was either not necessary or
not in agreement with local custom. The facility being too far away was also frequently mentioned, and this was mentioned as a barrier to facility-based deliveries as well. Home births are extremely common across the country, and only 10% of women deliver with a skilled birth attendant. The maternal mortality ratio of 6.76 per 100,000 live births is one of the highest in the world and has not improved significantly since 2005 (CSA, 2012; UNFPA, 2012).

The majority of child health indicators for Ethiopia are poor, although most have improved considerably since 2005. In 2011, the under-five child mortality rate for the country was 8.8%, half of what it was in 2000. The infant mortality rate was 59 per 1000 births, and the neonatal mortality rate was 37 per 1000 births. The indicators in Addis Ababa are better than the national averages: under-five child mortality is 5.4%, infant mortality 40 per 1000 births, and neonatal mortality 21 per 1000 births (CSA, 2012). Malnutrition, common in the general population, is most marked in children. Almost 1 in 3 (29%) of all children in Ethiopia are underweight as a consequence of either acute or chronic malnutrition (CSA, 2012). Chronic malnutrition, manifested as stunting, occurs in 40% of children under the age of five across the country and 22% of children in Addis Ababa. Acute malnutrition and wasting are seen in 10% of Ethiopian children and 4.6% of children living in Addis Ababa (CSA, 2012).

Although approximately 60% of its health funding comes from the government, Ethiopia is still the 7th largest recipient of international donor aid in the world (Ethiopia Federal HIV/AIDS Control and Prevention Office [HAPCO], 2010). This dependence requires the health care system to be accountable to multiple donors, and this may further complicate an already confusing and uncoordinated system (Krebs, 2012). In addition to lacking adequate internal funding for health care, Ethiopia has a critical shortage in the number of health care workers available for its population. There was only one trained health care worker per every 5000
citizens in 2011, and this negatively affects health care at all levels, including PMTCT. In order to meet the population demand, as well as the increasing demand for care by PLHIV, many tasks have been shifted from highly trained medical professionals to Health Extension Worker (HEWs) (WHO, 2008b). By 2013, over 34,000 HEWs had been trained (MOH, 2013b). The HEW program was initiated and has operated primarily in rural areas using local residents, but a modified program using nurses as Health Extension Professionals for urban areas has also been successfully launched in Addis Ababa (UNAIDS, 2012a). Although improving the health coverage gap considerably in the last several years, the HEW also adds to the complications of a decentralized health care system (EGPAF, 2013). The decentralized health care system in Ethiopia faces multiple challenges, including problems with maintaining supply chains, staffing, and lab services (Krebs, 2012).

**HIV in Ethiopia.** Life expectancy in Ethiopia is low: 49 years for women and 47 years for men (CSA, 2012). While multiple health conditions contribute to this, HIV has taken a large toll. In 2005, it was estimated that the average life expectancy in the country had been reduced by 5 years as a result of the HIV/AIDS epidemic (HAPCO, 2010). In 2010, HIV was the leading cause of death in the country and responsible for 12% of overall deaths across all age categories (HAPCO, 2010). The national prevalence of HIV in Ethiopia in 2012 was 1.8%, which is lower than that of many other African countries. (UNAIDS, 2012a). However, due to its high population, this equates to over 1.4 million people living with HIV in the nation, the third highest number of PLHIV in East Africa.

The prevalence of HIV is not equally distributed across the country. The epidemic has a strong gender component, with women having a significantly higher HIV prevalence rate (1.9-2.8%) than do men (1.0-1.8%) (PEPFAR, 2012; CSA, 2012). The apparent increase in
prevalence among females may be partially accounted for by higher HIV testing rates through ANC facilities. However, the HIV epidemic across the entire sub-Saharan African region shows a gender disparity towards females that is commonly attributed to gender violence, exploitation of women through intergenerational and transactional sex, and a cultural silence regarding sexuality (UNFPA, 2004).

HIV prevalence in Ethiopia is also markedly higher in urban areas than it is in rural areas (4.2% vs. 0.6%) (CSA, 2012). Addis Ababa has the highest HIV prevalence rate in the country, documented as 5.2%. This may actually be underestimated since only 78% of eligible 15-49 year olds in the city were tested for HIV (CSA, 2012). Over 60% of PLHIV in Ethiopia live in cities or towns as a result of this geographical disparity, despite the fact that the majority of the Ethiopian population lives in rural areas (UNAIDS, 2012a).

Awareness of HIV/AIDS is common, but comprehensive knowledge and understanding about it is not. Among men and women surveyed in Addis Ababa, 99% indicated that they were aware of HIV, but over 30% believed it could be transmitted by either a mosquito or supernatural means. Only 52% of those interviewed could identify that condom use and sexual fidelity were HIV prevention methods and that a person could look healthy and have HIV (CSA, 2012). In this same group, only 82% of women could identify both that breastfeeding could transmit HIV and that medication could help to prevent transmission to an infant; the understanding among men was lower (CSA, 2012). At a national level, only 20% of women and 32% of men were considered to have comprehensive basic understanding of HIV/AIDS (CSA, 2012).

The first national report on HIV that did not address high risk populations exclusively marked the population HIV prevalence at 5.2 % in 1996 (UNAIDS, 2012a). In response, the first national HIV/AIDS policy in Ethiopia was implemented in 1998; its objectives were to
encourage government, private sector, and community organizations to work together towards mitigating the social and economic consequences of AIDS (HAPCO, 2010; UNAIDS, 2012a). That initial plan also highlighted the need for the empowerment of women and other vulnerable populations, and it made support for orphans and others affected by the epidemic a top priority. By 2002, the AIDS epidemic was declared to be a public health emergency in the country, and the Federal HIV/AIDS Prevention and Control Office (HAPCO) was developed to move the nation’s HIV response forward. The government’s first national HIV strategic plan, implemented in 2004, set a target of providing universal access to HIV prevention, treatment, and care; free ARV treatment was rolled out in 2005 as part of this initiative (HAPCO, 2010; UNAIDS, 2012a). In the two years following the beginning of the program, the number of ART sites increased from 3 to 265 (Assefa & Kloos, 2008). The number of patients on ART increased by more than 10 times (8,276 to 92,450), and the number of patients receiving HIV/AIDS care of any kind went from 13,773 to 156,729 (Assefa & Kloos, 2008). The increase since that time has been slower. In 2011 the ARV coverage rate for the country was close to 56%, lower than that of many surrounding nations (World Bank, 2013).

Many NGOs and community based organizations have been involved with HIV/AIDS education and interventions in Ethiopia, and the government has taken on the role of coordinating and guiding their efforts. Recognition of the value of these partnerships is addressed in the second five-year national HIV strategic plan, which was implemented in 2011 (UNAIDS, 2012a). External funding from NGOs, governments, and other sources also contributes significantly to the HIV response in Ethiopia. Of the yearly national HIV/AIDS expenditure of approximately 250 million USD, over 85% comes from external sources (UNAIDS, 2012a).
Identified high risk groups in the Ethiopian HIV epidemic include commercial sex
workers, long distance truck drivers, men in uniform, mobile workers, refugees, and sero-
discordant couples. Young women involved in trans-generational sex are also at risk. Although
sex work is illegal in Ethiopia, it is commonly practiced and is tolerated by the government.
Limited data tracking of this population has been completed, but estimates from organizations
that reach out to sex workers are that the HIV prevalence for these women may approach 25%
(UNAIDS, 2012a). National HIV data for injection drug users and MSM is currently
unavailable.

PMTCT in Ethiopia. Women of reproductive age comprise 24% of the nation’s
population (UNAIDS, 2012a), and the prevalence rate in this age group is routinely tracked by
ANC sentinel site surveillance data. Just as in the overall population, urban HIV prevalence
among the ANC population is higher than rural prevalence of HIV (5.2% vs. 0.8%) (Bogale,
Boer & Seydel, 2010; CSA, 2012). The most recent data shows a declining HIV prevalence rate
among women age 15-24 years attending ANC, from 5.6% in 2005, to 3.5% in 2007, to 2.6% in
2011 (UNAIDS, 2012a). Although this decrease took place in both urban and rural areas, in
urban locations the decline was more marked (11.5 % in 2003 to 5.5% in 2009) (UNAIDS,
2012a). This decrease must be reviewed with caution, however. An increase in the number of
women being tested for HIV (and thus an increased denominator), the fact that more low risk
mothers are getting pregnant, and the expansion of PMTCT services in low HIV prevalence
zones may all contribute to the apparent decrease; there may be an actual decrease in prevalence
as well (Nigatu & Woldegebril, 2011). In 2012, there were an estimated 34,524 HIV+ pregnant
women in the country (MOH, 2013a).
The first National PMTCT guidelines were published in 2001 by the Ministry of Health, but the establishment of the first facilities did not occur until 2004 (Koricho, Moland & Blystad, 2010). The first 5 pilot sites were in hospital settings where nurses had been trained to provide PMTCT services and infant feeding counseling (Mirkuzie, Hinderaker & Morkve, 2010). In most of these initial sites, PMTCT services were fragmented and the infant feeding guidelines were poorly misunderstood (Koricho et al., 2010). In 2006, the government laid out a comprehensive HIV plan to combat the epidemic, including PMTCT, beginning with increasing the number of women who attend at least one ANC visit (UNAIDS, 2011; Mirkuzie et al., 2010). The plan included a scale up of PMTCT facilities, better linkage to maternal child health services, and the adoption of WHO 2010 Guidelines “Option A” regimen for vertical transmission prophylaxis (UNAIDS, 2011). In 2007, Ethiopia updated their national PMTCT plan according to WHO guidelines to include the recommendation for offering partner testing and counseling sessions (Mirkuzie et al., 2010).

As the PMTCT response developed, national and regional level steering committees were established by the Ministry of Health to develop plans for monitoring and evaluation, site expansion, quality improvement, and demand creation (MOH, 2013a). In December of 2011, an accelerated national eMTCT plan was launched with three objectives: reaching 90 percent of pregnant women with access to antenatal care services; ensuring universal access by pregnant women to a skilled attendant during delivery; and providing ARVs to at least 80 percent of HIV-positive pregnant women (MOH, 2013a). The roll-out of “Option B +” to select PMTCT sites began in May 2013 and was completed in all PMTCT sites by December 2013; this is seen by the MOH as a critical opportunities for improvement in PMTCT coverage nationally (MOH, 2013a).
The first point of the PMTCT cascade is accessing health care. The 2011 Demographic and Health Survey documents the rate of ANC coverage (women attending ANC for at least one visit) in Ethiopia as 34% (CSA, 2012). Despite the efforts of the government to increase ANC accessibility, large numbers of women are not accessing ANC services. Previous interviews have attributed this problem to cultural issues, the poor quality of health services offered, and the perception and attitude of the health care workers (MOH, 2009). Not understanding the benefits of ANC is also a barrier, and some women from smaller ethnic groups may avoid health care facilities due to a fear that they will not be able to understand the Amharic which is spoken there (Berhane, Hogberg, Byass & Wall, 2002).

The WHO guidelines for health care provider initiated “opt-out” testing were implemented in 2008, and an estimated 92% of women offered HIV testing at ANCs accept in both rural and urban populations ((Mirkuzie et al., 2010; Nigatu & Woldegebril, 2011). Despite the regulations for “opt-out” testing, however, many women are still being missed for testing during ANC visits. The 2011 DHS revealed that only 11% of women visiting ANC nationwide received same day HIV counseling, testing, and results (CSA, 2012). This was significantly higher (76%) in Addis Ababa. The Ministry of Health more recently estimated that 33% of all pregnant women (inclusive of those who do not access ANC) were tested for HIV in 2012 (MOH, 2013a). National performance data also shows that, even among those women who were HIV positive, 60% were not provided with ARV prophylaxis for PMTCT (HAPCO, 2012).

The number of health facilities with available PMTCT services increased rapidly from 171 in 2006 to 2,044 in 2012 (MOH, 2013b). However, these sites are often independent of ANC facilities, and the failure to link women across services results in a significant number of HIV + women being lost to follow up. In 2013, PMTCT services were available in only 64% of
all ANC facilities (MOH, 2013b). An estimated 1.3 million pregnant women were seen at non-PMTCT facilities in that year (MOH, 2013b). The scale-up of PMCT facilities is also highly variable across regions. The government continues to seek to improve PMTCT coverage, and the Health Sector Development Plan IV for Ethiopia stipulates that 100% of health centers and hospitals will be providing PMTCT services by 2015 (MOH, 2010).

Despite considerable improvements in ANC and PMTCT coverage, increased rates of HIV testing and identification, and government provision of ARVS to pregnant women free of charge, Ethiopia’s mother-to-child HIV transmission rate (inclusive of breastfeeding) in 2012 remained unacceptably high (20%) (MOH, 2013a). In 2012, only 41% of eligible women received efficacious ARV regimens for preventing mother-to-child transmission of HIV (UNAIDS, 2013). Although this coverage has increased consistently over the last several years (Figure 3), the increase has been much slower than that in other high-prevalence countries (UNAIDS, 2011).

Figure 3. Ethiopia Federal Ministry of Health (2013) estimates of the percentage of HIV+ pregnant women who received efficacious regimens for PMTCT in a one year time period, measured from July-June.
Additionally, only 10.2% of these women followed through to infant diagnosis at 6 months as recommended. Although there has been a decrease in the number of vertically transmitted HIV infections since 2009 of between 20-39% (UNAIDS, 2012a), approximately 9500 new infant infections were acquired in Ethiopia in 2012 (UNAIDS, 2013).

Ethiopia’s e-MTCT of HIV Plan is to be implemented nationwide from 2013 to 2015. Multiple ambitious Impact Targets are set under this plan, including reduction of the MTCT rate to less than 5% in 2015 and reduction of the number of new childhood HIV infections by 90% by 2015. In order to accomplish this, ambitious strategic objectives and outcome targets are also in place at multiple levels. Decreasing the unmet need for FP to 10%, increasing attended deliveries to 62%, and improving PMTCT and community linkages are goals set primarily for HCW and community HEWs, while government level responsibilities include the improvement of supply chain, HCW training, and availability of PMTCT services.

Loss to follow-up in the PMTCT system. Since the national PMTCT program was set in place in 2006, the availability of services has increased by 18 times. The high rate of loss to follow-up from the time of HIV diagnosis through to infant diagnosis, however, has not changed considerably (Figure 4). The myriad of potential reasons for this must be considered, some of which must be addressed from a national health system level and some from individual, community, or societal levels.

At a health system level, many problems still exist. Missed opportunities for diagnosis, the poor quality of post-test counseling and follow-up, high turnover and/or shortage of trained staff, and poor documentation and reporting systems in the country have been cited by the government as problematic (MOH, 2013b). Failure to link HIV + women to services was also a significant concern noted in a large observational study in Addis Ababa: in 60% of the cases in
which a pregnant women was identified as HIV+, she was not provided with initial ARV prophylaxis for PMTCT, despite its being available on-site (Ismael & Ali, 2009).

At a personal level, a woman must be fully invested in the process in order to successfully navigate and complete the complex PMTCT cascade. In the 2011 Demographic and Health Survey, only 20% of women and 32% of men nationwide were found to have comprehensive knowledge about HIV and its transmission, and many offered explanations for HIV transmission such as mosquito bites and supernatural means (CSA, 2012). This trend helps to explain why general awareness of HIV and PMTCT among Ethiopian women who attend ANC seems to be high, yet often not comprehensive. Considering the high rate of LTF among women in the PMTCT system, researchers in Addis Ababa surveyed women at ANC centers to ascertain the depth of their understanding of the virus (Deressa, Seme, Assefa & Enqusellassie, 2010). The vast majority of women (90%) knew HIV can be transmitted to their children, yet only 26% could accurately identify all three methods of HIV transmission to infants (pregnancy, labor and delivery, and breastfeeding) (Deressa et al., 2010). In a similar study in Arba-Mirch,
preventative measures such as use of ARVS and facility-based delivery could only be recalled by 26.5% of the women surveyed, and only 6.2% of the women could correctly explain all elements of PMTCT services (Merdekios & Adedimije, 2011). Failing to completely understand the gaps in knowledge among HIV + women regarding vertical transmission and PMTCT may limit the development of effective educational strategies and interventions.

Attrition from the PMTCT system must also be considered in the context of a myriad of other social, cultural, political, and independent pressures placed on an HIV + woman (Woldegiyorgis & Scherrer, 2012; Adedimeji, Abboud, Merdekios & Shiferaw, 2012). Low rates of male partner involvement and lack of acceptance by these partners has been identified in some Ethiopian sites as a barrier to PMTCT services (UNAIDS, 2012c; Deressa et al., 2010; Ismael & Ali, 2009). A high level of partner involvement has been shown in other contexts as a key to improving PMTCT adherence rates, and the national Ethiopian guidelines as of 2008 state that partner testing and counseling should be routinely offered (Mirkuzie, Hinderaker, Sisay, Moland & Morkve, 2011). However, these recommendations are not always followed. The number of partners tested in Addis Ababa actually declined from 2004-2009, and only 4.8% of women in Addis Ababa facilities received counsel that their partners should be tested (Mirkuzie et al., 2010). Aside from HIV testing, the effects of a man’s opinion on a woman’s reproductive health care use may be significant in other ways: disapproving of contraceptive use is an example (UNFPA, 2012). It has also been noted that Ethiopia has a tolerance of violence against women at all levels (family, community, school, religion, and state), and a fear of partner violence must be considered as a potential barrier to Ethiopian woman accessing PMTCT (Kedir & Admasachew, 2010).
In addition to partners, the influence of other family members, friends, and the community and their role in decision making for Ethiopian women must be considered. When decision making about breastfeeding was explored among HIV + women enrolled in PMTCT programs in Hawassa, Ethiopia, it was noted that both partners and in-laws were powerful voices of influence for the mothers (Woldegiyorgis & Scherrer, 2012). In one multi-national survey, 25% of HIV+ women indicated they had been excluded from family activities as result of their status (Anderson et al., 2012). In sero-discordant relationships among Ethiopian couples, social pressure from family members sometimes encourages the HIV- partner to leave the relationship (Hailemariam, Kassie & Sisay, 2012). Fear of such a situation may be a barrier to pregnant women disclosing their HIV status.

Health care professionals can educate women who go for ANC care regarding PMTCT, but the actual degree of influence they have is variable. When women in Northwest Ethiopia were questioned regarding their delivery choices, those who chose a facility noted that information offered by health care providers was important and that their presence made them feel safer during delivery. However, of the majority of women who chose to deliver at home, most indicated that the influence of culture and family and pragmatic reasons such as transportation were much stronger influences on their choice than the opinions of the health care workers (Gebrehiwot, Goicolea, Edin & San Sebastian, 2012). High levels of home based delivery remain problematic, averaging 80-90% nationwide. Even in Addis Ababa, the region with the highest rates of attended births, 20% of women are delivering without medical care (CSA, 2012).

A pilot test of HIV prevention programs done with illiterate Ethiopian women demonstrated that the women responded more positively to media messages that were socially
focused (such as peer to peer conversations) than to those which employed credible experts (such as physicians) (Bogale et al., 2010). This affirms the fact that social pressures of many kinds are important to Ethiopian women, and their influences should be explored (Woldegiyorgis & Scherrer, 2012). The fear of stigma from friends or communities can pose a barrier to accessing PMTCT services or adhering to its recommendations (Merdekios & Adedimije, 2011; Ismael & Ali, 2009). The successful Mother Support Groups started in 2008 in Ethiopia report a reduced fear of social stigma and a decrease in self-stigma as primary benefits (Hopem & Bodasing, 2009).

The role of faith in decision making about PMTCT may also be important to Ethiopian women. Faith is a dominant part of much of Ethiopian culture and plays a significant role in the lives of many Ethiopian people (Ofcansky, 1993); its influences cannot be ignored. Christianity and Islam are the primary religions in the nation; about 49% of the population are Orthodox Christians, 30% are Muslims, 18% are Protestants, and 3% follow traditional faith practices (CSA, 2012). There is evidence that faith plays a role in reproductive health decisions for Ethiopian women: 5.3% of women with unmet family planning needs reported religious prohibition as the primary barrier to their use. Another indication of the influence of religion on women’s health is that the use of contraceptives varies significantly among religious groups. Contraceptive use has grown rapidly and is highest among Orthodox Christians (35.1%) and Protestants (29.9%); it is lower among Muslim women (19.7%) and in other religious groups (16.9%) (UNFPA, 2012). Ethiopian women also frequently brought up religious beliefs when discussing their decisions about where to deliver their children. Many expressed that they trusted God and Saint Mary for a safe delivery and that the use of prayers by family were more
important than obtaining medical care (Gebrehiwot et al., 2012). The role of religious beliefs and people of influence in the faith community has not yet been evaluated in respect to PMTCT.

PEPFAR has called for all country plans to include the incorporation of faith based organizations in the future (Bachman & Phelps, 2012); interviews with PLHIV have also indicated that engaging faith leaders in HIV issues can have significant positive impacts (Anderson et al., 2012; Ackerman-Gulaid & Kiragu, 2012). Faith communities and faith-based organizations in Ethiopia have been credited with having a considerable impact on the nation’s HIV epidemic over the last decade (PEPFAR, 2012; International Orthodox Christian Charities, 2013). A National Inter-religious Group Anti-AIDS Network has been established, and there are HIV/AIDS Control Programs in the Orthodox, Catholic, Evangelical Christian, and Muslim communities. The Ethiopian Evangelical Church established an HIV/AIDS/STI prevention and control program in 1988 and has been extremely active, distributing educational material, providing support to PLHIV, and working with rehabilitation of high risk groups (Belachew & Seyoum, 2006). Evidence of the contribution of these leaders and organizations to PMTCT is limited, as their predominant concern thus far has been offering education for primary prevention and support for PLHIV (Belachew & Seyoum, 2006). If faith based leaders hold a large degree of influence over women and their health care decisions, engaging their support for PMTCT may positively affect adherence and should be further assessed.

**Justification for the Study**

The Ethiopian government has been very proactive in the fight against HIV, yet their PMTCT program still remains relatively ineffective (UNAIDS, 2012e). They have made addressing their persistent and unacceptably high levels of maternal and neonatal mortality a top
priority. They have set targets to have 85% of mother-child pairs on ARVs by 2015 (US Global Health Initiative, 2010) and to fully integrate PMTCT services into routine maternal, child and reproductive health services in order to attain the vision of an “HIV-free generation by the year 2020” (Deressa et al., 2010). New goals under the eMTCT 2013-2015 plan include reduction of the MTCT rate to less than 5% in 2015 and reduction of the number of new childhood HIV infections by 90% by 2015 (MOH, 2013b).

Despite such robust goals and efforts by the government to implement “best practices” in PMTCT, the failure to improve PMTCT uptake and adherence at this point in Ethiopia is striking. One PEPFAR representative stated that:

Ethiopia is a little interesting because they have been given significant amounts of money, but we've seen very little improvement. So they still have a really poor facility delivery rate. They still have the same antenatal attendance rates. We haven't seen a lot of changes. But Ethiopia's unique in that their government is very involved, which is a good thing. (Krebs, 2012, p 21)

The focus of the Ethiopian government to this point has been primarily in increasing the availability of services, but awareness is growing that attrition from PMTCT must be addressed (Krebs, 2012). Along with the low uptake of EID services and the low rates of male partner testing and support, the Ministry of Health highlighted LTF as one of three critical challenges facing the PMTCT system at the end of 2012 (MOH, 2013a). In order to increase the efficacy of future PMTCT interventions and promote maternal retention in care, the unique socio-contextual factors affecting Ethiopian women, including the beliefs, cultural and social norms, and individuals who have influence over their reproductive health decisions, must be considered. It is
not sufficient to provide HIV testing and ARVs without addressing the influences which will positively or negatively women’s desire and ability to effectively use the medications (Woldegiyorgis & Scherrer, 2012).

Innovative methods which will increase the adherence of Ethiopian women to PMTCT are needed, yet such methods cannot be effectively designed without understanding the barriers that are preventing them from accessing and adhering to proper treatment regimens. The research thus far into loss to follow-up from PMTCT in Ethiopia has primarily been quantitative and has not adequately addressed the potential reasons why loss to follow-up is occurring. A UNAIDS 2012 report suggested that qualitative research is needed to determine why, despite their increasing access to health care, pregnant women are not starting or maintaining ARVs in Ethiopia (UNAIDS, 2012a). At the conclusion of a large, multi-site ANC study in Addis Ababa, researchers asserted that greater efforts must be made to assess women’s needs so that barriers to accessing PMTCT services can be minimized in future interventions and strategies (Torpey et al., 2010). The fear of stigma needs to be further explored in the region (UNAIDS, 2012d), and there remains a gap in research surrounding the magnitude of influence of extended family members such as parents, in-laws, and other household members on women’s reproductive decisions (Busza et al., 2012). PMTCT interventions will not be culturally and socially acceptable if they are not targeted to the felt needs of Ethiopian HIV + women, and formative research is required to understand those needs (Leshabari, Koniz-Booher, Åstrøm, de Paoli & Moland, 2006).
Research with PLHIV Mothers at the Community Level

In 2012, Addis Ababa, Ethiopia’s capital had a population of 4 million people. The total fertility rate for women in the city was 4.8%, and an estimated 70,000 women in Addis Ababa were pregnant and eligible for PMTCT (CSA, 2012). The large pool of HIV+ pregnant women from which a study sample can be drawn and the socio-demographic variability of the urban context make Addis Ababa an ideal location for exploring influential factors in adherence and attrition from PMTCT.

Recognition of the value of obtaining the insight of PLHIV in planning is increasing across all spheres of the HIV epidemic. Treatment 2.0, a framework strategy presented by the WHO for improvement in HIV prevention and care, states that the engagement of PLHIV and their families in planning is essential to the program’s success (WHO, 2011c). UNAIDS also calls for PLHIVs to plan and help with all ongoing HIV prevention and care (UNAIDS, 2012d), and PEPFAR has included the incorporation of PLHIV in HIV intervention planning as a key component of its ongoing strategies (Bachman & Phelps, 2012). Understanding what is failing in the Ethiopian PMTCT system can be enhanced by gaining insight from those whom it most affects: HIV+ women with children. PLHIV mothers are a rich source of information as to factors which were beneficial or detrimental to their adherence to PMTCT, and their opinions are increasingly being recognized as integral to guiding program development.

Most research addressing PMTCT attrition in Ethiopia has been completed with women who are participating in the ANC system, yet a significant number of pregnant women still do not utilize these services. There is no literature currently available which addresses the influencing factors for PMTCT with Ethiopian women within their communities. The opinions and perceptions of women at this level must be researched in order to more adequately represent
the needs of the maternal population. Qualitative research with PLHIV women in the community can capture the experiences and opinions of those most affected by PMTCT, including both those who were LTF from PMTCT and those who effectively engaged in and completed the PMTCT continuum.

By meeting the critical needs for research among PLHIV mothers at a community level, this study will enhance current understanding of factors which contribute to the high rate of attrition from the PMTCT system. Factors which positively influence uptake and adherence to PMTCT will also be identified, and the results of the study can inform the design of future PMTCT interventions so that their effectiveness is increased.

**Research Question**

The primary research question which will be answered by the study is: What beliefs, attitudes, socio-cultural factors and key influences among HIV+ women in Addis Ababa contribute to their adherence to or attrition from the PMTCT system?

**Theoretical Framework**

Health outcomes are not simply shaped by individual behavior; they are affected by the interpersonal networks, local customs and practices, political and economic circumstances and environments in which people live. These influences interact and overlap in a web of causation, which has been labeled in health theory as the Social Ecological Model (SEM) of health. In addition to the key concept that health behavior is influenced by factors at multiple levels, the SEM also recognizes that there is reciprocal causation between the behavior and the social environment in which the individual functions (McLeroy, Bibeau, Steckler & Glanz, 1988).
SEM can help to provide a comprehensive framework for understanding the multiple and interacting determinants of health behaviors, as well as in designing interventions that target change at each level of influence. By recognizing that many forces shape an individual’s behavior and integrating individual and external influences into one framework, the ecological perspective also lessens the magnitude of the burden of responsibility placed on an individual for their behavior by other health behavior models.

In one of the foundational SEM models, McLeroy et al (1988) defined the 5 levels of influence on an individual’s health behavior: intra-personal, inter-personal, organizational, community, and public policy. The intra-personal level includes characteristics which influence behavior such as knowledge, skills, and self-efficacy, and the interpersonal level includes the influences of family, friends, and peers. The organizational level may encompass churches, health facilities, stores, and community organizations, as well as rules which may constrain certain behaviors. Community level influences include the broader social networks surrounding an individual along with community and cultural norms, and the final level of public policy incorporates local and national policies and laws that regulate health care or health behavior (McLeroy et al., 1988). The higher order levels are generally considered to be out of the control of any one individual person (Baral, Logie, Grosso, Wirtz & Beyrer, 2013).

Several updated versions of the SEM model have been used in public health research and intervention development since the initial development of the framework. All of the variations maintain the intra-personal and inter-personal levels of influence, but some models combine the organizational and community level factors. There is also variation in how these levels are defined: for example, physical structures are included in the organizational level in some models and in the community level in others. McLeroy’s model did not include a clearly defined level in
which to place broad influences such as gender inequality and violence, social injustice, demographic changes, economic hardship, or racism and discrimination. Multiple variations on the SEM model have re-defined the 5th level to encompass these issues and termed it as structural rather than simply public policy (Sweat & Denison, 1995; Poundstone, Strathdee & Celentano, 2004).

Variables above the intra-personal level can capture the essence of social structures which influence individual behavior, affecting population health outcomes in an indirect way. Factors such as material conditions, stigma, social norms, migration and labor, and public policy are not themselves risk factors for adverse individual health outcomes, but they create environments which can positively or negatively mediate that risk. Glass and McAfee (2006) refer to these factors as “risk regulators,” noting that can each lead to either opportunities or constraints.

Social Ecological Model and PMTCT

A woman encountering the PMTCT system will be affected by her own health knowledge, skills, and intentions, which are guided by both formal education and experiential learning. She also exists as part of a community of family, friends, and other people of influence, each of whom can motivate her to either enact or not enact a certain health-related behavior. Finally, the larger community and environmental context in which she lives includes issues such as cultural norms, socioeconomics, and gender inequality for her to consider, each of which may either enable her to perform the health behavior or negatively modify her desire or efficacy in doing so.
Commonly cited barriers to PMTCT use can easily be placed into the levels of influence of the SEM. The perception of risk and susceptibility to infant acquisition of HIV, the self-efficacy to take medications and get to appointments, and the mental health status of a mother are intra-personal level concerns. The influence of family or peer relationships may present a barrier at the inter-personal level, as may the withholding of financial resources for healthcare from a partner. The difficulty of getting to PMTCT facilities, cost of transport and user fees, and poor attitudes of health care workers fall into the organizational level. The community level may hold issues of cultural issues and social norms, while broad level gender inequality, economic hardship, worldviews and negative policy environments may also hinder PMTCT care.

Despite its integration into a larger context, the individual still remains at the center of the SEM model. Several commonly used health behavior theories such as the Health Belief Model and Theory of Planned Behavior focus attention virtually entirely on this level, and their constructs are important to consider for women engaging the PMTCT system. According to the Health Belief Model (HBM), beliefs drive behavior (Janz & Becker, 1984). In the HBM, an individual is affected by six constructs when making a decision about whether or not to adopt a health behavior: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cue(s) to action, and perceived self-efficacy (Janz & Becker, 1984). According to the Theory of Planned Behavior (TPB), the knowledge represented in these constructs is necessary but not sufficient to drive behavior. The attitude towards the behavior must also be weighed in light of the individual’s evaluation of the consequences of performing (or not performing) the behavior and the intention to perform the behavior. Subjective norms also drive the behaviors (Ajzen, 1991).
In consideration of PMTCT use, factors drawing from constructs from both of these theories have been implicated as barriers to PMTCT enrollment and adherence. Knowledge and understanding of HIV, which is inclusive of perceived susceptibility, perceived severity, and potential benefits and risks of PMTCT interventions, has been assessed among pregnant women in several studies (Painter et al., 2004; Stringer et al., 2008; Ahou et al., 2010). The effect of self-efficacy and perceived behavioral control have been measured primarily through identification of perceived barriers or negatively modifying factors from the environment, including such factors as difficulty in transportation or the financial and time burden of medical visits (Torpey et al., 2010; Ferguson et al., 2012; Busza et al., 2012). Low motivation and self-efficacy were highlighted in a systematic review of community-based PMTCT interventions, and personal feelings of “not being ready,” which could be indicative of self-efficacy, have also been noted to be barriers (Busza et al., 2012; Atwiine et al., 2013; Otieno et al., 2010). From TPB, social norms have been shown to have a great degree of influence on HIV disclosure and testing patterns in ANC clients, and fear of the social stigma of disclosure or partner disapproval has been expressed as a reason for not attending PMTCT clinics (Otieno et al., 2010; Duff et al., 2010; Chinkonde, Sundby & Martinson., 2009).

Most traditional HIV prevention approaches, and in large part PMTCT approaches, have focused on these individual levels of influence. A systematic review of global PMTCT interventions from 2006-2012 demonstrated that the majority were based on individual level theoretical models such as the HBM, and the interventions included primarily components of counseling and education aimed at increasing knowledge. The constructs of perceived severity and perceived susceptibility were frequently documented as highly important in these interventions, as was the perceived benefit of the HIV treatment (Busza et al., 2012).
The need for knowledge about HIV and cues to action for HIV + mothers are recognized as critical, and many interventions have documented improvement in knowledge and belief-based outcomes. However, these knowledge-based outcomes are not always resulting in an improvement in PMTCT uptake or adherence, for knowledge alone cannot remove perceived barriers (Busza et al., 2012). The responsibility the individual level approaches place on the mother in large part ignores the significance of the greater context in which she lives, and in many contexts this overestimates the potential of women to make their own decisions (Haampanda, 2013). According to Haampanda (2013), the lack of an ecological approach in PMTCT interventions is one of the most significant issues accounting for the ongoing problem of vertical HIV transmission on a global level.

Interventions based on other levels of the SEM are much less frequently documented. Inter-personal level interventions have resulted in increased adherence to ART for HIV + individuals in multiple interventions, but few are specific to PMTCT. The relatively recent success of forming peer support groups for PLHIV women is promising, however, and it may confirm that both social norms and self-efficacy play a role in encouraging adherence to PMTCT (Tonwe-Gold et al., 2009). Interventions focused on existing organizational level barriers, including such common issues as failure in supply chains, difficulty in accessing clinics, and lack of adequately trained staff are also rare (Busza et al., 2011; Otieno et al., 2010; Atwiine et al., 2013; Audereau et al., 2013). Cultural norms, stigma, and other social constraints are targeted or documented in PMTCT interventions very infrequently. National health policies have a direct effect on the PMTCT services offered to women, and public policy is a significant influencing factor for almost all health-related behaviors, including PMTCT utilization and adherence (Busza et al., 2012). In some contexts, interventions have included the policies shifting in a positive
direction. However, policy level changes surrounding gender equality, gender violence, and economic empowerment are infrequently documented across the PMTCT literature.

**Ethiopia**

As is the case across the global community, PMTCT studies in Ethiopia have utilized primarily individual level models of health behavior such as HBM and TPB; the importance of the constructs from these models can thus not be overlooked. In a study of voluntary HIV counseling and testing among antenatal attendees which used the HBM as a framework for its surveys. Perceived susceptibility to HIV was low among the women surveyed (37%), yet the perceived severity of HIV was high (67%) (Moges & Amberbir, 2011). Those women with high perceived susceptibility had a 3 times greater likelihood of testing than those who did not, and those who perceived benefit from the test were 95% more likely to test than those who did not believe the test had value (Moges & Amberbir, 2011). TPB studies also demonstrate the strong influence of subjective norms in the Ethiopian culture. These norms were identified as strong predictors of motivation to learn about HIV among Ethiopian college students (Gebreeyesus, Boer & Kuiper, 2007); intention to test for HIV was also strongly affected by subjective norms among ANC attendees (Mirkuzie, Sisay, Moland, & Astrom, 2011). The predictive value of the subjective norm in these studies may be a potential reflection of the collectivist culture and social norms of Africa as opposed to the West (Fekadu & Kraft, 2002).

PMTCT interventions in Ethiopia have also been enacted predominately at this intra-personal level, and some of these knowledge-based interventions have been effective. For example, the acceptance of HIV testing at ANCs has increased rapidly with the incorporation of pre-test counseling, and women demonstrate increased knowledge on surveys after attending
group education sessions. However, the lack of progress in PMTCT uptake and adherence demonstrates that factors beyond knowledge are influencing Ethiopian women. Cultural issues, social forces such as religion, and structural level concerns such as gender inequality must be considered, and the impact of the inter-personal relationships in the lives of the PLHIV women cannot be overlooked.

It is recognized that multiple factors contribute to PMTCT attrition among Ethiopian women, but it is not clear which of these factors holds the most influence. The overall nature of this study was therefore exploratory, seeking to understand these influences and the behavior of women in Addis Ababa in the PMTCT system in an effort to guide future research or interventions. Although some individual level constructs from HBM and TPB were used in design of quantitative survey measures, the predominately qualitative component of the study allowed for significant factors at any level of the SEM to emerge. The SEM was used as a framework to provide clarity into the impact of factors elicited through triangulation of data, and how they are interconnected. This study utilized a modified version of Poundstone’s SEM model (Figure 5), enabling researchers and public health providers to better identify which categories may hold the strongest influence on PMTCT attrition and be an optimal target for future interventions.

While many studies have categorized barriers to PMTCT use along a variation of the SEM, fewer have sought to understand the positive influences which may actually facilitate PMTCT use. Since risk regulators can present either constraints or opportunities to individual level behaviors, it is important to recognize and capitalize on positive influences in promoting PMTCT use (Glass & McAfee, 2006). Peer support, an inter-personal level influence, is documented in many locations as beneficial in increasing adherence and uptake of services.
Travel stipends, removal of user fees, and mobile clinics may increase uptake of services from an organizational level, whereas positive messages from religious communities may be significant sources of influence at the community level. Structural influences, while difficult to change, are powerful: empowerment of women through cash transfers as social protection and anti-discrimination laws may facilitate care at this level. The positive effect of such influences among PLHIV Ethiopian women has not been studied, yet they must exist. Women identified as “positive deviants”- those who had access to the same resources and encountered the same barriers to PMTCT and yet had a successful outcome- may provide critical insight into the factors with the greatest potential to effect positive change at a population level (Glass & McAfee, 2006). In this study, by speaking with women who have successfully navigated the PMTCT system and whose children are HIV-, these positive influences were also identified and the influences placed as facilitators into each level of the SEM framework.
Methodological Overview

In order to adequately cover both breadth and depth of the reasons behind attrition from PMTCT, an inductive, mixed methods approach was used for this study. Although qualitative methods were the core component of the study, quantitative data elements were used as supplemental components and integrated into analysis. The assumption that this integration provided findings greater than those that could be obtained independently. The choice of this research design stems from a pragmatic worldview which emphasizes the research problem above a particular method (Denscombe, 2002).

The methods were approached concurrently, with the eventual analysis using side-by-side comparisons and merging of the data to understand the variables from the perspective of both types of evidence (Creswell & Zhang, 2009). In-depth interviews allowed for broad elicitation of issues affecting PMTCT adherence, and focus groups were held in order to facilitate the exchange of ideas between PLHIV mothers regarding sources of influence in their lives and ways in which PMTCT interventions would be more effective (Krueger & Casey, 2009). This study was one of the first in Ethiopia which utilized qualitative analysis in the form of in-depth interviews and focus groups to explore the pregnancy experiences of PLHIV mothers and their interactions with the PMTCT system. Finally, quantitative surveys of PLHIV women were used to identify the prevalence of salient beliefs and understanding surrounding reproductive health issues in this population. They also sought to identify any differences between: 1) women who completed PMTCT and those who did not and 2) women with HIV infected children and those with healthy children.

The PI collaborated with professors at the Addis Ababa University (AAU) College of Public Health in completion of the research. The PI was responsible for overall management of
the research project, but Ethiopian colleagues were consulted at multiple junctures along the way. Their knowledge of Ethiopian culture and thought, as well as extensive experience in both qualitative and quantitative global health research, was invaluable in the design and revision of study tools, study design, and data analysis.

Participants and Sampling

Overall sampling for participants utilized “mixed purposeful sampling,” a method which is useful for helping to triangulate data (Miles & Huberman, 1994). PLHIV women were purposefully chosen, but a variation representative of the demographics of PLHIV women in Addis Ababa was sought. Women of varying ages, religions, ethnicities, economic and educational levels were recruited to participate, as well as women from different communities around Addis Ababa. This variation enabled stratification by variables in data analysis (Stenius, Makela, Miovsky & Gabrhelik, 2008).

Participants for this qualitative research were drawn from a variety of communities in Addis Ababa and were selected based on the recommendations of staff members from one of two PLHIV support programs. PLHIV women who had a child at least one year of age were eligible for participation in the study. Both PLHIV mothers who had delivered HIV+ children and those whose children are HIV- were chosen for participation. Women who were diagnosed with HIV after their last pregnancy were also included, allowing the PI to capture those who transmitted the virus to their children without knowledge of their status. Women with older children also had valuable insight into issues surrounding reproductive decisions in an HIV+ woman. In order to minimize bias occurring from sampling only women who were currently well supported, the
program staff also identified PLHIV mothers who were not involved in one of their programs to participate in the interviews (Table 1).

Table 1

Methods

<table>
<thead>
<tr>
<th>Tool</th>
<th>Purpose</th>
<th>Sample size</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview</td>
<td>Exploration of pregnancy experiences of HIV+ women</td>
<td>23</td>
<td>• Supported women with HIV+ children&lt;br&gt;• Supported women with HIV- children&lt;br&gt;• Supported women with HIV+ and HIV- children&lt;br&gt;• HIV+ women with children not supported by a network</td>
</tr>
<tr>
<td>Focus Group</td>
<td>Discussion about inter-personal level influences on HIV+ women and the PMTCT system</td>
<td>4 groups (6-8 women in each group)</td>
<td>• Supported women with HIV+ children&lt;br&gt;• Supported women with HIV- children&lt;br&gt;• Supported women with HIV+ and HIV- children&lt;br&gt;• HIV+ women with children not supported by a network</td>
</tr>
<tr>
<td>Survey</td>
<td>Individual level influences on HIV+ women</td>
<td>71</td>
<td>• Supported women with HIV+ children&lt;br&gt;• Supported women with HIV- children&lt;br&gt;• Supported women with HIV+ and HIV- children&lt;br&gt;• HIV+ women with children not supported by a network</td>
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For this study, four focus groups were held: two exclusively with women whose children are HIV+ and two exclusively with women whose children are HIV-. Each group consisted of six to eight women. Data analysis for the study was driven by theoretical saturation, and the PI and research assistant concurred that additional groups would not add greatly to the themes emerging in the discussion. Inductive analysis of qualitative data was performed concurrently with ongoing data collection, using the constant comparative method, and redundancy in data and themes was being seen by the 15th interview. However, as adequate representation of religions and local communities had not yet been obtained, interviewing continued until 23 interviews in total had been completed. Surveys were completed immediately following interviews as well as in a PLHIV program office. A total of 71 surveys were obtained.
Variables and Measures

The variables of interest for the research question are contained in the question itself: the beliefs, attitudes, socio-cultural factors and key influences that affect HIV+ women in Addis Ababa during pregnancy and may contribute to the effectiveness of PMTCT programs. Although the entire PMTCT Cascade includes the use of infant ARV and infant HIV diagnosis, the research question for this study was focused on issues affecting maternal adherence. Therefore, a modified version of the PMTCT Cascade in which maternal and infant adherence are separated (Figure 6) was used for this study. In all measurement tools, maternal adherence to the PMTCT system was defined as a mother taking HAART for her own health or ARVs for infant prophylaxis all the way through the completion of breastfeeding. Adherence was self-reported by the women for all measurement tools used.

Figure 6. A Modified PMTCT Cascade.

Although previously validated surveys covering PMTCT exist, these instruments assess predominately variables which relate to the individual level of influence. None were sufficiently comprehensive in their scope for an exploratory study which allows for the emergence of new variables, and they are not inclusive of other influences from the SEM model. Thus, in this
study, the PI and research collaborators designed new instruments to appropriately address the research question.

Instruments which have previously been used in HIV and PMTCT research were reviewed, with particular attention to those used in Africa. The Population Council’s Horizons AIDS Tool Kit contains multiple surveys from government and non-governmental agencies which have been utilized across the African continent to address different aspects of HIV. Those questions which were relevant to PMTCT or modifiable for use with PMTCT and addressed the intra-personal or inter-personal levels of influence from the SEM were extracted and used with the permission of Horizons (Horizons Program, 2013). In order to further explore the inter-personal level of influence, as well as to incorporate religious influences and other aspects of the social/community SEM level, the PI developed additional questions for the survey. A complete list of the origin of each survey question and the construct or SEM level it addresses is included in Appendix C. The interview and focus group guides were also independently developed by the PI. Consultation with Ethiopian research collaborators took place during design of the tools to ensure the relevancy of the new questions being asked, and elements of previously used instruments were adapted to suit the Ethiopian context. Evaluation of the instruments by multiple researchers helped to limit potential researcher bias.

The instruments designed include a semi-structured interview guide, focus group guides, and a structured questionnaire (Appendix D). Incorporated into these instruments are questions which allowed for elicitation of factors at all levels of influence of the SEM, including cultural influences which could be uncovered indirectly. The semi-structured, open-ended question interview guide was developed to explore the pregnancy experiences of PLHIV mothers. The main objective of these interviews was to gain a broad understanding of those experiences and to
identify variables which might have affected attrition from or adherence to PMTCT, including cultural and emotional issues which may be relevant factors. The focus group discussion guide was designed to assess several levels of influence. At the interpersonal level, questions centered on which people hold the strongest influence (both positively and negatively) on the women’s health decisions. Organizational level factors were addressed in questions regarding positive and negative experiences with the PMTCT system, while community level influence was addressed through inquiry into the role of religious faith in their experiences. Presenting an opportunity to suggest ways in which adherence to the PMTCT system may be encouraged for other mothers allowed for emergent factors from any SEM level, while intra-personal factors and relevant cultural issues could emerge in the focus groups at any time in the discussion. The surveys primarily focused at the individual knowledge level, with questions drawn from Health Belief Model constructs of perceived benefits, perceived barriers, severity and susceptibility, and self-efficacy. The secondary focus of the surveys was at the interpersonal level, with direct questioning regarding the importance of relationships in the participant’s health care. Demographic information was also obtained so that results could be stratified, and 2 outcomes of interest were addressed: adherence to the maternal PMTCT cascade and the HIV status of infants.

Revision of tools. Some revision of all tools was required after pilot testing. After discussion with a research assistant and pilot testing with 3 women, it was noted that the women did not understand the difference between the use of HIV medication for their own health and that used solely for PMTCT. They also did not understand the terminology PMTCT. All references to PMTCT were therefore changed to “medication used to prevent HIV from going to my baby.” The word “partner,” used to describe sexual partner or spouse, did not translate
clearly into Amharic and was being interpreted as a “neighbor”. Therefore, the term partner was revised to “husband,” with the broad interpretation of this word in the local language to mean any sexual partner.

Aside from these terminology changes, initial pilot testing of the interviews did not reveal anything that required revision. Slight revisions were made as data collection was ongoing, however, and the open-ended nature of the interviews allowed for this flexibility without compromising the validity of the data. Several interviews demonstrated that the women preferred to discuss their overall experiences with HIV rather than just their experiences in pregnancy. Thus, although pregnancy concerns were addressed, the overall focus and timing of the interview questions was shifted to more generic conversation about their HIV experiences. Questions inapplicable to women who had not actually been diagnosed with HIV at the time of their pregnancy were omitted during the interview with these participants.

The question “Did you think your child would be HIV +? Tell me what it was like waiting for the diagnosis for your child?” was deleted entirely after 4 interviews: it was both confusing to participants and potentially offensive. Finally, the original question regarding what the women would do over if possible was changed to a third party perspective: “Many women in Ethiopia do not take the PMTCT medication to prevent their babies from being infected. Why do you think they may not do this, and how could you help them to do so?”

The survey was revised significantly during the initial period of data collection. The time required to administer the survey was longer than anticipated, despite it being done entirely in Amharic. In order to simplify the survey, 13 questions were deleted, each of which overlapped with another question in some manner. All SEM levels were still addressed in the survey. Initially the survey asked whether medication was taken during each stage of PMTCT: pregnancy, delivery,
and breastfeeding. Pilot testing revealed that this was very difficult to understand for participants. The wording of the survey was therefore simplified to a yes or no response question: “I took medication to prevent HIV from going to my baby from pregnancy through breastfeeding.” This promoted less confusion for respondents but is also a limitation in data analysis, as a woman may answer affirmatively despite not having completed the entire PMTCT cascade.

The survey and focus group tools were translated into Amharic by two native speakers prior to the study beginning, and they were back-translated by two other native speakers to ensure accuracy of translation (Appendix E). Once the tools had been acceptably translated, they were pilot tested in the populations of interest, with revisions as indicated above.

Research Procedures

IRB approval was obtained from the University of South Florida and the Ethics Review Board of AAU. The Federal Ministry of Health of Ethiopia approved the study without additional IRB approval since it was done in conjunction with the University. The research project took place over a 2 month period of time in Addis Ababa, Ethiopia. The PI first located and hired an educated, bilingual primary research assistant. A two day training took place with the assistant, which included giving an overview of the research questions and their importance, data collection instruments, and practice in both administering the survey and moderating an interview and focus group. The assistant was also instructed in his responsibility to be compliant with strict confidentiality practices and ethical practices. As a nursing student, he was well equipped to understand medical issues, and he was an Addis Ababa native who also understood the cultural nuances of the work being done. After orientation and initial training, the assistant
reviewed the study tools with the PI and made recommendations for revisions (also incorporated as noted above).

As the assistant was being trained, the PI made contact with two large networks of PLHIV in Addis Ababa. Staff of both of these networks were oriented to the purpose and methodology of the study, as well as informed of the demographic distribution of participants that was required. Telephone calls were made to locate potential participants, after which data collection began. Focus groups and interviews took place concurrently according to availability of the participants.

Prior to participating in this study, all participants were informed of the goals of the study and their rights as a study participant. Participants were advised that they were free to refuse participation without consequence, and they were assured that no names or other identifiers would be recorded anywhere on the surveys or interviews in order to protect confidentiality. At the time of participation in interviews and focus groups, each individual was assigned a study number and consent was recorded by the researcher on an Informed Consent document (Appendix F) matching that number. For those who were illiterate, a modified signature was allowed on the consent form. Surveys were obtained at a PLHIV network office from a number of women who did not complete interviews or focus groups. The informed consent process was completed with these women in the same manner and consent forms obtained.

**Focus groups.** Focus groups were conducted in the primary local language, Amharic, with the research assistant moderating (Hennink, 2007). All four focus groups took place at the offices of the first PLHIV network, and a program staff social worker filled the role of note-taker during the sessions. The PI observed each session, enabling observation of the interactions between the participants, non-verbal cues in body language, and emotional responses to certain
topics. The notes of the PI and the translated notes of the note-taker provided references and context to the translated transcripts once data analysis began.

Focus groups were held sequentially, beginning with one group of women with HIV+ children and one group with HIV- children. Refreshments of soda or coffee, fruit, and the local snack “colo” were offered at the beginning of each session to encourage relaxation, and sessions took place outside in the courtyard of the office. As a group, participants were educated about the study purpose and design, reminded that the sessions were to be tape-recorded with identifying information removed, and informed about the IC process. Each participant completed the IC form, and basic demographic information was recorded in written form. Each session was recorded on a digital audio recorded and lasted between one and two hours. The women were each given 100 Ethiopian birr for their participation. At the conclusion of each session, the PI, note taker, and moderator de-briefed the session in order to capture the essence of the group and see if modifications were required. No modifications were required beyond that to wording made after pilot testing, as previously described.

The first session included participants who were supported by the first PLHIV network. In order to limit bias from these participants, a program social worker was asked to identify women in the surrounding communities who were HIV positive but not directly benefitting from their services. The subsequent 3 groups included all women who were not benefitting from social support from any organizations, two of which were with HIV- children and one with women with HIV+ children.

**Interviews.** In order to limit variability in the collected data and difficulty in analysis, the interviews were conducted bilingually by the PI and research assistant. At the recommendations of the program staff who located the participants, interviews were completed at the program
offices. Representatives from the PLHIV programs, who are highly trusted in the community, were therefore present, although not directly involved in the interviews. Their presence assured the participants of the positive intentions of the PI and encouraged their vulnerability in answering the interview questions. In order to obtain representative sampling of women in the community, the process for recruiting was on-going and flexible with the assistance of the PLHIV networks. Three women interviewed were not directly supported by any social service network, 12 were involved with one network and eight with the second.

After basic demographic information was obtained and informed consent completed, audio taping commenced and was discontinued when the interview was complete, averaging between 45 minutes to an hour and 15 minutes. At the conclusion of the interview, the research assistant administered the quantitative survey to the participant in Amharic; this was not audio-recorded. Survey completion time averaged 15 minutes, for a total session time of an hour to an hour and a half. The PI made handwritten notes about any relevant body language or emotion seen in participants throughout the session as necessary. Each woman was offered 100 birr for her participation.

**Surveys.** Each woman who was interviewed completed the survey, for a total of 23 respondents. Focus group participants did not express interest in completing the surveys after the sessions due to time constraints. To increase the power of the survey, a larger sample size was required. One staff member from a PLHIV network was therefore individually trained in survey administration and collected survey data in an ongoing, 3 week process. Participants for the surveys were located through the PLHIV program’s network, inclusive of both women who were program beneficiaries and those who were not. Informed consent was obtained for these women, and surveys were completed in 10-15 minutes each. The participants did not receive direct
compensation for their participation. Forty-eight women completed the surveys at the PLHIV program office, for a total of 71 surveys completed.

**Interviews with religious leaders and PLHIV program staff.** As adjunct information for the study and to inform cultural influences in the community, several individuals outside of the direct population of interest were interviewed. These included religious leaders (a pastor, an Orthodox priest, and a Muslim sheik); the HIV coordinator for a large NGO, the directors of two PLHIV networks; a pediatrician involved in PMTCT care at a local hospital; a PLHIV peer educator; and the director of the Ethiopian Medical Society. Informed consent for these professional interviews was obtained verbally, and no compensation was offered for participation. With the exception of the interviews with the sheik and priest, all sessions were conducted in English; the other two were conducted with the assistant translating. Each session was audio-recorded and transcribed by the PI. Results of analysis of these sessions will be reported in a separate document, but may be referenced in primary data analysis.

**Data Analysis**

As data collection was ongoing, the primary research assistant transcribed the audio tapes of two focus group sessions and translated them from Amharic to English. This process was also completed by an additional transcriptionist in order to check for accuracy; discrepancies were discussed and clarified to the satisfaction of both assistants and the PI. After consensus was reached, the remaining two focus group sessions were transcribed solely by the primary research assistant. The PI transcribed the audio tapes from the interviews in English directly. Two of these interviews were checked by an additional Amharic speaker for accuracy, both in the translation that occurred during the session and the transcription by the PI.
After quantitative data collection was complete, it was analyzed in SAS software as descriptive measures for beliefs, attitudes, and understanding relevant to PMTCT. Stratification by infant HIV outcomes and maternal PMTCT adherence was completed.

For the qualitative component, inductive data analysis was performed concurrently with ongoing data collection, using the constant comparative method. This process allowed the PI to uncover the dynamics between the core social, cultural, and emotional processes that affect PLHIV women during pregnancy (Strauss & Corbin, 1998). The sampling process was flexible, evolving as the study progressed. NVivo software was utilized to assist in data analysis (Hoover & Koerber, 2011). All translated transcripts were segmented by question (and by individual speaker in the case of focus groups) and uploaded into NVivo. The transcripts were read in their entirety by the PI, and an initial codebook was developed which included the five levels of the SEM and barriers or facilitators within each level (Appendix G). Broad coding was first done according to the levels of the SEM model, followed by axial coding to elicit key themes of either barriers or facilitators within the levels. The codebook was revised as analysis occurred, and selective coding completed the process as themes emerged from the data (Padgett, 1998). Since the PI independently coded the transcripts, recoding of several transcripts took place after the codebook was finalized in order to check accuracy. Through the inductive process, triangulation of all interviews, focus group sessions, and survey responses sought to identify potential strategies for behavioral and environmental change.

As themes emerged, several reflexive sessions were held with PLHIV participants to check the accuracy and representativeness of the findings and increase the trustworthiness of the study (Krefting, 1991). Additionally, the research assistant and PLHIV program staff checked findings for transparency and agreement with local culture and customs throughout the data...
analysis process. To increase the dependability of the findings, a data audit trail was maintained throughout the process (Padgett, 1998). All stages of the study were subject to review by a 4 member research advisory team at USF, as well as the AAU researchers, to look for omissions or inconsistencies and offer recommendations for improving the validity of the research.

**Summary of Terms**

The following terms have been referenced in the preceding section and may be used throughout the remainder of this document, in all sections and the appendices.

- **AAU**: Addis Ababa University
- **ACTG**: AIDS Clinical Trials Group
- **AIDS**: Acquired Immunodeficiency Syndrome
- **ANC**: Antenatal Center/Antenatal Care
- **ART**: Antiretroviral Therapy/Antiretroviral Treatment
- **ARV**: Antiretroviral
- **AZT**: Zidovudine
- **BF**: Breastfeeding
- **BFP**: Bolsa Familia Program
- **CDC**: Centers for Disease Control
- **CHW**: Community Health Worker
- **COPH**: College of Public Health
- **COPD**: Chronic Obstructive Pulmonary Disease
- **CSA**: Central Statistical Agency (Ethiopia)
- **DHS**: Demographic and Health Surveys
- **DITRAME**: Diminution de la Transmission Mère-Enfant du VIH en Afrique
- **DNA**: Deoxyribonucleic acid
- **EFV**: Efavirenz
- **eMTCT**: Elimination of Mother to Child Transmission of HIV
- **EID**: Early Infant Diagnosis
- **EIFDAA**: Ethiopia Interfaith Forum for Development, Dialogue and Action
- **EGPAF**: Elisabeth Glaser Pediatric AIDS Foundation
- **ELISA**: Enzyme linked immunosorbant assay
- **FDA**: Federal Drug Administration
- **GOE**: Government of Ethiopia
- **HAPCO**: Federal HIV/AIDS Prevention and Control Office
- **HBM**: Health Belief Model
- **HCT**: HIV Counseling and Testing
- **HEW**: Health Extension Worker
- **HAART**: Highly Active Antiretroviral Therapy
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<thead>
<tr>
<th>Acronym</th>
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<tr>
<td>HSDP</td>
<td>Health Sector Development Plan</td>
</tr>
<tr>
<td>IATT</td>
<td>Inter-agency Task Team</td>
</tr>
<tr>
<td>IRB</td>
<td>Institutional Review Board</td>
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<tr>
<td>LTF</td>
<td>Loss to Follow-up/Lost to Follow-up</td>
</tr>
<tr>
<td>MARPs</td>
<td>Most-at-Risk and/or Highly Vulnerable Populations</td>
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<td>MDGs</td>
<td>Millennium Development Goals</td>
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<td>MMR</td>
<td>Maternal Mortality Rate</td>
</tr>
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<td>MOH</td>
<td>Federal Ministry of Health (Ethiopia)</td>
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<td>MSM</td>
<td>Men Having Sex with Men</td>
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<td>MTCT</td>
<td>Mother to Child Transmission of HIV</td>
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<td>NGO</td>
<td>Non-governmental Organization</td>
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<td>NIH</td>
<td>National Institutes of Health</td>
</tr>
<tr>
<td>NNRTI</td>
<td>Non-nucleoside reverse transcriptase inhibitor</td>
</tr>
<tr>
<td>NRTI</td>
<td>Nucleoside reverse transcriptase inhibitor</td>
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<tr>
<td>NVP</td>
<td>Nevirapine</td>
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<tr>
<td>OVCs</td>
<td>Orphans and Vulnerable Children</td>
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<tr>
<td>PCR</td>
<td>Polymerase Chain Reaction</td>
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<tr>
<td>PACTG</td>
<td>Pediatric AIDS Clinical Trials Group</td>
</tr>
<tr>
<td>PBT</td>
<td>Problem Behavior Theory</td>
</tr>
<tr>
<td>PCP</td>
<td>Pneumocystis carinii pneumonia</td>
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<tr>
<td>PEPFAR</td>
<td>President’s Emergency Plan for AIDS Relief</td>
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<tr>
<td>PETRA</td>
<td>Perinatal Transmission Study</td>
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<td>PLHIV</td>
<td>People Living with HIV</td>
</tr>
<tr>
<td>PHPT</td>
<td>Perinatal HIV Prevention Trial</td>
</tr>
<tr>
<td>PI</td>
<td>Protease inhibitors</td>
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<tr>
<td>PI</td>
<td>Primary Investigator</td>
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<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission of HIV</td>
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<td>SBA</td>
<td>Skilled Birth Attendant</td>
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<tr>
<td>STI</td>
<td>Sexually Transmitted Infections</td>
</tr>
<tr>
<td>TBA</td>
<td>Traditional Birth Attendant</td>
</tr>
<tr>
<td>TDF</td>
<td>Tenofovir</td>
</tr>
<tr>
<td>TPB</td>
<td>Theory of Planned Behavior</td>
</tr>
<tr>
<td>TRA</td>
<td>Theory of Reasoned Action</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
</tr>
<tr>
<td>UNGASS</td>
<td>United Nations General Assembly Special Session</td>
</tr>
<tr>
<td>USDHHS</td>
<td>US Department of Health and Human Services</td>
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<tr>
<td>UNFPA</td>
<td>United Nations Population Fund</td>
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<td>UNICEF</td>
<td>United Nations Children’s Fund</td>
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<tr>
<td>USAID</td>
<td>United States Agency for International Development</td>
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<td>USF</td>
<td>University of South Florida</td>
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<tr>
<td>VCT</td>
<td>Voluntary Counseling and Testing</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>WRA</td>
<td>Women of Reproductive Age</td>
</tr>
<tr>
<td>3TC</td>
<td>Lamivudine</td>
</tr>
</tbody>
</table>
Conclusion

The need for further exploration for PMTCT attrition is high. Although the government and other stakeholders continue to seek to decrease the loss to follow up rate for Ethiopian women in PMTCT care, the reduction is happening far too slowly. Current interventions may be focused on areas which are not of highest importance to the PLHIV women themselves, and the experiences of these women should be explored in order to achieve better PMTCT outcomes in Ethiopia.

References


Von Massow, F. (2000). "We are forgotten on earth": international development targets, poverty, and gender in Ethiopia. *Gend Dev, 8*(1), 45-54. doi: 10.1080/741923410


SECTION II
MANUSCRIPT I

Perspectives of HIV+ Women on PMTCT in Addis Ababa, Ethiopia- a SEM Model

Target Journal: Journal of Health Care for the Poor and Underserved
Secondary Journal: BMC Public Health

Background

In 2012, 330,000 children were infected with HIV across the globe. Ninety percent of these children acquired the infection through vertical transmission, with their mothers passing the virus during pregnancy, delivery, or breastfeeding (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2012). This number is staggering in light of the fact that effective prophylactic medication for the Prevention of Mother to Child Transmission of HIV (PMTCT) is available and can reduce vertical transmission risk to less than 2% (Lallemant et al., 2004).

The process by which women learn of their HIV status, access and adhere to appropriate medications, and follow through with post-natal recommendations for feeding and medication usage, called the “PMTCT Cascade,” is complex, and multiple issues may limit a woman’s ability to follow it through to completion. Loss to follow up (attrition) from the system is a documented global problem. The global average for successful completion of the entire PMTCT cascade is estimated at 62%, yet adherence rates to every step of the cascade range from 99% to less than 1% (UNAIDS, 2013).
Globally, there has been a 52% decline in new HIV infections among children in the last decade (UNAIDS, 2013), but progress is still greatly hindered in some nations. In Ethiopia, a nation with a high fertility rate (4.8), low adherence to the PMTCT system is a documented issue. In 2012, only 41% of HIV+ pregnant women/children pairs received the most efficacious regimens of antiretrovirals (ARVs) required for PMTCT (UNAIDS, 2013), and, of those pairs, only 10.2% followed PMTCT through to the point of infant HIV testing. This lack of adherence has resulted in 9,000 new infant HIV infections (UNAIDS, 2013), an estimated mother to child transmission rate of 20% in 2012 (Ethiopian Ministry of Health [MOH], 2013a).

The government of Ethiopia has made addressing persistently high levels of maternal and neonatal mortality a top priority, a commitment that requires a dramatic effort towards improving PMTCT uptake and adherence. By 2015 Ethiopia aims to have 85% of mother-child pairs on ARVs (US Global Health Initiative, 2010) and to fully integrate PMTCT services into routine maternal, child and reproductive health services in order to attain the vision of an “HIV-free generation by the year 2020” (Deressa et al., 2010). New goals under the national “Elimination of MTCT” (eMTCT) 2013-2015 plan include reduction of the MTCT rate to less than 5% and a reduction in the number of new childhood HIV infections of 90% by 2015 (MOH, 2013b).

Identification of HIV+ pregnant women has risen significantly in Ethiopia in the last several years. Between 34% and 71% of pregnant women report visiting Antenatal Centers (ANCs) at least one time, and 92% of these women accept HIV testing (Ethiopian Central Statistical Agency [CSA], 2012; Nigatu & Woldegebril, 2011). The number of facilities offering PMTCT services has also increased 16-fold in the last six years (MOH, 2013b). In 2013, Ethiopia adopted the use of the simplified “Option B+” medication guidelines for PMTCT, under
which it is recommended that all HIV+ pregnant women should begin therapy at the time of diagnosis. This move dramatically expanded the number of women eligible for ARVs. Despite this proactivity, efforts to improve PMTCT uptake and adherence have been relatively ineffective (UNAIDS, 2012).

PLHIV (people living with HIV) mothers are a rich source of information regarding factors which may be beneficial or detrimental to their adherence to PMTCT, and their opinions are increasingly being recognized as integral to guiding program development on an international level. Furthermore, the lack of an ecological approach in PMTCT has been identified as one of the most significant issues in the ongoing problem of vertical HIV transmission globally (Haampandaa, 2013). The unique socio-contextual factors affecting Ethiopian women, including the beliefs, cultural and social norms, and individuals who have influence over their reproductive health decisions, must be considered if innovative methods to increase maternal adherence to PMTCT are to be developed. Thus, this study utilized a modified version of Poundstone’s Socio-Ecological Model (SEM) (Figure 1) as a framework for providing clarity into the factors which impact adherence for PLHIV mothers in Ethiopia.

The research thus far into loss to follow-up from PMTCT in Ethiopia has primarily been quantitative. Obtaining the perspective of PLHIV women from a qualitative perspective, using focus groups and interviews, will more comprehensively elicit influential factors in PMTCT adherence and can help target future interventions. Additionally, in light of the fact that a significant number of women are still not accessing ANC services, research with PLHIV mothers at a community level is critical in order to adequately represent the viewpoint of the maternal population. In the capital city of Addis Ababa, 70,000 pregnant women were eligible for PMTCT in 2012 (CSA, 2012). This made Addis Ababa an ideal location in which to obtain the
perspective of PLHIV mothers and from which this study could specifically elaborate on the following research question: What beliefs, attitudes, socio-cultural factors and key influences among HIV+ women in Addis Ababa contribute to their adherence to or attrition from the PMTCT system?

**Methods**

To adequately cover both breadth and depth of the reasons behind attrition from PMTCT, an inductive, mixed methods approach was employed. Qualitative methods were the core component of the study, supplemented by quantitative data elements that were triangulated in data analysis. In-depth interviews allowed for broad elicitation of issues affecting PMTCT adherence, and focus groups were held in order to facilitate the exchange of ideas between PLHIV mothers. Finally, quantitative surveys of PLHIV mothers were used to identify the
prevalence of salient beliefs and understanding surrounding reproductive health issues in this population. Study instruments incorporated questions which allowed for elicitation of factors at all levels of influence of the SEM. Approval and oversight for this project was granted by the University of South Florida’s IRB, the Ethics Review Board of Addis Ababa University, and the Federal Ministry of Health of Ethiopia. The research project took place over a 2 month period of time in Addis Ababa, Ethiopia.

Participants and Sampling

Overall sampling for participants utilized “mixed purposeful sampling,” choosing a variation of women representative of the demographics of the female PLHIV population in Addis Ababa. Women of varying ages, religions, ethnicities, economic and educational levels, and communities were recruited to participate from two local PLHIV support programs. PLHIV mothers who had a child at least one year of age were eligible for participation in the study. Both PLHIV mothers who had delivered HIV+ children and those whose children are HIV- were chosen for participation; women who knew their HIV status during pregnancy and those who did not were also sampled. To minimize bias occurring from sampling only women who were currently well supported, the program staff also identified PLHIV mothers who were not involved in one of their programs to participate in interviews.

Research Procedures

Interview and focus group guides were developed by the PI and Ethiopian colleagues. The quantitative PMTCT Survey incorporated questions from the Horizons AIDS Tool Kit (Horizons Program, 2013) which were adapted to suit the Ethiopian context, along with
additional questions developed by the research team. Maternal adherence to the PMTCT system was defined as a mother taking HAART for her own health or ARVs for infant prophylaxis through the completion of breastfeeding. Adherence was self-reported by the women for all measurement tools used. All study tools were translated into Amharic by two native speakers, back-translated by two other native speakers to ensure accuracy, and pilot tested with five women in the population of interest.

**Data Collection and Analysis.** Informed consent was first gained from all study participants. Qualitative and quantitative data collection took place concurrently. Four focus groups were conducted in Amharic, with a trained research assistant moderating and the PI observing. Two groups contained women with HIV+ children and two contained women whose children are not infected. Each group consisted of six to eight participants with a total of 27 participants. Interviews were conducted in English by the PI with the research assistant translating to Amharic. Interviews continued to the point of theoretical saturation. In total, 23 interviews were completed. Each woman who was interviewed also completed the quantitative PMTCT Survey. Additional surveys were collected from other PLHIV mothers to increase the sample size to a total of 71 completed surveys.

Audio tapes of all sessions were translated and transcribed verbatim and uploaded into NVivo software (Hoover & Koerber, 2011). The five levels of the SEM were used for initial broad coding. Emergent themes were then coded within these levels. Four transcripts were re-coded, and reflexive sessions were held with PLHIV participants to check the accuracy and representativeness of findings. PMTCT Survey data was analyzed in SAS software as descriptive measures for beliefs, attitudes, and understanding relevant to PMTCT. Chi-square analysis of differences between those who adhered to PMTCT and those who did not was also completed.
Quantitative and qualitative results were then grouped by SEM level, according to Figure 1. The intra-personal level encompassed the knowledge, beliefs, and attitudes of the study participants themselves regarding PMTCT, self-efficacy and intention. The inter-personal level was represented by individuals of influence close to the women: husbands, family members, friends and other peers. The organizational level included the health care system, health care workers, medication, supplies, and issues pertaining to medical care visits (such as transportation fees). The community level incorporated neighborhoods (“kebeles”) and neighbors, religions, and social organizations. The structural level included public policy, stigma and discrimination, gender and ethnic issues, socioeconomic concerns, and broad demographic shifts. Through the inductive process, triangulation of all interviews, focus group sessions, and survey responses was completed to identify the dominant barriers and facilitators to PMTCT adherence in Addis Ababa.

**Results**

**Overview**

Ninety-eight women in total participated in the study through focus groups (n=27), in-depth interviews (n=23) and the PMTCT Survey (n=48). No significant differences in demographic characteristics were reported between groups. The average age of participants was 31.7 years old. Approximately half (53.1%) were married. Ethnicity was divided into Amhara (58.2%), Oromo (22.4%), and other (19.4%). Participants were predominantly of the Orthodox religion (53.1%) followed by Protestant (42.8%) and Muslim (4.1%). Approximately one fourth of the women (25.6%) had no education; 22.4% had basic (1-5 years) education; 22.4% had secondary (7-9 years) education; and 29.6% had over 10 years of schooling. Women with higher
levels of income (defined as having 1-2 people living per room in the home) made up 42.9% of the sample; 45.9% had mid-level income (3-4 people per room); 11.2% had lower level income (5 or more people per room). Almost one in four women (22.4%) had children infected with HIV. Complete demographics of participants are shown in Table 1.

Table 1.

Demographics of participants

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<tr>
<th></th>
<th>All Surveys N=71</th>
<th>Independent Surveys N=48</th>
<th>Interviews with surveys N=23</th>
<th>Focus groups N=27</th>
<th>Total N=98</th>
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<td>45.8</td>
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<td>30-40</td>
<td>55.7</td>
<td>47.9</td>
<td>68.9</td>
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<td>13.0</td>
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<td>13.0</td>
<td>3.7</td>
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<td></td>
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<td>0.0</td>
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<td>.09</td>
<td>7.4</td>
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<td>42.8</td>
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<td># pregnancies since HIV diagnosis</td>
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<td></td>
<td></td>
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<td>0</td>
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<td>1</td>
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<td>90.6</td>
<td>43.5</td>
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<td>-</td>
<td>85.5</td>
<td>85.7</td>
<td>73.9</td>
<td>51.9</td>
<td>77.6</td>
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</table>
All quantitative data emerged from the PMTCT Survey which contained questions about the intra-personal, inter-personal, and community levels of the SEM. Results of the survey responses for all participants are presented in Table 2, along with those which varied significantly by PMTCT adherence. The open-ended nature of the qualitative study elicited data at all SEM levels and is presented accordingly. A summary of the most significant qualitative results is presented in Table 3.

Table 2.

PMTCT survey responses (%)

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<tr>
<th>Response</th>
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<th>Variation by PMTCT adherence</th>
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<td>Correctly identified all three modes of vertical transmission</td>
<td>14.1</td>
<td></td>
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<tr>
<td>Correctly identified risk of infant death with HIV</td>
<td>27</td>
<td></td>
</tr>
<tr>
<td>Correctly identified risk of infant HIV without PMTCT use</td>
<td>6</td>
<td></td>
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<tr>
<td>Correctly identified risk of infant HIV with PMTCT use</td>
<td>41</td>
<td></td>
</tr>
<tr>
<td>Had a problem with PMTCT in past</td>
<td>36</td>
<td></td>
</tr>
<tr>
<td>Anticipates a problem with PMTCT in future</td>
<td>26</td>
<td></td>
</tr>
<tr>
<td>Wants more children</td>
<td>38</td>
<td></td>
</tr>
<tr>
<td>Believes most women complete PMCT</td>
<td>41</td>
<td></td>
</tr>
<tr>
<td>Fears future baby would be HIV+</td>
<td>66</td>
<td>*P=0.042, OR=9.00</td>
</tr>
<tr>
<td>Can obtain PMTCT medicine</td>
<td>89</td>
<td></td>
</tr>
<tr>
<td>Can take PMTCT medicine</td>
<td>96</td>
<td></td>
</tr>
<tr>
<td>Thinks husband’s opinion is important</td>
<td>77</td>
<td></td>
</tr>
<tr>
<td>Think In-law’s opinion is important</td>
<td>62</td>
<td></td>
</tr>
<tr>
<td>Thinks friends’ opinions are important</td>
<td>97</td>
<td></td>
</tr>
<tr>
<td>Thinks religious leaders’ opinions are important</td>
<td>94</td>
<td></td>
</tr>
<tr>
<td>Thinks family’s opinions are important</td>
<td>89</td>
<td>*P=0.012, OR=7.67</td>
</tr>
<tr>
<td>Husband encourages PMTCT</td>
<td>69</td>
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</tr>
<tr>
<td>In-laws encourage PMTCT</td>
<td>35</td>
<td></td>
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<tr>
<td>Friends encourage PMTCT</td>
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<tr>
<td>Neighbors encourage PMTCT</td>
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<tr>
<td>Religion encourages PMTCT</td>
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<tr>
<td>Neighbors gossip about HIV</td>
<td>35</td>
<td>*P=0.043, OR=3.88</td>
</tr>
<tr>
<td>Religion thinks HIV is curse</td>
<td>28</td>
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</tr>
<tr>
<td>God influences health</td>
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Table 3.

*Qualitative results by SEM level*

<table>
<thead>
<tr>
<th>SEM level</th>
<th>Barriers</th>
<th>Facilitators</th>
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<tbody>
<tr>
<td>Intra-personal level</td>
<td>Hopelessness*</td>
<td>Counseling and education*</td>
</tr>
<tr>
<td></td>
<td>Lack of understanding*</td>
<td>Having hope</td>
</tr>
<tr>
<td></td>
<td>Carelessness</td>
<td>Interactions with PLHIV</td>
</tr>
<tr>
<td>Inter-personal level</td>
<td>Family discrimination</td>
<td>PLHIV peers*</td>
</tr>
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<td></td>
<td>Family and friend support</td>
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<tr>
<td></td>
<td></td>
<td>Husband’s support</td>
</tr>
<tr>
<td>Organizational level</td>
<td>Poor interactions with health care workers</td>
<td>Positive interactions with health care workers*</td>
</tr>
<tr>
<td>Social/community level</td>
<td>Neighbor stigma*</td>
<td>Religious institution support*</td>
</tr>
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<td></td>
<td>Holy water*</td>
<td>NGOs</td>
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<td>Media education</td>
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<tr>
<td></td>
<td></td>
<td>Neighbor support</td>
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<tr>
<td>Structural level</td>
<td>Poverty*</td>
<td>Anti-discrimination laws</td>
</tr>
<tr>
<td></td>
<td>Stigma</td>
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</tbody>
</table>

*Note* *Most significant results*

**Quantitative data. Intra-personal level.** Participants were asked a series of questions regarding their knowledge of PMTCT. Overall, the level of comprehensive knowledge about PMTCT was low. When asked to name the ways in which HIV can be transmitted from a mother to her infant, only 14.1% of the women correctly identified all three modes of transmission (during pregnancy, delivery, and breastfeeding). A higher percentage identified transmission during labor and delivery (67.6%) than during pregnancy (39.4%) and breastfeeding (35.2%). When asked to choose correct MTCT prevention from a list of possible options, more women identified that medications are needed in labor and delivery (95.8%) than during pregnancy (71.8%) or breastfeeding (66.1%). Almost a third of women (29.6%) chose the option to use infant formula instead of breastfeeding as a prevention method. While this is not inherently incorrect and has been advocated previously, it is not the current recommendation. There was no
significant association between levels of understanding and a woman’s overall educational level, marital status, income or religion.

PMTCT Survey questions also addressed perceived susceptibility to MTCT, severity of infant HIV infection, benefits of and barriers to PMTCT, and self-efficacy. The perceived severity of infant HIV infection was high. When asked what would happen to an HIV infected baby, 85.9% of survey respondents said the child would be sick; 51.4% the child would die; 31.9% the baby would be malnourished. Only 27% of women correctly identified the number of HIV infected children likely to die with no treatment.

The fear of infant infection (perceived susceptibility) in the population was also high. Eight-seven percent of women overestimated the number of children likely to be born to HIV infected mothers who were not being treated: only 6% correctly identified the risk. Sixty-six percent of those surveyed were also concerned that future children would be born with HIV. Non-adherents to PMTCT were nine times more likely to be afraid a future child would be infected with HIV than those who adhered to PMTCT (OR-9.00, 95% CI 1.03-74.76, p=.042). Twenty women also identified fear of infant infection as a primary reason for their decision to not have more children.

Perceived efficacy of medication was determined by asking how many infants were likely to be infected when born to an HIV positive mother who adhered to PMTCT. Only 41% of women correctly identified this risk, with the majority responding with overestimations. A higher percentage (75%) of those who did not adhere to PMTCT overestimated the risk of infant infection with treatment than did those who adhered to PMTCT (47%); the difference was not statistically significant. Completion of PMTCT was not a perceived norm: only 41% of women agreed that most women complete PMTCT medication through breastfeeding. Among study
participants, 89% felt they could obtain the medication necessary for PMTCT in a future pregnancy; 96% felt they would be able to take it correctly.

**Inter-personal level.** The PMTCT Survey presented women with true/false questions regarding how influential they find the opinions of different individuals in their lives to be. The opinion of friends was of highest importance, followed by family, husbands or partners, and in-laws. Overall, 97% of PLHIV mothers reported the opinions of friends were important, and 89% of participants reported the opinions of family members (inclusive of parents, siblings, and extended family) were important. The opinions of in-laws were reported as less important (62%). The importance of the opinions of family members was reported by a significantly higher number of those who completed PMTCT (94%) than those did not complete PMTCT (67%) (p =.02) \((OR -7.67, 95\% CI 1.44-40.92, p=0.017)\).

When asked on surveys if their husbands would support and encourage ARV use, 93.5% of married women said that their husband would do so. When asked if they thought PMTCT use would be difficult in a future pregnancy, four women (5.6%) indicated their husbands may present an obstacle.

**Community level.** A majority (68%) of those surveyed agreed that God is important to their health care, while 28% said their religion believes HIV is a curse. The opinion of religious leaders was important to 94% of participants. Only 36% of women from all three major religions agreed that their religious communities encouraged PMTCT use; it is not clear if the remaining communities discourage its use or are silent on the issue.

Only 37% of women surveyed said that their neighbors would actually be supportive of PMTCT use, and 35% of them were concerned that neighbors would gossip about them if their HIV status was known. Non-adherents to PMTCT were almost four times more likely to think
their neighbors would gossip about them than PMTCT adherents (OR 3.88, CI 1.0448 to 14.3863, p=.0428).

**Qualitative data. Intra-personal level barriers.** Women were asked in interviews and focus groups why HIV+ women may not adhere to PMTCT. The most frequently cited response given was “hopelessness,” which was expressed in a variety of different ways. Four women explicitly stated they had tried to commit suicide when diagnosed, while many others expressed depression about their own health and the widespread feeling that they were going to die. Women reported that although messages coming through media have shifted from “messages of death” toward more hopeful lessons in the last several years, some are still being told by friends and neighbors that HIV is a death sentence. Hopelessness about the medication itself, however, was a much more prevalent attitude. Concern about the likelihood of the supply of medication drying up prompted several women to not start taking it at all, while many expressed general mistrust of the medicine. Women reported since medicine is not able to completely cure the virus, they simply see no reason to take it and give up on it quickly. One woman stated that she would rather die than live having to take medication every day, while others mentioned not having to “suffer” from the medication side effects, particularly when they were living without adequate food intake. One participant said she was simply “exhausted” with the medication, and multiple women cited knowing others grow hopeless by simply tiring of the medication.

Contributing to this hopelessness is a general lack of understanding about ARV medicines and their use in PMTCT. Although many women affirmed receiving education, it was often perceived as confusing. One interviewee expressed a common opinion by stating “many, many times we learn about the medicine but never understand it.” The teaching that the medication must be taken with food greatly limited many women who live with food insecurity:
they either believe it will not work or are fearful of the side effects (such a “burning in the
body”). Fear of medication side effects even without food insecurity was also prevalent. One
woman said, “I shake and shake and think it will stay inside of me forever.” A few said women
regain strength when they do take the medication, so they may stop it or become forgetful at that
time. Misperceptions around medications included beliefs that there will always be a “little bit
of virus in my baby’s blood” and the inability of the medication to prevent this; HIV passes
through food or a toothbrush; HIV is a curse; the HIV virus “hides itself in me or my kids”
despite medication; and HIV is something scary “living outside of us” that medication cannot
reach. Several women in focus groups noted that the government needs to provide more
education about HIV and PMTCT, especially to impoverished communities. They stated more
information is needed about the importance of the medication, ways to manage side effects, the
fact that people with HIV are living longer, and that children of an HIV+ mother can grow up
and be healthy. It was suggested that PLHIVs will be better teachers than health care workers in
this situation.

“Carelessness” was also noted as a problem by many women in both interviews and focus
groups, expressed in such ways as “weakness,” “being lazy,” “being selfish,” and “not taking
responsibility.” Some participants stated that enough education is available on TV, through
clinics, and through non-governmental organizations (NGOs), but that some women do not listen
to it. They said: “if these women had a mind, they should watch it.” Participants described some
women coming to educational meetings just to have fun and not to truly learn about HIV. They
said others went to a clinic to get ARVs only when NGOs were offering food aid, and then they
threw the medication away. A few participants indicated that many women think the medication
is not important since it is free. Finally, many participants said things such as “I stopped the
medication and nothing happened, so why should I take it?” One focus group participant stated that women are careless because they “just don’t expect this outcome [HIV+ infant] after birth.”

**Intra-personal level facilitators.** Having an attitude of hope emerged as an important factor to encourage compliance with PMTCT. Several women expressed finding hope in God: “There is hope. The first thing is to trust God and take the medicine.” Another woman, who had attempted suicide when first diagnosed with HIV, noted that she now lives entirely by hope since finding God. Others received hope from listening to the counsel of HCW or friends, and many grew hopeful by watching friends other PLHIV women doing well. Almost half of those interviewed said it was the power of hope that changed their attitudes about HIV, which also directly affected their behaviors. Finding hope- either from friends, other PLHIV, religious institutions, or God- caused them to begin taking their medication. Having more concern for their babies than for themselves also promoted hope for over half of the women. One participant stated: ”Because if someone has hope in life, then even if they don’t care about themselves, they will care for their children.”

Many women stated that counseling and education about the importance of HIV medication are key facilitators of adherence. Expressing sorrow over her baby’s HIV infection when she did not understand the treatment, one woman said: "If I had had understanding about HIV, I would have saved my first baby like I did the other ones. Take the medication. Now if it happened, I would do my best to save the child from having the virus." Women in interviews explained that knowledge about PMTCT, although low overall, is improving through the efforts of many individuals and organizations. Several women described learning things recently such as the possibility of taking ARVs without food and how to disclose their status in working situations. Women reported this kind of knowledge facilitated their medication use.
Over two-thirds of all interview and focus group participants said their knowledge of PMTCT came primarily from Health Care Workers (HCW), and many had advised their friends that “doctors and HCW are the first to teach.” Participants shared how PLHIV mothers are being taught about medication compliance, labor and delivery, CD4 counts, breastfeeding, family planning and wound care in HIV and ANC clinics, and their overall HIV and PMTCT knowledge is increased by these interactions. Women also reported that additional education, although not as comprehensive as that from HCW, is coming through media, NGOs and churches. TV and radio were seen as helpful for extending awareness, while education offered in churches and by NGOS were perceived as providing deeper understanding of medication compliance.

The most frequently cited and effective way of offering HIV and PMTCT education was through the use of PLHIV as educators in any environment: teaching in home visits, in clinics, or during coffee ceremonies in the kebeles. Women stated that it is necessary to have other PLHIV teaching because people often do not truly understand medical workers. These PLHIV educators can also “give hope and action and boldness” through counseling, which promotes positive attitudes as well as increased knowledge. Multiple women expressed the hope gained by having another PLHIV as a model, along with their personal desire to have others learn from them. There was a strong sense of responsibility for peer support and education among the women. Said one focus group participant: “It’s my duty to teach because people are dying and for the future of our children.”

Inter-personal level barriers. A few women said they had experienced some discrimination from family members, describing concerns with siblings saying HIV was a curse and extended family refusing to share plates and utensils. Several others stated that fear of family
Discrimination may be a reason women would stop their ARVs, but this was only noted for families living in rural areas. A husband’s failure to disclose his HIV diagnosis to his spouse, leaving the relationship out of his own shame over HIV, and refusal to admit his part in HIV transmission were noted by individual women as complications in their HIV care. There were no described instances of husbands presenting direct barriers to PMTCT, however. There was also no discussion of in-laws or friends presenting barriers to PMTCT use.

**Inter-personal level facilitators.** Although there were a few expressed concerns over their lack of support for PMTCT, Ethiopian husbands were revealed more often as being significant facilitators for PMTCT and HIV care. Multiple women said their husbands provided encouragement for medication use and offered practical help with medication compliance. Others indicated that their husbands were important providers of emotional support, and many encouraged their wife not to give up on herself or her treatment. Two different women explained that they tried to divorce their HIV-husbands when they learned their HIV status, but these husbands chose to stay in the marriage and to support their wives.

Friends and family members (inclusive of parents, siblings, and extended family members) were both reported to be important sources of support. Although a few negative experiences were described, other family reactions to HIV and PMTCT described were overwhelmingly positive. Half of the women interviewed noted a family member to be supportive and important in their lives, and many mentioned their family encouraging medication adherence. One woman said of the support offered by her family: “it was the encouragement I need. ‘I am with you.’ I need such kinds of help.” When asked to whom they first disclosed their HIV status, women interviewed disclosed to family members the most often. Women also described friends offering hope and emotional support, encouraging medication
compliance through phone calls, texts, and home visits, and assisting with practical tasks such as cleaning and cooking meals. The opinions of in-laws were not mentioned in either positive or negative manners in interviews or focus groups.

Other PLHIV peers were by far the most frequently mentioned individuals who offer support for PMTCT adherence and have the most powerful influence on participants. One woman said “we need these friends to have a better life.” Fifteen of the women interviewed (65%) discussed the importance of their PLHIV peers without prompting, stating they encourage, offer hope, offer modeling, and teach each other. Some women reported that watching others’ CD4 counts increase encourages compliance with medication, and some PLHIV mothers keep each other accountable to their medication regimens by text, phone call, or home visits. PLHIV peers also encourage each other to not give up hope. A significant number of women stated they want to be peer supporters, themselves, offering modeling and support to others out of their own experiences. One woman said: "I will tell about myself. I will be a good example and tell my story...now I am going to tell other people and I can do something great for others."

**Organizational level barriers.** When asked in an open-ended survey question what problems they had encountered with PMTCT use, a few women included difficulties with health care facilities. While mentioned infrequently, these problems included the time required to navigate a complicated medical system, poor linkages between ART clinic and ANC, inconsistency in staff nursing, and being referred to several different hospitals for care. Medication shortages, broken lab equipment, confusing advice, and difficulty in paying for a lab fee were each mentioned as isolated incidents.

A few women in focus groups described experiences with poor health care worker attitudes, but each was noted as a one-time event rather than an ongoing problem. For example,
one participant reported that a nurse told her “don’t drop your blood on me” and refused to touch the same paper as she had. Another woman was told she would not be treated for her HIV unless her husband returned for testing, making her feel ashamed and undervalued. A third stated that doctors were irresponsible in her clinic and the nurses “treated her like nothing.” Some women also described variation between clinics and providers. "There are people [HCW] who will be like brothers and sisters and there will be people who are not so nice at all also” said one woman. Another said that monetary issues play a large role in the level of care received by patients in certain clinics.

When asked in focus groups and interviews, the majority of respondents actually indicated having good interactions with health care workers. The fear of poor interactions with health care workers was likewise only listed by two women as a possible complication of future PMTCT use on the surveys. However, in interviews participants discussed a perception that HCWs seem to be growing more careless in their work overall as NGOs are closing down many of their assistance programs. For example, one woman stated: "they are not as they used to be because the number of patients are increasing. Before I was getting attention, they asked me how are things going and how I am doing. Now they just give me medication and tell me goodbye because there are a lot of people.”

Organizational level facilitators. The overwhelming majority of discussions about interactions with HCWs were positive in both interviews and focus groups. There is a high level of trust in HCW as a whole, and almost two-thirds of the participants expressed their recommendations that other women go to clinics and HCWs for advice, counseling, and overall care. Many had personally received good advice from doctors or nurses, including checking CD4 levels, breastfeeding for six months with medication, keeping up with their medicine
regimens, and delivering their babies at the hospital. Others received a high level of encouragement in the clinic setting. Clinic staff members were described as welcoming and friendly, showed high levels of compassion, and gave hope to the patients that they could live. Some workers even cried along with patients in their difficulties, and others offered practical aid to help with the patient’s needs. The names of particular staff who had displayed incredible compassion were mentioned by several participants, and each was described as a vital contributor to restoring the woman’s hope. One focus group attendee said: "All the nurses were good to me. They were just like my family. They encourage me to take the medication; they gave me hope that I can live.”

**Social/community level barriers.** Participants described stigma from neighbors more so than from any other source. One woman shared that she had been “chased down to be beaten” by her neighbors; another woman described her neighbors calling HIV “the disease that caught her.” Several participants reported hearing neighbors talking about them, and others had experienced direct discrimination with exclusion from gatherings. Neighbors also had a more negative reaction to disclosure in general than did friends. The fear of stigma by neighbors is a PMTCT barrier, mentioned a few times by women in such descriptions as “not being able to get close.” One respondent noted that many women, when deciding about their healthcare, “would rather be friends with neighbors than take the medicine.”

Almost half of the women interviewed directly referred to the practice of drinking “holy water” as a powerfully influential reason for women not adhering to HIV medication or PMTCT services. Many of these women, and others in focus groups, had either exchanged their medication for holy water themselves or referenced knowing individuals personally who had done so. Although the teaching to discontinue medication and drink holy water is not widespread
in Orthodox congregations in the city, participants reported that the idea is entrenched into Orthodox culture. After they feel pressure from neighbors, family or friends to go to certain locations where holy water is distributed, women are told by the priest there to stop their HIV medication because it is not compatible with faith. Entoto is one of the most frequently visited sites for holy water, and many women said that “everyone who goes there throws away their medication.” Another popular site is Gorgorios, located in the forest away from Addis Ababa. Women who travel there in search of healing are also told to discontinue their ARVs.

Participants stated that women are taught in these holy water sites that faith and hope are not compatible with medication, and quite a few women explained that they knew women who had perished as a result of making the choice against using medication. One woman summarized the problem by saying ”they are more on religions than medicine.” Another woman, with tears in her eyes, explained that “so many people lost their lives because of the holy water. They will throw away the medicine and go to tsebel (holy water) and they die. There are people throwing away medicines.”

Several women reported personally drinking holy water in search of a cure, but they were disappointed when healing did not take place. One woman who took the water and stopped her ARVs developed tuberculosis, at which point she started her ARVs again. She now says “the priests were trying to kill me.” Many of the women interviewed now believe that holy water is acceptable but not sufficient without medication. Said one:

They can drink the holy water. But our responsibility is, that is for their spiritual, their soul, but this is for our flesh… Let them worship whatever they want, but they should take the medicine.
In general a lack of teaching about HIV or PMTCT in religious communities was reported. Protestant churches were reported by the women to be the most active in providing education and PLHIV support programs; these take place outside of regular congregational gathering times. Only two women stated in interviews they had ever encountered general HIV education in the Orthodox church. Muslim women had also not heard teaching related to HIV in their mosques, other than encouragements of abstinence before marriage and fidelity. Stigma from religious communities was not cited as a barrier to PMTCT.

**Social/community level facilitators.** NGO programs that support PLHIV are an integral part of the fabric of Ethiopian society. They have encouraged testing, offered education, and promoted social and practical support for PLHIV; this is done through linkages in the clinics, in the kebeles, through religious organizations or on their own. Women had received material aid such as infant formula and food stocks from some NGOS, and many had also received education about HIV and PMTCT from NGO-led seminars. As many of these programs are ending, however, women note there is an ensuing gap in public education and the social support given specifically to PLHIV.

Almost half of the women indicated that they had heard messages about HIV on the TV and radio. In the beginning of the HIV epidemic, the messages were “scary messages of death;” they have shifted more recently to anti-stigma messages and how a PLHIV can live a healthy, longer life through medication compliance. Awareness is being created through these programs, although several women suggested that not all people listen to it. One woman discussing HIV teaching, said that TV should absolutely be used for “such important things” rather than mindless entertainment.
While neighbors were detrimental influences on some PLHIV mothers, they were positive sources of support that facilitated PMTCT retention for others. Many participants perceived certain communities in the city as more open to PLHIV, and women shared purposefully moving to new locations in search of broader acceptance. Others, especially those who moved from rural areas, reported finding more acceptance from neighbors in Addis Ababa than in their villages. In general, some participants discussed a belief that discrimination from neighbors decreases with time. A few women interviewed described neighbors who had encouraged them to take medicine and supported them, and one stated her neighbors were “like a mother and father.” Community gatherings and coffee ceremonies in the kebeles were frequently mentioned as the best places for PLHIV women to teach about HIV and PMTCT; this speaks to the power of the community structure in the culture. Several kebele leaders had individually encouraged individual women to be strong and linked them to the social organizations which could provide more practical aid.

For those who did not find support in the community, many found the support through religious institutions. Specifically, HIV support was reported as taking place most frequently in Protestant churches. Only one woman noting having received social assistance from an Orthodox congregation and none mention mosque-based aid. Some of the Protestant churches operate service facilities directly out of their congregation, hosting coffee ceremonies for education and helping to develop peer support structures for PLHIV; others have created NGOs linked to the church which are entirely committed to the support of PLHIV. The assistance offered by Protestant churches in the form of food, shelter, and other such material goods is very important to many of the women, some stating that it gave them the motivation to go on living. The care and support demonstrated through prayer and social welfare activities left an even bigger
impression. “They treated us like family” and “they gave us love” are representative statements of the experiences many interviewees described. One woman said of their teaching “thank God for their teaching, I wouldn’t be alive without it.” Visits by pastors and church friends for prayer were described as a source of hope for PLHIV mothers, and an individual social worker from a church program was described as the biggest support in some women’s lives. The personal influence of the pastor’s care was mentioned, as well, and the importance of a religious leader is significant. Comments made by participants confirmed that people would be likely to listen to the advice of religious leaders if they taught about HIV and PMTCT. One interview participant said: “I think if people go to church and get information on HIV, there is a chance they will listen. Because whenever a priest teaches about HIV he can teach about God’s word. These two go together and people will understand and listen.”

Aside from the influence of the religious community and individual leader, women’s perspectives on faith and their own relationship to God were noted as very significant. Two-thirds of the women in interviews and focus groups mentioned that God is important to their health in some way. Beyond simply praying for a healthy child, many mentioned that God helps them look past stigma, deal with medication side effects, and gives them hope to continue taking the medicine. Several said that God is their only support and hope and they trust His control, while one woman said she had learned to “not expect good things from people, only God.” Many feel that hope in God is vital to improving PMTCT retention. Several explained the need to “give hope that God is above all and take the medicine” to other PLHIV, and one said she was “asking God to open ears to make PMTCT better.” Another woman interviewed affirmed that persevering in completing PMTCT is possible, but only with God’s help.
Structural level barriers. The study sample included women from varied economic levels, represented by having between only one and over five individuals per room living in their home. When asked what difficulties they either had experienced or anticipated in using the PMTCT system, several women from each of these categories listed financial concerns. Many others stated monetary issues as their primary reason for not desiring more children, and not having money, shelter, food, or a job were brought up multiple times in interviews. Not having food to take with medicine was cited as a reason for non-adherence to PMTCT in the interviews, and some women explained how they previously breastfed against medical advice because they could not afford formula. Others described how they had begged on the streets to obtain formula or other daily necessities. Several women in focus groups said the government should create job opportunities for women with HIV so they did not have to beg or be dependent on others; they believe the government should provide housing, as well.

In addition to the financial burden of paying rent, shelter was reported as a need for PLHIV mothers due to the structural barrier of stigma. Participants said that neighbors and landlords are the most common perpetrators of discrimination, and several women had been kicked out of rental units when their HIV status was disclosed. Outside of this community level, only a few women referred to experiencing stigma from family, members of religious communities, or health care workers. A small number listed “not wanting others to know” as a past or potential problem with PMTCT use, and one suggested that the government should impose stronger anti-discrimination laws.

Structural level facilitators. Women reported that some government sanctions against stigma are already in place and are making a difference. For example, a neighbor who made a discriminatory statement against one participant’s HIV+ child was put in jail for two weeks.
This, along with a generally increasing awareness of HIV from media messages and educational campaigns, gives women hope that HIV stigma is declining in general across Ethiopia. “It is not like it was before, it is easier to tell people now,” said one woman in an interview. She, like many others, tries to encourage more women to be open with their HIV status in order to continue to reduce stigma. The perception is that the more people hear about and come in contact with PLHIV who are living normal, healthy lives, the less discrimination will take place.

Improvements to poverty and its inherent difficulties have not been widespread, as noted by the expressed need of participants for housing and food subsidies. However, efforts by churches and NGOs are making a difference family by family. The material, practical support offered to PLHIV by several local churches is inclusive of such benefits as food, infant formula, children’s clothes, medication, and occasionally housing; quite a few women described this support as a lifeline and the motivation they needed to believe they could go on living.

**Discussion**

The eMTCT plan for Ethiopia for 2013-2015 (MOH, 2013b) focuses interventions at multiple SEM levels. It is vital to not only recognize the connectivity of these levels but to better understand which are the most relevant in contributing to PMTCT attrition or adherence. In order to address this need, this mixed-methods study analyzed beliefs, attitudes, socio-cultural factors and key influences among HIV+ women in Addis Ababa. Results suggest the strongest barriers to PMTCT use were found at the intrapersonal and community levels, while the strongest facilitators were at the interpersonal and community levels.
Barriers

Most PMTCT interventions have been aimed at the intra-personal level in Ethiopia. The lack of understanding and hopelessness seen in this level are critical to address. Current educational campaigns have succeeded in promoting a high level of awareness of HIV and MTCT. Consistent with previous studies among Addis Ababa ANC attendees (Deressa et al., 2010; Merdekios & Adedimije, 2011), however, our findings suggest this knowledge is not comprehensive. All three vertical HIV transmission risk periods were not well recognized, nor were the correct interventions. However, there was no association in the levels of understanding with a woman’s overall educational level, marital status, income or religion, which indicates that broad educational efforts are still needed.

In contrast to other African studies (Busza et al., 2012), understanding of the severity of infant HIV and levels of perceived susceptibility are high in this population. Self-efficacy and ability to take the medication were also ranked highly. The failure to understand the benefit of treatment, however, is a substantial problem. Failure to understand of the value of taking a chronic maintenance medication may be a demotivating factor that promotes the problem of hopelessness so frequently mentioned. It is also associated with carelessness, which was of significant concern in this qualitative study and may correlate with what was described in the eMTCT study as “low health seeking behavior” (MOH, 2013b). It is interesting that those who did not adhere to PMTCT overestimated the likelihood of infant infection while taking treatment when compared to PMTCT adherents. Although the difference was not statistically significant, the possibility that these women left PMTCT in part because they do not see its value should be further explored.
It is significant to note that women who were able to focus on the value of PMTCT treatment for truly helping their infant gained hope and stated dedication to doing whatever was necessary to care for their child. If women are not initially motivated to adhere to ART for their own care, a stronger message about the benefit of medication to their children may motivate them to begin in PMTCT (and perhaps stay on ART thereafter for their own care). Subjective norms have also been shown to be strong predictors of intention for other areas of HIV care (Gebreeyesus, Boer & Kuiper, 2007; Mirkuzie, Sisay, Moland, & Astrom, 2011): increasing the perception that many PLHIV mothers adhere to medication for their babies may be beneficial.

The lack of discussion about fear of disclosure to partners or negative male influence in the study was notable and surprising, considering the attention given to this problem by the eMTCT study and others (MOH, 2013b). The opinions of husbands ranked of lower importance than that of family and friends overall, and comments about husbands presenting obstacles to PMTCT were rare. Although lack of partner disclosure has been documented as a problem in other PMTCT locations (Ferguson et al., 2012), women in our study disclosed to their husbands as often as they did to family and friends and almost all interactions were positive. A previous study in Addis Ababa showed 78% of women disclosing to their partners, the majority of whom had positive reactions (Sendo, Cheri & Asfaw, 2010). Thus, there may be a need to differentiate interventions focused on partner disclosure according to urban or rural locations.

Religious and spiritual beliefs have also been documented as PMTCT barriers elsewhere (Busza et al, 2012). The belief in drinking holy water for healing in lieu of medication is problematic. Although this behavior may not be officially taught or condoned in Orthodox churches, it appears from the women’s perspectives to be deeply entrenched in the culture and
widely accepted and practiced. Significant educational effort is still needed to combat this practice, and the inclusion of Orthodox priests in these effects is vital.

Although of less importance, stigma and financial concerns were also common in this population, as in other African PMTCT studies (Otieno et al., 2010; Duff et al., 2010). Stigma at the community level and housing discrimination must be stopped: the national laws which ensure equitable access to treatment and support for PLHIV in housing and human rights (Ethiopian Federal HIV/AIDS Control and Prevention Office, 2009) must be better enforced. The provision of food, housing, and other material aid is vital for these women; new methods for providing economic empowerment for PLHIV are needed. However, an important lesson gleaned from interviews is that giving food in conjunction with HIV medication actually seems to detract from the importance of the medicine. Separation of material aid from medication in future endeavors would be wise.

Facilitators

The most powerful influences presented which facilitate PMTCT adherence were at the interpersonal and community levels. Women expressed their greatest help to be another individual coming alongside them for support, and the impact of PLHIV peers must not be overlooked. Not only are they valuable educators, but PLHIV peers can offer the support that is critical in overcoming hopelessness, lack of motivation, and the other obstacles that may come into an individual woman’s life. Women need to see models of peers who remind them that they can live normally, and the power of the hope this offers can directly affect their behaviors. Previously run PLHIV “mentor mother” support groups have been incredibly successful, documenting up to 95% HIV – delivery rates (MOH, 2013). Similar programs have run through
several NGOs, but their continuation is sporadic and uncertain. Consideration should be given to making them more widespread.

The eMTCT plan stresses the use of the Health Development Army (HDA) in PMTCT care (MOH, 2013b). This program assigns “one to five” networks in communities, with HDA members responsible for encouraging and facilitating many healthcare needs of the five family units assigned to their oversight (MOH, 2013b). Considering the large mandate the HDA has for many health concerns, however, the expectation that they can provide the critical mentoring support needed for PLHIV mothers may be unrealistic. PLHIV may be more effective additions to the health care workforce for PMTCT: they can provide the same linkages to HCW, provide one on one support, and even provide default tracing that is impractical with the time constraints of either HCW or HDA members. An initial investment in training more PLHIV women as mentors is likely to produce significant returns in the future, and they are readily available. A great number of the women in this study expressed their personal desire to participate in PLHIV care, and many have volunteered already.

Male engagement is being targeted as a key intervention in the future in the eMTCT plan. Although in other research, women were five times more likely to engage PMTCT with male support (Sendo, Cherie & Asfew, 2013), this was not mentioned a single time in this study as a way to improve the PMTCT system. The promotion of male engagement should not be abandoned, but perhaps its potential impact should be reconsidered in light of other factors. Although PMTCT adherence did not vary according to marital status in this study, the opinions of friends and family members were more valuable among PMTCT adherents than non-adherents. While these associations require further exploration, targeting family members and
friends for engagement and support, along with male partners, may be more beneficial than focusing on this population alone.

The eMTCT plan places considerable emphasis on the health facility concerns connected to low PMTCT utilization, including increasing availability of PMTCT services, improving linkages and referral systems, and strengthening the quality and attitudes of the HEW and HCW force. Weaknesses in these areas are documented reasons for attrition rate in other studies (Merdekios & Adedimije, 2011; Ferguson et al., 2012; Otieno et al., 2010; Atwiine et al., 2013); this study did not have the same findings. By and large, participants had positive and educational interactions with trusted HCW and are satisfied with the care they receive at ANC and PMTCT facilities. This should be an encouragement to the health care community.

The fact that maternal health can be positively affected by religious leaders is supported by the eMTCT agenda and previous studies (MOH, 2013b; MOH, 2013c). This study suggests the influence of these leaders may be worthy of even more attention, as it was considered greater than that of family, husbands, and in-laws. Educational campaigns need to harness the influence of these leaders to encourage PMTCT adherence and the issue of holy water and attrition also must be addressed.

The hope offered by religious communities is a vital facilitator for PMTCT adherence, similar of that offered by PLHIV peers. Some churches are doing excellent job engaging with HIV care and education, and their support is a “lifeline to go on living” for many PLHIV mothers. The practical support which may be offered is beneficial to the population; the social support is more vital. These communities should be targeted as key locations for education to increase demand for services and to promote retention through social support. Additionally,
neither the number of children born infected with HIV nor adherence to PMTCT varied by religion in this study, all major religious groups should be considered as targets for this support.

Limitations

Perceived power barriers between the research team and the participants, particularly in translated interviews, may have limited the transparency of participants. The use of a local research assistant and the trust between PLHIV staff members and participants sought to minimize this limitation. Locating the research at the program offices rather than in the communities also minimized most confidentiality concerns. While unidentified personal research bias on the part of the PI during research design, data collection, or data analysis is possible, and cultural barriers and misunderstandings are possible limitations of any international study (Yoder, 1997), the involvement of a multi-national research team, the use of multiple measures, triangulation of these results and reporting back to participants ensured the plausibility of the findings. The quantitative study would have been strengthened by the increased power of a larger sample size, but constraints of time and resources did not allow for this. Finally, it is recognized that this study addresses attrition from PMTCT for women in Addis Ababa, which is only one prong of a multi-faceted problem. It is not intended to address the other factors such as primary HIV prevention and family planning which affect the MTCT rate in Ethiopia. The results should not be generalized to the rural population of Ethiopia or to other locations, although they may inform future research efforts.
Conclusion

Reducing the MTCT to less than 5% in Ethiopia in 2015 will require concentrated and well-informed efforts, and there is a need to capitalize on the high self-efficacy of PLHIV mothers noted in this study with motivation, understanding, and support for PMTCT adherence. Basing recommendations on the perspectives of PLHIV mothers on PMTCT use offered in this study, future interventions should focus on three areas: 1) targeting educational efforts to the lack of understanding about chronic medication use, hopelessness, and the perceived incompatibility of holy water and ARV use; 2) investing in significant expansion of training and engaging PLHIV peers at every level of care and as active members of the health care workforce; and 3) using religious leaders and communities as vital conduits of education and support that offer hope to PLHIV mothers. Targeting interventions to these expressed needs of the PLHIV population will help to promote the highest retention in care.

References


SECTION III
MANUSCRIPT 2

Reducing PMTCT Attrition- the Advice of HIV+ Women in Addis Ababa
Target Journal- Qualitative Health Research
Secondary Journal– BMC Public Health or Social Science in Medicine

Background

Although HIV infections among children globally have declined by 52% in the last decade (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2013), 330,000 children were newly infected with HIV in 2012 (UNAIDS, 2012). Mother to Child Transmission (MTCT) accounted for 90% of these infections, despite the fact that highly effective prophylactic medication for Prevention of Mother to Child Transmission of HIV (PMTCT) is available (UNAIDS, 2012a). MTCT risk is less than 2% (Lallemant et al., 2004) if a mother fully adheres to the “PMTCT Cascade,” a process that involves maternal HIV testing and counseling, accessing medications at the time of diagnosis, adhering to medication usage through the completion of breastfeeding, following nutritional and delivery advice, and testing the infant for HIV (World Health Organization [WHO], UNAIDS, & United Nations Children Fund [UNICEF], 2011). Although each individual step may be straightforward, trying to successfully navigate all the steps in the PMTCT continuum can seem complex and overwhelming to an HIV-
infected mother. As a result, only 62% of women were estimated to have achieved successful completion of the entire PMTCT cascade globally in 2012 (UNAIDS, 2013).

Failure to follow this complex system through to completion (attrition) is a documented challenge in Ethiopia, where an estimated 9,500 infants acquired HIV in 2012 (UNAIDS, 2013). Only 41% of HIV + pregnant women/children pairs received the most efficacious regimens of anti-retrovirals (ARVs) required for PMTCT in 2012 (UNAIDS, 2013), and only 10% followed through to early infant diagnosis. Ethiopia’s 2012 MTCT rate was 20% (Ethiopia Federal Ministry of Health [MOH], 2013a), and the government has recognized the critical need for a significant improvement in PMTCT uptake and adherence. Reducing the MTCT rate to less than 5% and the number of new childhood HIV infections by 90% by 2015 (MOH, 2013b) are stated goals under the national “Elimination of MTCT” (eMTCT) 2013-2015 plan. The plan also highlights a target to have 85% of mother-child pairs on ARVs by 2015 (MOH, 2013b).

The focus of the Ethiopian government thus far has been primarily in increasing the availability of services, and the number of facilities offering PMTCT services has increased rapidly over the last few years (MOH, 2013a). HIV testing among pregnant women has also risen significantly in recent years (Ethiopian Central Statistical Agency [CSA], 2012; Nigatu & Woldegebriel). The number of those identified as HIV+ eligible for ARVs has expanded dramatically since the roll out of the simplified “Option B+” regimen in 2013. Despite these gains, efforts to improve the MTCT rate have been relatively ineffective (UNAIDS, 2012b), and attrition from PMTCT must be addressed (Krebs, 2012). Many factors can positively or negatively influence a woman’s ability to follow the PMTCT system through to completion, including systemic issues, social, cultural, and religious norms, peer and family relationships, and personal knowledge and beliefs. Those unique socio-contextual factors, which most
powerfully affect HIV+ Ethiopian women, must be considered if PMTCT interventions targeting high attrition rates are to be made culturally and socially acceptable (Leshabari, Koniz-Booher, Åstrøm, de Paoli & Moland, 2006).

Recognition of the value of obtaining the insight of PLHIV (people living with HIV) is increasing across all spheres of the global HIV epidemic, and their advice is being widely sought in program development (Anderson et al., 2012; WHO, 2011a; UNAIDS, 2012c). PLHIV mothers can help to identify the critical factors which may be either beneficial or detrimental to their adherence to PMTCT, and their advice about how to increase maternal adherence to PMTCT can offer insight (Karim et al., 2011). In Addis Ababa alone, 70,000 pregnant women were eligible for PMTCT in 2012 (CSA, 2012), providing access to a wealth of opinions and experiences from which to learn.

However, most attrition research in Ethiopia has been completed with mothers at antenatal centers, exclusive of the large number of women who fail to access medical care during pregnancy. Insight from women who were lost to follow up in the PMTCT system in Ethiopia has also been notably under assessed (Krebs, 2012). While researchers have suggested a need for formative qualitative research to understand the low uptake of PMTCT services and high attrition rates (UNAIDS, 2012a; Torpey et al., 2010), much of the research to date has been quantitative in nature. To fill these gaps and inform the development of innovative program designs aimed at addressing PMTCT attrition, an exploratory mixed methods study with PLHIV mothers in the community was implemented. The overall parent study focused on gaining a generalized understanding of the beliefs, attitudes, and socio-cultural factors which affect PLHIV women during their pregnancies. The qualitative elements reported in this paper explore the
primary influences that result in PMTCT attrition and explore, through the lived experiences of
PLHIV+ women, how best to overcome these factors.

Methods

In order to explore and fully identity the reasons for the high rate of attrition from
PMTCT in Addis Ababa, an inductive, mixed methods study was conducted. Qualitative
methods included in-depth interviews, which allowed for broad elicitation of issues affecting
PMTCT adherence, and focus groups, which facilitated the exchange of ideas between PLHIV
mothers. A quantitative survey provided additional information, and all methods were
triangulated in data analysis. This paper addresses the methods and results only from the
qualitative research. Approval and oversight for this project was granted by the University of
South Florida’s IRB, the Ethics Review Board of Addis Ababa University, and the Federal
Ministry of Health of Ethiopia. The research project took place over a two-month period in
Addis Ababa, Ethiopia.

Participants and Sampling

A variation of women representative of the demographics of the female PLHIV
population in Addis Ababa was recruited for the study using mixed purposeful sampling (Patton,
2002). Staff from two local PLHIV support programs identified women of varying ages,
ethnicities, religions, educational and economic levels, and communities to recruit. PLHIV
women who had a child at least one year of age at the time of the study were eligible and
mothers of both children infected with HIV and those with healthy children were chosen.
Women who were aware of having HIV during their pregnancy and those who did not know they
were infected were each sampled, and PLHIV mothers who were not involved in a support program were also identified to participate. These variations in sampling were chosen in order to minimize bias.

**Research Procedures**

Interview and focus group guides were developed by the PI in consultation with Ethiopian colleagues. These study tools were translated into Amharic by two native speakers, then back translated by two other native speakers to ensure accuracy. The tools were pilot tested with five women in the population of interest and revised as necessary before data collection began.

**Data Collection and Analysis**

Informed consent was gained from all study participants before data collection took place. A trained research assistant conducted four focus groups in the local language of Amharic, and each group was digitally recorded. The PI observed and debriefed each session with the research assistant. Two focus groups included mothers of HIV+ children, and two groups included mothers whose children are not infected. A total of 27 women participated in the focus groups, each of which consisted of six to eight participants.

In-depth interviews were conducted in English by the PI; the research assistant translated to Amharic during the sessions. Interviews took place at PLHIV program office and lasted between 45 minutes and one hour and half each. In total, 23 interviews were completed before the point of theoretical saturation was reached.
Inductive analysis of qualitative data using the constant comparative method was performed concurrently with ongoing data collection. Audio tapes of all sessions were translated and transcribed verbatim and uploaded into NVivo software (Hoover & Koerber, 2011). Structural coding of the transcripts was first done according to questions asked of the participants. Key themes which emerged as transcripts were reviewed were then written into a codebook before additional levels of coding were completed. Reflexive sessions were held with PLHIV participants to check the accuracy of findings (Krefting, 1991), and the research assistant periodically checked the analysis for agreement with local culture and customs. Four transcripts were re-coded to check accuracy once analysis was complete, and a data audit trail was maintained throughout the process.

Results

The results presented in this paper reflect the advice offered by participants for improving PMTCT retention and the barriers to PMTCT adherence that they find to be most significant. Fifty women in total participated in the qualitative element of the study: twenty-seven took part in focus groups and 23 participated in in-depth interviews. No significant differences in demographic characteristics were reported between groups. The average age of participants was 32.5 years old. Ethnicity was divided among Amhara (78%), Oromo (16%), and other (6%) groups. The religion of participants was mixed between Orthodox (46%), Protestant (46%), and Muslim (16%). Less than half of the women (42%) were married, with the remainder divorced, widowed, or otherwise single. Half of the women (50%) had no education; 20% had basic (1-5 years) education; 22% had secondary (7-9 years) education; and 8% had over 10 years of schooling. Women with higher levels of income (defined as having 1-2 people living
per room in the home) made up 36% of the sample; 50% had mid-level income (3-4 people per room); 14% had lower level income (5 or more people per room). Approximately one third of the women (34%) had children infected with HIV. Complete demographics of participants are shown in Table 1.

Table 1.

Demographics of participants

<table>
<thead>
<tr>
<th></th>
<th>Interviews N=23</th>
<th>Focus groups N=27</th>
<th>Total N=50</th>
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<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Under 30</td>
<td>26.1</td>
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<tr>
<td>30-40</td>
<td>60.9</td>
<td>55.6</td>
<td>58</td>
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<tr>
<td>Over 40</td>
<td>13.0</td>
<td>7.4</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Orthodox</td>
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<td>55.6</td>
<td>46</td>
</tr>
<tr>
<td>Protestant</td>
<td>52.2</td>
<td>40.7</td>
<td>46</td>
</tr>
<tr>
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<td>13.0</td>
<td>3.7</td>
<td>16</td>
</tr>
<tr>
<td><strong>Education</strong></td>
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<td></td>
<td></td>
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<tr>
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<td>63.0</td>
<td>50</td>
</tr>
<tr>
<td>Basic (1-5)</td>
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<td>7.4</td>
<td>20</td>
</tr>
<tr>
<td>Secondary (6-9)</td>
<td>21.7</td>
<td>22.2</td>
<td>22</td>
</tr>
<tr>
<td>Advanced(10+)</td>
<td>.09</td>
<td>7.4</td>
<td>8</td>
</tr>
<tr>
<td><strong>Income</strong></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Low</td>
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<td>11.1</td>
<td>14</td>
</tr>
<tr>
<td>medium</td>
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<td>51.9</td>
<td>50</td>
</tr>
<tr>
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<td>37.0</td>
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<td>66.7</td>
<td>58</td>
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<tr>
<td><strong>Ethnicity</strong></td>
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<tr>
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</tr>
<tr>
<td>+</td>
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<td>48.1</td>
<td>34</td>
</tr>
<tr>
<td>-</td>
<td>73.9</td>
<td>51.9</td>
<td>66</td>
</tr>
</tbody>
</table>
Barriers to PMTCT adherence

Women in the study were asked to share their views about existing or potential barriers or facilitators to PMTCT adherence, either from their own experiences or from that of other PLHIV women with whom they interact. A comprehensive list of these influences was generated from their responses and is reported as part of the parent study (Fleek et al, in process). In order to inform the advice given by participants for improving PMTCT adherence, only those barriers which were most frequently reported and generated the most discussion are addressed in this paper.

Hopelessness. Hopelessness was the most frequently mentioned barrier to PMTCT adherence among women in the study: it was cited by 22 different women. Hopelessness was expressed as directly giving up hope and was reported as women shared stories of their “despair” and thoughts of “giving up.” Some women even expressed “I desire not to live.” This theme was directly linked to the concept that HIV is a death sentence for all who contract it. Although this perception is changing slowly, it was reported to still be fairly widespread and to affect adherence to PMTCT. For example, one woman stated, “the biggest thing is being hopeless. They have doubt about being able to recover from the disease.” Another shared, “It’s because they give up hope they don’t think they can live like people and make it.” While many women shared stories of others, some women reported personally experiencing this hopelessness. One woman explained her feelings the first year after her HIV diagnosis by saying: “I lost my hope and I did not consider that I can live. I even lost my hope about my kid, also, and did not consider that I can live.” Actual suicidal attempts were reported by four participants at the time of their HIV diagnosis. Feelings of hopelessness also extended to a fear of death for the women’s
children. One participant explained that an HIV+ neighbor threw out her child’s ARV medication because “She has a mind that the baby is going to die, is not going to survive.”

**Concern about medication.** Concern over the use of ARV medication was reported as a barrier of equal importance to that of hopelessness. Participants reported that women frequently tire of taking a chronic medication, and they often doubt its efficacy since it is not completely curative. One woman explained the loss to follow up in PMTCT by saying “Another reason they are not taking the medicine is it is too much. They are exhausted with it.” Another stated that “They think the medicine will not help them from the virus so they became hopeless and they would rather die than living.” A third woman explained that “People are stopping the medicine because one, they give up on the medicine....they say, ‘since we are dying, why do we take this medicine? For how long will we take it? It is not going to cure us, so why are we taking it forever?’” One woman admitted that she frequently misses her own medication doses and stated:

> I will tell you for myself. I was also hopeless one time. I still think sometimes the medicine is not appropriate, it is from the devil. I sometimes skip the medicine because of the hopelessness and I am an example of why people are not taking their medicine. A big thing is the medication does not cure.

Several participants explained that ARVs are frequently thrown in the trash by pregnant women because “they doubt that the medication will work for them or either for the baby or the mother.”

Participants also expressed that many women have concerns about side effects of ARVs and how they must be taken. One woman succinctly stated, “People are just misinformed about the medication.” Other women reported a widespread teaching that ARVs must be taken with food and how this hinders the compliance of those who live with food insecurity. Some women
believe that taking the medicine without food would simply be ineffective, while others expressed concerns over side effects being enhanced without food. One participant said:

People are not taking the medication because of balanced diet. The medication has burning characteristics in our body. In order to avoid that burn we need to eat good food. Most people don’t have foods in their house, but so they will avoid taking the medication.

Another woman explained that:

People are giving up on their medication, because they just give up. They say it’s too much. It causes irritation and heartburn, and needs to have foods with it. As you know people are poor they don’t have foods to eat, so if they don’t have anything to eat, they also stop taking the medication.

Even without food insecurity, fear of the potential side effects of taking the medication was commonly expressed. One woman said:

I am thinking ‘for how long will I take this medicine?’ I know that I will take it forever. But I am thinking whenever I take the medicine, it will go inside me and stay there. So ‘how long, how long, how long?’ It makes me worried to take the medicine the rest of my life.

Other concerns. Other important barriers to PMTCT, which emerged less frequently in discussions, included carelessness, a fear of stigma, the use of holy water, and poverty. Several women stated that the HIV education available on TV, through clinics, and through non-governmental-organizations (NGOs) in the communities is sufficient for PMTCT, but that
carelessness is causing many PLHIV women not to listen to it. One woman expressed her viewpoint by saying “people are passing the virus to kids because they are careless of listening to the media and doctors.” Another explained, “The teachers are there, but the listeners aren’t.” Another woman explained that women practice carelessness when they “go against medical advice.” One woman stated:

They get pregnant and only go to clinic to deliver the baby. Just carelessness, they only go to clinic to deliver the baby and the go home. They are just careless, even [if they would] tell the provider they are HIV+ and then they would be protected but they don’t tell them. This is carelessness.

Several other participants explained that pregnant women are careless when they are “lazy,” don’t take responsibility for taking care of themselves, or are “selfish” when they do not act responsibly in the care of their children.

Stigma in communities was frequently mentioned as a possible barrier to PMTCT use. Several women reported having been forced by landlords to leave rented homes when their diagnosis was discovered, and others explained that neighbors often gossip about them. A few participants also expressed that a fear of discrimination from family members may hinder women from taking ARVs. Overall, however, several women reported that the level of HIV stigma has been decreasing in the last few years.

Almost half of the women interviewed directly referred to the practice of taking “holy water” for healing as a common reason that women do not adhere to HIV medication or PMTCT services. They reported that many women are encouraged by Orthodox neighbors and religious communities to discontinue their ARVS when they drink holy water as a sign of faith. One
woman explained: “If they need the healing, they have to leave the medication behind. When people are going to get the holy water they have to leave the medication. They are not allowed to take it.” Although they reported that the necessity of discontinuing medicine is not officially taught by Orthodox priests, many participants either had done so personally at one time or knew others who had. Several women described having seen women die as a result of this practice.

Several participants expressed that stark poverty is a significant limitation to PMTCT adherence. Not only does food insecurity hinder the ability of women to take ARVs, but several women reported having been forced to beg at times for food. Some women expressed concerns over difficulty finding shelter, while others stated that having to work long hours for others hindered their ability to follow through with medical care. Some women noted a search for employment took away the time they could use for medical care, while others noted that being impoverished limited the strength they had to care for their children well.

**Advice to Improve PMTCT**

As participants were asked about barriers to adherence to PMTCT, they were also asked their thoughts about what could be done to increase PMTCT retention. Through sharing opinions and advice that developed out of their own experiences, participants expressed the need for enhanced education and the implementation of government level interventions. Further, they stressed the importance of including PLHIV in all efforts to enhance knowledge of HIV and adherence to protocols.

**Enhancing education.** Enhancing educational efforts was reported as vital to increasing adherence to PMTCT protocols. Many participants stressed the importance of offering counseling and education to PLHIV mothers. One woman expressed that “without knowledge
and education, no one will take HIV medication.” Women stated that much more information is needed about the importance of taking ARVs and how to manage medication side effects if they occur. One participant addressed this by saying:

At the clinic, the clinic workers should tell the patients to understand the medicine. To go deeply, to understand the medicine deeply. If you tell the person the importance of the medicine, they will take it, but the most important thing is for them to understand, the teaching.

Women shared their own personal stories of how education had changed their own thoughts and behaviors in regards to stigma and taking medication adherence. For example, one described her experience by saying:

My view is at the beginning that HIV passes through eating somebody’s food and I was so afraid and I was disappointed and so I was afraid of going to the people or telling people about this stuff. But at the end from the TV I learned a lot and taking the medicine is important even if I am at work. So I do this, take the medication during work when it is time to take it.

Several women also noted a need to focus on the children, ensuring that women understand that children of an HIV+ mother can truly grow up and live healthy lives.

Women suggested that effective education could come through several different avenues, in addition to the teaching offered by health care workers in clinical settings. One possible method of education, which was controversial among participants, was that of media. Two women said that media is the next best vehicle for education after listening to medical providers.
A few women said that TV and radio programs are helpful for generating overall awareness of HIV and PMTCT, and some participants said that listening to these programs may be helpful in encouraging adherence as well. Several said that TV should absolutely be used for “such important things” as teaching about HIV and PMTCT, rather than just as “mindless entertainment.” Yet, other participants argued that education through media is already available but is not sufficient. Some said that many women do not listen to the media messages, and another said that education from the media is not taken seriously.

Several women from each of the three faiths suggested that it would be helpful to have more HIV education in their religious communities, particularly if taught by a leader. One explained that if a religious leader would teach about PMTCT, the people would be likely to “open their ears and listen.” Some women expressed personally having found it helpful to attend the HIV educational gatherings that are held in a few large Protestant churches in the city. They reported that the education is not being brought before the larger congregations, however, and none of the Muslim or Orthodox participants had experience with HIV education within their religious communities. “It’s good if a pastor talks about HIV,” said one Protestant participant. A Muslim participant stated that having any sort of HIV education in the mosque would be helpful, and several Orthodox women expressed the need for teaching explicitly about ARVs and holy water. One interview participant summarized her advice by saying “I would just tell them to accept it [PMTCT] according to each faith. Every single religious institution should educate the people.”

Many participants expressed the view that PLHIV individuals would receive the most attention and be the most effective educators in any situation. They suggested having PLHIV educators teach in religious institutions, clinics or hospitals, community coffee ceremonies or
during home visits. One woman suggested that PLHIV women should teach on the radio, and
another said that PLHIV women should teach on the streets in order to reach larger audiences.

**Implementation of government sponsored interventions.** Women in focus groups
were asked specifically what they wanted to tell the government about how to better control the
transmission of HIV to children. Several women expressed their belief that it is ultimately the
government’s responsibility to provide more widely distributed education about HIV and
PMTCT, especially to impoverished communities. Stronger legal action against discrimination
was mentioned by several, and one said that they should be responsible for educating the public
that PLHIV are equal members of society. Assistance in overcoming poverty was requested by
several participants: they suggested that the government create job opportunities for women with
HIV, offer food subsidies, and provide them with housing. While a few women made the
optimistic suggestion of “finding a vaccine and distributing it nationwide,” others simply
requested stronger support and encouragement for medical adherence. Many who asked for this
support and increased education explicitly suggested that it should come through PLHIV
counselors.

**PLHIV peers.** The recommendation to involve PLHIV in PMTCT interventions was
given by 24 different participants; this was over twice the number of times that any other idea
was suggested. Expressing the common thought that PLHIV should be more effectively utilized,
one woman advised that: “The government should assign trainer mothers who are living with
HIV already.” It was suggested that PLHIV women can function well as peer models and
volunteer social workers, and they can also function as links to community and religious
engagement in HIV care. Their role in education was also described by several participants as
vital.
Many of the women attested to having personally benefitted from interactions with other PLHIV women, stating their peers had encouraged them, offered them hope, set good examples, and taught each other well. When asked who supported her during her pregnancy, one woman said, “I have a friend also diagnosed with HIV who is the one who encourages me to go to clinic and take care of myself. She is the one.” Several said PLHIV peers are those who provide the critical emotional support needed to cope with the challenges of chronic medication use. Three participants stated that they had given up hope in taking their medicine in the past, but a PLHIV peer had actually helped them to change their minds and start taking the medicine again. Explained one woman, “During this pregnancy, I had almost given up on medicine and almost stopped. But my friend says “see I am taking the medicine, why will you stop? Please keep taking the medicine!” That is what she always tells me.” Others expressed that PLHIV peers are helpful in the practical challenges of taking ARVS, as well: a few said that a PLHIV peer keeps them accountable to taking their medication each day by calling, texting a reminder, or visiting their home. Several women reported being encouraged to take their ARVs when they see the health of PLHIV peers improve through strict medication adherence.

**Offering advice and hope.** Although they were not explicitly asked what practical advice they would to PLHIV pregnant women, many participants wanted to offer their suggestions. Most frequently, this advice involved seeking medical care, following the advice of health care workers, and adhering to medical therapy. Many women expressed that they had personally benefitted greatly from clinical care, so they wanted to encourage their peers to “listen to the doctor,” “do what the doctor says,” and “get checked.” Over half of the participants wanted to advise others about the importance of ARVs and that taking the medicine how it is prescribed is vital. Other practical advice they wanted to share included including to be careful about
transmitting HIV to others through blood, to breastfeed per current medical advice, and to “eat what they can find” in order to stay healthy and keep taking their medication.

Several women addressed issues of faith as part of the advice they would offer to their peers. One woman stated, “Those who take medicine are those who have faith and hope,” and that she would encourage any woman that she could to “do what is necessary to be healthy with God’s help.” Six different women expressed a desire to tell PLHIV peers about the importance of concepts such as “putting God first,” and “having hope that God is above all.” One participant wanted to advise women that they can take holy water, but that they must also be responsible for their children by taking ARVs. Another expressed a similar idea when she stated her advice to PLHIV peers:

I think God gave us [a] way out of perishing and we should use it. Faith has nothing to do with taking medicine or not, [you] need to be educated about importance of medication. Since [you] have faith [you] should take both medicine and holy water.
That's why people die.

Several participants also stated they want to tell PLHIV mothers not to be afraid of the opinions of other people. Three women expressly stated they want to tell their peers to “be open” about their HIV status, and one said she would tell her peers they should not “reject or deny their part.” Another woman said, “We need to be open and be friends. This will create more awareness.”

Many participants want to remind women that they are not alone and that they can overcome hopelessness by watching PLHIV peers taking their ARVs. One woman expressed the value of seeing healthy PLHIV peers after her own HIV diagnosis by saying: “I felt so bad, I
became hopeless. I was so worried about having a healthy baby, and I became hopeless because I heard about the HIV and thought we were going to die. I didn’t know. But after I found out there are people living, I became much more hopeful.” Several women reported that regularly try to offer necessary hope to their peers through being an example to them of how PLHIV can live well and have children who are growing up healthy. One stated, “When I see a woman who is hopeless, I go and tell them my story. I will tell people.” Another participant wanted to remind PLHIV women to have hope and to “get ready because the solution [for HIV] is on the way.” One stated that her desire for the future is to tell all PLHIV women:

There is hope. People can live with HIV if they take medication appropriately. The first thing we should do is trust in God and then to take the medication. The medicine does not hurt at all. To take the medicine as ordered and to have hope. Tell the people there is hope always.

**PLHIV volunteers.** In addition to offering advice and hope through personal interactions, participants expressed that PLHIV women can also be helpful in official capacities as clinic workers, educators, and counselors. One participant recommended that PLHIV women should be hired in every clinic to track all PLHIV pregnant women through their pregnancies. Others agreed that PLHIV women should be prioritized to be hired as part of the healthcare workforce. Several women noted that PLHIV should be regularly utilized in some capacity through any community-based programs that are ongoing or develop in the future.

The majority of women who expressed a need for increased PMTCT education agreed that PLHIV women would be the best teachers in any context and preferable to community leaders, religious leaders, or NGO workers. They explained the importance of using PLHIV
educators by noting how they can add elements of personal modeling and peer encouragement to education. One woman stated, “Someone who lives with the virus should teach, because that person can be a good example to others.” “If a patient tells them about it, people would be more willing to learn about it,” said another participant. Another stated that “[an educator] should be a person with HIV to be a good counselor also.” Many said that PLHIV should teach in both antenatal and general health care clinics, explaining that peer educators are capable of offering more clearly understood education than health care workers. Some women suggested sending PLHIV educators to religious communities to hold classes, while many suggested using PLHIV educators in communities to teach classes or hold coffee ceremonies.

Holding coffee ceremonies in communities or in individual homes is a very common Ethiopian custom, the women explained, and they are occasions in which “you can invite everyone and raise awareness.” One woman explained how she thought PMTCT education could be received well by saying: “the best method is to create a small group in church, or community, and have a coffee ceremony. Talk about interesting things and then talk about the virus.” Another explained that:

TV and radio are ok, but it [education] is better in the community. Like a coffee talk. We go door to door in a culture, and ask people for coffee. If we live here, we make coffee and ask people to come. We do not tell them it is for HIV, just coffee, then we talk.

Several participants suggested that those who gather for coffee ceremonies would take educational messages from that experience more seriously than they will from media messages, and a few referenced having personally learned a lot from attending coffee ceremonies offered by NGO programs. Two women stated that they are actively engaged in organizing coffee
ceremonies in their own communities for the purpose of teaching about HIV and that the gatherings are always very beneficial to those who attend.

Some women suggested that coffee ceremonies should take place as small gatherings in individual homes, in which case participation is encouraged and confidentiality is assured. They said that small groups of PLHIV gathering in this way can receive personal support as well as in-depth teaching. One participant suggested these meetings also provide a good chance to occasionally bring in an “expert in the field” for more extensive education. Other women affirmed the value of having larger coffee ceremony sessions in the communities, even extending invitations to individuals who are not HIV+. Four women stated their beliefs that offering this kind of gathering for teaching is a helpful way to create awareness, for “if the community knows they can help each other.” Another woman stated that community coffee ceremonies are very valuable for gathering interest, saying "Most [women] will come out for coffee then will go home with awareness of the [HIV] virus. I think this is the best way to reach.”

Frequent suggestions were also made that women are effective as peer mentors and counselors who make home visits to other PLHIV. Several women who are currently engaged in the practice of making home visits reported receiving great satisfaction from their roles. They stated that they like having the opportunity to offer counsel and “give a model example.” One counselor expressed what she enjoys about her volunteer work by saying, “I like going house to house serving people, visiting people, seeing the people hopeless in bed and encouraging them. This is what I like the most.” Another peer counselor said she enjoys her work because “by making them a kind of service, bringing it to them, it is possible to help them.” When asked to explain what she does on a home visit, one woman said:
First I give them greetings then after greeting, I will tell them about myself. Then before I ask their position, I will witness to myself. Then after, we will discuss on the current agenda. We have agenda like the health issue, and hygiene, and other things like that.

Another participant explained her role as a home counselor by saying:

I tell my example. ‘You see, I was so sick, I even wanted to kill myself. Now I am clean and I keep my hygiene and I am living a better life.’ That is what I say. ‘Look at me’, I say.

A third counselor, when asked what she would say when she visits the homes of individuals who are refusing to seek healthcare, said, “I would tell the lady about myself. I would be a good example. I would tell my story.” She expressed that the satisfaction in being able to encourage someone in this situation is what motivates her to continue to volunteer. Another woman who previously volunteered worked as a home based counselor explained from her experience the impact such visits can have:

I am one of the examples to the people to go to clinic and get medicine every 3 months. I tell them my life and my story. The people, now, they always tell me because of you we are living today…. There are 10 or 11 people now who are taking their medicine.

Women who were not personally engaged in peer counseling also affirmed the value of PLHIV women making home based visits. They suggested that such visits offer opportunities to provide in-depth education, to model how to take ARVs properly, and to check on medication adherence. Several women expressed that home visits can offer great personal emotional
encouragement to PLHIV peers. One participant who did not utilize PMTCT has a child who was infected with HIV during pregnancy. When she was asked what may have helped her to obtain PMTCT services if she had a second chance, she said: “I may have [taken medicine] if someone would have come and visited me about this [and showed] caring. And I would have gotten tested earlier.” Many women expressed a desire that home-based PLHIV counseling and education programs be greatly expanded. They noted that a few NGOs currently offer programs which include home visits, but that they are limited in scope and reach very few women overall.

**Desire to help.** Almost all of the women in the study expressed a personal desire to help their peers, and many of them said that they would be happy to be more actively engaged in offering PLHIV support as educators or peer counselors. Women described their interest in helping by saying they want to “pass along my experiences,” “model myself to them [peers],” or “witness to my own story.” Several women expressed a desire to offer hope for a normal life to their PLHIV peers. One woman expressed in an interview that “they [peers] will have hope if they will take us as an example that we take medicine and got better. We work like any regular person and make a living.” Another woman said she wants to offer encouragement and “wants to tell people who are hopeless my story.” A few were interested in “teaching on the street for future generations.”

Many women expressed a strong feeling of responsibility for passing along their knowledge, both to increase awareness about HIV and to show care for others. One said in an interview “we should advise them with leaning on the thought that it [HIV transmission] should end with us.” Believing that small efforts can have big effects, another participant encouraged the women in her focus group to get involved by saying:
In fact, we cannot reach everyone. Here we are few people present, but we can reach a thousand. If we can give good advice, good action and boldness, that is….We have all been trained about it [PMTCT]. If we have friends we need to pass on our experiences to them.

Another woman with an HIV+ child described why she personally got involved in peer support by saying:

I get very angry when I see kids are infected with the virus now, because during our time we didn’t have the medication to protect the babies from having the virus, but now I don’t know why people are so selfish and careless about their children. There might be hardship in the life but still that can’t be excuse for them to let the child have the virus.

She believes it is her responsibility to provide education that encourages women to care for their children, and she has become an active peer educator in clinics and communities.

Many of the women in the study reported already having been involved in supporting another PLHIV woman, either through engagement as a volunteer counselor with an NGO or through their own friendships. One woman described how happy she was when she encouraged a friend who had given up hope and the woman began taking her ARVs again. Another participant said that she calls or visits one of her friends every night to remind her to take her ARVs, and a third expressed that she also frequently helps friends remember to take their medication. Two different participants expressed that they generally “tell friends” about PMTCT whenever they have the opportunity. Another woman stated she frequently encourages her PLHIV peers to talk to each other, saying, “Concerning me, and people like me, we get strength from our discussion.”
Some participants expressed that they want other PLHIV women to look to their lives as examples. One woman stated that she frequently encourages others by saying, “look at me, I take my medicines and I am not sick.”

**Discussion**

While attrition from the PMTCT system in Ethiopia is a well-documented issue, the exact significance of each influence that affects a woman’s ability to complete the PMTCT cascade is not well understood. To better understand how the most significant barriers leading to attrition can be overcome, this study evaluated the lived experiences of PLHIV mothers in Addis Ababa. It also sought to bridge the gap between knowledge and practice, empowering PLHIV women to guide future implementation efforts by allowing their voices and opinions to be heard.

Results from this study suggest that overcoming hopelessness among PLHIV women and providing better education about vital factors affecting the use of ARVs must be addressed if more women are to effectively complete the PMTCT cascade. The study also demonstrated that these concerns, along with issues of carelessness, stigma, and poverty, could be effectively overcome by the use of PLHIV women as educators and peer counselors.

The eMTCT plan for Ethiopia for 2013-2015 (MOH, 2013b) contains goals targeted to improving PMTCT services at multiple levels, yet findings from this study suggest that a different focus may be necessary. Although the plan recognizes the key demand-side challenges of missed opportunities for service and the high attrition rate from PMTCT care, the majority of the plan’s goals and objectives are focused on improving the PMTCT system from within. However, in contrast to many studies which document low quality health care services or poor interactions with HCW as common reasons for PMTCT attrition (Merdekios & Adedimeji, 2011;
Ferguson et al., 2012; Otieno et al., 2010; MOH, 2013c), most women in this study described having very positive, encouraging experiences within the health care system and a high degree of trust in the advice they had received from HCW.

Participants expressed the need for increasing community awareness and understanding of PMTCT services as a greater concern; although not prioritized, the eMTCT plan does also recognize this need. National strategies to improve awareness include increasing media messages, male involvement, and the use of Health Extension Workers (HEW) and the Health Development Army (HDA) (MOH, 2013b). Some study participants agreed that increased media education may promote awareness, but none of the women suggested that engaging males would improve PMTCT retention. Further, although they did not refute the use of HEW and HDA, women advised that engaging PLHIV mothers in promoting awareness and education would be more valuable. Expectations that health workers alone can increase awareness and provide consistent support to PLHIV women are optimistic at best when considering their already heavy workloads.

**PLHIV Involvement**

Results from this study suggest that the PLHIV mothers are very interested in becoming involved in helping to reduce MTCT of HIV. Specifically, women desire to be voices of hope and encouragement to their peers through counsel, to serve as models for medication adherence and healthy lifestyles, and to share what they have learned with others as educators. The value of involving PLHIV in peer support groups and actively engaging PLHIV as peer educators and counselors is being increasingly recognized in other sub-Saharan African countries, with successful interventions documenting increased PMTCT adherence, improved infant health
outcomes, and up to 95% HIV-delivery rates (Busza et al., 2012; Kim et al., 2012; Leroux et al., 2013; Klein, 2013). These successes and our study findings suggest that the involvement of PLHIV mothers should be much greater than what is currently being recommended. Advice in national guidelines suggests engaging PLHIV networks for practical concerns such as providing clinic transportation for peers, but it fails to consider the potential for more important roles for these women.

Previously several successful Mother Support Groups were started in Ethiopia (Hopem & Bodasing, 2009) and PLHIV peer counselor programs were run through local NGOs. However, due to financial constraints, these programs have been sporadically sustained, with most no longer active: this further supports the critical need to capitalize upon the high level of motivation for involvement expressed among PLHIV mothers in Ethiopia. PLHIV peer educators and counselors can effectively address the most influential barriers to PMTCT adherence highlighted in the study.

The potential impact of this peer support is widely supported in the chronic disease literature prevalent in the US and other developed nations (Gallant, 2003; Heisler, 2007). These same peer support principles have the implication for even greater effect in low resources areas, allowing women to provide hope and positive reinforcement that can translate to behavior change (Lorig et al., 2001; Gallant, 2003). Particularly, PLHIV models who are adhering to a medication regimen and living a healthy lifestyle can be sources of encouragement who help women to overcome hopelessness and to be more attentive to caring for themselves. Further, women in the study expressed that focusing on their children inspired hope and gave them strength to continue taking their medication. Thus, PLHIV peers with healthy children can serve as living reminders of the possibility for having babies born free of HIV.
Results from this study suggest that a general failure to understand the benefit of ARV treatment either for a mother or her child remains a significant concern. Thus, while educational campaigns in Ethiopia have succeeded in promoting a high level of awareness of HIV and MTCT among the female population (Merdekios & Adedimeji, 2011; Deressa, Seme, Assefa, & Enqusellassie, 2010), it appears that a comprehensive understanding of the value of PMTCT services has not been reached. As the country rolls out Option B+, a more simplistic regimen hoped to promote higher levels of adherence, it may be an ideal time to incorporate PLHIV as peer educators in health clinics, communities, religious institutions, and the media. By targeting their messages to an understanding of how ARVs can both prevent infant HIV infection and also benefit a woman’s health, the teaching and support of PLHIV peers can help women to overcome the confusion about ARVs that prevents PMTCT adherence.

The concern over the use of holy water expressed in this study is significant, and it is clear that education encouraging medication adherence along with faith practices is needed within the Orthodox Church. Interviews with PLHIV elsewhere have indicated that engaging faith leaders in HIV issues can have significant positive impacts (Anderson et al., 2012; Ackerman-Gulaid & Kiragu, 2012); religious leaders have also been proven able to positively affect maternal health (MOH, 2013b; Yoder, 1997). Priests should play an important role in providing teaching about holy water, but their ability to reach women individually may be limited by time constraints. Orthodox PLHIV peer counselors could provide important additional personal support and enhance the education given in the church.

The difficulties expressed in the study of living jointly with HIV and in poverty are consistent with other studies completed in sub-Saharan Africa (Otieno et al., 2010; Duff et al., 2010). Poverty and poor health are often linked; poverty both directly limits access to health care
and indirectly limits access to prevention education (WHO, 2008; Loewenson, 2007). Direct provision of food, housing, and other material aid must be addressed at a government level, but PLHIV can play a role in addressing poverty, as well. Through starting and managing self-help groups, utilizing micro-loan models, and engaging with innovative new methods they design, PLHIV mentors may be able to provide economic empowerment for their peers. These strategies have been recommended as an important part of global HIV prevention (Interagency Task Team [IATT], 2013).

Weakly enforced national laws ensure equitable access to treatment and support for PLHIV, but better legal retribution for discrimination is needed from the government. (Krebs, 2012). PLHIV can have also play a role in fighting discrimination. Engaging more PLHIV women as community educators and members of community planning committees may promote increased HIV awareness and help to mitigate the effects of stigma in these locations. PLHIV women who were previously involved in mother support groups also reported that their own fear of social stigma decreased with participation (Hopem & Bodasing, 2009).

PLHIV women are being effectively utilized in the PMTCT healthcare workforce in order to prevent attrition in a number of countries (Elisabeth Glaser Pediatric AIDS Foundation [EGPAF], 2013). Not only can they provide individual and group counseling to PLHIV mothers at the clinic level, but PLHIV workers can promote linkages to health care systems through home based visits and provide default tracing for women who have dropped out of PMTCT care. The highly motivated PLHIV mothers in this study could greatly extend the reach of the current PMTCT system if engaged as part of the workforce. In addition, although not expressly discussed in this study, PLHIV peers may be effective in addressing issues beyond attrition that
also affect the MTCT rate: encouraging the use of institutional delivery and advocating for
exclusive breastfeeding are examples.

WHO’s Global Health Sector Strategy 2011-2015 (WHO, 2011b) recommends that
engaging PLHIV in planning interventions is essential for their success, and the United Nations,
UNAIDS and PEPFAR all support the incorporation of PLHIV in developing HIV/AIDS care
and prevention strategies (Anderson et al., 2012; UNAIDS, 2012c; Bachman & Phelps, 2012).
In light of such strong international recommendations, the advice given by women in this study
to engage PLHIV mothers should not be overlooked. Current efforts to improve the quality of
PMTCT services and the utilization of HEW and HDA to promote awareness may improve
uptake and retention in the PMTCT system. The potential impact of such programs, however,
should be reconsidered in light of the significant findings of this study. Giving greater attention
to the use of PLHIV mothers at a system wide level, investing in their training as educators and
counselors, and developing designated PLHIV peer support programs may result in markedly
greater improvement in PMTCT adherence and better infant health outcomes in the future.

Limitations

Cultural misunderstandings are inherent limitations to any international study, but the
involvement of a multi-national research team and close communication with a local research
assistant sought to minimize these barriers. The plausibility of findings was assured by reporting
them back to participants, as well as using both focus groups and interviews in data collection.
The use of a local research assistant enhanced the trust of participants, but the possibility remains
that perceived power barriers between the research team and the participants may have limited
their total transparency. Confidentiality concerns were minimized by holding research sessions at
the program offices rather than in the communities. Research bias during the design of the study, data collection, or data analysis was possible but limited by several collaborating researchers giving oversight in this area. Although the results of the study may inform future research efforts in other locations, they should only be interpreted for women in Addis Ababa and not be generalized to the rural population of Ethiopia nor other locations. Many factors affect the high rate of vertical HIV transmission in Ethiopia, and it must also be noted that this study only represents the opinions of PLHIV mothers on the specific problem of lack of adherence to PMTCT care. It does not address issues such as low uptake of ANC services or low institutional delivery rates.

**Conclusion**

Maintaining the motivation required to adhere to the entire PMTCT cascade requires that a PLHIV mother both understands the validity of the steps she is taking and receives support for the many challenges she faces. Making sure these requirements are met should be the primary target of any future interventions if the goal of reducing the MTCT to less than 5% in Ethiopia in 2015 is to be met. According to the advice of PLHIV mothers given in this study, programs should target educational efforts toward better understanding of the benefit of ARVs and interventions should be designed that help PLHIV mothers overcome a feeling of hopelessness. These barriers, and several others, can all be overcome by the use of PLHIV peers. Strong consideration should be given to investing in training and engaging PLHIV peers as active members of the health care workforce and significantly expanding their use in the communities as educators and counselors. Doing so will allow the expressed needs of the PLHIV population to be met more effectively and result in a decrease of attrition from PMTCT care.
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SECTION IV

Summary of Findings

The demographics of all study participants are seen in Table 4.1 (Appendix H). The average age of participants was 31.7 years old. Approximately half (53.1%) were married, with the remainder divorced, widowed, or otherwise single. Ethnicity was divided into Amhara (58.2%), Oromo (22.4%), and other (19.4%) people groups. Participants were predominantly of the Orthodox religion (53.1%) followed by Protestant (42.8%) and Muslim (4.1%). Approximately one fourth of the women (25.6%) had no education; 22.4% had secondary (7-9 years) education; 22.4% had basic (1-5 years) education; 29.6% had over 10 years of schooling. 42.9% had higher levels of income (defined as having 1-2 people living per room in the home), 45.9% were mid-level income (3-4 people per room), and 11.2% had lower level income (five or more people per room). Almost one in four women (22.4%) had children infected with HIV.

Summary of Quantitative Findings

Seventy-one surveys were completed. All survey data was analyzed according to demographic variables and two outcomes: maternal PMTCT adherence (self-reported) and infant HIV infection. To address perceived barriers to PMTCT use, women were also asked an open-ended question on surveys to identify problems they may have experienced in past PMTCT use or those they anticipated in the future. The predominant findings from the survey are: 1) the comprehensive level of understanding of PMTCT is low in the population; 2) The opinions of
friends, family and religious leaders are very important to the population; 3) No significant differences exist in age, religion, education, income, or marital status between adherents to PMTCT and non-adherents to PMTCT; and 4) No significant differences exist in age, religion, education, income, or marital status between women with HIV-infected children and women whose children are not infected with HIV. These results address each element of the overall study research question: What beliefs, attitudes, socio-cultural factors and key influences among HIV+ women in Addis Ababa contribute to their adherence to or attrition from the PMTCT system?

**Beliefs and attitudes.** A woman’s beliefs and attitudes about using PMTCT services are affected by her level of knowledge and understanding of their value. The level of overall comprehensive knowledge of PMTCT in the study population was low. Only 14.1% of participants correctly identified all modes of MTCT, with more identifying the potential to transmit HIV during labor and delivery than during pregnancy or breastfeeding. More women (95.8%) also knew that medication is needed in labor and delivery for prevention of MTCT than during pregnancy (71.8%) or breastfeeding (66.1%). Lack of adequate understanding of MTCT was also revealed in suggestions given by some participants that MTCT risk could be reduced by obtaining adequate nutrition, praying, abstaining from sexual activity during pregnancy; and keeping breast wounds cleaned during breastfeeding. Twenty one women also suggested that formula feeding was preferable for lowering MTCT risk.

Few women (6%) could correctly identify the risk of infant infection when a mother did not use PMTCT: this was overestimated by 87% of women and indicates a high level of perceived risk. Perceived severity of infant infection was also high, with 45% of women overestimating the risk of infant death with infection. A majority of women (66%) expressed a
fear of infant infection, and many mentioned it as a reason to not have more children. Non-adherents to PMTCT were almost 9 times more likely to be afraid a future child would be infected with HIV than those who adhered to PMTCT (OR=8.56, 95% CI 1.0217 to 71.6420, p=.048). Although attitudes of fear, high perceived risk and severity could potentially increase PMTCT adherence, their value is moderated by a low level of belief in the efficacy of the medicine (or benefit to PMTCT) in the population: the risk of infection while a mother adheres to PMTCT was overestimated by 53% of women. There is also a perception in the population that completion of PMTCT is not a norm: only 41% of women agreed that most women complete the medication through breastfeeding. There is a high level of self-efficacy in the population: 89% of women overall thought they could obtain PMTCT medication if needed in the future and most women (96%) thought they could correctly take it. This belief may improve PMTCT adherence.

**Socio-cultural factors.** When data is analyzed according to outcome, no significant differences exist in the socio-cultural factors of age, religion, education, income, or marital status between either adherents to PMTCT and non-adherents to PMTCT or between women whose children are HIV infected and women whose children are not infected with HIV. However, of the 36% of participants who said they had experienced a problem using PMTCT in the past, socio-cultural issues of money and transportation were most frequently cited as concerns. These were also frequently mentioned by the 26% of women who said they anticipated problems with PMTCT if they were to become pregnant in the future again.

**Key influences.** The survey demonstrated that the opinions of others are very influential to the study population. The opinions of friends were important to the highest percentage of
PLHIV women (97%), followed by the opinions of religious leaders (94%), families (89%), husbands (77%), and in-laws (62%). Friends were more likely to encourage PMTCT use (89%) than were husbands (69%), neighbors (37%), religious communities (36%), and in-laws (35%). Over half (63%) of women said that God is important to their healthcare.

Outcome analysis also demonstrated key influences for the population. The opinion of family was important to more PMTCT adherents (94%) than to non-adherents to PMTCT (67%) (OR 7.67, 95% CI 1.44-40.92, p=0.017). Non-adherents to PMTCT were almost 4 times more likely to think their neighbors would gossip about them than were PMTCT adherents (OR 3.88, CI 1.0448 to 14.3863, p=.0428). Those women who had healthy children were much more likely to report their friends would encourage PMTCT use as compared to those whose children were HIV+ (OR 12.50, 95% CI 1.7267 to 90.4893, p=.0124).

Summary of Qualitative Findings

Focus groups and interviews took place with women from various demographic backgrounds (Table 1). In-depth interviews were completed by 23 women, and 27 women were involved in the focus groups. Participants were asked directly in interviews and focus groups why HIV+ women may not adhere to PMTCT, and they were also asked for suggestions on how to increase adherence. A variety of other open-ended questions allowed for several predominant themes to emerge among participants.

Hopelessness, understanding, and carelessness. Hopelessness was the most frequently mentioned barrier to PMTCT adherence: it was cited by 22 different women. Participants explained that many women give up on HIV medication because it does not cure the illness, while some do not feel that they will be able to live. One woman expressed the common concern
well: “It’s because they give up hope they don’t think they can live like people and make it. But if they took us as an example and took it then they surely would have made it. ...... Now we work like any regular person and make a living. For the ones throwing away their medicine they need counseling because they have given up.” Conversely, many women expressed that hope could facilitate PMTCT adherence. Several women expressed finding hope in God, others received hope from listening to the counsel of HCW or friends, and many grew hopeful by watching friends or other PLHIV women doing well. Almost half of those interviewed said it was the power of hope that had changed their own attitudes about HIV, and this directly affected their medication adherence.

Not understanding ARV medication was the next most frequently cited barrier to PMTCT, mentioned by 20 women. Misperceptions about HIV in general, such as (the virus living outside an individual) exist, but they are not common. Participants noted the difficulty in understanding is more about the value of chronic maintenance medication, as well as concerns with side effects and the way the medication must be taken. They stated that although education is coming from multiple locations, it is often not being comprehended well. The majority of women who said more education is needed suggested it be offered in coffee ceremonies in the kebeles and with PLIHV teaching: a few women also suggested offering more education through the media or religious communities.

Some women said that enough education is available on TV, through clinics, and through NGOs, already, but that carelessness is causing many PLHIV women not to listen to it. Carelessness was referred to in terms such as women being “lazy,” “selfish,” or “weak,” and it was cited as another significant barrier to PMTCT adherence by 13 different participants. Having
more concern for their children than for themselves was noted by several women to overcome this attitude.

**The value of PLHIV peers.** The value of PLHIV peers to the women was extremely important. Over half of the women discussed the importance of their PLHIV peers without prompting. Participants described receiving personally receiving support from other PLHIV women, stating they encourage, offer hope, offer modeling, and teach each other. A few women said that PLHIV peers kept them accountable to their medication regimens by text, phone call, or home visits, and several stated that PLHIV peers had actually helped them to change their minds when they had given up hope in taking their medicine. Others mentioned the encouragement they received from watching the health of their PLHIV peers improve with medication compliance. Several women said PLHIV peers were those who provided the critical emotional support needed to cope with the challenges of chronic medication use.

When asked for specific advice on how to improve PMTCT adherence in Addis Ababa, 24 of the women suggested involving PLHIV in PMTCT interventions. This was over twice the number of times any other recommendation was given. Participants said that PLHIV women are capable of offering more clearly understood education than health care workers, and it was suggested that PLHIV women should be the ones to teach and counsel in all communities, health facilities, and NGOs in the future. Some women thought that PLHIV teaching in coffee ceremonies in communities would be highly effective, while others thought door-to-door home visits are of the greatest value. In addition to being educators, PLHIV can be peer models, volunteer social workers, and links to community and religious engagement in HIV care.

Almost half of the women involved in interviews or focus groups also stated they want to be peer supporters, themselves. They expressed this in ways such as their desire to “pass along my
experiences,” “be a model,” or “witness to my own story.” One woman said she “wanted to tell people who are hopeless my story.” There was a strong feeling of responsibility described by several women for passing along their knowledge and help to others, to “give good advice, good actions and boldness to others.” Almost of third of the women mentioned already having been involved in supporting another PLHIV woman, either through engagement as a volunteer with an NGO or through their own friendships.

**The importance of other individuals in the lives of participants.** Both families and friends were reported to be important to PLHIV women, and the majority of their responses to HIV were reported as positive. Siblings, extended family, and friends were all described as having offered support of some kind, either emotional or material, to participants. No women reported that their in-laws held either a positive or negative influence over their health care. Of the few women who discussed the influence of their husbands, they were described as being supportive of their HIV and PMTCT care. The few difficulties mentioned between participants and husbands involved his own HIV status and disclosure; no participants stated their husbands had been a barrier to PMTCT adherence.

**Religious influences.** Some of the most powerful barriers and also facilitators to PMTCT adherence described by participants came from religious influences. Almost half of the women interviewed directly referred to the practice of taking “holy water” for healing as an influential reason for women not adhering to HIV medication or PMTCT services. Many women reported knowing individuals who had died as a result of failing to take their ARVs when they went to take holy water instead. This practice was reported as deeply rooted in the Orthodox tradition, and the majority of those who participate do not feel simultaneous medication use is acceptable. Although participants said that Orthodox priests in neighborhood congregations in Addis Ababa
are not regularly condemning the use of ARVs, neighbors and other individuals from within their religious communities are encouraging the discontinuation of medication in favor of drinking holy water.

The influence of religious communities was also reported by many women to have a positive role. Peer support structures for PLHIV, coffee ceremony educational gatherings, and NGOs linked to churches which are entirely committed to the support of PLHIV were noted to be very helpful. In addition to education and occasional material aid, the churches offer emotional support, prayer, and care that is very valuable to the women. Some participants explained that it was church members or pastors who had helped to restore their hope in living. HIV support was most frequently mentioned in Protestant churches, although women from all three major religions agreed that religious leaders would be valuable educators in issues surrounding HIV and PMTCT. The value of a woman’s personal faith was also expressed by multiple participants: many find hope for living and strength through prayer and their belief in God.

**Organizational and structural issues.** Interactions with the health care community were reported as predominately positive by participants. Although a few negative experiences were described with individual health care workers, most participants expressed having had positive interactions in clinics and hospitals and receiving good education there. Listening to the advice of doctors, following their instructions, and receiving care at the clinic was the most commonly offered advice participants wanted to give to other PLHIV pregnant women.

Stigma against PLHIV was reported to be decreasing in Addis Ababa, but it still exists. Discrimination is most strongly felt at the neighborhood level: women described neighbors excluding them from activities and gossiping and landlords evicting them when their HIV status
was revealed. Outside of this community level, only a few women referred to experiencing stigma from family, members of religious communities, or health care workers.

Poverty was reported by several women as a significant concern to PLHIV. A few women described having begged for food and infant formula, and it was explained that women may not take their ARVs because they do not have food to eat with it. Suggestions the women wanted to offer to the government for improving PMTCT included providing food subsidies and housing to PLHIV individuals, as well as job opportunities.

**Discussion**

While both quantitative and qualitative data from this study had independently significant findings, the use of multiple methods increased confidence in the validity of the findings and limited the inadequacies of each individual method (Thurmond, 2001). By exploring PMTCT attrition from different perspectives through surveys, interviews, and focus groups, a greater depth of understanding of the problem was gained than could have come from a singular method (Patton, 2002). For example, it was clear from the survey data that there is a general lack of understanding about PMTCT in the population of study, but this data was insufficient on its own. When women in focus groups and interviews discussed their concerns with PMTCT, however, their responses highlighted the perceived lack of benefit of ARVs as a primary point of misunderstanding which is critical to future educational efforts. The use of mixed methods and triangulation thus helped to provide a balanced view of the complexities surrounding PMTCT attrition. Finally, as surveys were tabulated and qualitative data collection was ongoing, findings were reported back to participants so that they could clarify, confirm, or elaborate on the results.
presented. This contributed to the triangulation and data analysis and also improved the validity of the study.

The data supported through both methods must be highlighted as of particular interest. Both qualitative and quantitative data demonstrated that the comprehensive level of understanding of PMTCT is low in the study population. The survey revealed that many women cannot accurately identify all three modes of vertical transmission, nor can they correctly assess the risk of transmission with or without using PMTCT. The extensive discussion in focus groups and interviews surrounding the high level of confusion about ARV efficacy and side effects supports the fact that enhanced education is greatly needed.

Significantly more non-adherents to PMTCT reported neighborhood HIV gossip than did those who adhered to PMTCT on the survey. The indication from this quantitative data that neighborhood stigma is a concern which needs attention was confirmed through discussion in interviews and focus groups. Financial concerns were also suggested in the survey to be a barrier to PMTCT for a substantial number of women; qualitative data elaborated on the difficulties of living in poverty. Participants described in focus groups and interviews that most interactions with health care workers and the health care system are positive, and survey data confirmed this with a low percentage of women identifying health care system concerns to be a barrier to PMTCT.

Very little qualitative information was offered by participants about their husbands being either helpful or detrimental to PMTCT use, and the survey supported also indicated that the opinion of husbands was of less importance to PLHIV women than that of friends or families. In contrast, the opinions of friends were important to the highest percentage of PLHIV women, and more of those who adhered to PMTCT said they had support from friends than those who did not
on the survey. Interview and focus group discussions support the finding that friends can be very beneficial in encouraging PMTCT adherence, and exploring their use in interventions may be of value. The opinions of religious leaders were second only to that of friends in importance in the survey, a fact supported by women reporting in interviews that religious leaders could be effective in teaching about medication compliance. Almost two-thirds of women on surveys said that God is important to their healthcare, and comments about the importance of personal faith in interviews and focus groups were extensive. The significance of the problem of holy water use that was revealed in interviews and focus groups was not directly supported by quantitative data, as it was not included as part of the survey. Quantitative research to understand the prevalence of this problem may be valuable in the future.

**Dissemination of Findings**

Comprehensive findings from the study will be distributed to the research team at AAU and participating PLHIV organizations, as well as to individual participants as requested. Findings will also be distributed as a white paper to the Addis Ababa Health Bureau, the Ethiopian MOH, and other faith based and community based organizations involved in PMTCT in Ethiopia in order to provide recommendations for future intervention planning.

The study results have been written into the two manuscripts included in this dissertation and will be submitted to selected scientific journals. Additional manuscripts from the findings are also planned from further issues identified during the study and include:

- An executive summary overview of the key findings of the study, targeted to the Journal of the Ethiopian Medical Society and co-authored by an Ethiopian colleague
• A brief report on “The Role of the Religious Influences on PMTCT Adherence” (Supplemented by interviews with key religious leaders which were completed in conjunction with this study)

• A brief report on “The Perspectives of Program leaders and PLHIV women on PMTCT Attrition in Addis Ababa” “(supplemented by interviews with medical workers and NGO leaders)

• “Harnessing the Value of PLHIV peers in PMTCT Adherence”

Strengths and Limitations

Strengths. The mixed-methods design of this study was a strength, providing for more comprehensive findings and interpretation through the combination of qualitative and quantitative data than by the use of either method (Creswell & Plano Clark, 2007). The ability to triangulate data from focus groups, surveys, and interviews allowed for key factors to emerge at all levels of the SEM model, and the use of the model itself provided a strong framework upon which to base analysis of the data. Positive and close collaboration with the PLHIV networks, who have high levels of trust among the study participants, was invaluable to promoting transparency. It also helped to mitigate cultural bias on the part of the researcher. The use of a local research assistant, obtaining counsel from several Ethiopian physicians, and interaction with a strong advisory group were additional strengths.

Limitations. Cultural barriers and misperceptions are inherent limitations of any international study (Yoder, 1997), and the fact that the PI is not Ethiopian must be considered. However, effort was made to mitigate the influence of cultural factors and personal bias on the part of the PI by close interaction with Ethiopian colleagues, who were involved in all stages of
research design, data collection, and analysis. In the design of measures, including interview questions, focus group questions, and questionnaires, personal bias on the part of the PI and colleagues towards or against certain individuals or groups of people was also limited by use of the insight of multiple researchers, as well as the oversight of a research advisory team at USF who have experience in qualitative and international research.

Cultural or perceived power barriers between the PI or research team and the participants may have limited the transparency of the participants. In particular, conducting interviews through translation may have created a distance barrier between the interviewer and interviewee. However, use of a local research assistant, along with the trust developed between the PLHIV staff members and the participants mitigated this limitation. Confidentiality was a stated concern for several women, but locating the research at the program offices rather than in the communities alleviated their fears. Unidentified research bias during the data analysis process is also a potential limitation. The use of multiple measures, multiple participants, and multiple researchers for data collection and triangulation of these results sought to minimize this limitation, as did presentation of the results to participants to ensure the plausibility of the findings (Letts, et al., 2007).

There is currently no tracking system in place in Addis Ababa to locate pregnant women who received HIV testing and did not return, nor is there a system in place to track women who initiated PMTCT and ARV therapy but did not continue it throughout breastfeeding. The adherence of mothers to PMTCT was therefore self-reported and not validated by health system records, and this may have resulted in either over or under-reporting of PMTCT use. Constraints of time and resources were an additional limitation. The quantitative study could have been greatly strengthened by the increased power of a larger sample size, but resources were not
adequate to allow for this expansion of the study. The lack of variability in outcomes by patient demographics should be interpreted with caution in light of this limitation. The amount of cultural observation available to the PI was limited by time constraints, but this was somewhat mitigated by collaboration with Ethiopian colleagues. Finally, the use of only two PLHIV networks for sampling may be a limitation. Although the two combined networks do draw from 14 different communities, they may not have provided an entirely accurate representation of the population of PLHIV women in Addis Ababa at large.

**Conclusions and Implications for Practice**

Increasing access to ARVs, reducing the transmission of HIV infections and caring for the needs of HIV-positive individuals are high priorities for many global health organizations. The UN’s Millennium Development Goals and CDC’s Global Health Strategy each cite these concerns, while the UN Sustainable Development Goals extend make a call to end the AIDS epidemic by 2030. (United Nations, 2014a; Center for Global Health, 2012; United Nations 2014b). By directly inquiring about the needs of the PLHIV maternal population in Addis Ababa, this study provides valuable information that can lead to the implementation of interventions which can help to meet some of the ambitious targets set by these major organizations.

The study also addresses another key agenda in the global health community: reducing childhood morbidity and mortality. The Millennium Development Goals aimed to reduce under 5 mortality by 2/3; the Sustainable Development Goals set a target to completely end the preventable deaths of newborns and children under 5 by 2030. In fact, public health as a discipline is inherently interested in protecting the most vulnerable in a population, which includes and must prioritize children. By seeking to decrease the number of HIV+ children born
in Ethiopia, this study will directly impact mortality in the childhood period. Additionally, the contribution to a reduction in infant HIV infection can impact an entire generation as the expense and effort of providing chronic HIV care for many individuals will be substantially reduced.

Conclusions. The problem with attrition in PMTCT in Ethiopia is multifaceted and has been explored from many angles. This study was not intended to be a comprehensive evaluation of the PMTCT system, nor did it explore or attempt to answer the difficulties which arise at an organizational level (such as interrupted access to ARVs or lab tests or lack of human resources). It also did not explore the social and healthcare structure changes associated with the newly adopted Option B+ plan in the country. The study’s findings are not intended to be generalizable to women living with HIV in other countries; rather, it identified barriers to PMTCT that are specific to Ethiopian women living in Addis Ababa.

The purpose of this exploratory study was to allow the voices of PLHIV mothers to be heard and for their perspectives about PMTCT to emerge without being led by suggestive research questions. By offering rich descriptions of their personal experiences and opinions, the participants in the study clearly identified several key barriers to PMTCT use which are not currently being addressed in interventions and have not been widely discussed in previous research. Most notably, the hopelessness that is experienced by many PLHIV mothers and a common failure to understand the benefit of ARVs for PMTCT were both brought into sharp focus by the women’s explanations. In addition, the problem with the use of holy water hindering women’s adherence to PMTCT was an unexpected finding that was highlighted by many participants. These three issues alone may contribute considerably to PMTCT attrition, and it is extremely concerning that they are not being addressed in national PMTCT plans.
In fact, the primary focuses of the national PMTCT guidelines, as well as those of many NGO and partner agencies, are not generally representative of the demonstrated concerns of the PLHIV maternal population. Although the barriers of poverty and stigma noted in many planning guidelines were addressed by the women, many other issues highlighted in these reports did not emerge as felt needs of the population. The Ministry of Health (MOH) is giving a great degree of attention to scaling up and improving PMTCT services; the focus on improving health care system quality is being overemphasized when the population reported positive interactions with the health care community. The MOH reports a need for increased male engagement in PMTCT interventions, yet this was not expressed as a significant concern by study participants. PMTCT interventions are targeting expanding the use of HEW and the HDA, but the powerful influences of friends and religious leaders which were revealed in the study are largely being overlooked. Comments the women made about the benefits of engaging PLHIV mothers in interventions, their personal desires to be involved, and their requests to use PLHIV peers in PMTCT programs were some of the most striking parts of the qualitative findings. Current interventions are unfortunately paying little attention to this critical advice. Future study on why such marked differences in perspective exist between the population of interest and those who are seeking to address their needs would be extremely valuable.

A key finding from the study which merits further research is the role of religion in PMTCT. The powerful impact which religious beliefs can have on the behavior of women in Addis Ababa was highlighted by the stories they shared about the use of holy water. It is critical that broad and swift measures be taken to educate PLHIV mothers that ARVs should not be discontinued while drinking holy water, through generalized educational campaigns and the engagement of priests in teaching. This detrimental practice also demands more attentive study,
as there is a scarcity of research about the prevalence of the use of holy water and its effects in this population.

The impact of religious beliefs can also be very positive and should be further explored. The study data was rich with examples of women gaining hope from their own personal faith, and a few voiced strong testimonies about receiving hope from the social and emotional support they received from their religious communities. The power of positive influence that these communities could have is enormous, yet currently only a small number of them are actively engaging with the HIV epidemic. Finally, religious leaders have a high degree of influence in the population, and efforts are needed to involve them as key proponents for PMTCT uptake and adherence.

Several study participants with HIV infected children did not access health care during their pregnancies, and a few were unaware of their HIV diagnosis at that time. Their stories demonstrate that further study is needed about how to best engage with women at the community level in order to increase both awareness of and adherence to PMTCT. Doing so can encourage women to obtain HIV testing before pregnancy, and it can also capture those women who may not plan to utilize ANC services when they become pregnant. Since the highest vertical transmission risk during pregnancy is in the first trimester, identifying HIV+ women and beginning them on ARV treatment before pregnancy can have a significant impact. Participants reported a role for PLHIV counselors to play at this community level. Involving religious institutions, local leaders or community advocates should also be further explored.

It is interesting to note that variations in socio-economic status, marital status, ethnicity, religion, and educational level made little difference in the expressed concerns of the women, and they also did not affect PMTCT adherence. Recommendations suggested by this study
should therefore be seen as generalized to the PLIHV maternal population as a whole in Addis Ababa, rather than targeted to specific demographic groups.

Implications for practice. This study was completed with the goal of obtaining information which could be translated into public health practice. The discrepancies between the study’s findings and the expressed goals of many current PMTCT interventions is a poignant reminder to public health practitioners of the importance of conducting needs assessments and engaging the population of interest in the planning process. Doing so has the potential to produce much more effective results than basing interventions on the ideas and opinions of researchers and practitioners alone. Findings from this research can be utilized to design effective new PMTCT interventions and to enable modifications of existing programs so that they produce greater results.

The key recommendations which follow are guided by the insight and advice of PLHIV mothers given in this study:

- Capitalize on the high level of self-efficacy and interest in serving among PLHIV mothers by engaging them in the following ways:
  - Peer educators in clinics, religious institutions and communities
  - Peer counselors and mentors in clinics
  - Home based care counselors
  - Members of PMTCT workgroups, research teams, and planning committees
- Expand and improve education that promotes comprehensive understanding about PMTCT, including all 3 modes of vertical transmission
- Expand and improve education about the benefit of taking ARVs for pregnant PLHIV women, with particular attention paid to the reduction in risk of infection for the child
• Infuse all educational materials and interventions with messages of hope that
  o PLHIV women can live healthy lives despite having a chronic disease
  o PLHIV mothers can have children who are not infected with HIV
• Utilize the influence of religious communities and leaders to encourage PMTCT adherence in the following ways:
  o Provide clear teaching about the use of holy water and continuation of ARVs
  o Use religious communities to offer education, social and emotional support for PLHIV about all aspects of HIV care, including PMTCT

The hope of the PI is that findings from this study can be used in a way that results in a dramatic reduction in the number of infants infected with HIV in Ethiopia in the near future.
COMPREHENSIVE REFERENCES


Von Massow, F. (2000). "We are forgotten on earth": international development targets, poverty, and gender in Ethiopia. *Gend Dev, 8*(1), 45-54. doi: 10.1080/741923410


Appendix A
Extended Literature Review

Mother to Child Transmission of HIV

At the end of the 20th century, 33 million people were living with HIV, and AIDS was the 4th leading cause of death in the world (WHO, 1999). Barely two decades after it was first discovered, the HIV virus had implanted itself firmly in the landscape of human health history, and it continues to remain a pivotal component of many international health efforts. As it was increasingly recognized that a coordinated international response to the HIV/AIDS epidemic was needed, the Joint United Nations Programme on AIDS (UNAIDS) was developed in the early 1990s to lead the effort. The World Health Organization also plays a key role in setting guidelines and protocols for HIV care and prevention, and these two agencies help to set the tone for the international efforts required to stabilize and begin to reverse the spread of HIV.

In 2003, the WHO set a new “Three by Five” goal: by 2005, 3 million people living with HIV (PLHIV) across the globe would be on Anti-Retroviral medications (ARVs) by 2005 (WHO, 2005b). Since the drug trial ACTG019 first verified that zidovudine (AZT) delayed the onset of symptoms in HIV-positive patients in 1987, the field of ARV medications has expanded rapidly (Fischl et al., 1987). The many classes of ARVs in use (see Table 1) maintain and decrease HIV viral loads, increase the number of CD4 lymphocytes in patients, delay the onset of symptomatic AIDS infection, reduce long term complications of the virus, and protect against transmission (National Institute of Health, 2013).

In 2005, in an effort to improve the quality and duration of life for people living with HIV, global leaders expanded the “Three by Five” goal and pledged to provide “universal access” to ARVs by 2010 (United Nations, 2005). Although this goal was not met, coverage did increase considerably: by the end of 2010, approximately 50% of eligible patients worldwide
Table 1

*Classes of Anti-retroviral medications*

<table>
<thead>
<tr>
<th>Drug class</th>
<th>Mechanism of Action</th>
<th>Commonly used drugs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nucleoside/nucleotide RT inhibitors (NRTI)</td>
<td>Inhibits conversion of HIV RNA into HIV DNA by inserting faulty DNA building blocks into the HIV DNA chain</td>
<td>Zidovudine, Stavudine, Abacavir, Lamivudine, and Tenofovir</td>
</tr>
<tr>
<td>Non-nucleoside RT inhibitors (NNRTI)</td>
<td>Binds to reverse transcriptase enzyme, interfering with its ability to convert HIV RNA into HIV DNA</td>
<td>Nevirapine, Delavirdine, Efavirenz, and Rilpivirine</td>
</tr>
<tr>
<td>Protease Inhibitors (PI)</td>
<td>Interferes with the protease enzyme that HIV uses to produce infectious viral particles.</td>
<td>Lopinavir, Indinavir, Nelfinavir, Amprenavir</td>
</tr>
<tr>
<td>Fusion/Entry Inhibitors (FI)</td>
<td>Interferes with the virus’ ability to fuse with the cellular membrane, blocking entry into the host cell</td>
<td>Maraviroc and Enfuvirtide</td>
</tr>
<tr>
<td>Integrase Inhibitors (II)</td>
<td>Blocks integrase, the enzyme HIV uses to integrate genetic material of the virus into its target host cell</td>
<td>Raltegravir</td>
</tr>
</tbody>
</table>

were on ARVs (UNAIDS, 2012c). Coverage of children infected with HIV improved at a much slower rate, with only 24% of 3.4 million eligible children receiving ARVs in 2010 (WHO, 2011a). Across all ages, HIV related mortality and incidence both decreased on a global scale as access to ARVs expanded.

The magnitude of the HIV/AIDS epidemic is still staggering on a global scale, yet even within the epidemic certain populations are more vulnerable than others. Of the 3.1 million new HIV infections acquired globally in 2011, 330,000 occurred in children (UNAIDS, 2012d). This is a true public health crisis, for more than 50% of these newly infected children will die before their second birthday without appropriate care and treatment (WHO, 2007b).

Approximately 90% of childhood cases are acquired through vertical transmission, also called Mother- to- Child Transmission of HIV (MTCT) (UNAIDS, 2012d). The potential for vertical transmission during pregnancy and delivery was discovered early on in the HIV/AIDS
epidemic, in 1982 (Centers for Disease Control [CDC], 1982b). In 1985, a study confirmed that the HIV virus could also pass through breast milk (Ziegler, Cooper, Johnson, & Gold, 1985).

HIV viral loads increase during pregnancy, thereby increasing a woman’s potential to transmit the virus to her infant (Howell et al., 1997). A higher maternal viral load and advanced maternal immune deficiency also increase HIV transmission risk, as does exposure to maternal blood (DeCock et al., 2000). Acute chorioamnionitis (infection of the amniotic sac), prolonged rupture of membranes from induced labor, and invasive delivery procedures are also associated with increased risk of HIV transmission; vaginal delivery also carries a higher risk than cesarean sections (DeCock et al., 2000).

In the absence of interventions, the overall risk of MTCT is between 20-45%, but the risk level varies in different stages of pregnancy and breastfeeding. Estimated MTCT risk is between 5-10% during pregnancy (by placental transmission), 10-20% during labor and delivery, and 5-20% during breastfeeding (Tolle & Dewey, 2010). The overall risk for a non-breastfeeding mother who uses no intervention is approximately 20%. Six months of breastfeeding with no intervention will increase the risk to 30%, and 18-24 months of breastfeeding raises the MTCT risk to 35% (WHO, 2007a).

An infant is at risk of acquiring HIV infection from conception to the cessation of breastfeeding (Tolle & Dewey, 2010). This extended risk period requires a lengthy prevention process, and it requires intervention at multiple steps. The process, which has been termed the “PMTCT Cascade,” begins at maternal HIV diagnosis, continues through pregnancy and delivery, extends through breastfeeding, and reaches completion when the infant is appropriately tested for HIV (WHO, UNAIDS, & UNICEF, 2011). Some of the intervention steps required along the cascade include HIV testing and counseling, CD4 testing, initiation of ARVs,
nutritional counseling, adherence to medication, and infant HIV testing (Figure 1). Although each individual step may be fairly straightforward, trying to successfully navigate all the steps in the PMTCT continuum can seem complex and overwhelming to an HIV-infected mother. Outside influences such as social pressure, financial difficulties, and other responsibilities can further complicate the process, and many women do not complete all of the required steps as a result (WHO, 2010c).

MTCT clinical trials. It has been noted that few other aspects of HIV research have demonstrated results as dramatic as the perinatal HIV prevention trials (DeCock et al., 2000). The first groundbreaking study, PACTG 076, was published in the New England Journal of Medicine in 1994. This trial demonstrated that vertical transmission from mother to child could be reduced by 67% if the following conditions were met: the mother received AZT in both the antenatal and intrapartum period, and the infant received AZT while being formula-fed (Conner et al., 1994). In 1998, a Thai trial of a shorter course of AZT given antepartum and intrapartum resulted in a 38% reduction in HIV transmission (Shaffer et al., 1999). During the PETRA trial in 1999, the benefit of adding maternal AZT in the post-partum period was shown. Mothers who took AZT post-partum had a 52% reduction in MTCT, while only a 38% reduction was seen in
those who were only given AZT intrapartum (Hanna, 1999). That same year, a trial in Cote d’Ivoire showed a 37% reduction in transmission with short course AZT, even when an infected mother was breastfeeding (Wiktor et al., 1999). The following year, it was discovered that the MTCT rate was cut in half when women had cesarean sections (Read & Newell, 2005). An additional study found that MTCT of HIV could be reduced to less than 1% if AZT prophylaxis was combined with cesarean deliveries (Mandelbrot et al., 1998).

In 1999, a pivotal study occurred in which a 2-dose regimen of NVP (nevirapine) was given intrapartum and post-partum and the efficacy of this regimen compared to AZT prophylaxis. The trial, which took place in Uganda, resulted in a 47% reduction in HIV transmission for women who received the NVP regimen and were breastfeeding (Guay et al., 1999). This was comparable to results for AZT prophylaxis. While the discoveries to this point had certainly been promising, the MTCT rate could still be as high as 16% with either AZT alone or NVP alone (WHO, 2007b). Researchers began combining the two therapies, and the results were striking. When AZT was started at 28 weeks of pregnancy in addition to the single-dose NVP regimen and combined with short breastfeeding, the risk of MTCT decreased to 10% (WHO, 2007a). In 2001, the Cote d’Ivoire DITRAME + trial demonstrated a 6.2% transmission risk in breastfeeding mothers when AZT was combined with intra and post-partum NVP (Leroy et al., 2001); an extension of this study in 2003 reduced MTCT transmission to 4.7 % when lamivudine (3TC) was added to AZT (Chaix et al., 2006). In 2004, a Thai study produced a less than 2% transmission rate when a longer AZT regimen and NVP were combined in a non-breastfeeding population (Lallemant et al., 2004).

Further studies which have incorporated different classes of ARVs and the introduction of Highly Active Antiretroviral Therapy (HAART) in pregnant populations have continued to
demonstrate very promising results. The medical potential of bringing vertical transmission rates to under 2% has given many in the international health care community great hope and caused them to shift their terminology to “Elimination of Mother to Child Transmission” (eMTCT). Although a large number of infants are still acquiring HIV from their mothers due to failure at multiple points along the PMTCT cascade, vertical transmission rates of less than 2% have become the global target as of 2011 (UNAIDS, 2011a).

The use of HAART for PMTCT is the latest development in the field. In the Kesho Bora study, a multi-site trial in South Africa, Kenya, and Burkina Faso, women with CD4 counts between 200 – 500 were given HAART between 28 – 36 weeks of gestation. The study group had comparable MTCT rates to the control group, who had received AZT and single-dose nevirapine (Kesho Bora Study Group, 2012). The women on HAART, however, had lower vertical transmission rates at 12 months post-partum than did those in the control arm (Kesho Bora Study Group, 2012). The effect of the use of HAART on long term outcomes is a subject of ongoing study.

Global history of PMTCT. The first cases of MTCT in the antenatal and intrapartum period were reported in 1982 (CDC, 1982a). HIV transmission through breastfeeding was discovered in 1985, but it was not officially recognized as a mode of transmission by WHO until 1987 (WHO, 2003; Zeiger et al., 1985). By the mid-1990s, the WHO estimated that 700,000 infants worldwide were infected with the virus (Chin, 1990).

In 1996, the Food and Drug Administration (FDA) officially approved NVP as a reverse transcriptase inhibitor, and overall AIDS mortality dropped (Kuhn et al., 2009). The later discovery that single dose NVP reduced MTCT brought excitement to the health community, but the medication was still in large part considered too expensive for use in the developing world.
Despite the expansion of both research and education throughout the decade, the number of new HIV infections in women continued to grow. The epidemic rapidly took on a female face on the African continent, in particular, where a myth was widely circulated that men who were HIV+ could cure their infections by having sex with a virgin (Groce & Trasi, 2004). By 2000, HIV infection rates in pregnant women in some urban centers in eastern and southern Africa exceeded 25%, and infant and child mortality rates were estimated at 30-60% higher than they would have been in the absence of AIDS (DeCock et al., 2000).

The scripting of the Millennium Development Goals in 2000 brought PMTCT into focus as part of a broader development agenda. There are clear links to PMTCT for four of the eight goals: reduction in childhood mortality, improvement in maternal health, reduction in HIV/AIDS, and the promotion of gender equality (UN Millennium Project, 2005). Just prior to this, in 1999, the Inter-Agency Task Team (IATT) on the Prevention of HIV Transmission in Pregnant Women, Mothers, and Their Children had been established and tasked with promoting PMTCT scale-up worldwide (IATT, 2013a). The Millennium Development Goals and the IATT both recognized the need for coordinated global strategies which would address the needs of the international community. At its inception, IATT was comprised of UNAIDS, WHO, UNICEF, and the United Nations Population Fund (UNFPA). In 2001, the World Bank was added as a new member, then IATT further expanded in 2004 to include the CDC, the United States Agency for International Development (USAID), the Elisabeth Glaser Pediatric AIDS Foundation (EGPAF), Columbia University, Family Health International, the Catholic Medical Mission Board, and the Population Council. By 2007, multiple other organizations had joined IATT, including the Clinton Foundation, World Vision, Intrahealth, the Baylor Pediatric AIDS Initiative, and the International Community of Women Living with HIV/AIDS (IATT, 2013a).
In 2001, a Declaration of Commitment on HIV/AIDS issued at the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) committed its 189 Member State signatories to reduce the percentage of HIV-infected children born to mothers with HIV infection by 20% by 2005 and by 50% by the year 2010 (WHO, 2005b). There was some progress made toward the initial goal, and from 2004-2005, three of the countries in sub-Saharan Africa with the highest HIV prevalence rates (Namibia, South Africa, and Swaziland) more than doubled their rates of maternal ARV prophylaxis (WHO, 2005a). Despite this, in 2005 alone, an estimated 540,000 children were newly infected with HIV, with approximately 90% of these infections occurring in sub-Saharan Africa (WHO, 2007b).

In response to the ongoing crisis, the UN General Assembly again addressed the issue in 2005, committing to scale-up comprehensive national AIDS responses before 2010 (WHO, 2005b). The report from that session highlighted the fact that 10% or less of women in developing nations were receiving appropriate ARVs for PMTCT, despite MTCT having been drastically reduced by that time in the developed world. UN member states committed to increasing financing for PMTCT programs, integrating PMTCT into Maternal Child Health (MCH) programs, and engaging communities and HIV-positive individuals in the fight against vertical transmission. Each country also declared a commitment to the “Three Ones Principle:” one national strategy for PMTCT, controlled by one national coordinating authority, with one national monitoring and evaluation system (WHO, 2005b). Not long after the UNGASS meeting in 2005, the focus on increasing country ownership and developing local leadership capacity for PMTCT programs began to grow (WHO, 2007b). By the end of 2006, 71 countries had developed country-specific PMTCT policies and scale-up plans, and half of them were in the initial stages of implementation (WHO, 2007b).
As part of the 2005 meeting, a global target was set to reduce new HIV infections in children by 20%. However, at the end of 2006, only eight countries had exceeded the 40% maternal ARV prophylaxis uptake needed to meet this goal, and Botswana was the only African nation in the group (WHO, 2007b). In 2007, the WHO stated that women clearly represented the population with the most rapidly growing HIV infection rates worldwide, and over 60% of new infections in sub-Saharan Africa were occurring in women, infants, or young children (WHO, 2007b). In the same year, only 11% of HIV infected pregnant women worldwide received appropriate ARV therapy to prevent MTCT. The coverage rates in low and middle income countries were extremely variable, ranging from a high of 77% in Eastern Europe down to lows of 3% and 2% in West Africa and South Asia, respectively (WHO, 2007b). Nine out of the 10 countries that accounted for over 65% of all MTCT infections at the time were in sub-Saharan Africa; India was the only country outside of the region on this list (WHO, 2007b).

UNICEF and WHO issued a joint proposal in 2007 entitled “Acceleration of Prevention of Mother-to-Child Transmission (PMTCT) and Scale up of Linkages to Paediatric HIV Care and Treatment.” As part of this proposal, UNITAID was established in order to accelerate the distribution of HIV testing kits and ARVS in eight HIV high-burden countries (WHO, 2007b). Other organizations such as PEPFAR have also taken on increasing responsibility for scaling up distribution of ARVs in high priority countries over the last decade (PEPFAR, 2010). These initiatives, along with individual country commitments, have resulted in progress, and the number of new HIV infections in children dropped worldwide by 43 percent between 2003 and 2011 (UNAIDS, 2012d). The distribution of these infections throughout that time remained highly concentrated in certain countries, the majority of which were in sub-Saharan Africa. In response, PEPFAR established “PMTCT Acceleration Plans” in 2010 for Malawi, Mozambique,
Nigeria, South Africa, Tanzania, and Zambia, six countries with extremely high burdens of MTCT (PEPFAR, 2010). Other organizations made similar commitments to increase the coverage and focus on the regions containing the highest numbers of new childhood HIV infections.

Although progress was being made, the year 2011 still documented between 330,000 and 420,000 new infant HIV infections globally (Sullivan, Drobac, Thompson & Rodriguez, 2011; UNAIDS, 2012f). In 2011, UNGASS launched the “Global Plan,” an ambitious agenda that set a goal to eliminate all new infections among children by the year 2015 and to substantially reduce maternal mortality (UNAIDS, 2012c). Another goal under of the Global Plan is to provide ARVs to 15 million people, a large percentage of whom will be pregnant women. The WHO issued a similar strategy that same year entitled “The Global Health Sector Strategy 2011-2015;” it includes a target goal of reducing vertical transmission by 90% worldwide (WHO, 2011a). In order to effectively reduce and eliminate infant HIV infections, four key strategies were identified and recommended: 1) reducing the transmission of HIV to women of childbearing age; 2) meeting the family planning needs of HIV + women; 3) offering appropriate ARVs to HIV infected women and their infants; and 4) ensuring the well-being and support of HIV+ women and their families for treatment (UNAIDS, 2011a; WHO, 2010d). It was also recommended in this document that PLHIV be involved in planning HIV prevention services in order to increase the effectiveness of interventions (WHO, 2011a).

As a result of these commitments, the ARV coverage of pregnant women rose to 57% in low and middle income countries by 2012, an enormous improvement over previous years (UNAIDS, 2012d). In sub-Saharan Africa, the overall coverage was estimated at 59% (UNAIDS, 2012c). The scale-up of ARV coverage for exposed infants has not been as successful, although
it has also shown some improvement. Among the estimated 1.49 million infants who were born to mothers living with HIV in 2011, 42% received prophylactic ARVs, an increase from 32% in 2009 (WHO, 2011b). In sub-Saharan Africa, where approximately 90% of HIV infected children live, the percentage of eligible infants who received appropriate ARVs was up to 54% (UNAIDS, 2012d).

Many common problems exist in implementing PMTCT programs in the African region, including poor health system infrastructure, widely dispersed populations, lack of financing, and social and cultural concerns (Osumba, 2009; WHO 2010d). Even across Africa, however, the rates of maternal ARV coverage are highly variable. Botswana, Ghana, Namibia, South Africa, Swaziland and Zambia reached over 75% of eligible women with PMTCT services in 2011, while Sierra Leone, Cameroon and Rwanda achieved coverage rates of 50-74 % (UNAIDS, 2012e). Benin, Burkina Faso, Malawi, and Guinea reached only 25-49% of eligible pregnant women with PMTCT in 2011, and less than 25% of pregnant women living in Chad, Ethiopia, Angola, the Democratic Republic of the Congo, Angola, Eritrea, Nigeria, and South Sudan have been reached (UNAIDS, 2012e). As expected, countries which have the most improved coverage of maternal ARV services have also seen the greatest reductions in the number of new childhood HIV infections. Burundi, Kenya, Namibia, South Africa, Togo and Zambia have succeeded in reducing the number of new child infections within their borders by more than half (UNAIDS, 2012f).

There are a variety of reasons which account for this variability among nations, many of which are driven by the governmental response to the problem. In many nations with poorly functioning PMTCT systems, the government has been slow to respond to the epidemic. As an example, the Democratic Republic of the Congo did not devise a plan to transfer the ownership
of PMTCT programs from outside sources to local health systems until 2011. They also did not institute voluntary HIV testing for pregnant women until 2007, and they did so at that time only in labor and delivery units of hospitals (EGPAF, 2013). In 2006, by contrast, many other sub-Saharan African nations moved beyond voluntary testing and adopted “opt-out,” or “Provider Initiated Testing and Counseling” (PITC), according to the WHO guidelines. A systematic review of the effect of this policy change across the region showed an increase in testing that ranged from 13-66% (Verani, Hurley & Borse, 2013).

The governments of Botswana, South Africa, Namibia, Gabon, and Mauritius had all taken great initiative by funding more than half of their national HIV responses by the year 2011, although external funding sources still accounted for more than 50% of HIV investments in the entire region (UNAIDS, 2012f). In 21 priority countries in sub-Saharan Africa, services to prevent new pediatric HIV infections had also been fully integrated into maternal and child health care by 2011, demonstrating commitment on the part of national leadership to move forward with PMTCT acceleration (UNAIDS, 2012f). The political leadership for PMTCT programs in these nations is strong, and they demonstrate that success is possible in PMTCT programs, even in nations which have extremely high HIV prevalence rates.

The recent PMTCT scale-up efforts in Malawi also indicate that broad systemic changes can be made through strong and creative government leadership, even in resource poor settings. Although Malawi’s MTCT rate is still high, it has been declining quickly over the last several years. Between 2009-2011, the MTCT rate in Malawi decreased from 31% to 25%, and dramatic increases in patient enrollment have been seen since Option B+ was instituted. Since the plan’s implementation in July 2011, the number of pregnant women on ART has increased by 748% (UNAIDS, 2012b). Additionally, the new national plan under Option B+ required full
integration of ANC and PMTCT sites, which facilitates easier access to treatment for women and their children. UNICEF (2012) has noted that with the roll-out of Option B+, Malawi could potentially reduce their vertical transmission rate by 81% in 2015.

**WHO PMTCT guidelines.** Providing antiretroviral prophylaxis to pregnant women living with HIV has prevented more than 350,000 children from acquiring HIV infection since 1995 (WHO, 2011b). As the medical evidence for appropriate therapy has changed and the spectrum of HIV medications has expanded, the WHO took on the role of providing international guidance on appropriate therapy for HIV infected pregnant women and their infants. The first PMTCT guidelines issued by the WHO were introduced in 2001 and have undergone continual revision as the HIV epidemic evolved. New guidelines which were issued in 2004, 2006, 2010, and 2012 (Table 2) and will be discussed further later in this document. The comprehensive WHO guidelines also include detailed variations on these recommendations for treating women who are anemic, co-infected with tuberculosis, or infected with the HIV-2 strain (WHO, 2010b).

In addition to medication regimens, the WHO recommendations offer advice on other aspects of PMTCT care such as HIV testing and infant feeding. In 2006, the guidelines recommended that all PMTCT and ANC facilities utilize “opt-out testing” in order to increase HIV testing uptake, and they also gave extensive recommendations for pre-test and post-test counseling (WHO, 2006). Pretest counseling, according to the guidelines, was to be utilized to educate women and their partners about MTCT risk and HIV; post-test counsel would provide women or couples with the HIV test result, encourage disclosure and partner testing, and offer prevention education and referrals to support services (WHO, 2006).

**Breastfeeding guidelines.** The WHO has issued over 16 documents and recommendations on infant feeding practices for HIV+ women over the last several decades. Beginning in 1992, they
first recommended that breastfeeding should be the standard practice in HIV+ women in areas in which infectious disease and malnutrition were the primary causes of infant death (WHO, 1992). In 1997-98, the WHO published new infant feeding guidelines in which they advised that all HIV+ mothers should be counseled about various feeding options and allowed to make a choice. Many in the global health care community saw this position as a shift toward encouraging formula feeding, and newly developing PMTCT programs began to offer free infant formula in many locations (WHO, 2004). Support for this practice was strengthened by ongoing clinical studies. In the year 2000, data suggested that one third to one half of perinatal HIV infections in Africa were due to breastfeeding (DeCock et al., 2000); a meta-analysis by the Breastfeeding and HIV International Transmission Study Group in 2004 attributed 42% of infant infections to breast milk (Coutsoudis et al., 2004). The duration of breastfeeding was also shown to influence MTCT risk, with more extended breastfeeding leading to increased transmission rates (DeCock et al., 2000). However, it was discovered that the risk of HIV transmission in infants who were exclusively breastfed was actually lower than that among infants who were given mixed feeding regimens (Kourtis, Lee, Abrams, Jamieson & Bulterys, 2006).

In 2000, as the financial and logistical challenges of providing replacement feeding in low income contexts continued, the WHO highlighted the potential pitfalls of recommending formula feeding in low income environments. A meta-analysis demonstrated that infants who were not breastfed and received infant formula or other replacement food had a 6-fold increased risk of dying during their first two months of life, a 4-fold increased risk of dying between 2 and 3 months of age, and a 2.5-fold increased risk of death between 4 and 5 months compared with those who were breastfed. As a result, the WHO developed what was termed the “AFASS criteria.” In order for formula feeding to be recommended according to the criteria,
<table>
<thead>
<tr>
<th>Recommendation year</th>
<th>Maternal ARV regimen</th>
<th>Infant ARV regimen</th>
<th>Breastfeeding guideline</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>sd-NVP* at delivery</td>
<td>sd-NVP within 72 hours after birth</td>
<td>Formula feed if AFASS criteria can be met</td>
</tr>
<tr>
<td>2004</td>
<td>1. Initiate HAART regimen*</td>
<td>sd- NVP at birth and 7 days of AZT</td>
<td>Formula feed if AFASS criteria can be met</td>
</tr>
<tr>
<td></td>
<td>2. Preferred regimen: initiate AZT at 28 weeks of pregnancy &amp; sd- NVP at delivery</td>
<td>Acceptable alternative regimens:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• AZT + lamuvidine</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• sd-NVP</td>
<td></td>
</tr>
<tr>
<td>2006</td>
<td>1. Initiate HAART if CD4 &lt;200 or clinical stage 3 or 4</td>
<td>sd-NVP at birth and 7 days of AZT (28 days if mother HAART eligible and has taken &lt; 4 weeks)</td>
<td>Breastfeed unless AFASS criteria can be met</td>
</tr>
<tr>
<td></td>
<td>2. Initiate AZT at 28 weeks of pregnancy, sd-NVP at delivery, and 7 days of AZT and 3TC post-partum</td>
<td>HAART eligible and has taken &lt; 4 weeks</td>
<td></td>
</tr>
<tr>
<td>2010</td>
<td>1. Initiate HAART at diagnosis if CD4&lt;350</td>
<td>1. NVP or AZT for 4-6 weeks if mother HAART eligible</td>
<td>Exclusively breastfeed for 6 months if mother on ARVs unless AFASS criteria can be met</td>
</tr>
<tr>
<td></td>
<td>2. <strong>Option A</strong>: Initiate AZT at 14 weeks, NVP and AZT at delivery, tenofovir (TDF) or emtricitabine (FTC) for 1 week post-partum</td>
<td>2. <strong>Option A</strong>: sd-NVP at birth then NVP or AZT for 6 weeks, or one week after end of breastfeeding</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Option B</strong>: Initiate HAART at 14 weeks regardless of CD4 status</td>
<td><strong>Option B</strong>: NVP or AZT for 6 weeks regardless of breastfeeding</td>
<td></td>
</tr>
<tr>
<td>2012</td>
<td>Initiate HAART for all HIV+ pregnant women and continue for life regardless of CD4 count</td>
<td>NVP or AZT for 6 weeks regardless of breastfeeding</td>
<td>Exclusively breastfeed for 6 months if mother on ARVs unless AFASS criteria can be met</td>
</tr>
</tbody>
</table>

Notes: *single-dose nevirapine. †“Acceptable, Feasible, Affordable, Sustainable, and Safe” circumstances for formula feeding. ‡“Highly Active Anti-retroviral Therapy.” §Commonly used HAART regimens safe in pregnancy are AZT +3TC +NVP; AZT +3TC + (EFV); TDF+ 3TC +NVP; and TDF +3TC + EFV.
it should be “Acceptable, Feasible, Affordable, Sustainable, and Safe” (WHO, 2001). The circumstances of each individual mother should be considered in decision making with these guidelines: exclusive formula feeding was recommended if the AFASS criteria could be met and exclusive breastfeeding for the first few months of life if not (WHO, 2001). Mixed feeding, a common practice in which breastfeeding is mixed with early supplementation of fluids and solids, was discouraged in all cases due to an increased HIV transmission risk of over 75% when compared to exclusive breastfeeding (Iliff et al., 2005; Coovadia et al., 2007).

Another large study in South Africa found that infant mortality at 3 months was almost doubled in the group who received infant formula compared to those infants who were breastfed (Coovadia et al., 2007). As this study and other research confirmed the higher risk of all-cause infant mortality with formula feeding in many contexts, the WHO revised their guidelines again in 2006. Mixed feeding was still discouraged, but the agency changed their statement to read that exclusive breastfeeding was recommended unless replacement feeding could meet the AFASS criteria. Although this was technically the same recommendation as in 2001, the WHO hoped to increase their emphasis on exclusive breastfeeding by placing it first in the wording in the guidelines. This revision also removed the recommendation for cessation of breastfeeding at 6 months, for concerns of ongoing all-cause infant mortality in formula-fed infants extended beyond the 6 month period (WHO, 2007a).

The next infant feeding guidelines from the WHO were released in 2010. These recommendations stated that HIV + mothers who were on ARVs should exclusively breastfeed their infants for the first six months of life. They should continue breastfeeding and add complementary food for the first 12 months of life, and commercial infant formula should only
be given as replacement feeding if AFASS criteria were met. Finally, all cessation of breastfeeding should be done gradually, over a period of a month or more (WHO, 2010b).

The WHO guidelines have changed in response to scientific evidence as it evolves, but science often precedes practice. Since most national PMTCT programs were initially rolled out between 1999-2003, the 2001 guidelines on infant feeding predominated the training of health care workers in PMTCT. These guidelines promoted replacement feeding as the method of choice, and their influence is still being felt over a decade later. National policies and PMTCT implementers have had a difficult time keeping up with the rapidly changing guidelines, and this has hindered the effectiveness of any sort of infant feeding guidelines in many locations (Moland et al., 2010). In many locations, the primary problem has been that health care systems and training are fragmented, and many post-partum counselors do not adequately understand current PMTCT guidelines (Koricho, Moland & Blystad, 2010). In other situations, the attitudes of the infant feeding counselors toward breastfeeding play a more significant role.

Observation of nutritional counseling practices in Ethiopian sites revealed that many counselors were highlighting the risk of HIV transmission through breastfeeding to mothers and failing to explain the increased risk for infant mortality with replacement feeding if AFASS criteria were not met (Koricho et al., 2010). In some of these observed sessions, the possibility of breastfeeding was not even presented as an option to the mother. The majority of infant feeding counselors interviewed in both Ethiopia and Tanzania expressed their understanding of the 2006 WHO recommendations for breastfeeding in the absence of the AFASS criteria, yet they admitted to counseling primarily for formula feeding due to their own negative attitudes toward breastfeeding (Koricho et al., 2010; Leshabaari, Blystad & Moland, 2007).
It is not only counselors who have had difficulty keeping up with the shifting recommendations. HIV + mothers are frequently confused as well, and misunderstanding and fear for their child’s health often makes them doubt whatever feeding advice is given (Koricho, 2010). Although they were counseled to breastfeed because they did not meet the AFASS criteria, many impoverished mothers in Ethiopia still searched for infant formula because they believed they had “poisonous milk” (Koricho et al., 2010). Many of these mothers expressed a belief that breastfeeding would be wrong: several stated that chance of having a non-infected infant after breastfeeding “could only be through God’s mercy” (Koricho et al., 2010). The women expressed guilt and regret if they had to switch to breastfeeding when their money ran out, and some resorted to begging in order to afford formula (Koricho et al., 2010).

In addition to the confusion and fear they may invoke, the infant feeding guidelines may conflict with local customs (Engebretson et al., 2010). In most of sub-Saharan Africa, prolonged mixed feeding is standard, introducing complementary foods early in life while continuing to breastfeed for extended time periods. Ugandan mothers expressed that peer support would be critical in order to maintain the practice of exclusive breastfeeding for 6 months because of the emotional difficulty it would create (Nankunda, Tumwine, Nankabirwa & Tylleskär, 2010). Concerns such as this have led many mothers to combine breastfeeding and replacement feeding as the situation requires (Koricho et al, 2010).

**Medication guidelines.** A Technical Consultation was convened by the WHO in October of 2000, during which it was decided that all regimens shown to be effective in controlled clinical trials at the time could be recommended for use in MTCT prevention. These regimens include zidovudine alone, zidovudine plus lamivudine, and nevirapine alone (WHO, 2000b). Early in 2001 the WHO released a technical report which continued to support all three regimens
but highlighted the use of single-dose nevirapine due to its ease of use and the fact that a manufacturer was donating the medication free of charge. Under these guidelines, a single 200 mg dose of oral NVP was to be given to an HIV infected mother at the onset of labor, and a single oral dose of NVP suspension was to be given to her infant within the first 72 hours after birth (WHO, 2001).

2004 guidelines. Concerns for the emergence of resistant HIV viral strains was linked to short-course PMTCT regimens that do not fully suppress the virus, including single-dose nevirapine, as early as 2000 (Stringer, Sinkala, Rouse, Goldenberg & Vermund, 2002). However, the simplicity and practicality of delivering single-dose nevirapine compared to other regimens kept it in place as a practical PMTCT alternative when the provision of more effective regimens was not feasible. The 2004 WHO guidelines continued to recommend single-dose nevirapine for use in PMTCT programs in which other alternatives were not yet logistically possible. In more developed settings where other regimens were accessible, infected women without an indication for ART (anti-retroviral therapy) treatment for their own condition were to be given AZT starting at 28 weeks of pregnancy and single-dose NVP during labor and delivery. Their infants were to receive single-dose NVP at delivery and one week of AZT. Short course AZT plus lamuvidine was offered as an alternative to this regimen, and all women who needed HAART for their own health were to be initiated on the proper medications according to WHO guidelines (WHO, 2004).

2006 guidelines. Along with pre and post-test counseling and opt-out testing, the 2006 WHO guidelines recommended that all pregnant women should be HIV tested as early as possible in each new pregnancy. Repeat testing late in pregnancy was also recommended for HIV-negative women in high-prevalence regions, along with routine testing of all HIV-negative
women at the time of delivery (WHO, 2007b). The recommended medical regimen under these guidelines included appropriate ART treatment for women who were eligible based on clinical staging or CD4 testing (CD4 count < 200 or clinical stage 3 or 4). The emphasis on ART for the mother’s own health was a highlight of the 2006 guidelines, and it could be given in one of several triple therapy combinations. Infants born to these women would receive one week of AZT after delivery or 4 weeks of AZT if their mother had not taken ART for over 4 weeks.

For women who were not ART eligible for their own care, prophylactic regimens were to include the daily AZT initiated at 28 weeks of pregnancy, single-dose NVP, and a 7-day “tail” of AZT and 3TC. The AZT and 3TC tail was added to overcome rising nevirapine resistance, which at the time was about 12%. Due to concerns over this resistance, the recommendation for single-dose nevirapine as a treatment option was withdrawn under these guidelines (Colvin et al., 2007). HIV-exposed infants under the 2006 guidelines would receive single-dose nevirapine at delivery and a one-week course of AZT.

2010 guidelines. The 2010 guidelines emphasized three main points: 1) earlier ART for a larger group of HIV+ pregnant women to benefit both the health of the mother and prevent HIV transmission to her child during pregnancy; 2) longer provision of ARV prophylaxis for HIV+ pregnant women who do not need ART for their own health to reduce MTCT risk; and 3) provision of ARVs to the mother or child to reduce the risk of HIV transmission during the breastfeeding period.

Under the new recommendations, the CD4 count which would make a woman eligible for ART for her own therapy was raised from 200 to 350; this would include approximately 40% of HIV+ pregnant women worldwide. In non-pregnant adults, it was documented that initiating HAART at CD4 counts less than 350 produced better clinical outcomes and reduced HIV viral
loads. Pregnant women with CD4 counts less than 350 are at the highest risk of transmission at any time in the PMTCT continuum, and they account for greater than 75% of the MTCT risk. Over 85% of maternal deaths within 2 years of delivery also occur in this group of women, and maternal survival plays a key role in infant survival. The earlier initiation of ART offered a strong benefit to both maternal health and child survival, and a triple therapy HAART regimen was to be started as soon as diagnosed during pregnancy in these women. Their infants would receive NVP or AZT for 4-6 weeks, regardless of when their mother began ART.

For women who were not eligible for ART for their own health, ARV prophylaxis for PMTCT was to be started under these guidelines at 14 weeks of gestation, or as soon as possible. The biggest shift in these recommendations came with the addition of a new option for PMTCT prophylaxis, in addition to the previously recommended AZT therapy. It had been discovered by this time that the use of a HAART triple therapy regimen in mothers who did not require it for their own health was as effective as AZT plus single-dose nevirapine for PMTCT, so it was added to the guidelines as a second option. The choice of which prophylactic regimen to use was to be guided by country choice (WHO, 2010a).

Under “Option A,” AZT is given to the mother twice daily beginning at 14 weeks of gestation, along with intrapartum NVP and AZT. A tail of either tenofovir (TDF) or emtricitabine (FTC) for 1 week post-delivery is included to combat nevirapine resistance. Infants under this regimen will begin receive NVP at birth, then begin daily NVP or AZT for either 6 weeks or until one week following the cessation of breastfeeding.

“Option B” uses HAART for pregnant women, even if they are not eligible for therapy for their own ongoing care. The currently preferred regimens for triple therapy are either AZT +3TC +NVP or AZT +3TC +efaviren (EFV). Although concerns of teratogenicity with EFV
have not been proven in a statistically significant study, it is generally still avoided in the first trimester. TDF has been noted to be as efficacious as AZT and safe in pregnancy, and it may be substituted in either regimen.

If the mother is treated with HAART during pregnancy, no additional treatment is required in the intra-partum period. Infants will be given daily NVP or AZT from birth until 6 weeks of age, regardless of breastfeeding status. All infants under the 2010 guidelines should be PCR tested at 6 weeks and initiated on HAART if found to be HIV+.

Since the 2010 guidelines were released, clinical and community trials continue to compare the safety and efficacy of PMTCT regimens. When infant NVP was provided for an extended period of 14 weeks or 28 weeks post-delivery, the HIV transmission risk at 12 months was almost half of that for infants who received NVP for only 6 weeks (Jamieson et al., 2012; Taha et al., 2011). Outcomes also improved when mothers remained on HAART for longer periods of time. The Kisumu Breastfeeding Study in Kenya showed low rates of drug toxicity and vertical HIV transmission when triple drug therapy was given to mothers for up to 6 months post-partum (Thomas et al., 2011). The BAN study started maternal HAART after delivery and continued it for 28 weeks post-partum, and the infant HIV infection rates were lower in the study group than in the control group (Jamieson et al., 2012). The lowest MTCT rate among breastfed infants seen so far (1.1%) occurred in a study which compared 3 different HAART regimens (Shapiro et al, 2010). No currently published studies directly compare Option A and Option B outcomes, but the 1077 PROMISE study started in 2011 will provide this comparison. It will also evaluate the efficacy of the antenatal/intrapartum and postpartum components of Option A and Option B (Chi, 2012).
2012 guidelines. “Option B+”, first introduced and implemented in Malawi by their government in 2011, calls for a radical departure from former PMTCT thinking. Under Option B+, all HIV-infected pregnant women initiate lifelong ART at diagnosis, irrespective of their clinical or immunologic status. This option promotes inclusion with other MCH services, and ART is initiated earlier in pregnancy for most women since CD4 testing is not required. Option B+ has been recommended for many of the same reasons as Option B: the higher MTCT risk in mothers with CD4< 350, the large percentage of pregnant women who qualify for ART (over 40%), the faster reduction in HIV viral load which leads to decreased transmission rates, and improved maternal health. The recommendation to continue HAART after delivery regardless of the mother’s CD4 count is another new element of Option B+, and its proponents offer several suggestions for its potential benefits. The use of lifelong HAART will improve maternal health and survival, which will also have an indirect effect on reducing under-5 mortality (UNICEF, 2012). Additionally, long-term HAART may reduce MTCT risk early in future pregnancies. A 96% reduction in horizontal HIV transmission to sero-discordant, HIV-negative partners was seen when individuals with CD4 counts of 350–550 cells started ART (Cohen et al., 2011); lifelong HAART is therefore likely to provide primary prevention benefits to sexual partners as well (UNICEF, 2012).

In 2012, WHO issued an endorsement of Option B+ and highlighted the decreased MTCT risk, decreased maternal mortality risk, and simplification of the medication regimen for patients as key supporting evidence. The guidelines also pointed out that simplifying the delivery regimens may be an advantage to health care workers and health systems. When the 2010 guidelines first significantly increased the pool of women eligible for HAART, many in the health care community were concerned that inefficient delivery systems would not be able to
keep up with the increased demands for medication and CD4 testing (WHO, 2010d; Karim et al., 2011). With the elimination of the need for CD4 testing or clinical staging under Option B+, at least part of that concern is eliminated.

Some concerns exist about the safety of both Option B and Option B+, however, since the effects of long term exposure to HAART early in life may have on an infant are not well known. In a Botswana study of over 9000 women, use of HAART prior to conception was associated with higher risks for preterm delivery, low birth weight, and stillbirth (Chen et al., 2012). Maternal HAART has also been associated with an increased risk for severe infant anemia compared with maternal and infant AZT regimens (Dryden-Peterson et al., 2011). Concerns also exist about the potential effects of repeated exposure to HAART in women who do not require it for their own health (as could occur in multiple pregnancies utilizing Option B) (Mofenson, 2010). What effect long term ARV use may have on the quantity or quality of breast milk production is unclear, and there has been some evidence of the risk of antiretroviral drug resistance increasing among failed cases of HIV prophylaxis (Young et al., 2011; Chi et al., 2012).

The costs associated with PMTCT drug regimens have decreased dramatically over the last decade, and some pediatric formulations cost as little as a nickel or less per dose by 2010 (Johri & Ako-Arrey, 2011). With an estimated cost ratio of less than $1000 per infection averted, PMTCT is considered one of the most cost effective public health interventions available in low and middle income countries (Bollinger & Stover, 2006). The initially increased expense of offering Option B+ will hinder this performance, but over the long term it may actually decrease costs even further. New cost evaluations will be required as Option B+ is rolled out in an increasing number of countries (Johri & Ako-Arrey, 2011).
Adaptation of WHO PMTCT guidelines in Africa. The adaptation to the 2010 WHO guidelines in most locations in Africa was much faster than it had been in 2006. However, countries were still left to wrestle through the decision on which treatment option was best for their populations. In many cases, it was decided that Option A was more affordable and feasible for their health systems than was Option B at that time. Additionally, the thought of having to retrain multitudes of health workers in the use of a new medication regimen was daunting, and most of these workers were already familiar with the use of AZT. Skeptics also questioned the capacity of the health systems to maintain use of Option B (Ghantokis, Miller & Spensley, 2012).

For these reasons, most of the sub-Saharan African region adopted Option A when the 2010 WHO guidelines were initially released. Cameroon, Democratic Republic of the Congo, Kenya, Ghana, Lesotho, Mozambique, Namibia, South Africa, Swaziland, United Republic of Tanzania, Uganda, Zambia, Ethiopia, Zimbabwe, and parts of Nigeria all chose Option A for their national guidelines. Botswana, Côte d'Ivoire, Burundi, Chad, and parts of Nigeria chose Option B, and Malawi created Option B+ (Ghanotakis et al., 2012). Angola did not state an intention to adopt any of the WHO recommendations at the time (UNICEF, 2012).

By 2012, many Ministries of Health in the region were beginning to endorse universal antiretroviral treatment or prophylaxis for HIV-infected pregnant women and shifting to Option B. The reasons behind the broad shift are several. Primarily, there was a concern over lack of adherence to Option A for both mother and infant. Option A requires extended NVP be delivered to the infant throughout breastfeeding, and this provides a large window for attrition. Even in cases when NVP was being given regularly, it was often being dosed incorrectly by mothers (Changala et al., 2012). Option A is also more problematic for health systems, requiring more
complicated procurement of a variety of medications and difficulty in maintaining large supplies of NVP syrup (UNICEF, 2012). Additionally, the change in medication regimens for the mother required after delivery under Option A could be confusing (Shikawa et al., 2012). Finally, in order to receive proper intrapartum care under Option A, either a facility based delivery or one with a skilled birth attendant trained in PMTCT is required. This was problematic in many countries where home based delivery is common (UNICEF, 2012).

In addition to being easier for patients to take, Option B is more amenable to the goal of many PMTCT programs to integrate PMTCT with other health services. The same ARV regimen can be used for all adults under Option B, and this greatly simplifies health worker training and their workload. The introduction of a generic fixed dose combination of TDF/3TC/EFV in 2009 removed concerns over difficulty with medication administration, and it made concerns over cost less relevant (UNICEF, 2012). Ministers of Health were also gaining an increasing understanding of the cost-effectiveness of Option B over time (Chi et al., 2012). The growing support for Option B was a key starting point for potential transitioning to the 2012 addition of Option B +.

The Malawi Ministry of Health engaged in concentrated planning and extensive preparation for the roll-out of Option B+ before its implementation in July 2011 (Chirwa, Chimbwandira, Jahn & Batenganya, 2012). Over 4000 health workers had been trained and 600 new PMTCT/ART sites prepared before Option B+ went into effect, which helped the country significantly with the dramatically increased demand for HAART. Within one year of implementation, 45,000 pregnant women had started lifelong ART under the new guidelines, and that number is expected to continue to sharply increase as the strategy takes hold (Government of Malawi, 2012).
Angola, DRC, Ethiopia, Lesotho, Malawi, Mozambique, Namibia, Uganda, Tanzania, Zambia, Zimbabwe, and Rwanda, have all now adopted Option B+ and are in varying stages of preparing to bring services to scale (IATT, 2013b). In Uganda, the national guidelines now support Option B+, but little implementation has been completed due to funding issues (UNICEF, 2012). Other Ministries of Health that are piloting sites to evaluate Option B+ include Cameroon, Kenya, South Africa, and Swaziland.

**Global challenges and progress in PMTCT.** Although the scientific advances in ARVs have been enormous, many PMTCT systems are still failing to promote the reduction rates in infant HIV transmission being called for in the global community. A breakdown in any one of the steps along the PMTCT cascade can result in infant HIV transmission, and each woman must adhere faithfully to the entire continuum of care. The process starts when she gets tested for HIV, after which she must receive the test results, initiate treatment or prophylaxis, and adhere to the prescribed medications for the correct duration of time. Mothers must also give their exposed infants the proper ARV prophylaxis regimens and bring them for early HIV testing, ensuring prompt treatment if they are found to be infected. Systematic breakdowns are common along many points in the pathway; each can increase loss to follow-up (LTF) and reduce PMTCT program impact. It has been noted by health system researchers that the continual introduction of more effective ARV combination treatments will fail to yield high reductions in the number of childhood HIV infections in the absence of better performance at each step of the PMTCT continuum (Verani et al., 2013).

A meta-analysis of 44 studies in Africa and 75,172 HIV-infected pregnant women highlighted the problem of LTF in the PMTCT system. While 94% of pregnant women in the analysis accepted HIV testing under the opt-out approach, only 70% of those identified as HIV-
positive initiated any form of ART (Wettstein et al., 2012). In many PMTCT programs, women were either not tested quickly for HAART eligibility, or they did not receive their results on the same day and failed to return (Chi et al., 2012). Among those mothers who did learn that they qualified for HAART for their own health, only 62% initiated treatment (Wettstein et al., 2012). Of all pregnant women living with HIV in low and middle income countries in 2010, only 48% received an effective PMTCT regimen (excluding single-dose NVP) (WHO, UNAIDS & UNICEF, 2011). Finally, only 64% of HIV exposed infants had early HIV testing performed, and an even smaller percentage of infected infants received ART (Wettstein et al., 2012; EGPAF, 2013). Although adherence varies greatly across countries and programs, this analysis confirms that newer and more effective PMTCT approaches are required on a global scale. Every point of possible attrition must be addressed.

**Barriers to PMTCT uptake and adherence.** Possible reasons for women not to follow the PMTCT system through to completion exist on many levels, and each woman’s situation is different. Systemic, social, cultural, and religious influences, as well as personal beliefs, may all contribute to the high rate of attrition along the PMTCT cascade, and these influences often overlap. In a large systematic review of PMTCT studies from 2000-2010, most of which were completed in sub-Saharan Africa, attrition along the PMTCT pathway was associated with stigma, economic concerns, lack of partner disclosure, and poor interactions with the medical community (Ferguson et al., 2012). A systematic review of community based PMTCT interventions uncovered barriers to PMTCT regimens including low risk perception, low motivation or self-efficacy, poor mental or physical health, household inequality, low levels of partner disclosure, gender roles that do not prioritize women’s health, religious or spiritual beliefs, stigma, and a bad policy environment (Busza et al., 2012). In the same study,
interventions targeting male involvement, peer support, and mother to mother groups each increased adherence to PMTCT, but the authors noted that the results are not necessarily replicable to other locations. Both barriers to PMTCT and successful interventions exist in the context of a culture, community, and social system, and these vary widely across settings (Busza et al., 2012).

Lack of adequate knowledge about HIV and PMTCT is a common problem. In Uganda, a community based survey done with 100 women of reproductive age (WRA) revealed that 91% knew MTCT occurs and 72% were aware of PMTCT therapy; most recalled hearing messages about PMTCT from a health worker (Atwiine et al., 2013). However, only 7% had completely adequate knowledge about MTCT and understood all of the prevention steps required to prevent HIV transmission. Although 82% of the women knew MTCT could occur during labor and delivery, only 54% of them knew that breastfeeding was a risk and 23% that HIV could be transmitted during pregnancy (Atwiine et al., 2013). When Ugandan women were tracked and interviewed about their attrition from PMTCT programs, one of the main reasons they expressed for drop-out was failure to understand the importance of follow up and or the potential for infant death (Ahou et al., 2010). Lack of understanding about HIV and ARVs has also been cited as a barrier to access in Kenya (Otieno et al., 2010). In Cote D’Ivoire, an estimated 35% of ARV eligible women adhered to complete PMTCT regimens, and Painter and colleagues (2004) documented a common misunderstanding of HIV among women who refused medication.

We are told that the virus passes in the blood and my infant shares my blood. The contamination between me and my infant had already happened, so [there is] no hope of saving it. We have always been told that you can’t cure AIDS, so the medications that I heard about are nothing but an illusion for me. (Painter et al., 2004, p. 544)
Disbelief of their own HIV positive test results was also common in this population (Painter et al., 2004).

Many Ugandan mothers demonstrate a lack of understanding of how to properly take PMTCT medications, and as a result they do not completely comply with maternal regimens nor administer correct medications to their infants (Ahou et al., 2010). In Zambia, a nation with a reportedly very robust PMTCT program, a survey of over 10,000 women found that that access to PMTCT was widespread, and yet only a minority of HIV-infected women and HIV-exposed infants (30%) were actually receiving minimally adequate prophylaxis due to medication error (Stringer et al., 2008). Take-home nevirapine is given to Zambian women for home deliveries, but it is only being taken about 65% of the time (Stringer et al., 2008).

Many other barriers to PMTCT have been cited in African nations, yet all are very context specific. Difficulty in transportation and financial concerns have been cited in Uganda and Kenya (Atwiine et al., 2013; Otieno et al., 2010; Duff, Kipp & Wild, 2010); women who did not go to an HIV care program at all most frequently cited lack of money as a concern. Discontentment with the health care facility or providers is also common; this is expressed as “poor services,” and “dislike of the facility” (Otieno et al., 2010) or poor health care worker attitudes (Atwiine et al., 2013). Women in Cote d’Ivoire also expressed negative interactions with health care staff as having negatively affected their perception of the PMTCT program and encouraged them not to return (Painter et al., 2004).

Fear of partner violence has been expressed in Kenya (Otieno et al., 2010). Personal elements of other fears, lack of interest, or “not feeling ready,” are also common in both Kenya and Uganda (Atwiine et al., 2013; Otieno et al., 2010). Women’s fears regarding confidentiality and potential stigma are also significant (Otieno et al., 2010; Duff et al., 2010). The perceived
stigma from being seen attending a PMTCT clinic or being visited at home constituted reasons for non-attendance at services in Malawi (Chinkonde, Sundby & Martinson, 2009). In a study among Nigerian youth, although not specifically focused on PMTCT, it was discovered that religious ideals can have a large effect on the perception of risk of both acquiring and transmitting HIV (Smith, 2003); this is a largely unexplored issue in PMTCT.

Just as the barriers to PMTCT use are variable by location, certain elements of PMTCT systems may be attractive to women in one culture but not in another. Zambia has shown remarkable progress in PMTCT uptake and adherence since launching its national PMTCT program in 2005; reported uptake and adherence in some regions has reached 99% (Torpey et al., 2010). This success has led researchers to examine the program in hopes that it may be translated to other countries. They found several important components of Zambia’s system which contributed to its positive results, the first of which was initiation of PMTCT in accessible locations: hospitals, clinics, ANC monthly outreaches, and STI clinics. Another important element was the use of PLHIVS to encourage ARV adherence for HIV+ mothers, and community outreach and partner outreach were both incorporated into the program as important tools. Traditional and religious leaders also became involved in PMTCT mobilization and were credited with improving the program’s outcomes (Torpey et al., 2010). However, those researching the Zambian success carefully noted that the success of such a program is highly specific to the context in which it took place and was not necessarily translatable to any other country.

When the key elements of the Zambia intervention are examined in light of what is important to other cultures, the potential for the intervention to be successful varies. For example, while partner outreach was expressed as a critical component of Zambia’s PMTCT
system, Ugandan women did not express that their partner had great influence on their reproductive health decisions. When asked about reasons they had failed to follow through in the PMTCT system, concerns with their partner were not mentioned (Ahou et al., 2010). Free services, additional health education and counseling, and compassionate care were not mentioned as important components of Zambia’s success, and yet they were the three key factors indicated by Kenyan women as making PMTCT attractive (Duff et al., 2010). Other interventions such as community engagement and family focused care have all proven to increase PMTCT uptake and adherence in various regions, but the results are not consistent across locations (Tonwe-Gold, Ekouevi & Bosse, 2009).

Poverty and health. Although many differences exist between the cultures of African nations, there are also similarities. One of the most dominant influences on the lives of many African women is that of poverty, and the stress of living under its daily burdens can affect every aspect of their lives. Poverty can independently hinder access to health care, including PMTCT, and it also contributes to a myriad of social issues which each hinder that access further. Many of the commonly cited barriers to PMTCT use are directly related to the experience of living in poverty, and many others are indirectly influenced by its pressure. In order to better understand this formidable barrier to PMTCT use, an examination of the interplay between poverty, the social status of women, and difficulty with accessing health care is required.

The WHO states that poverty and poor health have an inseparable link (WHO, 2008a). The individual experience of poverty can be considered as a negative emotional and mental state, and it is compounded by a myriad of other factors. From a societal perspective, multiple dimensions of poverty can overlap and deprive individuals of opportunities to maintain their health. Lack of sufficient food or clean water limit health directly, while unemployment and
social inequalities more indirectly prevent the opportunity to be completely healthy. Lack of money for transportation may hinder access to needed medical care, and lack of education may limit the individual’s awareness of when symptoms need to be medically managed. For most people living in poverty, two or more of these factors co-exist and have additive effects on a person’s health (Loppie & Wein, 2009). In addition, poverty and poor health status are mutually influential. When poor health hinders the ability to work or retrieve the necessities of daily living, individuals can get caught in a ‘poverty–health’ trap (Whitehead, Dahlgren & Evans, 2001).

The “Fundamental Cause of Social Inequality Theory” points to social inequalities as the key drivers of health inequalities (Link & Phelan, 1995). This theory links elevated social positions to not only higher levels of education and possession of more material resources, but also to power. Power structures can come into play through family dynamics and gender inequalities, or they may negatively affect the interactions between the impoverished individual and health facility staff. As a result of lacking the benefits of an elevated social position, those in lower positions will suffer from more adverse health outcomes (Link & Phelan, 1995).

Many health conditions are either caused by or affected by poverty. Chronic diseases are more prevalent in poor populations, as are delayed development in children, certain types of cancer, and mental health problems (Loppie & Wein, 2009). Women of low socioeconomic status experience an increased incidence of sexually transmitted infections and unplanned pregnancies, and adverse birth outcomes and preterm deliveries are also experienced more frequently in this population (Ward, 1993). Infants born to poor mothers frequently suffer early in their lives, and 60% of them are born with at least one chronic disease or congenital defect (Ward, 1993). Both intentional and unintentional injuries affect the poor disproportionately, and
infectious diseases such as tuberculosis and HIV are more prevalent in impoverished populations (Ward, 1993; Loppie & Wein, 2009). Increased all-cause morbidity and higher levels of all-cause mortality are correlated with lower levels of education and lower income levels (Moss, 2002; Niewczyk & Lwebuga-Mukasa, 2008).

The poor will visit health care providers less frequently, and they may be more likely to perceive a lack of access than those with higher levels of wealth. When compared across multiple variables, poverty was the only socioeconomic indicator in the Commonwealth Fund Survey that had a significant influence on a woman’s ability to access health services (Mead, Witkowski, Gault & Hartmann, 2001). Poverty is also significantly correlated with less frequent use of preventative services such as breast and cervical cancer screening (Akinyemiju, 2012).

Socioeconomic status is noted as a key predictor of health care use in any society (Simmons, Anderson & Braun, 2008). The barriers faced by the poor in accessing health care are formidable: the distance to facilities, lack of funding for medication or treatment, and poorly operated and understaffed health facilities may all hinder their access to quality care (Ward, 1993). Even if these barriers can be overcome, the poor frequently find themselves being treated with little compassion by health care providers; this can diminish their desire to return. The WHO has also shown that the poor are less likely to receive recommended treatments for chronic diseases than are individuals of higher financial means, and they suffer from more health complications as a result (WHO, 2008a). Even within the confines of a society which is universally poor, women, children, the disabled, and ethnic minorities will suffer from a higher prevalence of health problems than others who are not as marginalized (Loppie & Wein, 2009).

*Poverty, social status, and health for women.* As a consequence of their standing in society and the difficulties they must face in their daily lives, women in many societies suffer
from a considerably larger number of health problems than do men (Roya & Chaudhurib, 2008). Even in developed nations, women are not as likely to have health insurance, to obtain health care, or to use preventive services as are men (Mead et al., 2001). Chronic disease, infectious disease, and malnutrition are all more prevalent in females on a global scale, as is all-cause mortality. The World Bank (2012) estimated that 6 million female lives are lost in excess mortality every year.

Financial concerns often limit women’s access to health care and treatment. In impoverished communities, financial barriers have been shown to be stronger determinants of health care access for women than they are for men (Myers, Louw & Pasche, 2011). In less developed regions, the low social status of women often denies them any decision-making authority over household resources, and male family members may choose to deny them financial resources for seeking care (Bhattarai, 2008). Such financial disempowerment limits access to health care and contributes to poor overall health (Roya & Chaudhurib, 2008). Financial concerns also affect women in the developed world: over 18% of American women with mental health problems indicated that financial concerns were barriers to their seeking treatment (Sherbourne, Dwight-Johnson & Klap, 2001).

The use of ANC or other health care services has been strongly linked to a woman’s socioeconomic status across the globe, independent of other factors (Koné-Péfoyo & Rivard, 2006). Women in impoverished communities commonly find accessing ANC difficult, and they are much less likely to deliver with a skilled birthing attendant than those women in more affluent communities. Both wealth and education level are directly correlated with ANC use, skilled birth attendant delivery, and use of post-natal care (Mohanty, 2012).
Women remain on the fringes of many societies. Although gender inequality is closely connected to poverty, women of all socioeconomic levels may suffer under its effect. Education, employment, and social mobility may each be hindered by gender inequality, as will opportunity for advancement and access to resources. Combined with frequent gender violence, these influences may all contribute to the high levels of poor nutrition, poor physical health, and poor mental and emotional health suffered by women (WHO, 2008a). Women frequently are responsible for a disproportionate share of household work, accounting for hours of hard physical labor in cleaning, washing, and walking many miles to secure a daily water supply.

Women in many cultures are rarely given access by males to disposable income which can be used for health care, or it is given in such limited amounts that even transportation to health care is not affordable (Tinker, 2000; Ir, Horemans, Souk & Van Damme, 2010). Additionally, their health concerns are frequently overlooked as unimportant. Muslim Ethiopian men, when asked about their wives’ health, said that gynecological problems were “Allah’s will for women” and therefore not worthy of household expenditure (von Massow, 2000). Violent or oppressive partners or male family members may forbid women to visit a health facility, or they may place such stringent travel restrictions on them that reaching health facilities is virtually impossible (Tinker, 2000). It also cannot be forgotten that in some societies women’s health care access is limited by the regulation that they may not see male health care providers (Ward, 1993; Tinker, 2000).

Women in impoverished settings are often dependent on male provision for survival. This dependence increases their vulnerability to gender violence, and women’s authority to challenge risky sexual behavior may be limited (WHO, 2010d). The physical, sexual, and emotional consequences of gender violence may increase their need to comply with the wishes of their
partners in sexual relations, decreasing their ability to refuse sex, to question her partner’s fidelity, or to request the use of a condom (Heise, Ellsberg & Gottmoeller, 2002; Krishnan et al., 2008).

Poverty and gender inequities have also been cited as drivers of the increasingly female HIV epidemic (Krishnan et al., 2008). The poor and marginalized are already more susceptible to HIV infection by the influence of many factors, and the addition of gender inequalities place poor women at much higher HIV risk (Piot, Greener & Russell, 2007). Poverty not only limits a woman’s access to health care, but it also limits her educational opportunities and access to prevention information and tools (Loewenson, 2007). Women are less likely overall than men to have comprehensive information about HIV transmission and the risks they face in sexual activity (UNAIDS & WHO, 2005). It has been recommended that HIV prevention strategies include gender-responsive economic empowerment to combat the societal and economic realities which shape a woman’s risk of acquiring infection (IATT, 2013b).

Unfortunately, poverty and oppression starts from an early age for many girls, and few chances are given throughout their lives to escape those forces. As poor mothers continue to have girls in societies which are not advocating for improvement in gender equity, the effects of these forces are passed down through generations. Anthropological researchers have increasingly been defining poverty as a chronic, rather than transient, condition, and intergenerational poverty is particularly prevalent for females (Cooper, 2011).

*Improving health for women living in poverty*. The global health community is aware that access to health care for the poor is a problem, and international agreements such as the Millennium Development Goals highlight the need for women, in particular, to be able to escape the poverty-health trap. In an effort to promote access to health care for impoverished women,
various interventions are being implemented across the globe, ranging from a simple reduction in user fees to giving cash transfers to women to use however needed in their homes. Each of the interventions has benefits and limitations, and a perfect solution for every location is yet to be discovered. Evaluating some of the most common methods used helps to identify continued gaps and barriers to access, as well as highlighting elements of the programs which are most beneficial.

User fees in health care facilities have been implemented in many low income communities in the past with the belief that they would improve the quality and equity of care. However, the imposition of user fees has not had its desired effect, but rather disadvantaged the poorest individuals and actually increased health disparities (Yates, 2009). Formal user fees are typically paid out of pocket, and they can be very costly when considered relative to the income of the poorest individuals in the community. In addition, many informal fees may also exist: supplies, medicines, and incentives to staff to provide better care are all the responsibility of the patient and their family, and they add up quickly (Harris et al., 2010; Yates, 2009). In some locations, the cost of the informal fees may actually be higher than the formal fees assessed by the facility (Yates, 2009).

Recent attempts to increase ANC coverage by removing user fees for maternal health care in several nations have been successful. ANC visits in Niger doubled when user fees were removed, and in-facility deliveries in Burundi increased by 61% (Paruzzolo, Mehra, Kes & Ashbaugh, 2010). When fees for general hospital services in Uganda were removed, women’s visits increased by 84%, most of which was among the extremely poor (Paruzzolo et al., 2010). In Ghana, ANC visits increased and health care workers reported improved working conditions; in Zambia the health care staff was positive that the program had improved medication access
and overall care (Ridde & Diarra, 2009). In Cambodia, a voucher program was offered to pregnant women to offset user fees, as well as transportation costs to a health care facility delivery. The number of antenatal care visits and health facility deliveries both improved for poor pregnant women under this program (Ir et al., 2010). The provision of travel vouchers and clinic vouchers in Uganda resulted in an increase in the number of facility based deliveries from 200 to over 500 in one month (Ekirapa-Kiracho et al., 2011).

Eliminating user fees is one way to decrease health care costs for the poor; the use of low-cost health insurance and voucher systems are other techniques which are being tested in various contexts. A community health insurance program in India invited community members to pay a yearly fee of approximately $.50, after which all of their hospitalization or clinic costs for the year would be covered. This cashless system eliminated patient fears of hidden health care costs at the hospital or clinic, and the program was highly successful in improving health care access, particularly among children and the poorest sectors of society (Devadasan et al., 2010). Rates of hospital admission for those insured under this program were twice that of the uninsured, independent of other factors.

The important variable which remained under the Indian insurance system was the distance a patient lived from a health care facility. Transportation fees were not paid for the patients, and longer distances still seemed to be a barrier to accessing care (Devadasan et al., 2010). A maternal health care voucher program in Cambodia sought to address this problem: it not only provided funds for the use of skilled birth attendants, but also vouchers to be used for local men to take the women to ANC and deliveries on their motorbikes. The program was very successful, and the percentage of facility based deliveries increased from 16.3% to 44.9% of women in the region when the system was implemented (Ir et al., 2010). A similar voucher
scheme in Bangladesh increased ANC attendance from 42% to 89%, while skilled attendant deliveries went from 2% to 18% among those who received the vouchers (Rob, Rahman & Bellows, 2009). Women interviewed after the Cambodia intervention reported that they enjoyed the easier access to ANC care and facility based deliveries that the program offered. However, some still expressed concerns that poor quality or non-compassionate health care services were offered and that improved service delivery at health care facilities was a necessity. This is in agreement with a large study of poor women in Bangladesh, who noted that the quality of care received at ANC was more important to them than the distance to the facility (Ahmed et al., 2006). Being poorly or inadequately treated by health care providers or facilities is frequently cited as a barrier to ANC use in many other locations (Finlayson & Downe, 2013).

It has been noted that increasing social support can effectively improve women’s access to health care, and one innovative way to improve women’s health is through the use of community led, participatory women’s groups. In Nepal, women’s groups collect community funds for maternal and infant care for their members, and they also produce and distribute safe delivery kits. In addition to the financial benefit, these groups function to increase knowledge and awareness of treatment options among their members (Myers et al., 2011). The areas in which these women’s groups were started have seen an increase in antenatal care, an increase in attended births, and a decrease in neonatal mortality (Manandhar et al., 2004).

Improving the accessibility and quality of health care services are both important, but the importance of making the services agreeable with local customs and challenges cannot be overlooked (Harris et al., 2010). With the intention of understanding why many women in LMIC don’t access ANC, Finlayson & Downe (2013) synthesized 21 qualitative studies that represented 1239 participants. Cultural issues such as fear of evil spirits, embarrassment, and the
perception that a normal pregnancy does not require medical attention were commonly expressed. A similar problem of failure to understand the value of health care services was indicated by Ugandan women when asked why they did not engage in post-natal care (Nabukera et al., 2006). Targeting health care services to be compatible with local customs and beliefs could have a significant effect on service uptake. Other than reducing costs, the only strategy found to enhance access to health screening programs among lower socioeconomic groups in the US was tailored communication that addressed barriers to screening particular to their demographic (Spadea, Bellini, Kunst, Stirbu & Costa, 2010). Programs which are targeted to a population are generally more effective than programs which are generalized: services can be targeted to women, to impoverished women, and to women of different ethnic and cultural backgrounds.

Finally, overall schemes which empower women are necessary to make health care more accessible. The concept of human rights promotes the idea of equal opportunity access to basic requirements for maintaining health; improving human rights for women would have a great influence on their ability to access and maintain these necessities (Dugassa, 2005). Economic interventions that lead to independence and more control for women may improve their health care access and reduce maternal morbidity and mortality (Kim et al., 2009; Padian et al., 2011; Purohit, 2011). In addition, there are benefits that extend across the family when women are empowered. When women are given land rights, for example, land productivity increases and household spending on food and education increases (Bird, Pratt, O’Neil & Bolt, 2004). Giving women cash transfers and other financial incentives also improves the nutrition of a family. A review of promising interventions in the form of social and economic protection will highlight the benefit that empowerment can have on a woman’s health and the health of her family.
**Social protection.** Social protection has been defined as “all public and private initiatives that provide income or consumption transfers to the poor, protect the vulnerable against livelihood risks, and enhance the social status and rights of the marginalized; with the overall objective of reducing the economic and social vulnerability of poor, vulnerable and marginalized groups” (Sabates-Wheeler & Devereux, 2007). Cash transfers, one commonly used form of social protection, are based on the provision of money to impoverished or vulnerable households or individuals. They are often given to the vulnerable (such as elderly and children), or to larger families who do not have sufficient income for subsistence. These transfers have the goal of enabling recipients to move out of poverty, and they are designed to build their financial and physical assets as a form of social protection (Adato & Bassett, 2009). Cash transfers are often implemented with one of several objectives in mind. A transfer can assist an individual or family by: 1) securing basic subsistence when illness has reduced income; 2) keeping children in school by offering fees and eliminating the need for the child to work; 3) preventing the sale of animals to pay for consumption; 4) enabling investment in small livestock for food and income generation; or 5) increasing women’s status and children’s nutrition through giving cash benefits directly to women (Adato & Bassett, 2009). These goals may overlap in many cases. Cash transfers are given in two different ways: conditional and unconditional. In the latter, money is given without obligation; in the former, transfer of funds is dependent on the recipient’s behavior. The behavioral goals are always such that would be used to improve the quality of life of the recipient. These programs have proven to be effective in a variety of cultural and social contexts.

**Social protection for health.** Access to health care has shown promise with the use of cash transfers. The transfers can make transportation costs and health service fees more
affordable, in addition to improving the overall standard of living for recipients (Goudge et al., 2009). It is well known that poverty hinders access to health care, and this translates to difficulty in accessing PMTCT services and/or other prenatal services for women. Cash transfers or care transfer securities can help to overcome this barrier. In Mexico, the Oportunidades program has successfully improved the quality of prenatal care and frequency of visits in rural environments (Barber & Gertler, 2009). In Honduras, ANC attendance increased by 19% when financial incentives were offered through a cash transfer program (Adato & Bassett, 2009). Both facility based deliveries and skilled birth attendance increased with cash transfers in India, Nepal, Bangladesh and Mexico (Lim et al., 2010; Powell-Jackson, Morrison, Tiwari, Neupane & Costello, 2009; Neupane, Tiwari, Morrison & Costello, 2008; Barber & Gertler, 2009).

Since they can be targeted for behavioral interventions at multiple levels, HIV and other infectious diseases spread by human to human contact are ideal disorders on which to focus cash transfer programs. Cash transfer has already demonstrated positive effects on the individual management of sexual behavior risk. In Tanzania, both men and women who received cash transfers if they remained free of sexually transmitted infections (STIs) had a 25% lower incidence of infection than did controls (World Bank, 2010). However, it was unknown if the behavioral effect would last beyond 12 months or when the incentives were withdrawn (de Walque et al., 2013). In Malawi, cash transfers increased all HIV testing rates by 27% and voluntary counseling and testing by 43% (Miller, Tsoka & Reichert, 2010).

Some studies in developed world populations have pointed to the fact that cash incentives can increase HIV medication adherence (Sorensen et al., 2007). In a HAART study using cash payments for medication adherence, significantly higher adherence was noted among those who received compensation when compared with those who did not (Rigsby et al., 2000). Adherence
among those receiving the incentives increased from 70% at baseline to 88% in the first week, but the differences did not persist after the incentive was withdrawn. In another study which tested HAART adherence among methadone users, monetary voucher reinforcement was associated with an increase in adherence from 56% to 78% (Sorensen et al., 2007). The improvement in this study also did not persist after the voucher was withdrawn. An incentive based system for an intervention such as PMTCT, which requires long term participation, will not necessarily result in sustained adherence to the system if an incentive is only given one time. If a series of incentives are given, however, it may effectively encourage the accomplishment of individual steps in the cascade, such as increasing the number of ANC visits or the number of health care deliveries.

Social protection cash transfer schemes have been recognized by UNAIDS for their importance both in addressing the underlying factors which drive the HIV epidemic as well as helping to mitigate its impacts (UNAIDS, 2011b). Cash transfers have the potential to improve HIV prevention, treatment and care, and support outcomes. Patients who report financial difficulties in purchasing ART in developing nations are significantly less likely to adhere to the medication than those who do not (Russell, 2004). Since the costs associated with treatment can put a huge dent in a family’s finances, providing food or cash transfers can increase treatment access and adherence (Russell, 2004). Proper treatment reduces transmission, and additional behavioral incentives may be effective in reducing transmission risk. The nutritional provision given through cash transfer programs can enhance the treatment outcomes of HIV + patients, and social protection programs can also help the families of people living with HIV sustain livelihoods. (Weiser et al., 2010). For these reasons, social protection has been identified as a strategic priority in the ongoing global HIV response (UNAIDS, 2011b).
Social protection for PMTCT. The use of cash transfers for PMTCT has not been widely studied, but there is reason to believe it may be beneficial. Conditional transfers could be given for many steps along the PMTCT cascade, including antenatal attendance, facility based delivery, maternal medication adherence, and infant testing and medication adherence. Additionally, targeted but unconditional transfers can help to provide ongoing care and support for HIV + women and their families, which is one of the four elements of WHO’s strategic vision to reduce MTCT (WHO, 2010c).

For any cash transfer programs, the situational context must dictate its details. In order to help researchers understand how incentives would be most beneficial in the local context, ethnographic research in the community and piloting the program in a small group prior to implementation have been recommended (Pettifor, MacPhaile, Nguyen & Rosenberg, 2012). Whether or not the program is conditional, who receives the payments, and which behaviors can be incentivized should each be carefully considered in light of the population being affected (Pettifor et al., 2012). Additionally, both the size and frequency of transfers must be considered in the local context, for what is effective in one population may not be effective in another (Medlin & DeWalke, 2008).

Pregnant women who are HIV + are the population of interest when considering cash transfers for PMTCT, and the type and frequency of incentives which would effectively motivate them should be considered. It has been reported that small, tangible incentives which are provided frequently and directly linked to behavior are more effective for cash transfer systems than larger payments which are given less often and linked to long-term outcomes (Pettifor et al., 2012). Since the successful completion of PMTCT is a lengthy, multi-step process, an incentive based on infant HIV status may not effectively sustain maternal motivation to participate. Giving
small incentives to the women at different steps the PMTCT continuum, such as at each ANC visit, each medication refill, and each checkup for the infant, may be advisable. Additionally, although some studies have indicated that the size of a transfer is not as significant as is the concept that a transfer is being given, it is still important to research what level of transfer would provide an adequate incentive for HIV+ women to complete PMTCT treatment (Filmer & Shady, 2009).

There are several potential problems with using cash transfer systems for PMTCT, beginning with the fact that they may not be sufficient to stand alone. It has been reported that a reduction or removal of health care fees at the state and institutional level must take place in addition to conditional cash transfers in order to increase uptake (Osrin & Prost, 2010). Broad scale changes must also be made on the supply side of the health care system in order to make conditional cash transfer effective; without investment in necessary supplies to meet increased demand, the system is impractical (Schubert & Goldberg, 2004; Banerjee, Duflo, Glennester & Kothari, 2010). Increasing the demand for PMTCT services through cash transfer programs will require a rapid scale-up of facilities. The additional burden placed on government systems to keep up with the accounting and distribution of cash transfers must also be considered a cost of program implementation (Kebede, 2006).

Targeting populations for cash transfer has also proven to be effectively difficult in many locations, and keeping the targeting criteria as simple as possible has shown the most success (Farrington & Slater, 2006). However, there is concern that targeting individuals or families based on certain characteristics such as HIV status may promote jealousy among non-recipients in communities with high poverty concentrations (Skovdal et al., 2012). In fact, UNAIDS is now advocating for the use of programs that are inclusive of HIV+ individuals but target recipients
independent of their HIV status (UNAIDS, 2011b). Called “HIV-sensitive” approaches, these programs include equally needy groups according to economic status. Targeting vulnerable children as recipients, for example, will reach many who are affected by HIV in their family as well as those suffering from other causes of poverty (UNAIDS, 2011b). Finally, HIV stigma may present a barrier to either conditional or unconditional transfer programs that target HIV + individuals. Incentives which are given at a clinic, for example, may require unwelcome disclosure of HIV status.

The ability of cash transfer programs to effectively increase the uptake of health care services is well documented, but their effects on actual health outcomes is less proven (Lagarde, Haines & Palmer, 2007). Several concerns must also be addressed if cash transfers are to be effectively used in PMTCT, and broadly targeting programs which affect all women at an ANC center or all women of reproductive age in a community may be necessary in order to address these issues. Despite these limitations, the successful uses of cash transfers to address behavioral risk factors, improve health care access and adherence, and improve economic status makes social protection an intervention worthy of strong consideration for use in PMTCT.

**Promising interventions for PMTCT.** While cash transfers and other forms of social protection are just emerging on the PMTCT landscape, other interventions have been ongoing for many years. The results of these interventions have been varied, but progress is being made on a global scale. In recent years, since ARVs have proven to be so effective, the focus of many NGOs and international collaborative bodies has shifted to providing technical assistance, capacity building, and monitoring and evaluation services for governments in high HIV prevalence countries (EGPAF, 2013).
It is universally recognized that having a strong health care infrastructure is a key to effective PMTCT programs, and shortages in finances, supplies, and facilities can present major limitations. With the large burden of HIV/AIDS in sub-Saharan Africa, the region also faces another critical problem: a severe shortage in human resources (WHO, 2008b). In order to meet the increasing demand for care by PLHIV, the redistribution of tasks from highly trained medical professionals to those with less training (“task-shifting”) is becoming a common and useful practice (WHO, 2008b). Nurses in Swaziland, for example, were given a license to prescribe ARVs. Extending the pool of medical providers available to treat PLHIV patients has significantly improved uptake and adherence to ARV (EGPAF, 2013). Task-shifting from formally trained medical providers to those trained outside of the medical system as Community Health Workers (CHWs) is also common. CHWs are being utilized in many rural locations across Africa for primary care and MCH, and they are increasingly being seen in urban sites as well. The use of CHWs allows for a greater number of women and children to be reached with medical care, and it may also improve ARV adherence rates for HIV+ patients (EGPAF, 2013).

Although task-shifting has many benefits, it also has limitations. A high degree of variability in outcomes within an organization administering PMTCT indicates that simply building infrastructure by increasing testing capacities and human resource pools alone is not sufficient; adequate staff training is also critical to a program’s success (Audureau, Kahn, Bessen, Saber & Ladner, 2013). Even formally trained medical staff must be appropriately trained in PMTCT interventions in order to make them effective. In 2006, a labor ward-based PMTCT program was implemented for nurses in Zambia, and the probability of HIV+ women receiving NVP treatment increased significantly as a result (Megazzini et al., 2010). This highlights the importance of properly training staff in key locations.
When task-shifting at health care facilities is not sufficient to effectively reach a high percentage of the pregnant population, mobile health care services may be utilized. In an attempt to reach those who will not engage the health care system on their own, mobile clinics have traditionally consisted of basic maternal and child health care and immunization administration. They are now expanding to incorporate elements of PMTCT such as HIV testing, CD4 testing, infant feeding counseling, and adherence counseling (EGPAF, 2013). Although there is not yet enough data to prove its utility, mobile technology is also of increasing interest to those designing HIV interventions (EGPAF, 2013).

Another rapidly growing trend in PMTCT interventions is the use of peer support groups or peer counselors. Many countries have introduced these groups for women who are HIV+, both prior to and during pregnancy; Tanzania has embraced this approach for pregnant women on a national scale. Uganda is utilizing HIV+ parents as peer counselors to increase the uptake of HIV testing for children, and HIV+ women are being included in the PMTCT workforce as counselors in a number of countries (EGPAF, 2013).

As scale up of PMTCT continues across African nations, engaging community support is also emerging as a promising intervention. Involving local leaders and working at this level can encourage and prepare women for HIV testing and care when they enter the ANC system, and it can also promote PMTCT adherence for women who require care (EGPAF, 2013). The value of partner support is also well-documented, yet little has been studied regarding the potential use of other family or community supporters to encourage PMTCT uptake and adherence. Mothers, grandmothers, traditional birth attendants, or religious leaders may be effective in counseling or influencing HIV+ mothers to adhere to PMTCT if trained appropriately, and the potential for their use should be further explored (Young et al., 2011).
Ethiopia

Ethiopia is the second most populous country in sub-Saharan Africa, with an estimated population of 83 million people (UNAIDS, 2012a). The population growth rate in the country is 2.7% per year, explained primarily by the high fertility rate of 5.7 children per woman (UNFPA, 2010). The population structure is pyramidal, and 44% of citizens are under the age of 15 (UNAIDS, 2012a). With close to 84% of the population living in rural areas, Ethiopia is one of the least urbanized countries in the world. It is also one of the most struggling nations in the world economically, and almost 33% of the population lives below the international poverty line (UNAIDS, 2012a). The annual per capita income for Ethiopian citizens is less than $390 (UNAIDS, 2012a). A large number of Ethiopians have received little or no education: 52% of females and 38% of males have never attended school. Young girls are frequently denied access to education in order to help generate family income or assist in domestic duties (von Massow, 2000). The number of girls attending school has risen rapidly, however: primary education for women increased from 11.8% in 2000 to 27.8% in 2011 (UNFPA, 2012). Only between 3% and 5% of the Ethiopian population have completed secondary education, although this number has been improving in among males in recent years (Ethiopian Central Statistical Agency [CSA], 2012). The same increase has not been seen in secondary education for the female population (UNFPA, 2012). In 2011, the national literacy rate for the country was 36%, yet only 23% of women were able to read (UNICEF, 2011).

The long-standing feudal system of government in Ethiopia was taken over by military force in 1974, after which the country suffered through nearly 20 years of political turmoil. After it became a federalist state in 1994, the country was divided into nine Regional States and two
City Administrations (Figure 2). Each of these areas are subdivided into 817 administrative “woredas” (districts), which are further divided into “kebeles” (UNAIDS, 2012a). The kebele is the smallest unit of governance in the country, and there were over 15,000 of them in the country in 2012 (CSA, 2012). In addition to the regions defined by the government, the highly populous nation is divided by many different things: geography, economic resources, climate, ethnicity, religion, and language are among them. Within its borders, Ethiopia is home to more than 80 different ethnic groups (CSA, 2012). The two largest ethnic groups, Oromo and Amhara, number in the millions; Tigray is the next largest group and includes only a third as many people. Many ethnic groups are as small as 100 members or less. Over 80 different languages are spoken across the country, although Amharic is officially declared as the national tongue (CSA, 2012).

![Figure 2. Federal HIV/AIDS Prevention and Control Office map showing the Regional Divisions of the Federal Democratic Republic of Ethiopia.](image)

The average age of marriage for Ethiopian women is 16.5 years and for men is 21 years (CSA, 2012). Eleven percent of women are married to a man who has more than one wife, with
two wives being the most common form of polygamy. Intergenerational sex is common: 21% of women ages 15-24 reported having sex with a man 10 years or older (CSA, 2012). This commonly takes place through the marriage of young girls to older men, and 10% of women will actually be married by the age of 15 (CSA, 2012). Although not as common as marriage, intergenerational sex takes place outside of marriage more often in urban locations. In Addis Ababa, many sexual relations between girls and older men were reported to be motivated by promises of employment, overseas travel, financial gain, or other gifts (Dugassa, 2005). Despite their engagement in early sexual activity, Ethiopian women are often hindered from discussing sexuality and health by cultural norms, and their ability to refuse or to advocate for protected sex may be limited (Cummings, Mengistu, Negash, Bekele & Ghide, 2006).

Many women in Ethiopia suffer from the effects of gender disparities and gender violence. Land rights are guaranteed by law for women, but these may be overcome by cultural norms and oppressive male family members (Cooper, 2011). Opportunities for educational attainment are limited for women, and rape and abduction is reported as common (Dugassa, 2005). Wife beating for any reason is an international human rights violation, yet it is widely accepted and practiced in Ethiopia (CSA, 2012). Across the nation, 68% of women expressed that wife beating is appropriate for certain reasons, including burning food, refusing sexual intercourse, arguing with her husband, neglecting children, or going out without permission. Only 30% of women who live in Addis Ababa think that wife beating for any reason is acceptable, but over 40% are unaware that there is a national law prohibiting domestic violence (CSA, 2012).

Across the country, 94% of women express difficulty in accessing health care. Health decisions are made for women exclusively by their husbands 25% of the time, while 61% feel
they have to consult their husbands and gain his acceptance regarding health care decisions (CSA, 2012). Over 40% of women were not allowed to participate in decisions regarding finances for the household, which limits their access to money for health care. Although health care access is generally better in urban locations than in rural communities, 74% of women in Addis Ababa expressed difficulty in obtaining health care. The most common reasons reported for the difficulty were lack of money, failure to get their husband’s permission, difficulty with transportation or distance to the health facility, or a heavy workload at home (CSA, 2012; Cummings et al., 2006).

Fifty-eight percent of Ethiopian women will give birth by the age of 20. The fertility rate in the country is 4.8 children/woman of reproductive age, with rural women having a higher number of children (5.5) than urban women (2.6) (CSA, 2012). There has been a marked increase in contraceptive use over the last decade, from 8.2% in 2000 to 28.6% in 2011. Urbanization and an increase in primary education for females have encouraged contraceptive use, as has a decline in child mortality (UNFPA, 2012). There has also been strong government encouragement offered in favor of family planning, specifically advocating for the use of Implanon. Almost 12% of Ethiopian women have adopted this long-acting method of contraception, but the uptake has not been as great in urban areas (UNFPA, 2012). Nationwide, the increase in contraceptive use has been credited in large part to the use of Health Extension Workers in rural areas, who distribute family planning information and administer injectable contraceptives in health posts. This accessibility and the ease of use of injectables probably best accounts for their popularity, and over 72% of women in the country choose this for their family planning method (UNFPA, 2012). Estimates of unmet family planning need range from 25.3% (UNFPA, 2012) to 47% (CSA, 2012), with several possible explanations. Apart from supply-side
issues, women with unmet family planning needs report a fatalistic attitude toward contraception (7.9%), religious prohibition (5.3%), or a husband’s opposition (80%) are their primary concerns (UNFPA, 2012).

The number of women who access ANC care during pregnancy has increased in the last decade, but it is still low. Thirty-four percent of women in the country reported having visited ANC at least once during their last pregnancy (CSA, 2012). When women in Addis Ababa were asked why they did not access ANC, the majority (68%) said that it was either not necessary or not in agreement with local custom. The facility being too far away was also frequently mentioned, and this was mentioned as a barrier to facility-based deliveries as well. Home births are extremely common across the country, and only 10% of women deliver with a skilled birth attendant. The maternal mortality ratio of 6.76 per 100,000 live births is one of the highest in the world and has not improved significantly since 2005 (CSA, 2012; UNFPA, 2012).

The majority of child health indicators for Ethiopia are poor, although most have improved considerably since 2005. In 2011, the under-five child mortality rate for the country was 8.8%, half of what it was in 2000. The infant mortality rate was 59 per 1000 births, and the neonatal mortality rate was 37 per 1000 births. The indicators in Addis Ababa are better than the national averages: under-five child mortality is 5.4%, infant mortality 40 per 1000 births, and neonatal mortality 21 per 1000 births (CSA, 2012).

Malnutrition is common in the general population, but most marked in children. Difficulties may begin in infancy, for many babies are not given nutrition that follows the WHO recommendations for infant feeding. Prolonged breastfeeding is common for Ethiopian women, and 84% of them breastfeed for up to 24 months (CSA, 2012). However, just over one half of infants are exclusively breastfed in the first 6 months of life as recommended by WHO; many are
given water, milk, or juice around 3 months of age. Complementary feeding is also frequently not started at 6 months of age as recommended. Almost 1 in 3 (29%) of all children in Ethiopia are underweight as a consequence of either acute or chronic malnutrition (CSA, 2012). Chronic malnutrition, manifested as stunting, occurs in 40% of children under the age of five across the country and 22% of children in Addis Ababa. Acute malnutrition and wasting are seen in 10% of Ethiopian children and 4.6% of children living in Addis Ababa (CSA, 2012).

The decentralized health care system in Ethiopia faces multiple challenges, including problems with maintaining supply chains, staffing, and lab services (Krebs, 2012). Although approximately 60% of its health funding comes from the government, Ethiopia is still the 7th largest recipient of international donor aid in the world (HAPCO, 2010). This dependence requires the health care system to be accountable to multiple donors, and this may further complicate an already confusing and uncoordinated system (Krebs, 2012). In addition to lacking adequate internal funding for health care, Ethiopia has a critical shortage in the number of health care workers available for its population. There was only one trained health care worker per every 5000 citizens in 2011, and this negatively affects health care at all levels, including PMTCT. The Health Extension Worker (HEW) program put into place by the government has actually improved that health coverage gap considerably in the last several years, but it also adds to the complications of decentralization. By 2010, over 30,000 HEWs had been trained, and that number continues to grow (Koblinsky et al., 2010). The HEW program was initiated and has operated primarily in rural areas using local residents who are non-health care workers. A pilot of the program for urban areas which uses clinically trained nurses as contact points to the public health system has also been successfully launched in Addis Ababa (UNAIDS, 2012a).
**HIV in Ethiopia.** Life expectancy in Ethiopia is low: 49 years for women and 47 years for men (CSA, 2012). While multiple health conditions contribute to this, HIV has taken a large toll. In 2005, it was estimated that the average life expectancy in the country had been reduced by 5 years as a result of the HIV/AIDS epidemic (Ethiopia Federal HIV/AIDS Control and Prevention Office [HAPCO], 2010). In 2010, HIV was the leading cause of death in the country and responsible for 12% of overall deaths across all age categories (HAPCO, 2010). The national prevalence of HIV in Ethiopia in 2012 was 1.8%, which is lower than that of many other African countries. (UNAIDS, 2012a). However, due to its high population, this equates to over 1.4 million people living with HIV in the nation, the third highest number of PLHIV in East Africa.

The prevalence of HIV is not equally distributed across the country. The epidemic has a strong gender component, with women having a significantly higher HIV prevalence rate (1.9-2.8%) than do men (1.0-1.8%) (PEPFAR, 2012; CSA, 2012). The apparent increase in prevalence among females may be partially accounted for by higher HIV testing rates through ANC facilities. However, the HIV epidemic across all of the sub-Saharan African region shows a gender disparity towards females that is commonly attributed to gender violence, exploitation of women through intergenerational and transactional sex, and a cultural silence regarding sexuality (UNFPA, 2004).

HIV prevalence in Ethiopia is also markedly higher in urban areas than it is in rural areas (4.2% vs. 0.6%) (CSA, 2012). Addis Ababa had the highest HIV prevalence rate in the country in 2011. Although it was documented as 5.2%, this may actually be underestimated since only 78% of eligible 15-49 year olds in the city were tested for HIV (CSA, 2012). Over 60% of
PLHIV in Ethiopia live in cities or towns as a result of this geographical disparity, despite the fact that the majority of the Ethiopian population lives in rural areas (UNAIDS, 2012a).

Awareness of HIV/AIDS is common, but comprehensive knowledge and understanding about it is not. Among men and women surveyed in Addis Ababa, 99% indicated that they were aware of HIV, but over 30% believed it could be transmitted by either a mosquito or supernatural means. Only 52% of those interviewed could identify that condom use and sexual fidelity were HIV prevention methods and that a person could look healthy and have HIV (CSA, 2012). In this same group, only 82% of women could identify both that breastfeeding could transmit HIV and that medication could help to prevent transmission to an infant; the understanding among men was lower (CSA, 2012). At a national level, only 20% of women and 32% of men were considered to have comprehensive basic understanding of HIV/AIDS (CSA, 2012).

The original research on HIV was completed primarily with at-risk populations in Ethiopia for the first few years of the epidemic. The first national report on HIV that did not address high risk populations exclusively was developed in 1996. This report marked the population HIV prevalence at 5.2%, and the epidemic at that time was labeled as generalized (UNAIDS, 2012a). In response, the first national HIV/AIDS policy in Ethiopia was implemented in 1998; its objectives were to encourage government, private sector, and community organizations to work together towards mitigating the social and economic consequences of AIDS (HAPCO, 2010; UNAIDS, 2012a). That initial plan also highlighted the need for the empowerment of women and other vulnerable populations, and it made support for orphans and others affected by the epidemic a top priority.

In 2002, the AIDS epidemic was declared to be a public health emergency in the country, and the Federal HIV/AIDS Prevention and Control Office (HAPCO) was developed to move the
nation’s HIV response forward. The government’s first national HIV strategic plan, implemented in 2004, set a target of providing universal access to HIV prevention, treatment, and care; free ARV treatment was rolled out in 2005 as part of this initiative (HAPCO, 2010; UNAIDS, 2012a). In the two years following the beginning of the program, the number of ART sites increased from 3 to 265 (Assefa & Kloos, 2008). The number of patients on ART increased by more than 10 times (8,276 to 92,450), and the number of patients receiving HIV/AIDS care of any kind went from 13,773 to 156,729 (Assefa & Kloos, 2008). The increase since that time has been slower. In 2011 the ARV coverage rate for the country was close to 56%, lower than that of many surrounding nations (World Bank, 2013).

Many NGOs and community based organizations have been involved with HIV/AIDS education and interventions in Ethiopia, and the government has taken on the role of coordinating and guiding their efforts. Recognition of the value of these partnerships is addressed in the second five-year national HIV strategic plan, which was implemented in 2011 (UNAIDS, 2012a). External funding from NGOs, governments, and other sources also contributes significantly to the HIV response in Ethiopia. Of the yearly national HIV/AIDS expenditure of approximately 250 million USD, over 85% comes from external sources (UNAIDS, 2012a).

Identified high risk groups in the beginning of the epidemic included commercial sex workers, long distance truck drivers, and men in uniform. Mobile workers and refugees have since been added to the list of most-at-risk populations, as have sero-discordant couples. Young women involved in trans-generational sex are also at risk, but research focused on this populations is somewhat limited.

Sex work is illegal in Ethiopia, but it is commonly practiced and is tolerated by the government. Limited data tracking of this population has been completed, so the number of
women who are engaging in transactional sex is uncertain. Some estimates from organizations that reach out to sex workers estimate that the HIV prevalence for these women may approach 25% (UNAIDS, 2012a). National data for injection drug users is unavailable, as is data on the number of MSM in the country. Homosexuality is largely taboo in Ethiopia, and its practice has not been well documented. The first national study to assess the number of MSM in the country and the HIV prevalence among them was started in 2012, and data collection is ongoing (UNAIDS, 2012a).

**PMTCT in Ethiopia.** Women of reproductive age comprise 24% of the nation’s population (UNAIDS, 2012a), and the prevalence rate in this age group is routinely tracked by ANC sentinel site surveillance data. Just as in the overall population, urban HIV prevalence among the ANC population is higher than rural prevalence of HIV (5.2% vs. 0.8%) (Bogale, Boer & Seydel, 2010; CSA, 2012). The most recent data shows a declining HIV prevalence rate among women age 15-24 years attending ANC, from 5.6% in 2005, to 3.5% in 2007, to 2.6% in 2011 (UNAIDS, 2012a). Although this decrease took place in both urban and rural areas, in urban locations the decline was more marked (11.5% in 2003 to 5.5% in 2009) (UNAIDS, 2012a). This decrease must be reviewed with caution, however. An increase in the number of women being tested for HIV (and thus an increased denominator), the fact that more low risk mothers are getting pregnant, and the expansion of PMTCT services in low HIV prevalence zones may all contribute to the apparent decrease; there may be an actual decrease in prevalence as well (Nigatu & Woldegebriel, 2011). In 2012, there were an estimated 34,524 HIV+ pregnant women in the country (Ministry of Health [MOH], 2013a).

The first National PMTCT guidelines were published in 2001 by the Ministry of Health, but the establishment of the first facilities did not occur until 2004 (Koricho et al., 2010). The
first 5 pilot sites were in hospital settings where nurses had been trained to provide PMTCT services and infant feeding counseling (Mirkuzie, Hinderaker & Morkve, 2010). In most of these initial sites, PMTCT services were fragmented and the infant feeding guidelines were poorly misunderstood (Koricho et al., 2010). In 2006, the government laid out a comprehensive HIV plan to combat the epidemic, including PMTCT, beginning with increasing the number of women who attend at least one ANC visit (UNAIDS, 2011a; Mirkuzie et al., 2010). The plan included a scale up of PMTCT facilities, better linkage to maternal child health services, and the adoption of WHO 2010 Guidelines “Option A” regimen for vertical transmission prophylaxis (UNAIDS, 2011a). In 2007, Ethiopia updated their national PMTCT plan according to WHO guidelines to include the recommendation for offering partner testing and counseling sessions (Mirkuzie et al., 2010).

As the PMTCT response developed, national and regional level steering committees were established by the Ministry of Health. Working groups within these committees consist of government health workers and also representatives from partner organizations. The current priorities for these working groups are monitoring and evaluation, site expansion, quality improvement, and demand creation (MOH, 2013a). Ethiopia has developed an accelerated national eMTCT plan for 2011-2015, but this document has not yet been published for review (F. Abdissa, personal communication, May 9, 2013). According to a conversation with the Urban Director of the Federal Ministry of Health, the country is now in the process of rolling out “Option B +” to all PMTCT sites (personal communication, May 9, 2013). It has been implemented in several districts, but training of PMTCT staff is ongoing. Current projections are to have Option B + operational country-wide by the end of 2013.
The 2011 Demographic and Health Survey documents a rate of ANC coverage (women attending ANC for at least one visit) for Ethiopia of 34% (CSA, 2012). Other reports have estimated the rate to be as high as 71% and projected that universal ANC coverage could happen by 2015 (Nigatu & Woldegebriel, 2011). However, analysis of those reports did not take into account multiple pregnancies for one woman which could account for overestimation. Even the higher coverage estimations result in a large number of women not accessing ANC services, and the reasons behind this are not entirely clear. Previous interviews have attributed it to the culture of the society, the poor quality of health services offered, and the perception and attitude of the health care workers (MOH, 2009). Not understanding the benefits of ANC is also a barrier, and some women from smaller ethnic groups may avoid health care facilities due to a fear that they will not be able to understand the Amharic which is spoken there (Berhane, Hogberg, Byass & Wall, 2002).

In 2007, the nation adopted the WHO guidelines for health care provider initiated “opt-out” testing, and this was implemented in 2008 (Mirkuzie et al., 2010). Acceptance of this opt-out testing is high; an estimated 92% of women offered HIV testing at ANCs accept in both rural and urban populations (Nigatu & Woldegebriel, 2011). Despite the regulations for “opt-out” testing, many women are still being missed for testing during ANC visits. The 2011 DHS revealed that only 11% of women visiting ANC nationwide received same day HIV counseling, testing, and results (CSA, 2012). This was significantly higher (76%) in Addis Ababa. The Ministry of Health has recently estimated that 33% of all pregnant women (inclusive of those who do not access ANC) were tested for HIV in 2012, but those data are not finalized (MOH, 2013a).
The number of health facilities with available PMTCT services has increased rapidly from 171 in 2006 to 1,445 in 2011 (UNAIDS, 2012a). However, only approximately 50% of those PMTCT facilities actually offered ARVs, which are a critical component of the PMTCT cascade (HAPCO, 2010). Additionally, these sites are often independent of ANC facilities, and the failure to link women across services results in a significant number of HIV+ women being lost to follow up. In 2010, PMTCT services were available in only 43% of all ANC facilities, and more women visited ANC sites that did not offer PMTCT than those that did offer it (Mirkuzie, Hinderaker, Sisay, Moland & Morvke, 2011). An estimated 1.3 million pregnant women were seen at non-PMTCT facilities in that year (Nigatu & Woldegebriel, 2011). The scale-up of PMCT facilities is also highly variable across regions. In Jimma district, PMTCT is only offered at one hospital, and the coverage of eligible women is only estimated at 1.1% (Hussein, Jira & Girma, 2011). This is in contrast to Addis Ababa, where, as of 2009, 52 health centers were offering PMTCT, 25 of which were private (Mirkuzie et al., 2011). The government continues to seek to improve PMTCT coverage, and the Health Sector Development Plan IV for Ethiopia stipulates that 100% of health centers and hospitals will be providing PMTCT services by 2015 (MOH, 2010).

Despite considerable improvements in ANC and PMTCT coverage, increased rates of HIV testing and identification, and government provision of ARVs to pregnant women free of charge, Ethiopia’s mother-to-child HIV transmission rate (inclusive of breastfeeding) in 2012 remained unacceptably high (30%) (MOH, 2013a). In 2011, only 24% of eligible women received efficacious ARV regimens for preventing mother-to-child transmission of HIV (UNAIDs, 2011a). Although this coverage has increased consistently over the last several years
(Figure 3), the increase has been much slower than that in other high-prevalence countries (UNAIDS, 2011a).

![Graph showing maternal ARV coverage from 2006-2007 to 2011-2012](image)

*Figure 3. Ethiopia Federal Ministry of Health (2013) estimates of the percentage of HIV+ pregnant women who received efficacious regimens for PMTCT in a one year time period, measured from July-June.*

Additionally, only 10.2% of these women followed through to infant diagnosis at 6 months as recommended. Although there has been a decrease in the number of vertically transmitted HIV infections between 2009 and 2011 of between 20-39% (UNAIDS, 2012a), 13,000 new infant infections were acquired in Ethiopia in 2011 (UNAIDS, 2011a).

**Loss to follow-up in the PMTCT system.** Since the national PMTCT program was set in place in 2006, the availability of services has increased by 18 times. The high rate of loss to follow-up from the time of HIV diagnosis through to infant diagnosis, however, has not changed (Figure 4).
Figure 4. UNICEF (2012) estimates of the percentage of HIV+ pregnant women in Ethiopia who completed individual steps of the PMTCT Cascade in 2011, demonstrating attrition from the system at each step.

The myriad of potential reasons for this must be considered. Stigma and discrimination, the poor quality of post-test counseling and follow-up, high turnover and/or shortage of trained staff, and high levels of home based delivery have all been cited; an inconsistent supply of commodities, malfunctioning logistics, and poor documentation and reporting systems in the country have been discussed as well (Ethiopia Federal Ministry of Health, 2009; HAPCO, 2010). Some of these issues must be addressed from a national health system level, while others require adjustments at individual, community, or societal levels.

At a health system level, many problems still exist. In addition to the previously mentioned fact that many PMTCT facilities are independent of ANC sites, other issues such as lack of appropriate follow-up mechanisms, inadequate access to ARV drugs, and poorly equipped manpower may factor in to the high attrition rate of women from the system (Merdekos & Adedimije, 2011). A study done in Oromia district, Ethiopia, in 2011, showed that health care restrictions and limitation of resources, erratic test supplies, and the routine use of “opt-in” testing (despite national guidelines stating opt-out testing is to be used) continued to be
barriers (Balcha, Lecerof & Jeppsson, 2011). Focus groups and interviews completed in ANC facilities in Addis Ababa revealed systemic barriers to PMTCT including inaccessibility of services, long waiting times, impoliteness of the health care providers, and poor health care worker attitudes (Deressa, Seme, Assefa & Enqusellassie, 2010). Thirty-six percent of women in Addis Ababa responding to the Demographic and Health Survey reported medication or services not being available was a difficulty they frequently encountered in health facilities of all kinds (CSA, 2012).

Missed opportunities for diagnosis and poor pre- and post-test counseling also continue to be problematic at many sites. Researchers observed 66 pre- and post-test counseling sessions in several PMTCT sites in Addis Ababa, evaluating the sessions for quality according to WHO guidelines. Although 98% of pregnant women attending ANC clinics providing PMTCT services were counseled under an “opt-out” system, a quarter of these women were not tested for HIV (Ismael & Ali, 2009). At times, it was observed that counselors were taking blood samples for HIV tests from clients without prior consent and pretest counseling, as well (Ismael & Ali, 2009). In addition, the quality of the counseling in many observations was poor. The implications of potential MTCT were discussed in 77.4% of the sessions, but in only 54.5% of the sessions were misunderstandings or incorrect beliefs of the clients assessed and corrected. Infant feeding recommendations were only discussed 50% of the time, and these were not always accurate (Ismael & Ali, 2009). A similar situation was observed with PMTCT counselors in a study in Hawassa, who were found to be giving breastfeeding advice that was not up to date with WHO guidelines (Woldegiyorgis & Scherrer, 2012).

Family planning was only discussed in 40% of the counseling sessions observed in Addis Ababa, and very few (25%) post-test counseling sessions addressed the social or cultural
implications of an HIV diagnosis (Ismael & Ali, 2009). PMTCT counselors are often ANC nurses or other health care workers who already have formidable workloads, and the training they are offered is frequently inadequate. The eight nurses responsible for counseling in the Addis Ababa study had all received basic initial PMTCT training, but none had received refresher training in over 5 years. As a result, much of the information they were sharing with clients was not up to date with current WHO guidelines (Ismael & Ali, 2009). Failure to link HIV + women to services was another significant concern noted in this observational study. In 60% of the cases in which a pregnant women was identified as HIV +, she was not provided with initial ARV prophylaxis for PMTCT, despite its being available on-site (Ismael & Ali, 2009).

At a personal level, a woman must be fully invested in the process in order to successfully navigate and complete the complex PMTCT cascade. Under “Option A”, a facility based delivery is required in order for PMTCT to be effective. However, home based delivery is extremely common in Ethiopia, and only 10% of women nationwide deliver with a skilled birth attendant (CSA, 2012). Even in regions with the highest rates of attended births, such as Addis Ababa, 20% of women are delivering without medical care (CSA, 2012). In an Arba-Minch hospital, only 15% of HIV + identified women returned for an institutional delivery, despite a thorough explanation of its importance having been given (Hussein et al., 2011). In locations such as this, where the institutional delivery rate is extremely low, HIV + women are frequently given a dose of nevirapine to take home and ingest at the time of delivery. Not only do 38% of these women fail to do so, but this nevirapine-only regimen is no longer recommended by the WHO as an acceptable option because of concerns for resistance (Hussein et al., 2011, WHO, 2012). In addition, giving women a single dose of medicine to take home neglects their need for ongoing ARV therapy after delivery, as well as the needs of the exposed infant.
In the 2011 Demographic and Health Survey, only 20% of women and 32% of men nationwide were found to have comprehensive knowledge about HIV and its transmission, and many offered explanations for HIV transmission such as mosquito bites and supernatural means (CSA, 2012). This trend helps to explain why general awareness of HIV and PMTCT among Ethiopian women who attend ANC seems to be high, yet often not comprehensive. Among women surveyed at a hospital based ANC program in Arba-Minch, awareness of PMTCT services and knowledge of at least some of its benefits was over 90% (Merdekios & Adedimije, 2011). Focus groups from an Addis Ababa study also indicated that broad scale awareness of PMTCT is being broadcast to women through TV and radio messages. Considering the high rate of LTF among women in the PMTCT system, however, researchers in Addis Ababa surveyed women at ANC centers to ascertain the depth of their understanding of the virus (Deressa et al., 2010). The vast majority of women (90%) knew HIV can be transmitted to their children, yet only 26% could accurately identify all three methods of HIV transmission to infants (pregnancy, labor and delivery, and breastfeeding) (Deressa et al., 2010). In an Arba-Minch ANC facility, all women surveyed understood that HIV testing is important for pregnant women, but very few understood the reasoning behind this. 92.0% of these women knew that HIV could be transmitted from an infected woman to her unborn child; only 15% could identify all three transmission modes (Merdekios & Adedimije, 2011). Preventative measures such as use of ARVS and facility-based delivery could only be recalled by 26.5% of the women surveyed, and only 6.2% of the women could correctly explain all elements of PMTCT services (Merdekios & Adedimije, 2011). Failing to completely understand the gaps in knowledge among HIV + women regarding vertical transmission and PMTCT may limit the development of effective educational strategies and interventions.
Attrition from the PMTCT system is connected to health system problems and a lack of understanding, and it must also be considered in the context of a myriad of other social, cultural, political, and independent pressures placed on an HIV + woman (Woldegiyorgis & Scherrer, 2012; Adedimeji, Abboud, Merdekios & Shiferaw, 2012). Fear of abandonment or divorce following a partner’s discovery of her HIV status has been cited women in many nations as a barrier to accepting PMTCT services (UNAIDS, 2012d); low rates of male partner involvement and lack of acceptance by these partners has been identified in some Ethiopian sites as a barrier to PMTCT services (UNAIDS, 2012d; Deressa et al., 2010; Ismael & Ali, 2009). It has also been noted that Ethiopia has a tolerance of violence against women at all levels (family, community, school, religion, and state), and a fear of partner violence must be considered as a potential barrier to Ethiopian woman accessing PMTCT (Kedir & Admasachew, 2010). National laws ensure equitable access to treatment and support for PLHIV, and each community has a representative designated to monitor HIV discrimination in housing and human rights issues. No national data is monitoring the enforcement of these policies, however. The contexts of power struggles and other sources of inequities that produce ill health through social patterns must be addressed if the effectiveness of the PMTCT system is to be improved (Krebs, 2012).

A high level of partner involvement has been shown in other contexts as a key to improving PMTCT adherence rates. For example, the uptake of nevirapine among Kenyan women increased by 8 times if her male partner was also counseled (Farquhar et al., 2004). In addition, women are 4 times more likely to acquire HIV during pregnancy, and vertical transmission risk is highest during the immediate period following transmission of the infection. Women who test HIV- at an initial ANC visit may still acquire the virus from an infected partner later in pregnancy. If the partner has not been tested and the couple is unaware of this possibility,
the woman may not be treated appropriately with PMTCT. In recognition of this, the national Ethiopian guidelines as of 2008 state that partner testing and counseling should be routinely offered (Mirkuzie et al., 2011). However, these recommendations are not always followed. The number of partners tested in Addis Ababa actually declined from 2004-2009, and only 4.8% of women in Addis Ababa facilities received counsel that their partners should be tested (Mirkuzie et al., 2010). Aside from HIV testing, the effects of a man’s opinion on a woman’s health care use may be significant in other ways. The influence Ethiopian men have on their partner’s reproductive health decisions has been suggested when evaluating unmet family planning needs. The women who expressed these needs frequently reported that their partner’s desire for more children or his disapproval of contraceptive use were their primary difficulties (UNFPA, 2012).

In addition to partners, the influence of other family members, friends, and the community and their role in decision making for Ethiopian women must be considered. In one multi-national survey, 25% of HIV+ women indicated they had been excluded from family activities as result of their status (Anderson et al., 2012). In sero-discordant relationships among Ethiopian couples, social pressure from family members sometimes encourages the HIV- partner to leave the relationship (Hailemariam, Kassie & Sisay, 2012). Fear of such a situation may be a barrier to pregnant women disclosing their HIV status. Common tradition throughout Ethiopia is that a woman in labor is accompanied by her husband, older relatives, and neighbors until the newborn’s umbilical cord is buried. The fear of being seen by relatives and friends while taking ARV tablets is highly prevalent, so home deliveries are often used as an excuse to avoid the stigma and risk of marital breakdown associated with disclosure of an HIV+ status (Merdekios & Adedimije, 2011). When decision making about breastfeeding was explored among HIV +
women enrolled in PMTCT programs in Hawassa, Ethiopia, it was noted that both partners and in-laws were powerful voices of influence for the mothers (Woldegiyorgis & Scherrer, 2012).

Health care professionals can educate women who go for ANC care regarding PMTCT, but the actual degree of influence they have is variable. In one study in Kenya, the responsiveness of women to a health care provider’s encouragement for facility based delivery was significantly higher for women of lower financial means than it was for women who had more money (Fotso, Ezeh, Madise, Ziraba, & Ogollah, 2009). In another study in Guyana, the influence of health care providers and counselors was significant: over half of women surveyed noted that the emotional support they received from nurses and counselors was beneficial and most reported that the advice they offered would be followed (Henry & Carlson, 2005). Reports of influence held by health care providers on Ethiopian women also indicate variability. When women in Northwest Ethiopia were questioned regarding their delivery choices, those who chose a facility noted that information offered by health care providers was important and that their presence made them feel safer during delivery. However, of the majority of women who chose to deliver at home, most indicated that the influence of culture and family and pragmatic reasons such as transportation were much stronger influences on their choice than the opinions of the health care workers (Gebrehiwot, Goicolea, Edin & San Sebastian, 2012).

A pilot test of HIV prevention programs done with illiterate Ethiopian women demonstrated that the women responded more positively to media messages that were socially focused (such as peer to peer conversations) than to those which employed credible experts (such as physicians) (Bogale et al., 2010). This affirms the fact that social pressures of many kinds are important to Ethiopian women, and their influences should be explored (Woldegiyorgis & Scherrer, 2012). Fear of stigma by not only families but friends and communities is still a
formidable barrier worldwide to HIV + women: 14% of PLHIV women report having been excluded from religious activities, 30% verbally or physically harassed, 30% forced to move, and 35% released from jobs as a result of their status (Anderson et al., 2012). The fear of this stigma can pose a barrier to accessing PMTCT services or adhering to its recommendations (Merdekios & Adedimije, 2011; Ismael & Ali, 2009). When routine formula feeding for HIV exposed infants was still the global recommendation, HIV + women in Hawassa were asked why they often chose to breastfeed. Most of the women explained their fear that formula feeding would expose their HIV status since prolonged breastfeeding is the culturally acceptable practice (Woldegiyorgis & Scherrer, 2012). Several Mother Support Groups were started in 2008 in Ethiopia, and they have documented success in providing social support to pregnant HIV+ women. Two of the primary benefits described by participants in these groups are a reduced fear of social stigma and a decrease in self-stigma (Hopem & Bodasing, 2009).

The role of faith in decision making about PMTCT may also be important to Ethiopian women. In a large study in urban Nigeria, it was shown that religious beliefs can play a significant role in perception of personal risk of HIV acquisition (Smith, 2003). Stigma against PLHIV has also been expressed within religious communities in several locations, often related to religious beliefs that people with HIV and AIDS are immoral (Banteyerga, Kidanu, Nyblade, MacQuarrie & Pande, 2003). Religious communities and organizations have impacted the HIV epidemic worldwide, and PEPFAR has called for all country plans to include the incorporation of faith based organizations in the future (Bachman & Phelps, 2012). Interviews with PLHIV have also indicated that engaging faith leaders in HIV issues can have significant positive impacts (Anderson et al., 2012; Ackerman-Gulaid & Kiragu, 2012).
Faith is a dominant part of much of Ethiopian culture and plays a significant role in the lives of many Ethiopian people (Ofcansky, 1993); its influences cannot be ignored. Christianity and Islam are the primary religions in the nation; about 49% of the population are Orthodox Christians, 30% are Muslims, 18% are Protestants, and 3% follow traditional faith practices (CSA, 2012). There is evidence that faith plays a role in reproductive health decisions for Ethiopian women: 5.3% of women with unmet family planning needs reported religious prohibition as the primary barrier to their use. Another indication of the influence of religion on women’s health is that the use of contraceptives varies significantly among religious groups. Contraceptive use has grown rapidly and is highest among Orthodox Christians (35.1%) and Protestants (29.9%); it is lower among Muslim women (19.7%) and in other religious groups (16.9%) (UNFPA, 2012). Ethiopian women also frequently brought up religious beliefs when discussing their decisions about where to deliver their children. Many expressed that they trusted God and Saint Mary for a safe delivery and that the use of prayers by family were more important than obtaining medical care (Gebrehiwot et al., 2012). The role of religious beliefs and people of influence in the faith community has not yet been evaluated in respect to PMTCT.

Faith communities and faith-based organizations in Ethiopia have been credited with having a considerable impact on the nation’s HIV epidemic over the last decade (PEPFAR, 2012; International Orthodox Christian Charities, 2013). A National Inter-religious Group Anti-AIDS Network has been established, and there are HIV/AIDS Control Programs in the Orthodox, Catholic, Evangelical Christian, and Muslim communities. The Ethiopian Evangelical Church established an HIV/AIDS/STI prevention and control program in 1988 and has been extremely active, distributing educational material, providing support to PLHIV, and working with rehabilitation of high risk groups (Belachew & Seyoum, 2006). The predominant concerns
of religious leaders and organizations thus far have been offering education for primary prevention and support for PLHIV (Belachew & Seyoum, 2006). Evidence of their contribution to PMTCT is limited, although it is possible that there may be encouragement for adherence within the PLHIV support systems. If faith based leaders hold a large degree of influence over women and their health care decisions, engaging their support for PMTCT may positively affect adherence and should be further assessed.

The need for more research. The Ethiopian government has been very proactive in the fight against HIV, demonstrating leadership similar to that shown by the governments of nations such as South Africa and Botswana. In contrast to these nations which have highly successful PMTCT programs, however, Ethiopia’s program still remains relatively ineffective (UNAIDS, 2012f). Ethiopia’s government has made addressing their persistent and unacceptably high levels of maternal and neonatal mortality its top priority. As part of this goal, they have set a target to have 85% of mother-child pairs on ARVs by 2015 by increasing both service and demand (US Global Health Initiative, 2010). Current national guidelines recommend an integrated approach of PMTCT services with routine maternal, child and reproductive health services at all levels to attain the vision of an “HIV-free generation by the year 2020” (Deressa et al., 2010). Despite such robust goals and efforts by the government to implement “best practices” in PMTCT, the failure to improve PMTCT uptake and adherence at this point in Ethiopia is striking. One PEPFAR representative stated that:

Ethiopia is a little interesting because they have been given significant amounts of money, but we've seen very little improvement. So they still have a really poor facility delivery rate. They still have the same antenatal attendance rates. We haven't
seen a lot of changes. But Ethiopia's unique in that their government is very involved, which is a good thing. (Krebs, 2012, p 21)

The focus of the Ethiopian government to this point has been primarily in increasing the availability of services, but awareness is growing that attrition from PMTCT must be addressed (Krebs, 2012). Along with the low uptake of EID services and the low rates of male partner testing and support, the Ministry of Health highlighted LTF as one of three critical challenges facing the PMTCT system at the end of 2012 (MOH, 2013a). Addressing this LTF is a component of demand creation, which is one of the four targets set in 2012 for the national PMTCT strategic working groups (MOH, 2013a).

The reasons for attrition from the PMTCT system are highly context specific and may vary greatly across countries, as do the results of PMTCT interventions. Qualitative studies in African nations have revealed some similarities across national boundaries, but also a large variation in the reasons systems seem to be failing or succeeding (Otieno, 2010; Duff et al., 2010; Chinkonde et al., 2009). In order to increase the efficacy of future PMTCT interventions, the unique socio-contextual factors affecting Ethiopian women, including the beliefs, cultural and social norms, and individuals who have influence over their reproductive health decisions, must be considered. It is not sufficient to provide HIV testing and ARVs without addressing the influences which will positively or negatively affect their desire and ability to effectively use the medications (Woldegiyorgis & Scherrer, 2012).

A UNAIDS 2012 report suggested that qualitative research is needed to determine why, despite their increasing access to health care, pregnant women are not starting or maintaining ARVs in Ethiopia (UNAIDS, 2012a). At the conclusion of a large, multi-site ANC study in Addis Ababa, researchers asserted that greater efforts must be made to assess women’s needs so
that barriers to accessing PMTCT services can be minimized in future interventions and strategies (Torpey et al., 2010). The fear of stigma needs to be further explored in the region (UNAIDS, 2012c), and qualitative research is needed to uncover what could increase male testing uptake (Farquhar et al., 2004). There remains a gap in research surrounding the magnitude of influence of extended family members such as parents, in-laws, and other household members on women’s reproductive decisions, as well (Busza et al., 2012). PMTCT interventions will not be culturally and socially acceptable if they are not targeted to the felt needs of Ethiopian HIV + women, and formative research is required to understand those needs (Leshabari, Koniz-Booher, Åstrøm, de Paoli & Moland, 2006).

Research with PLHIV mothers at the community level. In 2012, Addis Ababa, Ethiopia’s capital, had a population of 4 million people. The total fertility rate for women in the city was 4.8%, and an estimated 70,000 women in Addis Ababa were pregnant and eligible for PMTCT in 2011 (CSA, 2012). The large pool of HIV + pregnant women from which a study sample can be drawn and the socio-demographic variability of the urban context make Addis Ababa an ideal location for exploring influential factors in adherence and attrition from PMTCT.

Even with the recent scale up of ANC services, a large number of PMTCT eligible women in Ethiopia still do not access medical care during their pregnancies (Mirkuzie et al., 2010). Previous research on PMTCT attrition has focused on ANC attendees, and it has failed to capture these women. There is no literature currently available which addresses the influencing factors for PMTCT with Ethiopian women within their communities. Research at this level will provide the perspectives of both women who access ANC and those who do not and may be more generalizable to the population.
Recognition of the value of obtaining the insight of PLHIV in planning is increasing across all spheres of the HIV epidemic. Treatment 2.0, a framework strategy presented by the WHO for improvement in HIV prevention, care, and counsel, states that the engagement of PLHIV and their families in planning is essential to the program’s success (WHO, 2011c). UNAIDS also calls for PLHIVs to plan and help with all ongoing HIV prevention and care (UNAIDS, 2012c), and PEPFAR has included the incorporation of PLHIV in HIV intervention planning as a key component of its ongoing strategies (Bachman & Phelps, 2012). The opinions of PLHIV mothers about how to better retain women in the PMTCT system can offer excellent insight (Karim et al., 2011).

Understanding what is failing in the PMTCT system can be enhanced by gaining insight from those whom it most affects: HIV+ women who have delivered children since their diagnosis. PLHIV mothers are a rich source of information as to factors which were beneficial or detrimental to their adherence to PMTCT, and their opinions are increasingly being recognized as integral to guiding program development. As part of its Strategic Framework, the United Nations commissioned a multi-national study with PLHIV women in an on-line format in which their experiences in the PMTCT cascade were explored. Among the 601 respondents, gender based violence, health care worker stigma, minimal counseling time, and inadequate counsel about family planning were commonly expressed negative themes (Anderson et al., 2012). Male involvement, peer counseling, and immediate linkage to services were all noted as factors which encouraged women to complete the PMTCT cascade. Both positive and negative factors, however, varied according to the locations in which the women lived, as well as their socioeconomic status (Anderson et al., 2012).
Since no regional or national tracking of women and infants lost to follow up in the PMTCT system exists in Ethiopia, insight from these women has been notably under assessed (Krebs, 2012). The pregnancy experiences of PLHIV mothers who effectively engaged in and completed the PMTCT continuum have also not been explored. By meeting the critical needs for research among PLHIV mothers at a community level, this study will enhance current understanding of factors which contribute to the high rate of attrition from the PMTCT system. Factors which positively influence uptake and adherence to PMTCT will also be identified, and the results of the study can inform the design of future PMTCT interventions so that their effectiveness is increased.

**Theory**

Health outcomes are not simply shaped by individual behavior; they are affected by the interpersonal networks, local customs and practices, political and economic circumstances and environments in which people live. These influences interact and overlap in a web of causation, which has been labeled in health theory as the Social Ecological Model (SEM) of health. In addition to the key concept that health behavior is influenced by factors at multiple levels, the SEM also recognizes that there is reciprocal causation between the behavior and the social environment in which the individual functions (McLeroy, Bibeau, Steckler & Glanz, 1988). The SEM can help to provide a comprehensive framework for understanding the multiple and interacting determinants of health behaviors, as well as in designing interventions that target change at each level of influence. By recognizing that many forces shape an individual’s behavior and integrating individual and external influences into one framework, the ecological
perspective also lessens the magnitude of the burden of responsibility placed on an individual for their behavior by other health behavior models.

In one of the foundational SEM models, McLeroy et al (1988) defined the 5 levels of influence on an individual’s health behavior: intra-personal, inter-personal, organizational, community, and public policy. The intra-personal level includes characteristics which influence behavior such as knowledge, skills, and self-efficacy, and the interpersonal level includes the influences of family, friends, and peers. The organizational level may encompass churches, health facilities, stores, and community organizations, as well as rules which may constrain certain behaviors. Community level influences include the broader social networks surrounding an individual along with community and cultural norms, and the final level of public policy incorporates local and national policies and laws that regulate health care or health behavior (McLeroy et al., 1988). The higher order levels are generally considered to be out of the control of any one individual person (Baral, Logie, Grosso, Wirtz & Beyrer, 2013).

Several updated versions of the SEM model have been used in public health research and intervention development since the initial development of the framework. All of the variations maintain the intra-personal and inter-personal levels of influence, but some models combine the organizational and community level factors. There is also variation in how these levels are defined: for example, physical structures are included in the organizational level in some models and in the community level in others. McLeroy’s model did not include a clearly defined level in which to place broad influences such as gender inequality and violence, social injustice, demographic changes, economic hardship, or racism and discrimination. Multiple variations on the SEM model have re-defined the 5th level to encompass these issues and termed it as
structural rather than simply public policy (Sweat & Denison, 1995; Poundstone, Strathdee & Celentano, 2004).

Variables above the intra-personal level can capture the essence of social structures which influence individual behavior, affecting population health outcomes in an indirect way. Factors such as material conditions, stigma, social norms, migration and labor, and public policy are not themselves risk factors for adverse individual health outcomes, but they create environments which can positively or negatively mediate that risk. Glass and McAfee (2006) refer to these factors as “risk regulators,” noting that each can lead to either opportunities or constraints.

**Social Ecological Model and PMTCT**

A woman encountering the PMTCT system will be affected by her own health knowledge, skills, and intentions, which are guided by both formal education and experiential learning. She also exists as part of a community of family, friends, and other people of influence, each of whom can motivate her to either enact or not enact a certain health-related behavior. Finally, the larger community and environmental context in which she lives includes issues such as cultural norms, socioeconomics, and gender inequality for her to consider, each of which may either enable her to perform the health behavior or negatively modify her desire or efficacy in doing so.

Commonly cited barriers to PMTCT use can easily be placed into the levels of influence of the SEM. The perception of risk and susceptibility to infant acquisition of HIV, the self-efficacy to take medications and get to appointments, and the mental health status of a mother are intra-personal level concerns. The influence of family or peer relationships may present a
barrier at the inter-personal level, as may the withholding of financial resources for healthcare from a partner. The difficulty of getting to PMTCT facilities, cost of transport and user fees, and poor attitudes of health care workers fall into the organizational level. The community level may hold issues of stigma and discrimination, cultural issues and social norms, while broad level gender inequality, economic hardship, worldviews and negative policy environments may also hinder PMTCT care.

Despite its integration into a larger context, the individual still remains at the center of the SEM model. Several commonly used health behavior theories such as the Health Belief Model and Theory of Planned Behavior focus attention virtually entirely on this level, and their constructs are important to consider for women engaging the PMTCT system. According to the Health Belief Model (HBM), beliefs drive behavior (Janz & Becker, 1984). In the HBM, an individual is affected by six constructs when making a decision about whether or not to adopt a health behavior: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cue(s) to action, and perceived self-efficacy (Janz & Becker, 1984). According to the Theory of Planned Behavior (TPB), the knowledge represented in these constructs is necessary but not sufficient to drive behavior. The attitude towards the behavior must also be weighed in light of the individual’s evaluation of the consequences of performing (or not performing) the behavior and the intention to perform the behavior. Subjective norms also drive the behaviors (Ajzen, 1991).

In consideration of PMTCT use, factors drawing from constructs from both of these theories have been implicated as barriers to PMTCT enrollment and adherence. Knowledge and understanding of HIV, which is inclusive of perceived susceptibility, perceived severity, and potential benefits and risks of PMTCT interventions, has been assessed among pregnant women
in several studies (Painter et al., 2004; Stringer et al., 2008; Ahou et al., 2010). The effect of self-efficacy and perceived behavioral control have been measured primarily through identification of perceived barriers or negatively modifying factors from the environment, including such factors as difficulty in transportation or the financial and time burden of medical visits (Torpey et al., 2010; Ferguson et al., 2012; Busza et al., 2012). Low motivation and self-efficacy were highlighted in a systematic review of community-based PMTCT interventions, and personal feelings of “not being ready,” which could be indicative of self-efficacy, have also been noted to be barriers (Busza et al., 2012; Atwiine et al., 2013; Otieno et al., 2010). From TPB, social norms have been shown to have a great degree of influence on HIV disclosure and testing patterns in ANC clients, and fear of the social stigma of disclosure or partner disapproval has been expressed as a reason for not attending PMTCT clinics (Otieno et al., 2010; Duff et al., 2010; Chinkonde et al., 2009).

Most traditional HIV prevention approaches, and in large part PMTCT approaches, have focused on these individual levels of influence. A systematic review of global PMTCT interventions from 2006-2012 demonstrated that the majority were based on individual level theoretical models such as the HBM, and the interventions included primarily components of counseling and education aimed at increasing knowledge. The constructs of perceived severity and perceived susceptibility were frequently documented as highly important in these interventions, as was the perceived benefit of the HIV treatment (Busza et al., 2012).

The need for knowledge about HIV and cues to action for HIV + mothers are recognized as critical, and many interventions have documented improvement in knowledge and belief-based outcomes. However, these knowledge-based outcomes are not always resulting in an improvement in PMTCT uptake or adherence, for knowledge alone cannot remove perceived
barriers (Busza et al., 2012). The responsibility the individual level approaches place on the mother in large part ignores the significance of the greater context in which she lives, and in many contexts this overestimates the potential of women to make their own decisions (Haampanda, 2013). According to Haampanda (2013), the lack of an ecological approach in PMTCT interventions is one of the most significant issues accounting for the ongoing problem of vertical HIV transmission on a global level.

Interventions based on other levels of the SEM are much less frequently documented. Inter-personal level interventions have resulted in increased adherence to ART for HIV + individuals in multiple interventions, but few are specific to PMTCT. The relatively recent success of forming peer support groups for PLHIV women is promising, however, and it may confirm that both social norms and self-efficacy play a role in encouraging adherence to PMTCT (Tonwe-Gold et al., 2009). Interventions focused on existing organizational level barriers, including such common issues as failure in supply chains, difficulty in accessing clinics, and lack of adequately trained staff are also rare (Busza et al., 2011; Otieno et al., 2010; Atwiine et al., 2013; Audereau et al., 2013). Cultural norms, stigma, and other social constraints are targeted or documented in PMTCT interventions very infrequently. National health policies have a direct effect on the PMTCT services offered to women, and public policy is a significant influencing factor for almost all health-related behaviors, including PMTCT utilization and adherence (Busza et al., 2012). In some contexts, interventions have included the policies shifting in a positive direction. However, policy level changes surrounding gender equality, gender violence, and economic empowerment are infrequently documented across the PMTCT literature.
Ethiopia

As is the case across the global community, PMTCT studies in Ethiopia have utilized primarily individual level models of health behavior such as HBM and TPB; the importance of the constructs from these models can thus not be overlooked. In a study of voluntary HIV counseling and testing among antenatal attendees which used the HBM as a framework for its surveys, perceived susceptibility to HIV was low among the women surveyed (37%), yet the perceived severity of HIV was high (67%) (Moges & Amberbir, 2011). Those women with high perceived susceptibility had a 3 times greater likelihood of testing than those who did not, and those who perceived benefit from the test were 95% more likely to test than those who did not believe the test had value (Moges & Amberbir, 2011). TPB studies also demonstrate the strong influence of subjective norms in the Ethiopian culture. These norms were identified as strong predictors of motivation to learn about HIV among Ethiopian college students (Gebreeyesus, Boer & Kuiper, 2007); intention to test for HIV was also strongly affected by subjective norms among ANC attendees (Mirkuzie, Sisay, Moland, & Astrom, 2011). The predictive value of the subjective norm in these studies may be a potential reflection of the collectivist culture and social norms of Africa as opposed to the West (Fekadu & Kraft, 2002).

PMTCT interventions in Ethiopia have also been enacted predominately at this intra-personal level, and some of these knowledge-based interventions have been effective. For example, the acceptance of HIV testing at ANCs has increased rapidly with the incorporation of pre-test counseling, and women demonstrate increased knowledge on surveys after attending group education sessions. However, the lack of progress in PMTCT uptake and adherence demonstrates that factors beyond knowledge are influencing Ethiopian women. Cultural issues, social forces such as religion, and structural level concerns such as gender inequality must be
considered, and the impact of the inter-personal relationships in the lives of the PLHIV women cannot be overlooked.

It is recognized that multiple factors contribute to PMTCT attrition among Ethiopian women, but it is not clear which of these factors holds the most influence. The overall nature of this study is exploratory, seeking to understand these influences and the behavior of women in Addis Ababa in the PMTCT system in an effort to guide future research or interventions. Although some individual level constructs from HBM and TPB will be used in design of quantitative survey measures, the predominately qualitative component of the study will allow for significant factors at any level of the SEM to emerge. As these factors are elicited from conversations with PLHIV women and data is triangulated, use of the SEM as a framework may provide clarity into their impact and how they are interconnected. This study will utilize a modified version of Poundstone’s SEM model (Figure 5) and enable researchers and public health providers to better identify which categories may hold the strongest influence on PMTCT attrition and be an optimal target for future interventions.

While many studies have categorized barriers to PMTCT use along a variation of the SEM, fewer have sought to understand the positive influences which may actually facilitate PMTCT use. Since risk regulators can present either constraints or opportunities to individual level behaviors, it is important to recognize and capitalize on positive influences in promoting PMTCT use (Glass & McAfee, 2006). Peer support, an inter-personal level influence, is documented in many locations as beneficial in increasing adherence and uptake of services. Travel stipends, removal of user fees, and mobile clinics may increase uptake of services from an organizational level, whereas positive messages from religious communities may be significant sources of influence at the community level. Structural influences, while difficult to change, are
powerful: empowerment of women through cash transfers as social protection and anti-discrimination laws may facilitate care at this level. The positive effect of such influences among PLHIV Ethiopian women has not been studied, yet they must exist. Women identified as “positive deviants” - those who had access to the same resources and encountered the same barriers to PMTCT and yet had a successful outcome - may provide critical insight into the factors with the greatest potential to effect positive change at a population level (Glass & McAfee, 2006). In this study, by speaking with women who have successfully navigated the PMTCT system and whose children are HIV-, these positive influences can be identified and the influences can be placed as facilitators into each level of the SEM framework.
## Appendix B

### WHO PMTCT Guidelines

<table>
<thead>
<tr>
<th>Recommendation year</th>
<th>Maternal ARV regimen</th>
<th>Infant ARV regimen</th>
<th>Breastfeeding guideline</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>sd-NVP(^a) at delivery</td>
<td>sd-NVP within 72 hours after birth</td>
<td>Formula feed if AFASS(^b) criteria can be met</td>
</tr>
<tr>
<td>2004</td>
<td>1. Initiate HAART(^c) regimen(^d)</td>
<td>sd-NVP at birth and 7 days of AZT</td>
<td>Formula feed if AFASS criteria can be met</td>
</tr>
<tr>
<td></td>
<td>2. Preferred regimen: initiate AZT at 28 weeks of pregnancy &amp; sd-NVP at delivery</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Acceptable alternative regimens:</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• AZT + lamuvidine</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• sd-NVP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2006</td>
<td>1. Initiate HAART if CD4 &lt;200 or clinical stage 3 or 4</td>
<td>sd-NVP at birth and 7 days of AZT (28 days if mother HAART eligible and has taken &lt; 4 weeks)</td>
<td>Breastfeed unless AFASS criteria can be met</td>
</tr>
<tr>
<td></td>
<td>2. Initiate AZT at 28 weeks of pregnancy, sd-NVP at delivery, and 7 days of AZT and 3TC post-partum</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2010</td>
<td>1. Initiate HAART at diagnosis if CD4&lt;350</td>
<td>1. NVP or AZT for 4-6 weeks if mother HAART eligible</td>
<td>Exclusively breastfeed for 6 months if mother on ARVs unless AFASS criteria can be met</td>
</tr>
<tr>
<td></td>
<td>2. <strong>Option A</strong>: Initiate AZT at 14 weeks, NVP and AZT at delivery, tenofovir (TDF) or emtricitabine (FTC) for 1 week post-partum</td>
<td>2. <strong>Option A</strong>: sd-NVP at birth then NVP or AZT for 6 weeks, or one week after end of breastfeeding</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Option B</strong>: Initiate HAART at 14 weeks regardless of CD4 status</td>
<td><strong>Option B</strong>: NVP or AZT for 6 weeks regardless of breastfeeding</td>
<td></td>
</tr>
<tr>
<td>2012</td>
<td>Initiate HAART for all HIV+ pregnant women and continue for life regardless of CD4 count</td>
<td>NVP or AZT for 6 weeks regardless of breastfeeding</td>
<td>Exclusively breastfeed for 6 months if mother on ARVs unless AFASS criteria can be met</td>
</tr>
</tbody>
</table>

**Notes.**  
\(^a\) single-dose nevirapine.  
\(^b\) “Acceptable, Feasible, Affordable, Sustainable, and Safe” circumstances for formula feeding.  
\(^c\) Highly Active Anti-retroviral Therapy.  
\(^d\) Commonly used HAART regimens safe in pregnancy are AZT +3TC +NVP; AZT +3TC + (EFV); TDF + 3TC +NVP; and TDF +3TC + EFV.
# Appendix C
## Survey Questions and Constructs

<table>
<thead>
<tr>
<th>#</th>
<th>Question</th>
<th>Origin</th>
<th>SEM level and/or construct</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>When can HIV be passed from a mother to her child?</td>
<td>H¹</td>
<td>Intra-personal (Susceptibility)</td>
</tr>
<tr>
<td>2</td>
<td>If there are 10 HIV infected pregnant mothers, how many do you think would have babies born with HIV virus if they do not take treatment?</td>
<td>H</td>
<td>Intra-personal (Susceptibility)</td>
</tr>
<tr>
<td>3</td>
<td>If 10 babies are born to HIV + mothers who take all their medication and follow directions of medical providers for PMTCT, how many of them will be infected?</td>
<td>PI²</td>
<td>Intra-personal (Benefits)</td>
</tr>
<tr>
<td>4</td>
<td>What can a mother do to reduce the risk of transmission of HIV to her child during pregnancy?</td>
<td>H</td>
<td>Intra-personal (Benefits)</td>
</tr>
<tr>
<td>5</td>
<td>What can a mother do to reduce the risk of transmission of HIV to her child during delivery?</td>
<td>H</td>
<td>Intra-personal (Benefits)</td>
</tr>
<tr>
<td>6</td>
<td>What can breastfeeding mothers do to reduce the risk of the baby becoming infected with HIV during the breastfeeding period?</td>
<td>H</td>
<td>Intra-personal (Benefits)</td>
</tr>
<tr>
<td>7</td>
<td>If a baby is born with HIV, what will possibly happen to him/her?</td>
<td>PI</td>
<td>Intra-personal (Severity)</td>
</tr>
<tr>
<td>8</td>
<td>If 10 babies are born with HIV and receive no treatment, how many of the babies are likely to die before they are 2 years old?</td>
<td>PI</td>
<td>Intra-personal (Severity)</td>
</tr>
<tr>
<td>9</td>
<td>If you used PMTCT previously, did you have any problems?</td>
<td>H</td>
<td>Intra-personal/ (Barriers)</td>
</tr>
<tr>
<td>10</td>
<td>If yes, what problems did you have?</td>
<td>H</td>
<td>Intra-personal/ (Barriers)</td>
</tr>
<tr>
<td>11</td>
<td>If you are pregnant in the future and do plan to use PMTCT, do you think there may be any problems?</td>
<td>H</td>
<td>Intra-personal/ (Barriers)</td>
</tr>
<tr>
<td>12</td>
<td>If you do think there will be problems, what do you think those may be?</td>
<td>H</td>
<td>Intra-personal/ (Barriers)</td>
</tr>
<tr>
<td>13</td>
<td>Do you plan to have more children?</td>
<td>H</td>
<td>Intention</td>
</tr>
<tr>
<td>14</td>
<td>If you do NOT plan to have more children, why not?</td>
<td>H</td>
<td>Intra-personal/ (Barriers)</td>
</tr>
<tr>
<td>15</td>
<td>I am confident that I can get the medication necessary to prevent my baby from being infected.</td>
<td>H</td>
<td>Intra-personal (Self-efficacy)</td>
</tr>
<tr>
<td>16</td>
<td>I am confident that I would be able to take the medication correctly and faithfully.</td>
<td>H</td>
<td>Intra-personal (Self-efficacy)</td>
</tr>
<tr>
<td>17</td>
<td>The opinion of my husband is important to me</td>
<td>PI</td>
<td>Inter-personal</td>
</tr>
<tr>
<td>18</td>
<td>The opinion of my in-laws is important to me</td>
<td>PI</td>
<td>Inter-personal</td>
</tr>
<tr>
<td>19</td>
<td>The opinion of other family members is important to me</td>
<td>PI</td>
<td>Inter-personal</td>
</tr>
<tr>
<td>20</td>
<td>The opinion of my religious leader and community is important to me</td>
<td>PI</td>
<td>Social/Community</td>
</tr>
<tr>
<td>21</td>
<td>The opinion of my friends or other community is important to me</td>
<td>PI</td>
<td>Inter-personal</td>
</tr>
<tr>
<td>22</td>
<td>My faith influences my health care</td>
<td>PI</td>
<td>Social/Community</td>
</tr>
<tr>
<td>23</td>
<td>My husband thinks that PMTCT is helpful and would encourage me to use it</td>
<td>H</td>
<td>Inter-personal</td>
</tr>
<tr>
<td></td>
<td>Statement</td>
<td>Code</td>
<td>Category</td>
</tr>
<tr>
<td>---</td>
<td>---------------------------------------------------------------------------</td>
<td>------</td>
<td>----------------------</td>
</tr>
<tr>
<td>24</td>
<td>My in-laws think that PMTCT is helpful and encourage me to use it</td>
<td>H</td>
<td>Inter-personal</td>
</tr>
<tr>
<td>25</td>
<td>My friends think PMTCT is helpful and would encourage me to use it</td>
<td>H</td>
<td>Inter-personal</td>
</tr>
<tr>
<td>26</td>
<td>My neighbors think PMTCT is helpful and would encourage me to use it</td>
<td>PI</td>
<td>Social/Community</td>
</tr>
<tr>
<td>27</td>
<td>My religious community thinks that PMTCT is helpful and would encourage me to use it</td>
<td>PI</td>
<td>Social/Community</td>
</tr>
<tr>
<td>28</td>
<td>God will determine my baby’s health and nothing I do will change that.</td>
<td>H</td>
<td>Intra-personal (Susceptibility)/Social/Community</td>
</tr>
<tr>
<td>29</td>
<td>If my neighbors know I am going to the PMTCT clinic they will gossip about me</td>
<td>H</td>
<td>Social/Community</td>
</tr>
<tr>
<td>30</td>
<td>Using PMTCT can have benefits for my own health</td>
<td>PI</td>
<td>Intra-personal (Benefits)</td>
</tr>
<tr>
<td>31</td>
<td>My religious community thinks HIV is a curse from God</td>
<td>PI</td>
<td>Social/Community</td>
</tr>
<tr>
<td>32</td>
<td>Most HIV+ women use PMTCT all the way to the end of the program</td>
<td>PI</td>
<td>Subjective Norm/Social/community</td>
</tr>
<tr>
<td>33</td>
<td>I am afraid that if I have a child he/she will be infected with HIV</td>
<td>H</td>
<td>Intra-personal (Susceptibility)</td>
</tr>
</tbody>
</table>

Notes. ¹Horizons ²Primary Investigator
Appendix D
Study Tools

PLHIV Survey questions

Demographic information
☐ Age ___________ ☐ Marital status ___________
☐ Ethnicity ___________ ☐ Religion_________ ☐ Educational level________
☐ Number of rooms in home _________ ☐ Number of people in home____
☐ Number of pregnancies______________ ☐ Number of living children_____ 
☐ Number of times pregnant since HIV diagnosis _________
☐ Number of times used PMTCT _______________
☐ Number of children infected with HIV during pregnancy, delivery, or breastfeeding _________

Survey questions
1. When can HIV be passed from a mother to her child? (DO NOT read answers. Check only those mentioned by participant without prompting )
   ☐ Pregnancy ☐ Delivery ☐ Breastfeeding

2. If there are 10 HIV infected pregnant mothers, how many do you think would have babies born with HIV virus if they do not take treatment?
   ☐ None ☐ 1 TO 3 ☐ 4 TO 6 ☐ 7 TO 9
   ☐ All ☐ Don’t know

3. If 10 babies are born to HIV + mothers who take all their medication and follow directions of medical providers for PMTCT, how many of them will be infected?
   ☐ None ☐ 1 TO 3 ☐ 4 TO 6 ☐ 7 TO 9
   ☐ All (10) ☐ Don’t know

4. What can a mother do to reduce the risk of transmission of HIV to her child during pregnancy? (DO NOT read answers. Check only those mentioned by participant without prompting )
   ☐ Take medication ☐ Abstain from sex ☐ Use condoms
   ☐ Good nutrition ☐ Manage during labor
   ☐ Pray or visit religious leader ☐ Nothing can be done
   ☐ Don’t know ☐ Other ______________

5. What can a mother do to reduce the risk of transmission of HIV to her child during delivery? (DO NOT read answers. Check only those mentioned by participant without prompting )
   ☐ Take medication ☐ Manage during labor
   ☐ Pray or visit religious leader ☐ C-section
6. What can breastfeeding mothers do to reduce the risk of the baby becoming infected with HIV during the breastfeeding period? (DO NOT read answers. Check only those mentioned by participant without prompting)
☐ Take medication ☐ Give breast milk only/no other feeds to 6 months
☐ Use condoms
☐ Early weaning; give infant formula/ diluted cow’s milk
☐ Stop breastfeeding/ give infant formula or milk
☐ Pray or visit religious leader
☐ Better nutrition for both mother and baby ☐ Nothing
☐ Other __________

7. If a baby is born with HIV, what will possibly happen to him/her? (DO NOT read answers. Check only those mentioned by participant without prompting)
☐ Get sick ☐ Be malnourished ☐ Death ☐ Nothing ☐
Other________________________

8. If 10 babies are born with HIV and receive no treatment, how many of the babies are likely to die before they are 2 years old?
☐ None ☐ 1 TO 3 ☐ 4 TO 6 ☐ 7 TO 9
☐ 10 ☐ Don’t know

9. If you used PMTCT previously, did you have any problems? (If NO, skip to # 11)
☐ Yes ☐ No

10. If yes, what problems did you have? (DO NOT read answers. Check only those mentioned by participant without prompting)
☐ Transportation to PMTCT facility
☐ Difficult to understand the system
☐ My husband/partner wouldn’t allow me to go
☐ I have to take medication for too long
☐ I don’t like taking medication
☐ Medical staff treated me poorly
☐ I didn’t want people to know ☐ Money
☐ It took too much time ☐ Other ___________________
11. If you are pregnant in the future and do plan to use PMTCT, do you think there may be any problems?
☐ Yes  ☐ No  (If NO, skip to # 13)

12. If you do think there will be problems, what do you think those may be? (DO NOT read answers. Check only those mentioned by participant without prompting)
☐ Transportation to PMTCT facility  ☐ Difficult to understand the system
☐ My husband/partner won’t allow me to go  ☐ I have to take medication for too long
☐ I don’t like taking medication  ☐ Medical staff will treat me poorly
☐ I don’t want people to know  ☐ Money
☐ It takes too much time  ☐ Other ________________

13. Do you plan to have more children?
☐ Yes  ☐ No  ☐ Don’t know  (If YES, skip to #15)

14. If you do NOT plan to have more children, why not?  (DO NOT read answers. Check only those mentioned by participant without prompting. When question is complete, skip to #17)
☐ Fear of HIV  ☐ Spouse does not want more
☐ Already have enough children  ☐ Other
☐ Do not have money for more children

**True/false questions. (Read each question out loud and mark whether the participant says it is true or false).**

<table>
<thead>
<tr>
<th>Question</th>
<th>True</th>
<th>False</th>
</tr>
</thead>
<tbody>
<tr>
<td>15. I am confident that I can get the medication necessary to prevent my baby from being infected.</td>
<td>☐ True</td>
<td>☐ False</td>
</tr>
<tr>
<td>16. I am confident that I would be able to take the medication correctly and faithfully.</td>
<td>☐ True</td>
<td>☐ False</td>
</tr>
<tr>
<td>17. The opinion of my husband is important to me</td>
<td>☐ True</td>
<td>☐ False</td>
</tr>
<tr>
<td>18. The opinion of my in-laws is important to me</td>
<td>☐ True</td>
<td>☐ False</td>
</tr>
<tr>
<td>19. The opinion of other family members is important to me</td>
<td>☐ True</td>
<td>☐ False</td>
</tr>
<tr>
<td>20. The opinion of my religious leader and community is important to me</td>
<td>☐ True</td>
<td>☐ False</td>
</tr>
<tr>
<td>21. The opinion of my friends or other community is important to me</td>
<td>☐ True</td>
<td>☐ False</td>
</tr>
<tr>
<td>22. My faith influences my health care</td>
<td>☐ True</td>
<td>☐ False</td>
</tr>
<tr>
<td>23. My husband thinks that PMTCT is helpful and would encourage me to use it</td>
<td>☐ True</td>
<td>☐ False</td>
</tr>
</tbody>
</table>
24. My in-laws think that PMTCT is helpful and encourage me to use it  □ True □ False
25. My friends think PMTCT is helpful and would encourage me to use it  □ True □ False
26. My friends think PMTCT is helpful and would encourage me to use it  □ True □ False
27. My religious community thinks that PMTCT is helpful and would encourage me to use it  □ True □ False
28. God will determine my baby’s health and nothing I do will change that.  □ True □ False
29. If my neighbors know I am going to the PMTCT clinic they will gossip about me  □ True □ False
30. Using PMTCT can have benefits for my own health  □ True □ False
31. My religious community thinks HIV is a curse from God  □ True □ False
32. Most HIV+ women use PMTCT all the way to the end of the program  □ True □ False
33. I am afraid that if I have a child he/she will be infected with HIV  □ True □ False

**Interview questions**

General information about interviewees:

*Age, parity, number of living children, income, marital status, educational status, religion, HIV status of children, use of PMTCT*

1. In general, I am interested to know what some of your biggest concerns were while you were pregnant. (Probe – can you describe a memorable time during your pregnancy?)
2. Now, I would like to hear you describe the time you found out you were HIV positive. What did you think about then or what did you feel about it? (Probe- did you know what it was at the time (and for how long), who did you tell, and what did you feel?)
3. (if applicable)Now I would like you to think about the first time that you discovered you were pregnant and HIV+. Describe that time to me. (Probe- what did you think, how did you feel, who did you tell about it?)
4. At the time of your pregnancy, what did you know about HIV and transmission to your baby? Did you learn anything new about this transmission during your pregnancy? (Probe- what did you learn? Who taught you (medical staff, friends, etc?)
5. Tell me about your decision on how to take care of yourself during pregnancy. 3. (Probe-if you did not use prenatal care and/or HIV care, explain why not and other methods of care. If you did use prenatal or HIV services, describe a memorable experience there
6. (As applicable if took medication at all)
   a. You started taking medication for your baby not to have HIV but dropped out. Why did you do that?
   b. You took HIV medication to prevent your baby from being sick. How easy or hard was that to do all the way to the end?
7. How did your religious beliefs affect your pregnancy? (Probe-did the faith itself affect your healthcare, emotions, or thoughts about pregnancy and HIV? Did a religious leader or anyone in the religious community say anything about HIV or preventing it going to your baby during that time?)
8. Please tell me about the people who influence your health decisions (to go to doctor, prenatal care, etc) in your life
9. I have heard that some women know they have HIV but don’t take the medication to keep their babies from being sick. Why do you think that may be? Do you have any suggestions for helping them?

PMCT in Ethiopia- Focus group questions

1. When did you first learn about HIV and the ability to transmit it to infants? Who told you and what did they say?
2. Describe the person or people in your life who most influence your health care decisions and how they do that.
   a. Probe-did you talk to this person/people about HIV and/or transmitting it to a baby?
3. Does your religious community or religious leader ever talk about health? Do they talk about HIV? Do they talk specifically about how to prevent transmission to infants?
   a. If so, what do they say?
   b. If not, what would you like them to say about it?
4. Think back to the time you were last pregnant. If you did go to a doctor and took medication the whole time you were pregnant and during breastfeeding, describe a challenging part or a very helpful part for you in doing this. What helped you to continue?
   a. Follow up: If you did take the medications like this, explain a memorable experience (positive or negative) that you had with the medical system.
   b. Did anything negative ever happen to you as a result of using medical care and taking HIV medication to prevent your baby from being infected? Did anyone influence you to take the medication or not?
5. A lot of women get diagnosed with HIV, referred to take medication, and then either don’t go or go but later stop taking the medicine and their babies get infected. Why do you think they don’t keep going and taking the medication?

6. If you could tell someone in charge in the community, religious leaders, doctors, or government anything that would help more women to take medication so babies are not infected, what would you tell them?

7. Which of the following would be most useful to encourage a woman to take HIV medication to prevent her baby from being sick: radio ad, TV ad, community group, religious group, or medical provider? Why?

8. Is there anything that you want to add?
Appendix E
Surveys and Question Guides (Amharic)

PMTCT in Ethiopia- Survey questions

Demographic information
☐ Age _________ ☐ Marital status _________ ☐ Ethnicity _________
☐ Religion _________ ☐ Educational level _________
☐ # of rooms in home _________ ☐ # of people in home _________
☐ # of pregnancies _________ ☐ # of living children _________
☐ # of times pregnant since HIV diagnosis _________

Did mother take medicine during pregnancy, labor, and also breastfeeding (if breastfeeding)? (yes or no)

Is child infected with HIV? (yes or no)

Did child die from HIV? (yes or no)

Survey questions

1. When can HIV be passed from a mother to her child? (አንድ ከእናት ወደ ልጅ መተላለፍ የሚችለው መቼ ነው?)

2. If there are 10 HIV infected pregnant mothers, how many do you think would have babies born with HIV virus if they do not take treatment? (የደማቸው የሚገኝ ነፍሰጡር ይካሉ እና ወይም ያልያይም ይመስሎታል)

3. If 10 babies are born to HIV + mothers who DO take all their medication and follow directions of medical providers for preventing transmission to their babies, how many of them will be infected? (ከተወለዱ ልጅ ያይረስ ይመስሎታል)

Survey questions

Pregnancy 1 እርግዝን 1
Pregnancy 2 እርግዝን 2
Pregnancy 3 እርግዝን 3
4. What can a mother do to reduce the risk of transmission of HIV to her child during pregnancy? (DO NOT read answers. Check only those mentioned by participant without prompting)

☐ Take medication  ☐ Abstain from sex  ☐ Use condoms

☐ Good nutrition  ☐ Manage during labor

☐ Pray or visit religious leader  ☐ Nothing can be done

☐ Don’t know  ☐ Other

5. What can a mother do to reduce the risk of transmission of HIV to her child during delivery?

(DO NOT read answers. Check only those mentioned by participant without prompting)

☐ Take medication  ☐ Manage during labor

☐ Pray or visit religious leader  ☐ C-section

☐ Nothing can be done  ☐ Don’t know  ☐ Other

6. What can breastfeeding mothers do to reduce the risk of the baby becoming infected with HIV during the breastfeeding period? (DO NOT read answers. Check only those mentioned by participant without prompting)

☐ Take medication  ☐ Give breast milk only and no other feeds up to 6 months

☐ Use condoms  ☐ Stop breastfeeding/give infant formula or milk

☐ Pray or visit religious leader  ☐ Better nutrition for both mother and baby

☐ Nothing  ☐ Other

7. If a baby is born with HIV, what will possibly happen to him/her? (DO NOT read answers. Check only those mentioned by participant without prompting)

☐ Get sick  ☐ Be malnourished
8. If 10 babies are born with HIV and receive no treatment, how many of the babies are likely
to die before they are 2 years old?
☐ None
☐ 1 TO 3
☐ 4 TO 6
☐ 7 TO 9
☐ 10
☐ Don’t know

9. IF you used services/medications to prevent HIV for your baby when pregnant in the past,
did you have any problems? (If did not use services, skip to # 11)
☐ Yes
☐ No

10. IF you used services/medications to prevent HIV for your baby, what problems did you
have? (DO NOT read answers. Check only those mentioned by participant without prompting)
☐ Transportation to medical facility
☐ Difficult to understand the system
☐ My husband wouldn’t allow me to go
☐ I have to take medication for too long
☐ I don’t like taking medication
☐ Medical staff treated me poorly
☐ Money
☐ It took too much time
☐ Other

11. If you were pregnant in the future do you think there may be any problems preventing your
child from being infected with HIV? (If NO, skip to # 13)
☐ Yes
☐ No

12. If you do think there will be problems, what do you think those may be?
☐ Transportation to medical facility
☐ Difficult to understand the system
☐ My husband won’t allow me to go ☐ I have to take medication for too long ☐ I don’t like taking medication ☐ Medical staff will treat me poorly ☐ I don’t want people to know ☐ Money ☐ It takes too much time ☐ Other

13. Do you plan to be pregnant in the future? (If YES, skip to # 15) ከአወደፉቱ መፀነስ አቅደዋል? (መልስዎት ከሆነ ወደ ተራ ቁጥር 15 ይለፉ)
☐ Yes ☐ No

14. If you do NOT plan to have more children, why not? በተጨማሪ አይፈልግም ከአወድዎ ከውር የሚያስፇታል ያልገኝ እስገድ ነው? (DO NOT read answers. Check only those mentioned by participant without prompting . When question is complete, skip to #17)
☐ Fear of HIV ☐ Spouse does not want more ☐ Already have enough children ☐ Do not have money for more children ☐ Other

True/false questions እውነት/ውሸት ጥያቄዎች. (Read each question out loud and mark whether the participant says it is true or false) ከእያንዳንዱን መልስ ጮክ ብለው ያንብቡ እና ተሳታፊው እውነት ያለውን ያጥቁሩ::)

<table>
<thead>
<tr>
<th>Question</th>
<th>True</th>
<th>False</th>
</tr>
</thead>
<tbody>
<tr>
<td>15. I am confident that I can get the medication necessary to prevent my baby from being infected. ከአወድ ከጠቃሚ የሚያስፇታል ያልገኝ ከማየት እንደምችል ከሚለው ለእኔ አስፈላጊ ነው</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>16. I am confident that I would be able to take the medication correctly and faithfully. ከእኔ እንደምችል ከሚለው ያልገኝ ከማየት እንደምችል ከሚለው ለእኔ አስፈላጊ ነው</td>
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<tr>
<td>17. The opinion of my husband is important to me ከአገር ከፍቅር ከአስተሳሰብ ለእንራት ከሚለው ያልገኝ ከማየት እንደምችል ከሚለው ለእኔ አስፈላጊ ነው</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>18. The opinion of my in-laws is important to me ከአገር ከአስተሳሰብ ለእንራት ከሚለው ያልገኝ ከማየት እንደምችል ከሚለው ለእኔ አስፈላጊ ነው</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>19. The opinion of other family members is important to me ከአገር ከአስተሳሰብ ለእንራት ከሚለው ያልገኝ ከማየት እንደምችል ከሚለው ለእኔ አስፈላጊ ነው</td>
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</tr>
<tr>
<td>20. The opinion of my religious leader and community is important to me ከአገር ከአስተሳሰብ ለእንራት ከሚለው ያልገኝ ከማየት እንደምችል ከሚለው ለእኔ አስፈላጊ ነው</td>
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</tr>
<tr>
<td>21.</td>
<td>The opinion of my friends or other community is important to me.</td>
<td>True/False</td>
</tr>
<tr>
<td>22.</td>
<td>My faith influences my health care.</td>
<td>True/False</td>
</tr>
<tr>
<td>23.</td>
<td>My husband thinks that HIV medication is helpful and would encourage me to use it.</td>
<td>True/False</td>
</tr>
<tr>
<td>24.</td>
<td>My in-laws think that HIV medication is helpful and would encourage me to use it.</td>
<td>True/False</td>
</tr>
<tr>
<td>25.</td>
<td>My friends think that HIV medication is helpful and would encourage me to use it.</td>
<td>True/False</td>
</tr>
<tr>
<td>26.</td>
<td>My neighbors think HIV medication is helpful and would encourage me to use it.</td>
<td>True/False</td>
</tr>
<tr>
<td>27.</td>
<td>My religious community thinks that HIV medication is helpful and would encourage me to use it.</td>
<td>True/False</td>
</tr>
<tr>
<td>28.</td>
<td>God will determine my baby’s health and nothing I do will change that.</td>
<td>True/False</td>
</tr>
<tr>
<td>29.</td>
<td>If my neighbors know I am going to the clinic for HIV they will gossip about me.</td>
<td>True/False</td>
</tr>
<tr>
<td>30.</td>
<td>Using medication to prevent HIV for my baby can have benefits for my own health.</td>
<td>True/False</td>
</tr>
<tr>
<td>31.</td>
<td>My religious community thinks HIV is a curse from God.</td>
<td>True/False</td>
</tr>
<tr>
<td>32.</td>
<td>Most HIV+ women take HIV medication through breastfeeding to keep their babies from being infected.</td>
<td>True/False</td>
</tr>
<tr>
<td>33.</td>
<td>I am afraid that if I have a child he/she will be infected with HIV.</td>
<td>True/False</td>
</tr>
</tbody>
</table>
ፒኤምቲሲቲ በኢትዮጵያ የቃለ መጠይቅ ጥያቄዎች

ስለተሳታፊዎች አጠቃላይ መረጃ እድሜ፣ የእርግዝናዎች ቁጥር፣ በህይወት የላሉልጆች ቁጥር፣ ገቢ፣ የትዳር ጀንታ፣ የትምህርት ውንፈ፣ ኃይማኖት፣ የልጆች ኤች አይ ቪ ሁኔታ፣ የፒኤምቲሲቲ አጠቃቀም ማሟሟቂያ የቃለዎች - የስለእርስዎ እና ወደ የልጆች በተጨማሪ የንገሩኝ

1. በአጠቃላይ እርግዝ የነበር የትልቁ ይንቆቶች ትርጉ ይንድል። የትልቁ ይንቆቶች እኔ ያለማወቅ እፈልጋሉ።

2. እሁን ወደ ይች አይ ቪ+ እንደሆነ ያወቁበትን ግዜ ያርገለጹልኝ በሰማዎት ያወዳለሁ ብወይን የታሰቦት ይች እንደነበር ያውቁ ይህ ነበር?

3. ኃይማኖት የልጆች ወደ ደንስ ያቀለጹ ያስገለጹ ዘር ይች እንደነበር ያውቁ ይህ ውስጥ ይች እንደነበር ያውቁ ይህ ነበር?

4. ኃይማኖት ዯንግ ወደ ደንስ ያቀለጹ ያስገለጹ ዘር ይች እንደነበር ያውቁ ይህ ውስጥ ይች እንደነበር ያውቁ ይህ ነበር?

5. ዯንግ ወደ ደንስ ያቀለጹ ያስገለጹ ዘር ይች እንደነበር ያውቁ ይህ ውስጥ ይች እንደነበር ያውቁ ይህ ነበር?

6. ዯንግ ወደ ደንስ ያቀለጹ ያስገለጹ ዘር ይች እንደነበር ያውቁ ይህ ነበር?

7. ዯንግ ወደ ደንስ ያቀለጹ ያስገለጹ ዘር ይች እንደነበር ያውቁ ይህ ነበር?

8. ዯንግ ወደ ደንስ ያቀለጹ ያስገለጹ ዘር ይች እንደነበር ያውቁ ይህ ነበር?

9. ዯንግ ወደ ደንስ ያቀለጹ ያስገለጹ ዘር ይች እንደነበር ያውቁ ይህ ነበር?
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ፒኤምቲሲቲ በኢትዮጵያ- የትኩረት ቡድን ጥያቄዎች (ፒኤልኤችአይቪ እናቶች）
ማሟሟቂያ ጥያቄዎች- ስለ ልጆችዎ ይንገሩኝ፦ ስንት ወንዶች እና ሴቶች ልጆች አሎት እና ምን መጫወት ይወዳሉ？
ስንት ወንድሞች እና እህቶች አልዎት？
1. ለመጀመሪያ ግዜ ስለ ኤች አይ ቪ እና ወደ ህጻናት መተላለፍ መቻሉን የተማሩት መቼ ነበር? ማን ነገሮት እና እነሱ
ምን አሉ?
2. በህይወትዎ ውስጥ ስለጤናዎ እንክብካቤ ለሚያደርጉት ውሳኔዎች በአብዛኛው ተጽእኖ ስለሚያደርጉቦት ሰዎች እና
እንዴት እንደዚ እንደሚያደርጉ ይግለጹ
ሀ
በጥልቀት በመመርመር፦ እነዚህ ሰዎች/ይህ ሰው ስለ ፒኤምቲሲቲ አነጋግረዎታል? ኤች አይ
ቪ+ እና እርጉዝ እንደነበሩ ሲያውቁ ነገሩዋቸው?
3. የእርሶ የሃይማኖት ማህበረሰብ ወይም የሃይማኖት መሪ ስለ ጤና ምንግዜም ተናግረው ያውቃሉ? ስለ ኤች አይ ቪ
እና ፒኤምቲሲቲ ይናገራሉ ？
ሀ
ከሆነ ምን አሉ？
ለ
ካልሆነ እነርሱ ስለዚህ ጉዳይ ምን እንዲሉ ይፈልጋሉ？
4. እርጉዝ የሆነችው ጎረቤቶ ወይም ጓደኛዎ ኤች አይ ቪ + እንደሆነች ብታውቅ እና ለማን እንደምትነግር እና ምን
እንደምታደርግ ለማማከር እርስዎ ጋር ብትመጣ፥ ምን ይሉዋታል？ （በጥልቀት በመመርመር፦ አንድን ሰው
እንድታወያይ ይነግሩዋታል？ማንን？ ወደፒኤምቲሲቲ እንድትሄድ ይነግሩዋታ? ለምን ይነግሩዋታል ወይም ለምን
አይነግሩዋትም?
5. ለመጨረሻ ግዜ እርጉዝ የነበሩበትን ግዜ ያስቡ:: ፒኤምቲሲቲ ሄዳችሁ ለነበራችሁት እና ህክምናውን ለጨረሳችሁ
ያስቸገረው ወይም የረዳው ስለነበረው ክፍል ግለጹ
ሀ
በማስከተል: ወደ ፒኤምቲሲቲ ከሄዱ በፒኤምቲሲቲ ስርአት ውስጥ ስለሚያስታውሱት （
የአዎንታ ወይም አሉታ）ልምድ ያብራሩ
ለ
ፒኤምቲሲቲን በመጠቀሞት አሉታዊ ውጤት ደረሰብዎታል? እንዲከታተሉ ወይም
እንዳይከታተሉ ተጽእኖ ያደረገብዎት ሰው አለ? ከተከታተሉ ምን እያነቃቃዎት ነበር?
6. አብዛኛው ሴቶች በ ኤች አይ ቪ ይያዛሉ፣ ወደፒኤምቲሲቲ ይመራሉ፣ እና ወይ ይሄዳሉ ወይ አይሄዱም ግን
ፒኤምቲሲቲን መቼም አይጨርሱም። ለምን የማይመለሱ ይመስሎታል？
7. እርስዎ ሃላፊ ቢሆኑ ኖሮ ፒኤምቲሲቲን አሟልተው የሚያገባድዱ ሴቶችን ቁጥር ለማሻሻል ምን ያደርጋሉ?
ሀ
በማስከተል:ስርአቱን ምን ሊያሻሽለው ይችላል? ሴቶችን ፒኤምቲሲቲ እንዲከተሉ የሚያበረታታ
ምርጥ መንገድ ምን ሊሆን ይችላል?
ለ
በማስከተል፦ ከሚከተሉት ውስጥ አንድ ሴትን ከሁሉም በላይ ፒኤምቲሲቲ እንድትጠቀም
የሚያበረታቱት የትኞቹ ናቸው፦ የራዲዎ ማስታወቂያ፣ የቲቪ ማስታወቂያ፣ የማህበረሰብ ወገን፣
የሃይማኖት ወገን፣ወይም የጤና ባለሙያ
8. መጨመር የሚፈልጉት ነገር አለ？


Informed Consent to Participate in Research

Information to Consider Before Taking Part in this Research Study

IRB Study # ____________

We are asking you to take part in a research study called: PMTCT in Addis Ababa
The person who is in charge of this research study is Kimberly Fleek, who is a doctoral student at the University of South Florida. She is being guided in this research by Dr. Assefa Seme, a professor at Addis Ababa University.

Purpose of the study

The purpose of this study is to:

- Understand the pregnancy experiences of HIV + women and the influences on their reproductive health decisions in order to improve PMTCT service and decrease the number of babies being born with HIV.
- Offer feedback to both governmental and non-governmental organizations to improve the quality of PMTCT services.
- A doctoral student is completing a dissertation with this research.

Study Procedures

If you take part in this study, you will be asked to (only one of the following will apply):

- Answer questions for approximately 1.5 hours
- Attend a focus group at the program site which will last approximately 2 hours with other PLHIV women
- Answer a survey that will take approximately 15 minutes

Sessions will be taped and only study staff will have access to these tapes. All identifying information will be removed in the transcripts and the tapes will be kept by the PI for 1 year in a locked cabinet. After research is complete the tapes will be destroyed.
Total Number of Participants
About 500 women will take part in this study in surveys, interviews, and focus groups.

Alternatives
You do not have to participate in this research study.

Benefits
We are unsure if you will receive any benefits by taking part in this research study, but you will know that you have assisted in research which can prevent more children from being born with HIV.

Risks or Discomfort
This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study.

Compensation
You will be paid the equivalent of (only one of the following will apply):

- The equivalent in cash or goods of $10 USD for completing the interview or focus group plus any transportation costs to the study site.
- The equivalent in cash or goods of $3 for completing the survey.

Cost
There are no costs associated with your participation in the study.

Privacy and Confidentiality
We will keep your study records private and confidential. Certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

The research team, including the Principal Investigator and research assistants

Certain university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety. All the records will have identifying information removed.

The USF Institutional Review Board (IRB) and its related staff who have oversight responsibilities for this study, staff in the USF Office of Research and Innovation, USF Division of Research Integrity and Compliance, and other USF offices who oversee this research.

We may publish what we learn from this study. If we do, we will not include your name. We
will not publish anything that would let people know who you are.

**Voluntary Participation / Withdrawal**

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

You can refuse to sign this form. If you do not sign this form you will not be able to take part in this research study but your participation in the PLHIV program will not be affected.

**You can get the answers to your questions, concerns, or complaints by contacting:**

Dr. Assefa Seme  
AAU  
+251 911 22 81 93

**Consent to Take Part in this Research Study**

It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true.

**I freely give my consent to take part in this study.** I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

________________________________________  ____________
Signature of Person Taking Part in Study       Date

______________________________
Printed Name of Person Taking Part in Study

**Statement of Person Obtaining Informed Consent**

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I hereby certify that when this person signs this form, to the best of my knowledge, he/ she understands:

- What the study is about;
- What procedures/interventions/investigational drugs or devices will be used;
- What the potential benefits might be; and
- What the known risks might be.

I can confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in the appropriate language. Additionally, this subject
reads well enough to understand this document or, if not, this person is able to hear and understand when the form is read to him or her. This subject does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give legally effective informed consent.

_______________________________________________________________

Signature of Person Obtaining Informed Consent / Research Authorization

_______________________________________________________________

Printed Name of Person Obtaining Informed Consent / Research Authorization
## Appendix G
### Original Codebook

<table>
<thead>
<tr>
<th>Code</th>
<th>Working Definition</th>
<th>What it is</th>
<th>What it is not</th>
</tr>
</thead>
<tbody>
<tr>
<td>S</td>
<td>Test refers to anything in the structural element of SEM</td>
<td>Issues of demographic change, poverty, race or ethnic issues, gender violence, sexism, stigma or discrimination, or law and policy</td>
<td>Issues specific to the social or cultural situation such as religion, the effect of media, other social institutions or social capital</td>
</tr>
<tr>
<td>SEM</td>
<td>Text refers to anything in the social/community element of SEM</td>
<td>Culture, religion, the effect of media, social organizations, SE segregation, the physical environment, and social capital effects of networks and reciprocity or lack of social capital with NGOs</td>
<td>Issues related to direct interpersonal relationships, broad structural issues, or interpersonal or organizational concerns</td>
</tr>
<tr>
<td>IPE</td>
<td>Text refers to anything in the inter-personal level of SEM</td>
<td>Any interaction or thought regarding husband/sexual partners, family, friends, other social networks, positive in support or negative, including disclosure</td>
<td>Issues related to large social organizations, religion, culture, structural influences or interpersonal or organizational concerns</td>
</tr>
<tr>
<td>ORG</td>
<td>Text refers to anything in the organizational level of SEM</td>
<td>Issues related to health care access, linkages and referrals, prenatal care, positive and negative experiences with health care system</td>
<td>Issues not related to health care system</td>
</tr>
<tr>
<td>IND</td>
<td>Text refers to anything in the interpersonal level of SEM</td>
<td>Issues involving demographics, self-efficacy, knowledge about HIV, attitudes or emotions about HIV</td>
<td>Issues not related to the direct personal life of the individual that deal with organizational or systemic concerns</td>
</tr>
<tr>
<td>POV</td>
<td>Text refers to individual or societal issues concerning poverty or financial hardship</td>
<td>Discussion of experiences of self or others with financial difficulty or attitudes about poverty</td>
<td>anything not related to direct material poverty</td>
</tr>
<tr>
<td>STA</td>
<td>Test refers to stigma or discrimination related to HIV</td>
<td>Discussion of personal or second-hand experiences of stigma related to HIV</td>
<td>Laws or policy outside of Ethiopia</td>
</tr>
<tr>
<td>LAW</td>
<td>Test refers to current government policy or law about HIV or PMTCT</td>
<td>Discussion of any experiences or thoughts related to HIV in regards to law or government, including current and past laws and suggestions for government action in future</td>
<td>Change in individual’s understanding of or attitude about HIV</td>
</tr>
<tr>
<td>ETH</td>
<td>Text refers to broad social change in HIV in Ethiopia over last decade</td>
<td>Change in attitude or experiences over time about HIV, from a demographic or community perspective. Represents a shift in culture</td>
<td>Culture is not Ethiopian, issues of government or organizations or individual thoughts or attitudes</td>
</tr>
<tr>
<td>CUL</td>
<td>Text refers to any cultural issues specific to Ethiopia or ethnic groups</td>
<td>Experiences and attitudes and beliefs about religion of any kind, religious institutions, or faith including prayer; experiences of others regarding religion; teaching about HIV or religious institutions</td>
<td>Anything not directly pertaining to faith or religion; discussion of NGOs not religious in nature</td>
</tr>
<tr>
<td>REL</td>
<td>Text refers to any element of religion</td>
<td>Experiences and individual attitudes and beliefs about religion of any kind, religious institutions, or faith including prayer; experiences of others regarding religion; teaching about HIV or religious institutions</td>
<td>Anything not related to education from sources other than media</td>
</tr>
<tr>
<td>MED</td>
<td>Text refers to anything about masks and HIV</td>
<td>Messages and influence of TV, radio, or other media regarding HIV and/or PMTCT; attitude about media messages</td>
<td>Effect of religious organizations</td>
</tr>
<tr>
<td>NGO</td>
<td>Test refers to NGOs or other social organizations</td>
<td>Experiences of self or others with NGO or their staff or volunteers, positive and negative, practical and emotional support offered, effect on culture and community</td>
<td>Anything not related directly to interactions with other PLHIV individuals; past training; individual knowledge or attitude about HIV or PMTCT</td>
</tr>
<tr>
<td>DT</td>
<td>Test refers to desire of PLHIV to help others</td>
<td>Experiences past or present, or desire in future, to help other PLHIV women by volunteer, being example, modeling, attitudes about helping other PLHIV</td>
<td>Culture is not Ethiopian, issues of government or organizations or individual thoughts or attitudes</td>
</tr>
<tr>
<td>HUS</td>
<td>Test refers to husband, spouse, or sexual partner and HIV</td>
<td>Any experience or attitude with one’s husband or sexual partner, past or present</td>
<td>Anything not directly related to husband or sexual partner</td>
</tr>
<tr>
<td>FAM</td>
<td>Test refers to family other than husband and HIV</td>
<td>Any experience or attitude with one’s family, other than husbands, including in-laws, immediate or distant family, may be positive or negative</td>
<td>Anything not directly related to family; anything related to husband</td>
</tr>
<tr>
<td>OTH</td>
<td>Test refers to friends, neighbors, social workers, or other individuals and HIV</td>
<td>Any experience or attitude with individuals not in family network, including friends, neighbors, social workers, landlords, employees, or others</td>
<td>Anything related to family or husband</td>
</tr>
<tr>
<td>PHT</td>
<td>Test refers to PLHIV peers</td>
<td>Any experience or attitude about PLHIV peers, including past and present and desire to interact in future</td>
<td>Anything not related to PLHIV peers</td>
</tr>
<tr>
<td>SPP</td>
<td>Test refers to material and emotional support or influence given for healthcare and HIV care</td>
<td>Direct mention of or implied support offered by individuals, organizations or communities for healthcare and HIV care</td>
<td>Anything not related to support for HIV including individual attitudes and knowledge</td>
</tr>
<tr>
<td>DIS</td>
<td>Test refers to disclosure of HIV status</td>
<td>Experiences in past or present with disclosing HIV status to others and effect of disclosure; anecdotal story about other PLHIV disclosing status; emotion/thoughts about disclosing HIV status</td>
<td>Knowledge or attitudes about HIV not directly related to disclosing status</td>
</tr>
<tr>
<td>UHC</td>
<td>Test refers to use of ANC, PMTCT or other healthcare</td>
<td>Experiences with, knowledge of and attitudes about use of ANC, both positive and negative, for self or others, positive and negative aspects of ANC/PMTCT</td>
<td>Discussion of medication, knowledge, attitudes about HIV in general, or NGO or other organizational interactions</td>
</tr>
<tr>
<td>HCA</td>
<td>Test refers to attitudes of health care workers</td>
<td>Direct comment about positive or negative attitude of health care workers toward PLHIV women</td>
<td>Organizational issues such as supply chain interruption, medication SE, or difficulty accessing care</td>
</tr>
<tr>
<td>KIV</td>
<td>Test refers to knowledge and understanding of HIV</td>
<td>Test refers to knowledge of HIV in general and/or PMTCT, including lack of awareness, lack of understanding, information about pregnancy, delivery, medication, transmission, breastfeeding, CD4</td>
<td>Issues related to emotion or attitudes about HIV or PMTCT, knowledge of health care concerns not related to HIV</td>
</tr>
<tr>
<td>CNE</td>
<td>Test refers to lack of understanding of medication for HIV and PMTCT</td>
<td>Any comment related to personal or second hand experiences with medication including but not limited to: medication not being able to cure HIV, SE, lack of food, safety in pregnancy</td>
<td>Knowledge, attitudes or emotions about HIV not particularly related to medication use, such as use of condoms, needle safety, or breastfeeding</td>
</tr>
<tr>
<td>ATT</td>
<td>Test refers to any attitude or emotion surrounding HIV and/or PMTCT</td>
<td>Direct or implied comment about positive and negative attitudes or emotions of self or others about HIV and PMTCT, including but not limited to: carelessness, hopelessness, fear, concern for child, or stigma</td>
<td>Attitudes or emotions related to social or material concerns not related to HIV or PMTCT</td>
</tr>
<tr>
<td>HOP</td>
<td>Test refers to hope or hopelessness</td>
<td>Any direct or implied reference to hope or hopelessness related to HIV, including but not limited to: suicide, hopelessness about medication, hopelessness about life or being given hope by personal or religious support</td>
<td>Attitudes or knowledge not related to hope or hopelessness related to HIV</td>
</tr>
<tr>
<td>ADV</td>
<td>Test refers to advice given to other PLHIV women about PMTCT</td>
<td>Reference to what should be told directly to PLHIV women to encourage adherence to PMTCT</td>
<td>Suggestions for leaders to enact change at organizational, community, or government level for PMTCT</td>
</tr>
<tr>
<td>ADV</td>
<td>Test refers to advice given to government leaders to help PMTCT</td>
<td>Reference to a way for leaders to help with PMTCT adherence from organizational, community or government level</td>
<td>Advice given directly to women with HIV in counseling</td>
</tr>
<tr>
<td>REA</td>
<td>Test refers to personal or second-hand experiences or opinions about why PLHIV women may not complete PMTCT</td>
<td>Any reference to a reason medication may be stopped, not started, or not taken consistently</td>
<td>Reasons why ANC was not accessed in all</td>
</tr>
</tbody>
</table>
Appendix H
Demographics of All Participants

Table 4.1

Demographics of participants

<table>
<thead>
<tr>
<th></th>
<th>All Surveys N=71</th>
<th>Independent Surveys N=48</th>
<th>Interviews with surveys N=23</th>
<th>Focus groups N=27</th>
<th>Total N=94</th>
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<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 30</td>
<td>37.1</td>
<td>45.8</td>
<td>26.1</td>
<td>37.0</td>
<td>38.8</td>
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<tr>
<td>30-40</td>
<td>55.7</td>
<td>47.9</td>
<td>60.9</td>
<td>55.6</td>
<td>53.1</td>
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<tr>
<td>Over 40</td>
<td>8.6</td>
<td>6.3</td>
<td>13.0</td>
<td>7.4</td>
<td>8.1</td>
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<tr>
<td><strong>Religion</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Orthodox</td>
<td>54.9</td>
<td>61.2</td>
<td>34.8</td>
<td>55.6</td>
<td>53.1</td>
</tr>
<tr>
<td>Protestant</td>
<td>40.9</td>
<td>38.8</td>
<td>52.2</td>
<td>40.7</td>
<td>42.8</td>
</tr>
<tr>
<td>Muslim</td>
<td>4.2</td>
<td>0.0</td>
<td>13.0</td>
<td>3.7</td>
<td>4.1</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No education</td>
<td>11.3</td>
<td>0.0</td>
<td>34.7</td>
<td>63.0</td>
<td>25.6</td>
</tr>
<tr>
<td>Basic (1-5)</td>
<td>26.8</td>
<td>24.4</td>
<td>34.7</td>
<td>7.4</td>
<td>22.4</td>
</tr>
<tr>
<td>Secondary (6-9)</td>
<td>22.5</td>
<td>22.4</td>
<td>21.7</td>
<td>22.2</td>
<td>22.4</td>
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<tr>
<td>Advanced (10+)</td>
<td>39.4</td>
<td>53.2</td>
<td>.09</td>
<td>7.4</td>
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<tr>
<td><strong>Income</strong></td>
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<td>8.2</td>
<td>17.4</td>
<td>11.1</td>
<td>11.2</td>
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<tr>
<td>medium</td>
<td>43.7</td>
<td>42.8</td>
<td>47.8</td>
<td>51.9</td>
<td>45.9</td>
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<tr>
<td>High</td>
<td>45.0</td>
<td>49.0</td>
<td>34.8</td>
<td>37.0</td>
<td>42.9</td>
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<tr>
<td><strong>Marital status</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>62.0</td>
<td>65.3</td>
<td>52.2</td>
<td>33.3</td>
<td>53.1</td>
</tr>
<tr>
<td>Single (divorced, separated or widowed)</td>
<td>38.0</td>
<td>34.7</td>
<td>47.8</td>
<td>66.7</td>
<td>46.9</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amhara</td>
<td>49.3</td>
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<td>73.9</td>
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Appendix I
IRB Approval Letter

October 14, 2013

Katherine Smith
Chair, the Board

IRB

Expedited Approval for Initial Review

Title: "Prevention of HIV: Women on the Prevention of Mother to Child Transmission of HIV in Adolescents"

Study Approval Period: 10/15/2013 to 10/15/2014

Crap No. 05659

IRB No. 0032211

On 10/15/2013, the Institutional Review Board (IRB) convened and APPROVED the above application and all documents enclosed above.

Approval Impact:
Protocol Summary:
Protocol #IRB-Women on Prevention of Mother to Child Transmission of HIV in Adolescents

In the event of any requests, it is to be made until letter(s) of support are submitted and approved by the IRB as per the IRB Amendment process:

Consent (Informed Document)*:

IRB Date: 10/14/13

*Please use only official IRB stamped informed consent document(s) final under this Amendment. Title: "Prevention of HIV: Women on the Prevention of Mother to Child Transmission of HIV in Adolescents"

It is for the protection of the IRB that your study complies with the approved consent(s) which includes additional data/parameters consented to in this study. This adherence is of utmost importance and should be adhered to all research conducted under the approved consent(s). It is imperative that all procedures are conducted through the approved consent procedure(s) and by ICWReg. 011 and 21 CFR.

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IRB Approval Letter

Research Integrity and Compliance

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Katherine Smith
Chair, the Board

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Appendix J

Self-Reflection

The process of earning a PhD requires a large degree of perseverance and patience, and I found myself tempted at times during this process to make simply completing my research the end goal. My experiences interacting with the women in Ethiopia, however, were a poignant reminder to me that a research project should never be a goal in and of itself: the aim is for the research to effect change. During medical training I was taught that simply allowing a patient to speak will often lead to a diagnosis, and in public health coursework I was taught to complete needs assessments prior to implementing programs. I began my research assuming that all public health projects operate under this framework, and I was therefore startled by the reality of how few Ethiopian women living with HIV felt they had a voice of any kind (including into the programs which are theoretically designed for them). I was both humbled and saddened to hear repeated comments from study participants that I was the first person to ever have listened to their stories or asked for their opinions and left wondering if this oversight accounts for much of the lack of efficacy of current public health interventions in PMTCT.

It was also interesting operate in the primary role of a researcher rather than my accustomed role of a clinician. I am used to being able to “fix” things quickly by curing illness, and I wanted to offer something tangible that would quickly help these women: to give them medicine, to feed their children, to find them jobs, or to offer shelter. Yet despite the difficult circumstances under which they lived, not a single participant asked me to do any of these things. What the women did ask me for was hope: hope that they could live a long life, hope that their children would grow up healthy, hope that they could have more children who would not be infected with HIV, and hope that they could be heard and accepted as individuals who have
something of value to offer to others. This demonstrated to be that the seemingly most obvious needs are not always what weigh on people’s hearts; in roles of both researcher and clinician my primary responsibility must be to discover the true needs of the individual in front of me rather than what I perceive them to be.

As I walk away from this endeavor, I do so with a heart that has been humbled by the reality of those who suffer greatly yet fight with courage and a renewed commitment to listening to those I seek to serve. I am so grateful to have had the opportunity to interact with the women in Ethiopia. My prayer is that the time they shared with me will result in a better future for them and their children and will help to bring an end to pediatric HIV infection.