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MINISTRY OF HEALTH

**Evaluation of Access to and Utilization of
Services for the Prevention of Mother-to-Child Transmission (PMTCT) of HIV in Rwanda**

Summary report

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Acronyms

AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal care
ARV	Antiretroviral
ART	Antiretroviral therapy
CNLS	Commission Nationale de Lutte Contre le SIDA (National AIDS Control Commission)
DHS	Demographic and Health Survey
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
RWF	Rwanda Franc (currency)
HIV	Human Immunodeficiency Virus
ICAP	International Center for AIDS Care and Treatment Programs (Columbia University)
IRB	Institutional Review Board
IUD	Intrauterine device
LAM	Lactational amenorrhea method
MTCT	Mother-to-child transmission of HIV
PEPFAR	President's Emergency Plan for AIDS Relief
ONAPO	Office Nationale de la Population
PLWHA	People Living With HIV/AIDS
PMTCT	Prevention of mother-to-child transmission of HIV
SD-NVP	Single-dose nevirapine
TRAC	Treatment and Research AIDS Center (Ministry of Health, Rwanda)
UN	United Nations
UNAIDS	United Nations Joint Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
UTAP	University Technical Assistance Program
WHO	World Health Organization

Executive summary

In Rwanda, despite a relatively low HIV prevalence rate of 3%, an estimated 22,000 children under the age of 16 are living with HIV/AIDS and account for nearly 10% of all infections nationwide. As most of these infections are believed to be perinatally acquired, services to prevent mother-to-child transmission (PMTCT) have rapidly scaled up at the national level from 33 sites in 2002 to 234 in 2006. Until recently, single-dose nevirapine (SD-NVP) was the standard antiretroviral (ARV) prophylaxis for women and infants but in late 2006 more complex PMTCT regimens were adopted. As the introduction of these new regimens are likely to be accompanied by many on-the-ground challenges, it is important to highlight lessons learned with regard to access, uptake and ultimately adherence to the complete PMTCT package. To this end, the Government of Rwanda, through the Ministry of Health's Treatment and Research AIDS Center (TRAC) and in collaboration with Columbia University's International Center for AIDS Care and Treatment Programs (ICAP) and participation from the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), undertook an evaluation to:

- 1) Describe experiences with HIV testing among pregnant women (HIV-infected and uninfected) receiving antenatal care (ANC) services; and
- 2) Describe experiences with and identify factors affecting adherence to the PMTCT protocol, defined as mother-infant pairs ingesting single-dose nevirapine (SD-NVP) at the onset of/during labor for mothers and within 72 hours of delivery for infants, among HIV-infected women receiving ANC services.

We also explored women's (HIV-infected and HIV-uninfected, where appropriate) experiences with other aspects of PMTCT services, including the acceptability of ANC and delivery services; involvement of family members in decisions regarding HIV testing, delivery and ingestion of PMTCT prophylaxis; infant feeding and post-partum family planning knowledge, attitudes and practices; and referral from PMTCT to HIV care and treatment services.

Methods

A cross-sectional evaluation with both quantitative and qualitative data collection was conducted at 14 public-sector PMTCT sites from April-May 2006.

Quantitative data collection: Twelve sites were selected using multi-stage sampling techniques. Closed-ended interviews were completed with 162 HIV-uninfected women recruited at newborn vaccination sessions and 236 HIV-infected women (125 adherent and 111 non-adherent) over-sampled from PMTCT registers. Data analysis was stratified by HIV status, and among HIV-infected women, by adherence to the PMTCT protocol. Logistic regression was also conducted to identify determinants of key steps to adherence to the PMTCT protocol.

Qualitative data collection: Two sites with different patient populations were purposively selected. In-depth interviews were conducted with 26 HIV-infected women (13 adherent and 13 non-adherent) identified following the same procedures as in the quantitative component and 11 of their partners. Ten post-test counseling sessions were also observed.

Results

Counseling and testing. Over 90% of women were offered HIV testing during their first ANC visit as per the Rwandan national guidelines, with no significant difference by HIV status. HIV-infected and -uninfected women virtually universally reported “very strong” or “strong” recommendations from health workers to get tested, but reports of pressure to get tested were restricted to 12-15% of women, with no difference by HIV status. Disclosure rates were high although HIV-infected women were significantly less likely to disclose their results to their partners (84% vs. 96%) and more likely to share them with someone else (73% vs. 61%). About 95% of infected and uninfected women were requested to bring their partners for testing but ultimately only 47% and 61% of their partners, respectively, were tested during the index pregnancy. Forty percent of HIV-infected women and 19% of HIV-uninfected women said they were unaware of their partner’s HIV status and sero-discordance was reported by 21% of infected women and 3% of uninfected women. Among HIV-infected women, non-adherent women were less likely to be offered HIV testing at their first ANC visit when compared to women who adhered to the ARV prophylaxis protocol (88% vs. 95%). Disclosure rates to partners (79% vs. 88%) and others (62% vs. 82%) were lower among women who did not follow the PMTCT protocol. Only 39% of partners of non-adherent women were tested during the index pregnancy compared to 54% of adherent women and far more non-adherent than adherent women said they were unaware of their partners HIV status (47% vs. 34%). Non-adherent women were also significantly more likely to report having an HIV-uninfected partner (25% vs. 17%).

Qualitative data highlight important problems in the quality of HIV counseling and testing services, including top-down pre-test counseling group sessions with limited interaction between health workers and women, post-test counseling sessions that do not sufficiently address women’s immediate psychological needs, blood samples taken without formal consent, and threats of reduced access to labor and delivery services or ARV prophylaxis if women and/or their partners were not tested.

ANC. While the majority of women (62%), whether HIV-infected or -uninfected, made between two and three ANC visits during the index pregnancy, less than one-quarter made the recommended four or more visits. Similarly, more than half of all women made their first ANC visit during their second trimester but ~25% did not receive any ANC until their third trimester. Most women (>85%) indicated that they trusted the ANC staff “very much.” Among HIV-infected women, non-adherent women made significantly fewer ANC visits than adherent women and were also more likely to present at later gestational ages, with 39% of non-adherent women making their first ANC visit in the third trimester compared to 21% of adherent women. Non-adherent women were also less likely to note that they trusted the ANC staff “very much” compared to women who adhered to the ARV prophylaxis protocol (84% vs. 93%).

Delivery. Nearly all women were advised to deliver in a health facility at some point during their pregnancy, but ultimately only about half did so, with no significant difference by HIV status. While both adherent and non-adherent women were equally like to be advised to deliver in a health facility, far fewer non-adherent women (28%) than adherent women (86%) did so.

Qualitative data suggest that lack of transport, a social support network and/or money prevented some HIV-infected women from delivering in a health facility.

Adherence to the ARV prophylaxis (HIV-infected women only). While all adherent women received SD-NVP from a health worker at some point during their pregnancy or at delivery, only 61% of non-adherent women reported receiving it despite being tested for HIV during ANC. Ultimately, all adherent women (per definition) ingested SD-NVP and 85% of non-adherent women who received it ingested it, representing 52% of all non-adherent women. Non-adherent women who received the ARV prophylaxis but did not take it said this was because they had forgotten to do so (30%) or were afraid to take it (30%), their labor had progressed too quickly (20%) or because their husband was present (and presumably they had not disclosed their HIV-status) (20%).

While the infants of all adherent women received a dose of NVP following their birth, only 7% of infants born to non-adherent women ingested it. Even among non-adherent women who delivered in a health facility, only 19% of infants took the ARV prophylaxis. Among the non-adherent women who delivered outside a health facility, only 15% reported that they or a family member brought the newborn to the health facility for NVP ingestion. In 66% of these cases, however, this occurred beyond the recommended time period for infant ingestion of NVP (e.g. greater than 72 hours after delivery). Non-adherent women whose newborns were not brought to health facility most often indicated that they were not aware the child was supposed to come to the health facility (34%), were either ill, too weak or did not have any assistance to bring the child (30%), or did not think the child could get HIV (27%). Qualitative findings suggest that some men were unwilling to defy gender norms and bring their newborn to the health facility for the ARV prophylaxis when women were unable to do so.

Ultimately 42.0% of all 111 non-adherent women reported that neither they nor their child took SD-NVP, 47.0% that they took SD-NVP but that their child had not, 5.5% that only their child had taken SD-NVP, and 5.5% that either they or their child had taken SD-NVP but not at the recommended time.

Infant feeding (HIV-infected women only). Nearly all HIV-infected women (>95%) were advised to exclusively breastfeed their infant during/after their pregnancy and many (~65%) were also counseled about solely using artificial milk. Only 8% of all women, however, were advised specifically to avoid mixed feeding and a similar proportion of non-adherent women received no advice regarding infant feeding whatsoever during/after the index pregnancy. Nearly all (>90%) women had breastfed the index child at some point. Among ever breastfeeding women, ~25% mixed fed their infant, with this occurring more commonly among non-adherent women (35%) than adherent women (23%). Among women who were no longer breastfeeding when interviewed, 90% had weaned at 6 months as per the Rwandan national guidelines, but 18% of non-adherent women had breastfed more than six months compared to 2% of adherent women. Qualitative findings confirm significant misunderstandings regarding the risks of mixed feeding and a prevalent misconception that transmission during breastfeeding occurs primarily when the infant has scratches or cuts in its mouth. The in-depth interviews also highlight the tremendous anxiety that HIV-infected women face when breastfeeding.

Fertility preferences and family planning. HIV-infected women were substantially less likely than uninfected women (8% vs. 52%) to report wanting additional children. Infected women (79%) were more likely to have discussed family planning with a health worker during/after their most recent pregnancy than uninfected women (69%). Modern family planning use (mainly condom use) was more common among infected (46%) than uninfected women (14%). Overall, however, condom use was low, reported by only 31% of infected women and 5% of uninfected women. Among HIV-infected women, women who did not adhere to the PMTCT protocol were less to use modern family planning (35% vs. 56%) and condoms (25% vs. 37%). Qualitative findings suggest that barriers to effective family planning include health facilities' practice of requiring partner approval for female sterilization and men's strong desire for (additional) children and dislike of condoms.

Multivariate results. Multivariate logistical regression was used to examine the determinants of non-adherence to several steps of the PMTCT protocol, including:

1. Not receiving SD-NVP during pregnancy (i.e. before the expected date of delivery);
2. Not delivering in a health facility;
3. Mother and/or infant not ingesting SD-NVP at all or at the recommended time;
4. Mother not ingesting SD-NVP at all or at the recommended time; and
5. Infant not ingesting SD-NVP at all or at the recommended time.

Lower socio-economic status had little effect on women not receiving SD-NVP during pregnancy or not delivering in a health facility but was associated with non-adherence to the ARV prophylaxis protocol. When compared to women who made three or more ANC visits, women who made two or less were more likely to not receive SD-NVP during pregnancy, not deliver in a health facility, report that they or their newborn had not ingested SD-NVP at all or at the recommended time, or report that they alone had not ingested the ARV prophylaxis. Not being offered HIV testing at one's first ANC visit was associated with not receiving SD-NVP before delivery, and with non-adherence of mother-infant pairs and mothers alone. Reporting that one's partner was not tested during the index pregnancy was predictive of mother's not receiving and not ingesting SD-NVP. Not disclosing one's HIV status to someone other than a partner was associated with increased odds of non-adherence in mother-infant pairs and newborns not ingesting SD-NVP at all or at the recommended time. Maternal non-adherence also strongly predicted newborn non-adherence.

Recommendations

- Increasing information, education and communication at the community level to encourage pregnant women to receive ANC starting in their first trimester.
- Ensuring that true consent is obtained from all women who are tested for HIV and that women who decline testing are offered comprehensive pre- and post-natal services.
- Further investigation of the reasons for the provision of inadequate psychological support during post-test counselling sessions so that they can be best addressed: Is it a question of insufficient pre- and in-service training, health workers' subconscious approach to

avoiding burnout, the need for values clarification among health workers, or simply time constraints?

- Additional training for counselors regarding the importance of discussing disclosure with one's partner and at least one other confidante with HIV-infected women.
- Exploring alternate ways of engaging partners in HIV testing and other aspects of the PMTCT program, including discreetly (via letters from health facility staff) inviting partners to receive voluntary counseling and testing, involving partners in all phases of ANC, and working at the community level to promote more male involvement in the health of women and children (USAID, 2005).
- In cases where a SD-NVP is still used as the maternal ARV prophylaxis, providing the drug to women at their first ANC visit regardless of their gestational age as is being done in other sub-Saharan Africa countries, and/or active tracing of women who have not received it by the end of the eighth month of pregnancy.
- In cases where AZT is now provided from 28 weeks gestational age onwards, additional training to ensure that gestational dating is accurate.
- Improving PMTCT record keeping for ANC and delivery, including the printing of standardized national registers and the development of a list of HIV-infected women expected to deliver each month. This should be accompanied by strengthened communication between ANC and delivery units, particularly at sites that refer women to adjacent facilities for delivery.
- Enhanced, explicit and repeated counseling regarding the risks associated with mixed feeding.
- Further exploration of the barriers to the provision of permanent contraception to women who desire it regardless of whether they present with their partners.
- Promotion of effective links between PMTCT and care and treatment services, including use of two-way referral forms and active follow-up of women who are not registered in a care and treatment program within two weeks of referral.

Chapter 1: Background, evaluation objectives and methods

1.1 Introduction

Among the tragic consequences of the HIV/AIDS epidemic, especially in developing countries, is mother-to-child transmission (MTCT) of HIV. In 2005, an estimated 540,000 new infections occurred among children—approximately 1500 per day—almost all through transmission of the virus from mothers during pregnancy, childbirth or breastfeeding and the vast majority in sub-Saharan Africa (UNAIDS/WHO, 2006). Perinatally acquired HIV infection is associated with rapid progression of disease and death, particularly in resource-limited settings (Gray et al, 2001; Dunn D, 2003). Ultimately, over one-third of perinatally HIV-infected children die within 12 months of birth and more than half within two years (Newell et al, 2004).

The United Nations (UN) has called for a 20% reduction in the proportion of HIV-infected infants by 2005 and a 50% reduction by 2010 (United Nations General Assembly, 2001). To this end, the World Health Organization (WHO) and its UN partners are promoting four main approaches to the prevention of mother-to-child transmission (PMTCT) of HIV/AIDS, including: (1) primary prevention of HIV infection; (2) prevention of unintended pregnancies among HIV-infected mothers; (3) prevention of HIV transmission from HIV-infected mothers to their infants; and (4) care, treatment and support for HIV-infected mothers and their children (United Nations General Assembly, 2001).

From 2000 to 2002, the United Nations Joint Programme on HIV/AIDS (UNAIDS) piloted PMTCT programs in 11 resource-poor countries, including in Rwanda where despite a relatively low HIV prevalence rate of 3% (rural areas 2% and urban areas 7%) an estimated 22,000 children under the age of 16 are living with HIV/AIDS and account for nearly 10% of all infections nationwide (Institut National de la Statistique and ORC Macro, 2006). An evaluation of the Rwandan pilot PMTCT program showed favorable outcomes for pre-test counseling and testing uptake with 98% of antenatal care (ANC) clients receiving pre-test counseling and 83% of those undergoing counseling getting tested. While only 40% of the HIV-infected mothers who attended ANC took antiretroviral (ARV) prophylaxis, the uptake rate was the highest of all 11 countries included in the pilot and over three to four times that noted in many of the other countries (Rutenberg et al, 2003).

Based on the positive results from the pilot program, the Government of Rwanda began rolling out PMTCT services nationally in 33 ANC clinics in 2002. Since then, services have scaled up dramatically to 44 clinics in 2003, 120 in 2004, 209 in 2005 and 234 by October 2006 (TRAC, 2006). According to the Rwandan national PMTCT protocol, women are offered voluntary HIV counseling and testing at their first ANC visit and counselors encourage testing of their partners. Pre-test counseling is generally done in groups, while all women receive one-on-one post-test counseling. Rapid tests are used at all sites and thus results are available on the day of testing. HIV-infected women are strongly encouraged to deliver in a health facility. Until recently, single-dose nevirapine (SD-NVP) was the standard antiretroviral (ARV) prophylaxis for women and infants. Women were provided with SD-NVP when they presented for ANC from the third trimester of pregnancy onward and informed to take it at the onset of labor. SD-NVP for infants was available only at the facility and thus women who delivered at home were told to bring their

newborns to the facility within 72 hours of birth. In early 2006, however, a more complex PMTCT regimen was adopted as the standard of care for mother and infant. As part of this new protocol, women receive AZT from 28 weeks gestational age, SD-NVP at the onset of labor and AZT+3TC for one week following delivery. Newborns receive a four-week course of AZT, in addition to SD-NVP within 72 hours of birth. HIV-infected women are also referred to care and treatment (on-site if available and off-site otherwise). With regard to breastfeeding, women are counseled to breastfeed their infants exclusively for six months and then wean rapidly, or alternatively to practice exclusive replacement feeding. Finally, counselors encourage women to have their children tested for HIV at 15 months of age. Early infant diagnosis, which allows for testing of newborns at six weeks of age, is currently limited to a few pilot sites.

Routine monitoring data from 2005 highlight some of the strengths and weaknesses of the national PMTCT program (TRAC, 2006). According to these data, out of the approximately 200,000 women who received ANC, 96% were counseled about HIV testing and 90% underwent testing confirming the successes of the program in these areas. Nationally, however, only 47% of HIV-infected women identified in PMTCT programs delivered in a health facility. Among women who were provided with SD-NVP during their pregnancy, only 54% were documented to have taken the drug. Similarly, only slightly over half (58%) of the children born to HIV-infected women ingested NVP. The percentage of partners of screened women who accepted testing increased substantially from 13% in early 2003 to 33% in late 2005, but still remains low. Regarding child follow-up, 59% of HIV-exposed children were tested for HIV at 15 months of age and 12% were found to be HIV infected.

While these data are useful in identifying areas for improvement in the national program, additional information is needed to understand specific barriers of access to and utilization of PMTCT services so that targeted policy and programmatic interventions can be undertaken. Additionally, as the introduction of more complex ARV prophylaxis regimens for mother and infant alike are likely to be accompanied by many on-the-ground challenges, it is particularly important to highlight lessons learned with regard to access, uptake and ultimately adherence to the complete PMTCT package, particularly ARV prophylaxis ingestion. To this end, the Government of Rwanda, through the Ministry of Health's Treatment and Research AIDS Center (TRAC) and in collaboration with Columbia University's International Center for AIDS Care and Treatment Programs (ICAP) and participation from the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), undertook the evaluation described in this report.

1.2 Objectives

The primary objectives of the evaluation were two-fold:

- 1) To describe experiences with HIV testing among pregnant women (HIV-infected and uninfected) receiving ANC services^a; and

^a Initially, we also planned to identify factors affecting testing uptake during ANC. Pilot testing, however, indicated that the high rates of testing uptake in Rwanda would make it extremely difficult to identify sufficient numbers of women who had declined testing and could serve as a comparison or control group for those who had accepted

2) To describe experiences with and identify factors affecting adherence to the PMTCT protocol, defined as mother-infant pairs ingesting single-dose nevirapine (SD-NVP) at the onset of/during labor for mothers and within 72 hours of delivery for infants, among HIV-infected women receiving ANC services.

We also explored women's (HIV-infected and HIV-uninfected, where appropriate) experiences with other aspects of PMTCT services, including the acceptability of ANC and delivery services; involvement of family members in decisions regarding HIV testing, delivery and ingestion of PMTCT prophylaxis; infant feeding and post-partum family planning knowledge, attitudes and practices; and referral from PMTCT to HIV care and treatment services. As the Rwandan national PMTCT program is currently shifting from a SD-NVP regimen to a more complex regimen, the evaluation was designed to identify successes and challenges related to the delivery of high quality PMTCT services, rather than to a specific ARV prophylaxis regimen.

1.3 Methodology

1.3.a Evaluation design and sites

A cross-sectional evaluation with both quantitative and qualitative components was conducted at 14 public-sector PMTCT sites (Figure 1). All sites had been offering PMTCT services since January 1, 2005 and according to national statistics were expected to have sufficient numbers of HIV-infected women to meet site sampling requirements (see Sections 1.3.b and 1.3.c). Twelve sites were selected for the quantitative component using multi-stage sampling techniques and stratified by:

- Region (Kigali, North/East and South/West);
- Level of development (urban and rural); and
- Performance ("poor performing sites" and "high performing sites" defined using routinely collected TRAC statistics on PMTCT for the year 2005).

testing. We thus modified this study objective to focus exclusively on the testing experience among those who accept it.

Health Center where only 65% of women receiving ANC services accepted HIV testing. HIV prevalence ranged from 3% in Ruhango Health Center to 16% in Gitega Health Center, but was similar to the national average at most of the evaluation sites. At the time of data collection, eight sites also had HIV care and treatment services available on-site but none provided PCR testing for early infant diagnosis.

Table 1. Site characteristics and PMTCT caseloads (January 2005 – September 2005).

Site codes	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Urban site	Yes	Yes	No	No	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes	Yes
No. of deliveries	231	896	265	404	NA*	NA*	NA*	168	139	107	298	NA*	NA*	NA*
No. of women making first visit ANC visit	752	785	560	1071	1013	2809	434	744	904	697	565	1347	1580	1886
No. of women offered HIV test	595	810	560	1048	1013	2695	390	744	904	697	565	1347	1580	1886
No. of women accepting test	595	810	541	954	1013	2695	390	486	904	646	539	1347	1580	1886
No. of women testing infected	26	23	35	32	82	152	51	32	36	31	53	150	253	110
HIV prevalence (%)	4.4	2.8	6.5	3.4	8.0	5.6	14.0	6.6	3.9	4.7	9.8	11.1	16.0	5.8
No. HIV-infected women delivering in health facility	6	5	NA	12	55**	76**	20**	10	30	7	13	NA	NA	NA
No. of HIV-infected women known to have ingested SD-NVP	6	6	NA	12	55	87	17	10	9	5	5	NA	NA	NA
No. of newborns known to have ingested SD-NVP	5	5	NA	11	55	88	17	10	9	4	5	NA	NA	NA
HIV care and treatment services available on-site	No	Yes	Yes	No	Yes	Yes	Yes	No	No	No	No	Yes	Yes	Yes

NA: Data not available.

* No labor and delivery ward on-site.

** Refers to women who were found to be infected at the evaluation site but delivered at an affiliated hospital.

Site codes

1. Gitarama Health Center
2. Ruhango Health Center
3. Mugonero Health Center
4. Busoro Health Center
5. Gihundwe Health Center
6. Ruhengeri Dispensary
7. Nyagatare Health Center

8. Rulindo Health Center
9. Ruhunda Health Center
10. Ryamanyoni Health Center
11. Kabusunzu Health Center
12. Kacyiru Health Center
13. Gitega Health Center
14. Rwamagana Dispensary

1.3.b Quantitative methods

The quantitative component of the evaluation was comprised of a cross-sectional survey of both HIV-uninfected (n=162) and HIV-infected women (n=236). We aimed to recruit 15 HIV-uninfected women and 20 HIV-infected women per site. The sample of HIV-infected women was further divided into those who adhered to the PMTCT protocol, defined as mother-infant pairs who swallowed SD-NVP at the recommended time, and those who did not adhere to the protocol, defined as mother and/or baby not ingesting SD-NVP at all or not at the recommended time. Eligibility criteria for both the HIV-uninfected and HIV-infected sample included being ≥ 18 years of age, having received ANC services at the evaluation site during the index pregnancy, and having either an estimated or confirmed date of delivery in the 12 months preceding data collection.

HIV-uninfected women were recruited when they presented with their infants for routine immunization visits. In order to generate a sampling frame, data collection teams collected ANC cards or infant vaccination cards from all women who presented during the registration period of the immunization session.^b After excluding the cards of women who did not meet the eligibility criteria, the interviewers randomly selected 15 women to participate in the evaluation. If a woman declined participation after being informed about the evaluation, another card was randomly selected from the remaining ANC or infant vaccination cards until 15 women had been enrolled. At sites where ≤ 15 eligible women presented, all were invited to participate. No compensation was offered to participating uninfected women as they were interviewed during routine clinical visits.

HIV-infected women meeting the evaluation eligibility criteria were identified from pre-existing patient registers available at the sites. At each site, the patient registers were used to classify each eligible woman as having potentially^c adhered or not to the national PMTCT protocol. The names of the first 10 potentially adherent and 10 potentially non-adherent women were provided to outreach workers affiliated with the sites who then contacted the selected women at home and invited them to participate in the evaluation. When the information in the registers was not adequate to trace women, the local Association of People Living with HIV/AIDS was enlisted to assist in finding them. If a selected woman refused to participate, another woman in the same adherence sub-category (e.g. adherent or non-adherent) was selected from the patient registers. Women who agreed to participate were asked to return to the facility for an interview and received 1000 RWF to cover their transport costs. Adherence status was confirmed during the interviews and ultimately women's self-reports were used to classify them as adherent or non-adherent to the PMTCT protocol.

Seven female and two male interviewers were recruited in Kigali for data collection. An intensive two-week training which covered basic HIV concepts, the sampling methodology and the evaluation instruments was conducted by the evaluation Investigators and other evaluation

^b As immunization rates are high in Rwanda, recruiting HIV-uninfected women during infant vaccination sessions was assumed to generate an unbiased sample.

^c In many sites, poor data quality in the registers precluded a definitive classification of all women during the sampling phase.

staff. After completing the training, interviewers were divided into three data collection teams, which included a team leader and two to three interviewers. The team leader was responsible for introducing the team to the *Titulaire de Santé*, ensuring that the sampling procedures and evaluation protocol were followed, reviewing completed questionnaires for completeness and consistency, and completing a short facility questionnaire. Interviewers were responsible for explaining the evaluation in detail to eligible women, completing the informed consent process and conducting a face-to-face interview with consenting women using a closed-ended questionnaire.

The questionnaire (available upon request) had 7 sections which covered socio-demographic characteristics, experiences with ANC services, HIV testing and delivery, ARV prophylaxis uptake (HIV-infected women only), infant feeding practices (HIV-infected women only), and family planning knowledge, attitudes and practices. The questionnaire was drafted in French and English, translated into Kinyarwanda, and pre-tested at Gahanga and Kinyinya Health Centers, both in the Kigali region. Modifications to question wording and ordering were done following the pre-test. Interviews lasted an average of 35 minutes. Quantitative data were double-entered in a MS Access database and cleaned using MS Access and Epi-Info. Data analysis was done using SPSS Version 14.0. Comparisons between HIV-infected and -uninfected women, as well as between women who adhered to the national PMTCT protocol and women who did not, were done using the Chi-squared test for categorical variables, and the Student's t test and Mann-Whitney U test for continuous variables. Multivariate logistic regression analysis was conducted to examine determinants of several key outcomes related to adherence to the PMTCT protocol as described in Section 2.9.

1.3.c Qualitative methods

The qualitative component of the evaluation was comprised of in-depth interviews with 26 HIV-infected women and 11 of their partners, as well as observation of 10 post-test counseling sessions. As in the quantitative component of the evaluation, interview candidates were identified from pre-existing patient registers available at the sites, classified as having potentially adhered or not to the national PMTCT protocol and invited by an outreach worker to participate in an interview. Women who agreed were asked to return to the site for the interview and received 1000 RWF to cover their transport costs. Adherence status was confirmed during the interviews and ultimately women's self-reports were used to classify them as adherent or non-adherent to the PMTCT protocol. At the end of the in-depth interview, women were asked if they were willing to invite their partners to participate in a separate in-depth interview. Interviewers did not directly contact partners of women interviewed and, when partners were interviewed, information collected from one member of the dyad was not shared with the other. A convenience sample of post-test counseling sessions were observed over the course of 1-2 days at each site.

Three female interviewers were recruited in Kigali to conduct the in-depth interviews and observe the post-test counseling sessions, and were trained in basic HIV concepts, recruitment procedures and qualitative methods by an evaluation Investigator. The interviewers were responsible for explaining the evaluation in detail to potential participants, completing the

informed consent process, conducting in-depth interviews with consenting women and men, and completing counseling observation checklists when both women and providers consented.

The qualitative interview guide had 10 sections covering the following themes: knowledge and perceptions of HIV/AIDS, attitudes and decisions regarding HIV testing, pre- and post-test counseling experiences and perceptions, disclosure of test results, behavioral beliefs and normative beliefs regarding the PMTCT program, decision-making regarding ARV prophylaxis uptake, experiences with ARV prophylaxis, delivery experiences, attitudes and practices regarding infant feeding, and attitudes and practices regarding family planning. The interview guide was drafted in French and English by the evaluation Investigators based on a casual model of adherence that incorporated potential determinants from the Theory of Planned Behavior and the Health Action Process Approach (Conner and Norman, 2005) and the published literature. The guide was further refined by the qualitative interviewers, translated into Kinyarwanda, and pre-tested at Shiryongi Health Center in Kigali. Modifications to question wording and ordering were done following the pre-test.

Interviewers took notes during the interviews and also tape-recorded the sessions. In-depth interviews were done in one sitting and lasted an average of 55 minutes. Transcripts in Kinyarwanda were prepared by the interviewers using their hand-written notes and the tape-recordings, entered into a word processor and translated into French. Interviewers reviewed the translated transcripts and made any necessary corrections before the text was finalized for coding and analysis. Once the fieldwork was completed, the data were coded using QSR Nudist 6.0. Codes were derived from the evaluation objectives and from themes emerging from the data. The analysis was guided by the Theory of Planned Behavior and the Health Action Process Approach.

Evaluation Investigators developed checklists for the observation of the post-test counseling sessions in English which were subsequently modified in French for use by the Interviewers. The checklists guided the Interviewers in assessing the quality of the information shared and of the communication process during post-test counseling sessions and focused on areas highlighted in the national HIV testing guidelines for counselors. Interviewers rated the counselor's skills in specific areas as "low," "adequate," or "excellent." As the goal of the observation was to gain insight into the interaction between patients and providers, no "performance score" was derived from the checklists. Rather the information gathered during the observations was incorporated with that from the in-depth interviews.

1.4 Ethical considerations

The evaluation protocol was approved by the Research Committee of the Rwandan National AIDS Control Commission (CNLS), as well as by the Institutional Review Boards (IRBs) at Columbia University and the Institute of Tropical Medicine in Antwerp. All interviewers signed a confidentiality statement at the request of the CNLS. Respondents provided written informed consent for both quantitative and qualitative interviews. Both women and providers provided consent before the observation of post-test counseling sessions. No identifying information was collected on the survey questionnaires, tape-recordings, in-depth interview notes or observation

checklists. Completed questionnaires, in-depth interview transcripts and observation checklists were maintained in a locked drawer at Columbia University's office in Kigali. Informed consent forms were maintained in a separate locked drawer at Columbia University's office. Only the Evaluation Officer in charge of the evaluation locally had access to these documents.

1.5 Presentation of results

Quantitative and qualitative results are presented separately in Chapters 2 and 3, respectively. In Chapter 2, we present analyses of the survey data stratified by HIV status and, for HIV-infected women, further stratified by self-reported adherence to the ARV prophylaxis protocol. Additionally, for HIV-infected only, we present socio-demographic and service delivery determinants of: a) women not obtaining SD-NVP from a health facility prior to delivery, 2) women not delivering in a health facility, 3) mother-infant pairs not ingesting SD-NVP, 4) mothers not ingesting SD-NVP; and 5) infants not ingesting SD-NVP. In Chapter 3, we describe respondents' understanding of and experiences with PMTCT services in detail based on the qualitative data.

Chapter 2: Quantitative results

2.1 Recruitment and response rates

Table 2 shows recruitment rates for the quantitative portion of the evaluation, by HIV status, and among HIV-infected women, by adherence to the PMTCT protocol. All uninfected women invited to participate in an interview agreed. At several sites, however, a few such women left the clinic before their interview could be conducted. With regard to HIV-infected women, enrolling the target of 10 non-adherent women per site proved difficult in some sites. This resulted from the small number of potentially non-adherent women meeting the eligibility criteria, several women believed to be non-adherent on the basis of information available in the clinic registers reporting that they had indeed followed the recommended ARV prophylaxis protocol, or because several women believed to be non-adherent could not be located. Ultimately a total of 398 women were interviewed, including 162 HIV-uninfected women and 236 HIV-infected women—125 who reported that both they and their child took the ARV prophylaxis at the recommended time and 111 who reported that either they and/or their child had not taken it at all or at the recommended time

Table 2. Recruitment and response rates by HIV status and, among HIV-infected women, by PMTCT adherence status.

Site codes	1	2	3	4	5	6	7	8	9	10	11	12	All
HIV-uninfected women													
Invited to participate	12	13	13	14	12	16	14	13	15	17	17	16	172
Left before interview	1	0	0	1	0	0	0	0	0	3	3	2	10
Interviewed	11	13	13	13	12	16	14	13	15	14	14	14	162
HIV-infected women													
Adherent													
Sampled from registers	14	10	12	10	10	12	10	9	10	10	10	10	127
Could not be located	0	0	0	0	0	0	1	0	1	0	0	0	2
Invited to participate	14	10	12	10	10	12	9	9	9	10	10	10	125
Interviewed	14	10	12	10	10	12	9	9	9	10	10	10	125
Non-adherent													
Sampled from registers	9	10	10	11	11	16	15	12	10	14	10	11	139
Could not be located	1	4	5	2	0	0	9	0	0	0	2	5	28
Invited to participate	8	6	5	9	11	16	6	12	10	14	8	6	111
Interviewed	8	6	5	9	11	16	6	12	10	14	8	6	111
Total number interviewed	33	29	30	32	33	44	29	34	34	38	32	30	398

Site codes

- | | |
|---------------------------|------------------------------|
| 1. Gitarama Health Center | 7. Nyagatare Health Center |
| 2. Ruhango Health Center | 8. Rulindo Health Center |
| 3. Mugonero Health Center | 9. Ruhunda Health Center |
| 4. Busoro Health Center | 10. Ryamanyoni Health Center |
| 5. Gihundwe Health Center | 11. Kabusunzu Health Center |
| 6. Ruhengeri Dispensary | 12. Kacyiru Health Center |

2.2 Participant characteristics

Patterns by HIV status

Participant characteristics are summarized in Table 3. As per the sampling methodology, no significant difference is noted by HIV status in provincial or geographic residence. HIV-infected women, however, were significantly older than their HIV-uninfected counterparts (30 mean years vs. 28 mean years). While the majority of both HIV-infected (91%) and HIV-uninfected women (73%) were married or in a consensual union at the time of data collection, HIV-infected women were more likely than HIV-uninfected women to be single (11% vs. 6%), divorced (6% vs. 2%) or widowed (9% vs. 2%). Similarly, 15% of HIV-infected women reported being married or living with a partner who had another wife/partner compared to 9% of their HIV-uninfected counterparts, although this difference was not statistically significant. Overall, 21% of women interviewed had completed no or minimal schooling (0-3 years), 40% had completed primary school, and only 5% had attained higher education, with no significant differences by HIV status. While most respondents, whether HIV-infected (78%) or -uninfected (74%), were subsistence agricultural workers, HIV-infected women (10%) were more likely to be employed in unskilled labor than HIV-uninfected women (4%). Catholic and Evangelical churches (mostly Pentecostals) constituted the majority of religious affiliations in the evaluation sample, including in 65% of HIV-infected women and 74% of HIV-uninfected women, with no statistical difference between groups. HIV-infected women were slightly but significantly more parous than HIV-uninfected women (4.1 mean children vs. 3.4 mean children) and also tended to have more living children (3.1 mean living children vs. 2.8 mean living children), although there were no differences in household size (5.4 mean people vs. 5.2 mean people). HIV-infected women were also more likely to have had their last delivery 6 or more months before the interview than were HIV-uninfected women (43% vs. 26%). With regard to socio-economic status, while no difference by HIV status was observed in the likelihood of having a tile or iron sheeted roof, HIV-infected women were significantly less likely to use electricity or a petrol lamp/candle to light their homes (31% vs. 52%) or have a functioning radio (36% vs. 59%) than HIV-uninfected women.

Patterns by PMTCT adherence status

Among the 236 HIV-infected women, no significant differences in respondents' age, marital status, occupation, religious affiliation, parity, number of living children or measures of socio-economic status were observed between women who reported that they and their children ingested SD-NVP at the recommended time and those who reported not adhering to the ARV prophylaxis protocol. Non-adherent women, however, were significantly less educated than adherent women, with 56% of the women who did not adhere to the PMTCT ARV prophylaxis protocol having completed no or minimal schooling (0-3 years) compared to 36% of those who took SD-NVP as per the national protocol. Non-adherent women were also more likely than adherent women to live in smaller households than adherent women (5.1 mean people vs. 5.7 mean people).

Table 3. Participant characteristics by HIV status and, among HIV-infected women, by PMTCT adherence status.

	All women by HIV status				p-value	HIV-infected women by adherence status				
	Uninfected n=162		Infected n=236			Adherent n=125		Non Adherent n=111		p- value
	n	%	n	%		n	%	n	%	
Residential area										
Urban	82	50.6	115	48.7	0.710	65	52.0	50	45.0	0.290
Rural	80	49.4	121	51.3		60	48.0	61	55.0	
Provincial residence										
Kigali city	28	17.3	36	15.3	0.823	20	16.0	16	14.4	0.200
North/East	72	44.4	104	44.1		48	38.4	56	50.5	
South/West	62	38.3	96	40.7		57	45.6	39	35.1	
Age (years)										
Mean		28.3		30.2	0.002		30.7		29.8	0.200
18-19	5	3.1	4	1.7	0.120	3	2.4	1	0.9	0.300
20-24	53	32.7	41	17.4		17	13.6	24	21.6	
25-29	38	23.5	61	25.8		31	24.8	30	27.0	
30-34	37	22.8	72	30.5		42	33.6	30	30.5	
35-39	19	11.7	39	16.5		24	19.2	15	13.5	
≥40	10	6.2	19	8.1		8	6.4	11	9.9	
Marital status										
Married	67	41.4	64	27.1	<0.001	40	32.0	24	21.6	0.120
Consensual union	80	49.4	109	46.2		55	44.0	54	48.6	
Single	9	5.6	26	11.0		9	7.2	17	15.3	
Divorced/ Separated	3	1.9	15	6.4		7	5.6	8	7.2	
Widowed	3	1.9	22	9.3		14	11.2	8	7.2	
Among those in union, partner has other partner/wife	13	8.8	25	15.0	0.097	14	15.4	11	14.5	0.869
Education level										
None (0 years)	28	17.3	57	24.2	0.266	21	16.8	36	32.4	0.045
Very low (1-3 years)	32	19.8	48	20.3		24	19.2	24	21.6	
Primary school (4-6 years)	73	45.1	88	37.3		54	43.2	34	30.6	
Intermediate (7-9 years)	19	11.7	34	14.4		20	16.0	14	12.6	
High (>9 years)	10	6.2	9	3.8		6	4.8	3	2.7	

Table 3. Participant characteristics by HIV status and, among HIV-infected women, by PMTCT adherence status, continued.

Occupation									
Housewife/ Unemployed	18	11.4	30	12.9		18	14.6	12	10.6
Unskilled labor	7	4.4	23	9.9	0.005	11	8.9	12	10.9
Subsistence agricultural worker	123	77.8	173	74.2		91	74.0	82	74.5
Skilled labor/ Professional	10	6.4	7	3.0		3	2.4	4	3.6
Partner occupation									
Unemployed/ Unskilled	32	18.7	23	15.6	0.504	18	19.4	14	17.9
Subsistence agricultural worker	108	63.2	102	69.4		56	60.2	52	66.7
Skilled labor/ Professional	31	18.1	22	15.0		19	20.4	12	15.4
Religion									
None	0	0.0	10	4.2	0.027	4	3.2	6	5.4
Catholic	73	45.1	86	36.4		41	32.8	45	40.5
Protestant	8	4.9	23	9.7		12	9.6	11	9.9
Adventist	32	19.8	41	17.4		26	20.8	15	13.5
Muslim	3	1.9	8	3.4		5	4.0	3	2.7
Evangelical churches	46	28.4	68	28.5		37	29.6	31	27.9
Parity									
Mean		3.4		4.1	0.010		4.2		4.0
1	37	22.8	22	9.3	<0.001	10	8.0	12	10.8
2-3	60	37.0	79	33.5		41	32.8	38	34.2
≥4	65	40.1	135	57.2		74	59.2	61	55.0
Number of living children									
Mean		2.8		3.1	0.089		3.1		3.0
0-1	43	26.5	38	16.1	0.038	20	16.0	18	16.2
2-3	69	42.6	112	47.5		57	45.6	55	49.5
≥4	50	30.9	86	36.4		48	38.4	38	34.2
Time since delivery of index pregnancy (months)									
Mean		3.7		5.5	0.089		5.5		5.5
0-3	105	64.8	75	32.1	<0.001	40	32.0	35	32.1
4-6	15	9.3	58	24.8		31	24.8	27	24.8
>6	42	25.9	101	43.2		54	43.2	47	43.1

Table 3. Participant characteristics by HIV status and, among HIV-infected women, by PMTCT adherence status, continued.

Number of people in household (including respondent)										
Mean		5.2		5.4	0.319		5.7		5.1	0.023
≤3	29	17.9	29	12.3		17	13.6	12	10.8	
4-6	92	56.8	150	63.6	0.240	69	55.2	81	73.0	0.010
≥7	41	25.3	57	24.2		39	31.2	18	16.2	
Main means of lighting in home										
Electricity	18	11.3	7	3.0	<0.001	4	3.2	3	2.7	0.900
Petrol lamp/ Candle	65	40.9	65	27.5		33	26.4	32	30.1	
Paraffin wick	69	43.4	149	63.1		81	64.8	68	60.2	
Fire wood	7	4.4	15	6.4		7	5.6	8	7.1	
Main material in house roof										
Tiles/Iron sheets	142	87.7	206	88.0	0.573	111	89.5	95	86.4	0.500
Plastic sheeting	1	0.6	4	1.7		1	0.8	3	2.7	
Grass thatched	19	11.7	24	10.3		12	9.7	12	10.9	
Household has functioning radio										
	91	58.7	82	36.0	<0.001	48	40.0	34	31.5	0.180

2.3 HIV testing experiences

Patterns by HIV status

As Table 4 shows, most women (>80%) knew that they would be offered HIV testing as part of their ANC, although HIV-infected women were slightly but significantly less likely to have had this information than their HIV-uninfected counterparts (80% vs. 88%). Among the women who knew that HIV screening would be offered as part of their routine ANC, over half had learned this from family or friends, a third from health workers or through interaction with the health system during a prior pregnancy, and about one-tenth from the radio or public service announcements.

Ultimately, 92% of women interviewed reported having been offered HIV testing during their first ANC visit as per the Rwandan national guidelines, with no statistically significant difference by HIV status. Three percent of HIV-infected women noted that they had been tested prior to the index pregnancy and thus were aware of their HIV status when they first presented for ANC services. While the vast majority of women (>89%) reported that the explanations they received about the test had been clear, HIV-infected women were more than twice as likely as HIV-uninfected women to indicate that they had unanswered questions at the end of their pre-

counseling sessions (10% vs. 4%). Most of these women said that they would have wanted more information on partner discordance and risks of MTCT transmission, including those due to breastfeeding. While HIV-infected and -uninfected women virtually universally reported “very strong” or “strong” recommendations from health workers to get tested, reports of “pressure” to get tested were restricted to 12-15% of women, with no difference by HIV status. About 95% of women regardless of HIV status underwent testing the same day it was offered and 92% of them received their results on the day of testing itself.

Data not shown indicate that most women accepted testing because they wanted to know their status, although this was reported more frequently by HIV-infected women (92%) than by HIV-uninfected women (77%). Nearly twice as many HIV-infected (31%) as -uninfected (16%) women also reported accepting testing because they feared that they were infected and/or did not trust their partners. A small number of women, whether HIV-infected (13%) or -uninfected (9%), indicated that their decision to undergo testing was bolstered by the availability of HIV drugs at the health facility.

Most women discussed getting tested for HIV with their partners or with someone else (>68%) prior to their ANC visit. HIV-infected women, however, were significantly less likely to speak to their partners about HIV testing before presenting for ANC than were HIV-uninfected women (81% vs. 94%). When women did discuss getting testing with their partners, they often reported waiting for their partner’s permission before getting tested, although this was reportedly done less frequently among HIV-infected than -uninfected women (56% vs. 70%). Disclosure rates were generally high although HIV-infected women were significantly less likely to disclose their results to their partners (84% vs. 96%) and more likely to share them with someone else (73% vs. 61%). Among the few women who reported not disclosing their status to their partner, many indicated because this was because their partner was not available or no longer alive—reported less frequently among HIV-infected (62%) than -uninfected women (100%)—or because it was not necessary—reported by approximately 32% of all women (data not shown). A fair number of HIV-infected women who did not disclose their infection status to their partners said this was because they were afraid (31%), or feared their partner would get violent (21%) or leave them (21%).

About 95% of both HIV-infected and -uninfected women were requested to bring their partners for testing by a health worker but ultimately only 47% and 61% of partners of HIV-infected and -uninfected women, respectively, were tested during the index pregnancy. More than half (56%) of the HIV-infected women’s partners and 70% of the HIV-uninfected women’s partners who did not undergo HIV testing during their pregnancy reportedly had been tested previously. Nearly all women whose partners had ever been tested for HIV reported that they had shared their results with them, although disclosure was significantly less likely to HIV-infected than -uninfected women (92% vs. 97%). Ultimately, however, 40% of HIV-infected women and 19% of HIV-uninfected women reported being unaware of their partner’s HIV status. Sero-discordance was also reported by 21% of HIV-infected women and 3% of HIV-uninfected women. Interestingly, despite learning of their HIV status during their recent testing experience, HIV-infected women were significantly more likely to indicate that they would recommend a friend get tested than HIV-uninfected women (98% vs. 93%).

Patterns by PMTCT adherence status

Among HIV-infected women, several significant differences by adherence to the PMTCT protocol emerged. Non-adherent women were marginally statistically less likely to be offered HIV testing at their first ANC visit when compared to women who adhered to the ARV prophylaxis protocol (88% vs. 95%). Although there was no difference in the likelihood of knowing they would be offered HIV testing during ANC by PMTCT adherence status, non-adherent women were less likely to discuss getting tested with their partners prior to obtaining ANC care than adherent women (75% vs. 85%). Data not shown indicates that non-adherent women were far less likely to report that their decision to get tested was driven (at least in part) by the availability of HIV drugs at the health facility (8% vs. 17%) and also substantially more likely to note that they had been obligated to get tested by a health care worker or that testing was mandatory (6% vs. 1%). Disclosure rates to partners (79% vs. 88%) and others (62% vs. 82%) were also lower among women who did not follow the PMTCT protocol, although only the latter difference was statistically significant. When asked why they had not disclosed their results to their partners, fewer non-adherent women said that they were afraid to do so (22% vs. 46%) or afraid that their partners would leave them than adherent women (17% vs. 27%) but more non-adherent women feared their partners would be violent (33% vs. 9%). While non-adherent women were as likely as adherent women to report being asked to bring their partners for testing (~95%) and to state that their partners had been tested previously (~35%), only 39% of partners of non-adherent women were tested during the index pregnancy compared to 54% of adherent women. Not surprisingly, then, far more non-adherent than adherent women were unaware of their partners HIV status (47% vs. 34%). Non-adherent women were also significantly more likely to report having an HIV-uninfected partner (25% vs. 17%).

Table 4. HIV counseling and testing experiences by HIV status and, among HIV-infected women, by PMTCT adherence status.

	All women by HIV status				HIV-infected women by adherence status					
	Uninfected n=162		Infected n=236		p-value	Adherent n=125		Non Adherent n=111		p-value
	n	%	n	%		n	%	N	%	
Was aware of HIV test before presenting for ANC	142	87.7	189	80.1	0.047	102	81.6	87	78.4	0.500

Table 4. HIV counseling and testing experiences by HIV status and, among HIV-infected women, by PMTCT adherence status, continued.

Source of information on HIV testing in ANC										
Family/friend	94	52.5	129	55.1	0.590	69	52.7	60	58.3	0.390
Health worker/tested in previous pregnancy	68	37.9	78	33.3	0.330	46	35.1	32	31.0	0.510
Church	2	1.1	2	0.9	0.750	1	0.8	1	1.9	0.860
Radio/public service announcement	15	8.4	25	10.7	0.430	15	11.5	10	9.7	0.660
Time HIV test was offered *										
First ANC visit	150	92.6	217	91.9	0.814	119	95.2	98	88.3	0.051
Other ANC visit	12	7.4	13	5.5		2	1.6	11	9.9	
Tested before pregnancy	0	0.0	6	2.5		4	3.2	2	1.8	
Explanation before testing was unclear	7	4.3	24	10.2	0.032	9	7.1	15	13.5	0.110
Level of health worker's insistence on respondent getting tested					0.248					0.800
Very strong	152	95.0	214	90.7		114	91.2	100	90.1	
Strong	7	4.4	19	8.1		10	8.0	9	8.1	
Not strong	1	0.6	3	1.3		1	0.8	2	1.8	
Felt pressured to get tested	24	14.8	28	11.8	0.330	12	9.6	16	14.4	0.250
Discussed getting tested with husband / partner	153	94.4	187	80.6	<0.001	105	85.4	82	75.2	0.051
Waited for husband's/partner's permission before getting tested	106	70.2	104	55.9	0.007	61	58.7	43	52.4	0.397
Discussed getting tested with someone else	115	71.0	160	67.8	0.500	89	71.2	71	64.0	0.230
Tested the same day it was offered	151	93.8	226	95.7	0.362	118	94.4	108	97.3	0.300

Table 4. HIV counseling and testing experiences by HIV status and, among HIV-infected women, by PMTCT adherence status, continued.

Timing of receipt of test results										
Same day as tested	148	91.9	217	91.9	0.320	117	93.7	100	90.1	0.400
At a later ANC visit	6	3.7	4	1.7		1	0.8	3	2.7	
Next day/week after test	7	4.3	15	6.4		7	5.6	8	7.2	
Disclosed results to husband / partner	155	95.7	198	83.9	<0.001	110	88.0	88	79.3	0.070
Disclosed results to someone else	99	61.1	172	72.9	0.013	103	82.4	69	62.2	<0.001
Was asked to bring husband / partner for testing	154	95.1	222	95.3	0.920	118	95.9	104	94.5	0.600
Husband/partner tested during pregnancy	98	60.5	111	47.0	0.008	68	54.4	43	38.7	0.016
If not, husband ever tested	40	70.2	45	55.6	0.082	20	35.1	25	36.8	0.990
If husband ever tested, husband / partner disclosed results to respondent	133	97.1	143	91.7	0.048	83	94.3	60	88.2	0.180
Husband's/ partner's HIV status										
Infected	4	2.5	92	39.0	<0.001	61	48.8	31	27.9	0.004
Uninfected	128	79.8	49	20.8		21	16.8	28	25.2	
Not tested/ Unknown	30	18.5	35	40.3		43	34.4	52	46.8	
Would recommend HIV test to sister or friend	151	93.2	232	98.3	0.009	124	99.2	108	97.3	0.300

* Chi-square test compares proportion of women who were offered testing at first ANC visit vs. at any other time.

2.4 Experiences with ANC services

Patterns by HIV status

The majority of women (62%), whether HIV-infected or -uninfected, made between two and three ANC visits during the index pregnancy, as shown in Table 5. Less than one-quarter of all women made the recommended four or more visits. No significant differences in self-reported gestational age at first ANC visit were observed by HIV status, with more than half of all women presenting during their second trimester. A fair number of women (~25%), however, did not receive any ANC until their third trimester. Most (~40%) women reported traveling between a half hour and one hour to reach the ANC facility and another third traveled more than an hour, with no difference by HIV status. The median price paid for all ANC did not vary by HIV status and was 200 RWF. Regardless of how much women paid for their ANC, most (~50%) found the cost acceptable or low (~40%). Nearly all women and slightly but not significantly more HIV-infected women than HIV-uninfected women were encouraged to return for additional ANC by the facility staff (98% vs. 94%). Most (>85%) indicated that they trusted the ANC staff “very much.”

Patterns by PMTCT adherence status

Substantial and significant differences in the number of ANC visits, the gestational age at first ANC visits and level of confidence in the ANC staff were found between women who followed the national ARV prophylaxis protocol and those who did not. Non-adherent made significantly fewer ANC visits than adherent women (2.5 mean visits vs. 3.1 mean visits). They were also more likely to present at later gestational ages, with 39% of non-adherent women making their first ANC visit in the third trimester compared to 21% of adherent women. Women who did not take or whose infants did not take SD-NVP at all or at the recommended time were also less likely to note that they trusted the ANC staff “very much” compared to women who adhered to the ARV prophylaxis protocol (84% vs. 93%).

Table 5. Experiences with ANC by HIV status and, among HIV-infected women, by PMTCT adherence status.

	All women by HIV status				p-value	HIV-infected women by adherence status				
	Uninfected n=162		Infected n=236			Adherent n=125		Non Adherent n=111		p-value
	n	%	n	%		n	%	n	%	
Number of ANC visits										
1	20	12.3	33	14.0	0.566	10	8.0	23	20.7	0.008
2-3	106	65.4	142	60.2		76	60.8	68	59.5	
≥ 4	36	22.2	61	25.8		39	31.2	22	19.8	

Table 5. Experiences with ANC by HIV status and, among HIV-infected women, by PMTCT adherence status, continued.

Gestational age at first ANC visit (months)										
2-3	27	16.7	39	16.5	0.703	27	21.6	12	10.8	0.007
4-6	95	58.6	130	55.1		72	57.6	58	52.3	
≥ 7	40	24.7	67	28.4		26	20.8	41	36.9	
Travel time to reach ANC facility (minutes)										
≤ 30	41	25.3	39	16.5	0.099	22	17.6	17	15.3	0.642
31-60 minutes	64	39.5	103	43.6		51	40.8	52	46.8	
> 60 minutes	57	35.2	94	39.8		52	41.6	42	37.8	
Price paid for ANC (RWF)										
0	43	27.2	67	28.4	0.920	35	28.0	32	28.4	0.380
1-200	57	36.1	78	33.1		47	37.6	31	27.9	
201-500	41	25.9	63	26.7		29	23.2	34	30.6	
501-1000	15	9.5	24	10.2		13	10.4	11	9.9	
≥ 1000	2	1.3	4	1.7		1	0.8	3	2.7	
If paid for ANC, perception of cost										
High	13	11.4	21	12.4	0.660	13	14.4	8	10.1	0.590
Acceptable	53	46.5	86	50.9		43	47.8	43	54.4	
Low	48	42.1	62	36.7		34	37.8	28	35.4	
Encouraged to return for additional ANC visit	152	93.8	230	97.6	0.070	122	97.6	108	97.3	0.880
Level of trust in ANC staff *										
Very much	139	85.8	209	88.6	0.796	116	92.8	93	83.8	0.012
Somewhat	15	9.7	21	8.9		6	4.8	15	13.3	
Not at all	1	0.6	1	0.4		0	0.0	1	0.9	
Do not know/Refused to answer	5	3.1	4	1.7		3	2.4	2	1.8	

* Chi-square test compares proportion of women who “very much” trusted the ANC staff vs. all other women.

2.5 Experiences with delivery

Patterns by HIV status

As depicted in Table 6, nearly all women were advised to deliver in a health facility at some point during their pregnancy, with slightly but significantly more HIV-infected women receiving this advice (100% vs. 95%). Despite this recommendation, only about half of all women interviewed ultimately delivered in a health facility, with no significant difference by HIV status. When asked who participated in the decision regarding the place of delivery, most women indicated that they had some say in the decision themselves (~50%). Many (~25%) indicated that their partners were also involved in the decision, although this was less common among HIV-infected women than -uninfected women (20% vs. 28%). HIV-infected women were also more likely to report that the ANC clinic staff had participated in the decision than were HIV-uninfected women (16% vs. 4%). Women reported spending an average of 1500 RWF for their delivery. HIV-infected women had significantly fewer out-of-pocket costs than HIV-uninfected women (median: 1200 RWF vs. median: 1950 RWF). Nonetheless, there was no significant difference in ratings of the acceptability of the cost, with about 40% of all women noting it was “acceptable.”

Patterns by PMTCT adherence status

While both adherent and non-adherent women were equally like to be advised to deliver in a health facility, there were strong and highly significant differentials in the ultimate place of delivery by HIV status. Only 28% of non-adherent women delivered in a health facility compared to 86% of adherent women. Non-adherent women were more likely to report that they were involved in the decision regarding the place of delivery (58% vs. 44%) and less likely to report that their partners (16% vs. 22%) or ANC clinic staff (7% vs. 22%) were involved when compared to women who followed the ARV prophylaxis protocol. Despite being less likely to deliver in a health facility, non-adherent women reported paying more on average for their deliveries than adherent women (median: 2000 RWF vs. median: 1190 RWF), although this difference was not significant.

Table 6. Experiences with delivery by HIV status and, among HIV-infected women, by PMTCT adherence status.

	All women by HIV status				p-value	HIV-infected women by adherence status				
	Uninfected n=162		Infected n=236			Adherent n=125		Non Adherent n=111		p-value
	n	%	n	%		n	%	n	%	
Place of delivery										
Health facility	87	53.7	139	59.1	0.623	108	86.4	31	28.2	<0.001
Respondent's or family member's home	68	42.0	87	37.0		15	12.0	72	65.4	
En route to health center	7	4.3	9	3.8		2	1.6	7	6.4	
Involved in decision about delivery location *										
Respondent	127	54.3	163	50.6	0.374	83	44.9	80	58.4	0.016
Husband/partner	66	28.2	63	19.6	0.016	41	22.2	22	16.1	0.172
Other family member(s)	16	6.9	28	7.8	0.429	16	8.5	12	8.8	0.972
ANC clinic staff	9	3.8	50	15.5	< 0.001	41	22.2	9	6.6	< 0.001
Other	16	6.8	18	5.6	0.538	4	2.1	14	3.6	0.002
Advised to deliver in health facility during pregnancy	153	95.0	234	99.6	0.003	125	100.0	109	99.1	0.300
Price paid for delivery (RWF)										
Median (range)	1950 (0-42000)		1200 (0-71000)		0.012	1190 (0-25000)		2000 (0-71000)		0.199
0	5	5.8	28	20.1	0.008	23	21.3	5	16.1	0.545
1-2000	44	51.2	68	48.9		54	50.0	14	45.2	
>2000	37	43.0	43	30.9		31	28.7	12	38.7	
If paid for delivery, perception of cost										
High	16	19.8	31	28.7	0.140	24	29.3	7	26.9	0.800
Acceptable	33	40.7	49	44.4		35	42.7	13	50	
Low	32	39.5	29	26.9		23	28	6	23.1	

* May sum to more than 100% because of multiple responses.

2.6 Experiences with PMTCT prophylaxis (HIV-infected women only)

As shown in Table 7, the majority of HIV-infected women interviewed (>87%) were well aware that HIV could be transmitted from mother-to-child during labor, delivery and breastfeeding. Far fewer (35%), however, knew about transmission risks during pregnancy. There was no significant difference regarding knowledge of mother-to-child transmission risks by adherence status. Most women (~95%), regardless of whether they followed the ARV prophylaxis protocol, reported that a health worker discussed the risks of mother-to-child-transmission during or after their pregnancy. For the vast majority of women, the risks of MTCT were raised when they received their HIV test results (>92%) and/or at another ANC visit (>64%). Only 20% of non-adherent women and 53% of adherent women, however, reported discussion of MTCT at the time of their delivery. Similarly, only 35% and 52% of non-adherent and adherent women, respectively, indicated that MTCT risks were discussed after their delivery.

Not surprisingly, while all adherent women received SD-NVP from a health worker at some point during their pregnancy or at delivery, only 61% of non-adherent women reported receiving it. Among those who did receive the ARV prophylaxis during their pregnancy, most received it during their HIV post-test counseling (non-adherent 57% vs. adherent 44%), or at another ANC visit they or their husband made (for HIV testing) (non-adherent 41% vs. adherent 48%). Few women (~6%) who received SD-NVP during pregnancy or delivery, whether adherent or not, indicated that the health workers explanation of when and how to take the pill was unclear. Most women who received SD-NVP, regardless of adherence status (>75%) discussed whether or not to take the drug with their partners and/or with someone else, although discussion with family, friends or others was less common among non-adherent women (53%) than adherent women (71%). Among the women who did discuss taking SD-NVP with their partners, the majority (~65%) waited for their partners' permission before making a decision. In all but a small handful of cases, women reported that their partners were supportive (~85%) of their taking the ARV prophylaxis. In several cases and more frequently among non-adherent women than adherent women, however, women reported that their partners were not supportive (9% vs. 1%).

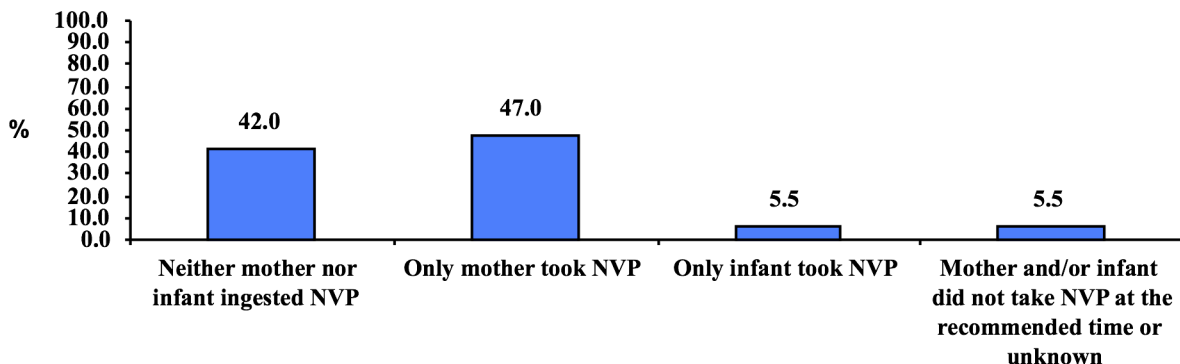
Ultimately, all adherent women (per definition) ingested SD-NVP and 85% of non-adherent women who received it ingested it. Non-adherent women who received the ARV prophylaxis but did not take it said this was because they had forgotten to do so (30%) or were afraid to take it (30%), their labor had progressed too quickly (20%) or because their husband was present (and presumably they had not disclosed their HIV-status) (20%) (data not shown). Among women who ingested SD-NVP, the majority, but significantly fewer non-adherent than adherent women, reported taking it at the onset of labor (58% vs. 70%). Women who ingested the drug at another point before, during or after their delivery explained that this was because they had been instructed to do so by a health worker (40%), their labor occurred too quickly or they had not realized they were in labor (25%), they had not received specific instructions about when to take the ARV prophylaxis (17%), or because they had simply forgotten to take it then (14%).

While the infants of all adherent women received a dose of NVP following their birth, only 7% of infants born to non-adherent women ingested it. Data not shown suggests that even among the non-adherent women who delivered in a health facility, only 19% of infants took the ARV prophylaxis, and that uptake was unknown for another 6%. Among the non-adherent women

who delivered outside a health facility, only 15% reported that they or a family member brought the newborn to the health facility for NVP ingestion. In 66% of these cases, however, this occurred beyond the recommended time period for infant ingestion of NVP (e.g. greater than 72 hours after delivery). Non-adherent women whose newborns were not brought to health facility most often indicated that they were not aware the child was supposed to come to the health facility (34%), were either ill, too weak or did not have any assistance to bring the child (30%), or did not think the child could get HIV (27%). Only 15% mentioned that it was because the health facility was too far.

As indicated in Figure 2, ultimately 42.0% of non-adherent women reported that neither they nor their child took SD-NVP, 47.0% that they took SD-NVP but that their child had not, 5.5% that only their child had taken SD-NVP, and 5.5% that either they or their child had taken SD-NVP but not at the recommended time. Appendices A and B show the pathways to adherence and non-adherence for all HIV-infected women in the study.

Figure 2. Types of non-adherence (mother-infant pairs) to the PMTCT protocol (n=111).



While the majority of all women reported being informed to have their child tested for HIV in the future, significantly fewer non-adherent women (74%) reported receiving this information than adherent women (92%). Just over one-third of women (39%) noted that they had been referred to HIV care and treatment services following their delivery with no difference by adherence status. While great and statistically significant variation in referral rates were seen by site (Busoro and Ruhunda 12% vs. Gihundwe 95%) and region (Kigali 28% vs. South/West 50%), no significant differences were observed by facility location (urban 44% vs. rural 35%) (data not shown). About one-third of women, whether adherent or not, reported having received home visits by an outreach worker either during or after their pregnancy. Non-adherent women, however, were significantly less likely to report that they received food supplements during or after their pregnancy than adherent women (36% vs. 21%).

Table 7. Experiences with PMTCT prophylaxis among HIV infected women by PMTCT adherence status.

	Adherent n=125		Non Adherent n=111		p-value
	n	%	n	%	
Knowledge regarding MTCT risks *					
During pregnancy	46	36.8	38	34.2	0.170
During labor and delivery	112	89.6	97	87.4	0.280
Through breastfeeding	116	92.8	98	88.3	0.230
Health worker discussed MTCT risks	119	95.2	105	95.5	0.927
Timing of discussion regarding MTCT risks *					
Upon receipt of HIV results	110	92.4	97	95.1	0.400
At another ANC visit	89	74.8	65	63.7	0.070
At/during delivery	63	52.9	20	19.6	<0.001
After delivery	62	52.1	36	35.3	0.010
At child consultation	49	41.2	40	39.2	0.800
Received SD-NVP from health worker at any point during pregnancy	125	100.0	68	61.3	<0.001
If received drugs, timing of receipt					
Upon receipt of HIV results	55	44.0	39	57.4	0.070
At another ANC visit/When husband was tested	60	48.0	28	41.2	
At/during delivery	10	8.0	1	1.5	
Explanation of how/when to take PMTCT drugs was unclear	6	5.6	5	7.4	0.465
Discussed taking PMTCT drugs with husband/partner	97	78.9	47	70.1	0.180
Discussed taking PMTCT drugs with someone else	89	71.2	36	52.9	0.010
Waited for husband's/partner's permission before making a decision	62	66.7	28	63.6	0.727
Husband's/partner's reaction regarding PMTCT drugs					
Supportive	81	85.3	39	82.2	
Not supportive	1	1.1	4	8.9	0.053
Indifferent	13	13.7	4	8.9	
If woman received SD-NVP at any point during pregnancy/delivery, drug was ingested	125	100.0	58	85.3	<0.001
If woman ingested SD-NVP, timing of ingestion					
When labor started	88	70.4	33	57.9	
Later during labor	37	29.6	21	36.8	0.036
After delivery	0	0.0	1	1.8	
Before labor started	0	0.0	2	3.5	

Table 7. Experiences with PMTCT prophylaxis among HIV infected women by PMTCT adherence status, continued.

If woman delivered at home, newborn brought to health facility for SD-NVP	17	100.0	12	15.2	<0.001
If newborn brought to health facility for SD-NVP, timing of newborn's visit					
Day of delivery	9	52.8	2	16.7	<0.001
1 day after delivery	8	47.1	1	8.3	
2 days after delivery	0	0.0	1	8.3	
≥3 days after delivery	0	0.0	8	66.7	
Newborn ingested SD-NVP	125	100.0	8	7.2	<0.001
Advised to have newborn tested for HIV in future	115	92.0	82	74.5	<0.001
Referred for HIV care and treatment during/after pregnancy	52	41.6	40	36.4	0.412
Received ≥1 home visit by health worker during/after pregnancy	45	36.0	35	32.9	0.532
Received food supplements during/after pregnancy	45	36.0	23	20.9	0.010

* May sum to more than 100% because of multiple responses.

2.7 Infant feeding practices (HIV-infected women only)

As indicated in Table 8, nearly all HIV-infected women (>95%) interviewed indicated that a health worker recommended they exclusively breastfeed their infant, with no difference by adherence status. Many women, but significantly fewer non-adherent than adherent women (60% vs. 72%), were also counseled about solely using artificial milk. Only 8% of women regardless of PMTCT adherence status, however, were advised specifically to avoid mixed feeding and fully 8% of non-adherent women reported receiving no advice regarding infant feeding whatsoever during or after the index pregnancy. Among those women who received information regarding exclusive breastfeeding, virtually all (>95%) were counseled to do so for 6 months, with no difference by whether the women followed the PMTCT protocol or not.

Most women reported discussing feeding options with their husbands/partners, with no significant difference by adherence status (non-adherent 62% vs. adherent 71%). Similarly, most women, regardless of whether they followed the PMTCT protocol or not, said they had waited for their husbands/partners permission to adopt a certain feeding method before selecting it (non-adherent 61% vs. adherent 72%).

Nearly all women reported ever breastfeeding the index child, with small but significant differences by adherence status (non-adherent 98% vs. adherent 91%). Among ever breastfeeding women, non-adherence to the prophylaxis protocol was associated with decreased reports of exclusive breastfeeding (non-adherent 65% vs. adherent 77%). Women who practiced mixed-feeding most commonly gave their children water (41%), followed by cow's milk or other milk (31%), porridge

(29%), fruits (22%), tea (14%) and traditional herbal drugs (10%), and did so mostly because they were weak/not producing sufficient breast milk (53%) or because the baby was constipated or had abdominal pain or they had mastitis (16%). Among women who were no longer breastfeeding when interviewed, 90% had weaned at 6 months as per the Rwandan national guidelines. Women who did not adhere to the PMTCT prophylaxis protocol were significantly more likely to breastfeed more than six months when compared to adherent women (18% vs. 2%). A modest proportion of women interviewed reported having received free artificial milk at some point in their pregnancy with no significant difference by adherence status (non-adherent 12% vs. adherent 16%). In most cases, they obtained this milk from a health facility, a family member or neighbor, or a PLWHA association (data not shown).

Table 8. Experiences with infant feeding among HIV infected women by PMTCT adherence status.

	Adherent n=125		Non Adherent n=111		p-value
	n	%	n	%	
Feeding methods recommended by health worker *					
Breastfeeding only	120	96.0	102	95.3	1.000
Artificial milk only	90	72.2	64	59.8	0.050
No mixed feeding	11	8.8	8	7.5	0.710
No advice	5	4.0	9	8.1	NA
Duration of breastfeeding recommended by health worker					
3 months	1	0.9	0	0.0	0.365
6 months	113	99.1	99	99.0	
12 months	0	0.0	1	1.0	
Explanation about feeding methods unclear	37	29.8	32	30.5	0.917
Discussed feeding options with husband/partner	86	70.5	66	62.3	0.189
Waited for husband's/partner's permission before making a decision about feeding options	62	72.1	40	60.6	0.140
Ever breastfed index infant	114	91.2	108	98.2	0.020
Infant ever given other food **					
Yes, before starting breastfeeding	14	12.3	13	12.0	0.040
Yes, while breastfeeding	12	10.5	18	16.7	
Yes, both before and while	0	0.0	7	6.5	
No, never gave anything but breast milk	88	77.2	70	64.8	

Table 8. Experiences with infant feeding among HIV infected women by PMTCT adherence status, continued.

Age of infant at weaning					
≤6 months	41	97.6	33	82.5	0.020
> 6 months	1	2.4	7	17.5	
Received free artificial milk (including formula, goat’s milk or cow’s milk) during pregnancy or after the delivery	15	12.0	17	15.5	0.400

* May sum to more than 100% because of multiple responses.

** Chi-square test compares proportion of women who never gave anything but breast milk vs. all other women.

NA: Chi-square not valid because cells with expected count <5 was >25%.

2.8 Family planning knowledge and practices

Patterns by HIV status

HIV-infected women were substantially less likely than HIV-uninfected women (8% vs. 52%) to report wanting additional children (Table 9). This difference held even after controlling for their higher parity (data not shown) and longer median duration since last delivery (data not shown). Most women (76%) discussed family planning with a health worker during/after their most recent pregnancy, with significant differences by HIV status (infected 79% vs. uninfected 69%). In most cases (~60%), these discussions occurred during the post-test counseling period. Hormonal contraceptives were reportedly discussed most frequently among both HIV-infected and -uninfected women. Only 68% of infected women and 45% of uninfected women reported that condoms were discussed during these sessions.

While >95% and >89% of all women were familiar with at least one family planning and at least one modern family planning method at the time of the evaluation, respectively, far more infected than uninfected women knew of condoms (62% vs. 36%). At the time of data collection, 54% of infected women reported using any family planning method, almost twice the proportion of uninfected women (32%). Modern family planning use was similarly more common among infected than uninfected women (46% vs. 14%). Condom use accounted for the majority of contraception among HIV-infected women (31%), while withdrawal was the most frequently reported method among HIV-uninfected women (18%). The vast majority (>69%) of both infected and uninfected women not using family planning at the time of the evaluation reported an intention to do so in the future. Among the HIV-infected women who indicated that they did not plan to use a method, most said this was because they were not sexually active (68%). While far fewer (16%) infected women noted that their partners were opposed to it, the proportion giving this response was more than twice the proportion of uninfected women (7%) who gave a similar response.

Patterns by PMTCT adherence status

While over 95% of both adherent and non-adherent women were familiar with family planning methods, women who did not adhere to the PMTCT protocol were less likely to report using a family planning method at the time of data collection than those who did not adhere to the PMTCT protocol (43% vs. 63%). Modern family planning use was similarly less common among non-adherent women (35% vs. 56%), as was condom use (25% vs. 37%).

Table 9. Family planning knowledge, attitudes and practices by HIV status and PMTCT adherence status.

	All women by HIV status				p-value	HIV-infected women by adherence status				p- value
	Uninfected n=162		Infected n=236			Adherent n=125		Non Adherent n=111		
	n	%	n	%		n	%	n	%	
Desires additional children (now or in the future)	80	52.3	19	8.4	<0.001	7	5.8	1	11.2	0.140
Family planning methods known ** **										
None	11	7.0	8	3.4	0.109	3	2.4	5	4.6	0.800
Pills	127	80.4	198	84.6		109	87.2	89	81.7	
Injection	130	82.3	199	85.6		112	89.6	87	79.8	
Condoms	58	36.3	146	62.4		82	65.6	64	58.7	
IUD	29	18.4	37	15.8		21	16.8	16	14.7	
Norplant	9	5.7	22	9.4		15	12.0	7	6.4	
Sterilization	11	7.0	29	12.4		17	13.6	12	11.0	
Rhythm/withdrawal	51	32.3	44	18.8		17	13.6	27	24.8	
Breastfeeding/LAM	1	0.6	2	0.9		1	0.8	1	0.9	
ANC staff discussed family planning during last pregnancy	111	68.5	186	78.8	0.022	103	82.4	83	76.1	0.237
Timing of discussion about family planning										
Upon receipt of HIV results	64	59.3	112	60.2	0.277	60	58.3	52	62.7	0.235
During another ANC visit	30	27.8	37	19.9		20	19.4	17	20.5	
After delivery	8	7.4	23	12.4		17	16.5	6	7.2	
At child consultation	6	5.6	14	7.5		6	5.8	1	1.2	

Table 9. Family planning, desire to have another children, knowledge, attitudes and practices by HIV status and PMTCT adherence status, continued.

Family planning methods discussed *									
None	2	1.9	2	1.1		1	1.0	1	1.2
Pills	95	88.8	160	86.0		89	86.4	71	85.5
Injections	100	93.5	166	89.2		95	92.2	72	85.7
Condoms	48	44.9	126	67.7	NA	73	69.9	55	65.1
IUD	21	19.6	36	19.4		20	19.4	16	19.0
Sterilization	9	8.4	20	10.8		10	9.7	10	12.0
Norplant	2	1.9	18	9.7		13	12.6	5	6.0
Rhythm/withdrawal	38	35.5	35	19.0		15	13.6	21	25.3
Breastfeeding/LAM	2	0.9	1	0.5		1	1.0	0	0.0
Family planning methods currently used ** ***									
None	111	68.5	109	46.2		46	36.8	63	56.8
Pills	5	3.1	10	4.2		7	5.6	3	2.7
Injections	5	3.1	19	8.1	<0.001	13	10.4	6	5.4
Condoms	8	4.9	74	31.4		46	36.8	28	25.2
IUD	1	0.6	0	0.0		0	0.0	0	0.0
Sterilization	1	0.6	3	1.3		2	1.6	1	0.9
Rhythm/withdrawal	30	18.4	23	9.7		13	10.4	10	9.0
Breastfeeding/LAM	2	1.2	3	1.3		2	1.6	1	0.9
If not currently using family planning, intend to use in future	72	68.6	77	76.0	0.268	30	73.2	47	77.0
If not currently using or do not intend to use, reasons for not being interested in family planning *									
Currently pregnant	0	0.0	1	4.0		1	8.3	0	0.0
Desires more children	19	65.5	1	4.0		0	0.0	1	7.7
Partner desires more children	3	10.3	1	4.0	NA	0	0.0	1	7.7
Not sexually active	4	13.8	17	68.0		10	83.3	7	53.8
God decides fertility	4	13.8	0	0.0		0	0.0	0	0.0
Religion/respondent or husband opposed	4	13.8	5	20.0		1	8.3	4	30.8
Afraid of side effects	2	7.4	1	4.0		0	0.0	1	7.7

* May sum to more than 100% because of multiple responses.

** Chi-square test compares proportion of women who had not heard of a single method vs. women who had heard of at least one method.

*** Chi-square test compares proportion of women who not using a single method vs. women who were using any method.

NA: Chi-square not valid because cells with expected count <5 was >25%.

2.9 Multivariate analysis

Multivariate analysis was used to understand better the determinants of adherence to the PMTCT protocol among HIV-infected women. As depicted in Appendices A and B, receipt of SD-NVP during pregnancy (i.e. before the expected date of delivery) and delivering in a health facility are intimately linked with and likely to be intermediate variables in the path to both maternal and infant ARV prophylaxis adherence. For this reason, we did not treat these variables as potential determinants of adherence, but rather examined determinants of these two variables, as well as of adherence among maternal-infant pairs, and adherence among women alone and infants alone in separate logistic regression models. Our outcomes were as follows:

- Not receiving SD-NVP during pregnancy (i.e. before the expected date of delivery);
- Not delivering in a health facility;
- Mother and/or infant not ingesting SD-NVP at all or at the recommended time;
- Mother not ingesting SD-NVP at all or at the recommended time; and
- Infant not ingesting SD-NVP at all or at the recommended time.

We predicted the likelihood of each outcome using individual-level covariates that reflect socio-economic status (i.e. marital status, education level), health-seeking behaviors (i.e. number of ANC visits made during pregnancy), experiences with the health-care system (i.e. time at which HIV test was offered, received SD-NVP from health facility before the expected date of delivery), partner dynamics (i.e. partner tested during pregnancy), and social support (i.e. disclosed test results to someone other than partner).

Both bivariate and multivariate logistic regression models were run for each outcome. All variables significant at the 0.10 level in the bivariate models were included in the multivariate models, as were respondent's age and evaluation site. We also tested for potential interaction terms. Variables not significant at the 0.05 level were removed from the multivariate models using the Likelihood Ratio test, although we forced age and evaluation site in all final models. Adjusted odds ratios and 95% confidence intervals from the final models are presented in Table 10.

Socio-economic factors appeared to have little effect on women not receiving SD-NVP during pregnancy or not delivering in a health facility (Models 1-2), with the exception of the relationship between religion and place of delivery: Catholic and Protestant women had significantly increased odds of not delivering in a health facility than women reporting other religious affiliations (Model 2). In contrast, socio-economic factors exerted a stronger influence on non-adherence to the PMTCT protocol. Unmarried women were significantly more likely to report that either they or their child did not ingest SD-NVP at all or at the recommended time than married women, as were women with no or little education when compared to women with more education (Model 3). Education was similarly associated with maternal non-adherence (Model 4). The number of ANC visits women made—a measure of health-seeking behaviors—almost universally impacted all of the outcome measures, with the exception being newborn non-adherence alone. Women who made two or fewer ANC visits during pregnancy were more likely to not receive SD-NVP during pregnancy, not deliver in a health facility, report that they or their newborn had not ingested SD-NVP at all or at the recommended time, or report that they alone

had not ingested the ARV prophylaxis than women who made more ANC visits (Models 1-4). The time when HIV testing was offered to women also strongly influenced several outcomes, and in fact, exerted more influence than almost all the covariates included in the models: Women who were not offered HIV testing at their first ANC visit but rather later in pregnancy were significantly more likely to not receive SD-NVP before delivery, to report that they and/or their newborn had not adhered to the PMTCT protocol or that they alone had not adhered (Models 1, 3-4). As is the case with the number of ANC visits women made, this variable most likely impacted adherence of mother-infant pairs through access to maternal SD-NVP given that it had no effect whatsoever on newborn adherence (Model 5). Partner dynamics, as measured by whether a woman's partner was tested for HIV during her pregnancy, was predictive of the woman not receiving SD-NVP and maternal non-adherence (Models 1 and 4). Reporting that one's partner was uninfected was also associated with non-adherence in mother-infant pairs, although this association was only marginally significant (Model 3). Not disclosing one's HIV status to someone other than a partner—a proxy for low levels of social support—was associated with increased odds of non-adherence in mother-infant pairs and newborns not ingesting SD-NVP at all or at the recommended time (Model 3 and 5). Maternal non-adherence was the only other covariate that impacts newborn adherence and was highly predictive of an infant not ingesting SD-NVP at all or at the recommended time (Model 5).

Table 10 Adjusted odds ratio of not receiving SD-NVP during pregnancy, not delivering in a health facility and not adhering to the PMTCT protocol.

Model	1		2		3		4		5	
Outcome	Not receiving SD-NVP before expected date of delivery		Not delivering in a health facility		Mother and/or infant not ingesting SD-NVP at all or at the recommended time		Mother not ingesting SD-NVP at all or at the recommended time		Infant not ingesting SD-NVP at all or at the recommended time	
Covariates	Adjusted OR *	95% CI	Adjusted OR *	95% CI	Adjusted OR *	95% CI	Adjusted OR *	95% CI	Adjusted OR *	95% CI
Marital status Unmarried (vs. married)	-	-	-	-	2.3	1.1, 4.8	-	-	-	-
Education None/<3 years (vs. more)	-	-	-	-	2.3	1.2, 4.4	2.7	1.3, 5.6	-	-
Religious affiliation Catholic/Protestant (vs. other)	-	-	2.5	1.3, 5.0	-	-	-	-	-	-
Number of ANC visits ≤2 (vs. ≥3)	2.2	1.1, 4.6	3.0	1.5, 5.8	4.5	2.3, 8.8	4.2	2.0, 8.8	-	-
Time HIV test was offered After first ANC visit (vs. at first ANC visit)	4.6	1.3, 15.4	-	-	3.9	1.2, 12.9	8.6	2.5, 29.7	-	-
Partner tested during pregnancy No (vs. yes)	2.1	1.0, 4.4	-	-	-	-	2.7	1.3, 5.8	-	-
Partner's HIV status Negative (vs. positive or unknown)	-	-	-	-	2.2	1.0, 4.7	-	-	-	-
Disclosed test results to someone other than partner No (vs. yes)	-	-	-	-	2.8	1.4, 5.8	-	-	2.7	1.3, 5.6
Received SD-NVP before expected date of delivery No (vs. yes)	-	-	2.7	1.3, 5.8	-	-	-	-	-	-
Mother ingested SD-NVP at the recommended time No (vs. yes)	-	-	-	-	-	-	-	-	17.1	6.8, 42.6

* All models control for respondent's age and evaluation site.

Chapter 3: Qualitative results

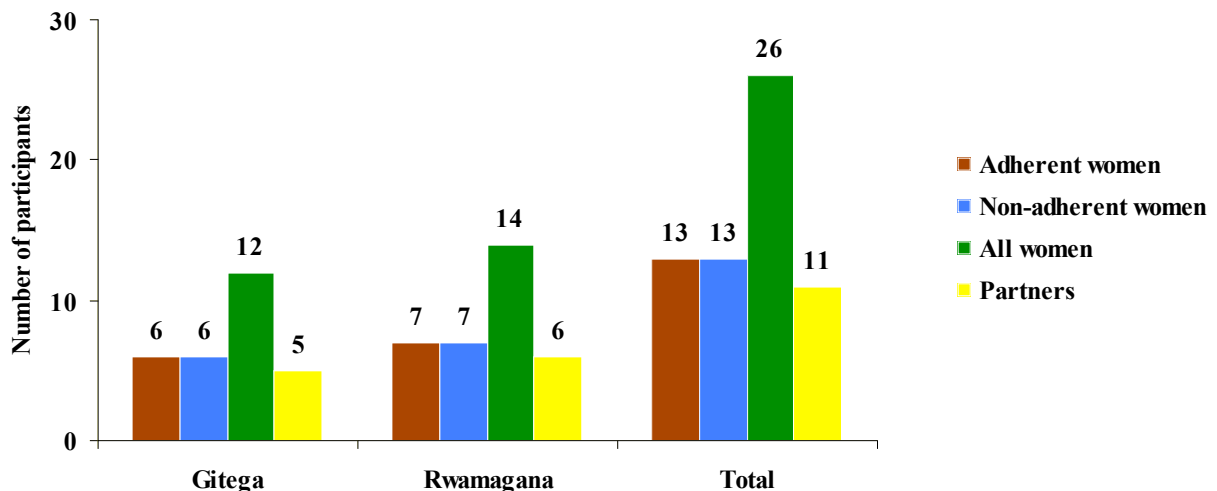
3.1 Site descriptions

As described in Section 1.3.a, two sites with contrasting characteristics were purposively selected for the qualitative portion of the study. The first site, Gitega Health Center, is located in central Kigali. As there is no labor and delivery ward on-site, women receiving PMTCT services there are routinely referred to the main teaching hospital, which adjacent to the site for delivery. Additionally, a non-governmental organization provides HIV-infected women accessing PMTCT services at the health center with food supplements (for themselves) and with cow's milk (for their newborns). The second site, Rwamagana Dispensary, is located in the Eastern province. While located in an urban center, it serves primarily women from surrounding rural areas and is thus referred to as the "rural site" in this chapter. There is no labor and delivery ward on-site and thus, women are referred to Rwamagana District Hospital, an annexed facility.

3.2 Participant characteristics

Figure 3 depicts the sample for the qualitative portion of the evaluation. In total, 26 HIV-infected women completed in-depth interviews, 12 in Gitega and 14 in Rwamagana. As per the sampling methodology, half of the women interviewed reported that both they and their child had ingested SD-NVP at the recommended time. Male partners of eleven of the women interviewed also participated in the evaluation and were approximately evenly distributed between adherent and non-adherent women.

Figure 3. Qualitative study participants by site.



Women averaged 32 years of age and six years of schooling. All but two had given birth prior to the index pregnancy and median parity was four. On average, women had delivered the index child five months prior to the interview. Women reported numerous religious affiliations, but

most were associated with Protestant churches. At the urban site, women reported mainly being house-wives, while at the rural site, most were subsistence agricultural workers. Partners averaged 37 years of age.

3.3 Knowledge of, attitudes regarding and reasons for accepting HIV testing

Most of the women interviewed knew they would be offered HIV testing as part of their ANC even before presenting to the clinic, reporting that information about HIV is widespread and often discussed on the radio.

When asked about the advantages and disadvantages of HIV testing during pregnancy, women consistently reported the main benefit as knowing “*what to do*”—how to preserve one’s own health, how to protect one’s partner, and particularly how to give birth to a healthy baby:

« It’s really useful since you know what kind of behavior to adopt and you can take drugs once you know you’re infected. » (urban site, age 39, non-adherent)

« Once you know your serological status, you can take steps to live longer. For example, I think that my child (referring to a child born prior to the index child) may have died because I didn’t know my serological status as I hadn’t been tested. After his birth, I gave him breast milk and when he died at two years and a half he was still breastfeeding. Maybe I infected him by breastfeeding. But if I had known my status at the time of his birth, I would have breastfed him only for 6 months and maybe he’d still be alive. » (rural site, age 38, adherent)

None of the participants at either site, including non-adherent women, reported any negative aspects to HIV testing.

Many women who accepted testing did so because they suspected they were infected, primarily because they or their partner had been ill or because they had tested infected previously. In some such cases, the availability of HIV testing during ANC served as an incentive for seeking out ANC itself:

« In fact, I was really sick and had been really sick for a while. I’d lost weight during my pregnancy. At home, I always felt desperate. I kept thinking about what would happen to me if I was tested and the results showed that I was infected. I wondered what I’d do so as not to give birth to a sick child. That’s what I thought then. But then I heard other women say that despite their infection, they’d given birth to uninfected children. So, I got the courage to go to the health center so that I could give birth to a healthy child....I only did it because I was pregnant. If I hadn’t been pregnant, I would never have gone to the health center. » (rural site, age 34, non-adherent)

In contrast, others accepted testing precisely because they believed they were uninfected:

« Since I thought that it was almost impossible for me to have HIV, I felt okay about it. I believed that it was impossible for me to get AIDS. I just decided to get tested because I saw others doing it. » (urban site, age 37, adherent)

« I had no problem at all. In fact, people are starting to get used to the program of AIDS testing. I felt that it was a good thing— to know my status. But, me, I was confident that I was uninfected. My positive results surprised me.» (rural site, age 34, adherent)

While HIV testing during ANC was acceptable to the vast majority of woman interviewed, both subtle and not so subtle pressure from health workers clearly influenced decisions to get tested. In some cases, women felt obligated to comply with HIV testing implying that HIV testing was a pre-requisite for participation in the ANC program. Others had blood samples taken without formal consent or were threatened with reduced access to labor and delivery services if they were not tested:

« Yes, I just wanted to get an antenatal consultation but once I arrived they tested me for AIDS too. So then I had to bring my husband so he could also be tested. They found out that he was not infected but that I was. » (rural site, age 38, adherent)

« Whether you accepted or not, you had to get tested because they told you that no one would help you during delivery if you weren't tested. They wouldn't even accept you in the big maternity in Kigali. Regardless of where you went, no one would accept you. In the end, you decide that instead of being sent back from place to place once you're in labor, you better accept the test. » (urban site, age 35, non-adherent)

Normative beliefs also influenced women's decision to get tested. Many described women who declined testing as "ignorant" and those who accepted it as "doing the right thing" or "accepting their obligations":

« I wanted to know my status, and anyway, how can any woman deliver without knowing her status? » (urban site, age 39, non-adherent)

« I went there knowing fully that all pregnant women had to be tested for HIV/AIDS. But I had already planned to get tested. And, since I happened to be pregnant, the test was an obligation. » (rural site, age 39, non-adherent)

« There are people that remain ignorant and think that testing is useless and even go so far as to deliver at home. I personally think that this results from their ignorance. » (urban site, age 22, non-adherent)

3.4 Pre- and post-test counseling experiences

Pre-test counseling

Women reported obtaining most of their information about HIV risks and testing during group pre-test sessions led by health workers. While expressing general satisfaction with these sessions, a number of women noted that such an approach limited discussion of sensitive issues, such as sexual behaviour and sexually transmitted infections:

« Some women asked questions but those women are used to doing that. They talk to nurses. . . They're not ashamed of talking about sex. » (urban site, age 20, adherent)

In some cases, women expected to raise these issues in individual consultations following the group sessions, but ultimately time constraints made this difficult:

« They taught us but we were running out of time. They started teaching us in the morning when they had other things to do and time was flying by, and soon it was 12 o'clock and we thought that we'd just ask our questions next time. » (urban site, age 35, non-adherent)

Post-test counseling

As was the case with pre-test counseling services, most women reported being highly satisfied with the care they received during their post-test counseling sessions:

« I was really scared but the counselor was very humble and called another doctor so they could counsel me together. They encouraged me and I ended up accepting my situation. Later on, I mixed in with the women who had come from my neighborhood and went back home. » (rural site, age 28, non-adherent)

« I thought the counselor behaved really well with me. I had no problem at all. She comforted me and later visited me to find out how I was doing. In fact, she helped me a lot and consoled me by telling me that AIDS is disease like any other and that I was not the only person who was living with it and that life had to continue. » (rural site, age 44, adherent)

Despite women's reported high levels of satisfaction with their post-test counseling experiences, accounts of these sessions suggest numerous instances of poor quality of care at both sites. Indeed, while discussion of the importance of partner testing is a key component of post-test counseling, in one site, several women reported that health workers threatened to withhold ARV prophylaxis if their partners were not tested. Others, as demonstrated by the quote below, received their results in the presence of multiple health workers, some of whom were engaged in administrative activities:

« There were two counselors in the room and I had confidence in both of them. I knew that a doctor is a doctor and that professional ethics would keep him from disclosing

my secrets... One person spoke while the other one was seated at the table and was busy with some other forms. » (rural site, age 39, non-adherent)

Additionally, despite the significance of the test results, many health workers seemed ill equipped to offer women the psychological support they needed. Indeed, several women reported receiving written rather than verbal results. Others noted that the post-test counseling focused too intensely on what they should not do, as opposed to what they could do and how they and their newborn could survive. Many were afraid to ask any questions after receiving their results.

« When giving me my results, she asked if I knew how to read and I said yes. So she asked me to read the piece of paper that she'd just given me. I asked her to explain to me what it said. She told me that I was infected with AIDS while giving me tablets. » (rural site, age 26, adherent)

« When they gave me my results, I was told to abstain from sex. I was told a list of things not to do like drinking and having unprotected sex. That's what I was told. » (rural site, age 38, adherent)

« I couldn't ask many questions because he had a lot to do. There were other clients waiting for their results. » (urban site, age 22, adherent)

3.5 Knowledge of MTCT

While both adherent and non-adherent women were relatively knowledgeable about HIV/AIDS and understood the risks of MTCT during pregnancy and labor, knowledge of the risks associated with breastfeeding, and particularly with mixed feeding, was minimal. Indeed, when asked about the risks of MTCT associated with breastfeeding only two of the 26 women interviewed explicitly mentioned mixed feeding. Rather, most women at both sites believed that transmission during breastfeeding occurred primarily when the child has scratches or cuts in his/her mouth:

« Transmission of HIV from mother to the child can happen during delivery, pregnancy or even during breastfeeding. They told us that we could infect our children if they have small cuts in their mouth. That's what they told us— to always check for cuts in the child's mouth when breastfeeding. » (urban site, age 22, adherent)

« He can get infected through what he drinks. For example, a child that starts eating or getting teeth can cut himself in the mouth. When he sucks, breast milk can get in the cut and he can get infected. » (rural site, age 26, adherent)

« If he's born to an infected mother, you must give him artificial milk or if you do breastfeed him, you must make sure that he hasn't cut himself or doesn't have sores in his mouth at least five times a day. We were told that if you breastfeed him and you find cuts in his mouth, you must stop breastfeeding immediately. » (urban site, age 22, non-adherent)

3.6 Decisions regarding delivery and delivery experiences

All women knew that it was advisable for HIV-infected women to deliver in a health facility. Nonetheless, most deliveries occurred outside such facilities. In some cases, women planned to deliver in a facility but their labor progressed so quickly that they were unable to get to the facility in time. Others desired to deliver in a facility but could not afford the maternity or transportation costs:

« My delivery took place at home without any problem since my labor was really quick. Why didn't I go to the health center even though I'd planned to earlier? It was raining and there was nobody who could help me get there since my husband was attending a funeral for someone from our cellule. That's why I delivered at home. » (rural site, age 39, non-adherent)

« Honestly, I don't want to lie to you, my husband had just gotten out of prison. We didn't have money and you know that doctors demand certain things and I didn't even have clothes for the newborn. I was ashamed of going without even the bare necessities. My husband had started to look for what was needed but in the meantime, I delivered. It was only a lack of basic necessities that kept me from coming. I really wanted to. I kept thinking that the only thing that could help me from having an infected child was luck. » (rural site, age 38, non-adherent)

3.7 Barriers and facilitators to adherence to the ARV prophylaxis protocol

Maternal adherence

Among the 13 non-adherent women interviewed, eight reported that they had not ingested SD-NVP at all. Two such women delivered before their final scheduled ANC consultation when they were to obtain the drug. In the majority of the remaining cases, patient-related factors contributed to their non-adherence. Several of these women, for example, delivered unexpectedly while away from home or en route to the health facility and did not have the drug with them. Others did not take the ARV prophylaxis because they had not disclosed their HIV status to family members or others who were present at the onset of labor:

« I sent my daughter to get her grandmother for me. When she came, I was deep in labor. I had planned to take it once my labor really got going. Since we had not told this old woman that we were infected, I was scared to take the drug in front of her because she would ask me why I was taking it. In fact she would suspect that we were infected, but I did not want any one to know. » (urban site, age 31, non-adherent)

Several women were misinformed about the purpose of taking the drug. One such woman, for example, confused messages about the need to take SD-NVP and encouragement to deliver in a

health facility, mistakenly believing that she did not need to take the drug if she planned to deliver in a facility, even if ultimately she arrived there after the delivery itself:

« The doctors had asked me to do all that I could so as to deliver in a health center. They had said that if you live far from the health center, you should rush to get to the health center, even after taking the tablet. I don't know, maybe it was stupid for me to think that doctors have all the power and that it wasn't necessary to take the tablet once you're in their hands. The labor pains started quickly while I was on my way and I didn't take the tablet. I didn't forget. I just thought that delivering in a health center was enough. » (rural site, age 28, non-adherent).

Another woman mistakenly believed the drug would speed up her delivery if she took it at the onset of labor^d and thus did not see any utility in taking it once her delivery was advanced:

« It's importance? They told us that when labor starts, you take it and your labor goes quicker and the child comes faster. So I didn't think it was important to take it since my labor was well underway. » (urban site, age 25, non-adherent)

In one case, a woman reportedly lost the ARV prophylaxis and was too ashamed to admit this to the health facility staff, despite her partner's reassurance that she should request a replacement pill:

« She told me that she was ashamed to go back since she thought it'd be a waste if they gave her another tablet after she lost the first one. I told her that those were her own ideas and not that of the doctors, adding that she really should have gone back to get another tablet. She replied that doctors would think that she wasn't serious and was absent-minded. » (male partner, rural site, woman age 48, non-adherent)

In direct contrast to the non-adherent women who did not take SD-NVP because they had not disclosed their HIV status to individuals who were present at the delivery, several of the 13 adherent women reported taking it precisely because someone who was aware of their HIV status reminded them to do so:

« Since I had it at my mother-in-law's place, when I felt the first contraction I sent a child to get her and the first question she asked me was if I had taken the tablet. I had actually forgotten and she reminded and she gave it to me. » (urban site, age 24, adherent)

« The doctor came to tell me that I was about to deliver, and asked me if I had taken the tablet. I said that I hadn't. He went to get one for me and gave it to me. » (rural site, age 39, adherent)

^d Interestingly, this idea was also shared by an adherent woman: *« Really, the tablet did me some good since I delivered really quickly—in less than an hour. »* (rural site, age 38, adherent)

Whether women were adherent or not, however, their partners rarely played a role in the decision to take SD-NVP or in assisting them to ensure that it was indeed ingested. Ultimately, few of the men interviewed knew whether their wives had in fact taken the ARV prophylaxis:

« The relations between husband and wife are a secret. Sometimes the husband only impregnates the wife and does not follow the progress of the pregnancy. So she doesn't tell him anything and at the end only she knows the importance of the tablet. It's her business and it's her program. » (rural site, male partner, age 48, woman non-adherent)

Infant adherence

Five of the 13 non-adherent women reported that their child had not received the ARV prophylaxis at all or within 72 hours of birth. In many cases, fear of disclosing their own HIV status prevented women from obtaining the ARV prophylaxis for their newborns:

« No, I didn't give him to anyone else because I didn't want anyone to know. » (urban site, age 31, non-adherent)

A lack of social support also contributed to infants not receiving SD-NVP. Indeed, while several women reported that they were too weak or too busy caring for their other children to bring the newborn to the health center themselves and requested that their spouses do so, their requests were rarely met. Interviews with both women and their partners suggested that men's reluctance to bring their newborns to the facility stemmed from their own fears regarding disclosure as well as their unwillingness to defy gender norms:

« I requested my husband to take the baby to the doctor. He replied that he couldn't. He said that if the baby had been a boy he might have been able to but since it was a girl, he couldn't. I think that he lied to me because he does whatever he can to hide his infection. » (rural site, age 32, non-adherent)

« Honestly, I forgot. It's only because you're young that you don't understand these things. Normally, in Rwandese culture, no man will take a child to the doctor. If you do, whomever you meet along the way will laugh at you. We men are not used to such practices. » (rural site, male partner, age 48, woman non-adherent)

Additionally, just as some women expressed confusion about when they were to ingest SD-NVP, some were uncertain about the timing of infant administration of the drug.

« They informed us that there is a time frame during which you must administer the drug to the baby so as to prevent him/her from being infected by AIDS. Beyond that time the drug will not work. We went there on the fourth day after baby's birth and we were told that it was too late... We learned then that we were supposed to bring the baby within 3 days of birth. » (rural site, age 39, non-adherent)

Others, particularly those in the rural site, encountered problems in the continuity of care. They attempted to contact or visit a health center so their child could get SD-NVP but were unsuccessful.

« No, he didn't get it. When I told that woman that the baby needed to take a drug to stop AIDS infection, she accompanied me to the health center. They told us that they didn't yet have the PMTCT program.^c » (rural site, age 36, non-adherent)

« I thought about it 45 hours after the baby was born. That's when I wrote a letter to the counselor at the health center who had counseled me, but he was in Kigali. It was too late. » (rural site, age 39, non-adherent)

3.8 Dilemmas regarding infant feeding

Nearly all study participants faced dilemmas regarding infant feeding. Few women, particularly in the rural site, could afford milk substitutes and thus, most were left with no choice but to breastfeed, which often provoked great anxiety:

« I definitely thought that was the best method in my situation. It was impossible to find money to buy him cow's milk while I was still too weak to work. Breastfeeding was then a last resort for me. » (rural site, age 34, adherent)

« We who are poor and survive off the land only think about survival—our survival but also that of our children who may die of hunger. So when you're aware of your misery and that you are infected and you do not have the means to feed your child cow's milk, you feel a very deep agony. » (rural site, age 28, non-adherent)

« Yes the decision was difficult. It goes without saying that if I had the money, I would have given him something else. I would not have breastfed him. » (rural site, age 32, adherent)

« To tell you the truth, I was scared. Apart from lacking the means, I preferred not to breastfeed him because I was always worried that I would infect him. I was completely agonizing over the situation—I kept looking in the baby's mouth to check if he had any cuts. I kept him away from his older siblings so he wouldn't get any scratches or cuts. Really, I don't now how to explain it but I was always anxious. Even now, I keep him close by. » (rural site, age 32, non-adherent)

The few women who used milk substitutes also struggled with their decision, fearing they would not bond with their newborn or that they would be stigmatized due to the association between artificial feeding and HIV:

« It's very tormenting and you don't feel as close to the baby as when you breastfeed, but that's how it is. » (urban site, age 24, adherent)

^c This woman consulted a facility other than the one where she received her ANC and was tested for HIV.

« The decision really upset me. What upset me most was that after waiting for so long to have a baby, I was advised not to breastfeed him. I missed that opportunity of taking the child into my hands and breastfeeding him as other mothers do. Not having the opportunity to breastfeed my baby upset me even more than when I learned that I was infected. The situation was really painful for me. When I looked at my baby that I was depriving of breast milk and yet still wasn't sure that doing so would stop him from getting infected, I felt really sad. » (rural site, age 34, non-adherent)

« In rural areas, when you do not breastfeed your baby, you get endless nasty comments from people. » (rural site, age 39, non-adherent)

Whether women chose to artificially feed or exclusively breastfeed their children, reports of mixed feeding were common. In the urban site, where milk substitutes were provided to HIV-infected women, frequent supply shortages and small rations led many women to provide both breast milk and milk substitutes to their newborns. In other cases, women had insufficient breast milk:

« They say that if you breastfeed the baby and give him cow's milk at the same time, you might infect him. But when I come here and go back home empty-handed and then the baby cries, my husband tells me to breastfeed him. It happens to me often—I come and spend the whole day without breastfeeding him. We spend the whole day here from morning to 3 pm. He can cry the whole time and I don't have any money to buy anything for him. You can see that he's crying. I'm sure I don't have any breast milk but I just give him the nipple and he just sucks. » (urban site, age 22, adherent)

« Because I don't have enough milk to satisfy him, they only gave me milk for one week. By the time I brought the baby, he was starving. They gave me a little bit of milk and recommended that I give him a mix. They said that I'd have enough milk after a week but that still hasn't happened. So, sometimes I give him cow's milk and sometimes I give him breast milk. What can I do? » (urban site, age 29, adherent)

Similarly, while most women who were reportedly exclusively breastfeeding were largely aware of the recommendation to wean rapidly at six months, poverty prevented many from following it:

« They told us to breastfeed for six months only. But it's difficult for me to wean him at six months since I don't have the means to get him milk. The only option I have is to take a hoe and work on other people's land in exchange of money. Weaning the child is a really difficult decision for me. » (rural site, age 26, adherent)

« Yes, they tell us what we can give him. But without money, you cannot wean him. There are even women who wean their babies but end up breastfeeding them again because they don't have anything else to give them. » (rural site, age 26, adherent)

« After she weaned him, the baby had really bad diarrhea. I told her to breastfeed him again. I added that if it was going to infect him then let him be infected. After all, from

what I could see, the baby was already infected. Wasn't he infected already since he wasn't born at the health center where they could give him drugs?» (rural site, male partner, age 49, woman adherent)

3.9 Fertility desires and family planning use

All but two women reported they did not want to have additional children. Among the reasons cited were the risk of MTCT and the desire to protect their own health. Nonetheless, despite their own fertility preferences, some women were pressured to have additional children by their partners:

« He doesn't think about the fact that we'll leave our children behind. He didn't have a child with the previous wife and when I think about it I realize that he wants me to have more children with him. I don't think he plans for the future of our children. But I'm going to tell his mother so that she can convince him. Maybe he'll listen to her .» (urban site, age 20, adherent)

« I told him that if he intends to continue having children than he better marry other women because I can't have another child given my fragile health state. When we discussed this, he laughed. I told him that he was joking in difficult circumstances. I told him that I had become an invalid and that it would become worse if I had more children. I asked him how he would deal with a wife who would stay at home from morning to evening but wasn't capable of preparing a meal for her husband who would be working the land. I then advised him to marry other wives since he was still young and in good shape. » (rural site, age 26, adherent)

Interviews with several men confirmed their desires for additional children persisted after they learned of their and/or their partners' HIV status:

« I found out that I had HIV 11 years ago. I prayed to the Lord who finally helped me to have a healthy boy since I didn't want to die without having a child. . . I prayed saying, 'Lord I accept to commit this sin because all I want is to have a child who is not infected.' » (urban site, male partner, age 19, woman non-adherent)

«It really upset me to think that my wife is infected and we haven't yet had a child together. Some time later I inadvertently had unprotected sex with her, without a condom, since I couldn't accept that she could die without having a child with me. » (urban site, male partner, age, 20, woman's adherence status unknown)

When women were decided to use family planning, they faced multiple obstacles. On the one hand, partners were reluctant to use condoms or expressed religious opposition to family planning:

« Frankly speaking, I don't know. When I suggest we use condoms my husband doesn't hear me. He tried at first but then he refused and now I'm worried that I might be pregnant since I haven't had my period in two months. » (urban site, age 20, adherent)

« He never liked condoms. This is how it goes: He puts the condom on but he removes it before ejaculating. That means that most of the time we finish without a condom. He couldn't wear it until the end. So I told him that it didn't serve any purpose to put on a condom and remove it before ejaculating. It'd be better not to use it at all. » (rural site, age 34, non-adherent)

« The problem is that he doesn't believe in any ONAPO methods. For him, sex with a condom is a sin. » (rural site, age 34, non-adherent)

On the other hand, health facilities required partners' consent before providing family planning:

« My friend, I really don't know what to do. I came to the health facility planning to ask to have my fertility stopped, but I learned that they won't do it without my husband's permission. I realized that there was nothing I could do and I gave up. But I really didn't want to have any more children. » (rural site, age 44, adherent)

Even when their spouses were present, health workers reportedly refused women permanent contraceptives:

« In fact we decided that we were going to use a permanent method. When I had my baby in that big maternity in Kigali, they refused. They told me to come back with my husband but I told them that my husband had come with me and that we could call him, but they refused that too. » (urban site, age 29, adherent)

« We went together. He came with me and I told them to give me permanent contraceptives so that I never conceive again since I was infected. They refused and told me that they can only do this with my husband's blessing. I told them that we had come together but they never talked to him. I don't know why. » (urban site, age 25, non-adherent)

Many couples desiring to limit childbearing were left with no choice but to try to abstain from sexual intercourse altogether:

« We decided to practice abstinence until I got sterilized. When he comes home, we sleep together without having sex. We ended up getting used to it. » (rural site, age 39, adherent)

Not surprisingly, then, ultimately six of the 24 women who desired to end their childbearing reported having unintended pregnancies.

Chapter 4: Discussion and recommendations

As part of an evaluation of the Rwandan national PMTCT program, quantitative and qualitative methods were used to describe experiences with HIV testing during pregnancy and, among HIV-infected women, to identify determinants of adherence to a SD-NVP ARV prophylaxis protocol at 14 public-sector ANC sites. The quantitative phase was conducted at 12 randomly selected PMTCT sites and was intended to provide a snapshot of PMTCT experiences nationwide. In total, 236 HIV-infected women—125 who reported that both they and their newborn had ingested SD-NVP at the recommended time and 111 who said that either they or their child had not taken the ARV prophylaxis at all or at the recommended time—and 162 HIV-uninfected women who had received ANC at one of the evaluation sites during their last pregnancy completed closed-ended interviews. Qualitative data gathered through in-depth interviews with 26 HIV-infected women and 11 of their partners, as well as observation of 10 post-test counseling sessions, at two purposively selected sites complement the quantitative data and permit a more detailed examination of how women perceive and experience the PMTCT program.

Several limitations of the evaluation should be noted. First, some of the HIV-infected women believed to non-adherent to the national PMTCT protocol (according to available information in the site's registers) could not be located during data collection for the quantitative phase. It is possible that the socio-demographic profiles and health-seeking behaviors of these women differ from those of the women interviewed and thus that our sample of non-adherent women is not representative of all such women. Additionally, as HIV-infected and –uninfected women interviewed in the quantitative phase had delivered their last pregnancy on average 5.5 and 3.7 months before data collection, respectively, we cannot rule out the possibility of recall bias or that this recall bias was more acute among HIV-infected women than –uninfected women given their longer median time since their delivery. Finally, women were interviewed at health facilities which may have impacted their willingness to respond frankly to questions regarding the quality of services and interactions with providers.

Nonetheless, by combining quantitative and qualitative data to explore multiple aspects of the Rwandan PMTCT program, this evaluation offers important insights that should be considered as the program shifts from a SD-NVP protocol for mother and newborn alike to more complex ARV prophylaxis regimens. Key findings and recommendations for programmatic improvements and further investigation follow.

HIV counseling and testing

High rates of access to HIV testing and uptake of testing have been reported since the initiation of the PMTCT program in Rwanda. Data collected through this evaluation suggest that an *opt in* approach is increasingly being replaced by an *opt out* approach. Regardless of the model used, consent remains a critical aspect of the testing process. Quantitative and qualitative data collected in this evaluation, however, indicate that this practice is not always followed. The vast majority of women (>91%) reported “very strong” recommendations from health workers to get tested and some (10-15%) women felt pressured to accept testing. Several women reported

having been tested without their consent and others were threatened with reduced access to labor and delivery services if they were not tested.

Similarly, while the majority of women reported being satisfied or very satisfied with their ANC, the quality of HIV counseling appears poor. Women reported that pre-test counseling generally consisted of top-down group sessions with minimal interaction between health workers and women. Based on our observation of a small sample of post-test counseling sessions and women's reports of these sessions during in-depth interviews, health workers often used scripted text when providing test results and appeared ill equipped to deal with women's substantial psychological needs when the results indicated they were HIV-infected. Indeed, several aspects of the national recommendations for HIV counseling (TRAC, 2002) appear to be insufficiently followed, including discussion of women's ability to share their test results with family members and/or the existence of social networks for PLWHA. When they did occur, these discussions were often stereotyped and vague. Additionally, while counseling regarding the importance of partner testing is an important component of post-test counseling, data from in-depth interviews suggests that in some cases, health workers exerted undue pressure and coerced women to have their partners tested. Indeed, at one site, there were multiple reports of health workers threatening to withhold access to the ARV prophylaxis if women failed to return with their partners.

Adherence to the ARV prophylaxis protocol

The evaluation data suggest several bottlenecks in adherence to the ARV prophylaxis. First, over one-third of non-adherent women never received the ARV prophylaxis from a health worker during their pregnancy despite all consulting ANC at a site that provides PMTCT services. Multivariate analysis indicates that among other factors, women who made two or less ANC visits were less likely to receive SD-NVP before their expected date of delivery. Qualitative data suggests that this may result from health workers reluctance to distribute SD-NVP at the first ANC visit even if it occurs in the third trimester and/or incorrect assessment of gestational age and thus the expected date of delivery. Not surprisingly, then, a fair number of women reportedly delivered before they were able to obtain the ARV prophylaxis.

Second, despite universal recommendations to deliver in a health facility where ingestion of the ARV prophylaxis can be monitored, only 28% of non-adherent women did so. Surprisingly, multivariate analysis suggests that socio-economic factors have little effect on the ultimate place of delivery. Making two or less ANC visits (as opposed to three or more), however, was strongly associated with not delivering in a health facility. It is unclear if this is a result of sub-optimal utilization of all formal health care services among non-adherent women or rather a question of the reduced number of ANC visits made by non-adherent women leading to fewer opportunities for health workers to reinforce the importance of delivering in a health facility.

Third, even among women who delivered in a health facility, ingestion of SD-NVP by mother and child was not fully achieved. Indeed, 35% of the 31 non-adherent women who delivered in a health facility never ingested the ARV prophylaxis and 19% of their newborns did not receive their dose of the drug. Qualitative data suggest that at least in the case of the mothers this may have resulted from women not arriving at the health facility in the first stage of labor. As the survey data indicate great variability by site in the proportion of women who delivered in a

health facility but did not receive SD-NVP (0-67%), however, it is likely that service-delivery factors also contributed to this problem. While some women may not have disclosed their HIV status upon arrival at the health facility, it is possible that health workers did not always verify women's HIV status on their ANC cards or simply did not have time to administer the drug to all HIV-infected women or their newborns.

Multivariate analysis suggests that in addition to service delivery factors, measures of socio-economic status, partner dynamics and social support also impacted whether mother-infant pairs ultimately ingested the ARV prophylaxis. Indeed, low levels of education, being unmarried, living with an uninfected partner, and not having disclosed one's test results to someone other than a partner were all independently associated with non-adherence in women and newborns. Education may impact adherence in several ways including facilitating communication with health workers, increasing retention of information provided by health workers and enhancing implementation of the recommendations regarding ingestion of the ARV prophylaxis. We note, however, that non-adherence was high (40%) even among women who had completed seven or more years of schooling. The other factors (marital status, partner's HIV status and disclosure to someone aside from one's partner) highlight the importance of communication and social support both within and outside of the couple dyad in facilitating adherence to the ARV prophylaxis protocol, but further investigation is needed to disentangle the relationship between those factors and their relative importance in determining adherence. Qualitative data show clearly the contribution of gender roles to maternal and newborn non-adherence and in particular help explain why only 15% of infants born at home were brought to a health facility for ingestion of SD-NVP. Indeed, some of the men interviewed explained that that it was "inappropriate" for them to bring the newborn to the facility for the ARV prophylaxis even when women were unable to do so. Additionally, aside from a few exceptions, men was notably absent in women's accounts of their experiences with the PMTCT prophylaxis.

Infant feeding

While overall approximately 95% of all HIV-infected women who participated in the quantitative component of the evaluation reported having ever breastfed their infants, fully 30% of such women said they had practiced mixed.^f This is not surprising given that only 8% of women indicated that they had been counseled specifically to avoid mixed feeding. The in-depth interviews further highlight important and dangerous misconceptions regarding infant feeding. Indeed, when asked specifically about the risks of MTCT associated with breastfeeding, only two women mentioned mixed feeding. Rather, most women reported that transmission during breastfeeding occurs primarily when the child has scratches or cuts in his/her mouth. Additionally, women described significant anxiety regarding the possibility of their transmitting HIV while breastfeeding their children and the vast majority indicated that they would have used artificial milk had it been available to them. At the one qualitative site where such a program existed, however, women reported frequent shortages which only further contributed to the prevalence of mixed feeding.

^f As we did not use infant feeding diaries, we suspect that the true of the rate of mixed feeding may well be higher.

Fertility desires and family planning

We found a significantly decreased desire for additional childbearing among HIV-infected vs. - uninfected women and high levels of familiarity with modern family planning methods among both groups of women. Nonetheless, over half of the infected women interviewed were not using family planning at the time of data collection and condom use was limited to 31% of such women. In-depth interviews suggest important barriers to effective family planning at both the partner and health systems level. Indeed, women reported that their partners pressured them to have additional children and/or refused to use condoms. Additionally, women noted that health workers often require partner consent before providing women with permanent family planning. Even when women's partners had consented and accompanied them to the facility, however, several women were still unable to obtain the method they desired. Further investigation about factors reducing accessibility to family planning within health centers are warranted.

Referral to care and treatment services

While access to HIV care and treatment services is increasing rapidly in Rwanda, less than half of the HIV-infected women who participated in the quantitative phase of the evaluation had been referred to such services with great variability by site.

Recommendations

Specific recommendations include:

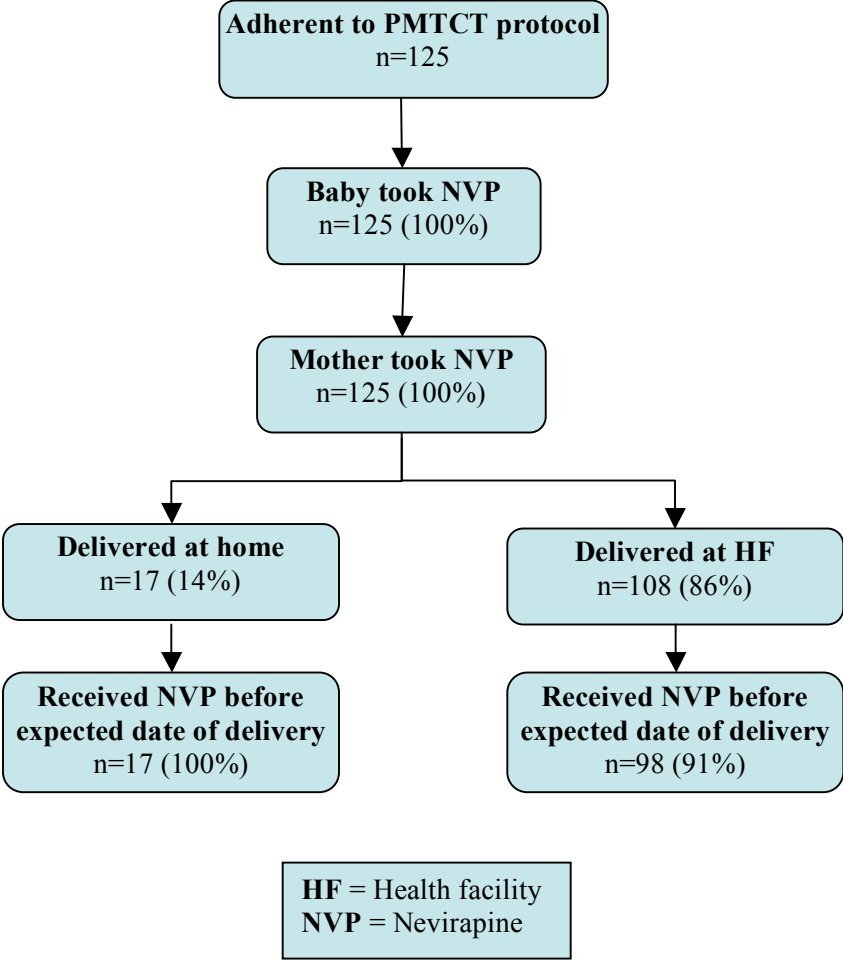
- Increasing information, education and communication at the community level to encourage pregnant women to receive ANC starting in their first trimester.
- Ensuring that true consent is obtained from all women who are tested for HIV and that women who decline testing are offered comprehensive pre- and post-natal services.
- Further investigation of the reasons for the provision of inadequate psychological support during post-test counselling sessions so that they can be best addressed: Is it a question of insufficient pre- and in-service training, health workers' subconscious approach to avoiding burnout, the need for values clarification among health workers, or simply time constraints?
- Additional training for counselors regarding the importance of discussing disclosure with one's partner and at least one other confidante with HIV-infected women.
- Exploring alternate ways of engaging partners in HIV testing and other aspects of the PMTCT program, including discreetly (via letters from health facility staff) inviting partners to receive voluntary counseling and testing, involving partners in all phases of ANC, and working at the community level to promote more male involvement in the health of women and children (USAID, 2005).

- In cases where a SD-NVP is still used as the maternal ARV prophylaxis, providing the drug to women at their first ANC visit regardless of their gestational age as is being done in other sub-Saharan Africa countries, and/or active tracing of women who have not received it by the end of the eighth month of pregnancy.
- In cases where AZT is now provided from 28 weeks gestational age onwards, additional training to ensure that gestational dating is accurate.
- Improving PMTCT record keeping for ANC and delivery, including the printing of standardized national registers and the development of a list of HIV-infected women expected to deliver each month. This should be accompanied by strengthened communication between ANC and delivery units, particularly at sites that refer women to adjacent facilities for delivery.
- Enhanced, explicit and repeated counseling regarding the risks associated with mixed feeding.
- Further exploration of the barriers to the provision of permanent contraception to women who desire it regardless of whether they present with their partners.
- Promotion of effective links between PMTCT and care and treatment services, including use of two-way referral forms and active follow-up of women who are not registered in a care and treatment program within two weeks of referral.

References

1. Conner M and Norman P (eds). 2005. *Predicting Health Behavior. Research and Practice with Social Cognition Models, 2nd Edition*. Buckingham, United Kingdom: Open University Press, USA, 2005, 375 p
2. Dunn D, HIV Paediatric Prognostic Markers Collaborative Study Group. Short-term risk of disease progression in HIV-1-infected children receiving no antiretroviral therapy or zidovudine monotherapy: a meta-analysis. *Lancet*. 2003; 362:1605–1611.
3. Gray L, Newell ML, Thorne C, Peckham C, Levy J. Fluctuations in symptoms in human immunodeficiency virus-infected children: the first 10 years of life. *Pediatrics*. 2001; 108:116–122.
4. Institut National de la Statistique du Rwanda and ORC Macro. 2006. *Rwanda Demographic and Health Survey 2005*. Calverton, USA: INSR and ORC Macro.
5. Newell ML, Coovadia H, Cortina-Borja M, Rollins N, Gaillard P, Dabis F. Mortality of infected and uninfected infants born to HIV-infected mothers in Africa: a pooled analysis. *Lancet*. 2004; 364:1236–1243.
6. Rutenberg N, Baek C, Kalibala S, Rosen J. *Evaluation of United Nations-supported pilot projects for the prevention of Mother-to-Child transmission of HIV*. UNICEF: New York, 2003.
7. Treatment and Research AIDS Center (Ministry of Health, Rwanda). *Manuel du conseiller en conseil et dépistage volontaire du VIH/SIDA*. TRAC: Kigali, Rwanda, 2002.
8. Treatment and Research AIDS Center (Ministry of Health, Rwanda). *TRAC net Data, 2005*. TRAC: Kigali, Rwanda, 2006.
9. UNAIDS/WHO. *Global summary of the HIV and AIDS epidemic Geneva: World Health Organization, 2006*. UNAIDS: Geneva, Switzerland, 2006.
10. USAID. *Rwanda: Male involvement in preventing mother-to-child transmission of HIV*. Retrieved January 24, 2007, from <http://africastories.usaid.gov>.
11. United Nations General Assembly. *Special Session on HIV/AIDS: Declaration of Commitment on HIV/AIDS*. United Nations: New York, USA, 2001.

Appendix A. Pathways to adherence to the national PMTCT protocol, n=125 adherent mother-infant pairs.



Appendix B. Pathways to non-adherence to the national PMTCT protocol, n=111 non-adherent mother-infant pairs.

