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**A Positive Dimension: Exploring Factors that Enhance Utilization of  
and Adherence to Prevention of Mother-to-Child Transmission  
(PMTCT) of HIV Services in an Urban Setting in Kenya**

A dissertation submitted in partial fulfillment of the requirements for the degree  
of Doctor of Philosophy in Public Policy and Administration at Virginia Commonwealth  
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## **Dedication and Acknowledgements**

I dedicate this dissertation to my family. Each of you, in your own way, has made this journey possible and my dream a reality. To mom and dad: thanks for instilling in me the values of hard work and determination at a young age and for your sacrifice to give my siblings and me a better chance in life. To my siblings: I am deeply indebted to you for your support, encouragement, mentorship and inspiration. Thank you all for believing in me and for loving me unconditionally.

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## **Glossary of Acronyms**

3TC	Lamivudine
AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal clinic
AFASS	Acceptable, Feasible, Affordable, Sustainable and Safe
ART	Antiretroviral Therapy
ARVs	Antiretroviral drugs
AZT	Azidothymidine
EBF	Exclusive Breastfeeding
EFV	Efavirenz
eMTCT	Elimination of mother-to-child transmission
FTC	Emtricitabine
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
HPs	Herbal Practitioners
MTCT	Mother-to-Child Transmission of HIV/AIDS
NVP	Nevirapine
PLWA	People Living with AIDS
PMTCT	Prevention of Mother-to-Child Transmission of HIV/AIDS
sd-NVP	Single-dose Nevirapine
SRH	Sexual and Reproductive Health
STI	Sexually Transmitted Infection
TBAs	Traditional Birth Attendants
TB	Tuberculosis
TDF	Tenofovir Disoproxil Fumarate
UNAIDS	Joint United Nations Program on HIV/AIDS
UNGASS	United Nations General Assembly Special Session
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VCT	Voluntary and Counseling
WHO	World Health Organization

## Abstract

A Positive Dimension: Exploring Factors that Enhance Utilization of and Adherence to Prevention of Mother-to-Child Transmission (PMTCT) of HIV Services in an Urban Setting in Kenya

By: Lydia Karuta Murithi, M.P.P.

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Public Policy and Administration at Virginia Commonwealth University.

Virginia Commonwealth University, 2013

Director: Janet R. Hutchinson, Ph.D.  
Professor, Public Policy and Administration  
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Despite expansive scale-up of prevention of mother-to-child transmission (PMTCT) of HIV services in Kenya over the last decade, Kenya remains one of the countries contributing high numbers of children living with HIV globally and among the 22 PMTCT global plan priority countries. Using a mixed methods approach this study examined enabling factors –individual, social and structural – that enhance utilization of and adherence to PMTCT services in a plural urban setting in Kenya. The study was conducted from October-December of 2012 at St. Mary's Mission Hospital, Lang'ata. HIV-positive birthmothers whose infants were HIV-negative at the time of the study were purposively selected to participate. All informants completed an interviewer-administered questionnaire (n = 55) and a subset (n = 15) participated in in-depth interviews. Contrary to the assertions of multiple studies that failures of PMTCT programs are a result of inadequate knowledge of mother-to-child transmission and PMTCT interventions, lack of support and acceptance by family and community, as well as poor quality of services, this

study found these factors to be statistically insignificant in explaining PMTCT achievements. The study further found that HIV/AIDS related stigma and gender imbalances create many missed opportunities for HIV-positive mothers to apply acquired knowledge on mother-to-child transmission and PMTCT interventions, mobilize support from family and community, and access more affordable care. Factors found to influence women's decisions to utilize and adhere to PMTCT services include supportive counseling, striving for motherhood, maternal attachment and concern for the child's wellbeing, assurance of confidentiality and testimonials of other successful mothers. Based on the study findings, policy recommendations have been proposed along with suggestions for future research.

## **Chapter I: Introduction and Background**

### **Introduction:**

Acquired Immunodeficiency Syndrome (AIDS) is a fatal chronic condition caused by the human immunodeficiency virus (HIV). By weakening the immune system, HIV progressively destroys the body's ability to fight infections. HIV is a sexually transmitted disease. It can also be spread by contact with infected blood, or from mother-to-child during pregnancy, childbirth or breastfeeding. There is no cure for HIV/AIDS but there are medications (antiretroviral drugs -ARVs) that can dramatically slow the progression of the disease. While there have been great strides in the prevention of HIV transmission and care of people living with AIDS since the first case was discovered in 1981, HIV continues to decimate populations in developing countries and more gravely in sub-Saharan Africa.

This chapter will provide a global overview of the HIV/AIDS pandemic, followed by a discussion of HIV/AIDS situation in sub-Saharan Africa and Kenya; and finally narrow down to prevention of mother-to-child transmission of HIV (PMTCT). It is imperative to note that global HIV estimates were revised downwards in 2007<sup>1</sup> and as such, revised estimates will be used throughout this chapter for consistency purposes.

### **Global Overview of HIV/AIDS:**

HIV, the virus that causes AIDS, “acquired immunodeficiency syndrome,” has become one of the world’s most serious health and development challenges. Since the

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<sup>1</sup> Kaiser Family Foundation. “HIV/AIDS Policy Fact Sheet: Understanding the New UNAIDS Estimates.” 2008. <http://www.kff.org/hivaids/upload/7742.pdf>

first cases were reported in 1981, nearly 30 million people have died of AIDS worldwide, and another 34 million are currently living with HIV/AIDS.<sup>2,3</sup> While cases have been reported in all regions of the world, almost all those living with HIV (97%) reside in low- and middle-income countries, particularly in sub-Saharan Africa.<sup>4</sup> Data shows that HIV primarily affects individuals in their most productive years; more than half of new infections are among those under age 35.<sup>5</sup> Unfortunately, most people living with HIV or at risk for HIV do not have access to prevention, care, and treatment, and there is still no cure.

According to a joint report by UNAIDS/WHO/UNICEF<sup>6</sup>, the number of people living with HIV increased from 29 million in 2001 to 34 million in 2010 as a result of continuing new infections, people living longer with HIV, and general population growth. The global prevalence rate (the percent of people ages 15–49 that are infected) has leveled since 2000 (1.1%) and was at 0.8% in 2010. A total of 1.8 million people died of AIDS in 2010 making HIV a leading cause of death worldwide and the number one cause of death in Africa.

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<sup>2</sup> UNAIDS. “World AIDS Day Report.” 2011.  
<http://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2011/november/20111121wad2011report/>

<sup>3</sup> UNAIDS. “Report on the Global AIDS Epidemic.” 2010.  
[http://www.unaids.org/globalreport/global\\_report.htm](http://www.unaids.org/globalreport/global_report.htm)

<sup>4</sup> Ibid.

<sup>5</sup> Kaiser Family Foundation. “U.S. Global health policy: The global HIV/AIDS epidemic.” 2009. <http://www.kff.org/hivaids/upload/3030-14.pdf>

<sup>6</sup> WHO/UNAIDS/UNICEF. “Towards universal access: Scaling up priority HIV/AIDS interventions in the health sector.” 2010.  
<http://www.who.int/hiv/topics/universalaccess/en/index.html>

Women represent half of all people living with HIV worldwide, and more than half (59%) in sub-Saharan Africa.<sup>7</sup> Studies show that women are more vulnerable to HIV than men, both because of their greater biological susceptibility if exposed to HIV and their greater social vulnerability to being exposed to an HIV-positive partner. Women's greater social vulnerability stemming from gender inequalities, differential access to services, and sexual violence increase their likelihood of being exposed to HIV. Biologically, women are more exposed to HIV infection than men. Male to female transmission of HIV is between two and four times more efficient than female to male. Additionally, young women are especially vulnerable to HIV infection through sexual intercourse because the immature genital tract of girls is more likely to tear during sexual activity, creating a higher risk of HIV transmission.<sup>8</sup>

Globally, there were 3.4 million children living with HIV in 2010, 390,000 new infections among children, and 250,000 AIDS deaths. There are approximately 16.6 million AIDS orphans (children who have lost one or both parents to HIV), most of who live in sub-Saharan Africa (89%).<sup>9</sup>

The HIV epidemic not only affects the health of individuals, it impacts households, communities, and the development and economic growth of nations. Many

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<sup>7</sup> WHO. "World health statistics." 2009.  
[http://whqlibdoc.who.int/publications/2009/9789241563819\\_eng.pdf](http://whqlibdoc.who.int/publications/2009/9789241563819_eng.pdf)

<sup>8</sup> Higgins, J.A. et al. "Rethinking Gender, Heterosexual Men, and Women's Vulnerability to HIV/AIDS." *American Journal of Public Health*, (2010):100(3): 435-445.  
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2820057/>

<sup>9</sup> UNAIDS. "Report on the Global AIDS Epidemic." 2010.  
[http://www.unaids.org/globalreport/global\\_report.htm](http://www.unaids.org/globalreport/global_report.htm)

of the populations hardest hit by HIV also suffer from other infectious diseases, food insecurity, and other serious health and economic problems.<sup>10</sup>

Despite these challenges, new global efforts have been mounted to address the epidemic, particularly in the last decade, and there are signs that the epidemic may be changing course. As such, the number of people newly infected with HIV and the number of AIDS-related deaths has declined, contributing to the stabilization of the epidemic. Statistics show that new HIV infections peaked in the late 1990s and declined by 15% between 2001 and 2010.<sup>11</sup> The decline is attributable to natural trends in the epidemic and scale-up in antiviral viral treatment. In fact, the number of people with HIV receiving treatment in resource poor countries has increased more than 20-fold since 2001, reaching 6.6 million in 2010.<sup>12</sup>

Still there were 2.7 million new HIV infections in 2010 – which calculates to slightly more than 7,000 new HIV infections per day. Most new infections are transmitted heterosexually, although risk factors vary. In some countries, men who have sex with men, injecting drug users, and sex workers are at significant risk. Although HIV testing capacity has increased over time, enabling more people to learn their HIV status, the majority of people with HIV are still unaware they are infected.<sup>13</sup>

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<sup>10</sup> UNAIDS. “Report on the global AIDS epidemic.” 2008.  
[http://data.unaids.org/pub/GlobalReport/2008/JC1511\\_GR08\\_ExecutiveSummary\\_en.pdf](http://data.unaids.org/pub/GlobalReport/2008/JC1511_GR08_ExecutiveSummary_en.pdf)

<sup>11</sup> UNAIDS. “UNAIDS World AIDS Day Report.” 2011.  
<http://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2011/november/20111121wad2011report/>

<sup>12</sup> UNAIDS. “UNAIDS World AIDS Day Report.” 2011.  
<http://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2011/november/20111121wad2011report/>

<sup>13</sup> UNAIDS. “Report on the Global AIDS Epidemic.” 2010.  
[http://www.unaids.org/globalreport/global\\_report.htm](http://www.unaids.org/globalreport/global_report.htm)

## HIV/AIDS in Sub-Saharan Africa:

The HIV/AIDS epidemic has had its most profound impact to date in sub-Saharan Africa. The majority of people living with HIV/AIDS (67%), with new HIV infections (70%), and who die of AIDS (70%) are in this region, which only accounts for about 12% of the world's population.<sup>14</sup> (See Figure 1) HIV is the leading cause of death in the region and studies have found declines in life expectancy due to HIV in many of the hardest hit countries in sub-Saharan Africa, especially those in southern Africa. There are 5.6 million people living with HIV in South Africa alone, the greatest number of any country in the world, and Swaziland has the world's highest HIV/AIDS prevalence rate at 26.1% -- the percent of the population living with HIV/AIDS<sup>15</sup>

An even higher proportion of the children living with HIV in the world are in Africa, an estimated 91%. There are a number of reasons for this. First, more women of childbearing age are HIV-infected in Africa than elsewhere. Second, African women have more children on average than those in other continents, so one infected woman may pass the virus on to a higher than average number of children. Third, nearly all children in Africa are breastfed. Breastfeeding is thought to account for between a third and a half of all HIV transmission from mother to child. Finally, new effective drugs that reduce transmission from mother-to-child before and around childbirth are far less readily

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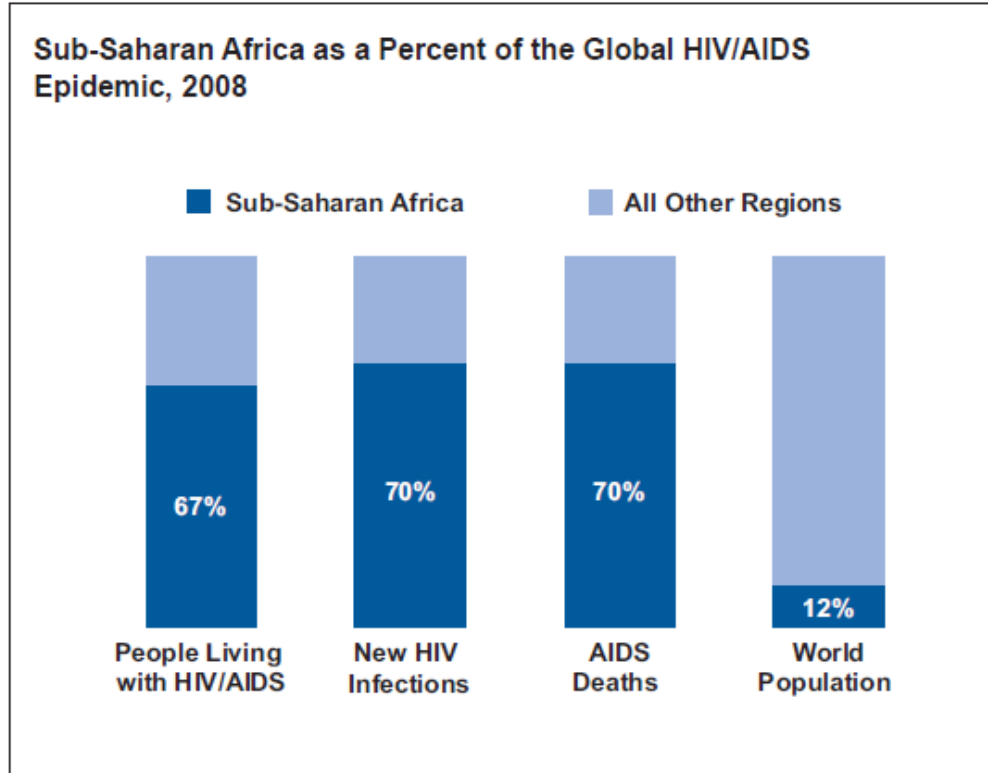
<sup>14</sup> WHO/UNAIDS/UNICEF. "Global HIV/AIDS Response: Epidemic Update and Health Sector Progress Towards Universal Access Progress Report." 2011.  
[http://www.who.int/hiv/pub/progress\\_report2011/en/index.html](http://www.who.int/hiv/pub/progress_report2011/en/index.html)

<sup>15</sup> Kaiser Family Foundation. "HIV/AIDS policy: HIV epidemic in sub-Saharan Africa."  
2009. <http://www.kff.org/hivaids/upload/7391-08.pdf>



available in developing countries, including those in Africa, than in the industrialized world.<sup>16</sup>

Figure 1: HIV/AIDS Statistics



Source: Kaiser Family Foundation. "HIV/AIDS policy: HIV epidemic in sub-Saharan Africa." 2009

Almost all countries in sub-Saharan Africa have generalized epidemics, their prevalence rates are greater than 1%, and in 9 countries rates exceed 10%.<sup>17</sup> Women comprise the majority of those living with HIV/AIDS in the region and young people are at particular risk. The epidemic has already posed serious development challenges for the region, where most countries are already considered to be low-income and heavily or

<sup>16</sup> WHO. "Treatment of Children Living with HIV."  
<http://www.who.int/hiv/topics/paediatric/en/index.html>

<sup>17</sup> Ibid.

moderately indebted – according to the World Bank,<sup>18</sup> affecting communities, families, livelihoods, and numerous sectors of society. Some of these countries also face other challenges that may exacerbate or be exacerbated by HIV, including food insecurity, internal migration, as well as civil and ethnic conflict.

Amidst these challenges, there have been success stories and even new, encouraging signs. The latest country estimates indicate that in most sub-Saharan African countries, HIV prevalence has stabilized decreasing the region's adult prevalence rate from 8.8% in 2000 to 5% in 2010. In 22 countries, national models of HIV prevalence shows that the incidence of HIV infection declined by more than 25% between 2001 and 2009 – including in some of the countries with the largest epidemics in the region: Ethiopia, Nigeria, Zambia and Zimbabwe.<sup>19</sup>

Additionally, there is evidence of reduced risk behavior in some parts of the region as a result of HIV programming. For instance, in studies carried out between 2001 and 2005, eight out of eleven countries in sub-Saharan Africa reported an increase in condom use.<sup>20</sup> Furthermore, male circumcision is an emerging prevention strategy with promising positive outcomes. Three randomized controlled clinical trials were conducted in Africa to determine whether circumcision of adult males will reduce their risk for HIV infection. The study conducted in South Africa<sup>21</sup> was stopped in 2005, and those in

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<sup>18</sup> World Bank. "Country Classification." 2010  
[www.worldbank.org/data/countryclass/countryclass.html](http://www.worldbank.org/data/countryclass/countryclass.html)

<sup>19</sup> WHO/UNAIDS/UNICEF. "Global HIV/AIDS Response: Epidemic Update and Health Sector Progress Towards Universal Access Progress Report." 2011.  
[http://www.who.int/hiv/pub/progress\\_report2011/en/index.html](http://www.who.int/hiv/pub/progress_report2011/en/index.html)

<sup>20</sup> UNAIDS. '[Report on the global AIDS epidemic](#)' Chapter 3: Progress in Countries. 2006

<sup>21</sup> Auvert B. et al. "Randomized, Controlled Intervention Trial of Male Circumcision for Reduction of HIV

Kenya<sup>22</sup> and Uganda<sup>23</sup> were stopped in 2006 after interim analyses found a statistically significant reduction in male participants' risk for HIV infection from medical circumcision.

The two aforementioned factors – condom use and male circumcision – are critical to the reduction of HIV transmission in Africa given the high rate of multiple sexual partners prevalent in some parts of the region. For instance, in 2006, a joint UNAIDS and Southern African Development Community (SADC) group of experts concluded that high rates of concurrent - or overlapping - sexual partnerships (prevalent in eastern and southern Africa), combined with low rates of male circumcision and infrequent condom use, were the major drivers of the AIDS epidemic in southern Africa<sup>24</sup> -- the region hardest hit by the epidemic.

On another positive advancement, most countries in sub-Saharan Africa have developed national responses to HIV/AIDS through National AIDS Commissions, legislation, programs, and services.<sup>25</sup> This is an indication that these countries are taking ownership in the fight against HIV/AIDS among their populations.

Despite these commendable strides, though, the rate of infection in sub-Saharan Africa remains strikingly high compared to other regions of the world. (See figure 2).

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Infection Risk: the ANRS 1265 Trial. *PLoS Med.* 2005 Nov;2(11):e298. Erratum in: *PLoS Med.* 2006 May;3(5):e298.

<sup>22</sup> Bailey RC. et al. "Male circumcision for HIV Prevention in Young Men in Kisumu, Kenya: a Randomized Controlled Trial." *Lancet.* 2007 Feb 24;369(9562):643-56.

<sup>23</sup> Gray RH, Kigozi G, Serwadda D, et al. "Male circumcision for HIV Prevention in Men in Rakai, Uganda: a Randomized Trial." *Lancet.* 2007 Feb 24;369(9562):657-66.

<sup>24</sup> SADC. "Expert Think Tank Meeting on HIV Prevention in High-Prevalence Countries in Southern Africa." Maseru, Lesotho; 2006.

<sup>25</sup> Ibid.

Table 1: HIV Prevalence and Incidence by Region

<b>HIV Prevalence &amp; Incidence by Region</b>			
<b>Region</b>	<b>Total No. (%) Living with HIV end of 2010</b>	<b>Newly Infected in 2010</b>	<b>Adult Prevalence Rate 2010</b>
<b>Global Total</b>	<b>34 million (100%)</b>	<b>2.7 million</b>	<b>0.80%</b>
Sub-Saharan Africa	22.9 million (67%)	1.9 million	5.00%
South/South-East Asia	4.0 million (12%)	270,000	0.30%
Eastern Europe/Central Asia	1.5 million (4%)	160,000	0.90%
Latin America	1.5 million (4%)	100,000	0.40%
North America	1.3 million (4%)	58,000	0.60%
Western/Central Europe	840,000 (2%)	30,000	0.20%
East Asia	790,000 (2%)	88,000	0.10%
Middle East/North Africa	470,000 (1%)	59,000	0.20%
Caribbean	200,000 (0.6%)	12,000	0.90%
Oceania	54,000 (0.2%)	3,300	0.30%

Source: Kaiser Family Foundation. "U.S. Global Health Policy: The Global HIV/AIDS Epidemic." 2011.

### HIV/AIDS in Kenya:

Kenya is one of the countries most affected by HIV/AIDS epidemic. An estimated 1.6 million people are living with HIV, around 1.1 million children have been orphaned by AIDS and in 2011 nearly 62,000 people died from AIDS-related illnesses.<sup>26</sup>

In 2011, approximately 6.2% of the adult Kenyan population was HIV-infected – a 40% decrease from the mid-nineties epidemic's peak rate of 10.5%.<sup>27</sup> This decline is thought to be partially due to an increase in education and awareness, but also from high death rates.<sup>28</sup> Sexual transmission is the primary driver of Kenya's epidemic.

Heterosexual transmission with a union or primary partnership accounts for an estimated 44% of new infections.<sup>29</sup>

<sup>26</sup> UNGASS. "The Kenya AIDS Epidemic: Update 2011." 2011.  
<http://www.unaids.org/en/dataanalysis/datatools/aidsinfo/>

<sup>27</sup> Ibid.

<sup>28</sup> UNGASS. "Country Report – Kenya. Kenya Office of the President, Ministry of Special Programmes." 2008. [http://data.unaids.org/pub/Report/2008/kenya\\_2008\\_country\\_progress\\_report\\_en.pdf](http://data.unaids.org/pub/Report/2008/kenya_2008_country_progress_report_en.pdf)

<sup>29</sup> UNGASS. "The Kenya AIDS Epidemic: Update 2011." 2011.  
<http://www.unaids.org/en/dataanalysis/datatools/aidsinfo/>

Kenya has a generalized epidemic, with the virus having spread beyond discrete groups to affect the whole society. However, HIV has especially heavily affected certain populations; for instance, HIV prevalence exceeds 18% among men who have sex with men and people who inject drugs, and 29.3% of all female sex workers are living with HIV.<sup>30</sup> It is nonetheless important to note that these groups are socially marginalized and subject to criminal penalties for engaging in behavior that defines them. As such, they are difficult to reach with HIV prevention, treatment and care; and the degree to which HIV is affecting them has not been entirely investigated.

Historically, urban residents have always had a higher prevalence rate than their rural counterparts but that gap has considerably narrowed over the years. With regard to economic status, the rich have a higher prevalence rate (7.2%) compared to the poorer Kenyans (4.6%).<sup>31</sup> This is attributed to money, power and lifestyle.

Kenya's epidemic disproportionately affects women who account for 59.1% of all adults living with HIV. Among people 15 and 49 years, HIV among women (8.0%) is nearly twice that among men (4.3%).<sup>32</sup> Similar to the global trend, this gap is affiliated to women's biological vulnerability to HIV infection and other social-cultural factors such as gender inequality and sexual violence.<sup>33</sup> The large number of sexually acquired HIV

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<sup>30</sup> Ibid.

<sup>31</sup> Kenya National Bureau of Statistics, ICF Macro. "Kenya Demographic and Health Survey 2008-09." 2010

<sup>32</sup> UNGASS. "The Kenya AIDS Epidemic: Update 2011." 2011.  
<http://www.unaids.org/en/dataanalysis/datatools/aidsinfo/>

<sup>33</sup> UNGASS. "Country Report – Kenya. Kenya Office of the President, Ministry of Special Programmes." 2008. [http://data.unaids.org/pub/Report/2008/kenya\\_2008\\_country\\_progress\\_report\\_en.pdf](http://data.unaids.org/pub/Report/2008/kenya_2008_country_progress_report_en.pdf)

infections among women has given rise to substantial transmission to newborns, with an estimated 12, 894 children becoming newly infected in 2011.<sup>34</sup>

The government of Kenya declared HIV a national disaster in 1999 following which a national response strategy was launched. Kenya's response to HIV is guided by a strategic plan that aims to harmonize and align the HIV-related activities of diverse partners and stakeholders. Coordinated by the National AIDS Control Council, the HIV response builds on the robust engagement of civil society and people living with HIV. The National AIDS and STI Control Program, within the Ministry of Health, administer the bulk of HIV-related services in Kenya.

Funding for HIV programming in Kenya comes from a range of donors. However the U.S. government's PEPFAR program is the single largest HIV initiative in Kenya. In addition to serving as a cornerstone of Kenya's efforts to bring antiretroviral treatment to scale, PEPFAR also supports HIV prevention programming, blood safety interventions, assistance for children orphaned or made vulnerable by the epidemic, and capacity-building interventions. The Global Fund, which is the second largest donor contributor to HIV/AIDS funding in Kenya, mainly focuses on tuberculosis (TB) and the intersection of HIV and TB. Numerous other donors and development partners aid in Kenya's response to HIV. For example, the U.K. Department for International Development finances HIV prevention programming, including community mobilization efforts, and the Governments of Germany and Japan also contribute to the HIV response. The Clinton Foundation has supported pediatric HIV treatment programs, while the United Nations

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<sup>34</sup> UNGASS. "The Kenya AIDS Epidemic: Update 2011." 2011.  
<http://www.unaids.org/en/dataanalysis/datatools/aidsinfo/>

(UN) partners and other international players provide HIV-related technical support and capacity-building assistance.<sup>35</sup> (See Table 2)

The government of Kenya has pledged \$34 million annually for five years to go towards HIV and AIDS programs, and domestic funding doubled between 2008 and 2010. However, the international donor community accounts for more than 80% of all HIV spending in Kenya.<sup>36</sup>

Table 2: Estimated Financial Contributions for HIV Programs in Kenya 2009-2010<sup>37</sup>

Source	US\$ Million
U.S. Government	510.0
United Nations System	9.0
Global Fund to Fight AIDS, Tuberculosis and Malaria	32.5
U.K. Government	5.0
Clinton Foundation	11.7
Government of Germany	4.5
Government of Japan	2.6
Government of Kenya	34.0
World Bank Credit (Total War on AIDS)	20.0
<b>Total</b>	<b>629.3</b>

While many people in Kenya are still not being reached with HIV prevention and treatment services, some positive developments have been noted. Studies indicate that Kenyans on average are less than half as likely to have multiple sex partners than in the late 1990s, while condom use has more than doubled. Kenya is also a global leader in scaling up voluntary medical male circumcision for adult males, which reduces the risk of

<sup>35</sup> UNGASS. “The Kenya AIDS Epidemic: Update 2011.” 2011.  
<http://www.unaids.org/en/dataanalysis/datatools/aidsinfo/>

<sup>36</sup> Ibid.

<sup>37</sup> Ibid.

female-to-male HIV transmission by at least 60%.<sup>38</sup> Additionally, access to treatment is increasing – 72% of adults who need treatment are receiving it, with around 200,000 additional people on treatment in 2011 than in 2009.<sup>39</sup> Unfortunately, as with many countries, the proportion of eligible children receiving antiretroviral treatment is much lower (49%). This demonstrates that Kenya still has some way to go in providing universal access to HIV treatment, prevention and care.

### **Prevention of Mother-to-child Transmission of HIV (PMTCT):**

HIV infection transmitted from an HIV-infected mother to her child during pregnancy, labor, delivery or breastfeeding is known as mother-to-child transmission (MTCT). In the absence of any interventions transmission rates range from 15-45% (5-10 per cent during pregnancy, 10-20 per cent during labor and delivery and 5-20 per cent through breastfeeding). With effective interventions this rate can be reduced to less than 2% in non-breastfeeding populations, and to 5% or less in breastfeeding populations.<sup>40</sup>

Effective prevention of mother-to-child transmission involves simultaneous support for several strategies that work synergistically to reduce the odds that an infant will become infected as a result of exposure to the mother's virus. Through the reduction in overall HIV among reproductive-age women and men, the reduction of unwanted pregnancies among HIV-positive women, the provision of antiretroviral drugs to reduce the chance of infection during pregnancy and delivery and appropriate treatment, care

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<sup>38</sup> Ibid.

<sup>39</sup> UNAIDS. "World AIDS Day Report." 2011.  
[http://www.unaids.org/en/resources/campaigns/20121120\\_globalreport2012/results/](http://www.unaids.org/en/resources/campaigns/20121120_globalreport2012/results/)

<sup>40</sup> WHO. "PMTCT Strategic Vision 2010 – 2015: Preventing mother-to-child transmission of HIV to reach the UNGASS and Millennium Development Goals." 2009.  
[http://www.who.int/hiv/pub/mtct/strategic\\_vision/en/index.html](http://www.who.int/hiv/pub/mtct/strategic_vision/en/index.html)



and support to mothers living with HIV (including infant feeding), programs are able to reduce the chance that infants will become infected.<sup>41</sup>

In ideal conditions, the provision of antiretroviral prophylaxis and replacement feeding can reduce transmission from an estimated 15-45% with no intervention to around 1-2%.<sup>42</sup> In high-income countries mother-to-child transmission has been virtually eliminated thanks to effective voluntary testing and counseling, access to antiretroviral therapy, safe delivery practices, and the widespread availability and safe use of breast-milk substitutes.<sup>43</sup> If these interventions were used worldwide, they could save the lives of thousands of children each year.

Unfortunately, most countries in the developing world have not yet reached all pregnant women with these services, let alone significantly reduced HIV prevalence among reproductive-age individuals or unwanted pregnancies among HIV-positive women. In 2010, around 390,000 children under 15 became infected with HIV, mainly through mother-to-child transmission.<sup>44</sup> About 90% of children living with HIV reside in sub-Saharan Africa where, in the context of a high child mortality rate, AIDS accounts for 8 percent of all under-five deaths in the region.<sup>45</sup>

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<sup>41</sup> WHO. "PMTCT Strategic Vision 2010 – 2015: Preventing mother-to-child transmission of HIV to reach the UNGASS and Millennium Development Goals." 2009. [http://www.who.int/hiv/pub/mtct/strategic\\_vision/en/index.html](http://www.who.int/hiv/pub/mtct/strategic_vision/en/index.html)

<sup>42</sup> Ibid.

<sup>43</sup> De Cock et al. "Prevention of mother-to-child HIV transmission in resource-poor countries: translating research into policy and practice." JAMA 283(9), March 2000. <http://www.ncbi.nlm.nih.gov/pubmed/10703780?dopt=Abstract>

<sup>44</sup> Note: there is no available data for a smaller age range on pediatric HIV.

<sup>45</sup> UNAIDS. "Report on the Global AIDS Epidemic." 2010. [http://www.unaids.org/globalreport/global\\_report.htm](http://www.unaids.org/globalreport/global_report.htm)

In July 2010, the World Health Organization (WHO) issued new HIV and AIDS guidelines on treatment for PMTCT and on HIV and breastfeeding intended primarily for use in low-and middle-income countries, or resource-poor settings.<sup>46</sup> Treatment recommendations are presented algorithmically below. (See Figure 2) With regard to breastfeeding, WHO recognizes that replacement feeding could be difficult to fully implement in low-income countries due to practical realities such as lack of access to clean water, incorrect dilution and storage of formula, inadequate access to formula, low post-natal follow-up and underlying cultural values attached to breastfeeding. As a result, the current WHO's guidelines recommend replacement feeding on condition that it is acceptable, feasible, affordable, sustainable and safe (AFASS criteria).<sup>47</sup> Given that breastfeeding is the only realistic option available to most HIV-positive mothers in low-income settings, WHO recommends exclusive breastfeeding for six months followed by mixed feeding where both the mother and the infant are on ARVs or exclusive breastfeeding for six followed by rapid weaning where the mother is not on ARVs.<sup>48</sup>

Prevention of mother-to-child transmission (PMTCT) is essential to achieving the 2015 United Nations Millennium Development Goals (MDGs) of reducing child mortality, improving maternal health, and combating HIV and AIDS infection, malaria, and other diseases.

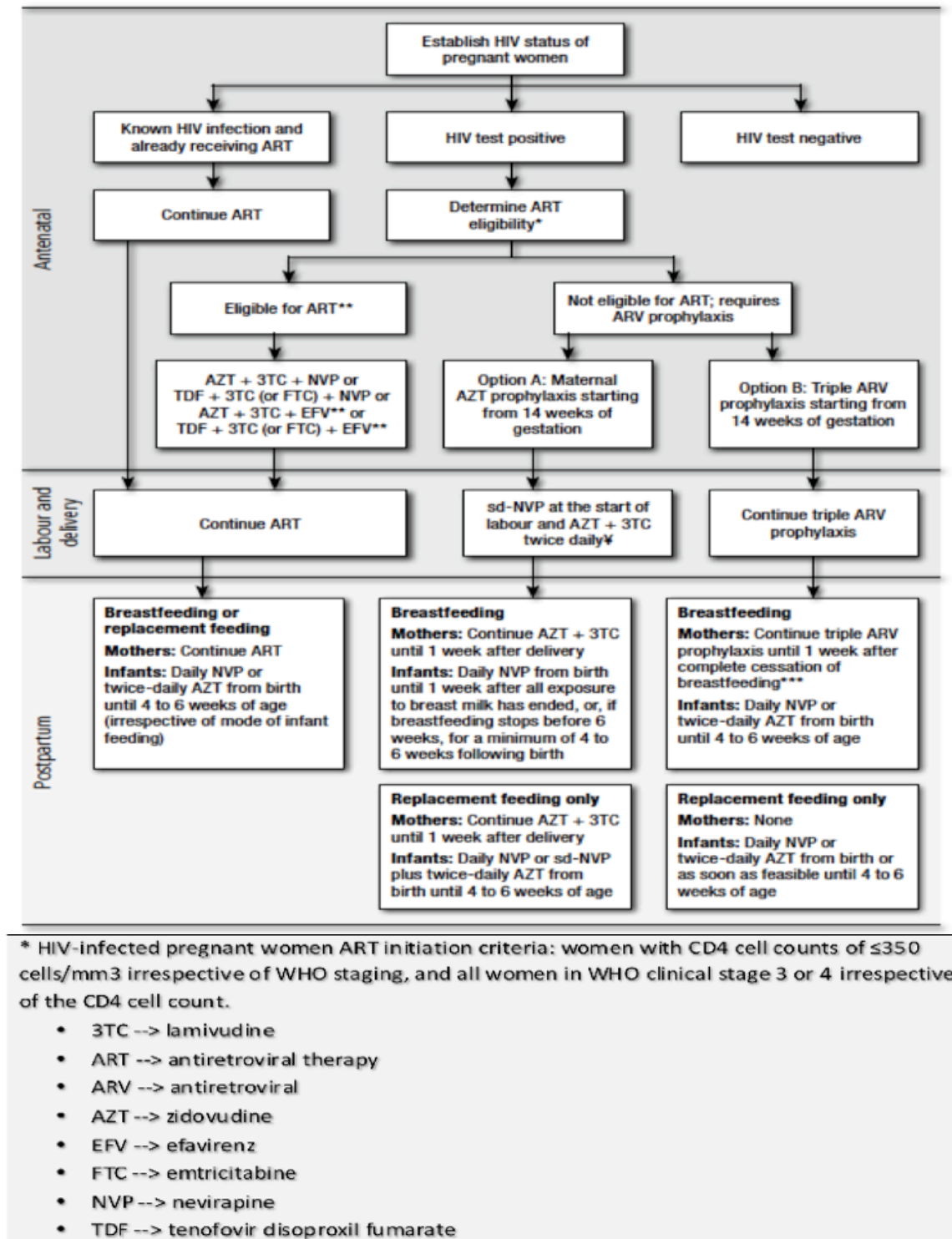
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<sup>46</sup> WHO. "Antiretroviral Drugs for Treating Pregnant Women and Preventing HIV Infection in Infants: Recommendations for a Public Health Approach." 2010.  
[http://whqlibdoc.who.int/publications/2010/9789241599818\\_eng.pdf](http://whqlibdoc.who.int/publications/2010/9789241599818_eng.pdf)

<sup>47</sup> WHO/UNAIDS/UNICEF. "Guidelines on HIV and Infant Feeding: Principles and Recommendations for Infant Feeding in the Context of HIV and a Summary of Evidence." 2010  
[http://www.who.int/maternal\\_child\\_adolescent/documents/9789241599535/en/](http://www.who.int/maternal_child_adolescent/documents/9789241599535/en/)

<sup>48</sup> Ibid.

Figure 2: WHO Algorithm for the 2010 PMTCT Recommendations<sup>49</sup>



<sup>49</sup> Ibid.

Within the context of the MDGs, in 2001 the United Nations General Assembly set a target for 80% of pregnant women and their children to have access to essential prevention, treatment and care by 2010 to reduce the proportion of infants infected by HIV by 50%.<sup>50</sup> Ever since, the UNAIDS reports that several countries have advanced efforts to prevent the mother-to-child transmission of HIV. By 2010, according to the *UNAIDS' Report on the Global AIDS Epidemic*<sup>51</sup> four countries in sub-Saharan Africa – Botswana, Namibia, South Africa and Swaziland had achieved more than 80% coverage of antiretroviral prophylaxis to prevent mother-to-child transmission. Seven other countries in sub-Saharan Africa had coverage levels of 50% to 80%.

Sub-Saharan Africa as a whole achieved 54% [40%–84%] coverage. In East and Southern Africa, 68% [53%–95%] of pregnant women living with HIV received antiretroviral medication to prevent mother-to-child transmission in 2009 (up substantially from 15% in 2005). In West and Central Africa, however, coverage lags at 23% [16%–44%].<sup>52</sup> The gap in reaching the target of 80% coverage of antiretroviral prophylaxis for preventing mother-to-child transmission is concentrated in a handful of countries, with 14 countries comprising more than 80% of the global gap. Nigeria alone now contributes to 32% of the gap, with the Democratic Republic of the Congo next, contributing 7% of the gap.<sup>53</sup> (See Figure 2)

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<sup>50</sup> United Nations. “UNGASS Declaration: Resolution adopted by the General Assembly; Declaration of Commitment on HIV/AIDS.” 2001.  
[http://data.unaids.org/publications/irc-pub03/aidsdeclaration\\_en.pdf](http://data.unaids.org/publications/irc-pub03/aidsdeclaration_en.pdf)

<sup>51</sup> UNAIDS. “Report on the Global AIDS Epidemic.” 2010.  
[http://www.unaids.org/globalreport/global\\_report.htm](http://www.unaids.org/globalreport/global_report.htm)

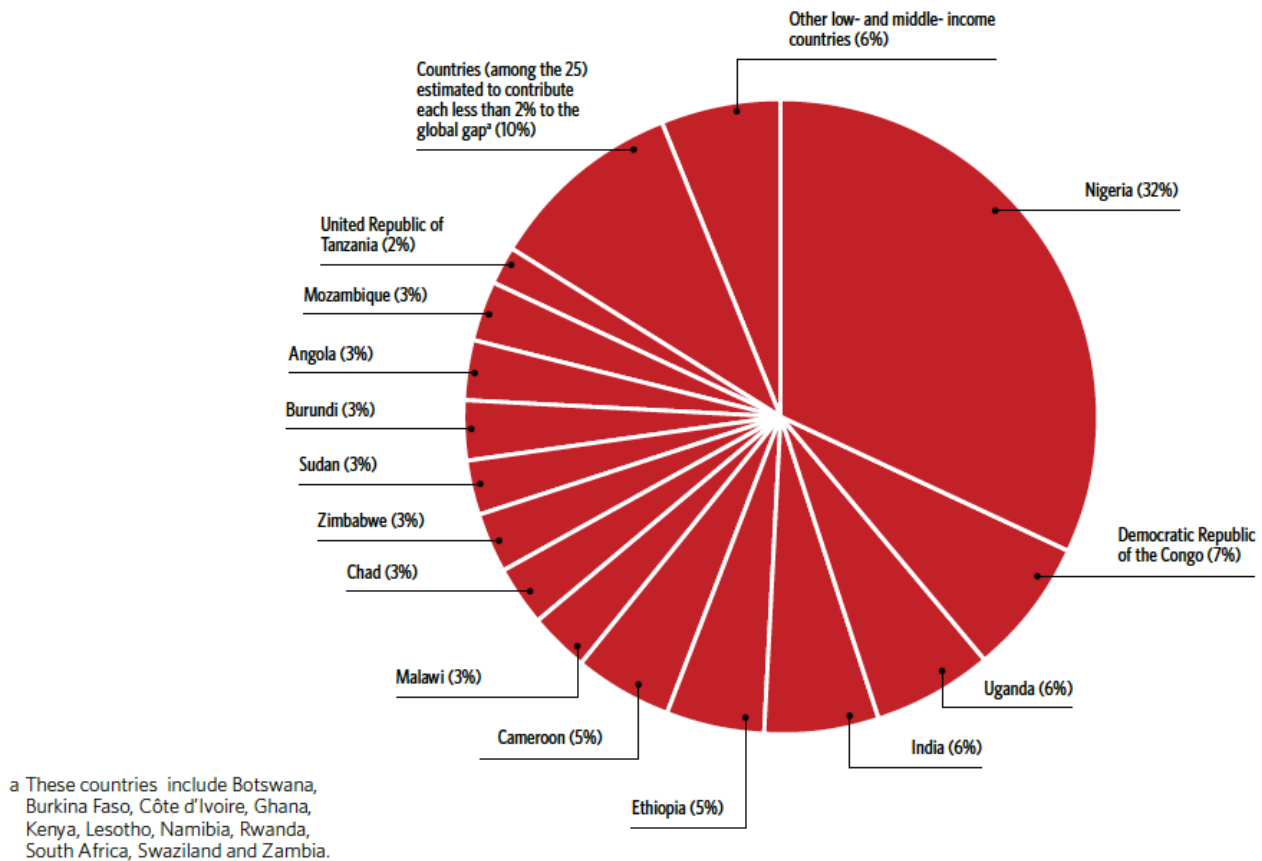
<sup>52</sup> Ibid.

<sup>53</sup> WHO/UNAIDS/UNICEF. “Towards universal access: Scaling up priority HIV/AIDS interventions in the health sector.” 2010.  
<http://www.who.int/hiv/topics/universalaccess/en/index.html>

With improved treatment regimens and strengthened commitment to scale-up PMTCT response, at the end of 2010 the global community committed itself to further accelerate this progress through an initiative with the goal to virtually eliminate new pediatric HIV infections by 2015. Virtual elimination is defined as the reduction of MTCT to less than 5%.<sup>54</sup>

Figure 3: PMTCT Focus Countries

**Contribution of the 25 countries with the largest number of women needing antiretrovirals for preventing mother-to-child transmission of HIV to the global gap in reaching 80% of those in need, 2009**



Source: WHO Towards Universal Access 2010

<sup>54</sup> WHO/UNAIDS/UNICEF. "Towards the Elimination of Mother-to-Child Transmission of HIV: Report of a WHO Technical Consultation 9-11 November 2010 Geneva, Switzerland." 2010. [http://www.who.int/hiv/pub/mtct/elimination\\_report/en/](http://www.who.int/hiv/pub/mtct/elimination_report/en/)

It might be worth noting that from an issue framing standpoint, PMTCT is perceived as an effort to save lives of innocent children and pregnant women – unlike the case for other at-risk groups like men who have sex with men, injected drug users, or commercial sex workers. The political palatability of the PMTCT issue is therefore an undeniable factor in the massive scale-up of PMTCT interventions.

### **Effectiveness of Prevention of Mother-to-child Transmission of HIV (PMTCT) Programs:**

As noted in the preceding section, PMTCT interventions when effectively implemented can virtually eliminate the risk of childhood HIV infection and improve maternal survival. However, what many believed at the outset would be a relatively simple matter of incorporating antenatal HIV diagnosis and maternal-infant antiretroviral prophylaxis into routine pregnancy and newborn care has in practice been frustratingly difficult to bring to scale.<sup>55</sup>

To begin with, the majority of women in low and middle-income countries has never been tested for HIV and is therefore unaware of their status.<sup>56</sup> This means that effective PMTCT programs must provide counseling and testing services to determine which women are in need of assistance. Beyond testing, infected women must adhere to a critical pathway – referred to as the PMTCT cascade – of events that must be in place for the prophylaxis to be delivered.<sup>57</sup> (See Figure 3)

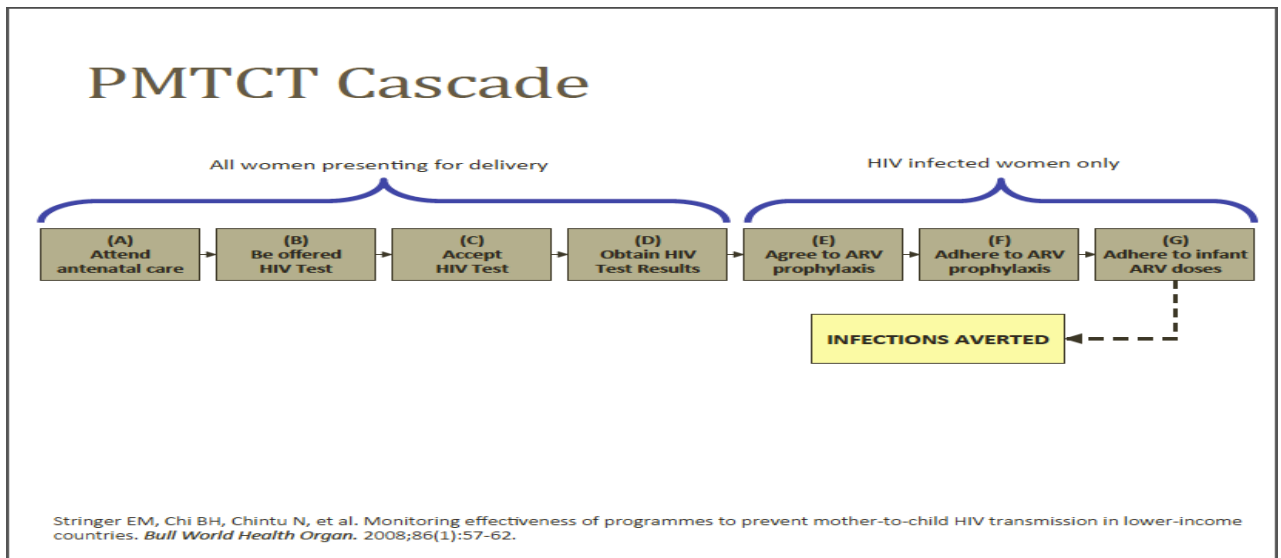
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<sup>55</sup> Stringer, Elizabeth M. et al. “Coverage of Nevirapine-Based Services to Prevent Mother-to-Child HIV Transmission in 4 African Countries.” *JAMA* 304(3) (2010):293-302  
<http://jama.ama-assn.org.proxy.library.vcu.edu/content/304/3/293.abstract>

<sup>56</sup> WHO/UNAIDS/UNICEF. “Towards universal access: Scaling up priority HIV/AIDS interventions in the health sector.” 2010.  
<http://www.who.int/hiv/topics/universalaccess/en/index.html>

<sup>57</sup> Stringer, Elizabeth M. et al. “Monitoring Effectiveness of Programmes to Prevent

Figure 4: PMTCT Cascade



Studies have shown that attrition along each step of the cascade can be significant. For example, in many high-HIV prevalence settings, significant proportions of women decline HIV testing or fail to return to collect their test results.<sup>58, 59</sup>

Additionally, even after a woman is diagnosed with HIV, there is no guarantee that she will agree to ARV drug prophylaxis. Studies in Burkina Faso, Côte d'Ivoire and Kenya have found that up to 40–60% of HIV-infected women decline short course ZDV prophylaxis in pregnancy once diagnosed.<sup>60, 61</sup> Reasons for non-acceptance of testing or

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- Mother-to-Child HIV Transmission in Lower-Income Countries.” *Bulletin of the World Health Organization*, Vol.86(1), (2008):57-62. <http://www.who.int/bulletin/volumes/86/1/07-043117/en/>
- <sup>58</sup> Perez F. et al. "Prevention of Mother to Child Transmission of HIV: Evaluation of a Pilot Programme in a District Hospital in Rural Zimbabwe." *BMJ* 329(7475) (2004). <http://www.ncbi.nlm.nih.gov/pubmed/15539670>
- <sup>59</sup> Ekouevi D.K. et al. "Acceptability and Uptake of a Package to Prevent Mother-to-Child Transmission using Rapid HIV Testing in Abidjan, Côte d'Ivoire", *AIDS* 18(4), (2004). <http://www.ncbi.nlm.nih.gov/pubmed/15090779>
- <sup>60</sup> Meda, Nicolas et al. "Field Acceptability and Effectiveness of the Routine Utilization of Zidovudine to Reduce Mother-to-Child Transmission of HIV-1 in West Africa." *AIDS*, Vol.16(17), (2002):2323-8. <http://www.ncbi.nlm.nih.gov/pubmed/12441805>
- <sup>61</sup> Songok EM et al. "The Use of Short-Course Zidovudine to Prevent Perinatal Transmission of Human Immunodeficiency Virus in Rural Kenya." *The American Journal of*

interventions certainly vary among these settings, but may be tied to poor understanding, patient denial and fear of stigma.<sup>62</sup>

Failure of any of the multiple sequential steps of PMTCT care results in cumulative losses of pregnant mothers from PMTCT services, with increased risk of HIV transmission to their infants. A study carried out by UNICEF between January 2000 and June 2002 shows that of more than half a million women who attended clinics in twelve countries, only 71% received counseling; of those who were counseled, only 70% took an HIV test; among women who tested HIV positive, only 49% received preventive drugs.<sup>63</sup>

Similarly, a multicounty evaluation of four African countries (Cameroon, Cote d'Ivoire, South Africa and Zambia) examined the effectiveness of PMTCT services at both the community and facility level. The study found that of the 3,244 HIV-positive pregnant women who delivered in health centers offering PMTCT services in the four countries, 84% were offered testing, 57% adhered to maternal ARV prophylaxis and 49% adhered to infant ARV prophylaxis.<sup>64</sup> (See Figure 4) Yet another study in Zambia demonstrates attrition along the PMTCT cascade.<sup>65</sup> (See Figure 5)

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*Tropical Medicine and Hygiene*, Vol.69(1), (2003):8-13. <http://www.ajtmh.org/content/69/1/8>

<sup>62</sup> Stringer, Elizabeth M. et al. "Monitoring Effectiveness of Programmes to Prevent Mother-to-Child HIV Transmission in Lower-Income Countries." *Bulletin of the World Health Organization*, Vol.86(1), (2008):57-62. <http://www.who.int/bulletin/volumes/86/1/07-043117/en/>

<sup>63</sup> UNICEF. "Evaluation of United Nations-Supported Pilot Projects for the Prevention of Mother-to-Child Transmission of HIV." 2003. [http://www.oecd.org/LongAbstract/0,2546,en\\_35038640\\_35074394\\_35160447\\_35046507\\_1\\_1\\_1\\_00.html](http://www.oecd.org/LongAbstract/0,2546,en_35038640_35074394_35160447_35046507_1_1_1_00.html)

<sup>64</sup> Stringer, Elizabeth M. et al. "Coverage of Nevirapine-Based Services to Prevent Mother-to-Child HIV Transmission in 4 African Countries." *JAMA* 304(3) (2010):293-302 <http://jama.ama-assn.org.proxy.library.vcu.edu/content/304/3/293.abstract>

<sup>65</sup> Mandala, Justin et al. "Prevention of Mother-to-Child Transmission of HIV in Zambia: Implementing Efficacious ARV Regimens in Primary Health Centers." *BMC Public Health*, 9:314 (2009). <http://www.biomedcentral.com/1471-2458/9/314>



Figure 5: PMTCT Attrition - Cameroon, Cote' d'Ivoire, South Africa and Zambia

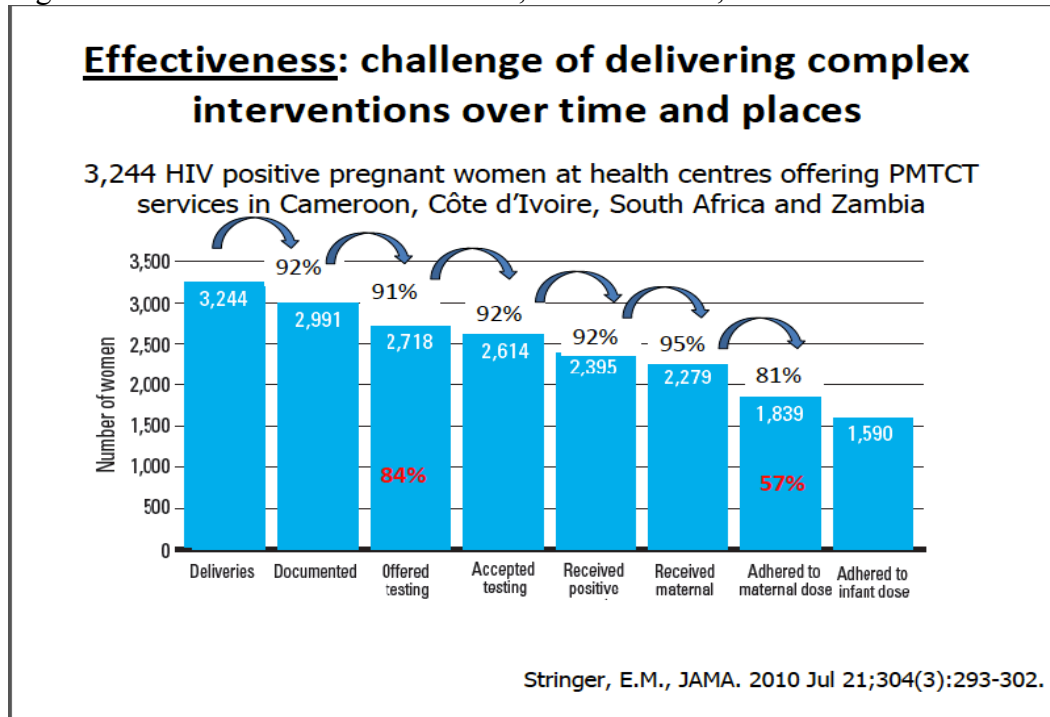
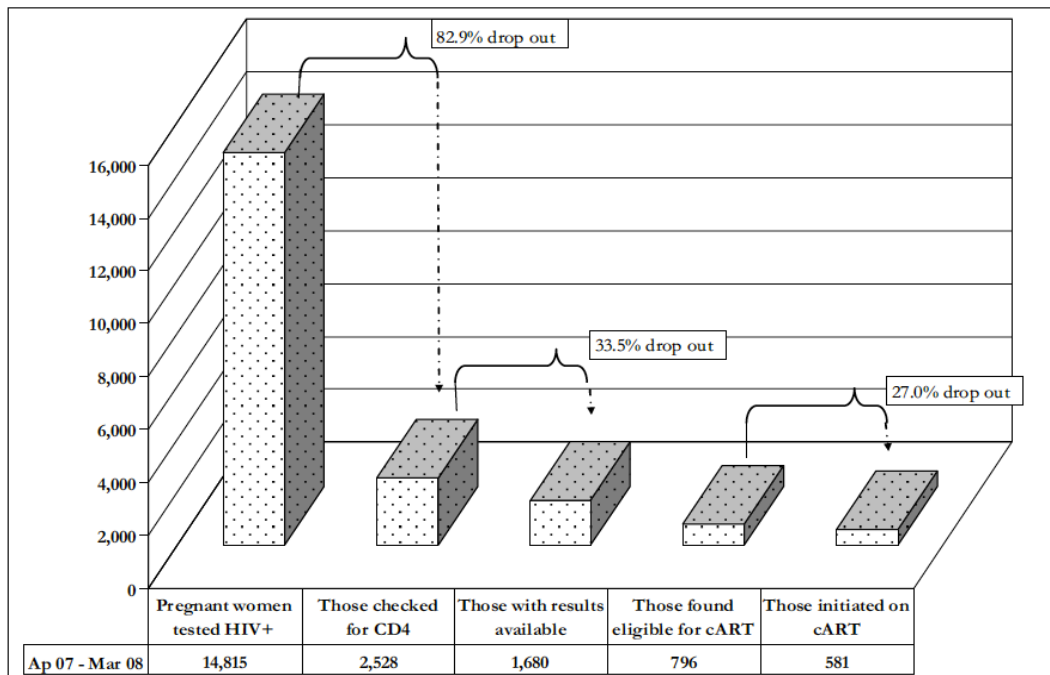


Figure 6: Attrition Cascade in Implementing Efficacious ARV Regimens in Zambia



Source: Mandala, Justin et al. BMC Public Health, 2009; 9:314

Several other studies in resource-constrained countries have shown that such high dropout rates are not unusual.<sup>66,67,68,69</sup> However, they have also found that some PMTCT programs perform much better than others.

### **PMTCT Programming in Kenya:**

Since the launch of PMTCT and pediatric HIV treatment and care programs in Kenya in the year 2000, there has been a substantial scale-up, with 4000 (90%) of 4400 facilities with maternal child health services offering PMTCT services in 2010.<sup>70</sup> Antenatal care (ANC) utilization is high overall (92%), though more than 75% of women access ANC after the third month, that is, after the point of optimal PMTCT regimen initiation. Access to skilled attendants at delivery is moderate (44%), with pronounced disparities in access between the poorest (20%) and the wealthiest fifth (81%) of women.<sup>71</sup>

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<sup>66</sup> Stringer J.S. et al. "Effectiveness of a City-wide Program to Prevent Mother-to-child HIV Transmission in Lusaka, Zambia." *AIDS* 19(12) (2005).  
<http://www.ncbi.nlm.nih.gov/pubmed/16052086?dopt=Abstract>

<sup>67</sup> Manzi M. et al. "High Acceptability of Voluntary Counselling and HIV- testing but Unacceptable Loss to Follow Up in a Prevention of Mother-to-Child HIV Transmission Programme in Rural Malawi: Scaling-up Requires a Different Way of Acting." *Trop Med Int Health* 10(12), (2005). <http://www.ncbi.nlm.nih.gov/pubmed/16359404>

<sup>68</sup> Barker, Pierre M. et al. "Antiretroviral Drugs in the Cupboard are Not Enough: The Impact of Health Systems' Performance on Mother-to-Child Transmission of HIV." *Journal of acquired immune deficiency syndromes* Vol:56 iss:2(2011):45-8.  
[http://journals.lww.com/jaids/Fulltext/2011/02010/Antiretroviral\\_Drugs\\_in\\_the\\_Cupboard\\_are\\_Not.17.aspx](http://journals.lww.com/jaids/Fulltext/2011/02010/Antiretroviral_Drugs_in_the_Cupboard_are_Not.17.aspx)

<sup>69</sup> Wilfert C. "Site Specific Factors Influencing Access to PMTCT Services, Trends with Time, and Suggestions for Improvement." *XVI International AIDS Conference*, August 2006.  
<http://globalhealth.kff.org>

<sup>70</sup> Republic of Kenya. "Prevention of Mother-to-Child Transmission of HIV (PMTCT) and Pediatric HIV and AIDS Care and Treatment – Technical Review Report." November 2010.  
<http://nascop.or.ke/index.php>

<sup>71</sup> UNICEF. "Kenya PMTCT Factsheet." 2010. <http://www.unicef.org/kenya/>

Approximately 63% of pregnant women were tested for HIV in 2009. The proportion of pregnant women living with HIV reached with ARVs for PMTCT increased from 24% in 2004 to 73% in 2009. However, that of HIV-exposed infants reached with ARVs for PMTCT over the same period of time is much lower – from 20% in 2004 to 49% in 2009.<sup>72, 73</sup>

HIV transmission from mother-to-child is still high in Kenya. A United Nations General Assembly Special Session (UNGASS) country report in 2010<sup>74</sup> estimated that 1 in 5 babies born to HIV-infected mothers in Kenya are infected with HIV. An estimated 220,000 children were living with HIV in 2011, with approximately 13,000 new child infections that year, most of which were a result of mother-to-child transmission.<sup>75</sup> It is believed these high rates account for the high infant mortality rate in Kenya.<sup>76</sup>

Consequently, Kenya remains one of the countries contributing high numbers of children living with HIV globally<sup>77</sup> and among the 22 PMTCT global plan priority countries.<sup>78</sup>

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<sup>72</sup> USAID. “Kenya HIV/AIDS Health Profile.” September 2010.  
[http://www.usaid.gov/our\\_work/global\\_health/aids/](http://www.usaid.gov/our_work/global_health/aids/)

<sup>73</sup> UNICEF. “Kenya PMTCT Factsheet.” 2010. <http://www.unicef.org/kenya/>

<sup>74</sup> UNGASS. “Country Report – Kenya. Kenya Office of the President, Ministry of Special Programmes.” 2010.  
<http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2010countries/>

<sup>75</sup> UNGASS. “The Kenya AIDS Epidemic: Update 2011.” 2011.  
<http://www.unaids.org/en/dataanalysis/datatools/aidsinfo/>

<sup>76</sup> UNGASS. “Country Report – Kenya. Kenya Office of the President, Ministry of Special Programmes.” 2010.  
<http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2010countries/>

<sup>77</sup> Republic of Kenya. “Prevention of Mother-to-Child Transmission of HIV (PMTCT) and Pediatric HIV and AIDS Care and Treatment – Technical Review Report.” November 2010.  
<http://nascop.or.ke/index.php>

## Summary:

Over the past 30 years, since the first cases of human immunodeficiency virus (HIV) infection were identified in 1981, the number of children infected with HIV has increased dramatically in developing countries because the number of HIV-infected women of childbearing age has risen. Sub-Saharan Africa bears the greatest burden of the HIV epidemic, which includes pediatric AIDS.

Globally, there were 3.4 million children living with HIV in 2010, 390,000 new infections among children, and 250,000 AIDS deaths. Mother-to-child transmission of HIV, also known as vertical transmission, is the main route by which childhood HIV infection is acquired; the risk of perinatal acquisition is 15-45% without intervention.

However, great advances have been made to control transmission of the virus from mother to infant. In the United States and in other industrialized nations mother-to-child transmission has been practically eliminated. Following these advances, several ambitious goals for pediatric AIDS control in developing countries have been set by various international bodies, including virtual elimination of mother-to-child transmission by 2015.

Unfortunately, despite the availability of proven interventions for the prevention of mother-to-child HIV transmission (PMTCT) and substantial donor investments for implementing them in developing countries, the outcome – HIV-free infants – is far from optimal. As such, pediatric AIDS remains a major public health challenge in developing nations.

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<sup>78</sup> WHO/UNAIDS/UNICEF. “Towards the Elimination of Mother-to-Child Transmission of HIV: Report of a WHO Technical Consultation 9-11 November 2010 Geneva, Switzerland.” 2010.  
[http://www.who.int/hiv/pub/mtct/elimination\\_report/en/](http://www.who.int/hiv/pub/mtct/elimination_report/en/)

Kenya like many other African nations has made some commendable strides on scaling-up PMTCT. However, it remains one of the countries contributing high numbers of children living with HIV globally and among the 22 PMTCT global plan priority countries. In this context, there is an urgent need to examine reasons for PMTCT failures and contextualize accessibility and adherence challenges faced by HIV- infected mothers and their infants.

In an effort to contribute towards that goal, this study employs a mixed method approach in gathering information from HIV-positive mothers receiving PMTCT services at St. Mary's Hospital Lang'ata – a mission hospital in the outskirts of Nairobi city in Kenya. The objective of the study was to explore enabling factors –individual, social and structural – that enhance utilization of and adherence to PMTCT services in a plural urban setting in Kenya.

A detailed review of available literature on the subject is provided in the next chapter.

## Chapter 2: Literature Review

### Introduction:

HIV infection transmitted from an HIV-infected mother to her child during pregnancy, labor, delivery or breastfeeding is known as mother-to-child transmission (MTCT). Each year, close to half a million children aged 15 and under become infected with HIV. Almost all of these infections occur in developing countries, and more than 90% are the result of mother-to-child transmission.<sup>79</sup>

The prevention of mother-to-child transmission (PMTCT) is a highly effective intervention and has huge potential to improve both maternal and child health. Effective PMTCT involves simultaneous support for several strategies that work synergistically to reduce the odds that an infant will become infected as a result of exposure to the mother's virus. Through the reduction in overall HIV among reproductive-age women and men, the reduction of unwanted pregnancies among HIV-positive women, the provision of antiretroviral drugs to reduce the chance of infection during pregnancy and delivery and appropriate treatment, care and support to mothers living with HIV (including infant feeding); programs are able to reduce the chance that infants will become infected.<sup>80</sup> In ideal conditions, the provision of antiretroviral prophylaxis and replacement feeding can reduce transmission from an estimated 15-45% with no intervention to around 1-2%.<sup>81</sup> In

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<sup>79</sup> WHO. "PMTCT Strategic Vision 2010 – 2015: Preventing mother-to-child transmission of HIV to reach the UNGASS and Millennium Development Goals." 2009.  
[http://www.who.int/hiv/pub/mtct/strategic\\_vision/en/index.html](http://www.who.int/hiv/pub/mtct/strategic_vision/en/index.html)

<sup>80</sup> Ibid.

<sup>81</sup> Ibid.

fact, in the United States and Europe, mother-to-child transmission is nearly eliminated.<sup>82,83</sup>

Services to prevent mother-to-child HIV transmission (PMTCT) are therefore important entry points for HIV/AIDS prevention, treatment and care services for women, their children and families. In 2001, the United Nations General Assembly set a target for 80% of pregnant women and their children to have access to essential prevention, treatment and care by 2010 to reduce the proportion of infants infected by HIV by 50%.<sup>84</sup> By 2010, according to the *UNAIDS' Report on the Global AIDS Epidemic*<sup>85</sup> four countries in sub-Saharan Africa – Botswana, Namibia, South Africa and Swaziland had achieved more than 80% coverage of antiretroviral prophylaxis to prevent mother-to-child transmission – demonstrating that national scale-up of PMTCT services in resource-limited settings can be achieved.<sup>86,87</sup> Based on these encouraging results, in 2010 HIV

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<sup>82</sup> United States Centers for Disease Control and Prevention. “Diagnoses of HIV infection by age.” 2010. <http://www.cdc.gov/hiv/topics/surveillance/basic.htm#hivaidsage>

<sup>83</sup> Ciaranello, Andrea L. et al. “What Will It Take to Eliminate Pediatric HIV? Reaching WHO Target Rates of Mother-to-Child HIV Transmission in Zimbabwe: A Model-Based Analysis.” *PLoS Medicine*, Vol.9(1) (2012).  
<http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1001156>

<sup>84</sup> United Nations. “UNGASS Declaration: Resolution adopted by the General Assembly; Declaration of Commitment on HIV/AIDS.” 2001.  
[http://data.unaids.org/publications/irc-pub03/aidsdeclaration\\_en.pdf](http://data.unaids.org/publications/irc-pub03/aidsdeclaration_en.pdf)

<sup>85</sup> UNAIDS. “Report on the Global AIDS Epidemic.” 2010.  
[http://www.unaids.org/globalreport/global\\_report.htm](http://www.unaids.org/globalreport/global_report.htm)

<sup>86</sup> WHO. “PMTCT Strategic Vision 2010 – 2015: Preventing mother-to-child transmission of HIV to reach the UNGASS and Millennium Development Goals.” 2009.  
[http://www.who.int/hiv/pub/mtct/strategic\\_vision/en/index.html](http://www.who.int/hiv/pub/mtct/strategic_vision/en/index.html)

<sup>87</sup> UNAIDS. “Report on the Global AIDS Epidemic.” 2010.  
[http://www.unaids.org/globalreport/global\\_report.htm](http://www.unaids.org/globalreport/global_report.htm)

prevention and treatment organizations emphasized a new goal: the “virtual elimination” of pediatric HIV infection – defined as the reduction of MTCT to less than 5%.<sup>88</sup>

However, despite recent progress in coverage of PMTCT interventions, the impact is not fully realized. Globally, HIV/AIDS is now the leading cause of mortality among women of reproductive age and, in several high-burden countries such as South Africa and Zimbabwe, HIV is the leading cause of maternal mortality. Furthermore, even in countries with scaled-up PMTCT coverage utilization and adherence to these services is very low and the impact of these interventions is not clearly demonstrated by a decrease in pediatric infections, HIV-free survival, and improved maternal and child health.

In this context, there is an urgent need to examine reasons for PMTCT failures and contextualize accessibility and adherence challenges faced by HIV- infected mothers of HIV-infected infants.

The literature reviewed in this study covers two key areas. First, a theoretical framework for the study, which is a nested model, including: (1) the health care utilization model, and (2) the PMTCT cascade model. Second, a review of contributing factors that have been found to influence women’s health seeking behavior in relation to mother-to-child transmission of HIV will be summarized under the following themes: knowledge of mother-to-child transmission and perceptions of PMTCT interventions, social constructions of breastfeeding, and skilled versus unskilled care.

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<sup>88</sup> Moszynski P. “Global elimination of mother to child HIV transmission is now achievable, say agencies.” *BMJ* 341: c5152. (2010).



### **Theoretical Framework:**

A nested model, which includes the health care utilization model, and the PMTCT cascade model, will be used to provide a theoretical framework for the study. While the health utilization model presents a broader overview of women's health-seeking behavior in general, the PMTCT cascade model provides more detailed analysis of the specific parameters unique to PMTCT services.

### **The Health Care Utilization Model:**

Individual decision-making is important in health seeking because it allows a choice between several alternatives. If the choice is to seek care, then several options could be made on where and when to seek care. Utilization of health services is one measure of decision-making and health-seeking behavior.<sup>89</sup>

In this study, barriers to seeking PMTCT services have been conceptualized based on a model designed by Andersen in 1968 and modified by the International Collaborative Study on Health Care by Kroeger in 1983.<sup>90</sup> The model classifies factors that influence care seeking into three categories:

1. An individual's predisposing demographic characteristics: age, sex, marital status, status in the household, household size, ethnic group, degree of cultural adaptation, formal education, occupation, assets (land, livestock, cash, income), social network interactions.

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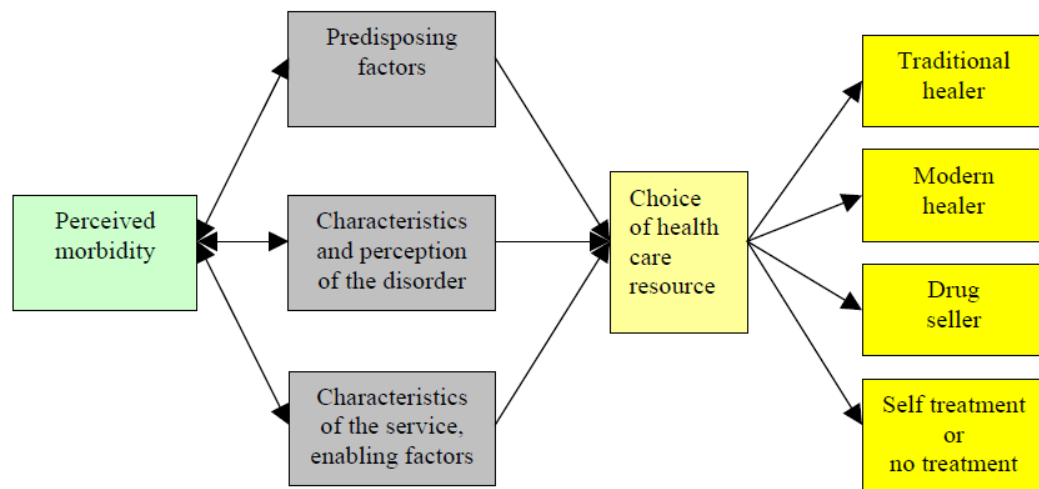
<sup>89</sup> Andersen, R. & Neuman, J.F. "Societal and individual determinants of medical care utilization in the United States." *Milbank Memorial Fund Quarterly/Health and Society*, 51:95-124. 1975. <http://www.dcp2.org/file/29/wp14.pdf>

<sup>90</sup> Ibid.

2. Characteristics of the disorder and their perception: chronic or acute, severe or trivial, etiological model, expected benefits or treatment (modern versus traditional), psychosomatic versus somatic disorders.
3. Characteristics of the service (health service system factors and enabling factors): accessibility, appeal (opinions and attitudes towards traditional and modern healers), acceptability, quality, communication, and costs.

An individual's perceived morbidity and the interaction of these factors guides their choice on the utilization of health care resources. (See Figure 1 below)

Figure 7: Kroegers Model, 1983

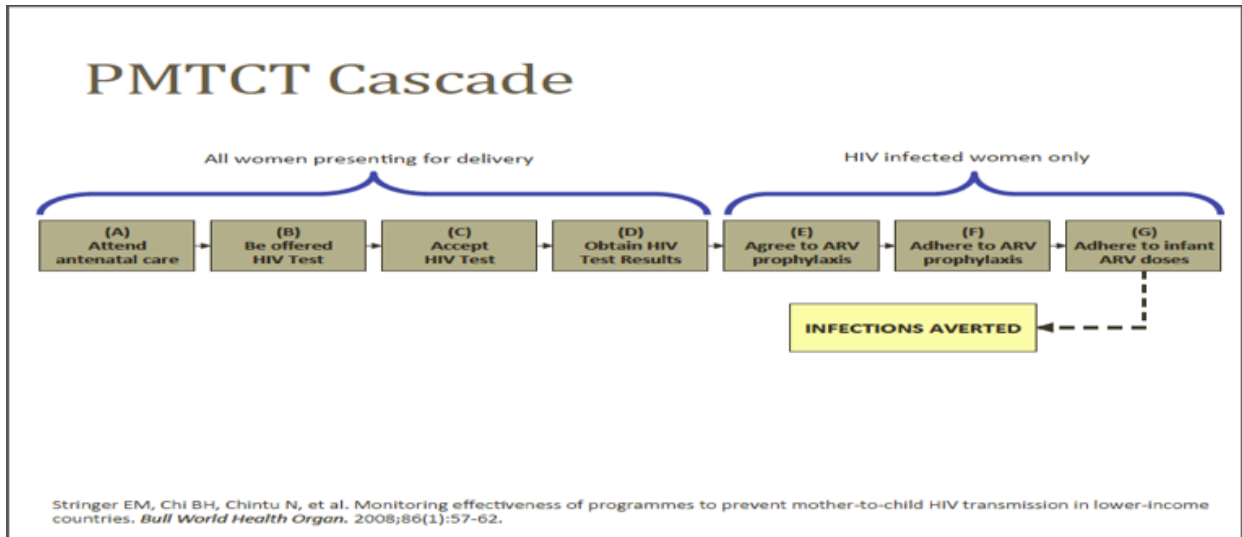


### **The PMTCT Cascade Model:**

As earlier discussed in the introduction chapter, PMTCT interventions entail a continuum of care referred to as the PMTCT cascade that HIV-positive pregnant women need to follow to reduce the odds that their infants will become infected with HIV virus. It was further noted that attrition along the cascade is rampant contributing to high mother-to-child HIV infection rate in resource-constrained settings. The cascade model

will therefore be used to analyze women's decision-making process at each stage of the cascade.

Figure 8: PMTCT Cascade



### Literature Review Themes:

Understanding care-seeking practices and barriers to prevention of mother-to-child transmission (PMTCT) of HIV is necessary in designing effective programs to address the high disease burden due to HIV/AIDS. A number of studies on access and utilization of PMTCT services that illustrate (albeit in part for some) the above models have been conducted. These studies could be summarized into the following themes: (1) Knowledge of mother-to-child transmission and Perceptions of PMTCT interventions; (2) Social constructions of breastfeeding; and (3) Skilled versus unskilled care.

### Knowledge of Mother-to-Child Transmission and Perceptions of PMTCT Interventions:

A study in Nigeria found knowledge of PMTCT programs and interventions to be critical. The study aimed at identifying level of awareness and knowledge of PMTCT

services that can be utilized in improving access. The methodology consisted of 20 individual in-depth interviews spread over Adabeji, Adeoyo/Agbadagbudu, Jakiru/Onipasan –and Eleta communities, and in Ibadan among household heads, religious and community based leaders. Key factors identified were low knowledge of mother-to-child transmission, lack of knowledge of the PMTCT services, inadequate community sensitization, and inadequate healthcare facilities. This study suggested that the success of PMTCT programs demands a shift towards a more community-based approach, which calls for strong advocacy, enlightenment and community mobilization for improved awareness and utilization of PMTCT services.<sup>91</sup>

Another study conducted in Uganda explored perceptions, care-seeking practices and barriers to PMTCT among young and HIV-positive women. A household survey (10,706 women aged 14–49 years), twelve focus group discussions and 66 key informant interviews were carried out between January and April 2009 in Wakiso district, central Uganda. Results show that access to PMTCT services (family planning, HIV counseling and testing and delivery at health units) was poor. Decision-making was an important factor in accessing PMTCT services. Socioeconomic factors (wealth quintile, age, education level) and institutional practices also influenced access to PMTCT. Overall, having had an HIV test was highest when both men and women made decisions together or when women were empowered to make their own decisions. This was significant across wealth quintiles ( $p=0.0001$ ), age groups ( $p=0.0001$ ) and education levels ( $p=0.0001$ ). The least level of HIV testing was when men made decisions for their

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<sup>91</sup> Oyedunni S. et al. "Community Gate Keepers' Awareness and Perception of Prevention of Mother-to-Child Transmission of HIV Services in Ibadan, Nigeria." *African Journal of Reproductive Health*, Vol. 11, No. 1 (Apr., 2007), pp. 67-75. <http://www.jstor.org/stable/30032489>

spouses; and this was the case with family planning and deliveries at health units. Other barriers to PMTCT were fear of women and male spouses to have an HIV test and the perception that HIV testing is compulsory in antenatal clinics. In conclusion, to increase access to PMTCT among women, especially the young, poor and least educated, there is a need to empower them to make decisions on health seeking, and also to educate men to support their spouses to make good decisions. Other barriers like fear of having an HIV test should be addressed through appropriate counseling of clients.<sup>92</sup>

Similarly, a study in India examining the reasons for inadequate utilization of PMTCT services arrived at comparable findings. The study sought to examine the socio-demographic factors associated with “lack of follow-up” among HIV-infected women enrolled in a large-scale private sector PMTCT program in Maharashtra, India between 2002 and 2008. Data on HIV-infected women who were enrolled during pregnancy (N=734) and who reported live birth (N=770) were used to analyze factors associated with lack of follow-up before delivery and after delivery, respectively. Bivariate and multivariate analyses were conducted to estimate the associations between lack of follow-up and socio-demographic factors using generalized linear models. The study found that women with less than graduate level education, from a poor family, who were registered after 20 weeks of pregnancy and whose partners were HIV non-infected or with unknown HIV status were more likely to be lost to follow-up. The study pointed to the need for innovative and effective counseling techniques for less educated women, economic empowerment of women, better strategies to increase uptake of partner’s HIV testing,

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<sup>92</sup> Mbonye, A. K; Hansen, K. S; Wamono, F.; Magnussen, P. "Barriers to Prevention of Mother-to-Child Transmission of HIV Services in Uganda." *Journal of Biosocial Science*, vol. 42, no. 2, pp. 271-283, Mar 2010.  
<http://journals.cambridge.org.proxy.library.vcu.edu/action/displayAbstract?fromPage=online&aid=7101260>

and early registration of women in the program to improve adherence in PMTCT programs. The study emphasized that the need for innovative counseling techniques is even greater for PMTCT programs in the public health sector as the women accessing care in the public sector are likely to be less educated and economically more deprived.<sup>93</sup>

Furthermore, a study aimed at determining rates and co-factors of accessing HIV care by HIV-infected women exiting maternal care was carried out in Kenya. In the study, a cross-sectional survey of women who had participated in a PMTCT research study and were referred to care programs in Nairobi, Kenya was conducted. With a median of 17 months following referral, women were located by peer counselors and interviewed to determine whether they accessed HIV care and what influenced their care decisions. Fisher's exact test was used to assess the association between client characteristics and access to care. Peer counselors traced 195 (82%) residences, where they located 116 (59%) participants who provided information on care. Since exit, 50% of participants had changed residence, and 74% reported going to the referral HIV program. Reasons for not accessing care included lack of money, confidentiality, and dislike of the facility. Women who did not access care were less likely to have informed their partner of the referral, and were less likely to believe that highly active antiretroviral therapy (HAART) is effective. Among those who accessed care, 33% subsequently discontinued care, mostly because they did not qualify for HAART. Factors cited as barriers to access included stigma, denial, poor services, and lack of money. Factors that were cited as making care attractive included health education, counseling, free services,

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<sup>93</sup> Panditrao, Mayuri et al. "Socio-demographic factors associated with loss to follow-up of HIV-infected women attending a private sector PMTCT program in Maharashtra, India." *AIDS Care*, Vol.23(5) (2011): 593-600  
<http://www.tandfonline.com.proxy.library.vcu.edu/doi/abs/10.1080/09540121.2010.516348>

and compassion of service providers. The study concluded that a substantial number of women exiting maternal care do not transition to HIV care programs. The study suggested partner involvement, a standardized referral process, and more comprehensive HIV education for mothers diagnosed with HIV during pregnancy to facilitate successful transitions between PMTCT and HIV care programs.<sup>94</sup>

Yet another assessment on PMTCT adherence in South Africa links socio-demographic factors to sub-optimal program results. In the study counseling and clinical notes of 100 Zulu women enrolled in PMTCT multicenter (Kesho Bora Study) were examined. Extracted information was supplemented by unstructured, free-ranging interviews conducted by trained adherence counselors on 43 consecutive women attending the trial clinic over a two-week period. Adherence was defined as good (>95% adherence), or poor (<95% adherence). The study found reasons closely related to sub-optimal adherence to include therapy misconceptions/misunderstandings, sharing antiretroviral drug with relatives, domestic violence, poverty and issues relating to disclosure and stigma.<sup>95</sup>

Closely linked to the aforementioned socio-demographic factors, another study in South Africa further found women's reproductive desires had an effect on their decision to adhere to PMTCT interventions. The purpose of this study was to investigate family planning needs, knowledge of HIV transmission and HIV disclosure in a cohort sample that had undergone PMTCT in a resource poor setting. Five public clinics implementing

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<sup>94</sup> Otieno, Phelgon A. et al. "Determinants of failure to access care in mothers referred to HIV treatment programs in Nairobi, Kenya." *AIDS Care*, Vol. 22(6) (2010): 729-736. <http://dx.doi.org/10.1080/09540120903373565>

<sup>95</sup> Mephams, S et al. "Challenges in PMTCT antiretroviral adherence in northern KwaZulu-Natal, South Africa." *AIDS Care*, Vol.23(6) (2011): 741-7 <http://dx.doi.org/10.1080/09540121.2010.516341>

PMTCT from Qaukeni Local Service Area, O.R. Tambo District in the Eastern Cape were studied. The sample at postnatal care consisted of 758 women with known HIV status. From 116 HIV-positive women 76.3% and from 642 HIV negative women 85.2% got counseling on safe sex during pregnancy but only 65.8% and 62.3% of the women respectively reported practicing safe sex during pregnancy, which did not differ by HIV status. Postnatally, almost all women received counseling on family planning, yet use of contraceptives and condoms were low. Among HIV-positive women, PMTCT knowledge and younger age of the mother were associated with pregnancy desire, and among HIV negative women HIV disclosure to the partner, younger age of the mother and having a lower number of children were associated with pregnancy desire. High pregnancy desires (yet lower than for HIV negative women); low contraceptive and condom use were found among HIV-positive women. The study concluded that HIV prevention and family planning must acknowledge the reproductive desires of HIV-positive women and men.<sup>96</sup>

With regard to antiretroviral drugs (ARVs), four replicate studies done in Botswana, South Africa and Rwanda -- specifically on mother and infant adherence to PMTCT drugs -- show similar intertwined findings. The studies interviewed HIV-positive antenatal women enrolled in various PMTCT programs in these countries. Baek et al.<sup>97</sup> found that among women in Botswana common reasons for maternal non-adherence included being away from home without their medication, running out of pills,

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<sup>96</sup> Peltzer, Karl; Chao, Li-Wei; Dana, Pelisa. "Family Planning Among HIV Positive and Negative Prevention of Mother to Child Transmission (PMTCT) Clients in a Resource Poor Setting in South Africa." *AIDS and Behavior*, vol. 13, no. 5, pp. 973-979, Oct 2009  
<http://www.springerlink.com.proxy.library.vcu.edu/content/p2031n27nu7t1323/>

<sup>97</sup> Baek C., et al. "Evaluation of HIV Counseling and Testing in ANC Settings and Adherence to Short Course Antiretroviral Prophylaxis for PMTCT in Francistown, Botswana." *Washington, DC: Population Council*, 2009.



forgetting to take pills and being busy with other things. Reasons for infant non-adherence included not understanding how to give azidothymidine (AZT) to the infant, being away from home, being busy, forgetting and sleeping through the dose time. The study indicated that it is important to address disclosure in the context of PMTCT services as adherence to the program recommendations is likely to be easier for women who have partners that are aware of and supportive of their status and need for prophylactic medications.

Peltzer et al.<sup>98</sup> studied determinants of nevirapine prophylaxis adherence in the Gert Sibande district in South Africa and found that if women had disclosed their HIV status and the fact that they are on ARV prophylaxis, have knowledge of PMTCT and knew the HIV status of their infant, they were more likely to adhere to their treatment than those who did not disclose their HIV status.

An identical study by Peltzer, Sikwane and Majaja<sup>99</sup> in the district of Nkangala, South Africa observed that in addition to the findings of the previous study, community factors such as having visited a traditional birth attendant (TBA) during pregnancy, lack of male involvement, discrimination and stigma contribute to sub-optimal maternal and infant prophylaxis adherence. The study suggests that support from health workers, family members, partners and the community may be important to attain optimal levels of participation and adherence. According to Delvaux et al.<sup>100</sup> discussion of HIV screening

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<sup>98</sup> Peltzer K., et al. "Determinants of Adherence to a Single-dose Nevirapine Regimen for the Prevention of Mother-to-Child HIV Transmission in Gert Sibande District in South Africa." *Acta Paediatrica* (2010) 99: 699–704.

<sup>99</sup> Peltzer, Karl; Sikwane, Elisa ; Majaja, Mmapaseka. "Factors Associated with Short-course Antiretroviral Prophylaxis (dual therapy) Adherence for PMTCT in Nkangala district, South Africa. *Acta paediatrica* Vol. 100(9) (2011): 1253-7

<sup>100</sup> Delvaux T. et al. "Determinants of Non-adherence to a Single-dose Nevirapine

with partner, partner willingness to have HIV testing or being effectively tested for HIV have been shown as predictors of acceptance of HIV testing by pregnant women and of compliance with single-dose nevirapine uptake in Rwanda.

Finally, a very recent study investigated individual, social and structural reasons for incident cases of vertical HIV transmission in the era of free access to PMTCT services in South Africa. The mixed-methods study was conducted in Soweto, South Africa from June-August, 2009. Participants were birthmothers of HIV-infected infants born after 1 December 2008. All participants completed an interviewer-administered questionnaire. Women also participated in a focus group (n = 10) or individual structured interview (n = 35). Mean age of participants (n = 45) was 28.7 years (SD = 5.4). The study found the reasons for PMTCT failure to be: a) failure of per-guideline prescription of ARV strategies for infants (31%) and/or mothers (57%); b) maternal refusal of treatment (n = 5); c) preterm delivery (31%); d) delayed ANC attendance because of facility-related barriers and maternal apprehension around HIV testing; e) fear of stigma; f) maternal difficulty with administering infant AZT (n = 9) and g) maternal confusion about infant feeding.<sup>101</sup>

### **Social Constructions of Breastfeeding:**

Complementary breastfeeding represents an important source of risk of HIV infection for infants born to HIV-positive mothers. The World Health Organization

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Regimen for Prevention of Mother-to-Child HIV Transmission in Rwanda.” *J Acquir Immune Defic Syndr* (2009) 50: 223–30.

<sup>101</sup> Laher, Fatima et al. “Conversations With Mothers: Exploring Reasons for Prevention of Mother-to-Child Transmission (PMTCT) Failures in the Era of Programmatic Scale-Up in Soweto, South Africa.” *AIDS Behavior Journal*, Vol.16(1), (2011) 91-98.  
<http://www.springerlink.com.proxy.library.vcu.edu/content/x010821745727w5q/>

recommends that infants born to HIV-positive mothers receive either replacement feeding or exclusive breastfeeding (EBF) followed by early weaning.<sup>102</sup> Beyond the clinical and epidemiological debate, it remains unclear how acceptable and feasible the two options are for rural populations in sub-Saharan Africa. To fill this knowledge gap, a qualitative study explored both the socio-cultural construction and the practice of breastfeeding in the Nouna Health District, rural Burkina Faso. Information was collected through 32 individual interviews and 3 focus group discussions with women of all ages, and 6 interviews with local *guérisseurs* (healers). The findings indicate that breastfeeding is perceived as central to motherhood, but that women practice complementary, rather than exclusive, breastfeeding. The findings also indicate that women recognize both the nutritional value of breast milk and its potential to act as a source of disease transmission. The findings suggested that given the socio-cultural importance attributed to breastfeeding and the prevailing poverty, it might be more acceptable and more feasible to promote exclusive breastfeeding (EBF) followed by early weaning than replacement feeding. A set of operational strategies is proposed to favor the prevention of mother-to-child transmission of HIV in the respect of the local socio-cultural setting.<sup>103</sup>

Another study conducted in Ivory Coast points to the fact that the decision on infant feeding option does not only depend upon the mother but also on the father and more specifically on couple interactions. In Abidjan, Ivory Coast, HIV-positive women

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<sup>102</sup> UNICEF. "Children and AIDS: Fourth Stocktaking Report." 2009.  
[http://www.unicef.org/publications/index\\_51902.html](http://www.unicef.org/publications/index_51902.html)

<sup>103</sup> Hofmann, Jennifer et al. "Breast Milk as the "Water that Supports and Preserves life:" Socio-cultural Constructions of Breastfeeding and their Implications for the Prevention of Mother to Child Transmission of HIV in sub-Saharan Africa." *Health Policy* 89 (2009) 322–328. [www.elsevier.com/locate/healthpol](http://www.elsevier.com/locate/healthpol)

and their infants were followed over two years in Ditrane Plus, a prevention of mother-to-child transmission (PMTCT) project. Using data from this project and from interviews conducted with couples and women, the study analyzed the construction of decisions and practices concerning the application of preventive infant feeding options. Differences may be found between women and men in discourses regarding their attitudes, which are in part related to their conceptions of motherhood and fatherhood. The study found that when men know their wife is HIV positive and is involved in the PMTCT project, they play an active role in applying the advice received. However, women do not always need the support of their spouse to undertake preventative behavior. Examining how men and women manage the infant feeding options for prevention in a context of HIV transmission prevention reveals the different attitudes and common experiences of women and men. These differences appear first at the decision-making level. For women, most decisions are taken in opposition to the image of the “good mother” and the judgment of the people around them, which leads them to set aside HIV prevention. Women's fears and hesitations reveal the difficulty of their choice. This is not the case for their spouses. Indeed, once informed about the HIV-positive status of their wife and after having accepted this status, they unwaveringly decide to prevent any risks. These differences in their positions are also manifested in the way in which artificial feeding is put into practice. The study hypothesized that if HIV transmission prevention through maternal breastfeeding is the preventive advice that has been more attractive, the status of father and spouse offers the man the voice and a more weighty decision than that of his wife, as is the case in several African societies. The pressures from the people around them are thus weaker for them. Once their decision is made, the man's position is firm

concerning artificial feeding. This attitude shows their distance from cultural norms once they were educated on HIV transmission through breastfeeding. Additionally, the health provider project team also plays an important role in the adoption of such by women and men. The implementation of preventive options is a complex process in which three groups of actors (women, men and the project team) interact. The study findings suggest that to optimize PMTCT programs for couples, it is essential that this dynamic be taken into account.<sup>104</sup>

### **Skilled versus Unskilled Care:**

Another issue that relates to the effectiveness of PMTCT interventions is the issue of skilled versus unskilled birth attendants. Worldwide, 34% of deliveries have no skilled attendant. This means 45 million births occur at home without skilled health personnel each year. Skilled attendants assist in more than 99% of births in more developed countries versus 62% in developing countries. In five countries the percentage is less than 20%.<sup>105</sup> Although the proportion of births assisted by skilled attendants has been steadily rising from 47% in 1990 to 62% in 2008,<sup>106</sup> progress needs to be accelerated. Sub-Saharan Africa, South- East Asia and the Caribbean are furthest away from achieving the universal coverage agreed on by WHO Member States in 2005.<sup>107</sup> Many more midwives

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<sup>104</sup> Traore, Annick Tijou et al. "Couples, PMTCT programs and infant feeding decision-making in Ivory Coast." *Social Science & Medicine*, vol. 69, no. 6, pp. 830-837, Sep 2009.

<sup>105</sup> WHO. "Skilled Birth Attendants." 2008.

[http://www.who.int/making\\_pregnancy\\_safer/events/2008/mdg5/factsheet\\_sba.pdf](http://www.who.int/making_pregnancy_safer/events/2008/mdg5/factsheet_sba.pdf)

<sup>106</sup> Ibid.

<sup>107</sup> WHO, "Skilled Attendant at Birth Updates." 2006.  
<http://www.who.int/reproductivehealth/en/>

need to be trained and posted close to where women live, and nearby hospitals need to be staffed with doctors.

Historical and observational evidence indicates that skilled care at birth reduces the risk of maternal mortality. Industrialized countries halved their maternal mortality ratios in the early 20th century by providing professional midwifery care at childbirth. By improving the access to hospitals after the Second World War, maternal deaths were reduced to the current low levels. Malaysia, Sri Lanka and Thailand halved their maternal mortality ratios within 10 years by increasing the number of midwives in the 1950s and 1960s. Over a further 15-year period, Thailand reduced its maternal mortality ratio from 200 to 50 maternal deaths per 100 000 live births by deploying even more midwives and by increasing the capacity of hospitals at the district level. Between 1983 and 2000, Egypt doubled the proportion of deliveries assisted by skilled birth attendants and reduced its maternal mortality ratio by 50%.<sup>108</sup>

Although WHO advocates that every pregnant woman seek care from a skilled provider, traditional birth attendants (TBAs) are part of the birthing process throughout the developing world, assisting in the births of a substantial portion of the world's newborns. Usually self-taught or informally trained, TBAs also provide advice and practical help in cleaning, cooking and caring for the households of pregnant women and new mothers. Because TBAs generally hold a position of respect and influence within their communities, they are uniquely equipped to inform and assist women and their families in preparing for birth. A study in Zambia on PMTCT scale-up reviewed that

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<sup>108</sup> WHO. "Skilled birth attendants." 2008.  
[http://www.who.int/making\\_pregnancy\\_safer/events/2008/mdg5/factsheet\\_sba.pdf](http://www.who.int/making_pregnancy_safer/events/2008/mdg5/factsheet_sba.pdf)

about 90% of pregnant women will attend antenatal clinic at least once, however less than 50% return to deliver in the health facility.<sup>109</sup> This occurrence underscores the vital role played by traditional birth attendants in the African setting.

Recognizing the widespread role of traditional birth attendants (TBAs) and herbal practitioners (HPs) in health care at community level in Nigeria, a study was set out to assess their knowledge, attitudes and practices in relation to HIV infection and prevention. Questionnaires were administered to a convenience sample of 189 participants in 20 local government areas of Lagos State. The findings were that knowledge of modes of transmission of HIV was less than adequate and included lack of knowledge of the existence of HIV/AIDS amongst some practitioners' claims for the ability to treat HIV/AIDS, failure to name major avenues of transmission and confusion of HIV/AIDS with other conditions. The use of measures to prevent infection of clients and themselves showed that normal standards of infection control are not adhered to. Considering that traditional birth attendants deliver as many as 60% of children born in Nigeria and that use of the services of herbal practitioners extends across the entire society in both rural and urban settings, this is seen as reason for concern. It is suggested that better incorporation of TBAs/HPs into the well-developed primary health care system offers not only a way of overcoming the risks of infection posed by traditional health practices but also offers an opportunity to extend the reach of voluntary counseling and testing and prevention of mother-to-child infection programs. The research has shown the need for appropriate training of TBAs, to enable them to recognize the risk of HIV infection in

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<sup>109</sup> Torkey, Kwasi, et al. "Increasing the uptake of prevention of mother-to-child transmission of HIV services in a resource-limited setting." 2009.  
<http://www.biomedcentral.com/1472-6963/10/29/prepub>

their own practices and to encourage them to adopt universal precautions against spreading infection. It is also recommended that they be more extensively integrated as primary health care workers in voluntary counseling and testing (VCT) and PMTCT programs in Nigeria. Further, it is suggested that referrals made between the traditional practitioners and professional health care providers can be an effective and successful element of HIV/AIDS prevention and control programs.<sup>110</sup>

### **Summary and Discussions of the Current Study:**

The literature reviewed discusses a range of factors that act as barriers to utilization and adherence to PMTCT services and as such contribute to sub-optimal performance of PMTCT programs. These factors could be summarized in the following groups: (1) factors that relate to knowledge and perceptions of PMTCT services, (2) factors that relate to infant feeding choices, (3) factors that relate to access to PMTCT services, and (4) factors that relate to stigma and discrimination. (See Table 3)

Inadequate knowledge that results to misunderstandings and misconceptions of PMTCT services was associated with poverty, low education levels, and insufficient sensitization. With regard to infant feeding choices, breastfeeding was perceived as a central motherhood responsibility in most African cultures, which makes the option of exclusive breastfeeding followed by early weaning a more acceptable intervention than replacement feeding within the African setting. Access to PMTCT services was affected by distance and transportation cost to the hospital, inadequate healthcare facilities and preferences of traditional birth attendants (TBAs) over skilled care.

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<sup>110</sup> Omowunmi, Ahmed et al. "Knowledge, Attitudes and Perceptions of HIV/AIDS among Traditional Birth Attendants and Herbal Practitioners in Lagos State, Nigeria." *African Journal of AIDS Research*, vol. 3, no. 2, pp. 191-196, 2004



Table 3: Summary of Findings from the Reviewed Studies

Interest of Study	Location	Target Population	Key Findings/Results
knowledge of PMTCT programs and interventions	Ibadan, Nigeria	household heads, religious and community based leaders	low knowledge of mother-to-child transmission, lack of knowledge of the PMTCT services, inadequate community sensitization, and inadequate healthcare facilities
perceptions, care-seeking practices and barriers to PMTCT	Wakiso District, Uganda	young HIV-positive women	poor access to PMTCT services, socioeconomic factors (wealth quintile, age, education level) and institutional practices influenced access to PMTCT, utilization of PMTCT services was higher when women were empowered to make their own decisions
reasons for inadequate utilization of PMTCT services	Maharashtra, India	HIV-infected women enrolled in a large-scale private sector PMTCT program	women with less than graduate level education, from a poor family, who were registered after 20 weeks of pregnancy and whose partners were HIV non-infected or with unknown HIV status were more likely to be lost to follow-up
rates and co-factors of accessing HIV care	Nairobi, Kenya	HIV-infected women exiting maternal care	barriers to access included stigma, denial, poor services, and lack of money
socio-demographic factors to sub-optimal PMTCT program results	KwaZulu-Natal, South Africa	Zulu women enrolled in PMTCT	reasons closely related to sub-optimal adherence to PMTCT services include therapy misconceptions/misunderstandings, sharing antiretroviral drug with relatives, domestic violence, poverty and issues relating to disclosure and stigma
investigate family planning needs, knowledge of HIV transmission and HIV disclosure	Tambo District ,South Africa	Women enrolled in PMTCT program	women's reproductive desires had an effect on their decision to adhere to PMTCT interventions
reasons for mother and infant non-adherence to PMTCT drugs	Botswana, South Africa and Rwanda	Women enrolled in PMTCT program	reasons for non-adherence include being away from home, being busy, forgetting and sleeping through the dose time
reasons for sub-optimal nevirapine prophylaxis adherence	Nkangala, South Africa	Women enrolled in PMTCT program	having visited a traditional birth attendant (TBA) during pregnancy, lack of male involvement, discrimination and stigma contribute to sub-optimal maternal and infant prophylaxis adherence
reasons for MTCT in the era of free access to PMTCT services	Soweto, South Africa	birthmothers of HIV-infected infants	failure of per-guideline prescription of ARVs, maternal refusal of treatment, preterm delivery, delayed ANC attendance, fear of stigma, maternal difficulty with administering infant AZT, maternal confusion about infant feeding
socio-cultural construction and the practice of breastfeeding	Nouna Health District, Burkina Faso	women of all ages and local <i>guérisseurs</i> (healers)	given the socio-cultural importance attributed to breastfeeding and the prevailing poverty, it might be more acceptable and more feasible to promote exclusive breastfeeding (EBF) followed by early weaning than replacement feeding.
investigate decision making on infant feeding options	Abidjan, Ivory Coast	HIV-positive women on PMTCT	women, men and healthcare workers are important actors in infant feeding decision making, male involvement makes men supportive of safer infant feeding options.
assess knowledge, attitudes and practices of TBAs in relation to HIV infection and prevention	Lagos, Nigeria	traditional birth attendants (TBAs)	inadequate knowledge of MTCT and HIV in general, normal standards of HIV transmission control on the clients, infants and TBAs not adhered to.

Stigma was found to be a huge impediment to HIV testing and disclosure, male involvement in PMTCT programs, and ultimately a deterrent to utilization and adherence to PMTCT interventions due to fear of rejection or discrimination.

In linking the aforementioned findings of the reviewed studies with the earlier discussed nested model (which included both the Health Care Utilization Model and the PMTCT Cascade Model) the following observations could be made. First, that individual's health-seeking behavior – as demonstrated throughout the literature – is influenced by their beliefs about cause and transmission of disease; and these vary in different societies, cultures, education levels, and access to, and attitude of health.

Second, the stigma surrounding HIV/AIDS makes it difficult for individuals to openly seek treatment even when services are readily available for fear of negative reaction or rejection by the community, family or partner.

Third, it is evident that PMTCT interventions are complex – not merely technical public health interventions – and that their eventual success is dependent on individual, social and structural factors that are, regrettably, not always taken into account in the design of the programs. This observation is further reinforced by the tremendous levels of attrition along the PMTCT continuum of care as demonstrated within the PMTCT cascade model.

However, this area of study is relatively new and more research is needed to further examine and deepen our understanding on access, utilization and adherence to PMTCT services across socioeconomic, regional, gender, age and education sub-groups. Additionally, studies that have attempted to address these issues, thus far, have primarily

focused on the failures of PMTCT programs and not much is known about the factors attributed to those that succeed.

To that end, the current study is aimed at building on existing literature and introducing a positive dimension into this area of research. The study will focus on HIV-positive mothers receiving PMTCT services at St. Mary's Hospital Lang'ata – a mission hospital in the outskirts of Nairobi city in Kenya. The objective of the study is to explore enabling factors –individual, social and structural – that enhance utilization of and adherence to PMTCT services in a plural urban setting in Kenya.

### **Research Questions and Hypotheses:**

The study seeks to answer the following question:

What are the individual, social and structural factors that enhance utilization of and adherence to PMTCT services?

To address the above question, the following hypotheses were tested.

1. Women's knowledge of mother-to-child transmission and PMTCT interventions is positively related to utilization and adherence to PMTCT services;
2. Support and acceptance by partner, family and the community with regard to the women's HIV- positive status positively affect their favorable decisions on PMTCT interventions (testing, treatment and infant feeding) utilization and adherence;
3. The quality of PMTCT services – health facility characteristics including healthcare personnel – is positively related to utilization and adherence to PMTCT interventions.

A mixed method approach was employed to gather information from HIV-positive mothers receiving PMTCT services at St. Mary's Hospital Lang'ata. A detailed description of the study design follows in the methodology chapter.

## Chapter 3: Research Design and methodology

### Introduction:

Innovative PMTCT programs are being scaled-up in sub-Saharan Africa with a goal to virtually eliminate pediatric HIV infection by the year 2015. Despite the positive strides that have been made in Kenya with regard to scaling-up PMTCT coverage around the country, mother-to-child transmission remains a major challenge as reflected by the fact that Kenya is one of the countries contributing to the high numbers of children living with HIV globally<sup>111</sup> and among the 22 PMTCT global plan priority countries.<sup>112</sup>

As such, there is an urgent need to seek a deeper understanding of how PMTCT programs are received and experienced by the Kenyan HIV infected women. A few studies that have attempted to achieve this goal have primarily focused on the factors that contribute to PMTCT failures. To bring a different perspective and new insights to the subject, the current study will lay emphasis on the positive side of the story by interviewing HIV infected birthmothers who have given birth to HIV-free infants. The objective of the study is to examine enabling factors – individual, social and structural – that enhance utilization and adherence to PMTCT services in a plural urban setting in Kenya.

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<sup>111</sup> Republic of Kenya. “Prevention of Mother-to-Child Transmission of HIV (PMTCT) and Pediatric HIV and AIDS Care and Treatment – Technical Review Report.” November 2010. <http://nascop.or.ke/index.php>

<sup>112</sup> WHO/UNAIDS/UNICEF. “Towards the Elimination of Mother-to-Child Transmission of HIV: Report of a WHO Technical Consultation 9-11 November 2010 Geneva, Switzerland.” 2010. [http://www.who.int/hiv/pub/mtct/elimination\\_report/en/](http://www.who.int/hiv/pub/mtct/elimination_report/en/)

### **Study Setting:**

The study was conducted from October-December 2012 at St. Mary's Mission Hospital, Lang'ata – a mission hospital in the outskirts of Nairobi city in Kenya. The hospital was founded by a missionary doctor and Catholic priest Fr. Bill Fryda and was opened in July of 2000. In addition to an inpatient capacity of 350 beds, the hospital serves about 250,000 outpatients in a year (between 500 -700 per day).

Situated right next to the massive Kibera slum, the largest slum in sub-Saharan Africa which houses almost one million people, the hospital's mission is to “provide quality and affordable healthcare in service to the poor.”

As of December 2012, approximately 3300 HIV/AIDS patients (3000 adults and 300 children) were receiving care at the Comprehensive Care Center (CCC) in St. Mary's hospital. And between October-December 2012, a total of 350 HIV-positive mothers were receiving PMTCT services at the center. According to the center's staff reports and data, the PMTCT program maintains a success rate of over 90%, that is, HIV-free infants born of positive mothers).

### **Research and Hypotheses:**

This study seeks to answer the following question:

What are the individual, social and structural factors that enhance utilization of and adherence to PMTCT services?

To address the above question, the following hypotheses will be tested.

1. Women's knowledge of mother-to-child transmission and PMTCT interventions are positively related to utilization and adherence to PMTCT services;

2. Support and acceptance by partner, family and the community with regard to the women's HIV- positive status positively affect their favorable decisions on PMTCT interventions (testing, treatment and infant feeding) utilization and adherence;
3. The quality of PMTCT services – health facility characteristics including healthcare personnel – is positively related to utilization and adherence to PMTCT interventions.

### Research Design:

A mixed method approach is employed for comparison and elaboration purposes. First, all informants completed a structured questionnaire with the assistance of the interviewer. Thereafter, a fewer number of informants participated in in-depth interviews to further clarify and elaborate on the observations and findings made from the survey. This approach is in line with Morgan's argument that in contemporary mixed methods research designs, different methods are assigned to different goals within the overall study and the results from one method are used to enhance the performance of another method.<sup>113</sup>

### Sampling:

A total of 55 women were purposely selected to participate in the study. This number was found to be both manageable and comparable to other studies. Women were eligible to participate in the study if they were 18 years or older, were able to provide

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<sup>113</sup> Morgan, D. L. "Connected Contributions as a Motivation for Combining Qualitative and Quantitative Methods." In L. Curry, R. Shield, & T. Wetle (Eds.), *Improving Aging and Public Health Research: Qualitative and mixed methods* (pp. 53 – 63). 2006. Washington, DC: American Public Health Association.

voluntary written informed consent, were HIV positive and had given birth to an HIV-free infant within the last one year and were receiving care at St. Mary's Mission Hospital Lang'ata PMTCT Clinic. The PMTCT clinic staff identified eligible women prior to their clinic appointment; then the clinic officer briefly described the study and invited women to receive additional information from the researcher in a private clinic room. All informants completed an interviewer-administered questionnaire (n = 55) and a part of the group was randomly selected to participate in in-depth interviews (n = 15).

### **Measures:**

Principal independent variables included knowledge and perceptions of mother-to-child transmission and PMTCT interventions, partner/family/community support and acceptance, and quality of PMTCT services.

Knowledge and perceptions of mother-to-child transmission and PMTCT interventions were measured by women's literacy levels (defined by individual's level of formal education) opinions and attitudes on HIV transmission and prevention; attitudes towards routine testing of pregnant women; opinions on counseling before and after HIV testing; attitudes towards reproductive choices of HIV-positive women; and attitudes towards male involvement in PMTCT programs.

Partner, family and community support and acceptance were measured by HIV status disclosure; knowledge of partner's HIV status; partner involvement in PMTCT program; opinions and attitudes towards infant alternative feeding methods; opinions on HIV/AIDS related stigma; and involvements with community HIV support groups.

Quality of PMTCT services was measured by attitudes and opinions towards health facility infrastructure; confidence levels on availability of effective PMTCT



regimens; patients' satisfaction with waiting time and duration of consultation at the clinic; and levels of satisfaction with the services provided by the doctors, nurses and counselors.

The principal dependent variables included utilization and adherence to PMTCT services. These were measured by planning for and having a safe delivery in a health facility, practicing safer infant feeding methods, compliance with prescribed maternal and infant ARVs dosage and schedules, and regular clinic attendance.

Demographic variables collected include: age, marital status, status in the household, household size, ethnic group, formal education, religious affiliation, occupation, and economic status.

#### **Data Collection:**

Ethical approval was sought and obtained from St. Mary's Mission hospital's Research Ethics Committee. Approval was also sought and given for the research by the Virginia Commonwealth University Institutional Review Board. Once the approval was granted, the PMTCT clinic staff identified eligible women prior to their clinical appointments; then the clinic officers briefly described the study to the selected women and invited them to receive additional information from the study researcher in a private clinic room. Those willing to participate were asked to sign a voluntary informed consent form. Each woman enrolled in the study completed a structured questionnaire with the assistance of the interviewer.

Thereafter, fifteen women from the group were randomly selected to participate in in-depth interviews. In-depth interviews lasted for about 30 minutes each. A digital voice recorder was used to record the interview discussions. Interviews were conducted in

Swahili then transcribed verbatim and thereafter translated into English. Confidentiality was maintained by use of code numbers instead of names during study proceedings and no identifying particulars were documented on interview forms.

Upon completion of the interviews, an honorarium roughly equivalent to 5 U.S. dollars was given to participants in respect of their time and transport cost reimbursement.

The structured questionnaire solicited information on demographics, knowledge of PMTCT interventions, HIV testing, disclosure, quality of services, delivery and feeding choices, clinic attendance for mother and infant and use of ARVs. In-depth questions will be organized around antenatal care, delivery, and postnatal experiences including infant feeding and HIV related stigma.

### **Data Analysis:**

The quantitative data were analyzed using SPSS. Descriptive statistics were calculated and logistic regression analyses were used to check for associations between dependent and independent variables.

Data from in-depth interviews were analyzed qualitatively using content analysis. Krippendorff defines content analysis as a systematic, replicable technique for compressing many words of text into fewer content categories based on explicit rules of coding.<sup>114</sup> Holsti offers a broader definition of content analysis as, "any technique for making inferences by objectively and systematically identifying specified characteristics of messages."<sup>115</sup>

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<sup>114</sup> Krippendorff, K. Content Analysis: An Introduction to Its Methodology. Newbury Park, CA: Sage, 1980.

<sup>115</sup> Holsti, O.R. Content Analysis for the Social Sciences and Humanities. Reading, MA: Addison-Wesley, 1969, p.14.

As such, a number of steps were taken as part of the process of content analysis. First, the researcher read through the data several times to make sense of “what is going on.” That is, to gain a holistic view of the data. Once the researcher was fully immersed in the data, the data was organized for coding and analysis.

The next step was to organize the qualitative data. This process included open coding, creating categories and abstraction. Open coding means that notes and headings were written in the text while reading it. The written material was read through again, and as many headings as necessary were written down in the margins to describe all aspects of the content. The headings were then collected from the margins on to coding sheets and categories were generated at this stage.

Consequently, the lists of categories were grouped under higher order headings – a process known as abstraction. The aim of grouping data was be to reduce the number of categories by collapsing those that are similar or dissimilar into broader higher order categories. As Holsti notes, categories provide a means of describing the phenomenon, to increase understanding and to generate knowledge. When formulating categories by inductive content analysis, the researcher comes to a decision, through interpretation, as to which things to put in the same category.<sup>116</sup>

Finally, the main categories were named using content-characteristic words or themes. The generated themes were then discussed in detail and exemplified using excerpts from the transcripts.

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<sup>116</sup> Ibid.

## **Chapter 4: Findings**

### **Introduction:**

The objective of this study was to explore enabling factors –individual, social and structural – that enhance utilization of and adherence to PMTCT services in a plural urban setting in Kenya. A mixed method approach, which included a survey questionnaire and in-depth interviews, was employed for comparison and elaboration purposes. A total of 55 mothers receiving PMTCT care at St. Mary’s Mission Hospital, Lang’ata were purposely selected to participate in the study. First, all selected women completed a structured questionnaire with the assistance of an interviewer. Thereafter, 15 women participated in in-depth interviews.

### **Quantitative Analysis:**

The quantitative data were analyzed using SPSS. Descriptive statistics were calculated and logistic regression analyses were used to check for associations between dependent and independent variables.

### **Demographic Characteristics:**

A total of 55 mothers were included in the study. The demographic variables of age, marital status, head of household, education, occupation, family size, religious affiliation, and ethnicity were measured. The mean age of the sample was 29 years (with the youngest mother being 19 and the oldest 39 years). Majority of the women were married (76%), while 16% were single and about 8% divorced, separated or widowed. Every married woman stated that the partner (husband) was the head of the household. With regard to education level, 15% reported to have completed primary school, while 38%

had completed high school and 47% had attained an education level of college and above. Approximately one third of the women had some form of a paying job, either blue-collar or white-collar. Another third were self-employed and the remaining third unemployed. The largest percentage of the mothers (84%) had 1 to 2 kids while the remaining 16% had 3 to 4 kids. Over 90% identified with Christianity (58% Protestants and 36% Catholics) and the remaining 6% were Muslims. The women came from 9 different ethnic groups. (See Table 4)

### **Health Seeking Behavior Characteristics:**

To explore health seeking behavior characteristics of the mothers, the following variables were measured. Antenatal clinic (ANC) entry, disclosure, partner HIV status, partner involvement in PMTCT, delivery (where the child was delivered, whether full-term or pre-term, and mode of delivery), infant feeding choices, travel time and transportation cost to the hospital, clinic appointments attendance, adherence to medication dosage and schedules, source of HIV information, stigma, and community support system.

Generally, most mothers attended their first antenatal clinic (ANC) visit relatively early, on average at 3.8 months. This observation is limited to the mothers' ANC attendance while pregnant with their last infants. Based on the Kenyan government ministry of health regulations, HIV testing is one of the procedural tests provided to pregnant women and it is normally offered during the patient's first ANC visit.

About 8 in 10 of the women had disclosed their HIV status to someone (44% to partner, 12% to mother, 12% to friend and 12% to other) while the remaining 2 in 10 of the women had kept their status private.

Table 4: Demographic Characteristics of Participating Mothers (n = 55)

<b>Characteristic</b>		
Mean Age	29.7 years	
Minimum Age	19 years	
Maximum Age	39 years	
	<b>Frequency (n)</b>	<b>Percentage (%)</b>
Marital Status		
Single	9	16.4%
Married	42	76.4%
Divorced/Separated	3	5.5%
Widowed	1	1.8%
Education level completed		
Primary	8	14.5%
Secondary	21	38.2%
College and Above	26	47.3%
Form of employment		
White collar job	14	25.5%
Blue collar job	4	7.3%
Self-employed	18	32.7%
Unemployed	19	34.5%
Number of children		
One	22	40%
Two	24	43.6%
Three	5	9.1%
Four	4	7.3%
Religious affiliation		
Christian - Protestant	32	58.2%
Christian - Catholic	20	36.4%
Muslim	3	5.5%
Ethnic identity		
Kalenjin	1	1.8%
Kamba	10	18.2%
Kikuyu	23	41.8%
Kisii	4	7.3%
Luhya	5	9.1%
Luo	8	14.5%
Meru	2	3.6%
Nandi	1	1.8%
Taita	1	1.8%

Ninety three percent of the sampled women reported to have a partner. And of those who had a partner, 63% were aware of their partner's HIV status while 37% were not aware of their partner's HIV status. Of those aware of their partner's status, 37% reported that they were HIV positive and 26% reported that their partners were HIV negative. Additionally, of those with partners, 43% said that their partners had attending ANC/PMTCT clinic with them at some point while 57% said their partners had never attended ANC/PMTCT clinic with them.

Nearly all women (54 out of the 55) delivered their babies at the hospital with only one reported to have delivered at home. Six of the infants (11%) were delivered pre-term, defined as birth before 8.5 months gestation. Thirty women (55%) had a natural delivery, 4 women (7%) had an emergency caesarean delivery and twenty-one (38%) had an elective caesarean delivery. The majority (50 women) breastfed their infants exclusively for six months, while a few (4 women) used baby formula, and only one woman mixed-fed her child.

Slightly more than half of the women said it took them two hours or more to get to the hospital. And 64% described their transportation cost to the hospital as expensive. More than 60% of the women expressed dissatisfaction with the waiting time at the clinic. However, most women reported that they attended their clinic appointments regularly (91%). In reference to medication adherence, 69% indicated that they strictly followed prescribed medical dosage and schedules. And about three quarters of the women found it fairly easy to follow prescribed medical dosage and schedules.

Table 5: Health Seeking Behavior Characteristics of Participating Mothers (n = 55)

<b>Characteristic</b>		
First ANC attendance average	3.8 months	
	<b>Frequency (n)</b>	<b>Percentage (%)</b>
HIV Status Disclosure		
No one	14	17.7%
Partner	35	44.3%
Mother	10	12.7%
Friend	10	12.7%
Other	10	12.7%
Knowledge of Partner's HIV status		
Yes - Positive	19	34.5%
Yes - Negative	13	23.6%
No	19	34.5%
Does not apply	4	7.3%
Partner involvement in PMTCT		
Yes	22	40%
No	29	52.7%
Don't apply	4	7.3%
Delivery location		
Home	1	1.8%
Health facility	54	98.2%
Mode of delivery		
Natural	30	54.5%
Caesarean-emergency	4	7.3%
Caesarean-elective	21	38.2%
Full-term vs. pre-term delivery		
Full-term	49	89.1%
Pre-term	6	10.9%
Infant feeding method		
Exclusive formula	4	7.3%
Exclusive breastfeeding	50	90.9%
Mixed-feeding	1	1.8%
Clinic appointments attendance		
Never missed an appointment	50	90.9%
Missed 1 or 2 appointments	4	7.3%
Missed more than 3 appointments	1	1.8%
Adherence to medication dosage and schedule		
All the time (never missed a dose)	38	69.1%
Some or most of the times	17	30.9%



Majority of the women sought information with regard to their health and HIV from health professionals. Other sources of information included television, radio, Internet and friends. Over 80% of the women felt that people living with AIDS (PLWA) experience some level of stigma. And finally, a large proportion (93%) reported that they did not belong to any form of a community support group. (See Table 5)

### **Hypotheses Testing:**

Binary logistic regression analyses were used to check for associations between dependent and independent variables. To run the regressions the following steps were taken. First, independent variables were classified into three groups based on the study hypotheses. *Group1* was made of variables that measured knowledge and perceptions of PMTCT services; *group2* those that measured partner, family and community support; and *group3* those that measured quality of PMTCT services. Variables in each group were then tested for multicollinearity – no variables were found to be collinear. Thereafter, each group of independent variables was measured against each of the four dependent variables, which included: delivery at a health facility, safe infant feeding method, regular clinic attendance and adherence to medication dosage and schedules. In all the twelve models run none of the independent variables were found to be statistically significant. A summary of *p-values* from the models output is provided on the regression analyses summary table below (see Table 6).

Table 6: Logistic Regression Analyses Summary

<b>Dependent Variable</b>	<b>Independent Variables</b>	<b>P-Values</b>
Delivery at a health facility (1)	Perceptions of PMTCT services	0.998
	Knowledge on PMTCT	0.999
	Knowledge of HIV transmission	0.999
	Education level	0.585
Delivery at a health facility (2)	Knowledge of partner's HIV status	0.403
	Partner involvement in PMTCT	0.997
	Opinion on HIV status disclosure	0.865
	Opinion of HIV related stigma	0.998
	Membership to a community support group	0.999
Delivery at a health facility (3)	Overall rating on the hospital's services	0.998
	Level of satisfaction with the waiting time	0.897
	Level of confidence in obtaining prescribed medication	0.999
	Rating on ANC/PMTCT clinic doctors	0.997
	Rating on ANC/PMTCT clinic nurses	0.260
	Rating on ANC/PMTCT clinic counselors	0.998
Safe infant feeding method (1)	Perceptions of PMTCT services	0.491
	Knowledge on PMTCT	0.999
	Knowledge of HIV transmission	0.999
	Education level	0.646
Safe infant feeding method (2)	Knowledge of partner's HIV status	0.997
	Partner involvement in PMTCT	0.998
	Opinion on HIV status disclosure	0.735
	Opinion of HIV related stigma	0.816
	Membership to a community support group	0.999
Safe infant feeding method (3)	Overall rating on the hospital's services	0.462
	Level of satisfaction with the waiting time	0.997
	Level of confidence in obtaining prescribed medication	0.999
	Rating on ANC/PMTCT clinic doctors	0.465
	Rating on ANC/PMTCT clinic nurses	0.987
	Rating on ANC/PMTCT clinic counselors	0.458
Regular clinic attendance (1)	Perceptions of PMTCT services	0.045
	Knowledge on PMTCT	0.999
	Knowledge of HIV transmission	0.999
	Education level	0.651
Regular clinic attendance (2)	Knowledge of partner's HIV status	0.517
	Partner involvement in PMTCT	0.791
	Opinion on HIV status disclosure	0.390
	Opinion of HIV related stigma	0.710
	Membership to a community support group	0.999
Regular clinic attendance (3)	Overall rating on the hospital's services	0.966
	Level of satisfaction with the waiting time	0.893
	Level of confidence in obtaining prescribed medication	0.804
	Rating on ANC/PMTCT clinic doctors	0.736
	Rating on ANC/PMTCT clinic nurses	0.589
	Rating on ANC/PMTCT clinic counselors	0.811
Adherence to medication dosage and schedules (1)	Perceptions of PMTCT services	0.096
	Knowledge on PMTCT	0.697
	Knowledge of HIV transmission	0.501
	Education level	0.543
Adherence to medication dosage and schedules (2)	Knowledge of partner's HIV status	0.627
	Partner involvement in PMTCT	0.366
	Opinion on HIV status disclosure	0.560
	Opinion of HIV related stigma	0.105
	Membership to a community support group	0.999
Adherence to medication dosage and schedules (3)	Overall rating on the hospital's services	0.241
	Level of satisfaction with the waiting time	0.088
	Level of confidence in obtaining prescribed medication	0.996
	Rating on ANC/PMTCT clinic doctors	0.499
	Rating on ANC/PMTCT clinic nurses	0.495
	Rating on ANC/PMTCT clinic counselors	0.611

### **Qualitative Analysis:**

Qualitative data, collected through the survey's open-ended question and in-depth interviews, were analyzed using content analysis. The following themes were identified: supportive counseling, striving for motherhood, maternal attachment and concern for the child's wellbeing, assurance of confidentiality and the testimonials of mothers who had experienced success with the PMTCT program. Relevant quotations were selected from in-depth interview transcripts and open-ended question narratives to exemplify identified themes.

### **Emergent themes:**

#### **Supportive Counseling:**

The value of counseling was a consistent talking point and the most prevalent theme throughout the interviews. The majority of the mothers singled out counseling as the key element of the PMTCT interventions that played the greatest role in their decision making process especially with regard to testing, disclosure, initiating ARVs, and rapid weaning at six months – all steps along the PMTCT cascade perceived by mothers to be extremely difficult and distressful.

A positive HIV test was unwelcome news and devastating to those who found out about their status for the first time at the ANC clinic. Mothers explained that counseling was critical for them to come to terms with the realities of HIV/AIDS, accept themselves, and act in a balanced way to preserve their health and protect the unborn child. Here are some of the most illustrative quotes from the interview transcripts:

“Testing positive was very hard. I was suicidal. I wanted to kill my child and the father. But the doctors counseled me and made me realize I was not alone. They told me that HIV was not the end of life. So I chose to live and take medication. I never believed that a child (born of a positive mother) could be negative but the

doctors provided me with the right information. My husband is positive as well. I was very angry with him at first because I have never cheated on him and I know for sure he infected me. But through counseling I accepted it and we now live harmoniously. The key to this journey is to accept and take drugs.”

“I didn’t know my status until I came to the ANC clinic and they requested me to get tested. I declined at first. But the doctor insisted that it was good to get tested and know my status. So I went for the test and it came out positive. I did not accept it the first time. I thought they were lying to me. So I tested a second time and it came out positive. I did it again a third time and it was again positive. I just couldn’t believe it. But through a lot of counseling I gradually accepted that I am sick and started on medication to save my child. Now here I am today.”

“At the beginning it was very difficult. I even found it hard to come to the clinic because I thought people around the hospital would know that I am positive. But with a lot of counseling I have become strong and accepted my status.”

“There is a doctor I spoke with who I will always remember. He told me that HIV is a disease like any other and if I accept it and take care of myself I will live. I was so hopeless then but that doctor gave me the courage to live. The medication has been very helpful. I was very frail when I started but after taking these drugs I have regained my strength. I was also provided with nutrition advice when I came in. So I eat well and take good care of myself. And here I am looking strong. My baby is perfectly healthy too.”

“I was tested at ANC about 3 years ago and turned out positive. I was discouraged and lost hope in life. Doctors tried to talk to me about PMTCT but I was not ready to follow on the program or accept my status. So I failed to protect my first-born son and he was born HIV positive. He died at 3 months and had spent his entire life in hospital. For my second child I tried my level best. I did not want to put my child through the same agony so I followed the doctor’s advice. Now I have a healthy HIV negative 9 months old daughter. See, at the beginning I thought HIV was a death sentence. I just wanted to die and have my baby die too. I thought taking ARVs was a waste of time. I totally refused any help and I sat and waited to die but I didn’t die. After so much counseling and advice from the doctors I came around and followed every detail I was given. I now have the strength to encourage others and tell them the importance of drugs and the need to live positively. There is life after HIV testing.”

“For me the diagnosis was a rude shock. I almost gave up. And at the time I was just healing from the loss of my first child. Counseling has helped me so much. The hospital has taught me a great deal... self-esteem and self-importance is very crucial in this journey. HIV is not a death sentence; it is manageable so long as you have the knowledge and are able to accept help.”

Another daunting task expressed by mothers in relation to HIV testing was that of breaking the news of their positive status to a partner, family member or a close friend. To a number of women, couples therapy provided a convenient platform for disclosure and partner testing.

“When I first got tested I was alone. I was not with my husband. And when I got home I did not tell him about it. I was afraid of his reaction. So I told him that the doctor had said that we must go to the next clinic together. When we came back together we both got tested and were found to be both positive. We then made the choice of starting on medication together. See if I had told him upfront that I had been tested and I was positive he probably would have blamed it on me. He would not have accepted to come to the clinic with me. So I told him the doctors had said they would not treat me if he did not come with me to the clinic. I wanted for him to know his status too. So we got tested together and were counseled together and told what to do to protect our child.”

“After learning my status I was so disappointed. In my mind I was sure that my husband would never own up to the fact that he infected me. I was so mad at him but could not confront him because he is violent. But when I went home and told him to come with me to the clinic for my next appointment he agreed. So we came back together and got tested. Of course his results came out positive too. We got counseled and were both put on ARVs.”

“When I found out that I was HIV positive I asked my husband to accompany me to the next clinic appointment so we came and got tested again together. And he was found to be negative. That was very hard. I did not know how to face him. But the counselor was very helpful and gave us information on how to live as discordant couple. Our marriage has changed quite a bit since then. But my husband still loves his kids and works hard to provide for us.”

“When we got tested my husband tested negative and I tested positive which made it very difficult for me. But we were counseled and we decided to live a positive life and not dwell on blame games since what had happened could not be reversed.”

To some mothers, initiating ARVs was a difficult step to take due to worries about side effects and the fact that treatment is a lifetime commitment. Here are stories from two women on how counseling helped them overcome their fears and empowered them to initiate and adhere to ARVs.

“When I first came here I had very low CD4 count.<sup>117</sup> The doctors encouraged me to take medication. But the fact that ARVs are a lifetime thing was dreadful and difficult to accept. It took a lot of counseling to overcome my fears. Today these drugs have become part of me and I see them as my food. I did suffer side effects on earlier days but they have now subsided”

“I was reluctant to start on ARVs because I had heard that they have very severe side effects. But the doctor counseled me and made me understand that I needed them for my own good and for the sake of my child. I am so grateful to that doctor because if it were not for him I don’t know where I would be today. My health has really improved since I started taking these drugs. And my 7 months old baby is negative. If I could advise any HIV patient out there I would tell them ARV’s are very important. You may fail to shower but please never forget to take your medication.”

Exclusive breastfeeding followed by rapid weaning at six months was the predominant mode of infant feeding applicable to majority of the mothers receiving care at St. Mary’s hospital PMTCT clinic. Though an effective method in reducing the chances of mother-to-child transmission of HIV, the harsh realities of rapid weaning were distressful to mothers and their babies.

“It hasn’t been easy. It takes a lot of commitment especially with weaning at six months. The baby cried all night long. It took a lot of courage to stop her from breastfeeding. A baby crying all night long and you have breast filled with milk but you can’t breastfeed is tormenting. It took so much strength and support from the counselor to get through it. She was resistant to other foods but after about one month she got used to it. Drugs to stop milk production also helped.”

“It was very hard. It’s just too rough. You see your baby cry non-stop. She is used to breast milk and all over sudden you take that away and then she rejects other foods... it’s really tough. One day I called the doctor in the middle of the night and luckily he picked up. If he hadn’t I think I would have given in that night. But he reminded me that I was doing this for the good of the baby so I stayed firm. Thankfully it’s been two months now and she has adjusted.”

“My husband is not aware of my status so we fought a lot over the breastfeeding issue. I made him believe that the baby did not want to breastfeed. I even put some pepper on my nipples so the baby would reject them. It was very hard but I came to talk to the counselor often and he was very supportive and encouraged

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<sup>117</sup> CD4 cells are a type of white blood cell that fights infection. The CD4 count helps tell how strong an individual’s immune system is, indicates the stage of HIV disease, guides treatment, and predicts how the disease may progress.

me. I also avoided other people because I did not want to be asked many questions and when the questions came up I said the baby had voluntarily refused to breastfeed.”

“To stop breastfeeding at six months was difficult. I told people that my baby had voluntarily refused to breastfeed. But personally I was hurting inside. I wished I could have breastfed my child until he begins to walk. But the thought of keeping him safe kept me going. After talking with the doctor about it he encouraged me and even gave me pills to reduce my milk production.”

### **Striving for motherhood, maternal attachment and concern for the child’s wellbeing:**

PMTCT services were perceived as a gift to HIV-positive women as the interventions made it possible for them to bear children that are free of the virus. To many women, this gift of motherhood gave them a purpose in life and ultimately a reason to stay alive. In the following narratives mothers explain how their desire for motherhood, attachment to their children and concern for their wellbeing informed their choices with regard to PMTCT utilization and adherence.

“In 2004 I delivered my second child and he became positive because I was not provided with any PMTCT services. So what has given me strength is that I don’t want my child to go through what his deceased sibling went through. I promised myself that I would do my level best to save this child. This time around the hospital was good at testing, advising and counseling me. These services were not available back in 2004. Now that they are available I am happy to adhere to them.”

“I really wanted a child and my HIV status was not going to take that away. Through counseling I learned that you could live a positive life and for a long time and have healthy children so long as you follow the doctor’s instructions and take your medication. I am a living testimony that PMTCT works. It’s so possible; I am here today and my child is negative.”

“When I tested positive life lost meaning. But the thought of the baby I was carrying gave me a reason to live. Because the baby is so innocent I did not want to do anything that would hurt him. I also did not want him to be born with HIV. So I accepted to take medication and follow the doctor’s advice.”

“My first-born child is 8 years old. I wanted to live and raise him up. Now I have a second-born, which means that my strength and desire to live has doubled. Anytime I feel stressed or hopeless I pinch myself and shake it off. Just the

thought of leaving my kids is extremely daunting. Plus I am the first-born in my family so there is no one else who would be able to care for my children if I died and left them.”

“My mother died when I was young (8 years old). From my experience, I cannot imagine my son living without a mother. I want to be alive for as long as I can. Besides, the fact that he can live a HIV free life is a gift. There is no way you can give up on that. A mother will go an extra mile for the love of the child.”

“You can’t give up because you have kids. They need you to see them succeed, go to school and live a good life. The thought of leaving them with my mother or husband is too much for me to take. The kids give me a reason to live.”

“You know at the bottom of my heart I know he (husband) is the one who brought this disease to me. He is the one who has affairs outside our marriage. But I did not confront him. There was no need of fighting him and causing additional stress since we were already sick and fighting would not help. We resolved to stay strong and bring up this baby because if we decide to fight the child will suffer the most.”

“My strength is my child. Since I got pregnant I made up my mind to give her the best. So when I came to the clinic and tested positive I decided I have to live and protect this child. Though at some point I was too tired and asked the doctor for an abortion. But the doctor encouraged me and said that he believed in me. He said I would make it so I picked myself up and continued. It’s not been an easy journey. But the love for this child has kept me going.”

### **Confidentiality:**

The majority of the mothers stressed that confidentiality of their HIV status was critical due to the stigma associated with HIV/AIDS. They expressed fears of being rejected or abandoned by their partners, causing hurt or shame to their loved ones and being discriminated against by their friends and communities. As such, mothers went to great extents to keep their status private including traveling for extra miles to get to a far off hospital. Many reported that they found solace in St. Mary’s hospital’s commitment to protecting patient’s privacy.

“One more thing, people should be careful about whom they share their HIV status with. Some people will talk behind your back and others will isolate you.



Some will not even share utensils with you. So people should choose very carefully who they open up to. Doctors will not isolate you. They will help you. But other people are not like that.”

“I have kept it (HIV status) a secret because of fear of stigma. It would kill me if people started treating me differently. I have no way of telling what people will say so to play it safe I keep it to myself. As for my mother, she has high blood pressure. So I don’t want to overburden her... I travel from Machakos the day before my appointments and stay at a friend’s place (in Nairobi). I then come to the clinic very early in the morning. If I am lucky I am able to go back home the same day. But if the lines are too long then I stay at my friend’s place again and travel back home the following day. I come all the way because no one knows me here. I know if I went to a hospital near my village everyone will be talking about me.”

“There are other closer places I could go to for these services but I come here because of how kind the service providers are. Everyone here treats you like a human being. You can’t even tell you have HIV because they treat you just like they treat everybody else. And they speak to you privately. They don’t shout about your status in front of other people like some hospitals do.”

“I can’t trust friends. They will talk behind your back. For my family I don’t want pity. Them thinking I am dying. I don’t have the courage to tell them. I don’t even tell my boss or co-workers that I am coming to the hospital. I don’t want them to guess that I have HIV. This hospital is far from my office so the chances of meeting someone I work with here are slim.”

“The doctors at St. Mary’s hospital have also been very helpful. They are very friendly. They give you hope that you can make it. They understand people are afraid of disclosure for fear of causing pain or being a burden. There is also the issue of stigma and backstabbing. Doctors here don’t force you to disclose your status to anybody unless you’re willing.”

“The friendliness of the doctors, nurses and counselors has played a big role. They make you feel so worthy of attention and care. They are very polite and kind. And they honor the privacy and confidentiality of patients.”

“As for my husband, I am taking my time because he claims to be negative. Hopefully with time we will open up to each other. The counselor suggested that I bring my husband with me to the clinic so we can both get tested and counseled together but I am so afraid that he will abandon me if it turns out that he is negative for sure.”

“I haven’t disclosed my status to anyone. So I keep everything about these interventions very private. I have been thinking of telling my partner but I am afraid he could hurt me. He is a policeman. I am afraid to disclose to my kids, as

they are still young. My kids love me to death. It would shatter their lives to know I am positive.”

“With regard to disclosure, there is a lot of stigma. My in-laws have isolated us since they learned we are positive. I haven’t told my own family because I don’t want to hurt them. My mother suspects but she doesn’t know the truth for sure. She is afraid to ask me, I know.”

### **Testimonials:**

Testimonials on the successes of PMTCT, either from a personal experience, that of a close friend or even a national figure played an important role in familiarizing the interventions and validating their potential. To those that had been through the path of PMTCT before, their own experiences were a source of self-confidence. To those that were braving the trail for the first time, the testimonies of others gave them hope and strength to forge ahead.

“I have had three kids through PMTCT – 8 years, 4 years and 1 year old. I met my husband back in 2004 and he stuck by me despite the fact that I was HIV positive and he was negative. His family especially the siblings were so against our marriage. They would ask, “Why is our son marrying a grave?” Now they look at our kids and they don’t believe that I am positive. But deep down I know that I have it (HIV). It’s all about following the doctors’ instructions. My in-laws now treat me with respect. The big thing for them was that I could give birth to healthy kids.”

“This is my second child through PMTCT so I was aware that it works. I also felt more comfortable and sure of myself this time around. The first time I was skeptical but it worked. I just followed the doctor’s advice and took the medication. I feel so blessed to have two healthy kids.”

“I lost a child 3 years ago due to mismanagement of treatment. So I decided that for this baby I have to be more diligent and take good care. PMTCT has become more common, familiar and the best form of raising a child for those of us who are HIV positive. The doctors here do a very good follow-up. Their good counseling and encouragement goes a long way. Even at delivery they really take very good care of us.”

“When I first tested positive in 2008, I was given ARVs. I was very weak then with a CD4 count of 200.<sup>118</sup> The drugs made me strong so from then I knew there was hope. Then before I conceived I was provided with information on PMTCT services, which really helped. Plus I knew of an HIV positive woman whose baby is negative which made me believe that these services really do work.”

“Well, first of all, I spoke to other mothers who had experienced the same (are HIV positive) and have healthy babies. One of them is actually a good friend of mine and she is the one who introduced me to the others. The stories of these mothers gave me hope and the courage to conceive. See, the thought of having an infected child was too much for me. But I decided to take a chance because these mothers made me believe that it was possible to have an HIV free child.”

“The fact that I knew my status before I conceived made me more focused. I was aware that there was a possibility of having an HIV free child. I have also seen people living positively with HIV so long as they take their drugs and follow the doctor’s instructions. They live a long life.”

The name of Asunta Wagura, a Kenyan AIDS activist who has lived with HIV for over twenty-five years and delivered two kids through PMTCT, was referenced in almost every conversation during the interviews. Asunta, who is also the Founder and Executive Director of the Kenya Network of Women Living with Aids (KENWA), is a strongly committed advocate for reproductive rights of HIV- positive women and uses her own life as an exemplification that positive women can live a fulfilled life regardless of their HIV status. Asunta has written a column for many years in the *Daily Nation* (Kenya’s largest newspaper) in which she updates her readers about her life with HIV. She has also authored an autobiography, “*From Heartbreak to Daybreak*” in which she recounts an emotional journey from childhood to contracting and coping with the HIV virus.

To a number of mothers, Asunta is more than a testimony; she is a heroine, a role model and an icon. Though many acknowledged that they do not have the courage to live

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<sup>118</sup> CD4 counts are reported as the number of cells in a cubic millimeter of blood. A normal CD4 count is from 500 to 1,500 cells per cubic millimeter of blood.

their lives openly like Asunta does, they unanimously lauded her boldness and spoke to ways that she had positively impacted their lives. Here are a few select examples.

“Asunta is my role model.”

“I find people like Asunta to be very encouraging. Looking at her you get hope that there is life with HIV.”

“I was afraid for many years but after listening to Asunta I thought I would try conceiving. That decision has changed my life completely and I owe it to her. I hope one day I could also use my life to inspire and encourage other people like she does.”

“I kept my HIV status a secret for about a year. But after listening to Asunta I gathered the courage to open up and reach out to my family and a few trusted friends. They say a problem shared is halfway solved and it’s true. I feel much lighter now.”

“I admire Asunta so much. She is so open about her life and you can tell that she is happy. I hope to get there one day.”

I love Asunta. I read all her articles in the newspaper. She is a gift to people like us (those who are HIV positive).”

“If Asunta can stay alive for more than twenty years and have healthy kids so can I. HIV is not the end of life.”

### **Summary of Findings:**

Utilization and adherence to PMTCT services by the informants was generally high, whereby 98% of the mothers delivered their babies at a health facility and practiced a safer infant feeding method, 91% attended their clinic appointments regularly and 63% strictly adhered to medication dosage and schedules. Explanatory variables hypothesized in the study, including knowledge of mother-to-child transmission and PMTCT services, support and acceptance, and quality of services were found to be statistically insignificant. According to the mothers, supportive counseling, striving for motherhood, maternal attachment and concern for a child’s wellbeing, assurance of confidentiality and

testimonials of mothers who had experienced success with the PMTCT program were the factors that best explained their health seeking behavior and choices – in this case, utilization and adherence to PMTCT services.

## Chapter 5: Discussion, Conclusions and Recommendations

### Introduction:

Despite significant challenges, the global expansion of prevention of mother-to-child transmission (PMTCT) of HIV services has been massive in the past decade. This expansion is particularly evident in sub-Saharan Africa, which achieved an overall coverage of 54% [40%–84%] by the end of 2010. Following these advances, UN agencies, national governments and implementing partners have launched an elimination of mother-to-child transmission (eMTCT) of HIV campaign aimed to lower transmission rates to less than 5% worldwide by 2015.

Unfortunately, despite the availability of proven interventions for the prevention of mother-to-child HIV transmission (PMTCT) and substantial donor investments for implementing them in developing countries, the outcome – HIV-free infants – is far from optimal. In 2011, around 330,000 children under the age of 15 became infected with HIV and an estimated 230,000 died from AIDS. Almost all of these infections were as a result of mother-to-child transmission and among children living in sub-Saharan Africa.<sup>119</sup>

Kenya, like many other sub-Saharan African nations, has made some commendable strides on scaling-up PMTCT. In 2010, 90 per cent of facilities with maternal child health services in Kenya offered PMTCT services. Approximately 63% of pregnant women were tested for HIV in 2009. The proportion of pregnant women living with HIV reached with ARVs for PMTCT increased from 24% in 2004 to 73% in 2009 and that of HIV-exposed infants reached with ARVs for PMTCT from 20% in 2004 to

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<sup>119</sup> UNAIDS. “Report on the Global AIDS Epidemic.” 2012.  
[http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/2012\\_1120\\_UNAIDS\\_Global\\_Report\\_2012\\_with\\_annexes\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/2012_1120_UNAIDS_Global_Report_2012_with_annexes_en.pdf)

49% in 2009.

However, Kenya remains one of the countries contributing high numbers of children living with HIV globally and among the 22 PMTCT global plan priority countries. In this context, there is an urgent need to examine PMTCT programming in Kenya and contextualize accessibility and adherence challenges faced by HIV- infected mothers.

Based on the literature reviewed, studies that have attempted to address these issues, thus far, have primarily focused on the failures of PMTCT programs and not much is known about the factors attributed to those that succeed.

To that end, the current study was aimed at building on existing literature and introducing a positive dimension into this area of inquiry. The study employed a mixed methods approach, which included a survey questionnaire and in-depth interviews and focused on HIV-positive mothers receiving PMTCT services at St. Mary's Hospital Lang'ata – a mission hospital in the outskirts of Nairobi city in Kenya. The study sample was purposively selected and comprised of 55 mothers whose infants tested HIV negative at the time of the study. The objective of the study was to explore enabling factors – individual, social and structural – that enhance utilization of and adherence to PMTCT services in a plural urban setting in Kenya.

### **Principal Findings:**

The study found that utilization and adherence to PMTCT services by the informants – mothers whose infants tested HIV negative at the time of the study – was generally high. The majority (98%) delivered their babies at a health facility and practiced a safer infant feeding method. Additionally, 91% of the mothers attended their

clinic appointments regularly and 63% strictly adhered to prescribed medication dosage and schedules.

Explanatory variables hypothesized by the study, including knowledge on mother-to-child transmission and PMTCT interventions, support and acceptance by family and community, and quality of services were found to be statistically insignificant. Based on conversations with the mothers, a host of other variables including accessible, sensitive and supportive counseling, the desire to be mothers, maternal attachment and concern for the child's welfare, assurance of confidentiality and testimonials of other successful mothers were identified as the enabling factors that influenced women's decisions to utilize and adhere to PMTCT interventions.

## **Discussion:**

### **Hypothesized Variables:**

To start with, it is important to note that explanatory variables hypothesized in this study were derived from available literature on PMTCT programming. Equally notable is the fact that available studies reviewed were focused on the failures of PMTCT programs and not on successes. This is a characteristic that distinguishes this research from earlier studies. As such, the assumption made with regard to this study's hypotheses was that the reverse of what explains PMTCT failures would explain its success. However, this assumption does not hold with this study's findings.

As discussed in the literature review in chapter two, inadequate knowledge of mother-to-child transmission and PMTCT interventions, lack of support and acceptance by family and community, as well as poor quality of services were found to be primary factors that explained the shortcomings of PMTCT programs – as they deterred the



patient's choice to utilize or adhere to interventions. Based on these findings, it was therefore logical to presume that a reverse of these deficiencies would enhance the performance PMTCT programs; that is, knowledge of mother-to-child transmission and PMTCT interventions, support and acceptance by family and community, and high quality services would be positively associated with utilization and adherence to PMTCT services guidelines. The findings of this study do not support these assumptions and, in fact, appear to demonstrate that these factors are not significantly related to patient failures, at least for the PMTCT patients interviewed in this research.

The data reveals some interesting trends with regard to women's health seeking behaviors that are illustrative of this study's findings. Most intuitive is the overwhelming evidence that women's choices on seeking and adhering to services were to a great extent affected by the difficulties of HIV status disclosure and gender imbalances in their relationships with their husbands and partners.

One would expect that such an important occurrence, as HIV infection would be disclosed to the husband or partner; however, such was not the case for the majority of patients interviewed. For example a proportion of 80% of the interviewed women reported to have disclosed their HIV status to someone (44% to partner, 12% to mother, 12% to friend and 12% to other) while the remaining 20% said they had not disclosed their status to anybody. Of those who had a partner, 63% were aware of their partner's HIV status while 37% were not. And of those aware of their partner's status, 37% reported that they were HIV positive and 26% reported that their partners were HIV negative.

Women evidenced a range of behaviors from mild reluctance to disclose to a desperate fear of doing so. For instance, mothers admitted that they isolated themselves from friends and family to avoid being questioned about their infant feeding choices, especially rapid weaning at six months. Others owned to the fact that they gave false excuses to their partners, family or friends whenever confronted with questions on breastfeeding or hospital visits.

Perhaps the most striking observation was on cost and travel time to the hospital. Whereby, more than half of the interviewed women indicated that it took them two hours or more to get to the hospital and 64% described their transportation cost to the hospital as expensive. In-depth interview conversations further revealed that some mothers chose to seek care at St. Mary's hospital primarily because it was far-off from their living premises or work places to minimize the chances of encountering someone who might recognize them be it a neighbor, colleague, family member or friend. This suggests that women would rather spend more time and money in order to conceal their HIV status than seek treatment near their homes. This observation sits at odds with multiple studies that have described long distance and high transportation cost to the hospital as a health access factor that negatively impacts utilization and adherence to health services due to loss of follow-up. Clinic follow-up for the interviewed group was 91%.

Closely linked to the above finding is that more than 60% of the women expressed dissatisfaction with the waiting time at the clinic yet the majority (91%) attended their clinic appointments regularly. In fact, after discussing the long queues they have to encounter at each hospital visit, mothers were quick to add that at the end of the day what really mattered to them was the kindness of the doctors and that their health

information was kept confidential. As one woman put it, “So long as the doctor will take his time and listen to me when my turn comes and will keep our conversations and my health information private, I don’t mind waiting.” Once again, this observation is a deviation from conventional wisdom that contends that long waiting times at clinics are disincentives to patients for following up on their appointments.

Another interesting finding was the existing gap between women’s knowledge (on mother-to-child transmission and PMTCT interventions) and application of the said knowledge. For instance, 93% of the women responded with a “Yes” to the question on whether there was a need for a pregnant HIV-positive woman to practice safe sex. Most mothers were even able to articulate that use of protection was also necessary for a breastfeeding positive mother. However, a number of them admitted that they did not practice safe sex either because they had not disclosed their status to their partners or because they could not get their partners to agree on using protection. Additionally, the majority of the mothers (96%) strongly agreed that male partner involvement in the PMTCT programs was important. However, of those with partners, only 43% reported that their partners had attended ANC/PMTCT clinic with them at some point compared to 57% who said their partners had never attended ANC/PMTCT clinic with them. This leads us to the conclusion that acquisition of knowledge does not necessarily result in its correct application. That is, just because women were knowledgeable about the importance of safe sex in preventing their unborn babies or breastfeeding infants from contracting HIV did not automatically mean that they could make their partners use condoms. Similarly, women could not force their partners’ involvement in PMTCT programs even though they agreed that male partnership was valuable.

The above scenarios create missed opportunities with regard to reaching out for support, application of acquired knowledge and access to more affordable quality PMTCT services. This study argues that these missed opportunities explain the observed disconnect between hypothesized factors and the achievements of PMTCT.

Furthermore, the patient interviews for this study demonstrate the effects of stigma and gender imbalance on PMTCT programming. Stigma refers to attitudes or perceptions of shame, disgrace, blame or dishonor associated with the disease.<sup>120</sup> HIV/AIDS-related stigma comes from a powerful combination of fear and shame. Over 80% of the interviewed women felt that people living with AIDS (PLWA) experience some level of stigma. The negative relationship between stigma and disclosure has been well documented in the literature. This study reflects findings in previous studies on women in developing countries that found barriers to disclosure to include fear of accusations of infidelity, abandonment, discrimination and violence.<sup>121</sup>

Research suggests that women's social and economic vulnerability and gender inequality makes it less likely that they will succeed in negotiating protection, and less likely that they will leave a relationship that they perceive to be risky. A recent study conducted by researchers in Botswana and Zambia in collaboration with researchers from the International Center for Research on Women (ICRW) found that men were more likely to abandon a HIV-positive partner. It also pointed out that women would initially

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<sup>120</sup> Cock, K.M.D., et al. "Shadow on the Continent: Public Health and HIV/AIDS in Africa in the 21st Century." *The Lancet*, (2002) 360, 67-72.

<sup>121</sup> Medley, A., et al. "Rates, Barriers and Outcomes of HIV Serostatus Disclosure among Women in Developing Countries: Implications for Prevention of Mother-to-Child Transmission programmes. *Bulletin of the World Health Organisation*, (2004) 82, 299-307.

get angry with a HIV-positive partner, but ultimately accept him.<sup>122</sup> These findings align with the current study findings with regard to women's inability to negotiate for safe sex despite their knowledge on the threats of unprotected sex to their health and that of their infants. The fear of abandonment by a male partner and the reciprocal tendency to forgive a HIV-positive male partner was also evident.

### **Emergent Themes:**

Conversations with mothers on their journeys along the PMTCT continuum of care and reasons that persuaded them to adhere to the suggested guidelines generated the following themes: supportive counseling, striving for motherhood, maternal attachment and concern for the child's wellbeing, trust that confidentiality will be maintained and the testimonials of mothers who had experienced success with the PMTCT program.

### ***Supportive Counseling:***

Counseling was the most talked about and probably the most regarded element of the PMTCT interventions. Mothers credited their ability to get through difficult and distressful realities of HIV/AIDS to the psychological and emotional support they received through counseling. A positive HIV test can be scary, stressful and to some a life shattering experience. But through proper counseling mothers were able to accept themselves and make informed decisions to preserve their own health and protect their babies from contracting HIV. Moreover, the value of counseling was not limited to HIV testing but extended throughout the PMTCT continuum of care. Mothers reiterated that status disclosure and partner testing, initiating ARVs and rapid weaning at six months

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<sup>122</sup> International Center for Research on Women (ICRW). "Approaches for Empowering Women in the HIV/AIDS Pandemic: a Gender Perspective." 2009.  
<http://www.un.org/womenwatch/daw/csw/hivaids/Gupta.html>

were among the steps that demanded a lot of emotional strength and where supportive counseling were invaluable.

Couples therapy provided a convenient platform for disclosure and partner testing for mothers who were afraid of blame, abandonment or violence from their partners. Counseling also empowered mothers to initiate and adhere to ARVs by demystify the confusion around the dreaded side effects associated with the drugs. Furthermore, counseling was instrumental in keeping mothers focused during the distressful rapid weaning transition at six months for those who breastfed exclusively – an experience some mothers described as tormenting.

***Striving for motherhood, maternal attachment and concern for the child's wellbeing:***

With HIV-related care and treatment services becoming more accessible, HIV-positive women are regaining their health, living longer, and planning for their futures. This includes making decisions about their sexuality and about the possibility of starting or expanding a family. Being infected with HIV does not remove the desire of motherhood and related socio-cultural expectations of childbearing and parenthood. Besides, children improve women's position in society and are a sign of a happy and fulfilled life. PMTCT makes it possible for people living with HIV to actualize childbearing. To some mothers, the desire for motherhood was the driving force behind their commitment to PMTCT interventions.

Another aspect of motherhood that influenced women's decisions while negotiating the challenges of living with HIV was the inherent quality of maternal nurturance. Beyond a strong commitment to protect their infants from the HIV virus,

women expressed a genuine desire to love and nurture their children. To some, this gave them a purpose in life and ultimately a reason to stay alive.

***Confidentiality:***

Confidentiality is the first of the three guiding principles for testing and counseling in PMTCT settings – the other guiding principles are informed consent and post-test support and services. Confidentiality is central to developing trust between doctors and patients. Without assurances about confidentiality, patients may be reluctant to seek medical attention or to give doctors the information they need in order to provide good care.

While observing patients' privacy is a common medical practice supported by law, the issue of disclosure especially in the context of PMTCT programming remains highly problematic. This is mainly because male partner involvement in PMTCT is vital not only for psychosocial support to their female counterparts but also for adherence to safe sexual practices. Additionally, PMTCT interventions infringe on the cultural norms of motherhood with respect to infant feeding guidelines hence posing a cultural conformity challenge to mothers. Therefore, family or community support, if sought, would lessen the burden on HIV-positive mothers who choose alternative infant feeding methods of exclusive breastfeeding followed by rapid weaning at six months.

The majority of the mothers stressed that confidentiality of their HIV status was critical due to the stigma associated with HIV/AIDS. They expressed fears of being rejected or abandoned by their partners, causing hurt or shame to their loved ones and being discriminated against by their friends and communities. As such, mothers went to great extents to keep their status private including traveling for extra miles to get to a far-

off hospital. Many women lauded St. Mary's hospital's commitment to protecting patient's privacy and their couples' therapy initiative that provide a setting conducive for partner testing and disclosure.

***Testimonials:***

Generally as human beings, we tend to seek opinions of others when it comes to making decisions on areas in which we do not have a lot of experience or knowledge. It is, therefore, a psychological fact that our views as humans are interdependent. Testimonials can be defined as reviews or opinions from gratified consumers that attest to the credibility, reliability and trustworthiness of the consumed product/service. Testimonials are thus important in building confidence of potential consumers. When seeking health services, it is common for patients to seek opinions of others in order to gauge the benefits and reliability of a given health service.

Testimonials on the successes of PMTCT, either from the experience of a close friend or a national figure played an important role in familiarizing mothers with the interventions and validating their potential. To women who had prior personal experience with PMTCT services, their decision to take yet another chance was in itself a testament to their confidence in the program.

Asunta Wagura, a renowned Kenyan AIDS activist who has lived with HIV for over twenty-five years and delivered two children through PMTCT, was referenced in almost every conversation during the interviews. Asunta puts a face to a Kenyan HIV-positive mother who is living a fulfilled life regardless of her HIV status. She writes about her experiences in the *Daily Nation* (Kenya's largest newspaper) and is the Founder and Executive Director of the Kenya Network of Women Living with Aids



(KENWA). Asunta is an important and influential advocate for reproductive rights of HIV-positive women.

In the global fight against HIV several individuals have helped put a face to HIV/AIDS either by living publicly and advocating for people living with AIDS (PLWA) or by dying from the disease. Ryan White, Elizabeth Glaser, Rock Hudson, Earvin Johnson, Greg Louganis, Freddie Mercury, Zackie Achman provide just a few examples.

### **Policy Implications and Recommendations:**

Based on the findings discussed in this chapter, the following recommendations can be made.

#### **1) Intensify campaign against stigma.**

As evidenced by the study findings, HIV interventions cannot be fully effective in a stigmatizing or discriminatory environment. Yet, while most national HIV policies call for reducing stigma and discrimination, few programs have been able to operationalize effective stigma reduction strategies.<sup>123</sup> Any intensified campaign against HIV should focus on two levels of stigma: internalized stigma and projected stigma. Internalized stigma can be described as the stigma felt by people living with AIDS (PLWA), which often leads to self-isolation. This form of stigma can be reduced through strengthening the social capital of PLWA by fostering network formation, building skills (e.g., advocacy, stigma reduction), and facilitating involvement of PLHIV as partners in project activities.

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<sup>123</sup> USAID: “Health Policy Initiative: HIV Stigma – A Health Policy Approach.” September 2010 [http://www.healthpolicyinitiative.com/Publications/Documents/1257\\_1\\_EOP\\_Brief\\_HIV\\_Stigma\\_Health\\_Policy\\_Approach\\_FINAL\\_Sep.pdf](http://www.healthpolicyinitiative.com/Publications/Documents/1257_1_EOP_Brief_HIV_Stigma_Health_Policy_Approach_FINAL_Sep.pdf)

Projected stigma can be minimized by a continued effort to mobilize diverse sectors and leaders to break the silence surrounding HIV. Faith-based organizations, government institutions as well and the private sector make key stakeholders in a campaign against HIV stigma. Academic institutions should also be encouraged to integrate stigma sensitization into curricula for health professionals. Influential opinion leaders including journalists, political figures, and community elders should also be encouraged to speak out against stigma and discrimination.

## **2) Address gender imbalances through women's empowerment.**

Recognizing that some of the barriers women face in disclosing HIV test results to their partners have their roots in underlying gender norms and social attitudes about HIV/AIDS, there is a need for initiatives that address these broader issues. Women's empowerment programs are an example of an intervention that could help shift gender norms and ultimately facilitate HIV status disclosure to sexual partners.

Women's empowerment involves improving women's access to economic resources by ensuring that they have property and inheritance rights, have access to credit, receive equal pay for equal work, have the financial, marketing and business skills necessary to help their businesses grow, have access to the agricultural extension services to ensure the highest yield from their land, have access to formal sector employment, and are protected in the informal sector from exploitation and abuse.

Yet another form of empowering is by promoting women's decision-making at the household, community, and national levels by promoting women's education, leadership and participation.

### **3) Counseling training and support for PMTCT healthcare workers (educative training, toolkits, coordinated information sharing).**

Given the valuable impact of counseling to the overall effectiveness of PMTCT interventions, it is critical that PMTCT healthcare workers including nurses, midwives, doctors, social workers and counselors be equipped with adequate counseling skills. Health facilities should work closely with their human resource departments to ensure that their staff is trained on basic counseling skills and supported to undertake continuous HIV counseling training courses. Coordinated information sharing between departments and health facilities should also be encouraged to develop best practices that would enhance counseling skills and ultimately improve patient's experience when undertaking counseling. Furthermore, health facilities should work closely with educational, national and international entities to acquire counseling materials such as toolkits and user guides. One such useful resource is a toolkit for PMTCT health workers developed by the International Center for AIDS Care and Treatment Programs (ICAP).<sup>124</sup>

### **4) Mediated disclosure.**

To help address the disclosure issue, a mediated form of disclosure in which either the counselor mediates the disclosure between couples in the clinic or the client is encouraged to identify a trusted family member or friend to mediate the disclosure process in the home, offers a potentially effective and culturally sensitive approach to supporting women.

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<sup>124</sup> ICAP. "Improving Retention, Adherence, and Psychosocial Support within PMTCT Services: A Toolkit for Health Workers." 2010. <http://www.womenchildrenhiv.org/wchiv?page=wx-resource&rid=21300>

### **5) Use of mobile telemedicine in PMTCT programming.**

According to the *Journal of Mobile Technology in Medicine (JMTM)*,<sup>125</sup> mobile phone technology is increasingly playing a role in healthcare delivery, management of various health conditions and in the training of healthcare professionals. Based on data from the International Business Machine Corporation (IBM), 90% of all phones in Africa are mobile phones.<sup>126</sup> This shows the capacity for mobile technology to play an important role in facilitating patient care in low-resource settings. As such, PMTCT programs should leverage the ubiquitous mobile technology to improve service delivery. For instance, mobile phones could be used as a tool for sending and receiving short text messages (SMS). Simple reminders for clinic appointments or anti-retroviral treatments could be easily communicated through an SMS. Aside from keeping patients continuously in touch with their health care providers, mobile phones can also be a useful tool for providing doctors with valuable information through pictures.

### **6) Promote maternal/fetal/infant attachment.**

As exemplified by the study findings, maternal attachment plays an important role in the health seeking decisions of pregnant women and mothers in connection to their unborn babies and infants. In addition, maternal attachment is an important component of maternal identity and is essential in promoting healthy growth and development in the child. As such, PMTCT programs should consider integrating maternal attachment education and awareness within their prenatal and postnatal services. According to the

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<sup>125</sup> Journal of Mobile Technology in Medicine (JMTM)  
<http://www.journalmtm.com/>

<sup>126</sup> IBM. "Is Mobile Africa's Future?"  
[http://www.ibm.com/smarterplanet/global/share/19jan2012/mobile\\_africa/](http://www.ibm.com/smarterplanet/global/share/19jan2012/mobile_africa/)

attachment parenting theory, the process of attachment begins before birth as the parents plan for the pregnancy or discover that the mother is pregnant. The mother feels fetal movement, begins to accept the fetus as an individual, and makes plans for the baby after birth. In the first minutes and hours after birth, a sensitive period occurs during which the baby and the mother become intimately involved with each other through behaviors and stimuli that are complementary and provoke further interactions.<sup>127</sup> Touch, eye contact, breastfeeding, baby wearing – also known as kangaroo care, communication, and maternal participation in routine care all enhance feelings of and closeness to the child.

#### **7) Improve sexual and reproductive health (SRH) services for HIV-positive women.**

Sexual and reproductive rights apply to all individuals, regardless of their HIV status. With HIV-related care and treatment services becoming more accessible, HIV-positive women are regaining their health, living longer, and planning for their futures. HIV-positive women – like all women worldwide – have the right to decide when and if to have children. To make this right a reality, all women need access to comprehensive sexual and reproductive health (SRH) information and services. Integrating comprehensive SRH care, including family planning and safe abortion care, into HIV prevention, care, and treatment services is an important way to ensure HIV-positive women have the information and tools they need to make informed reproductive choices and improve their overall health. Program managers and health workers should be trained to provide comprehensive, nonjudgmental, and high-quality SRH care and support to HIV-positive women.

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<sup>127</sup> Carter-jessop, L. “Promoting maternal attachment through prenatal intervention.” *The American Journal of Maternal Child Nursing.* (1981), Vol.6(2), pp.107-12

## **8) Uphold patient's confidentiality.**

Maintaining confidentiality is an important responsibility of all healthcare workers and is essential to establishing and maintaining patients' trust. Information that is shared between healthcare workers and patients must be kept private. Additionally, patients should be informed that personal and medical information, including HIV test results, might only be disclosed to other healthcare workers in order to ensure that the patient receives the appropriate medical care. However, only those directly involved in the patients care should have access to the medical records. Supportive staff at HIV clinics, such as receptionists and other administrative staff, should be trained on the necessity of confidentiality and maintenance of patient's confidentiality should be a condition of continued employment. Equally important, healthcare workers should be sensitive when communicating with patients to maintain privacy. Furthermore, all medical records and registers, whether or not they include HIV-related information, should be kept confidential and stored in a safe, secure place.

## **9) Promote peer education in PMTCT programming.**

Peer education typically involves training and supporting members of a given group to effect change among members of the same group. Peer education is often used to effect changes in knowledge, attitudes, beliefs, and behaviors at the individual level. Peer education is also known to generate demand for services in the intended audience. This approach could be used to promote PMTCT efforts through information sharing among HIV-positive mothers and promotion of success stories on PMTCT. Peer education should also be integrated, where possible, with community health and development initiatives for sustainability.

### Limitations of the study:

Limitations of the study included purposive rather than random selection of informants, which theoretically limits generalizability. A comparison of the study sample demographics to those of the general population of Kenyan women of childbearing age (15-49yrs) as per the *Kenya Demographic and Health Survey (KDHS) 2008-09*<sup>128</sup> shows that the sample is somewhat skewed – especially with regard to women’s education attainment. (See Table 7) This is an indication that purposive selection of informants may have introduced some selection bias. Additionally, a purposive sample would not be representative of all women receiving care at St. Mary’s Mission Hospital PMTCT program. As such, findings from this study may only be generalized to the patients included in the study. Furthermore, bias introduced by the investigator in the collection and analysis of the data remains a constant threat. As Smith and Osborn point out, qualitative analysis is inevitably a personal process and the analysis itself is interpretative work, which the investigator does at each of the stages.<sup>129</sup>

However, a number of measures were put in place in an attempt to enhance validity and reliability of the study findings. First, the researcher consulted with experts in the field throughout the process of this inquiry to minimize potential bias and increased reliability. Additionally, the study employed a mixed methods approach, which made it possible to compare quantitative and qualitative data. Furthermore, preliminary results of the study were shared with informants for validation.

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<sup>128</sup> Kenya National Bureau of Statistics (KNBS) and ICF Macro. “Kenya Demographic and Health Survey 2008-09.” Calverton, Maryland: KNBS and ICF Macro. 2010  
<http://www.measuredhs.com/pubs/pdf/FR229/FR229.pdf>

<sup>129</sup> Smith, J., and Osborn, M. Interpretative Phenomenological Analysis. In J.A. Smith, ed. *Qualitative Psychology: A Practical Guide to Methods*. London: SAGE, 2003.

Table 7: Demographic Comparison of the Study Sample to the General Population

Demographic Characteristics	Sample (Women included in the study)	Nairobi (Women within the County of Nairobi)	Kenya (Women in the general population)
Median age at first birth	N/A <sup>130</sup>	23yrs	19.9yrs
	<i>Percentage of women in the sample</i>	<i>Percentage of women age 15-49yrs</i>	<i>Percentage of women age 15-49yrs</i>
Completed Primary School	14.5%	17.8%	17%
Completed Secondary School	38.2%	20.5%	9%
College and above	47.3%	25.3%	5%
Married women	76.4%	N/A <sup>131</sup>	54.2%
Employed women	65.5%	58.5%	57%

### Conclusion:

The effectiveness of PMTCT interventions does not rely only on access, health education and a functional healthcare system. Rather, the interplay of these factors and the context in which they exist proves to have an iterative effect on these programs. HIV/AIDS related stigma and gender imbalances create many missed opportunities for HIV-positive mothers to apply acquired knowledge, mobilize support from family and community, and access more affordable care. In an environment riddled with such challenges, supportive counseling, striving for motherhood, maternal attachment and concern for the child's wellbeing, assurance of confidentiality and testimonials of other successful mothers are vital elements that explain HIV-positive mothers' resolve to utilize and adhere to PMTCT services.

<sup>130</sup> This demographic characteristic was not measured by the study. Sampled women were between 19-39yrs of age.

<sup>131</sup> Women's marital status statistics by counties were not provided in the Kenya demographic and health survey (KDHS) report.



### **Future Research:**

A major contribution of this study to the literature on PMTCT is the introduction of a positive dimension in evaluation of PMTCT programs. Findings reveal a disconnection between factors that have been associated with failures of PMTCT in explaining its success. More research is needed to test this relationship in different settings. In addition, further studies would be useful to extend our understanding on the generated variables found to enhance PMTCT utilization and adherence, which include counseling, striving for motherhood, maternal attachment and concern for the child's wellbeing, confidentiality and testimonials.

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## Appendix A: Survey Questionnaire

Case ID Number \_\_\_\_\_

### PMTCT Adherence and Utilization Questionnaire

The purpose of this questionnaire is to explore factors that enhance utilization of and adherence to prevention of mother-to-child transmission of HIV (PMTCT) services in a plural urban setting in Kenya. Please note that your participation is voluntary and the data is anonymous and confidential. Your clinical care is not dependent on their participation in this research.

Sometimes talking about this subject may be uncomfortable. But you do not have to talk about any subjects you do not want to talk about, and you may stop the interview at any time. If you become upset, the study staff will give you names of counselors to contact so you can get help in dealing with these issues. This questionnaire will take 30 minutes.

---

#### PMTCT Knowledge and Perceptions:

##### *To what level do you agree or disagree with the following statements?*

1. The government should require HIV/AIDS testing for all pregnant women to ensure that their babies will be born HIV free.
  - ☐ Strongly agree
  - ☐ Somewhat agree
  - ☐ Neither agree nor disagree
  - ☐ Somewhat disagree
  - ☐ Strongly disagree
2. Counseling before or after HIV testing is important.
  - ☐ Strongly agree
  - ☐ Somewhat agree
  - ☐ Neither agree nor disagree
  - ☐ Somewhat disagree
  - ☐ Strongly disagree
3. It is okay for a HIV positive woman to conceive.
  - ☐ Strongly agree
  - ☐ Somewhat agree
  - ☐ Neither agree nor disagree
  - ☐ Somewhat disagree
  - ☐ Strongly disagree

4. It is important for a male partner to be involved in the PMTCT program.
- ☐ Strongly agree
  - ☐ Somewhat agree
  - ☐ Neither agree nor disagree
  - ☐ Somewhat disagree
  - ☐ Strongly disagree

***Please answer the following questions.***

5. If a pregnant woman is HIV positive, is there a need for her to practice safe sex?
- ☐ Yes
  - ☐ No
  - ☐ Don't know
6. Can birth-control pills or injections protect a woman from HIV during sex?
- ☐ Yes
  - ☐ No
  - ☐ Don't know
7. How can HIV be transmitted from mother-to-child?
- ☐ During pregnancy
  - ☐ At labor and delivery
  - ☐ Through breastfeeding
  - ☐ All of the above

Disclosure and PMTCT Services:

8. Who have you disclosed your HIV status to?
- ☐ No one
  - ☐ Mother
  - ☐ Partner
  - ☐ Friend
  - ☐ Other (specify)
9. If you have a partner, are you aware of their HIV status?
- ☐ Yes – positive
  - ☐ Yes – negative
  - ☐ No
  - ☐ Does not apply
10. Has your partner ever attended ANC/PMTCT clinic with you?
- ☐ Yes
  - ☐ No
  - ☐ Does not apply

11. How far along in your pregnancy with your last child were you when you first visited the ANC clinic? \_\_\_\_\_
12. Where was your last child delivered?
- ☐ Home
  - ☐ Health facility
  - ☐ Other/born before arrival
13. Was your last child delivered full-term or pre-term?
- ☐ Full-term
  - ☐ Pre-term
14. Was your last child delivered naturally or through cesarean?
- ☐ Naturally
  - ☐ Caesarean-emergency
  - ☐ Caesarean-elective
15. What infant feeding method did you use with your last child?
- ☐ Exclusive formula
  - ☐ Exclusive breastfeeding
  - ☐ Mixed-feeding
16. What is your travel time to the hospital?
- ☐ Less than 30 minutes
  - ☐ 30 minutes to 1 hour
  - ☐ 1 hour to 2 hours
  - ☐ More than 2 hours
17. How would you rank your transportation cost to the hospital?
- ☐ Very cheap
  - ☐ Somewhat cheap
  - ☐ About average
  - ☐ Somewhat expensive
  - ☐ Very Expensive

Perceptions on healthcare providers and the health facility:

18. How would you rate the overall quality of services you receive at this hospital?
- ☐ Poor
  - ☐ Fair
  - ☐ Good
  - ☐ Very good
  - ☐ Excellent

19. How satisfied or unsatisfied are you with the waiting time at the ANC/PMTCT clinic?
- ☐ Not satisfied at all
  - ☐ Slightly satisfied
  - ☐ Moderately satisfied
  - ☐ Very satisfied
  - ☐ Extremely satisfied
20. How confident, or not, are you that you would be able to obtain the prescribed medication including (HIV medications) when you need them?
- ☐ Not at all confident
  - ☐ Slightly confident
  - ☐ Moderately confident
  - ☐ Very confident
  - ☐ Totally confident
21. How would you rate the quality of doctors at the ANC/PMTCT clinic?
- ☐ Poor
  - ☐ Fair
  - ☐ Good
  - ☐ Very good
  - ☐ Excellent
22. How would you rate the quality of nurses at the ANC/MPTCT clinic?
- ☐ Poor
  - ☐ Fair
  - ☐ Good
  - ☐ Very good
  - ☐ Excellent
23. How would you rate the quality of counselors at the ANC/MPTCT clinic?
- ☐ Poor
  - ☐ Fair
  - ☐ Good
  - ☐ Very good
  - ☐ Excellent

ARVs Adherence Questions:

24. Do you follow the medication schedule and dosage on the medicine bottle(s)?
- ☐ Never
  - ☐ Some or most of the time
  - ☐ All the time (never missed a dose)

25. How easy or difficult is it for you to follow the appropriate medication schedule and dosage?
- ☐ Very easy
  - ☐ Somewhat easy
  - ☐ Somewhat difficult
  - ☐ Very difficult
26. Do you attend all your clinic appointments regularly?
- ☐ Yes, I have never missed an appointment
  - ☐ I have missed one or two appointments
  - ☐ I have missed more than 3 appointments

HIV Stigma and Community Perceptions:

27. If you have a question about HIV/AIDS, who do you ask or where do you go to get the information?
- ☐ Health professionals
  - ☐ TV
  - ☐ Radio
  - ☐ Internet
  - ☐ Friends
  - ☐ Family
  - ☐ Community or public meetings
  - ☐ Other (specify)
28. If a person knows that he or she has HIV/AIDS, do you think that he/she should keep it private or tell other people in the community?
- ☐ Should keep it private
  - ☐ Should confide in someone they trust
  - ☐ Should tell other in the community
  - ☐ Don't know/Not sure
29. Are people with HIV/AIDS shunned by other individuals?
- ☐ Yes
  - ☐ Partly
  - ☐ No
  - ☐ Don't know/Not sure
30. Are you a member of any community support group?
- ☐ Yes
  - ☐ No

Demographic Questions:

31. What is your age? \_\_\_\_\_



32. What is your marital status now?
- ☐ Single
  - ☐ Married
  - ☐ Divorced/Separated
  - ☐ Widowed
33. Who is the head of your household?
- ☐ Me
  - ☐ My partner
  - ☐ My parents
  - ☐ My in-laws
  - ☐ Other (Specify)
34. What is your tribe? \_\_\_\_\_
35. Which religion do you identify with?
- ☐ Christian – Protestant
  - ☐ Christian – Catholic
  - ☐ Muslim
  - ☐ Hindu
  - ☐ Other (specify)
36. What is the highest level of education you have completed?
- ☐ None
  - ☐ Primary
  - ☐ Secondary
  - ☐ College and above
  - ☐ Other (specify)
37. How many children do you have? \_\_\_\_\_
38. Do you plan on having more children in the future?
- ☐ Yes
  - ☐ No
  - ☐ Don't know/Not sure
39. What is your occupational type?
- ☐ White-collar job
  - ☐ Blue-collar job
  - ☐ Self-employed
  - ☐ Unemployed
40. If you have a partner, what is their occupation?
- ☐ White-collar job
  - ☐ Blue-collar job

- ☐ Self-employed
- ☐ Unemployed
- ☐ Does not apply

41. How would you rank your economic status?

- ☐ Poor
- ☐ Middle class
- ☐ Rich

Open-ended question:

Based on your own experience with the PMTCT program could you explain to me how you got through each step of the way and what has kept you going?

This image shows a full page of white paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page, providing a template for handwriting practice or general note-taking. There are no margins, text, or other markings on the page.

**Thank you for your time!**

## Appendix B: Survey Questionnaire Swahili Translation

Nambari ya Kesi \_\_\_\_\_

### **Maswala ya Ufuatiliifu na Utumiaji wa Huduma za Kuzuia Uambukizi wa Virusi vya Ukimwi kutoka kwa Mama Kwenda kwa Mwanawe**

Kiini cha maswala haya ni kuchunguza sababu zinazoweza ufuatiliifu na utumiaji wa huduma za kuzuia uambukizi wa virusi vya ukimwi kutoka kwa mama kwenda kwa mwanawe. Tafadhali fahamu ya kwamba ushiriki kwa utafiti huu ni chaguo lako mwenyewe na pia majibu yako hayatapeanwa wazi au kuhusianishwa nawe.

---

#### ***Unakubaliana au kutokubaliana na mawazo yafuatayo kiasi gani?***

1. Serikari inapaswa kuhitaji wamama wote wajawazito wapimwe virusi vya ukimwi ili kuhimiza ya kwamba wanao watazaliwa bila virusi vya ukimwi.
  - ☐ Nakubali kabisa
  - ☐ Nakubali kiasi
  - ☐ Sikubali wala sikatai
  - ☐ Sikubali kiasi
  - ☐ Sikubali kamwe
2. Ni muhimu kupewa mawaidha kabla na baada ya kupimwa virusi vya ukimwi.
  - ☐ Nakubali kabisa
  - ☐ Nakubali kiasi
  - ☐ Sikubali wala sikatai
  - ☐ Sikubali kiasi
  - ☐ Sikubali kamwe
3. Ni sawa mama aliyeambukizwa na ukimwi kupata mimba.
  - ☐ Nakubali kabisa
  - ☐ Nakubali kiasi
  - ☐ Sikubali wala sikatai
  - ☐ Sikubali kiasi
  - ☐ Sikubali kamwe
4. Ni muhimu mume kujihusisha na huduma za kuzuia uambukizi wa virusi vya ukimwi kutoka kwa mama kwenda kwa mwanawe.
  - ☐ Nakubali kabisa
  - ☐ Nakubali kiasi
  - ☐ Sikubali wala sikatai
  - ☐ Sikubali kiasi
  - ☐ Sikubali kamwe

***Tafadhali jibu maswali yafuatayo.***

5. Kama mama mjamzito unavirusi vya ukimwi, kuna sababu yake kutumia njia za kujipinga anapofanya mapenzi?
  - ☐ Ndio
  - ☐ La
  - ☐ Sijui
6. Je, tembe au sindano za kuzuia mimba zaweza kumzuia mwanamke asipatwe na virusi vya ukimwi anapofanya mapenzi?
  - ☐ Ndio
  - ☐ La
  - ☐ Sijui
7. Je, ni njia gani ambazo virusi vya ukimwi kutoka kwa mama vinaweza kumpata mwanawe?
  - ☐ Mtoto akiwa tumboni
  - ☐ Wakati wa kuzaa
  - ☐ Wakati wa kunyonyesha
  - ☐ Kwa njia hizi zote
8. Ni nani umeambia kuhusu hali yako ya ukimwi?
  - ☐ Hakuna
  - ☐ Mamaangu
  - ☐ Mume
  - ☐ Rafiki
  - ☐ Wengineo (eleza)
9. Ikiwa una mume, unajua hali yake ya ukimwi?
  - ☐ Ndio – anavirusi
  - ☐ Ndio – Hanavirusi
  - ☐ La
  - ☐ Sina mume
10. Je, mumewe amewahi udhuria kliniki ya wajawazito au ya huduma za kuzuia uambukizi wa virusi vya ukimwi kutoka wa mama kwenda kwa mwanawe?
  - ☐ Ndio
  - ☐ La
  - ☐ Sina mume
11. Ulipokuwa na mimba ya mtoto wako wa mwisho, ulienda kliniki ya wajawazito siku ya kwanza ukiwa na mwezi au wiki ngapi? \_\_\_\_\_

12. Wanao wa mwisho alizaliwa wapi?
- ☐ Nyumbani
  - ☐ Hospitali/cliniki
  - ☐ Kwengineko/njiani
13. Je, mtoto wako wa mwisho alizaliwa akiwa amefikisha mwezi tisa au kabla?
- ☐ Akiwa amefikisha
  - ☐ Kabla ya kufikisha
14. Je, mtoto wako wa mwisho alizaliwa kwa njia ya kawaida au kupitia upasuaji?
- ☐ Njia ya kawaida
  - ☐ Kupitia upasuaji (kigafla)
  - ☐ Kupitia upasuaji (kwa kujitajia)
15. Ulimlisha mwanao wa mwisho kwa njia gani?
- ☐ Maziwa ya formula pekee
  - ☐ Kunyonyesha pekee
  - ☐ Mchanganyiko
16. Wewe huchukua muda gani kufika hospitalini?
- ☐ Chini ya dakika therathini
  - ☐ Dakika therathini hadi lisali moja
  - ☐ Juu ya masaa mawili
17. Unaoneleaje kuhusu bei ya nauli unayolipa kufika hospitalini?
- ☐ Rahisi sana
  - ☐ Rahisi kiasi
  - ☐ Bei nafuu
  - ☐ Ghali kiasi
  - ☐ Ghali sana
18. Unaoneleaje kuhusu hali ya huduma zote unazopata katika hospitali hii?
- ☐ Mbaya
  - ☐ Sawa tu
  - ☐ Mzuri
  - ☐ Mzuri sana
  - ☐ Mzuri kabisa
19. Unatosheka au hautosheki na muda anaotumia kungoja huduma katika kliniki ya wajawazito au ya uzuiaji wa uambukizi wa viini vya ukimwi kutoka kwa mama kwanda kwa manawe?
- ☐ Sitosheki kamwe
  - ☐ Natosheka kidogo
  - ☐ Natosheka kiasi

- ☐ Natosheka sana
  - ☐ Natosheka kabisa
20. Una matumaini ya kwamba utapata madawa uliyoandikiwa?
- ☐ Sina matumaini kamwe
  - ☐ Nina matumaini kidogo
  - ☐ Ninamatumaini kiasi
  - ☐ Ninamatumaini makubwa
  - ☐ Ninamaumaini kabisa
21. Unaoneleaje hali ya madaktari katika kliniki ya wajawazito au ya uzuiaji wa uambukizi wa viini vya ukimwi kutoka kwa mama kwanda kwa manawe?
- ☐ Mbaya
  - ☐ Sawa tu
  - ☐ Mzuri
  - ☐ Mzuri sana
  - ☐ Mzuri kabisa
22. Unaoneleaje kuhusu hali ya wauguzi katika kliniki ya wajawazito au ya uzuiaji wa uambukizi wa viini vya ukimwi kutoka kwa mama kwanda kwa manawe?
- ☐ Mbaya
  - ☐ Sawa tu
  - ☐ Mzuri
  - ☐ Mzuri sana
  - ☐ Mzuri kabisa
23. Unaoneleaje kuhusu hali ya counselors katika kliniki ya wajawazito au ya uzuiaji wa uambukizi wa viini vya ukimwi kutoka kwa mama kwanda kwa manawe?
- ☐ Mbaya
  - ☐ Sawa tu
  - ☐ Mzuri
  - ☐ Mzuri sana
  - ☐ Mzuri kabisa
24. Je, unafuatilia maagizo ya kunywa dawa au kumeza tembe kama yanavyioandikwa kwenye chupa au pakiti?
- ☐ Sijawahi
  - ☐ Wakati mwingine au karibu kila wakati
  - ☐ Kila wakati (sijawahi kosea maagizo)
25. Nivigumu au ni rahisi kwako kuyafuatilia maagizo ya kunywa dawa au kumeza tembe?
- ☐ Rahisi sana
  - ☐ Rahisi kiasi
  - ☐ Vigumu kiasi

- ☐ Vigumu sana
26. Wewe uhudhuria kliniki wakati wowote kama unavyohitajika?
- ☐ Ndio, sijawahi kosa siku yotote unayohitajika
  - ☐ Nimekosa mara moja au mbili
  - ☐ Nimekosa kushinda mara tatu
27. Ukiwa na swala kuhusu ukimwi, wewe hupata ujumbe wako kutota wapi?
- ☐ Madaktari/wauguzi
  - ☐ Televisheni
  - ☐ Redio
  - ☐ Mitambo ya computa
  - ☐ Marafiki
  - ☐ Familia
  - ☐ Jamii au mikutano ya jamii
  - ☐ Kwengineko (taja)
28. Mtu akijua ya kwamba ana ukimwi, unafikiria anapaswa kuweka siri yake au kuwaambia watu kwa jamii?
- ☐ Kuweka siri
  - ☐ Kuwaambia watu kwa jamii
  - ☐ Sijui/Sina hakika
29. Je, watu walio na ukimwi hutengwa na watu wengine?
- ☐ Ndio
  - ☐ Wakati mwingine
  - ☐ La
  - ☐ Sijui/Sina hakika
30. Je, wewe ni mshirika wa kundi lolote la wamama katika jamii?
- ☐ Ndio
  - ☐ La
31. Una umri gani? \_\_\_\_\_
32. Je wewe umeolewa au la?
- ☐ La sijaolewa
  - ☐ Ndio nimeolewa
  - ☐ Tuliafanya talaka/tumeachana
  - ☐ Mimi ni mjane
33. Kichwa cha jamii yako ni?
- ☐ Mimi
  - ☐ Mume wangu

- ☐ Wazazi wangu
- ☐ Wazazi wa mume wangu
- ☐ Wengineo (eleza)

34. Kabila lako ni gani? \_\_\_\_\_

35. Dini yako ni gani?

- ☐ Mkristiano – sio mkatoleki
- ☐ Mkristiano – mkatoleki
- ☐ Mwisilamu
- ☐ Muhindi
- ☐ Nyingine (eleza)

36. Wewe ulifikisha masomo wapi?

- ☐ Sikwenda shelu ata
- ☐ Shule ya msingi
- ☐ Sekondari
- ☐ Koleji na juu
- ☐ Kwingineko (elezea)

37. Unawatoto wangapi? \_\_\_\_\_

38. Je, unapanga kupata watoto wengine?

- ☐ Ndio
- ☐ La
- ☐ Sijui/Sina hakika

39. Unafanya kazi gani?

- ☐ Kazi ya ofisi
- ☐ Kazi ya mkono
- ☐ Nimejiajiri
- ☐ Sina kazi

40. Kama unamume, yeye hufanya kazi gani?

- ☐ Kazi ya ofisi
- ☐ Kazi ya mkono
- ☐ Nimejiajiri
- ☐ Sina kazi

41. Kiwango chako cha fedha ni?

- ☐ Maskini
- ☐ Katikati
- ☐ Tajiri



This image shows a full page of white paper with horizontal blue ruling lines. The lines are evenly spaced and run across the width of the page, providing a template for handwriting practice or general writing. There are no margins, text, or other markings on the page.

## Appendix C: In-Depth Interview Protocol

Case ID Number \_\_\_\_\_

The purpose of this interview is to explore factors that enhance utilization of and adherence to prevention of mother-to-child transmission of HIV (PMTCT) services in a plural urban setting in Kenya. Please note that your participation is voluntary and the data is anonymous and confidential. Your clinical care is not dependent on their participation in this research. Sometimes talking about this subject may be uncomfortable. But you do not have to talk about any subjects you do not want to talk about, and you may stop the interview at any time. If you become upset, the study staff will give you names of counselors to contact so you can get help in dealing with these issues. This interview will take 30 minutes.

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NB: In-depth interviews are aimed to follow-up on questions that arise from the survey questionnaire for elaboration purposes. As such, each interview is expected to mirror the responses of each individual participant for the most part. However, below are general questions that will guide the discussions.

1. Tell me how you learned of your pregnancy with your last child and your HIV status.
2. Who did you disclose this information to first and why?
3. Were you able to access all the drugs you needed during your pregnancy? (Including HIV drugs)
4. How did you make your decision on where your child would be born? (At home or at the hospital)
5. Tell me about your delivery experience.
6. How did you make the decision on what feeding method to follow for your child?
7. How would you describe your experiences with the ANC/PMTCT clinic staff, nurses, and doctors?
8. How supportive has been your partner and family on this whole journey?
9. Do you belong to any community support group that has been of help to you in this journey?
10. Looking back, what would you say has been your ultimate source of strength through this process?

## **Appendix D: Consent Form**

### **RESEARCH SUBJECT INFORMATION AND CONSENT FORM**

**TITLE:** A Positive Dimension: Exploring Factors that Enhance Utilization of and Adherence to Prevention of Mother-to-Child Transmission of HIV (PMTCT) Services in a Plural Urban Setting in Kenya.

**VCU IRB NO.:** #HM14625

If any information contained in this consent form is not clear, please ask the study staff to explain any information that you do not fully understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

#### **PURPOSE OF THE STUDY**

The purpose of this study is to learn how you successfully got through each step of the PMTCT program and what factors helped you follow the program guidelines and treatment. You are being asked to participate in this study because you receive PMTCT services at St. Mary's Mission Hospital, Lang'ata and your child is free of HIV virus.

#### **DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT**

If you decide to be in this research study, you will be asked to complete a questionnaire and you may also be selected to participate in an in-depth interview. The questionnaire and the in-depth interview will take 30 minutes each. You will also be asked to consent to this consent form after you have had all your questions answered and understand what will happen to you.

In this study you will be asked to respond to questions on your personal experience with the PMTCT program at St. Mary's Hospital. You will also be asked about factors in your family and community that have helped you through each step of the program. Some of your answers will be recorded on a questionnaire and others tape recorded to make sure that all your ideas are well captured, but no names will be recorded on the tape or paper.

Significant new findings developed during the course of the research, which may relate to your willingness to continue participation will be provided to you.

#### **RISKS AND DISCOMFORTS**

Sometimes talking about this subject may be uncomfortable. But you do not have to talk about any subjects you do not want to talk about, and you may stop the interview at any time. If you become upset, the study staff will give you names of counselors to contact so you can get help in dealing with these issues.

#### **BENEFITS TO YOU AND OTHERS**

You may not get any direct benefit from this study, but the information we learn from people in this study may help us design better PMTCT programs.

## **COSTS**

There are no costs for participating in this study other than the time you will spend responding to questions on the questionnaire.

## **PAYMENT FOR PARTICIPATION**

At the end of the interview you will receive KSh.400 (if you complete the questionnaire only) and KSh.800 (if you complete both the questionnaire and the in-depth interview) in cash as a token of appreciation for your time and to cover your transport cost.

## **ALTERNATIVES**

The alternative is for you not to participate in this the study.

## **CONFIDENTIALITY**

Your data will be identified by Case ID numbers, not names, and stored separately from medical records in a locked research area. Access to all data will be limited to study personnel.

We will not tell anyone the answers you give us; however, information from the study and the consent form signed by you may be looked at or copied for research or legal purposes by Virginia Commonwealth University. Also, personal information pertaining to you may be shared or copied by authorized agents of governmental agencies in Kenya.

Some of your responses will be audio taped, but no names will be recorded. At the beginning of the session, you will be asked to use initials only so that no names are recorded. The tapes and the notes will be stored in a locked cabinet. The tapes will be kept until they are transcribed and the study has been completed.

## **VOLUNTARY PARTICIPATION AND WITHDRAWAL**

You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study.

Your participation in this study may be stopped at any time by the study staff without your consent. The reasons might include:

- the study staff thinks it necessary for your safety;
- you have not followed study instructions;
- administrative reasons require your withdrawal.

Your clinical care is not dependent on your participation in this research.

## **QUESTIONS**

If you have any questions, complaints, or concerns about your participation in this research, contact:

**Dr. Konya W.P**  
**Medical Director and Director in Charge**  
**Email: wpkonya@gmail.com**  
**Phone: 254722704250**

OR

**Dr. Janet Hutchinson**  
**Principal Investigator**  
**Phone: (804) 828-8041**  
**Email: jhutch@vcu.edu**

The researcher/study staff named above is the best person to call for questions about your participation in this study.

If you have any general questions about your rights as a participant in this or any other research, you may contact:

Office of Research  
Virginia Commonwealth University  
800 East Leigh Street, Suite 113  
P.O. Box 980568  
Richmond, VA 23298  
Telephone: (804) 827-2157

Contact this number for general questions, concerns or complaints about research. You may also call this number if you cannot reach the research team or if you wish to talk with someone else. General information about participation in research studies can also be found at <http://www.research.vcu.edu/irb/volunteers.htm>.

## **CONSENT**

I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. I can give verbal consent to participate and do not need to sign the form, however, if I choose to sign I can. I will be given a copy of the consent form once I have agreed to participate.

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Participant name printed

Participant signature

Date

Signature of Person Conducting Informed Consent Discussion / Witness	Date
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Principal Investigator Signature (if different from above)	Date
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## Vita

Lydia Karuta Murithi was born in June 29, 1980 and she is a Kenyan citizen. She earned her Bachelor of Arts degree in Economics and Sociology from the University of Nairobi, Kenya in 2002. In 2008, she graduated with her Masters of Public Policy degree from George Mason University where she majored in Global Medical and Health Policy. Lydia has worked with various international health organizations both in Kenya and the U.S. at different capacities including advocacy, research, and program management on key public health issues including HIV/AIDS, malaria, TB, and reproductive health. She is a member of Phi Kappa Phi, Pi Alpha Alpha and Phi Beta Delta honor societies.